LEFT IN THE WAITING ROOM: A VIRTUAL INTERVENTION FOR SIBLINGS OF YOUTH WITH DISABILITIES

MARIE HOOPER

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Abstract

Evidence-based, psychosocial interventions for siblings of youth with disabilities are rare, but those that do exist typically occur in-person. Research is lacking on the impact of virtual support groups for siblings. This dissertation comprises two studies that describe the adaptation of an in-person intervention- *SibWorks*- into a virtual format (*iSibWorks*) and the psychosocial functioning of siblings before and after participating in the six-week *iSibWorks* intervention. The objectives of Study One included: (1) Adapt the in-person *SibWorks* group intervention for use on a virtual healthcare platform; and (2) Assess the acceptability of the adapted intervention, *iSibWorks.* Siblings were youth aged 8 to 12 years who had a sibling with a disability, and their caregivers. One week after the final session, siblings and their caregivers participated in separate semi-structured interviews, which were analysed using qualitative content analysis to examine intervention acceptability. The adaptation was successful and *iSibWorks* was deemed acceptable and beneficial. Suggestions were provided to enhance the intervention's future delivery, content, and engagement. The objective of Study Two was to evaluate the impact of participating in *iSibWorks* on psychosocial functioning at three time-points: before the intervention, one-week post-intervention and three-months post-intervention. Symptom severity at baseline was examined in relation to changes in psychosocial functioning over time. Validated measures were employed: Youth Self-Report (YSR; siblings) or Child Behavior Checklist (CBCL; caregivers) and Strengths and Difficulties Questionnaire (SDQ; siblings and caregivers). Participants (12 siblings and 13 caregivers) reported significant improvements in psychosocial functioning from baseline to post-intervention and these gains were maintained at three-month post-intervention. Participants reporting a high level of psychosocial difficulties at baseline demonstrated greater gains at follow-up. Overall, *iSibWorks* is a promising intervention to support the psychosocial

functioning of siblings. Further research using control groups and comparing delivery models directly is recommended.

Keywords: Siblings, Intervention, Virtual, Psychosocial, Disability

Dedication

To my extraordinary daughter, Sloane.

From such a young age, you've shown a depth of understanding, patience, and love far beyond your years. You've stood by your brother with grace and resilience, often waiting while the world seemed to revolve around his needs. This dissertation is a testament to your quiet strength and support. You have been a constant light in our lives, and for all the moments you have sacrificed, this is for you.

I love you.

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List of Abbreviations

Abbreviation	Meaning
ACT	Acceptance and Commitment Therapy
ADHD	Attention-Deficit/Hyperactivity Disorder
ANOVA	Analysis of Variance
ASD	Autism Spectrum Disorder
CBCL	Child Behavior Checklist
CAD	Canadian Dollar
CBT	Cognitive Behavioural Therapy
COVID-19	Coronavirus Disease 2019
ID	Intellectual Disability
iSibWorks	Virtual version of the SibWorks program
NDD	Neurodevelopmental Disorder
RCT	Randomized Controlled Trial
SD	Standard Deviation
SDQ	Strengths and Difficulties Questionnaire
TD	Typically Developing
YSR	Youth Self-Report

CHAPTER 1. Introduction

A sibling relationship is typically the most prolonged relationship individuals will have in their lifetime (Cicirelli, 1995; O'Brien et al., 2009). According to the Canadian Social Survey conducted in 2022, more than 70 percent of Canadian families include siblings – two or more children – and approximately half of Canadians between the ages of 15 to 49 years intend to have more than one child (Government of Canada, 2023). Most research to date has emphasized a caregiver's role in supporting their children's psychological outcomes by maintaining an optimal home environment that provides emotional warmth and a space for children to flourish (Gantriis et al., 2019; Kendrick et al., 2000). In families with multiple children, caregivers are responsible for facilitating sibling relationships and fostering family cohesion characterized by emotional bonding, unity, and a sense of belonging within the family unit (American Psychological Association, n.d.; Rivera et al., 2008). Family cohesion involves engaging in emotional conversations and depending upon family members for psychological support. However, maintaining an optimal home environment that promotes family cohesion can be challenging, due to the complex nature of sibling relationships and associated conflict (Kim et al., 2007).

While sibling relationships are often marked by conflict and rivalry, they can also be profound sources of emotional support, companionship, and personal growth. Positive experiences with siblings, such as shared laughter, mutual support, and deep bonds of trust, play a crucial role in developing empathy, social skills, and resilience (McHale et al., 2012; Howe et al., 2014). Research indicates that siblings frequently act as confidants and role models, fostering a sense of belonging and promoting emotional security within the family unit (Tucker et al., 2013).

Current literature suggests that thoughts, feelings, and behaviours in relation to the family unit, or family dynamics are influenced by levels of family cohesion (Deng et al., 2022; Jabbari et al., 2023). Although sibling conflict has been found to decline across childhood to early adolescence, factors like a mother's acceptance of sibling intimacy (i.e., warmth and closeness) and father-child conflict (i.e., related to domains like household tasks, bedtime, curfew, etc.) influence the sibling relationship as well (Kim et al., 2006). These factors are associated with increased sibling intimacy versus conflict, respectively. Therefore, caregivers who are focused on facilitating acceptance and warmth among family members encourage the formation of secure sibling relationships and promote an overall sense of well-being in the family unit (Fosco & Lydon-Staley, 2020; Jabbari et al., 2023).

Sibling Relationships and Psychological Outcomes

Researchers have assessed the specific influence of sibling relationships on an individual's psychological outcomes. This has been evaluated across multiple domains, including siblings' transitions from preschool or childhood to adolescence (Buhrmester et al., 1990; Dunn et al., 1994a; Dunn et al., 1994b; Kim et al., 2006; Kim et al., 2007), parental separation (Shumaker et al., 2011), and body dissatisfaction in both siblings (Johnson & Salafia, 2022). The impact of factors such as family size, family processes, sibling age gap, and sibling temperament have also been explored (Brody et al., 1994; Newman, 1996). Prior to addressing these factors, the nature of sibling relationships has frequently been overlooked by family therapists due to the misconception that it does not impact therapeutic outcomes (Pfouts, 1976; Young, 2007). However, findings from research on sibling relationships suggest that certain qualities may act as either protective or risk factors for the maintenance of psychological problems within the family unit (Bedford, 1989). For example, internalising (e.g., anxiety, social withdrawal) and

externalising (e.g., anger, lying) psychological problems for both siblings were found to be associated with sibling relationship qualities such as increased conflict as well as decreased warmth and intimacy throughout childhood and adolescence (Dirks et al., 2015). The qualities of warmth, intimacy, and conflict appear to impact siblings' relationships with their caregivers as well, indicating that a multidimensional approach to family therapy focusing on these features of sibling relationships may benefit the entire family unit (McGuire et al., 1996).

The central premise of family therapy is to improve family dynamics via implementing systemic changes and addressing clinical problems within the family unit (American Psychological Association, n.d.). For instance, a family-centered intervention to support families of children with developmental disabilities facilitated the well-being of family members by: (1) setting developmental targets with caregivers for their children with disabilities (e.g., improving social skills, personal care, etc.) and (2) providing actionable steps for caregivers and typically developing (TD) siblings to address their personal needs (McConkey et al., 2023). This home-based intervention in Ireland, known as the *Brighter Futures Service*, involved monthly visits from support staff and telephone conversations between visits. While this intervention was based upon a family-centered approach and improved social inclusion for families, it mainly emphasized supporting the well-being of caregivers and their children with disabilities. However, research has expanded to explore the psychological impact that having a sibling with a disability may have on TD siblings.

Psychological Impact of Sibling Disability on their Relationships

The sibling dynamic is particularly significant in families where one sibling has a disability. Typically developing siblings (TD siblings) often exhibit increased levels of patience, responsibility, and advocacy skills, which enhance their social and emotional development

(Petalas et al., 2012; Shivers et al., 2019). However, TD siblings have also reported experiencing loneliness and resentment (Rossiter & Sharpe, 2001). Therefore, gaining a comprehensive understanding of both the positive and negative aspects of sibling relationships is essential for creating effective interventions that support psychosocial functioning.

Research to date has focused mostly upon sibling pairs where one sibling has a psychiatric disorder, neurodevelopmental disorder, cancer, and/or another chronic illness (Baca et al., 2010; Constantinou et al., 2023; Fjermestad et al., 2019; Fox et al., 2002; Houtzager et al., 2005; Pepler et al., 1981; Stock et al., 2016). In particular, researchers have examined the risk of psychiatric and neurodevelopmental disorders (NDDs) developing in the TD siblings of children with these disabilities (Jokiranta-Olkoniemi et al., 2019; Taffoni et al., 2019). Although some literature indicates that TD siblings may be at a greater risk for acquiring similar psychological disabilities to their siblings (Estes et al., 2018; Howlin et al., 2015; Miller et al., 2015; Pilowsky et al., 2007), many researchers are now more focusing on the impact of having a sibling with a disability on sibling relationships and the psychosocial adjustment of TD siblings (Hayden et al., 2023; Lemoine & Schneider, 2022; Rochefort et al., 2023; Rum et al., 2022).

It has often been assumed that children with disabilities negatively impact their TD siblings, resulting in relationships that lack reciprocity, promote behavioural issues, and hinder psychosocial adjustment (Burke & Montgomery, 2001; Sharpe & Rossiter, 2002). One group of researchers investigated the relationship between family cohesion and quality of sibling relationships in families with TD siblings and those where one sibling had a disability (Taylor et al., 2023). Although caregivers raising TD siblings reported higher levels of family cohesion than families where one sibling had a disability, relationships between children with Down syndrome and their siblings were considered more positive than those between TD siblings.

Furthermore, despite the psychosocial difficulties often noted between TD siblings of individuals with Down syndrome and other family members (Roper et al., 2014), another study found that these sibling relationships were characterized as positive overall (Lemoine & Schneider, 2022). To further explore assumptions about relationships between individuals with disabilities and their TD siblings, Hayden and colleagues (2023) examined behavioural adjustment and sibling relationship quality between TD children and their siblings with intellectual disabilities (IDs). Their research identified reciprocal relationships between siblings and found that behavioural adjustment for both of the siblings was associated with positive (e.g., intimacy and companionship) and negative (e.g., antagonism and quarrelling) attributes of the sibling relationship, indicating that the behaviours of both siblings impact the relationship, not just the sibling with a disability (Hayden et al., 2023).

Other aspects of psychosocial adjustment that may influence TD siblings – henceforth referred to as siblings – growing up alongside individuals with disabilities have also been investigated. For example, it has been suggested that twin siblings of children with disabilities demonstrate increased levels of cognitive empathy toward others relative to twins where neither have a disability (Rum et al., 2022). While it is important to account for the positive aspects of these sibling relationships, a recent scoping review by Rochefort and colleagues (2023) utilized developmental trauma theory to describe difficulties with psychological adjustment in siblings of individuals with challenging behaviours, autism spectrum disorder (ASD), and intellectual disabilities (IDs). This review highlighted that trauma-related symptoms were reported by siblings in most studies and emphasized the need to address these symptoms by creating specific supportive resources for them.

Psychosocial difficulties in siblings may be exacerbated by sibling-focused parentification, which refers to siblings assuming adult-like duties and becoming responsible for engaging in caregiving behaviours for their siblings with disabilities (Levante et al., 2023). Sibling-focused parentification often leads to distress in siblings and the degradation of family relationship quality, especially if the sibling's relationship with their caregivers is poor prior to engaging in these caregiving behaviours (Levante et al., 2023). Flett and Hewett (2013) coined the term *disguised distress* to describe the subset of children who "experience profound distress yet keep it hidden or disguised because of a personality style characterized by self-concealment and a tendency to engage in perfectionistic self-presentation" (p. 12). It is common for caregivers with multiple children to become overwhelmed by the responsibility of supporting their child with a disability or chronic illness (Kirchhofer et al., 2022). However, this may increase disguised distress and also lead to siblings becoming *glass children* in their families. This term emerged from interviews with people aged 20 to 68 years who had a sibling with a disability or chronic illness, due to them feeling as though they were 'invisible' to people around them (Hanvey et al., 2022). Probing their lived experiences throughout childhood and adolescence, researchers identified that siblings: (1) felt unseen in their social environments, (2) had difficulties interpreting their family dynamics or life struggles, and (3) experienced guilt or self-blame due to an inability to provide continuous support for their siblings and caregivers. The value of social support systems to deal with these experiences was also noted as a theme, such that siblings would have appreciated opportunities to socialize with others in similar circumstances and to receive regular psychosocial support from family or friends.

Recognising that siblings of children with disabilities can experience challenges, services for families of individuals with disabilities have offered caregiver-mediated interventions to

support siblings, such as providing caregivers with tools to improve their children's communication skills and prosocial behaviours (Sheikh et al., 2019; Yoder et al., 2021). Others have focused on helping caregivers use strategies to protect sibling mental health and strengthen the caregiver-sibling relationship, largely by providing caregiver-sibling social support groups (Haukeland et al., 2020; Fredriksen et al., 2023; Kirchhofer et al., 2022). The caregiver-mediated interventions found to be most helpful in promoting sibling mental health were those that facilitated open communication among siblings and their caregivers (Cate & Loots, 2001; Haukeland et al., 2020; Incledon et al., 2015). These interventions strengthened caregiver-sibling relationships by providing siblings with a safe space to discuss their concerns and, in turn, allowing caregivers to validate their feelings about these issues.

