April 2019

Community Based Support Group for Siblings of Children with Down Syndrome: A Pilot Study

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A thesis submitted in partial fulfillment of the requirements for the degree in Master of Arts

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Abstract

The developmental delays associated with Down syndrome (DS) have been shown to affect the well-being of all family members. Research has shown that typically developing (TD) siblings experience increased maladjustment such as internalizing difficulties, behavioural problems and increased stress, however there has been limited research focusing on interventions for this population. Two sibling dyads participated in this pilot study examining the effects of a social support group for TD siblings overall adjustment. Although there was a lack of strong empirical evidence supporting the intervention, five qualitative themes emerged outlining their coping, emotions, experiences and sibling relationships. This research can help inform future researchers and practitioners to develop appropriate supports and interventions for this population of children and youth.

Keywords: social-emotional adjustment, Down syndrome, typically developing siblings, coping, social support program.
Acknowledgements

I would like to thank all the people who contributed to the work described in this thesis. Firstly, I thank my supervisor, Dr. Nicole Neil. Her passion and energy towards research examining areas of applied behaviour analysis and developmental disabilities is inspiring. Dr. Neil welcomed me on her research team and provided me with many invaluable opportunities throughout my masters’ program that contributed to a rewarding graduate school experience. She consistently allowed this paper to be my own work, but used her expertise to guide me when she thought I needed it. I would also like to extend my gratitude to the London Down Syndrome Association and the families that participated in this study by offering their extended time and energy. Their lives are extremely busy and their eagerness to commit to a 9-week program is very much appreciated.

I want to acknowledge Dr. Jason Brown as the second reader of this thesis. I am extremely grateful for his guidance and generosity that he conveyed and his valuable feedback and encouragement. I want to thank Dr. Brown, Dr. Alan Leschied, and Dr. Susan Rodger for the opportunity to be a part of such an amazing graduate program. Their support, approachability, and humor were essential in shaping myself to be an educated and successful researcher and practitioner.

To my fellow colleagues, I will be forever grateful for being able to share this educational experience with you. You all provided unwavering support throughout this program and I am very appreciative. To my close friends, I thank you for your understanding and consolation throughout my graduate school experience.

Finally, I would like to thank my parents, Joe and Rosa Amicarelli. I sincerely thank them for their unconditional love, support and guidance. I appreciate all the values you have instilled in me. No words can adequately express my gratitude. To my brother, Adam, thank you for your persistent encouragement throughout this academic journey, and supporting me every step of the way. Thank you.
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Chapter 1: Introduction

Down syndrome (DS), the most common genetic cause of intellectual disabilities, is a chromosomal disorder present at birth due to the presence of an extra chromosome 21, affecting 1 in 1000 births worldwide (World Health Organization [WHO], 2017). The developmental delays associated with DS such as impaired physical, behavioural, communicative, cognitive and/or social abilities have been shown to affect the well-being of all family members, not just the well-being of parents (Choi & Van Riper, 2013). Previously, most interventions for families supporting a child with DS have focused on the parents' well-being, ignoring the effects on the typically developing (TD) sibling. Therefore, understanding what TD siblings of children with DS experience and developing targeted intervention programs for them may help prevent negative adjustment outcomes for TD siblings in the future. The purpose of this study is to evaluate the effects of a targeted intervention on the psychosocial adjustment of siblings of children with Down syndrome and gain a comprehensive understanding of their experiences.

This literature review begins with a theoretical framework to better understand TD siblings experiences and the results of this thesis are interpreted through this model. Since the current literature lacks information specific to families of children with DS, we draw on research with other developmental disabilities such as autism and chronic illnesses for the purposes of the current literature review to understand the sibling experience, adjustment, and effective intervention approaches.

Theoretical Framework

The majority of the research in this field has not considered a theoretical framework to understand the experiences and needs of TD siblings. The current study, however, uses a bioecological framework (Bronfenbrenner, 1979) to gain a comprehensive understanding of TD
siblings' experiences and develop appropriate interventions that can meet their needs.

Bronfenbrenner’s theory divides a person’s environment into five different levels: microsystem, mesosystem, exosystem, macrosystem and the chronosystem. When the chronosystem was added (Bronfenbrenner, 2005) Bronfenbrenner also placed a greater emphasis on processes and the role of the biological person, developing the Process-Person-Context-Time Model (PPCT).

Researchers have used this framework to review this field of research; however only some of the aspects of this theory have gained empirical support.

In Bronfenbrenner’s model, the person includes personal characteristics and motivations that individuals bring to any social situation (Bronfenbrenner & Morris, 2006). These have been further subcategorized into demand characteristics, resource characteristics, and force characteristics. Demand characteristics are stimuli immediately apparent to another person (i.e., age, gender, and skin colour), resource characteristics are not immediately apparent and relate to mental and emotional resources (i.e., past experiences, skills, and intelligence), and force characteristics are individual differences in temperament, motivation, and persistence (Tudge, Mokrova, Hatfield, & Karnik, 2009, p. 200). Demand characteristics are particularly important when examining TD siblings adjustment and experience. For instance, an individual’s role within their family will govern their perceived expectations and responsibilities that are placed on them (Vroegh, 1971). Further, individuals’ perceptions of their place in the family constellation, based on their sex, age, and birth order, influences how they feel about themselves and how they interact with others (Findler & Vardi, 2009). Although researchers have not explicitly used this theoretical lens in their research, we can use this framework to interpret existing findings in the literature. For example, researchers have highlighted the influence of biological sex of TD siblings on their own development. Orsmond and Seltzer (2007) have revealed that more females
than males report long-term positive impact of having a sibling with a developmental disability. An additional demand characteristic that is also important for TD sibling research is their age, and stage of development as each stage fosters new capacities, goals, and social expectations (Berk, 2012).

The microsystem consists of contexts that are closest to an individual and interact with their psychological lives. The microsystem includes the interactions of siblings with their immediate environments such as with family, school, community and sibling support programs. Powell and Gallagher (1993) demonstrated that parental attitudes regarding the sibling with a developmental disability is a powerful influence on the TD siblings adjustment. Additionally, socioeconomic advantages and early intervention support for the family also appears to buffer TD siblings against some of the potential negative effects of having a brother or sister with a developmental disability (Findler & Vardi, 2009). Therefore, researchers could examine the psychological resources of TD siblings including self-esteem, coping abilities and communication skills in the microsystem (Saxena & Adamsons, 2013).

The last level of the bioecological framework that has empirical support in TD sibling research is the macrosystem. The macrosystem is the sociocultural environment, consisting of the cultural values, laws, customs and resources of the context in which an individual develops (Bronfenbrenner, 1979). This system examines the societal views towards individuals with disabilities, the prevalence of intervention services and the funding available for services, and research. Cultural values about developmental disabilities often influence the laws and societal policies that are established in a given community which subsequently impact the development of community resources for families affected. Lobato and colleagues (2011) examined the psychological and school functioning of Latino and non-Latino TD siblings of children with
learning disabilities and their results indicated that Latino siblings had more maladjustment. Research has suggested that sociodemographic stress and strong familial values such as sibling caretaking and companionship among Latinos may increase psychological vulnerability (Lobato, Kao, & Plante, 2005). Apart from culture and traditional practices, macrosystem elements also include laws and social policies that might influence the allocation of societal resources.

Researchers have used similar ecological and family theories to examine and understand TD sibling adjustment. Specifically, Benson and Karlof (2008) examined which child, parent, and family factors in the microsystem are predictive of adjustment in siblings of children with autism spectrum disorders (ASD). They interviewed and surveyed 72 parents to examine individual and family factors that influence the psychological factors of TD siblings such as family climate, parental involvement, stressful life events, severity of symptoms, and sociodemographic information. Results revealed that the severity of symptoms of the sibling with ASD and the intensity of the parent’s involvement in the TD child’s education were significantly related to both prosocial behaviour and overall adjustment difficulties. This study highlights the importance of various family and social factors that interact within the presence of a sibling with a disability to affect the adjustment of the TD sibling. Therefore, a bioecological theoretical orientation can provide a deeper understanding of TD siblings’ adjustment and overall experiences by examining the siblings in various contexts as well as within and between these contexts, over time.

**TD Sibling Experiences**

Siblings will be in the lives of family members with developmental disabilities for longer than anyone; they will likely be there after parents have passed and special education services have concluded. Throughout their lives, TD siblings share most of the experiences that parents of
children with developmental disabilities describe, including isolation, a need for information, concerns about the future and caregiving demands (Conway & Meyer, 2008). Moreover, TD siblings may have experiences that are unique to being a sibling to someone with a developmental disability such as resentment, peer issues, embarrassment, and pressure to achieve (Meyer & Vadasy, 1997; Naylor & Prescott, 2004). Despite TD brothers and sisters’ lifelong relationship with their sibling with a developmental disability, accurate understanding of their experiences and needs for support remains limited (Hodapp, Glidden, & Kaiser, 2005). Therefore, it is important for researchers and clinicians to ask TD siblings about their experiences, stressors, emotions, and sibling relationships in order to capture a comprehensive understanding of their well-being and develop appropriate support programs and services.

Although research using TD siblings’ voices to explore their experiences is sparse, a few common themes have been identified in qualitative reports. One of the themes present across multiple studies was the difficult task of dealing with other people’s reactions and behaviours. For TD siblings, an outside world that does not appreciate and understand their sibling’s different needs and abilities can be challenging. Siblings described having to cope with the attitudes and, often unhelpful reactions of others such as laughing (Moyson & Roeyers, 2012). Moreover, others’ reactions and the need to explain their brother or sister’s disability often led to feelings of embarrassment, disappointment, frustration and anger (Petalas et al., 2009).

Another prominent theme voiced by TD siblings in qualitative reports was their concern about the future (Petalas et al., 2012). Short-term, this presented in concerns for their siblings adjustment and experience in high-school. Some siblings also had long-term worries regarding the care and well-being of their sibling with a developmental disability and their future caregiving role and its effects. This theme emerged in intervention studies as well, thus
suggesting that it is a common concern for TD siblings. Furthermore, some TD siblings disclosed to researchers there was tension between what their parents wanted their sibling with a developmental disability and what they thought was best for them.

A third important theme revealed in the literature is acceptance of their sibling’s disability. This has been argued to be significant for TD siblings’ well-being as it subsequently helps them deal with potential negative effects such as maladjustment and guilt (Moyson & Roeyers, 2012). Specifically, based on sibling reports researchers have theorized that being able to accept the disability helps TD siblings deal with situations which are difficult because of their siblings disability (Taylor, Fuggle, & Charman, 2001). Since their siblings’ disability is not going to go away, acceptance helps to normalize their siblings’ special needs, embrace the positives, and respect them for who they are. Thus, there is evidence to support acceptance as a protective influence for TD siblings’ healthy psychological adjustment.

However, varying degrees of acceptance have been reported by the different qualitative reports in the literature (Moyson & Roeyers, 2012; Petalas, Hastings, Nash, Reilly, & Dowey, 2012). Research reported TD siblings expressed views on a continuum of acceptance ranging from positive acceptance, to wishing change (Petalas et al., 2012). Although many TD siblings acknowledge their siblings for who they were and perceived the disability as an inseparable part of them researchers noted that it does not alter the fact that having a sibling with a developmental disability can be hard (Petalas, Hastings, Nash, Dowey, & Reilly, 2009).

Lastly, siblings have acknowledged that they need support and help. Initially they expect to get this support from their parents but often hesitate because they do not want to “bother” their parents with their worries when their parents have many other worries of their own (Moyson & Roeyers, 2012). Petalas and colleagues (2012) found that some siblings have used extended
family members and friends for support or as a distraction technique. Additionally, the researchers found TD siblings who had participated in a support group and they said that they found it valuable to share their experiences and confide in people who share similar experiences (Petalas et al., 2009). Therefore, TD siblings may need support and assistance provided by individuals outside of the family system in order to adequately address their needs.

The research in this field suggests that the sibling experience for children who have a sibling with a developmental disability may be different from their peers’ experiences since TD siblings often deal with unique behaviours, situations, and internal experiences. Furthermore, their relationship with their sibling may be different from those that exist between typically developing children, resulting in a need for further examination and understanding in order to appropriately support this population.

Adjustment

In general, sibling focused research has examined the broad category of adjustment problems (e.g., emotion regulation, social development and behavioural problems) in TD children who have a sibling with a developmental disability, suggesting they have an increased risk of maladjustment; however, this literature has yielded mixed results (Choi & Van Riper, 2013). A number of studies have indicated that TD siblings are more likely to experience internalizing difficulties (Lovell & Wetherell, 2016), behaviour problems (Verte, Roeyers, & Buysse, 2003) and social impairments (Ormond & Seltzer, 2007). For example, when TD children who had a sibling with an ASD were compared to their peers with neuro-typical siblings, self-report and parent report measures of depressive symptomatology exposed that siblings of children with ASD reported more depressive symptomatology compared to their peers. Further, Senel and Akkok (1996) found that TD children who had a sibling with a
disability experienced greater stress and poorer adaptation compared to their TD sibling counterparts.

Some studies indicate differences for individuals that have a sibling with DS than other developmental disabilities. Specifically, in a longitudinal study Hastings (2007) compared the adjustment of siblings of children with different developmental disability etiologies (i.e., ASD, DS, mixed etiology of intellectual disability). Results from parent reports and interviews across time suggested that TD siblings with a brother or sister with DS had fewer behaviour problems than siblings of children with ASD. In addition, it has been argued that TD siblings of children with DS had less difficulty adapting than TD siblings of children with a developmental disability other than DS (Fishman, Wolf, Ellison, & Freeman, 2000). Although there are mixed findings about the adjustment of TD siblings of children with DS, there is sufficient evidence to suggest that they do present with their own adjustment and skill needs.

In order to develop interventions that effectively meet TD sibling’s adjustment needs it is important to investigate the various factors that influence their adjustment. Coping skills and social support have received the most empirical support in the literature. For example, Cebula (2012) examined 132 families supporting a child with an ASD and their TD siblings, with a specific focus on the psychosocial adjustment of the TD sibling. Using data collected from questionnaires completed by parents, teachers and siblings, a significant relationship between social support and TD sibling adjustment was found. Specifically, TD siblings who reported higher levels of social support had higher levels of self-concept. Moreover, Orsmond, Kuo, and Seltzer (2009) used self-report questionnaires and phone interviews to investigate the psychological well-being, coping strategies and social support of 142 TD adolescents who had a sibling with ASD. Their results revealed that depressive symptoms were negatively related to
coping strategies and social support. Further, they found that positive affect was positively related to social support. Therefore, TD sibling’s social support and coping strategies should be targeted for future interventions.

Although there is a body of research that suggests siblings with a brother/sister who have a developmental disability experience adjustment problems, there is a lack of research examining the specific supports TD siblings need. To address this limitation, researchers (Arnold, Heller & Kramer, 2012) used a qualitative study to ask adults who have a sibling with a developmental disability questions to gather descriptive information about their support needs (i.e., what programs would you like to see targeted towards siblings of people with disabilities?). The most popular response was sibling support services as participants stated that they wanted ways to connect with others, share information and provide support. For example, one sibling commented that “group support with other siblings would enable conversation about issues” and that it would allow them to feel less “alone and isolated.” Therefore, more opportunities are needed for siblings of people with developmental disabilities to connect, network, and share information and resources. This research gained information from the sibling perspective that gave insight to what resources are desired to meet their support needs.

Sibling Focused Interventions

Well-being interventions have been suggested to help improve psychological outcomes (including anxiety, depression, stress, self-esteem and coping) of siblings of children with a disability and/or illness (Smith, Pereira, Chan, Rose, & Shafran, 2018). These interventions have taken various forms, including group interventions (Smith & Perry, 2005), sibling training (Ferraioli, Hansford & Harris, 2012) and camps (Sidhu, Passmore, & Baker, 2002). Many of these sibling focused interventions have used psychoeducational strategies to help improve TD
sibling adjustment (Smith et al., 2018). Research has suggested that TD siblings’ adjustment can be enhanced by training in skills they can use to interact with their brother or sister with a developmental disability, to comprehend them, to handle difficult behaviours, and deal with reactions of others (Moyson & Roeyers, 2012). These researchers have postulated that by learning these skills, TD siblings can control their own adjustment process and take control of the situation, which enhances their overall quality of life. For example, one study used a randomized control trial to assess a six-week family-based psychoeducational intervention for parents and TD siblings of children with a disability or chronic illness. The intervention was delivered to participants individually through written informational packages and telephone support (Giallo & Gavidia-Payne, 2008). Pre- and post-treatment questionnaires revealed a decrease in the TD siblings’ emotional symptoms, perceived intensity of daily stress and use of avoidance coping; however, there was no observed increase in social support. Given that TD siblings have reported a desire for social support, rather than exclusively psychoeducational information, support groups have been developed as another approach to address TD sibling needs. These groups typically involve meeting other siblings who have a brother/sister with a developmental disability to discuss issues and emotions, learn coping strategies and learn about the disabilities of their siblings (Conway & Meyer, 2008).

The most popular program used to address young siblings’ need for peer support and information is Sibshops (Meyer & Vadasy, 1994). Sibshops is a sibling support program involving group meetings for TD siblings who have a brother/sister with a disability, this approach has been established for 25 years in the United States and has become an increasingly popular model for supporting siblings in the UK (Conway & Meyer, 2008). To evaluate the programs efficacy, researchers interviewed 16 TD siblings and administered questionnaires
before and after participation in the Sibshop program (D’arcy, Flynn, McCarthy, O’Connor & Tierney, 2005). Researchers found high social validity (i.e., siblings “enjoyed” or “loved” meeting other siblings) such that 19% of TD siblings talked about what it was like to have a sibling with a disability before the Sibshop program compared to 75% during Sibshops. Further, more than half reported hearing stories told by other siblings to which they could relate. Therefore, Sibshops was successful at meeting the programs goals such as meeting other siblings, discussing common joys and concerns, providing information and education about the implications of specific disabilities and discussing ways to handle common experiences. This finding is imperative to the applied value of the intervention because it demonstrates that the techniques used achieved the intended outcomes, which were relevant and useful to the participants. Although Sibshops has been shown to be a socially valid program, there has been limited research that has examined the effectiveness it has on the adjustment of TD siblings. Thus, it is unknown whether this intervention had a palpable impact that helped TD siblings in ways that are evident in everyday life.

Lobato and Kao (2002) contributed to sibling intervention research by evaluating the effectiveness of a program similar to Sibshops on the adjustment of TD siblings to their sibling’s chronic illness or developmental disability. Their intervention, titled Siblink, consisted of six 90-minute group meetings with other siblings where they discussed topics such as disability knowledge, identifying and managing emotions, and problem-solving challenging situations. Results from sibling reports of negative adjustment and parent reports of sibling global behaviour functioning displayed a significant decrease in depressive symptomatology following the intervention. Although this is one of the few studies that examined the effectiveness of sibling focused interventions their sample was diverse, consisting of TD siblings with brothers or
sisters with varying illnesses and diagnoses. Thus, the intervention would not have been focused on characteristics associated with certain developmental disabilities, such as DS.

However, a recent study aimed to target TD siblings who had a sibling with ASD, and developed an intervention focused on ASD characteristics, which reduced within group variability by focusing only on one developmental disability (Kryzak, Cengher, Feeley, Flenup, & Jones, 2015). Their community intervention involved a skills program for the sibling with ASD, a support group for the TD siblings and an inclusive recreation activity for all the children together. They examined TD sibling depression and anxiety symptoms, ASD knowledge, and peer network before and after the support group using self-report questionnaires. Results showed significant improvements in the TD siblings’ adjustment and peer network. Specifically, there were significant decreases in negative self-esteem and total depression scores as well as in physiological anxiety.