Addressing the Needs of Siblings of Individuals with Disabilities

The most common approach to supporting the psychosocial functioning of siblings and providing resources that target communication has been in a group format with siblings and/or their caregivers. For instance, *Siblings Australia* have created and promoted resources for siblings, caregivers, and healthcare providers (Siblings Australia, 2024). Resources also include sibling-focused psychosocial interventions (*SibWorks*), online modules based on supporting siblings (*SibWise*), and guidance for future planning (*SibPlan*). Through collaboration with international researchers and policymakers from the United States, Canada, the United Kingdom, and Italy, *Siblings Australia* continually advocates for siblings of individuals with disabilities or chronic illnesses. This organization offers hundreds of workshops to families and healthcare providers in Australia, all while engaging in strategic conversations with policymakers to raise awareness about the needs of siblings. A similar initiative from the *Canadian Centre for Caregiving Excellence*, known as *Siblings Canada*, is dedicated to supporting adult caregivers

who are providing care for their sibling with a disability (Canadian Centre for Caregiving Excellence, 2024). They do this by offering a sibling mentorship program, virtual events, and other workshops (e.g., Acceptance and Commitment Training Workshop), alongside conducting research on how to facilitate financial security for siblings acting as caregivers.

Literature investigating the needs of siblings provides insight into elements that should be considered when developing resources for their support. Some groups of researchers have explored the influence of specific disabilities on psychosocial outcomes, including Down syndrome (Shivers et al., 2019b), IDs (Shivers & McGregor, 2019), ASD (Shivers et al., 2019a), and psychosis (Bowman et al., 2014). Other studies have evaluated disabilities related to diagnoses such as cancer (Faust et al., 2022; Faust et al., 2023) and chronic illness in general (Pinquart, 2023). However, to conceptualize common experiences among siblings of individuals with special needs, these disabilities and associated diagnoses have often been aggregated (Hanvey et al., 2022; Sommantico et al., 2020). The perspectives of siblings reported across these studies indicate difficulties with cognitive, behavioural, and emotional aspects of their sibling relationships. These findings illustrate the importance of enhancing social support systems for siblings of children with disabilities or chronic illnesses and considering siblings while engaging in care planning to improve family well-being.

It is critical to address siblings' needs as early as possible due to the potential life-long implications (Banks et al., 2001). For example, semi-structured interviews conducted with adult siblings of individuals with learning disabilities or challenging behaviours revealed that these experiences contributed to the development of their personalities, and how they understood family dynamics. Many of them also reported considering the needs of their siblings with disabilities when choosing their careers (Chase & McGill, 2019). Researchers described these

siblings as *invisible carers* due to their extensive involvement in their siblings' lives that is rarely recognized. In fact, caring for their siblings with disabilities or chronic illnesses often begins when these siblings are young (Nuttall et al., 2018; Woodgate et al., 2016). To illustrate this, siblings of children with chronic illnesses report helping with medical management of their siblings' conditions to maintain normal family functioning (Nabors et al., 2019).

Caring for a person with a disability or someone who is chronically ill is typically viewed as the primary role of caregivers (i.e., parents), with siblings playing a secondary role (Sanderson et al., 2019). However, adult siblings of individuals with profound intellectual and multiple disabilities have reported that they do not feel adequately prepared to act as their siblings' caregivers when their parents are no longer able to (Kruithof et al., 2022), even though they are often expected to provide support for their siblings' recreational, employment, and housing needs (Sanderson et al., 2019). These siblings have urged parents and healthcare professionals to help mitigate this stress by communicating with them about their expected roles as future caregivers (Kruithof et al., 2021; Kruithof et al., 2022). While government policies tend to describe these siblings as *young carers*, siblings report that it is important to emphasize their *sibling* relationship more than their potential role as caregivers to maintain a more equitable relationship (Meltzer, 2017). Since siblings feel responsible for acting as caregivers for their siblings with disabilities when their parents are gone (Kruithof et al., 2022), it is imperative to assist them with this endeavor by strengthening their psychosocial support systems from an early age.

Psychosocial Interventions for Siblings of Individuals with Disabilities or Chronic Illnesses

Researchers and healthcare providers have successfully implemented in-person psychosocial interventions to support siblings. Evidence-based interventions, like *SibWorks*, emphasize cognitive behavioural therapy (CBT) principles to address psychosocial outcomes and

provide opportunities for siblings to learn coping strategies with individuals who are experiencing similar circumstances as them (Engelhardt-Lohrke et al., 2020; Roberts et al., 2015). Cognitive Behavioural Therapy is a therapeutic modality that combines cognitive- and behavioural-based theories to help individuals with identifying and challenging their maladaptive thoughts or behaviours (American Psychological Association, n.d.). This therapeutic modality has been found to be particularly helpful for siblings, due to its ability to address their feelings of invisibility within the family unit and provide them with strategies for expressing their emotions to caregivers. Some interventions that are predicated upon other therapeutic modalities or theories – like problem solving and play therapy – have also been explored (Guan et al., 2021). Findings suggest that all of these interventions improved anxiety and depression symptoms in siblings of children with cancer and enhanced outcomes related to positive coping and improved self-construct (Barrera et al., 2018; Barrera et al., 2020; Besani et al., 2018; Jo et al., 2018; Neville et al., 2016; Salavati et al., 2014; Wu et al., 2016).

Due to the inconsistency in research exploring psychosocial interventions for siblings, it is unclear whether a specific intervention design is particularly beneficial. In a scoping review of 58 articles by Nguyen and colleagues (2023), interventions for siblings of individuals with NDDs were not consistent in terms of the participants. Out of the 54 interventions included in this review, participants included siblings alone, both children and their siblings with NDDs, siblings and their caregivers, and the entire family unit. This makes it challenging to identify specific design parameters and characteristics that predict effectiveness. To our knowledge, researchers have not investigated other design elements known to augment interventions for siblings, such as mode of delivery and age-appropriateness of activities.

***SibWorks*: An Evidence-Based Psychosocial Intervention for Siblings of Individuals with Disabilities.** *SibWorks* is an in-person, group-based, psychosocial intervention designed by Kate Strohm (sibling and teacher) and Dr. Monique Nesa (psychologist) at *Siblings Australia*. *SibWorks* is "designed for children aged 8-12 have a brother or sister with a disability" (Siblings Australia, 2024). Using targeted therapeutic intervention in a group setting, *SibWorks* is "support(s) siblings by building their emotional wellbeing and resilience and connecting with others who share the same experience" (Siblings Australia, 2024). The intervention's sessions are structured to provide siblings with social support through engagement with other siblings, information about disabilities, strategies to deal with their emotions, and activities to improve their self-esteem with the ultimate aim of "better understand(ing) and accept(ing) their brother or sister with a disability [which] can add to the strength of the relationship" (Siblings Australia, 2024). Altogether, six sessions are conducted by a trained *SibWorks* facilitator and aim to support the emotional well-being of siblings via an intervention based upon aspects of CBT.

To assess the efficacy of *SibWorks* for siblings, this intervention was offered to youth aged 8 to 12 years who were all siblings of individuals with disabilities (Roberts et al., 2015; Roberts et al., 2016). Studies evaluating this intervention indicated that *SibWorks* significantly improved psychosocial outcomes for participating siblings. However, the in-person delivery model limits its accessibility in a number of ways. Research on the virtual delivery of *SibWorks* has not been conducted to date.

Siblings Australia (2024) offers various programs to support siblings of children with disabilities. SibWorks was chosen for virtual adaptation for several key reasons. First, it was developed by Sibling Australia's founder, Kate Strohm, alongside clinical psychologist Dr. Monique Nesa, ensuring a strong research-based and clinically supported foundation.

Additionally, its goals and objectives translated well to an online format. The program's structure made it easy to break down objectives into individual virtual sessions while fostering a sense of community among siblings with shared experiences. According to Siblings Australia, some key outcomes of the program include helping siblings better understand disability and functional change, feel less alone, develop coping strategies, and build a more positive sense of self (Siblings Australia, 2024).

Dissertation Objectives and Rationale

SibWorks is one of the few validated interventions for siblings and holds promise for adaptation to increase its accessibility. The aim of this dissertation was to explore the use of *SibWorks* in a virtual format with Canadian siblings. The Objectives were to: (1) Adapt *SibWorks* to *iSibWorks* for use on a virtual platform with youth siblings in grades three to eight (aged 8 to 14 years); (2) Assess the acceptability of *iSibWorks* using qualitative interviews with the sibling participants and their caregivers; and (3) Implement *iSibWorks* with siblings and evaluate their psychosocial outcomes pre- and post-intervention using standardized measures. This dissertation presents the work addressing these objectives in the following way: Chapter 2 details the adaptation of the *SibWorks* intervention to a virtual intervention – *iSibWorks* – and the results of an acceptability study with siblings and their caregivers (*Study One*). Chapter 3 describes the implementation of *iSibWorks* with a broader sample of siblings and their psychosocial outcomes (S*tudy Two*).

CHAPTER 2. Study One: Acceptability of a Virtual Intervention, iSibWorks, for Siblings of Youth with Disabilities – A Qualitative Approach

Acceptability studies examine whether an intervention is satisfactory to its participants and its suitability for larger-scale implementation (Orsmond & Cohn, 2015). Since *iSibWorks* is

one of the first virtual, group-based interventions for siblings to be conducted within a Canadian context, it was important to first conduct an acceptability study before offering the intervention on a larger-scale. As such, our first study focused on adapting *SibWorks* to *iSibWorks* for its application in a virtual environment (*Objective 1*) and examining the acceptability of *iSibWorks* among siblings and their caregivers (*Objective 2*).

Results of this study provided insights that helped the team enhance components of the intervention and allowed for augmentation of facilitation techniques, session content, recruitment strategies, and research procedures before the broader implementation of *iSibWorks*.

CHAPTER 3. Study Two: Pilot Study of iSibWorks for Siblings of Youth with Disabilities – A Quantitative Approach

Siblings often suffer silently due to feelings of guilt and engage in perfectionism to reduce stress or pressure on the family unit (Fisman et al., 2000). The aim of this pilot study was to gain a better understanding of siblings' psychosocial functioning and evaluate the impact of *iSibWorks* on their psychosocial functioning.

Pilot studies focus on the outcomes of a novel intervention via controlled evaluation of responses from participants throughout the program (Orsmond & Cohn, 2015). The pilot study described in Chapter 3 examined changes in psychosocial functioning by employing validated outcome measures pre- and post-participation in the *iSibWorks* intervention and assessed whether these changes were maintained three months after intervention completion (*Objective 3*). There were two hypotheses related to this Objective: (1) Siblings and their caregivers will report increased levels of psychosocial adjustment for youth after completing *iSibWorks,* which will be maintained 3-months post-intervention; and (2) Siblings with more severe symptoms (i.e., worse

functioning) at baseline will experience greater improvements in psychosocial functioning after completing the intervention and 3-months post-*iSibWorks* than those with less severe symptoms.

CHAPTER 4. Summary and Discussion

This dissertation aimed to understand whether *SibWorks* could be successfully adapted to a virtual platform (*iSibWorks*) while maintaining program rigour and staying true to its original content. Since siblings can experience significant psychosocial challenges, analyzing both youth- and caregiver-proxy qualitative and quantitative data helped us better understand the role *iSibWorks* could play in positively impacting siblings' mental health and behaviour. In this final chapter, implications for future work with siblings and their caregivers are also discussed.

CHAPTER 2. Adapting and Providing a Virtual Psychosocial Intervention, *iSibWorks*, for Siblings of Youth with Disabilities – A Qualitative Acceptability Study

Over 200,000 Canadian youth are identified as having disabilities (Easter Seals, 2016). In Ontario alone, one out of nine youth are living with a disability (Stapleton et al., 2015) and most of these youth have at least one sibling (Conway & Meyer, 2008). Generally, the services for families of individuals with disabilities predominantly focuses on caregiver needs (Barakat & Kazak, 1999) and often overlook the needs of siblings (McCullough & Simon, 2011). This model of care results in siblings experiencing negative psychosocial symptoms that are not addressed (Flett & Hewitt, 2013). This oversight is problematic, because research has shown that siblings are at high risk for the development of psychosocial difficulties, including social, emotional, and behavioural problems (Bachanas et al., 2001; Wiener et al., 2001). Difficulties with overall wellbeing and quality of life, self-esteem issues, internalising and externalising symptoms, as well as other behavioural problems have all been noted, although there is some variability depending on the type of disability (Bowman et al., 2014; Faust et al., 2023; Hanvey et al., 2022; Pinquart, 2023; Shivers et al., 2019; Shtayermman, 2022; Sommantico et al., 2020). Due to these difficulties, there is a critical need for interventions that support siblings.

Some risk factors associated with the development of psychosocial difficulties among siblings of children with disabilities include: (1) Demographics, such as the age and gender of the sibling (Cuskelly & Gunn, 2006), birth order of siblings (Rossiter & Sharpe, 2001), and socioeconomic status (Giallo et al., 2014); (2) Severity of their sibling's disability (Vermaes et al., 2012); (3) Mental health status of caregivers (Fisman et al., 2000); and (4) Quality of family functioning (Giallo & Gavidia-Payne, 2006).

Psychosocial interventions for siblings aim to provide social-emotional support, often by helping build resilience via psychoeducation and the development of positive relationships with other individuals who have siblings with disabilities (Engelhardt-Lohrke et al., 2020; Guan et al., 2021; Kirchhofer et al., 2022; Mooney-Doyle et al., 2021; Nguyen et al., 2023; Wolff et al., 2022a; Wolff et al., 2022b). For example, Wolff and colleagues (2022b) conducted a systematic review on psychosocial interventions for siblings of individuals with NDDs, which suggested that psychosocial interventions for siblings can increase their knowledge of NDDs, enhance their self-esteem, and optimize their social support systems. These findings are not limited to interventions that focus on providing siblings with skills to support themselves. A systematic review investigating interventions that provide psychoeducation for caregivers to help support siblings also found that youth increased their knowledge of their siblings' condition(s), improved their psychosocial adjustment, and improved their quality of life after their caregivers completed these interventions (Mitchell et al., 2021).