**Gaps in the Literature**

Although TD sibling’s adjustment and well-being has gained more attention within the field of research that examines families caring for children with developmental disabilities, this literature has many gaps. First, there is limited research that examines the effectiveness of interventions such as Sibshops on TD sibling adjustment and well-being. Further, the research that has addressed this has examined a variety of disabilities and chronic illnesses within the same study. The only group that has received targeted interventions and research is TD siblings with a brother/sister with ASD. Therefore, to date there have been no empirical studies that have targeted an intervention for TD siblings with a brother/sister with DS and further evaluated the success of the intervention. Secondly, the research in this field typically employs quantitative or qualitative designs exclusively when evaluating the effects of an intervention. Furthermore, the
quantitative research studies in this field have tended to focus on potential behavioural, social, and emotional difficulties for TD siblings; however, by directly attending to the TD siblings voices, qualitative research can reveal both the positive and negative experiences faced by TD siblings. Therefore, a mixed-method research design can enable the researchers to investigate how the intervention affects both outcomes and experiences of TD siblings during the program. Lastly, the majority of these interventions have exclusively involved the TD siblings, excluding the sibling with a disability from participation in the intervention. However, it may be beneficial to incorporate the other sibling in a portion of the intervention to allow the TD sibling to generalize and implement some of the skills they learn in their support group (i.e., a coping strategies).

**Current Study**

Although there is a limited body of research examining the experiences and adjustment of TD siblings of children with DS, there is some existing evidence that suggests that they may be at risk for maladjustment. Moreover, there has been a lack of research focusing on interventions aimed to protect TD siblings of children with DS against various negative outcomes. Therefore, this pilot investigation will contribute to the research by comprehensively exploring TD siblings’ experiences and social-emotional adjustment and subsequently evaluating the use of a social support group with psychoeducation techniques to improve their social-emotional well-being.

This pilot investigation focused on exploring and addressing the needs of TD children who have a brother or sister with DS and subsequently evaluating the effects of a community based support group for TD siblings. Specifically, the researchers aimed to qualitatively explore TD siblings’ feelings and emotions, coping strategies, stressors, and their sibling relationship through qualitative analysis of the weekly support group. In addition, this study investigated the
effectiveness of a targeted social support program on the social-emotional adjustment of TD siblings, purposely examining the effects this program had on coping strategies and internalizing and externalizing symptoms. Based on the limited findings in previous literature, it was hypothesized that coping strategies will increase following participation in the intervention and negative internalizing and externalizing symptoms will decrease. Therefore, this mixed method design allowed researchers to understand how qualities of the social support group affected TD siblings experiences during participation and the overall outcomes of the intervention.

Chapter 2: Method

Participants

Participants consisted of two sibling dyads between the ages of 5 and 17 years, with one being TD and the other with a diagnosis of DS (see Table 1). A third sibling dyad was originally enrolled in the program, however they dropped out following the first week of the group due to a scheduling conflict. The first participant was Katie, a 16-year-old female who has a younger sister (Emily) with Down syndrome. Katie is a caring, good-natured, responsible teenager who expressed hopes of pursuing a career in a helping profession. Katie had to miss one group session due to a mission trip, attending eight sessions of the sibling support group. The second participant, Chad, is a 10-year-old male who has a younger brother (Garret) with Down syndrome. Chad is energetic, smart, attentive, and competitive. Chad likes video games and golf. Chad attended all nine sessions of the sibling support group.

Participants were recruited via flyers distributed to listservs supporting families with an individual with DS and agencies or professionals providing direct services to children with DS in the London and surrounding area. Organizations were contacted via email using the email addresses posted on their public websites to distribute electronic flyers. Families contacted the
researchers to receive a letter of information and further details about participating in the study. Ethics approval was obtained from Western University’s Ethics Review Board (see Appendix A) and parental informed consent and child assent was obtained prior to enrollment in the program.

Table 1: Participant Demographic Characteristics

<table>
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<th>Participant 1</th>
<th>Participant 2</th>
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<tbody>
<tr>
<td>Age</td>
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<tr>
<td>Gender</td>
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<td>Male</td>
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<td>Race</td>
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<td>Informant</td>
<td>Biological Mother</td>
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<tr>
<td>Sibling with DS</td>
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<tr>
<td>Age</td>
<td>14 years</td>
<td>6 years</td>
</tr>
<tr>
<td>Gender</td>
<td>Female</td>
<td>Male</td>
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</tbody>
</table>

Materials

Pre-post adjustment measures. Parents completed a demographic questionnaire and questionnaires about the adjustment of their TD children. In addition, TD siblings completed measures about their depression and anxiety symptoms, and coping strategies.

Demographic questionnaire. Parents completed a demographic questionnaire developed for the purpose of this study. Parents reported the siblings’ race, age, gender, and cultural and ethnic background. In addition, they answered questions regarding medical, behavioural and communication needs of their child with Down syndrome. For their TD child they provided information regarding previous counselling services and whether they have had thoughts about harming themselves or others. Parents were asked to indicate their marital status and legal guardianship if applicable.

Child Depression Inventory (CDI), 2nd Edition. The CDI-2 (Kovacs, 2011) is a comprehensive assessment of depression for children aged 7-17 years, consisting of 28 items describing depressive symptoms on a 3-point ordinal scale ($\alpha = .94$). The CDI-2 includes an overall score and subscales for negative mood, interpersonal problems, ineffectiveness,
anhedonia, and negative self-esteem. Each item is scored from 0 to 2, and the sum of all item scores yields the total CDI score, which ranges from 0 to 54. Higher scores indicate more depressive symptoms. Children completed the assessments independently or with the assistance of their parents or a research assistant. The CDI has extensive support for its reliability and validity (e.g., Saylor et al. 1984).

**Revised Children’s Manifest Anxiety Scale – 2nd Edition (RCMAS-2).** The RCMAS-2 (Reynolds & Richmond, 2008) is a measure of anxiety for children aged 6-19 years. It consists of 49 items divided into five different scales (physiological anxiety, $\alpha = 0.68$; worry, $\alpha = 0.80$; social anxiety, $\alpha = 0.78$; defensiveness, $\alpha = 0.70$ and total anxiety $\alpha = 0.89$). Children respond either “yes” or “no” to each statement. The physiological anxiety, worry, social anxiety and defensiveness scales are summed to yield a total anxiety score. Higher scores indicate higher anxiety symptomatology.

**Children’s Coping Strategies Checklist (CCSC) and How I Coped Under Pressure Scale.** CCSC is a self-report inventory in which children describe their coping efforts. TD siblings will complete this 62-item self-report questionnaire to measure a child’s dispositional style of coping, specifically how they usually cope when faced with a problem (Ayers & Sandler, 2000). The items are categorized into four dimensions and further divided into various subscales: active coping (i.e., cognitive decision making, direct problem solving, seeking understanding, and positive cognitive restructuring), distraction (i.e., physical release of emotions and distracting actions), avoidant coping (i.e., avoidant actions and cognitive avoidance), and support seeking (i.e., problem-focused support and emotion-focused support). TD siblings will rate the frequency of the strategies described in each statement or question on a 4-point scale (1 = never, 2 = sometimes, 3 = often, and 4 = most of the time). Scores for each dimension are derived by
taking the mean of the subscale scores for the subscales that compose that dimension with higher scores indicating greater use of the strategy. The dimensions have an average Cronbach alpha of .79. The CCSC was originally developed for children aged 9-13 years; however, it has been used with children aged 7-18 years (Roesch et al., 2010; Van der Veek, Derkx, de Haan, Benninga, & Boer, 2012).

**Child Behaviour Checklist (CBCL).** Parents completed the school-age (6-18 years) version of the CBCL (Achenbach & Rescorla, 2001) for their TD children about difficulties now or within the past 6 months. Parents rated statements about the behaviour of their children on a 3-point scale (0 = not true, 1 = somewhat or sometimes true, and 2 = often or very true). The questionnaire contains 118 statements. Total (CBCL-T), internalizing (CBCL-I) and externalizing (CBCL-E) scores were computed separately for TD siblings. Both validity and reliability are high with extensive normative data for this measure (Achenbach & Rescorla, 2001).

**Research Design**

This pilot study used a mixed-method case study design to gain a comprehensive understanding of TD sibling’s adjustment and evaluate the effectiveness of a community based support group. Specifically, a pre-post design was used to measure overall adjustment before and after the 9-week intervention. Furthermore, secondary analysis of the video recordings taken during the support group was done to gain qualitative information regarding the TD siblings’ experiences and overall adjustment.

**Measurement**

**Pre-post adjustment measures.** TD sibling adjustment was measured before and after the intervention through standardized self-report and parent-report measures.
**Qualitative measures.** Video recordings of the weekly TD sibling support were used retrospectively for an exploratory qualitative examination. Each group session was transcribed verbatim by two trained research assistants. The interventionist used multiple open-ended questions throughout the support group to ask participants about their sibling relationship (i.e., “what do you like about your sibling?”, “what are some challenges you face with your sibling?”), feelings and emotions (i.e., “what are your feelings towards your sibling?”, “what are common emotions you experience?”), and coping strategies (i.e., “how do you cope with any stressors in your life?”).

**Content analysis.** For the purposes of this study, researchers followed the qualitative content analysis procedure outlined by Creswell (2007). First, the researcher read all of the support group transcripts to gain an overall sense of meaning. Second, each session’s transcript was reviewed by the researcher to identify units of meaning (verbatim responses). All personal identifiers were blinded from the statements and pseudo names were used for all participants and the individuals they referenced in their statements (i.e., their siblings). In the third step, meaning units were reviewed and coded to identify the essential meaning of each. In the fourth step, codes were reviewed and organized into themes to ensure consistency and applicability. Lastly, the themes were constructed, described using codes, and exemplified using direct quotes (meaning units) from the support group transcripts. Following this initial analysis, a trained research assistant independently worked through these five steps. Subsequently to the secondary qualitative content analysis, the two researchers reviewed the themes previously constructed and highlighted the similarities and differences between the analyses to develop the final themes.
Procedure

Pre-assessment. Following recruitment, families completed a 1.5-h pre-assessment in their homes with the assistance of study personnel. During the pre-assessment TD siblings and their parents completed the demographic questionnaire, the parent-report questionnaires used to measure child adjustment (CDI, RCMAS-2, CCSC, and CBCL), and several other parent report measures not included for analysis in this study.

Intervention. The social support program began following the completion of all pre-assessments of the participants. The program was delivered at a community agency in London and ran for 2-hours, taking place over nine weeks. For the first hour of each session TD siblings attended the sibling support group; then during the second hour both siblings attended recreation time together. The TD sibling support group was video recorded for future analyses.

Sibling support group. The support group consisted of a nine-week psychoeducational program that was adapted from Sibshops (Meyer & Vadasy, 1994) and Kryzak and colleagues (2015). The interventionist administering the support group sessions was a master’s level counselling psychology student with field experience in counselling settings. The curriculum was developed to have lessons and activities specifically focused on characteristics of DS. Each week covered a specific topic; in the first weeks, topics focused on learning about the group and other group members, while the latter weeks focused on sharing feelings, Down syndrome education, coping strategies and positive self-esteem. Siblings participated in various activities and discussions to learn more about each weekly topic. During the fifth session, a guest speaker was present for the full hour to talk with the TD siblings about having a sibling with DS. The guest speaker was a young adult that has an older sister with DS and was able to share her experience
and answer many questions for the participants. Each session ended with a weekly homework assignment that was completed at home independently or with their siblings.

Recreation time. Recreation time followed the curriculum developed from Kryzak and colleagues (2015). Activities and structure was intended to mimic physical education classes at school, including stretching, relay races and cooperative games between siblings. Games were those that would likely be played in other settings by peers and are appropriate for children of varied ages and abilities (i.e., freeze dance, Simon says, and red rover).

Post-assessment. After the intervention, families completed a 1.5-hour post-assessment in their homes with the assistance of study personnel and completed the same self-report questionnaires as in the pre-assessment (CDI, RCMAS-2, CCSC, CBCL).

Chapter 3: Results

Quantitative Results

Child self-report measures.

Participant 1. In contrast to our hypothesis, Katie’s scores on all four subscales of the CCSC decreased from pretest to posttest. Since Katie scored in the average range on the CDI at baseline, it is not surprising that her score remained in the average range post-intervention. In support of our hypothesis, Katie’s scores on the RCMAS were in the average range at pre-test and decreased to below average post-test suggesting she experienced less anxiety following the intervention. Katie’s scores on all self-report measures are summarized in Table 2.

Participant 2. In contrast to our hypothesis, Chad’s reported scores on all four subscales of the CCSC decreased from pretest to posttest. Chad scored in the average range on all subscales of the CDI at baseline, following the intervention all subscales remained in the average range with exception to the ineffectiveness subscale which increased to above average,
suggesting levels of ineffectiveness increased post intervention. In contrast to our hypothesis,

Chad’s scores on the RCMAS increased from average to above average following the
intervention suggesting that he experienced more anxiety following the intervention. However,
the social subscale remained in the average range from baseline to follow-up. Chad’s scores on
all self-report measures are summarized in Table 2.

Table 2: Child-Reported Measures of Coping, Depression, and Anxiety.

<table>
<thead>
<tr>
<th>Measure</th>
<th>Participant 1</th>
<th></th>
<th>Participant 2</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pre</td>
<td>Post</td>
<td>Pre</td>
<td>Post</td>
</tr>
<tr>
<td>CCSC</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Active coping</td>
<td>3.1</td>
<td>2.8</td>
<td>2.8</td>
<td>2.3</td>
</tr>
<tr>
<td>Avoidance coping</td>
<td>2.4</td>
<td>2.2</td>
<td>3.2</td>
<td>2.5</td>
</tr>
<tr>
<td>Support seeking</td>
<td>3.1</td>
<td>2.7</td>
<td>2.3</td>
<td>1.9</td>
</tr>
<tr>
<td>Distraction coping</td>
<td>2.7</td>
<td>2.5</td>
<td>2.0</td>
<td>1.4</td>
</tr>
<tr>
<td>CDI-2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>Average</td>
<td>Average</td>
<td>Average</td>
<td>Average</td>
</tr>
<tr>
<td>Emotional problems</td>
<td>Average</td>
<td>Average</td>
<td>Average</td>
<td>Average</td>
</tr>
<tr>
<td>Negative mood/physical symptoms</td>
<td>Average</td>
<td>Average</td>
<td>Average</td>
<td>Average</td>
</tr>
<tr>
<td>Negative self-esteem</td>
<td>Average</td>
<td>Average</td>
<td>Average</td>
<td>Average</td>
</tr>
<tr>
<td>Functional problems</td>
<td>Average</td>
<td>Average</td>
<td>Average</td>
<td>Average</td>
</tr>
<tr>
<td>Ineffectiveness</td>
<td>Average</td>
<td>Average</td>
<td>Average</td>
<td>Above Average</td>
</tr>
<tr>
<td>Interpersonal problems</td>
<td>Average</td>
<td>Average</td>
<td>Average</td>
<td>Average</td>
</tr>
<tr>
<td>RCMAS-2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>Average</td>
<td>Below average</td>
<td>Average</td>
<td>Above Average</td>
</tr>
<tr>
<td>Physiological</td>
<td>Average</td>
<td>Below average</td>
<td>Average</td>
<td>Above Average</td>
</tr>
<tr>
<td>Worry</td>
<td>Average</td>
<td>Below average</td>
<td>Average</td>
<td>Above Average</td>
</tr>
<tr>
<td>Social</td>
<td>Average</td>
<td>Below average</td>
<td>Average</td>
<td>Average</td>
</tr>
</tbody>
</table>

Note. CCSC = Children’s Coping Strategies Checklist. Mean scores were reported. Higher scores reflect higher frequency of engagement.

CDI = Child Depression Inventory. Scores were norm referenced and categorized into below average, average, and above average groupings.

RCMAS = Revised Children’s Manifest Anxiety Scale. Scores were norm referenced and categorized into below average, average, and above average groupings.
Parent report measure.

**Participant 1.** Katie’s mother reported scores in the normal range before and after the intervention for both internalizing and externalizing subscales of the CBCL (see Table 3).

**Participant 2.** Chad’s mother reported scores in the normal range before and after the intervention for both internalizing and externalizing subscales of the CBCL (see Table 3).

Table 3: *Parent-Reported Child Behaviour Checklist*

<table>
<thead>
<tr>
<th>Measure</th>
<th>Participant 1</th>
<th>Participant 2</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pre</td>
<td>Post</td>
</tr>
<tr>
<td>CBCL</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>Normal</td>
<td>Normal</td>
</tr>
<tr>
<td>Internalizing</td>
<td>Normal</td>
<td>Normal</td>
</tr>
<tr>
<td>Externalizing</td>
<td>Normal</td>
<td>Normal</td>
</tr>
</tbody>
</table>

*Note.* Scores are norm referenced into normal, borderline clinical and clinical ranges. CBCL = Child Behavior Checklist.

**Qualitative Results**

A content analysis was performed to identify themes from participant responses (Creswell, 2007). The researcher reviewed the entire transcript of the weekly support group, coded individual statements into general topics, and categorized coded topics into overarching themes. Direct statements from participants are noted by use of quotation marks. Five themes were identified which included *negative feelings and experiences, positive perceptions and experiences, the role of being a sibling, forbearance,* and *coping strategies.* Each theme and the corresponding meaning codes are outlined in Table 4.

Table 4: *Qualitative Themes and Meaning Codes*

<table>
<thead>
<tr>
<th>Themes of the TD Sibling Experience</th>
<th>Meaning Codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Negative feelings and experiences (n =19)</td>
<td>Challenging sibling behaviour (n = 8)</td>
</tr>
<tr>
<td></td>
<td>Embarrassment (n = 4)</td>
</tr>
<tr>
<td></td>
<td>Annoyance (n = 3)</td>
</tr>
<tr>
<td></td>
<td>Negative sibling quality (n = 2)</td>
</tr>
<tr>
<td></td>
<td>Nervous (n = 2)</td>
</tr>
</tbody>
</table>
Theme 1: Negative Feelings and Experiences. Being the sibling of a child with DS can be a daunting task, and at times the challenges may seem overwhelming, especially when you are a child or adolescent. Undoubtedly, some circumstances are perceived as more challenging than others. The participants described their thoughts, feelings, and experiences when faced with some of their siblings’ difficult behaviours, qualities, and needs. The emotional and practical challenges varied between siblings, however there were some commonalities. Specifically, both siblings disclosed a time that they were embarrassed from their siblings’ behaviour. Katie mentioned a reoccurring social predicament that is quite embarrassing for her.

“Whenever I introduce her to someone she feels really awkward or embarrassed so she often smacks me on the bum or says something that’s embarrassing because she doesn’t know how to react so it kind of makes me mad when she does that because it’s awkward”

Another common challenge according to the participants was finding alone time, away from their sibling. Although they emphasized enjoying spending time with their sibling, they also expressed the need for opportunities to do things without their brother or sister and have a place of their own at home. Furthermore, both participants explained that when they are enjoying their personal hobbies and activities there is still persistent communication from their siblings, resulting in annoyance and frustration.
“If I am sleeping over at my Grandma’s or something he will always facetime me because he always wants to be with me. He never wants to leave me alone which gets really annoying.”

Despite understanding and empathizing with the difficulties their siblings face day-to-day, both participants explained that there are days on which the irritating and challenging conduct of their brother or sister can give them a hard time.

“When she has a really bad day at school and then acts up at home too – she just does things that she knows irritates you”

Additionally, participants discussed the various qualities of their siblings that significantly impacted their day-to-day stressors and have subsequently been difficult to deal with. A sibling quality that both participants found frustrating was their sibling’s speed when doing simple tasks or getting ready in the morning.

“Emily I swear is a turtle, seriously. That really bothers me.”

Lastly, when Katie discussed the reality of her and her sister attending the same high school next year, she expressed worry and concern. Not only was Katie anxious about the presence of her sisters challenging behaviour at school but she was additionally worried about the future role she will have to assume as her older sister.

“I am just kind of nervous because she has really bad habits like pulling down her pants or whatever and I just don’t know if I can do that”

**Theme 2: Positive Perceptions and Experiences.** Although participants acknowledged the challenges associated with having a brother or sister with DS, they both expressed a number of positive aspects and perceptions. The participants reported having fun with their siblings and highlighted different activities they enjoy doing with their brother or sister with DS. Both of the participants recognized positive qualities and traits in their siblings. They described how they
happily engaged in imaginative play and shared humor, intimacy, and the special bond they share with their sibling.

“I love it that she says I love you a lot. She’s always saying that”

“She’s overall a really energetic person. She’s just fun to be around.”

“He makes me laugh.”

For Katie, the experience of having a sibling with DS was highly valued and appreciated. She articulated immense love towards her sibling and felt that she had gained positively and learnt from her sibling.