Despite these benefits, interventions supporting siblings' needs are scarce. Where they do exist, they are typically held in-person (Guan et al., 2021; Nguyen et al., 2023), which can be a barrier due to geographical location and the physical burden of bringing siblings to support groups when families already experience a significant number of stressors. Virtual interventions could potentially improve the accessibility and convenience of participating in a sibling support group (Fell et al., 2022; Gettings et al., 2015; Kuhlthau et al., 2022; Meltzer, 2022; Veerman et al., 2023). The recent COVID-19 pandemic highlighted both that healthcare programs must be nimble (Farrugia & Plutowski, 2021) and that virtual mental health interventions can be acceptable to both healthcare providers and patients (Liverpool et al., 2020; Patel et al., 2020).

Prior research showed that audio-conferencing (Gettings et al., 2015), telephone guidance (Giallo & Gavidia-Payne, 2006), and online messaging forums (Tichon, 2015) can be used to support groups of siblings, although the lack of a visual component may limit opportunities for youth to build relationships with other siblings. However, virtual interventions providing support to date have only been explored with teenagers (Fell et al., 2022; Kuhlthau et al., 2022) or have been limited to providing online games to siblings of individuals with specific disabilities (Veerman et al., 2023). It is therefore unknown whether virtual interventions to support younger siblings are acceptable.

SibWorks is a community-based, in-person psychosocial sibling support intervention that originated in Australia and aims to increase sibling resilience, improve familial relationships, and help siblings develop social support networks (Roberts et al., 2015; Roberts et al., 2016). Results from a randomized controlled trial (RCT) of *SibWorks* showed that siblings who participated in the intervention demonstrated fewer emotional and behavioural difficulties than siblings in the control group, both immediately after the intervention and three months later (Roberts et al., 2015). Delivering the evidence-based *SibWorks* intervention online could potentially make it more accessible and have greater reach, given that this type of intervention is scarce. However, before delivering the virtual version of this intervention widely, it is important to evaluate the acceptability of the intervention for the target users (Perski & Short, 2021). While the acceptability of virtual health interventions can be measured in different ways, two core aspects of acceptability are willingness to engage with the intervention and satisfaction after having engaged with the intervention (Nadal et al., 2020).

This study therefore had two objectives: (1) Adapt *SibWorks* to a virtual platform (*iSibWorks)*; and (2) Explore participants' engagement and satisfaction with the *iSibWorks* intervention.

Method

Participants

In total, six participants who had a sibling with a disability, and four of their caregivers participated in semi-structured interviews as part of the intervention. Four of the participants came from two families. The definition of disability used was purposefully broad and encompassed a confirmed or caregiver-reported diagnosis of physical and/or mental disabilities, including NDDs such as ASD and attention-deficit hyperactivity disorder (ADHD). There was no minimum length of time since diagnosis. Other inclusion criteria were: (1) children in grades 3 to 8 (aged 8 to 14 years); (2) siblings with disabilities aged up to 18 years; (3) at least one caregiver available to participate; (4) reliable Internet connection; and (5) ability to understand English. Study materials were reviewed carefully with any caregivers who only had some English proficiency. Children were excluded if they were unable to engage in online learning for at least 30 minutes or if they exhibited behaviour that could significantly disrupt group functioning as established through parental report. Advertisements for the study were posted on Holland Bloorview Kids Rehabilitation Hospital (Holland Bloorview; Toronto, Canada) social media platforms. Participant recruitment occurred from October to November 2020. Approval for this study was obtained through the Research Ethics Board at Holland Bloorview (#151). Eligible siblings and caregivers interested in participating were invited to a virtual onboarding session where they learned more about the study and could ask any questions. Once siblings and caregivers provided parental consent (Appendix C) and informed assent (Appendix D), they

were then oriented to the relevant technology platform and demographic information was collected by a member of the research team via phone or video call.

Procedure and Materials

Objective 1: Adaptation of SibWorks to a Virtual Format (*iSibWorks*). The original *SibWorks* manual included six weekly in-person sessions that were two hours in duration, or two weekly sessions at five hours in duration for siblings between the ages of 8 to 12 years. For more information on the practical implementation of *SibWorks*, see the Australian Government's website (https://aifs.gov.au/research_programs/evidence-and-evaluation-support/cfc-program-profiles/SibWorks). *SibWorks* was centered around four interconnected principles: (1) Whole Family Approach; (2) Family Centered Care; (3) Prevention or Early Intervention; and (4) Peer Support. Strohm and Nesa (2005) conceptualise the *Whole Family Approach* as the need to empower all family members when there is a child with a disability in the family. This includes siblings, as their relationship is typically the longest-lasting in a young person's life (Cicirelli, 1995; O'Brien et al., 2009). Strohm and Nesa propose that this approach makes the family unit as a whole more resilient (Strohm & Nesa, 2005). *Family Centered Care* refers to healthcare providers recognizing that families themselves are the experts in their child's care. *Prevention or Early Intervention* refers to the assumption that by addressing a sibling's needs early, mental health issues can be either prevented or ameliorated as soon as possible. Sibling groups can become an important part of their mental health strategy. This can be achieved through *Peer Support,* such that when youth meet and connect with others with similar experiences, they are better equipped to cope with adversity.

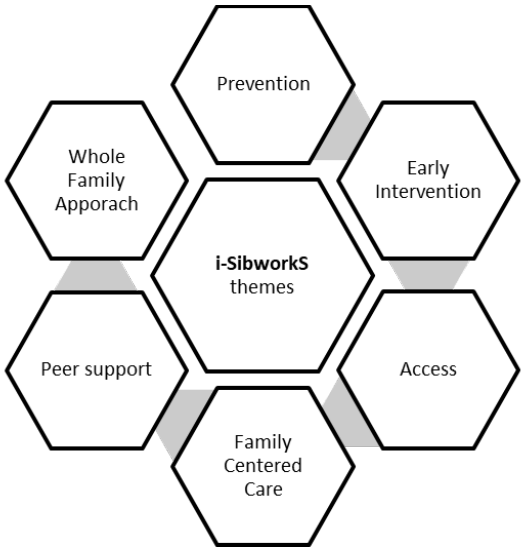
The research team utilised the original *SibWorks* manual to adapt *SibWorks* for its virtual delivery as *iSibWorks*. Content was refined via regular team meetings and discussions with target

users, such as siblings and their caregivers. Adaptations were then reviewed and validated by multiple healthcare professionals on the team, including one of the original creators of *SibWorks* (KS). While the adapted intervention continued with the same four principles as the original *SibWorks*, *iSibWorks* added a fifth principle, *Access*, given its emphasis on making this intervention readily available for siblings in need. These principles are rooted in a 'wraparound' approach, suggesting that they are co-occurring, holistic, and equally important, rather than being stepwise and siloed (Figure 1).

To enhance the effectiveness of iSibWorks, key cognitive-behavioural therapy (CBT) strategies were incorporated to support siblings' emotional well-being. These strategies included stress management and problem-solving techniques, equipping participants with structured methods to identify stressors and develop actionable coping strategies (Roberts et al., 2015). Emotional regulation and expression were emphasized through guided discussions and interactive activities, allowing siblings to explore and articulate their emotions in a supportive environment (Haukeland et al., 2020).

A core component of the intervention was cognitive restructuring, which helped siblings recognize and reframe unhelpful thoughts, reducing feelings of guilt or invisibility within their families (Mallory et al., 2024). Resilience-building was also prioritized by fostering peer connections and shared experiences, reinforcing a sense of validation and belonging (Werner-Seidler et al., 2018). Additionally, psychoeducational resources were provided to caregivers, ensuring that learned coping techniques could be reinforced at home, extending the benefits of the intervention beyond the virtual sessions (American Psychological Association, n.d.).

Figure 1. *Intervention Values*



Objective 2: Acceptability of *iSibWorks*. Demographic questionnaires were completed by siblings and their caregivers through *REDCap*, a secure online platform designed to collect, track, and export research data (https://www.project-redcap.org/; Harris et al., 2009). Siblings reported their age, gender, and any previous social support services received (Appendix A). Caregivers reported information on their household, family income, previous social support services and demographics for the sibling with a disability (Appendix B).

***Delivery of iSibWorks*.** Once the intervention was adapted, *iSibWorks* was delivered on *Zoom for Healthcare* which is a secure, web–based platform (video, audio, chat) specifically approved for health care providers to provide clinical treatment (e.g., direct patient care, clinical case conferences). This occurred across six weekly sessions lasting approximately 60 minutes. Each session covered a specific topic and included physical movement, arts/crafts, and/or reflective activities. Siblings participated in the sessions, while caregivers received weekly handouts on the session content and parenting tips related to this content (see Appendix E for a sample handout). Groups were offered on weekday evenings and facilitated by (MH). A research assistant, (HA) also attended all sessions and took field notes. Two *iSibWorks* groups

were delivered for the purpose of examining acceptability: one for siblings in grades 3 to 5 (8 to 11 years) and another for siblings in grades 6 to 8 (11 to 14 years), with three participants in each group. Activities were tailored to be age-appropriate, but the topics and session outcomes remained the same for both groups. If necessary, caregivers helped siblings access the virtual platform or materials to participate in sessions.

Engagement with Intervention. Field notes were taken throughout *iSibWorks'* sessions by the facilitator (MH) and research assistant (HA). Notes included siblings' attendance, camera use, involvement in discussions and activities, and responses to polling during sessions. Polling occurred randomly throughout the intervention to help with facilitating future sessions.

Semi-Structured Interviews. One week after intervention completion, all participating siblings and their caregivers were invited to engage in separate 20- to 30-minute semi-structured qualitative interviews to learn about the acceptability, perceived utility, and future recommendations regarding *iSibWorks*. While caregivers did not participate in the intervention, they were still invited to share their perspectives on *iSibWorks* and provide suggestions for improvement.

To create the interviews with siblings, the research team relied on previous literature and their clinical experiences to create the interview guides for siblings (Appendix F) and their caregivers (Appendix G). The interviews comprised open-ended questions and prompts about different aspects of the intervention, including the group environment and intervention structure. The interviews were conducted on *Zoom for Healthcare*, audio-recorded, and transcribed verbatim by the research team. See Figure 2 for study flow and data sources.

Figure 2. *Study Flow and Data Sources*

Data Analysis

Descriptive statistics were employed to summarise demographic and session attendance information. Both MH and HA analysed the interview transcripts using qualitative content analysis. This process included coding and categorizing the data through creating a living codebook (Coffey & Atkinson, 1996; Hsieh & Shannon, 2005). An initial codebook was co-created by MH and HA through discussion. Their discussion was guided by their experiences with siblings throughout the *iSibWorks* sessions and principles for developing living codebooks as per Coffey and Atkinson (1996). Once MH and HA agreed upon a flexible list of initial codes, they applied line-by-line open coding to two interview transcripts separately. MH and HA then met to finalise the codebook with definitions for codes as well as to ensure agreement regarding emerging codes and categories throughout data analysis for the remaining interview transcripts. The analytic strategy of coding involved: (1) Applying codes (one or two words) to different concepts in the interview transcripts; (2) Clustering text with similar codes together and applying a label that summarised these ideas (categories); and (3) Examining these categories to observe connections or links between them (Coffey & Atkinson, 1996; Saldaña, 2016). Multiple readings of the interview transcripts allowed for deeper conceptualization of the codes and categories (Kvale, 1994). Verbatim quotations were then used to support the findings. Reviewing field notes collected during *iSibWorks* also aided the reflection process (Morrow, 2005). For instance, we reviewed notes about group energy levels, discussions, and interest in activities to further understand the siblings' experiences with the *iSibWorks* intervention.

Results

Objective 1: Adaptation of SibWorks to a Virtual Format (iSibWorks)

The adaptation of the in-person *SibWorks* to *iSibWorks* was guided by the original *SibWorks* manual. First, content was reduced from 2 hours to 60 minutes per session by adapting activities for delivery online and transferred to *PowerPoint* presentations to optimize engagement on a virtual platform. Other adaptations included: (2) Removing the trickle-in activities due to the waiting room feature on *Zoom for Healthcare*; (3) Removing participant manuals and sharing content in the presentations instead to enhance discussions about the material; (4) Adding more visuals to help maintain attention and enhance understanding of topics; (5) Including movement breaks to strengthen online learning and provide opportunities for releasing energy; (6) Optimizing activities for virtual delivery to maintain learning outcomes during activities (e.g., utilising the whiteboard feature on *Zoom for Healthcare* instead of a personal workbook to facilitate collaboration and maintain attention); (7) Reminding participants of the limits of confidentiality to enhance engagement with the intervention, transparency, and trust prior to each session; and (8) Offering online polls for feedback and collaboration throughout the intervention. See Table 1 for more information regarding virtual adaptations.