“I try to picture myself without her and I can’t. She’s the reason why I am going for educational assistant, she is the reason I am learning so much about kids and I love it. She is my little ray of sunshine and I love it”

**Theme 3: The Role of Being a Sibling.** Much like typical sibling relationships, our participants described what it means to be a sibling along with the various roles and responsibilities that they take on. Though, being a TD sibling to someone with DS can have some unique qualities; thus, some distinctive roles emerged. With both participants being the older sibling to their brother or sister with DS, they displayed a precocious sense of responsibility. This included ensuring that their siblings were well behaved, being a person of support and comfort, and teaching them certain skills (i.e., cooking) in order for their sibling to be less dependent on them for completing certain tasks. The participants mentioned different situations that have occurred which indicated their own sense of responsibility and additionally asserted the expectation that others have for them to be responsible for their sibling with DS. For example, Katie cited a recent situation that occurred at school.

“When she came for new student day, she would go into the library and lay on the floor misbehaving. So everyone is running at me saying Katie get your sister off the floor, your sister is acting up.”
Another prominent sibling role that arose was the positive relationship they share and the essential impact it has on their sibling with DS. Not only did the participants describe the level of support and comfort they provide to their siblings, but they also depicted how they are a very important role model for their brother or sister with DS.

“I am Emily’s role model and we do a lot of things together so if I wasn’t there all the time for her she would be a lot more down and out”

Moreover, since the participants have such a pivotal role in their siblings’ life, they explained that they have an obligation to spend quality time with them to continue to foster their sibling bond and fulfill their siblings need.

“He always wants to play with me”

In addition, the sibling role extended to having to explain, educate, and advocate on their siblings behalf to various people outside of the family including friends.

“Sometimes I have people ask me what it’s like and I just say it is normal, she has different needs than I do. She is slower and needs more things.”

**Theme 4: Forbearance.** Some of the challenging behaviours, needs, and qualities of the brother or sister with DS illustrated in the first theme can be hard for the TD sibling to bear. Therefore, the participants look for ways to deal with these situations. The participants showed great understanding of their siblings’ behaviour and unique needs. While their siblings’ behaviours and needs may be challenging, they were able to demonstrate understanding and adjust in a way that would be beneficial for both themselves and their sibling. For example, Katie realized that being reactive when her sister is upset may only worsen the situation, therefore she developed a different approach to deal with her sister when she gets angry.

“The older Emily gets she doesn’t have as many temper tantrums. But when she does I will try to make myself look really sad. I will try to, not fake it, but act really upset so she feels bad. But if I get mad at her there is no point in trying to converse.”
For some situations participants thought it was better to ignore the behaviour. However, this was reported as not always being effective, consequently participants often had to adjust to their siblings’ behaviour to reduce conflicts.

“If she is annoying me then I will ignore her or I just give her something to do like make her think that she is helping me doing my homework by writing something down like give her something to do. She likes to be helpful but isn’t always helpful.”

Another challenge for these siblings was balancing their wants and needs with those of their siblings. For example, Chad has had to develop different strategies to accommodate his brothers desire to spend time with him in his room and his own want and need for a private space at home. Thus, he has had to problem solve to adjust to these differing demands.

“I will hide something in the house and give him a map to find it. His birthday party is tomorrow and I made a room pass because he really likes to come into my room but I don’t like it.”

Participants were able to show a growing ability to adjust, be patient, and show tolerance towards their siblings’ unique forms of play and behaviour. The participants reported that after a while they get used to the behaviour. Moreover, Katie has even learnt to appreciate some aspects of her sister’s engagement in imaginary friends and found joy in it herself.

“It’s fun, but it gets annoying. I mean you get used to it.”

**Theme 5: Coping Strategies.** Given the various challenging experiences these TD siblings face, it was important to talk about coping strategies. Coping was one of the topics highlighted in the support group curriculum; however, following the group conversation on coping strategies and discussing what they are and when one would use them, the participants had difficulty identifying strategies that they are actively using or have used in the past. Nevertheless, the participants did identify a few different coping strategies that they commonly
use when they are experiencing negative emotions (i.e., sad, mad, nervous). Both participants stated that they engage in activities that distract them from whatever is causing them distress.

“Play piano.”

Another shared strategy between both participants was escaping the situation and spending some time alone, away from the stressor, and avoiding the problem all together.

“Go into my room and lock the door”

Lastly, both participants expressed difficulty talking to people about their stressors and emotions. Despite identifying different people in their lives that they trusted, they both suggested that did not want to involve or burden anyone else into their struggles.

“No, I don’t like to talk to someone when I am mad because then I get them mad and it is just... negatively going all the way around. So I just keep it to myself.”

“If I told someone it would be a mess too because they would tell someone, and they would tell someone”

Chapter 4: Discussion

The purpose of this pilot study was to explore and address the needs of TD children who have a brother or sister with DS while subsequently evaluating the effects of a targeted community based support group on their social-emotional adjustment. TD siblings have often been ignored, misunderstood and unsupported, but nevertheless they are expected to behave and act more maturely than their peers with typically developing siblings, and these added responsibilities naturally increase as they grow older. Although the lack of attention on TD siblings by clinicians and researchers may be attributed to limited time, funds, and resources these TD siblings are children themselves, and have an equal right to adequate support. By using a bioecological lens in this initial investigation we can frame our knowledge of their unique experiences, social-emotional adjustment, and overall needs to enhance their support.
This pilot study aimed to address the needs of TD siblings by qualitatively exploring their feelings, emotions, coping strategies, stressors, and the nature of their sibling relationship all of which were discussed in the weekly sibling support group. Furthermore, a sibling support group curriculum was adapted from previous research to specifically target TD children who have siblings with DS. In order to determine the effectiveness of this targeted sibling support group, TD siblings internalizing and externalizing symptoms, as well as their coping strategies we examined before and after participating in the group.

**Interpretation of Findings**

The effectiveness of the support group on TD siblings’ overall adjustment was measured through standardized measures of depression, anxiety, and coping strategies before and after the intervention as well as standardized parent report measures of TD sibling internalizing and externalizing symptoms. Parent reports and sibling self-reports did not reveal strong evidence for the effectiveness of this support group; however, limited conclusions can be made due to the sample size. Since neither parent reported clinically significant levels of internalizing or externalizing symptoms at baseline, it is not surprising that the scores did not change following the intervention. This pattern was replicated for TD siblings’ self-reported depression. This is consistent with the findings about maladjustment in TD siblings in which some siblings show clinical maladjustment and others do not. It is also possible that the children’s self-reports underestimated their difficulties at baseline. TD siblings of children with disabilities have been found to report less pronounced difficulties at baseline compared to parents and direct observation by researchers (Rossiter & Sharpe, 2001). This may reflect siblings downplaying their difficulties so as not to add to parental stress, or wanting to give the impression of being the “good” child in the family.
The same pattern observed in the parent reports and TD sibling self-reported depression was not present for the TD siblings self-reported anxiety. Specifically, Katie and Chad both reported average levels of anxiety at baseline; however, at follow-up Katie’s self-reported scores were below average whereas Chad’s scores were above average. Katie’s scores suggest that she experienced average feelings of anxiety before the support group but her anxiety decreased to below average levels after the support group. Since there was no control group, this decrease cannot be attributed to the support group exclusively; however future research can investigate this preliminary finding further. On the other hand, Chad’s reported anxiety was average prior to participating in the support group but increased to above average levels at the end of the intervention. Although the group facilitator ensured that the support group’s discussions balanced both positive and negative aspects of being a sibling to a child with DS; it could be the case that the support group conducd TD siblings to develop a greater awareness of their difficulties and negative experiences. Conjointly, one of the aims of the support group was to encourage emotional expression, insight, and reflection; thus, it may be possible that the development of these skills generated a greater awareness and understanding of their individual experiences which resulted in more accurate responses post-intervention on the anxiety questionnaire. It could also be the case the Chad was more honest in his responses on the questionnaires following the group if he felt more comfortable with and less judged by the research assistants than he did at the baseline assessment. In conclusion, there are a host of other potential factors that could have contributed to both of the TD siblings changes in scores at post-intervention for their symptoms of anxiety, all of which will need to be empirically tested before any definitive conclusions can be made.
In contrast to the researchers hypothesis, TD siblings’ self-reported coping strategies decreased post intervention. Although this is not what the researchers initially hoped for, it is important to note that both participants had decreased avoidant coping strategies. This finding is partly supported in previous research; for instance, Roberts and colleagues’ (2015) examination of a controlled trial of the SibworkS program showed that TD siblings engaged in less avoidant coping strategies at post-intervention. This finding is beneficial for the participants since avoidance coping has been significantly positively correlated with health problems and risk behavior (Steiner, Erickson, Hernandez, & Pavelski, 2002). Furthermore, a greater reliance on avoidance coping has been significantly associated with more depression, anxiety, and physical symptoms (Holahan & Moos, 1991). Given that avoidance strategies (i.e., avoidant actions, repression, wishful thinking, and denial) have been shown to be unhelpful in times of heightened stress (Lengua, Sandler, West, Wolchik, & Curran, 1999) it is possible that siblings may benefit from understanding the reality of the disability while having opportunities to discuss their concerns.

Although this initial investigation of the effects of a community-based support group revealed limited evidence to support the intervention’s effectiveness, the qualitative analysis revealed five themes that highlighted the TD siblings’ unique experiences. While this study did not make specific hypotheses for the qualitative component of the study, it was anticipated that the results would describe the lived experiences of TD siblings of children with DS and highlight the unique experiences they encounter to inform how future support programs can meet their needs. Given that the two TD siblings that participated in the support group had a rather large age difference, their current experiences, difficulties, and overall adjustment varied. Nonetheless,
common themes emerged in the qualitative analysis that described their experiences of being a sibling to someone with DS.

The first theme reported herein is consistent with previous research involving siblings of children with various developmental disabilities, particularly reports of difficulties with finding private time (Luijkx, van der Putten, & Vlaskamp, 2016; Moyson & Roeyers, 2012), strange behaviours (Mascha & Boucher, 2006), and feelings of embarrassment (Roeyers & Mycke, 1995). The most frequently mentioned negative feelings by the participants were embarrassment, annoyance, frustration, and worry or concern. Although most of these feelings were shared, worry and concern was only expressed by Katie. It could be possible that worry and concern regarding the future and sibling welfare is more relevant for adolescents, as they are beginning to grapple with their own future plans. Petalas and colleagues’ (2009; 2012) research discovered worry and concern to be a significant theme with their adolescent sample whereas it did not appear with their younger child sample. This alludes to worry and concern being particularly relevant to adolescents and accentuates age and developmental differences in TD siblings experiences. Another difficulty the TD siblings shared was finding alone time, away from their sibling with DS. Not having alone time, or the incessant communication from their sibling was often a precipitating factor for many of the previously mentioned negative feelings they experienced. Though the participants discussed many negative feelings and experiences, this is not uncommon from sibling relationships of two typically developing children, however the causing of these feelings may be distinctive.

Despite the presence of these negative feelings and experiences, both TD siblings showed that they were forbearing towards their brother or sister with DS, albeit with difficulty and at great personal cost. This theme has been previously identified in qualitative research suggesting
that developing tolerance, understanding and adapting to the behaviour acts as coping strategies for the TD siblings (Luijkx et al., 2016; Moyson & Roeyers, 2012). For the TD siblings in this study the emergent theme found among coping strategies were activities or behaviours that allowed them to be distracted and isolated from the stressor. Additionally, both participants expressed difficulty talking to other people about their stressors and feelings. Other TD siblings have expressed this same concern in previous research, specifically they related that they avoided discussing their sibling to others and often denied the difficulties that they experience and the various stressors in their lives (Corsano, Musetti, Guidotti, & Capelli, 2017). There has been little research systematically exploring TD siblings’ coping strategies in the context of having a brother or sister with a developmental disability.

It has been reinforced in the literature that having a sibling with a developmental disability is challenging, however the TD siblings in this study were able to balance their negative experiences and difficulties with positive perceptions and experiences. Hastings (2007) has already stressed the importance of studying TD siblings’ own perceptions of positive contributions and the investigation of the functional significance of these perceptions for adjustment. Therefore, by giving TD siblings the opportunity to talk about their life as an individual and as a sibling to someone with DS, we received a “full” story about the siblings’ experience – the good and the bad. Positive perceptions and experiences were present for both participants; for instance, they both shared positive moments and likeable qualities in their sibling. Further, Katie was able to reflect on her increased tolerance and understanding of disability and diversity, a profound appreciation for her sister, and a sense of having gained from her sibling relationship. Other qualitative studies have delineated positive aspects of the sibling experience revealing similar accounts of TD siblings in the current study such as recognizing
positive qualities and recounting joyful memories (Petalas et al., 2009; 2012). It has been asserted that TD siblings’ positive perceptions may serve a functional role in siblings’ adaptation to growing up with a brother or sister with DS (Taunt & Hastings, 2002). Thus, the positive experiences and perceptions of being a sibling to a brother or sister with DS discussed in the present support group may bolster TD siblings’ overall adjustment.

The last important theme revealed in this study was the participants description of their role as a sibling. A sense of responsibility was a prominent theme in the support group discussions by the TD siblings. They both shared various caretaking and teaching responsibilities assumed both at home and in the community. Katie’s sense of responsibility was much greater than Chad’s, this could be attributed to a number of factors such as gender, age, and personality. There could be a possible positive impact when a TD sibling has responsibility for their sibling with a disability such as leading them to select a profession related to improving practices for people with disabilities (Marks, Matson, & Barraza, 2005). This precocious sense of responsibility is not unique to the participants in our study, Corsano and colleagues (2017) also found that siblings felt a sense of responsibility for their brother or sister with DS. It could be the case that both participants had this feeling of responsibility since they were older than their siblings with DS; however, future research would need to investigate this further. The TD siblings role extended to advocating and explaining on their brother or sisters behalf. Similar themes have been found in previous research. For example, many siblings have had difficulty dealing with their peers or community members lack of understanding (Petalas et al., 2012). Lastly, both TD siblings identified the important and positive role they play in their siblings lives. Although this has yet to be revealed in previous literature, this positive orientation to their relationship may have positive implications for their relationship and adjustment.
In conclusion, our findings suggest that these siblings have a complex, realistic view of their brother or sister, encompassing both positive and negative feelings. This is harmonious with other qualitative research, stressing that TD children and adolescents have a mixed perspective on the experience of having a sibling with a developmental disability (Corsano et al., 2017; Petalas et al., 2012).

**Clinical Implications**

Due to the pilot approach of this study, conclusions are limited though there are a number of implications for future research and clinical practice. It was evident in this study that the participants had a large age gap and had differing experiences both in the support group and in their current life circumstances. Similar to the current study, most studies on siblings have grouped together siblings of all ages (from early childhood to adolescence), and therefore it is difficult to interpret age-based differences in outcomes (Orsmond & Seltzer, 2007). For instance, the information that was shared and the level of insight and reflection was different for each participant. Thus, increased introspection may not be intuitively accessed in younger siblings and this may have implications for the support and promotion of siblings’ positive emotional well-being. This is relevant for practitioners developing support groups for TD siblings as they may want to acknowledge different developmental stages and create age appropriate curriculums accordingly.

This study recruited participants based on one single characteristic: being a sibling of an individual with DS. The implication behind this inclusion criterion is that all siblings require interventions and supports. Overall, our participants did not have clinical concerns at baseline; thus, it is possible that sibling-focused activities which oftentimes focuses on difficulties with siblings, may actually increase problematic functioning for siblings, a phenomenon demonstrated
in other areas of child and adolescent psychology (e.g., Lilienfeld, 2007). Given the prominent presence of positive experiences in the qualitative findings, it appears imprecise to assume that a sibling is experiencing problems because of their sibling status alone. Therefore, it is important not to take a well-adjusted TD sibling and suggest participation in a support group until a rigorous investigation of the potential risks and benefits of sibling support groups is completed. Practitioners may want to acknowledge and build on the positive views held by TD siblings, rather than initially assuming that they are primarily burdened with negative experiences.

Lastly, a few intervention studies focused on siblings of children with a developmental disability have had a strong focus on educating siblings about the developmental disabilities (Lobato & Kao, 2002; Smith & Perry, 2005). Within the present TD siblings’ accounts, a need for knowledge did not emerge as a theme, suggesting that this may be much less relevant to TD siblings. Parents and professionals need to be aware of the issues siblings face at different developmental stages and recognize the different needs. Therefore, ethically, interventions should only be recommended to families and TD siblings if evidence exists that the intervention is meeting a need for that TD sibling in question. All TD siblings can still be recruited, however a more cautious, reasonable, and evidence-based approach for allocating TD siblings into groups is necessary.

**Limitations**

Limitations of the current pilot study can inform future research. First, the current sample is too small to allow us to detect significant changes from the standardized measures collected before and after the intervention. Additionally, a larger sample would also enable the in-depth investigation of the response patterns that emerged from the qualitative data. For the current study, we experienced a low response rate by families from invitations to participate. In addition,
we had one sibling dyad drop out at the beginning of the program. Unfortunately small sample sizes is a common theme in the literature examining support groups for TD siblings of children with developmental disabilities (Tudor & Lerner, 2015). Therefore, the sample size was limited and replications of this work will help to illuminate whether larger samples of siblings have similar outcomes.

When researchers have examined the various barriers preventing families from participating in a variety of interventions, a number of factors have emerged. Specifically, Koerting and colleagues’ (2013) review revealed situational barriers (i.e., transportation, child care, financial difficulties, inconvenient timing and/or venue, and other commitments) and psychological barriers (i.e., stigma) to participation in interventions. This study did not provide participating families with any financial compensation for their time and/or transportation, based on previous research this could be considered a limitation to the intervention and restrict some eligible families to participate. Moreover, this program occurred on Saturday mornings in the fall, thus again inevitably restricting families with prior commitments on that date and time. Nonetheless, the program tried to deliver the intervention on days and times that would reach the most affected families and welcomed feedback from participating families regarding dates and times for future programs.

Given the small sample size it was not possible to divide the TD siblings up by age into subgroups. As previously mentioned, the two participating TD siblings had a significant age difference and thus were presently experiencing different conflicts and experiences individually and with their sibling with DS. In addition to their various life stages, their cognitive skills and abilities varied. Although the support group facilitator ensured that the information was
presented and discussed in a way that both participants could understand, individually tailored curriculums for different cohorts may enhance the effects of the program.

Another limitation presented during the pre-post administration of the self-report measures for the TD siblings. Specifically, the younger participant asked for assistance and clarification when completing the various questionnaires at the initial baseline assessment, resulting in a research assistant reading aloud certain questions and being present when they were being completed. This may have caused a social desirability bias on the measures of depression, anxiety, and coping. Subsequently, ununiform administration of measures across participants was present as the older participant completed these questionnaires independently.

Although the support group curriculum used was manualized, which is a first step to ensuring treatment fidelity, we did not directly measure the extent to which the curricula were followed. It will be important in future research to include treatment fidelity measures to ensure the support group provides the intervention intended.

Lastly, the pre-post comparison component of this study used one group who participated in the sibling support group; this design cannot control for a host of confounds. Additionally, no follow-up measures were used to assess the long term outcomes of the program. Thus, comparison to a control group who receives a different intervention or no intervention would provide a more rigorous demonstration of the effects of support groups on siblings of children with DS.

**Future Research**

These limitations notwithstanding, our study provides useful insights into TD siblings’ experiences of having a brother or sister with DS, and with the evaluation of the support group can be used to inform future research and development of support programs. To address the
outstanding limited sample size future research could explore different ways to make the program more accessible to the many families originally invited into this study. Given that this program is designed as a universal prevention program, offering the program in a different format may encourage more parents to enroll their children. Also, future research can examine systemic barriers in the macrosystem (i.e., respite and funding) that may have contributed to low participation rates.