Table 1. *iSibWorks Content, Outcomes, Original SibWorks Activities, and Virtual Activity Adaptations*

Week	Topic	Content	Outcomes	Original *SibWorks* Activities	Virtual Activity Adaptations
1	Getting to Know Each Other	1. Getting to Know Each Other 2. Introduction to the Group 3. Getting to Know Each Other's Family 4. Reinforce Manners and Consequences	1. To develop a safe and supportive environment where siblings can share experiences and express their feelings 2. To develop connections and a sense of belonging 3. To develop a clear understanding of group purpose 4. To find out expectations of participants 5. To negotiate clear rules around listening, respect and confidentiality 6. To focus on children as individuals, not just as siblings	• Find Someone Who… • Name Game • Pass the Parcel • Ball Name Game • Draw Your Family (workbook) • Rules (butcher paper)	• Would You Rather? • Interest Inventory • Name Game • Draw Your Family (paper) • Collaborative rule setting with whiteboard feature on Zoom
2	Exploring Differences	1. What Do We Know About Each Other? 2. Exploring Similarities and Differences	1. To explore the differences and similarities siblings have with their own siblings, their families,	• Truth or Lie Game • Our Similarities and Differences (manual) • Ball game	• Two Truths and a Fib • Our Similarities and Differences (paper)

		3. Learning About Disabilities	and each other, recognizing their uniqueness 2. To build knowledge and understanding about disabilities 3. To identify activities that siblings enjoy doing with and without their brother or sister with special needs	• Sibling Disability Simulation Activity: Back-to-Back Drawing; Leading Partner; Puzzle with Socks • Upside Down Cards	• If You're Hot, You're Hot game • Disability Discussion (without simulation) • Indoor Scavenger Hunt
3	Friendly & Not-So-Friendly Feelings	1. Things I Like Doing 2. Exploring Feelings 3. Social Supports	1. To help siblings learn to identify a range of feelings 2. To enhance awareness of feelings regarding having a brother or sister with a disability 3. To increase siblings' understanding that it is okay to have 'good' and 'not so good' feelings 4. To explore the expression of these feelings in an appropriate way, particularly the more difficult feelings	• Things I like Doing • Jellybaby Activity • Facing our Feelings • Ball Game • Hands of Support • Other Supports	• Things I like Doing • Emotion Wheel • Heads Up Game

			5. To identify support networks and recognize the types of support available		
4	Problem Squashing	1. Problem Squashing 2. Practicing Problem Squashing	1. To understand and demonstrate problem-solving skills in order to cope with various challenges 2. To recognize siblings are not alone in their experiences 3. To learn specific strategies about how to deal with various challenges siblings face such as how to tell others about special needs, how to deal with teasing, etc.	• Statues • Problem Squashing (workbook) • Problem Swapping (workbook) • Role Plays (small groups)	• Freeze Dance • Problem Squashing (Zoom whiteboard) • Problem Swapping (Zoom whiteboard) • Group Reflection & Discussion
5	Wiping Out Worries	1. Exploring Feelings & Coping 2. Coping Skills 3. Coping Skills in Practice	1. To identify and apply coping skills to deal with more challenging situations 2. To understand some problems are solvable, and some are not	• Problem Squashing Practice (workbook) • Lucky Dip • Ways to cope (workbook) • Laughter Yoga • The Robber and the Runners	• Problem Squashing Practice (Zoom whiteboard) • Lucky Dip (online) • Ways to cope (Zoom whiteboard) • Deep Breathing • Guided Imagery

			3. To learn strategies to cope emotionally if a problem cannot be solved		• Laughter Yoga
6	Leaving Stronger & Supported	1. Integration of Information 2. Finding Meaning 3. Closure & Evaluation	1. Review and reflect on learnings and the group experience 2. To enhance siblings' knowledge about personal strengths in themselves and in their brother or sister with a disability 3. To discuss things siblings have learnt about themselves and others 4. To establish longer-term support systems with each other 5. To integrate past sessions to help siblings find meaning in their situation 6. To evaluate participants' group experience	• Things That Make Me Me (workbook cards) • Exploring Strengths (worksheets) • Special Boxes • Reflect on Murals • What I've Learnt • Evaluation (paper)	• Things That Make Me Me (paper) • Exploring Strengths (Zoom whiteboard) • Warm Fuzzies Activity • Personal Murals to share • What I've Learnt Drawing • Evaluation (online)

Findings from the implementation of iSibWorks demonstrated similar psychosocial improvements to the original in-person SibWorks program. Both interventions led to enhancements in emotional regulation, behavioural coping strategies, and social functioning among participating siblings. These improvements were sustained over a three-month follow-up period. Notably, while both programs were well-received, participant satisfaction ratings were slightly higher for the in-person SibWorks program, with 92.11% of participants recommending it, compared to 65.57% of iSibWorks participants (Mallory et al., 2024; Roberts et al., 2015). However, the virtual format of iSibWorks improved accessibility, particularly for families facing geographical or logistical barriers, supporting its feasibility as an alternative delivery model for sibling interventions.

Objective 2: Acceptability of iSibWorks

All six of the siblings who took part in *iSibWorks,* and their four caregivers participated in the semi-structured interviews (four of the participants came from two families; see Table 2 below). Siblings were youth in grades 3 to 7 (between 8 to 12 years old; median age 10 years) and four were male. See Table 2 for more demographic information.

Table 2. *Demographics for Youth Siblings, Siblings with Disabilities, and Caregivers*

Demographic Characteristics	*N*
Youth siblings	6
Mean age at time of intervention, *in years*	10
Median age at time of intervention, *in years*	10
Mean school grade at time of intervention	5
Gender	
Male	4
Female	2
Attended other mental health group or receiving additional support services	
Yes	0

No	6
Siblings with disabilities	4
Mean age at time of intervention, *in years*	10
Median age at time of intervention, *in years*	11.5
Type of disability[a]	
Autism spectrum disorder	1
Epilepsy	2
Genetic condition	1
Global developmental delay	2
Hypotonia	1
Non-verbal	1
Birth order of sibling with disability	
First	2
Second	1
Third	1
Receiving social support services	
Yes	2
No	2
Caregivers[b]	4
Receiving support services[c]	
Yes	0
No	3
Income (CAD)	
Less than 30,000	1
Greater than 100,000	3
Number of caregivers in household	
One	1
Two	3

[a] Siblings could have more than one disability.
[b] There are fewer caregivers than youth because two pairs of youth were from the same home.
[c] One caregiver did not respond to this question.

Field notes indicated that there was 100% attendance on weeks one, two, three, five and six. One participant missed the session on week four (83.3% attendance). There was a stated expectation that all cameras remain turned on, and participants only turned their cameras off

when permitted to do so. Notably, participants engaged with the intervention by participating in all activities and polling exercises (e.g., participants rated their enjoyment of an activity). Polling responses illustrated that half of the siblings *liked* the activity *Two Truths and a Fib* (n = 3/6), whereas the other half *liked it very much* (n = 3/6). Polling responses varied for the *Deep Breathing/Imagery* exercise, such that two siblings mentioned they felt *neutral* about this activity (n = 2/6); in contrast, all other siblings *liked it* (n = 2/6) or *liked it very much* (n = 2/6).

Acceptability of *iSibWorks* Intervention: Qualitative results. Three categories were identified to help understand the acceptability of *iSibWorks* to participants: (1) Satisfaction with the delivery of *iSibWorks*; (2) Perceived benefits of participating in *iSibWorks*; and (3) Suggestions for the improvement of *iSibWorks*. A summary of each category is provided along with exemplar quotes.

***Category 1: Satisfaction with the Delivery of iSibWorks*.** Siblings from both age groups and their caregivers reported satisfaction with the intervention's delivery. Overall, siblings described the activities as enjoyable and engaging. One sibling also valued the accessibility of virtual care. Caregivers reported that siblings were engaged and had demonstrated that *iSibWorks* was fun, useful, and welcoming. Two further sub-categories were identified: Design of *iSibWorks* and Quality of experiences.

Design of iSibWorks. The weekly, 60-minute virtual sessions included interactive activities that were appreciated by participants across all ages. They particularly enjoyed the combination of playing games and having discussions:

> I liked that there were things that they asked us and it was fun and we played a few games. We are doing activities and we are having fun (Sibling 03, 8 years old).

> I liked playing the games and also figuring out how to like deal with problems (Sibling 04, 11 years old).
>
> There seemed to be a lot of back and forth between whatever was going on the screen and them [the sibling]; she'd move around, she'd get this, she'd get that, the drawing and writing stuff out … so it seemed to be interactive and a lot of back and forth rather than just listening to you know, strategies, or whatever was being covered that week. I think that was good (Caregiver 03 of an 8-year-old and a 12-year-old).

Caregivers also valued receiving updates on session activities via weekly handouts. For instance, one caregiver noted:

> I enjoyed the communication to parents like to afterwards letting us know what was discussed without actually sharing with us what the kids themselves discussed, just the general themes. I appreciated that (Caregiver 04 of an 11-year-old).

The pace of the intervention was well-received as well. For example, siblings noted that the session pace was '*fine*' (Sibling 03, 8 years old) and '*good'* (Sibling 06, 11 years old). Sibling 06 further indicated:

> I think it was pretty like straightforward it was not – wasn't like too like fast, like oh gosh I'm doing this now but I was only getting started on this like five seconds ago, no it wasn't like that, I think it was like perfectly paced (11 years old).

In terms of the virtual format, one sibling reported that it offered increased convenience and access to the intervention. For example:

> I didn't have to move or drive somewhere. I think it was just easier like that because it was just like to open my laptop and just go like that (Sibling 05, 12 years old).

Quality of Experiences. The sessions were described as fun and comfortable by siblings in both age-groups. For example, siblings found the activities fun and entertaining as follows:

> The activities we did were pretty fun sometimes, usually it was really fun (Sibling 01, 9 years old).
>
> It was really fun to like have, like having something like to do (Sibling 05, 12 years old).
>
> It was a great experience (Sibling 02, 9 years old).

For example, all siblings mentioned that their favourite activity was the *Lucky Dip Wheel* from week five. This activity focused on developing coping strategies for worrying by answering psychoeducation questions associated with the number they were allocated. Participants liked to see the wheel spin and then answer the question related to their given number. Caregivers echoed that they believed their children had a fun and enjoyable experience while attending the group sessions. One caregiver noted:

> I can tell when he's enjoying something and when he is appeasing me to make me think that he's enjoying something. I really felt like I could tell from his responses that he really did enjoy it and he was sad that it was ending … I mean [my child] looked forward to going so that was my – my number one goal was for him to have this outlet and to enjoy it and the fact that he looks forward to it (Caregiver 04 of an 11-year-old).
>
> Both of my kids liked it a lot and they really looked forward to it. So, I was very impressed with that (Caregiver 02 of a 9-year-old and an 11-year-old).

Siblings also described the group as a safe and comfortable space. Comfort was a central feeling experienced in group sessions. Participants were able to share their stories and personal circumstances in a non-judgmental group environment. They mentioned:

> I liked how, um, everybody was open to talk and we didn't – it was just not like oh, um, you're going to talk it was like everybody was able to talk and like, have their own like, um, well what they had to say (Sibling 05, 12 years old).

Category 2: Perceived Benefits of Participating in iSibWorks. This category describes the perceived outcomes of participating in *iSibWorks*. This included three sub-categories: Connecting with others in similar situations; Learning applicable skills and strategies; and Improved self-esteem and/or mood.

Connecting with Others in Similar Situations. Meeting other siblings with similar experiences was a central component of *iSibWorks*. The siblings enjoyed meeting other group members and the group aspect of the intervention was described as one of its biggest benefits. Siblings described:

> At school there is usually not a lot of people that also have a brother or sister with autism … I was happy to talk to people who have same experiences of me (Sibling 01, 9 years old).

> I thought it was fun and cool and I got to meet other kids like who have – who have a sibling like I do (Sibling 04, 11 years old).

> There's like other people there who know how you feel, so it is better. I liked the fact that I met other people who were kind of, you know, like the same as me, like similar (Sibling 06, 11 years old).

> I like that it was done in a group because, um, it gave me like an idea of what people were experiencing with something maybe a little bit different or like totally different (Sibling 05, 12 years old).

> I like that there were different people that I didn't meet, and I made … I made friends with them (Sibling 03, 8 years old).

Caregivers also emphasized the importance of having their youth connect with other siblings, stating that they did not have such an experience prior to *iSibWorks*. They described:

> I think it's really important … she doesn't know who else who encounters these kinds of challenges throughout her days and her life … she felt more connected with kids that have these kinds of challenges and so they can share their feelings with I think that's important (Caregiver 01 of a 9-year-old).

> I think they enjoyed seeing other kids on the screen and other kids that are sort of maybe not the same shoes but [in] similar shoes, so I know sort of every week they looked forward to logging on (Caregiver 03 of an 8-year-old and a 12-year-old).

> I really just wanted him to have a small group of other kids to connect with in a guided fashion that understood the experience of having a sibling with disabilities (Caregiver 04 of an 11-year-old).

Learning Applicable Skills and Strategies. All siblings noted that they learnt new strategies and tools they could use when they feel stressed or sad. Participants reported that the session topics were relevant to their lives, and the psychosocial challenges they may face. For example, Sibling 05 noted that *'the problem squashing [topic] really helped me'* (12 years old). While many topics were relevant, the tone of the group did not feel too serious or direct:

> I like that they weren't talking during the topics but you actually made it so there is a game in it (Sibling 02, 9 years old).

They described examples of instances they could envision themselves applying the knowledge they learnt during the group:

> Because then if you are like me, feeling sad or annoyed, like somebody bullying you or you know at school, or about your brother or sister than like just regularly, but then, you know like what to do and then how to deal with it (Sibling 02, 9 years old).
>
> It helped me with different things to like, um, like deal with different stuff I didn't really know how to deal with as much as I did before (Sibling 05, 12 years old).
>
> I didn't know how to cope with some problems. I also was not good at getting rid of my problems … coping [topic] was fun (Sibling 04, 11 years old).
>
> Umm, because sometimes you can have problems and you can squash them and then you will make you feel better (Sibling 03, 8 years old).

Caregivers also mentioned:

> In her demeanor, I believe that you know, she was identifying that okay, I [sibling who attended the group] like Roblox. He's [sibling with a disability] not really into Roblox. You know, I like video games. He's not really into it. So, I think she just kind of had a better understanding of it. She didn't talk about it, but I can tell that she was more understanding that he's different – 'I'm different and that's just the way it is', I think – I felt like there was some more patience with that. There was more understanding (Caregiver 01 of a 9-year-old).
>
> I think the games that they played and … then some of the strategies you taught them about coping and I am sure it's in there somewhere. I kind of bring it up once in a while (Caregiver 02 of a 9-year-old and an 11-year-old).

Improved Self-Esteem and/or Mood. Siblings reported that they felt participating in the intervention increased their confidence and helped them learn more about their siblings. It made them feel good to gain knowledge and skills from *iSibWorks*. A sibling and two caregivers noted:

> You could lose confidence if you thought that you're like the only one with a sibling with disabilities or something in that, like, category. I never really lost my confidence in the first place but it [*iSibWorks*] definitely boosted it (Sibling 06, 11 years old).
>
> I think maybe it did have a positive or noticeable impact, you know, maybe a little bit more because she was very happy and she was very passionate about [*iSibWorks*]. She seemed to be in a better mood (Caregiver 02 of a 9-year-old and an 11-year-old).
>
> So this program I feel like everyone's given the…same platform they all start from the same place and they're all trying to bloom. I guess, you know, they're trying to like find themselves. So it's a good (Caregiver 01 of a 9-year-old).

Category 3: Suggestions for the Improvement of iSibWorks. This category outlines recommendations for three aspects of *iSibWorks* that captured suggestions provided by both siblings and caregivers: Delivery improvements; Content recommendations; and Participation enhancement.

In terms of *Delivery improvements*, although siblings had provided positive feedback on the virtual nature of the intervention, they also mentioned that they may also like opportunities for in-person interactions. This was due to screens sometimes hurting their eyes and an eagerness to further develop their connection with other siblings. Caregivers recommended extending the duration of the intervention because they also felt that youth would benefit from more opportunities to connect with siblings in similar circumstances. Siblings' *Content recommendations* included placing a greater emphasis on their personal experiences to increase the applicability of coping strategies provided throughout *iSibWorks*. For example, this included providing distress tolerance techniques for when their siblings were admitted to the hospital. Siblings also indicated that including music and more opportunities for breakout room activities

in sessions may augment engagement with the intervention. To support *Participation enhancement in iSibWorks*, siblings recommended including more people in groups, thus expanding their social support systems to include more siblings. Caregivers were interested in receiving additional information about the activities utilised in the group to deliver psychoeducation – perhaps via a live meeting – and weekly reminders for sessions. See Table 3 for a compilation of quotations supporting and expanding upon these recommendations.

Table 3. *Recommendations for Future iSibWorks Delivery, Content, and Participation*

Suggestion	Supporting Quotation
Delivery improvements	
Providing in-person aspects	In COVID I do [like online], but if there wasn't any COVID I would really like to try it in-person too (Sibling 02, 9 years old). [I would like to have an] in-person club for siblings (Sibling 04, 11 years old).
Increasing duration of iSibWorks	I think they would have loved for it to go longer actually to be an ongoing thing (Caregiver 02 of a 9-year-old and an 11-year-old). Something more ongoing for siblings it'd be nice for them to … connect with another sibling, you know beyond what goes on with the Zoom calls just to be able to you know, sometimes it's whatever's going on around them and they just need to reach out to someone that might understand. To be able to have that ability to connect with someone that's in similar shoes (Caregiver 03 of an 8-year-old and a 12-year-old).
Content recommendations	
Expanding on psychoeducation	Like to teach it when you feel really sad or like stressed because your sister or brother is like 'cause it happens to me like when 'cause she goes to the hospital and like kind of feel how to find joy in that and how to not feel sad or something (Sibling 02, 9 years old).
More breakout room activities	There is not much to change besides the breakout group thing because that would be fun and because it was really fun to do so (Sibling 02, 9 years old).
Incorporation of music	You know how we work we do and wrote things down too. Maybe there could be like

	music in the background into [it as well] (Sibling 02, 9 years old).
Participation enhancement	
Including more participants	Maybe adding a bit more people [to the group] (Sibling 06, 11 years old).
Emphasizing caregiver engagement	I would have liked a bit more information so that I could or even games you played so that we could re-play [the games] if they enjoy. But if it was stuff, we could just generate some more talking points with them (Caregiver 02 of a 9-year-old and an 11-year-old).
	Maybe the parent or guardian. they have one session for them to kinda go through this [the materials]. I know you guys send out the handout and stuff but it's different when you're participating, you know live … so just have the parents kind of say - this is what we did and this is how we address it … more maybe a session for the parents to just go over things and discuss it … because reading it is different than being part of the discussion and the feedback and so forth (Caregiver 01 of a 9-year-old).
Improving logistics for caregivers	The only thing I can think of is a reminder email the day of with that week's Zoom link, that would make it easier from a parents perspective because go – I would I'm sure there's a way to organize yourself better than I was doing but just with everything that's going on online right now and my email inbox fills up so fast and having to go back and try and find it. I know we were late a couple of times because of that so that would really be the only thing that sticks out to me really (Caregiver 04 of an 11-year-old).

Discussion

This study described the adaptation of an in-person, validated intervention for siblings of youth with disabilities, *SibWorks*, to a virtual format for delivery on a video-conferencing platform *iSibWorks*. In addition to the four interconnected principles of *SibWorks* (*Whole Family Approach*, *Family Centered Care*, *Prevention or Early Intervention*, and *Peer Support*), the adapted intervention included a fifth principle, *Access*. This principle aligns with previous literature suggesting that access is often a barrier for youth in need of mental health services (Liverpool et al., 2020).

An important study objective was to assess the acceptability of *iSibWorks* to the participants. Responses from both sibling participants and their caregivers indicated that participants valued the intervention's virtual design and felt that the content was enjoyable. Responses also suggested that *iSibWorks* benefitted siblings' psychosocial outcomes by providing them with an optimal environment to connect with others, learn coping strategies, and increase mood and/or self-esteem. Our findings align with previous literature investigating in-person interventions that show siblings are eager to form connections with others and develop coping strategies to reduce feelings of isolation and being different from their peers (Guan et al., 2021; Hanvey et al., 2022; Kirchhofer et al., 2022; Wolff et al., 2022b).

In terms of feedback for improvement, responses outlined how to enhance certain aspects of the intervention's delivery, content, and participation. Siblings suggested offering in-person opportunities, incorporating further psychoeducation, including music or more breakout room activities as well as increasing group sizes, whereas caregivers suggested creating an ongoing *iSibWorks* intervention and offering them more information on session content as well as providing weekly email reminders about sessions.

This study offers further evidence supporting the notion that siblings benefit from developing positive social support systems and the opportunity to explore their feelings about having siblings with disabilities (Chase & McGill, 2019; Conway & Meyer, 2008; Tomeny et al., 2017). This also offers preliminary evidence regarding the acceptability of adapting an in-person, sibling-focused intervention for delivery online. As alluded to by one participant, adapting in-person interventions for youth siblings may help increase the accessibility of psychosocial interventions and decrease caregiver stress by removing the need to travel. Although siblings mentioned that it was favourable to have online sessions – especially during the COVID-19 pandemic – they also suggested including in-person aspects to the intervention. This response was likely exacerbated by feelings of social isolation that many youths experienced throughout the pandemic (Janssen et al., 2020; Neubauer et al., 2021). Indeed, adapting *iSibWorks* to an online platform, beyond a pandemic, would also benefit siblings living in rural and remote geographic locations, increasing support and accessibility (Miller-Matero et al., 2024).

Strengths and Limitations

Siblings and their caregivers voiced their satisfaction with the delivery of *iSibWorks*, so a main strength of this study was our successful adaptation of an evidence-based, manualised intervention that provided a virtual support group for youth siblings during the COVID-19 pandemic (Roberts et al., 2015; Roberts et al., 2016). Due to the intervention's virtual delivery, siblings were able to access social support and improve their perceived psychosocial functioning throughout pandemic-related lockdowns. Another strength of this study was our emphasis on testing the acceptability of *iSibWorks*. Acceptability testing is recommended for virtual interventions prior to pilot testing, but researchers often disregard this step (Nadal et al., 2020; Perski & Short, 2021). Conducting acceptability testing with our participants provided early

indicators that the intervention met their needs and suggested that formal evaluation of psychosocial outcomes would be a helpful next step with future potential for adoption among siblings and their caregivers. The study also resulted in valuable suggestions regarding future implementation of *iSibWorks* to further increase youth engagement with the intervention.

Several limitations can also be noted for the adaptation to *iSibWorks*. For example, eligibility criteria for participation included English proficiency and a reliable Internet connection. This may have reduced the accessibility of *iSibWorks* for siblings in need of support from culturally diverse backgrounds or for those with unreliable access to technology. Current research suggests that it is imperative to ensure equitable access to healthcare by providing interpretation and technological services for individuals in need (Cheng et al., 2022; Martin et al., 2020; Ng et al., 2021; Okoniewski et al., 2022; Plys et al., 2023; Saeed & Masters, 2021; van der Rijken et al., 2016). Moreover, results from this study are based on a relatively small sample of participants, including siblings from the same home. This limitation was likely exacerbated by circumstances associated with the COVID-19 pandemic, although small sample sizes are often noted in qualitative health research (Green & Thorogood, 2018).

Participant recruitment for this study was through Holland Bloorview, which is known for offering specialized healthcare to youth with disabilities (https://hollandbloorview.ca/about-us/about-HB). Therefore, utilising Holland Bloorview's social media platform for recruitment may have reduced diversity in relation to sibling disability type and age. Our sample comprised primarily siblings of youth with neurological and neurodevelopmental disabilities. It would be important to establish whether the content of *iSibWorks* would have to be adapted in any way for siblings of youth with physical disabilities. The few studies that have compared siblings of those with physical and neurodevelopmental or mental health conditions do not show any differences

in their support needs (Orm et al., 2022; Smith et al., 2018). However, many conditions are co-occurring, which makes this an important area for future study. The goal of recruitment for this study was to invite a broad range of individuals to participate, but this opt-in approach to participation may have increased the likelihood of self-selection bias (Herranz-Zarzoso et al., 2022). Taken together, these limitations may affect the generalizability of results to contexts with different populations (Cho & Trent, 2006; Sinclair et al., 2018).

Implications and Future Research

Future research should investigate the efficacy of the adapted virtual intervention by employing validated emotional and behavioural functioning measures pre- and post-intervention, as well as using a comparison group. The original, in-person *SibWorks* intervention was evaluated in this way and used a waitlist control methodology (Roberts et al., 2015). There are currently no efficacy studies of virtual, sibling-based interventions for youth like *iSibWorks*. Recruiting a large sample of participants to increase the validity of results – including siblings of individuals varying in age and disability type – is also recommended. Although this comes with recruitment challenges, the virtual nature of *iSibWorks* may help to facilitate larger sample sizes.

Siblings are rarely considered in the process of care planning for a child with a disability and often lack psychosocial support as their caregivers experience high levels of stress throughout this process (Kruithof et al., 2021; Leane, 2019; Leane, 2020). Evidence of the efficacy of sibling-focused psychosocial interventions could be used to urge policymakers to recognize the societal benefits of supporting siblings and amplify calls for siblings to be included in the provision of services to families (Kruithof et al., 2022). Allocating virtual services to siblings may be a cost-effective manner to help prevent the poor mental health outcomes they may develop, enhance accessibility to resources, and help strengthen siblings enough to assist

with caring for their loved ones in the future (Naylor & Prescott, 2004; Saxena, 2015). In addition, collaborating with youth siblings and listening to their voices is crucial to ensuring that their needs are being met to the greatest extent possible.

Therefore, future research could consider a hybrid approach, with some virtual and some in-person components. For instance, in-person, support group sessions could be held without psychoeducational components, to emphasize the importance of lighthearted conversations between siblings and further facilitate their development of healthy support systems. Adapting *iSibWorks* in this manner would maintain the accessibility of online psychoeducation, while offering the valuable in-person interactions requested by participants. It would be important to involve siblings in the design process and place their voices at the forefront of this work to maximize the acceptability of any future intervention. For example, investigating contexts in which siblings prefer in-person, online, or hybrid delivery may help with acceptability. In addition, sibling-related needs and experiences may vary significantly depending on the nature of the disability. Future studies could explore the efficacy of *iSibWorks* within disability-specific groups to better tailor the intervention to the unique needs of different populations.

Conclusion

This is the first study to demonstrate the adaptation of an in-person, evidence-based intervention for use on a virtual platform with youth. Siblings and their caregivers provided preliminary evidence indicating acceptability of *iSibWorks*. These findings underline the importance of providing siblings with opportunities to connect with others in similar situations and to support siblings' positive psychosocial development outcomes. Our hope is for siblings to be considered more routinely in healthcare spaces that treat youth with disabilities. When given the space to discuss their feelings, siblings and their caregivers demonstrated gratitude for

psychosocial interventions that take their perspectives into account. As seen throughout this qualitative study, siblings and their caregivers are open to discussing how these interventions may best support them; now it is time we listen.