Moving forward in the research, being a TD sibling should not be maintained as the sole inclusion criterion. Therefore, it is incumbent upon researchers in this field to consider the many other variables that may warrant a child to be a candidate for sibling support groups. Effective sibling-focused interventions and support groups may necessitate categorization beyond the diagnostic categories of their sibling with a disability. Consistently, reporting of sibling demographic and developmental factors, and consideration of how these factors may relate to sibling outcomes, will be valuable in future studies to identify at-risk siblings and selecting appropriate services for them. This greater focus on different TD sibling factors can help with the development of subgroups and/or cohorts of participating siblings. Subgroups and cohorts can be created for different siblings presenting with different needs. This may include different groups for siblings who present with different levels of maladjustment, different age groups, and differing sibling relationship needs. In addition, various factors in the TD siblings’ person context such as gender, birth order, age, cognitive and interpersonal abilities, and psychological functioning could reveal interesting processes for the future design of sibling support groups. Various factors intrinsic to the child such as their ability to manage stress, coping strategies, and individual cognitive styles, could reveal useful ways of explaining how different aspects of the intervention impact different children.
Finally, understanding the influence of the chronosystem further could be explored by taking a life-span approach to the study of siblings. Longitudinal studies that follow families through their lifespan and transitions, and those that track the developmental age of the TD sibling would prove very useful in targeting areas of support for children and youth of different ages. Therefore, this study undertook an underexplored research question providing a basis from which future research and clinical services can be directed. It is important that future work in this field considers the limitations and gaps currently presented in this specific area of study and set forth to create services for this unique population of youth that can be carefully, rigorously, and effectively tested for their utility and lead to useful and worthwhile resources for TD siblings.

Summary

In conclusion, these initial findings, though limited, suggest the need for further investigation of sibling support groups for brothers and sisters of children with DS. Building on the limited sibling support group literature, this program and research contribute by focusing on siblings of children with DS and including both qualitative and quantitative analyses to measure TD siblings outcomes and experiences during and after the intervention.
References


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93-205.

Developmental Psychology, 4, 407–411

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Appendix A: Ethics Approval

Date: 11 February 2019
To: Dr. Nicole Neil

Project ID: 108669

Study Title: Evaluation of a Social Skills Program for Children with Developmental Disabilities and their Siblings: Pilot and Randomized Controlled Trial

Application Type: Continuing Ethics Review (CER) Form

Review Type: Delegated

Meeting Date: 01/Mar/2019
Date Approval Issued: 11/Feb/2019
REB Approval Expiry Date: 14/Feb/2020

Dear Dr. Nicole Neil,

The Western University Non-Medical Research Ethics Board has reviewed this application. This study, including all currently approved documents, has been re-approved until the expiry date noted above.

REB members involved in the research project do not participate in the review, discussion or decision.

The Western University NMREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the Ontario Personal Health Information Protection Act (PHIPA, 2004), and the applicable laws and regulations of Ontario. Members of the NMREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB. The NMREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 0000941.

Please do not hesitate to contact us if you have any questions.

Sincerely,

Daniel Wyworski, Research Ethics Coordinator, on behalf of Prof. Randall Graham, NMREB Chair

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).
# Appendix B: Support Group Curriculum

<table>
<thead>
<tr>
<th>Week</th>
<th>Purpose</th>
<th>Activity Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Week 1</td>
<td>Meet and learn about the other siblings in the group.</td>
<td>Three things in common game – Each sibling pairs up with another sibling. Each pair must find three things that they have in common and write them down on paper. After they finish, each pair shares what they learned with the rest of the group.</td>
</tr>
<tr>
<td>Week 2</td>
<td>Share things about themselves and their families with the group.</td>
<td>Similarities and differences game – Siblings pair up. Each sibling uses a different colour marker. On a sheet of paper, they draw a Venn diagram with an oval for each sibling. The siblings in each pair discuss what the similarities and differences are about themselves and their families. They fill in the diagram showing their similarities and differences.</td>
</tr>
<tr>
<td>Week 3</td>
<td>Share how their siblings make them feel. Identify and share good and bad feelings about their siblings using specific examples.</td>
<td>Faces of feelings – On a worksheet with four blank faces, each child draws a different expression of how their sibling with DS makes them feel. Siblings share the different faces with the group.</td>
</tr>
<tr>
<td>Week 4</td>
<td>Down syndrome knowledge.</td>
<td>Short book on DS – Group facilitator reads through the book with the siblings, giving them an opportunity to ask questions throughout.</td>
</tr>
<tr>
<td>Week 5</td>
<td>Guest Speaker (young adult TD sibling of someone with DS).</td>
<td>Open discussion – Give siblings an opportunity to talk to someone older who has grown up with a sibling with DS. Siblings came with questions that they wished to ask the guest speaker.</td>
</tr>
<tr>
<td>Week 6</td>
<td>Discuss coping strategies.</td>
<td>Fortune teller activity – Siblings make a fortune teller and write 8 different coping strategies that they like to do.</td>
</tr>
<tr>
<td>Week 7</td>
<td>Share why they are important to their sibling and discuss positive self-esteem.</td>
<td>Positive shield activity – Siblings write/draw various things on their shield that can protect them from negative self-talk.</td>
</tr>
<tr>
<td>Week 8</td>
<td>Review all topics discussed in group.</td>
<td>Jeopardy – Siblings play jeopardy with questions about the information and skills learnt in the group.</td>
</tr>
<tr>
<td>Week 9</td>
<td>Good-bye Party.</td>
<td>Good-bye cupcake party – Siblings decorate their own cupcakes with various toppings.</td>
</tr>
</tbody>
</table>
Invitation to Participate in Research
A Social Skills Program for Children with Down Syndrome and Their Siblings

We are looking for volunteers to take part in a study to determine if a social skills program for children with Down syndrome and their typically developing siblings will improve the sibling relationship and the social, communication, and play/leisure skills of children with Down syndrome. To participate, families must have a child with Down syndrome, with a typically developing sibling. Both siblings must be between 5 and 17 years old.

Children with Down syndrome can present with social and communication impairments that affect their interactions with peers and siblings. Typically developing siblings often do not have skills to help increase positive interactions with their siblings who have Down syndrome. As a result, siblings may limit the amount of time they spend together, children with Down syndrome may miss opportunities with their siblings that could enhance generalization of skills and development of wider social networks, and the typically developing siblings may show poor adjustment.

How it works:

As a parent or caregiver you will be asked to:
- Complete a 1.5 hour pre- and post-assessment

Children will attend 2-hour sessions on Saturday mornings for 10 weeks beginning October 2018.

During the first hour, children with Down syndrome participate in individually designed interventions that address:
- Social skills
- Communication skills
- Play/leisure skills

At the same time, typically developing siblings participate in their own group activities involving:
- Lessons on developmental disabilities
- Arts and crafts
- Games

During the second hour, all of the children reconvene for a supervised recreation session together where they play:
- Relay races
- Bean bag tosses
- Obstacle courses

If you would like more information on this study or would like to receive a letter of information about this study please contact the researcher at the contact information given below.

Contact Information

Dr. Nicole Neil,
PhD, BCBA-D
Faculty of Education
Western University,
519-661-2111
Appendix D: Email Script for Recruitment Organizations

Subject Line: Sharing an Invitation to Participate in a Research Study

Hello,

My name is Nicole and I'm an assistant professor at the University of Western Ontario. I have received your email address from [insert method of obtaining contact information]. I am emailing to request that you share a recruitment flyer about our study with members of your organization via email or on your website.

Briefly, the study’s purpose is to determine if a social skills program for children with Down syndrome and their typically developing siblings will improve the sibling relationship and the social, communication, and play/leisure skills of children with Down syndrome.

During the study, children will attend 2-hour sessions for 10 weeks. The program begins in January 2018 and will be held on the following dates:
January 13, 20, and 27
February 3, 10, 17, and 24
March 3, 10, and 24

During the 1st hour, children with Down syndrome participate in individually designed interventions that address social skills, communication skills, play/leisure skills. During the sibling support group, typically developing siblings will be provided lessons and activities that focused on characteristics of Down syndrome. During the second hour, all of the children reconvene for a supervised recreation session together where they play, relay races, bean bag tosses, obstacle courses, and other games together. Parents or caregivers will be asked to complete a 1.5 hour pre- and post-assessment.

I have attached a recruitment email and recruitment flyer to this email. If you would like more information on this study about this study please contact me at the contact information given below.

Thank you,

Nicole Neil, PhD, BCBA-D
Assistant Professor
Coordinator, MPED Applied Behavior Analysis
Faculty of Education
Appendix E: Letter of Information and Consent

**Project Title**

Evaluation of a Social Skills Program for Children with Developmental Disabilities and their Siblings – Pilot and Randomized Controlled Trial

**Document Title**

Letter of Information and Consent – Parent/Guardian

**Principal Investigator + Contact**

Principal Investigator  
Nicole Neil, PhD, BCBA-D, Faculty of Education  
Western University

1. **Invitation to Participate**

You are being invited to participate in this research study about the effectiveness of a social skills program for children with developmental disabilities and their typically developing siblings because you are the parent or guardian of a sibling dyad where one sibling is diagnosed with a developmental disability.

2. **Why is this study being done?**

Children with developmental disabilities present social and communication impairments that affect their interactions with peers and siblings. Typically developing siblings often do not have skills to help increase positive interactions with their siblings who have developmental disabilities. As a result, siblings may limit the amount of time they spend together, children with developmental disabilities may miss opportunities with their siblings that could enhance generalization of skills and development of wider social networks, and the typically developing siblings may show poor adjustment.

The purpose of this study is to determine if a social skills program for children with developmental disabilities and their typically developing siblings will improve the sibling relationship and the social, communication, and play/leisure skills of children with developmental disabilities.

3. **How long will you be in this study?**

It is expected that you will be in the study for 24.5 hours over 15 weeks. There will be two 1.5-hour pre and post assessment sessions, two 0.5 hour assessment sessions, 10 2-hour intervention sessions, and one 0.5 hour follow-up assessment session during your participation in this study.

4. **What are the study procedures?**

If you are taking part in the randomized controlled trial, you will be randomly assigned to the treatment or control group. If you are in the treatment group you will receive treatment as soon as the study commences. If you are in the control group your treatment will be delayed for up to
six months. Members of the control group will be asked to complete assessments while they are waiting for their treatment.

If you choose to participate you will be asked to:

**Complete a 1.5 hour pre-assessment in your home.**
This will include
- Completing parent and child questionnaires regarding your children’s behavior and the quality of their interactions.
- Researchers will video record your child with a developmental disability and his or her sibling while playing games together.
- Your child without a developmental disability completing questionnaires about his or her emotions and relationship with his or her sibling.