CHAPTER 3. A Pilot Study of a Virtual Psychosocial Intervention, *iSibWorks*, for Siblings of Youth with Disabilities

Offering psychological services via virtual platforms has become increasingly common in the 21st century (American Psychological Association, 2024). Research has explored the efficacy of utilising these platforms with youth and their families or caregivers, especially during and following the COVID-19 pandemic (Philippe et al., 2022). These interventions are often referred to as eHealth, mHealth, or virtual programs due to their application on web-based mediums. While they can be offered via mobile phone applications, emails, and podcasts, videoconferencing platforms on the Internet are most common (Han & Kim, 2022; Liptáková et al., 2022; Sommers-Spijkerman et al., 2021; Winter et al., 2022). The goal of virtual health interventions is often to increase accessibility and affordability for services that are offered, as well as to reduce wait times and facilitate choice regarding an individual's preferred modality for receiving healthcare services (Donker et al., 2015; Gega et al., 2022; Rogers et al., 2017). A range of different psychological interventions have been offered through virtual programs, including mindfulness, cognitive behavioural therapy (CBT), acceptance and commitment therapy (ACT), and peer support groups (Liu et al., 2023; Marcu et al., 2022; O'Connor et al., 2018; Spijkerman et al., 2016; Thompson et al., 2021). Using virtual interventions with children and youth may be particularly helpful because of its convenience and ability to support families within a wider geographical reach, in addition to youth familiarity and comfort with technology (Khanna & Carper, 2022; Opie et al., 2024a; Opie et al., 2024b).

Studies have looked at both the efficacy and adherence of eHealth interventions. Liptáková and colleagues (2022) conducted a systematic review to investigate adherence to virtual mindfulness-based programs prior to the pandemic. Of 69 studies included, only eight

studies implemented interventions with families, youth, or their caregivers and were highly heterogeneous. These studies included a self-guided online intervention with families experiencing mental illness (Stjernswärd & Hansson, 2017), interventions for youth to facilitate smoking cessation with a mobile application (Pbert et al., 2019), managing insomnia with digital delivery of content on multiple platforms (Werner-Seidler et al., 2018), and reducing stress with asynchronous online modules (Antonson et al., 2018) or by combining virtual and/or in-person modes of delivery (Puolakanaho et al., 2019). The remaining three interventions aimed to help caregivers of children with chronic health conditions by offering self-directed web-based lessons (Sairanen et al., 2019) and to support women experiencing maternal stress through a mobile application (Hunter et al., 2019) or self-directed learning on a web-based platform (Potharst et al., 2019).

Three recent systematic reviews have explored virtual interventions tailored specifically to improving psychosocial outcomes (Han & Kim, 2022; Sommers-Spijkerman et al., 2021; Winter et al., 2022). Although two of them (Sommers-Spijkerman et al., 2021; Winter et al., 2022) found significant improvements in multiple areas of mental health, specifically related to depression, stress, mindfulness, anxiety, and well-being, they focused solely on mindfulness interventions conducted with people aged 18 years or older. The third systematic review and meta-analysis evaluated virtual ACT for all ages (Han and Kim, 2022). Included were four articles describing ACT with caregivers (n = 3) or adolescents (n = 1), using synchronous online sessions for parents of children with chronic health conditions (Douma et al., 2021) or life-threatening illnesses (Muscara et al., 2020). They used various combinations of synchronous and asynchronous approaches to supporting adolescents through a web-based intervention (Lappalainen et al., 2021). Broadly, the virtual interventions implemented with youth, caregivers,

and/or families indicated improvements in psychosocial or health-related outcomes (Han & Kim, 2022). However, one significant gap in the research is the efficacy of virtual psychosocial interventions for siblings of children with disabilities.

Siblings of individuals with disabilities (herein 'siblings') are often prone to difficulties with their psychosocial functioning over time (Bowman et al., 2014; Faust et al., 2023; Hanvey et al., 2022; Pinquart, 2023; Shivers et al., 2019; Shtayermman, 2022; Sommantico et al., 2020). These difficulties range from externalising and internalising psychosocial difficulties such as social withdrawal and anxiety, to issues with emotion regulation, attention, and/or somatic complaints (Habelrih et al., 2018; Neece et al., 2010; Pilowsky et al., 2004; Ross & Cuskelly, 2006; Yaldız et al., 2021). Recent research suggests that complexities within the family unit, such as limited time with caregivers or self-imposed pressures to be perfect may result in emotional distress for siblings and lead to behavioural issues (Arcous et al., 2024; Skotko & Levine, 2006). Given the challenges experienced by siblings and their caregivers, these psychosocial difficulties tend to strain relationships among family members and contribute to unhealthy interactions that further complicate family dynamics (Bhattashali et al., 2018; Caroli & Sagone, 2013; Mulroy et al., 2008). Because of this, in-person psychosocial interventions that support siblings by offering them coping strategies, promoting their communication and empathy skills, and alleviating their concerns regarding sibling relationships have been found to improve emotional well-being and contribute to a more harmonious family environment (Chan & Goh, 2014; Greenberg et al., 1999; Kilmer et al., 2010; Wofford & Carlson, 2017).

However, in families where one (or more) children have a disability, attending in-person interventions may not be possible due to logistical challenges associated with travelling, such as time, cost, and childcare requirements (Feriante et al., 2022; Gettings et al., 2015; Zgierska et al.,

2024). Children with disabilities may also have mobility challenges and rehabilitation appointments that make it difficult for families to regularly engage in activities for siblings (Ballantyne et al., 2019; Polfuss et al., 2019; Ziviani et al., 2014). As such, siblings need more accessible interventions to support their psychological, social, and emotional outcomes (Lamsal & Ungar, 2021). Virtual interventions may provide access to psychosocial interventions for siblings who would otherwise be unable to access care (Horn et al., 2022; Powell et al., 2024). Researchers developed a virtual intervention centered on mind-body relaxation techniques for teenage siblings of youth with ASD, called *SibChat* (Fell et al., 2022). While siblings reported that *SibChat* was acceptable and feasible, the outcome measures used to evaluate the program's efficacy were not validated measures of psychosocial functioning (Fell et al, 2022; Kuhlthau et al., 2022). Furthermore, the sample was limited with only teenage siblings of autistic children included. There is therefore a significant gap in our understanding of the efficacy of virtual interventions for siblings.

Mallory et al. (2024) explored the feasibility and acceptability of iSibWorks, a virtual adaptation of the SibWorks program designed to support the emotional well-being of siblings of youth with disabilities. Their study used qualitative methods, including semi-structured interviews with siblings and caregivers, to gather feedback on the program. Participants generally responded positively, noting that iSibWorks helped them feel more connected, improved their self-esteem, and deepened their understanding of their sibling's disability. These findings highlight the potential benefits of the program and lay the groundwork for future research on its long-term impact.

Building on this initial study, Study 2 shifts the focus to a quantitative assessment of iSibWorks and its effectiveness in improving psychosocial functioning among siblings. While

the first study provided valuable qualitative insights into emotional and behavioral changes after the program, this study takes a more data-driven approach, using validated measures (YSR/CBCL, SDQ) to assess outcomes. A key focus is examining how siblings' baseline psychosocial difficulties influence their response to the intervention, comparing those with higher versus lower symptom severity. By taking this approach, the study aims to offer a clearer picture of how individual differences shape the program's impact, contributing to a broader understanding of its effectiveness.

SibWorks is an in-person intervention that has been found to significantly improve emotional and behavioural functioning for siblings of children with disabilities (Roberts et al., 2015). To increase access to this intervention, we recently adapted *SibWorks* to *iSibWorks* for implementation on a virtual platform (*Zoom for Healthcare*). Qualitative interviews with participants showed that both siblings and their caregivers found *iSibWorks* to be an acceptable intervention and that they valued the opportunity for siblings to connect with others who were in a similar situation to them (Hooper et al., 2024). They also reported that the CBT strategies they had learned through *iSibWorks* were easily applicable to their lives. Establishing evidence of the efficacy of *iSibWorks* using validated measures is now needed before broader implementation of the program. Earlier work explored whether participating in *iSibWorks* impacted a sibling's perceived social support or quality of life, but found no significant differences in responses between pre-program and one week after the child participated in the program (Mallory et al., 2024). They did not conduct longer-term follow up. The measures used also did not target the internalising and externalising behaviours commonly noted with siblings and that have a significant impact on their lives (Mallory et al., 2024; Ostendorf & Gedela, 2017; Wood et al., 2008).

The overarching aim of the current study was therefore to quantitatively evaluate the *iSibWorks* virtual program for siblings to identify whether it impacted psychosocial functioning over time. We were interested in whether there was a change in total problems, emotional problems, conduct problems, hyperactivity or inattention, peer relationship problems, prosocial behaviour, anxiety/depression, somatic complaints, rule-breaking behaviour, and aggressive behaviour. We hypothesised that: (1) siblings and caregivers would report that siblings participating in *iSibWorks* had better psychosocial functioning from pre-*iSibWorks* to one-week post-intervention and at the 3-month follow-up; and (2) siblings with poorer psychosocial functioning at baseline would benefit from *iSibWorks* to a greater extent than those with better psychosocial functioning.

Method

Design

The study used a pre-post follow-up, single-arm design, evaluating outcomes at baseline (before starting the intervention), immediately after completing the program, and three months post-*iSibWorks.* Approval for this study was obtained through the Research Ethics Board at Holland Bloorview (#328) and York University.

Participants

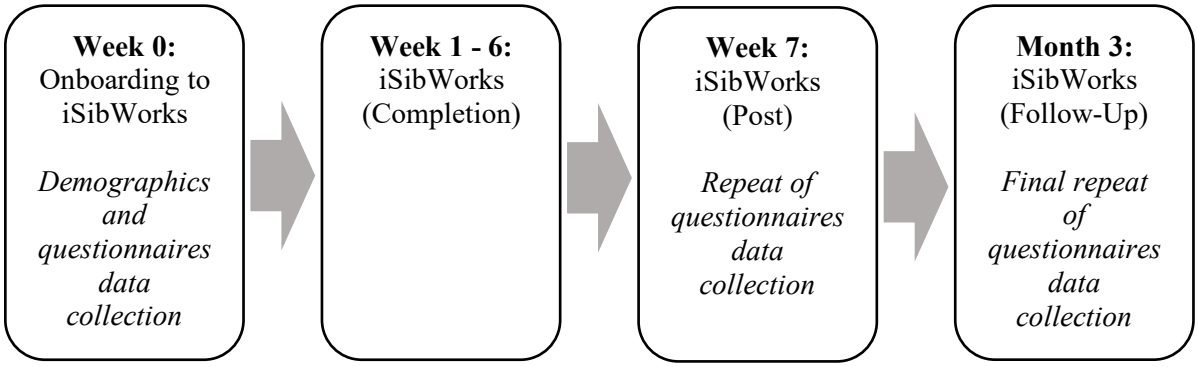
Sibling inclusion criteria were: (1) Being a sibling in grades 3 to 8 (8 to 14 years) of youth with disabilities; (2) Ability to comprehend and communicate in English; (3) Access to a reliable Internet connection; (4) Had at least one caregiver who would complete parent-report measures. A sibling's eligibility was not dependent upon a minimum length of time from a confirmed or self-reported diagnosis. Caregiver inclusion criteria were: (1) Had a child participating in the study; (2) Able to communicate in English sufficiently to complete measures.

Participant recruitment occurred via convenience sampling at Holland Bloorview as well as Kinark Child and Family Services in Toronto, Ontario and via their social media platforms. Eligible siblings and their caregivers were enrolled in *iSibWorks* divided into two grade-based groups: grades 3 to 5 and grades 6 to 8. Once siblings and caregivers provided informed assent and parental consent, they were then oriented to the relevant technology platform and demographic information was collected by a member of the research team via phone or video call.

Procedure and Materials

Our research team sent flyers to initially introduce the study, followed by a discussion with siblings and caregivers. If they demonstrated an interest in the study and fit the inclusion criteria, siblings and their caregivers were invited to participate in an onboarding session. Upon receiving their assent and consent forms, onboarding to *iSibWorks* included collecting demographic information and completing validated questionnaires. Siblings joined *iSibWorks* in the same sessions once a week for six week. Their caregivers were offered information sheets prior to, and in preparation for, each session (Appendix C). Weekly sessions lasted approximately 60 minutes. each. At week seven (one-week post-intervention) and three months following the intervention (intervention follow-up), participants were asked to complete the same questionnaires offered during the onboarding session. Therefore, our outcome measures of interest were examined at three time points (pre, post, follow-up; see Figure 3).

Figure 3. *Study Flow and Data Sources*



Questionnaires. Data collection sessions took approximately 75 minutes each, during which surveys were administered through *REDCap*. Siblings and their caregivers completed separate questionnaires. Younger siblings who were unable to read the questionnaires were guided by a member of the research team. Siblings' self-report questionnaires and their caregivers' related proxy-report questionnaires are described in Table 4.

Table 4. *Siblings' Self-Report and Caregivers' Proxy-Report Questionnaires*

Measure	Purpose	Duration
Sibling Self-Report: Demographic Form	To collect demographic information such as age, gender, services received, etc., during onboarding to *iSibWorks*.	5 minutes
Caregiver Proxy-Report: Demographic Form	To collect demographic information on child age, gender, disability, birth order of children, previous services, etc. during onboarding to *iSibWorks*.	10 minutes
Sibling Self-Report: Youth Self Report (YSR)	To detect behavioural and emotional disorders in children and adolescents over time (pre, post, and follow-up for *iSibWorks*); *one version*: 11 to 18 years.	20 minutes
Caregiver Proxy-Report: Child Behavior Checklist (CBCL)	To detect behavioural and emotional disorders in their children over time (pre, post, and follow-up for *iSibWorks*); *one version*: 6 to 18 years.	20 minutes
Sibling Self-Report: Strengths and Difficulties Questionnaire (SDQ)	To evaluate psychological adjustment and detect emotional or behavioural problems over time (pre, post, and follow-up for *iSibWorks*); *one version*: 11 to 17 years.	10 minutes
Caregiver Proxy-Report: Strengths and Difficulties Questionnaire (SDQ)	To evaluate psychological adjustment and detect emotional or behavioural problems in their children over time (pre, post, and follow-up for *iSibWorks*); *two versions*: 4 to 10 years and 11 to 17 years.	10 minutes

Demographic Form. During the onboarding session for this pilot study of iSibWorks, demographic information was collected from both siblings and their caregivers. Siblings were asked about their age, gender, and any previous social support services they had received. Caregivers provided details about their household structure, family income, prior support services accessed by the sibling, and some background information about the child with a disability. These forms helped us better understand the study participants and can be found in Appendix A (Sibling Demographics Form) and Appendix B (Caregiver Demographics Form).

Youth Self-Report (YSR) or Child Behavior Checklist (CBCL). This study assessed psychosocial functioning using two widely recognized tools: the Youth Self-Report (YSR) and the Child Behavior Checklist (CBCL). The YSR, designed for youth aged 11 to 18, includes 112 items that evaluate emotional, behavioural, and social difficulties (Achenbach & Dumenci, 2001). The CBCL serves as the caregiver-reported equivalent, completed by parents of children aged 6 to 18, with 113 items assessing similar domains (Achenbach & Rescorla, 2004). These measures were selected for their strong psychometric properties, extensive use in research, and ability to capture both internalizing and externalizing difficulties (Achenbach & Rescorla, 2004). Both the YSR and CBCL categorize responses into eight subscales: **anxious/depressed symptoms, withdrawn/depressed behaviours, somatic complaints, social difficulties, thought problems, attention issues, rule-breaking behaviours, and aggression.** An additional "Other Problems" category captures concerns such as excessive talking or bedwetting. Participants rate items on a 3-point Likert scale (*0 = Not True, 1 = Somewhat or Sometimes True, 2 = Very True or Often True*), with higher scores indicating greater psychosocial challenges. A total problems score reflects the cumulative difficulties reported across all

subscales.

Strengths and Difficulties Questionnaire (SDQ). To supplement the YSR and CBCL, the study also included the **Strengths and Difficulties Questionnaire (SDQ)**, a 25-item measure available in both self-report and caregiver-report formats. The SDQ assesses five domains: **emotional difficulties, conduct issues, hyperactivity/inattention, peer relationship challenges, and prosocial behaviour** (Goodman, 1997). Responses follow a 3-point scale, and the total difficulties score is calculated by summing the first four subscales, excluding prosocial behaviour. The SDQ was selected for its efficiency, sensitivity to change, and prior use in sibling intervention research, including controlled trials of *SibWorks* (Roberts et al., 2015, 2016), where it was instrumental in identifying predictors of emotional and behavioural outcomes (Goodman & Goodman, 2009; Stone et al., 2010).

While the SDQ was initially chosen as the primary measure, the CBCL was incorporated to provide a more **comprehensive assessment**. Unlike the SDQ, which focuses on core emotional and behavioural issues, the CBCL captures a broader spectrum of concerns, including somatic complaints, thought disturbances, and social difficulties (Becker et al., 2015; Rescorla et al., 2007). Its widespread use in both clinical and research contexts ensures strong reliability and validity (Achenbach & Rescorla, 2004).

Moreover, including the CBCL allowed for a **dual-informant approach**, integrating both self-reported sibling experiences and caregiver perspectives. Research suggests that children and parents often perceive emotional and behavioural difficulties differently, leading to discrepancies in reporting (Rescorla et al., 2007; Stone et al., 2010). By incorporating both perspectives, this study aimed to capture a more **nuanced and accurate** understanding of how *iSibWorks* influences sibling well-being.

Data Analysis

Group level statistical analyses were conducted. These analyses were computed with the Statistical Package for the Social Sciences (SPSS) software, version 28. Descriptive statistics for siblings and their caregivers were generated to report participant demographics. For each questionnaire assessing psychosocial adjustment (YSR/CBCL, SDQ), a 2x3 repeated analysis of variance (ANOVA) was conducted with informant type (siblings, caregivers) as the between-groups factor and time (pre, post, follow-up) as the within-groups factor. To test the first hypothesis, these mixed ANOVAs determined if there was an effect of time – on (a) *total problems* standardized scores as per the YSR/CBCL and (b) *total difficulties* raw scores based on the SDQ – by informant. Analyses for the second hypothesis followed a similar method, such that two 2x3 mixed ANOVAs were conducted to assess if there was also an effect of time (pre, post, follow-up; within-groups factor) on total responses to psychosocial questionnaires (YSR/CBCL, SDQ) that depended upon symptom severity at baseline (low, high; between-groups factor). Cut-off scores for inclusion in the high symptom severity group were defined as borderline elevation standardized scores on the YSR/CBCL (score of ≥60) and abnormal raw scores on the SDQ (score of ≥17). Therefore, a total of four mixed ANOVAs were conducted for this study. The Shapiro-Wilk, Levene, and Mauchly tests confirmed assumptions of normality, homogeneity of variances, and sphericity, respectively, prior to conducting each mixed ANOVA for this research; appropriate corrections were made if an assumption was violated (e.g., Greenhouse-Geisser correction for lack of sphericity). If results yielded $p < 0.05$, all potential treatment contrasts and confidence intervals were estimated using Tukey's procedure. Post hoc tests were adjusted for multiple comparisons with Bonferroni's correction.

Results

Twenty-five participants (12 siblings, 13 caregivers) completed the psychosocial questionnaires at all three time points (pre, post, and follow-up). This sample included seven sibling-caregiver pairs (n = 14), five siblings without their caregivers (n = 5), and six caregivers of siblings between 8 to 10 years who were considered ineligible to complete self-report questionnaires (n = 6). Approximately 58% of siblings who participated in *iSibWorks* were female and participants had a median age of 11.5 years. Data were normally distributed across both the YSR/CBCL and SDQ questionnaires. Siblings attended six weekly intervention sessions: six children were in the younger group (8 to 10 years) and 12 siblings were in the older group (11 to 13 years). Caregivers were given handouts outlining the content prior to each session. The scope of disabilities for siblings was broad, ranging from chronic health conditions to neurodevelopmental and other psychological disorders. More demographic information about participants and siblings with disabilities is provided in Table 5.

Table 5. *Demographics for Participants and Siblings with Disabilities at Baseline*

Demographic Characteristics	*N*
Sibling participants	12
Mean age at time of intervention, *in years*	11
Median age at time of intervention, *in years*	11.50
Mean school grade at time of intervention	6.42
Gender	
Male	5
Female	7
Attended other mental health group or receiving additional support services	
Yes	2
No	10
Caregiver participants[a]	13

Receiving support services	
Yes	3
No	9
Income (CAD)	
Less than 30,000	1
31,000 to 50,000	3
51,000 to 70,000	1
71,000 to 90,000	4
91,000 to 100,000	1
Greater than 100,000	2
Number of caregivers in household	
Two	9
Three or more	3
Siblings with disabilities[b]	19
Mean age at time of intervention, *in years*	9.19
Median age at time of intervention, *in years*	9.50
Type of disability[c]	
Attention deficit hyperactivity disorder (ADHD)	9
Autism spectrum disorder (ASD)	4
Oppositional defiant disorder (ODD)	4
Learning disability (LD)	2
Developmental coordination disorder (dyspraxia)	2
Epilepsy	2
Genetic condition (SZT2/SCN8A)	2
Down syndrome	1
Cerebral palsy	1
Cloacal malformation	1
Ulcerative colitis	1
Asthma	1
Global developmental delay (GDD)	1
Sensory processing disorder	1
Anxiety	1
Concussion	1
Cortical visual impairment (CVI)	1
Non-verbal	1
Non-ambulatory	1
Fine motor difficulties	1
Birth order of sibling with disability	
First	5
Second	3

Third	3
Fourth	2
Youngest	5
Receiving social support services	
Yes	13
No	5

[a] One caregiver did not respond to any questions on the demographic questionnaire.
[b] Information about siblings with disabilities was provided by caregivers at baseline for all participants included in this study; one caregiver provided information about two of their children with disabilities.
[c] Siblings could have more than one disability.

Hypothesis 1: Psychosocial Adjustment after Completion of iSibWorks

Two 2x3 mixed ANOVAs were conducted to assess if siblings and/or caregivers (informant type) reported significantly different levels of psychosocial adjustment for youth at pre, post, and follow-up (time) based on responses to the YSR or CBCL and SDQ. While these ANOVAs did not demonstrate a significant interaction between informant type and time, results indicated a significant main effect of time for both the YSR/CBCL and SDQ. A large effect of time was found based on responses to the YSR/CBCL (partial $\eta^2 = .24$), whereas a medium to large effect (partial $\eta^2 = .14$) was noted for responses on the SDQ. There was no main effect of informant type for either questionnaire. The intervention scores at pre, post, and follow-up as well as further details about results are provided in Table 6; post hoc tests for the YSR/CBCL and SDQ were conducted, which can be found in Table 7.

Table 6. *Means, Standard Deviations, and 2x3 Mixed ANOVA Statistics for Hypothesis 1*

Variable	Siblings		Caregivers		Mixed ANOVA			
	M	*SD*	*M*	*SD*	Effect	*F* ratio	*df*	Partial η^2
Total problems (YSR/CBCL)								
Pre	56.83	6.99	58.08	9.21	I	0.56	1	.02
Post	52.25	9.35	55.23	11.29	T	7.21**	2	.24

	Follow-Up	50.92	9.85	54.92	11.62	I*T	0.60	2	.03
Total difficulties (SDQ)									
	Pre	12.83	4.73	9.77	6.98	I	1.12	1	.05
	Post	11.50	5.54	9.23	7.05	T	3.83*	2	.14
	Follow-Up	10.17	5.47	8.31	5.98	I*T	0.34	2	.01

Note. N = 25 (12 siblings, 13 caregivers for YSR/CBCL and SDQ). ANOVA = analysis of variance; I = informant; T = time.

*p<.05. **p<.01.

Youth Self Report (YSR) or Child Behaviour Checklist (CBCL). Pairwise differences among responses to the YSR or CBCL on factor levels for time (pre, post, follow-up) were examined. Results illustrated significant differences in psychosocial adjustment between pre (M = 57.48, SD = 8.07) and both post (M = 53.80, SD = 10.30) and follow-up (M = 53.00, SD = 10.78). T-scores in this context indicate levels of psychosocial adjustment: higher t-scores (e.g., 57.48 pre-intervention) reflect greater psychosocial problems, whereas lower t-scores (e.g., 53.00 at follow-up) signify improvements. These findings demonstrate decreased total problems from pre-intervention to one week after participants completed *iSibWorks* (post) and three months later (follow-up). No differences were noted between post and follow-up intervention responses, suggesting that improvements in psychosocial adjustment were maintained at follow-up.

Strengths and Difficulties Questionnaire (SDQ). Although a significant main effect of time was noted for the SDQ (Table 6), post hoc tests did not indicate any significant differences (Table 7). Despite this, contrast results demonstrated a significant linear trend $F(1, 23) = 5.72$, $p = .025$, partial $\eta^2 = .20$, for total difficulties. For the SDQ, higher scores on total difficulties reflect greater psychosocial challenges, while lower scores indicate improvement in

adjustment. There was a large effect that as time increased (pre, post, follow-up) psychosocial adjustment improved (total difficulties scores decreased). The *M* (*SD*) raw scores for pre, post, and follow-up total difficulties were 11.24 (6.09),10.32 (6.34), and 9.20 (5.70), respectively (mean differences can be found in Table 7).

Table 7. *Hypothesis 1 Post Hoc Comparisons for Time with Bonferroni's Correction*

Variable			95% CI	
Comparisons	Mean Time Difference	Std. Error	Lower Bound	Upper Bound
Total problems (YSR/CBCL)				
Pre vs. Post	3.72**	0.93	1.31	6.12
Pre vs. Follow-Up	4.54*	1.44	0.83	8.24
Post vs. Follow-Up	0.82	1.39	-2.77	4.41
Total difficulties (SDQ)				
Pre vs. Post	0.94	0.66	-0.77	2.65
Pre vs. Follow-Up	2.06	0.86	-0.17	4.29
Post vs. Follow-Up	1.13	0.36	-0.68	2.94

*p<.05. **p<.01.

Hypothesis 2: Impact of Symptom Severity on Psychosocial Adjustment after Completion of iSibWorks

Two additional 2x3 mixed ANOVAs were conducted – one per psychosocial questionnaire (CBCL/YSR and SDQ) – to assess if severity of psychosocial maladjustment (low, high) at baseline influenced responses over time (pre, post, follow-up). Given that there was no significant main effect of informant type (siblings versus caregivers; Table 6) on responses to

both questionnaires, data were analysed at the group level. Findings demonstrated a significant interaction between symptom severity and time with a medium effect (partial $\eta^2 = .12$) on responses to the SDQ, whereas only large main effects for these independent variables were found in relation to the YSR/CBCL. Notably, the Greenhouse-Geisser correction was applied to the CBCL/YSR values because the assumption of sphericity was violated. Additional results are provided in Table 8 and further described for each psychosocial adjustment questionnaire below.