**Complete a brief support group check-in form every week**
This will include
- Completing a questionnaire regarding your typically developing child’s behaviors
- Your child without a developmental disability completing a questionnaire about their behaviors

**Schedule 10, 2-hour social skills program sessions once per week at a community agency.**
During the program we provide skills instruction for children with developmental disabilities, a support group for typically developing siblings, and inclusive recreation activities for all the children together. For the first hour of each session, children with developmental disabilities receive individualized skills intervention, while siblings attend the support group. During individualized skills intervention, children with a developmental disability will receive instruction to address social, communication, and play/leisure skills that are important for interacting with their siblings.

During the sibling support group, typically developing siblings will be provided lessons and activities that focused on characteristics of developmental disabilities. Each week will cover a specific topic; in the first few weeks, topics focus on learning about other group members, while the latter weeks focus on developmental disability knowledge. During the support group, typically developing siblings will be given weekly assignments to complete at home with their siblings. Families are responsible for transporting these sheets to and from the group. At the end of the study they are given to the families for their own use or disposal. You will also be asked to provide a snack for sharing during the support group. If you are unable or do not wish to provide a snack, the researchers will arrange to provide a snack on your behalf.

The second hour of each session all children will attend recreation time together. During recreation participants will engage in activities intended to mimic “field days” and physical education classes at schools, including stretching, relay races, cooperative games between siblings (e.g. both siblings in a hula hoop trying to walk around the gymnasium to target locations, catching a ball, or bean bag toss), freeze dance, Simon says, red rover, and red light, green light, 123. Games are those that would likely be played in other settings by peers and were
appropriate for children of varied ages and abilities. Children will be expected to follow rules throughout the program. Examples include: Keep hands to ourselves, listen to others, and stay in recreation area unless with an instructor. Children who repeatedly do not follow the rules will be asked to sit out of programming for short periods of time. Individual instruction will be provided to assist with following the rules. During the recreation time, each sibling dyad will be pulled aside individually to video record them playing the same games as during the pre-assessment. This is to assess the sibling relationship.

Complete two 0.5 hour assessments in your home.
One will occur during the week between the 3rd and 4th program sessions. The other will occur during the week between the 7th and 8th program sessions. This will include: Researchers will video record your child with a developmental disability and his or her sibling playing games together.

Complete a 1.5 hour post-assessment in your home.
This will include
- Completing parent and child questionnaires regarding your children’s behavior and the quality of their interactions.
- Researchers will video record your child with a developmental disability and his or her sibling while playing games together.
- Your child without a developmental disability completing questionnaires about his or her emotions and relationship with his or her sibling.

Complete a 0.5 hour follow-up assessment in your home approximately 4 weeks after the last program session.
This will include:
- Researchers will video record your child with a developmental disability and his or her sibling while playing games together.

Throughout your children’s participation, they will be video recorded as part of the social skills program’s procedures and curriculum, including skills instruction, sibling activities, and recreation sessions. Video recording of sessions will take place to ensure treatment integrity and for purposes of data collection. Video recordings will be viewed by project staff only, and will be kept in a locked office.

5. What are the risks and harms of participating in this study?
Generally, the procedures used in this study present no risks to your child beyond what you might encounter in everyday activities.

For your child with a developmental disability, when certain procedures are introduced, it is possible that there may be a short-term increase in problem behavior or stress. To reduce this risk, sessions are supervised by a Dr. Nicole Neil, a Board Certified Behavior Analyst with experience in reducing problem behavior and anxiety.

For your typically developing child, talking about his or her sibling with a developmental disability might be emotional or stressful. To minimize this possibility, the research will balance
discussions of stress with discussions of positive aspects. To minimize this risk, interventionists administering the support group are students of counselling and with field experience in counselling settings. A referral to a community counselor will be available if you feel like there is anything that has come up for you or your child in the research process that is upsetting.

A potential risk of participation in this research is a loss of confidentiality, but measures will be taken to protect identities of all participants, as described in the confidentiality section.

6. What are the benefits?
Participants will benefit directly in that we will determine what social skills your children have, and conduct an individualized intervention with the goal of improving social skills. Typically developing siblings may learn about the nature of their sibling’s developmental disability and develop new coping strategies and positive social interaction skills. This research may lead to the development of more efficient and effective intervention/counseling/recreation programs for children with developmental disorders and their siblings.

7. Can participants choose to leave the study?
If you decide to withdraw from the study, you have the right to request withdrawal of information collected about you. If you wish to have your information removed please let the researcher know.

8. How will participants’ information be kept confidential?
All information about participants will be coded with a number so that your and your children’s names are not readily associated with all the information. Identifiers will be kept separate from study data. All information (codes and corresponding names as well as video recordings) will be kept in a locked file cabinet in the principal investigator’s office. Electronic files will be stored on a password protected device. Access to all data will be limited to the study personnel. Representatives of The University of Western Ontario Non-Medical Research Ethics Board may require access to your study-related records to monitor the conduct of the research.

While we do our best to protect your information there is no guarantee that we will be able to do so. The inclusion of your child’s name and birth date may allow someone to link the data and identify you.

Please be advised that although the researchers will take every precaution to maintain confidentiality of the data, the nature of the group activities prevents the researchers from guaranteeing confidentiality. The researchers will remind participants to respect the privacy of your fellow participants and not repeat what is said in the groups to others or disclose the identities of other participants.”

If data is collected during the project which may be required to report by law we have a duty to report. Exceptions to this confidentiality include any situation where a child is observed to be at-risk for abuse or neglect; we have a legal duty to file a report under Section 13 of the Child, Family, and Community Service Act. In any situation where a child is observed to put him or herself at risk, we will follow guidelines outlined by the College of Psychologists of Ontario.
The principal investigator will keep any personal information about you in a secure and confidential location for a minimum of 5 years. A list linking your study number with your name will be kept by the researcher in a secure place, separate from your study file.

If the results of the study are published, your name will not be used.

9. **Are participants compensated to be in this study?**
   You will not be compensated for your participation in this research.

10. **What are the Rights of Participants?**
    Your participation in this study is voluntary. You may decide not to be in this study. Even if you consent to participate you have the right to not answer individual questions or to withdraw from the study at any time. If you choose not to participate or to leave the study at any time it will have no effect on your care.

    We will give you new information that is learned during the study that might affect your decision to stay in the study.

    You do not waive any legal right by signing this consent form

11. **Whom do participants contact for questions?**
    If you have questions about this research study please contact Principal Investigator: Nicole Neil

    If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Human Research Ethics

        **This letter is yours to keep for future reference.**

12. **Consent**

**Written Consent**

1. **Project Title**
   Evaluation of a Social Skills Program for Children with Developmental Disabilities and their Siblings – Pilot and Randomized Controlled Trial

2. **Document Title**
   Letter of Information and Consent – Parent/Guardian

3. **Principal Investigator + Contact**
   **Principal Investigator**
   Dr. Nicole Neil, PhD, BCBA-D, Faculty of Education
   Western University
I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

CONTACT FOR FUTURE STUDIES
Please check the appropriate box below and initial:
___ I agree to be contacted for future research studies
___ I do NOT agree to be contacted for future research studies

Please check one of the two boxes to indicate whether you give your permission for video recordings of your child to be shown at research and training conferences attended by teachers, researcher, students, and parents

☐ YES ☐ NO

____________________  ____________________  __________________
Print Name of Participant   Signature   Date (DD-MMM-YYYY)

My signature means that I have explained the study to the participant named above. I have answered all questions.

____________________  ____________________  __________________
Print Name of Person (Obtaining Consent)   Signature   Date (DD-MMM-YYYY)

Child’s Name: ______________________________________________________

Parent / Legal Guardian / Substitute Decision Maker (Print): ______________
Parent / Legal Guardian / Substitute Decision Maker (Sign): ______________
Parent / Legal Guardian / Substitute Decision Maker (Date): __________
Appendix F: Assent Letter

Project Title: Evaluation of a Social Skills Program for Children with Developmental Disabilities and their Siblings – Pilot and Randomized Controlled Trial

Principal Investigator: Nicole Neil, PhD, BCBA-D, Faculty of Education, Western University

Assent Letter

1. Why you are here.
Dr. Neil wants to tell you about a study that will look at a program for brothers and sisters to talk and play together. She wants to see if you would like to be in this study. There will also be other researchers working with Dr. Neil on this study.

2. Why are they doing this study?
Dr. Neil and her researchers want to see if coming to the program helps you and your brother or sister play together and talk with each other. She also wants to see if coming to the program helps you understand your brother or sister, and helps you understand your emotions.

3. What will happen to you?
If you want to be in the study:
   1. You will be asked to answer questions about your feelings and the teachers and counselors will write down information about things that you do with your brother/sister during the program.
   2. When you come to the program with your brother/sister, you will play with them and other children. You will also play games with other kids and talk with them about your family and feelings. Sometimes we will want to video record you when you are playing with other kids.

4. Will there be any tests?
There will not be any tests or marks for this study.

5. Will the study help you?
By helping us, it will let us know more about things you like and did not like about the program and things that worked well or did not work well. It can help more kids have programs in the future.

6. What if you have any questions?
You can ask questions at any time, now or later. You can talk to teachers, your family or someone else.

7. Do you have to be in the study?
You do not have to be in the study. No one will be mad at you if you do not want to do this. If you do not want to be in the study, just say so. Even if you say yes, you can change your mind later. It is up to you.
I want to participate in this study.

Print Name of Child

___________________________________________________________________________

Signature of Child

___________________________________________________________________________

Date________________________________

Age __________________________________

Signature of Person Obtaining Consent

____________________________________
Curriculum Vitae

Name
Ashley Amicarelli

Education
2017-2019 Master of Arts in Counselling Psychology, Western University, London, ON.

Awards and Scholarships
2018-2019 Dr. Benjamin Goldberg Research Grant
2017-2019 Admissions Scholarship, Western University

Professional and Research Experience
2018-2019 Intern-Psychological Services
Thames Valley District School Board
London, ON.
2018-2019 Group Facilitator-Parents of children with FASD
London Family Court Clinic
London, ON.
2018-2019 Rehabilitation Facilitator-Assisted Living/Transitional Program
Dale Brain Injury Services
London, ON.
2014-2017 Research Assistant-Personality and Emotion Development Lab
Western University
London, ON.