Table 8. *Means, Standard Deviations, and 2x3 Mixed ANOVA Statistics for Hypothesis 2*

Variable	Low		High		Mixed ANOVA			
	M	*SD*	*M*	*SD*	Effect	*F* ratio	df	Partial η^2
Total problems (YSR/CBCL)								
Pre	52.53	4.76	64.90	6.05	S	22.97**	1	.50
Post	47.80	7.38	62.80	6.94	T	6.93**	1.61	.23
Follow-Up	48.53	7.71	59.70	11.59	S*T	1.17	1.61	.05
Total difficulties (SDQ)								
Pre	9.19	3.96	22.00	2.83	S	23.95**	1	.51
Post	8.48	4.89	20.00	3.74	T	7.35**	2	.24
Follow-Up	7.90	4.92	16.00	5.03	S*T	3.22*	2	.12

Note. $N = 25$ (15 low, 10 high for YSR/CBCL and 21 low, 4 high for SDQ). ANOVA = analysis of variance; S = symptom severity; T = time.

*$p<.05$. **$p<.01$. ***$p<.001$.

Youth Self Report (YSR) or **Child Behaviour Checklist (CBCL).** Between-group findings collapsing responses across time points indicate that siblings and caregivers in the high

symptom severity group (*M* = 62.47, *SE* = 2.08) reported significantly greater total problems, or worse psychosocial adjustment, than those in the low symptom severity group (*M* = 49.62, *SE* = 1.67). We also found significant group differences for the main effect of time on YSR/CBCL responses (Table 9). These differences reflected trends noted previously, such that participants reported significantly better psychosocial adjustment at both post and follow-up relative to baseline (pre-*iSibWorks*); mean difference values provided in Table 9 are based upon estimated marginal means, but the *M* (*SD*) values for each time point match those provided above. Importantly, these results are expected given the nature of inclusion in the low versus high symptom severity group and findings related to hypothesis 1 of this study (see Tables 6 and 7).

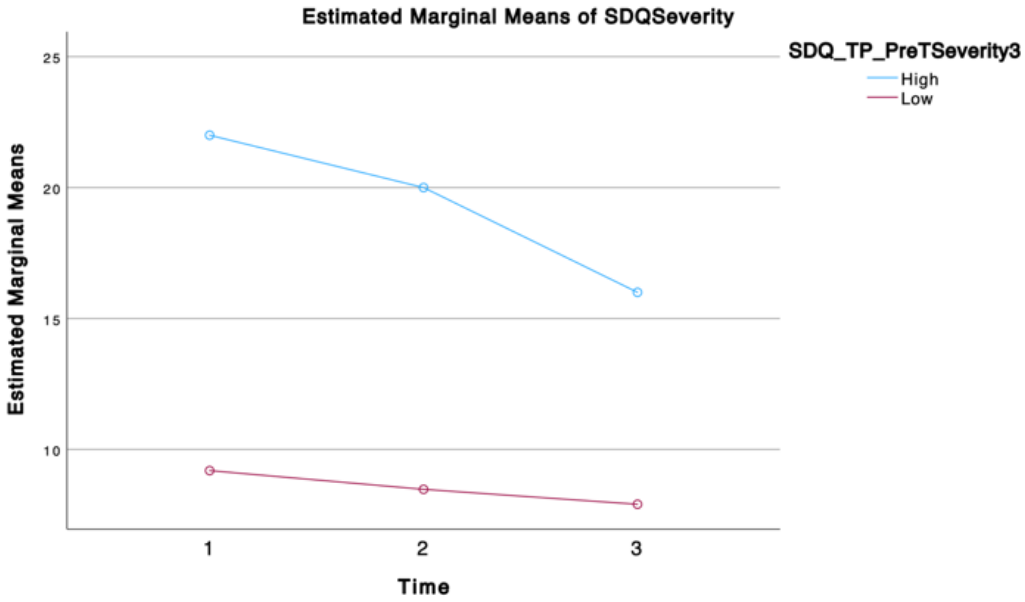
Strengths and Difficulties Questionnaire (SDQ). Data were re-analysed to determine simple main effects for symptom severity and time due to the significant interaction between these factors. As shown in the interaction plot (Figure 4), results suggested that the effect of time on psychosocial adjustment as per total difficulties SDQ scores is dependent upon symptom severity level. Specifically, siblings and caregivers who reported greater total difficulties at baseline (high symptom severity; *M* = 22.00, *SE* = 1.92) also reported greater improvements to psychosocial adjustment after completion of *iSibWorks* (post: *M* = 20.00, *SE* = 2.38; follow-up: *M* = 16.00, *SE* = 2.47). In contrast, levels of psychosocial adjustment were similar across time for participants who reported fewer total difficulties at baseline (Table 9). These findings provide preliminary evidence that siblings who describe struggling more with psychosocial adjustment may experience greater improvements after completion of *iSibWorks* relative to those who report fewer difficulties.

Table 9. *Hypothesis 2 Post Hoc Comparisons for Symptom Severity, Time, and Symptom Severity x Time Interaction*

Variable			95% CI	
Comparisons	Mean Difference	Std. Error	Lower Bound	Upper Bound
Symptom severity: Total problems (YSR/CBCL)				
High vs. Low	12.84***	2.68	7.30	18.39
Time: Total problems (YSR/CBCL)				
Pre vs. Post	3.42**	0.93	1.02	5.81
Pre vs. Follow-Up	4.60*	1.49	0.76	8.44
Post vs. Follow-Up	1.18	1.37	-2.34	4.71
Time x Symptom Severity: Total difficulties (SDQ)				
Low – Pre	9.19	0.84	7.46	10.92
Low – Post	8.48	1.04	6.33	10.62
Low – Follow-Up	7.91	1.08	5.68	10.13
High – Pre	22.00	1.92	18.04	25.96
High – Post	20.00	2.38	15.09	24.91
High – Follow-Up	16.00	2.47	10.90	21.10

*p<.05. **p<.01. ***p<.001.

Figure 4. *Interaction Plot for Symptom Severity x Time as per Strengths and Difficulties Questionnaire (SDQ)*



Discussion

Results from the current study provide preliminary support for our hypotheses that (1) Improvements in psychosocial adjustment would be reported by siblings and caregivers following their participation in the *iSibWorks* intervention; and (2) Siblings who indicated that they were having high levels of difficulties with psychosocial adjustment prior to *iSibWorks* would report greater benefits from their completion of the intervention than those disclosing less difficulties at baseline. Sibling responses indicated improvements in psychosocial adjustment from pre-*iSibWorks* to after its completion at both post and follow-up. However, pairwise comparisons only detected significant differences between time points – pre-intervention to post and pre-intervention to follow-up – for responses on the YSR/CBCL. Although a significant linear relationship between time and SDQ responses was detected, these findings suggest that the YSR/CBCL may be better able to monitor changes in psychosocial adjustment throughout *iSibWorks*. This may be because the YSR/CBCL is a comprehensive assessment found to be developmentally sensitive for monitoring clinical issues that require intervention relative to the more generalized SDQ, which offers less detail about youth's specific stressors and their

associated emotional complexities (Bühler, 2019; Lynch et al., 2021). Given that psychosocial difficulties may go unnoticed in siblings, the YSR/CBCL likely provides more insight to their unique challenges. There was no significant interaction between time and informant responses on either questionnaire, suggesting that siblings and caregivers detected similar improvements in psychosocial adjustment that were maintained at follow-up three months later. A significant interaction was described for the SDQ, suggesting that siblings who reported poorer psychosocial adjustment at baseline benefitted more from *iSibWorks*, whereas only significant main effects of time and symptom severity were found for the YSR/CBCL.

Studies evaluating virtual interventions designed to help siblings of youth with disabilities improve their psychosocial functioning are scarce. Roberts and colleagues (2015) utilised SDQ responses from caregivers to investigate emotional and behavioural outcomes following the original, in-person *SibWorks* intervention. Their study demonstrated between-group differences indicating that children in the treatment group improved in emotional and behavioural functioning compared to those in the control group. These improvements were maintained at three months post-intervention (follow-up). However, the follow-up assessments only included caregiver-reported responses. The present research expands upon these findings by evaluating our virtual adaptation of *SibWorks* (i.e., *iSibWorks*), which demonstrated that *both* siblings and caregivers reported enhancements in emotional, behavioural, and social functioning, which were sustained over a 3-month period. This suggests that providing siblings with the intervention content online (*iSibWorks*) may produce similar psychosocial improvements to offering this content in-person (*SibWorks*).

Our work to date on *iSibWorks* enhances our understanding of how siblings respond to psychosocial interventions alongside siblings in similar situations. Feedback in a previous study

has shown that the majority of siblings in both *iSibWorks* and *SibWorks* reported that they were happy with *iSibWorks* or thought that other siblings would like to join the intervention (65.57% and 92.11%, respectively; Mallory et al., 2024). More than 85% of both siblings and their caregivers have also reported that *SibWorks* was helpful and enjoyable (Roberts et al., 2015). When results from those studies are taken together with the qualitative findings in Chapter 2 of this dissertation and results described in the present study, it appears that the CBT-based *SibWorks* and *iSibWorks* interventions are acceptable and efficacious in some areas of psychosocial functioning.

Strengths and Limitations

A major strength of this study is that both the siblings who took part in the intervention and their caregivers were included in the analyses. Researchers conducting studies assessing outcomes for siblings of youth with disabilities have typically only described results from either siblings *or* their caregivers and do not evaluate responses based on both youth and caregiver reports. While we did not encounter significant differences between sibling and caregiver responses, a large body of literature suggests that responses on measures probing psychosocial outcomes with youth – such as the YSR/CBCL and SDQ – may differ by informant type (i.e., self- versus proxy-report) and, in turn, distort a clinician's understanding of the youth's social, emotional, and/or behavioural functioning (Bjerke et al., 2018; Bonadio et al., 2022). In the current study, consistency between youth and caregivers reports of the number of total problems (YSR/CBCL) and/or difficulties (SDQ) as well as improvements with siblings' psychosocial adjustment was found at all three time points (pre, post, follow-up). By assessing participant outcomes from two informants, we were better able to ascertain the benefits of engaging with the *iSibWorks* intervention. Importantly, the present research expands upon previous findings by

investigating responses to different questionnaires for related constructs at pre, post, and follow-up (Mallory et al., 2024).

Another strength of this study is that there was greater diversity in the disabilities than in our initial study of acceptability, which were solely neurological and/or neurodevelopmental in nature. The siblings in the current study are therefore more representative of the broader population of siblings of children with disabilities, allowing us to better understand the potential impact of *iSibWorks*. Recent literature indicates that it is uncommon for researchers evaluating the efficacy of psychosocial interventions to assess intervention effects longer than immediately after the intervention (Hill et al., 2016). Our findings are therefore potentially more robust given that the improvements were maintained at three months post-intervention.

As with many implementation and assessment studies for interventions with siblings and/or caregivers (e.g., Barlow & Ellard 2004; Reyes-Portillo et al., 2014; Wolff et al., 2022b), our small sample size (n = 25) may be considered a significant limitation in this research. Eighteen siblings completed onboarding questionnaires, with 15 completed at post-intervention, and 13 at the 3-month follow-up (n = 12 completed questionnaires at all three time points; 66.67% sibling retention). A much lower retention rate was seen with caregivers, with only 28.26% of caregivers completing the measures at all three time-points. This may be due to increased pressures experienced by caregivers throughout pandemic lockdowns and/or difficulty coping with these evolving circumstances alongside other caregiving responsibilities for their children with disabilities (Siracusano et al., 2021). However, we were able to use robust inferential statistics for conservative sample sizes with normal data (ANOVA; Muth et al., 2016; Oberfeld & Franke, 2013), which enabled us to be confident that our findings accurately

demonstrate the effect of participating in *iSibWorks* on siblings' psychosocial functioning over time.

An additional limitation of this study is that some siblings and caregivers were not dyads. Although more than half of sibling-caregiver participants selected for inclusion were dyads (n = 14), the caregivers for the remaining five siblings chose not to complete the measures for unknown reasons. The children of six caregivers were younger than 11 years (the minimum age for the validated measures used in this study). We chose not to exclude these data to ensure we captured a broad age range for siblings as well as the perspectives of the siblings themselves, even if their caregivers did not take part. Consequently, our results should be interpreted with some caution, although it is notable that there were no significant differences based on informant responses.

Implications and Future Research

Although positive feedback was obtained from an earlier evaluation of *iSibWorks,* no statistical improvements were found with the Social Support Scale for Children (SSSC) and Pediatric Quality of Life (PedsQL™) questionnaires (Mallory et al., 2024). This highlights the importance of implementing a series of questionnaires with participants to comprehensively assess their psychosocial functioning throughout *iSibWorks*. The present study indicates that the YSR/CBCL and SDQ should be included in future assessments. These measures (YSR/CBCL and SDQ) emphasise psychological symptoms assessed through specific constructs and appear to be more sensitive to therapeutic change (Achenbach & Rescorla, 2004; Goodman, 1998), whereas the SSSC and PedsQL™ questionnaires have been found to assess relatively stable traits like social support and quality of life in a broader sense, rather than assessing specific symptoms associated with psychosocial functioning (Huisman et al., 2024; Martens et al., 2023; Michielsen

et al., 2010; Varni et al., 1999). Notably, *iSibWorks* is based upon CBT principles and the YSR/CBCL evaluates constructs that closely align with programme outcomes addressed via weekly activities (e.g., emotion wheel and problem squashing). Given the increased acceptability of virtual interventions following the COVID-19 pandemic (d'Halluin et al., 2023), clinicians should consider offering *iSibWorks* when families who are seeking healthcare for a child with a disability and include a sibling.

After conducting their initial research on *SibWorks*, Roberts and colleagues (2016) published a second study that investigated predictors of reduced emotional and behavioural difficulties according to caregiver responses on the SDQ. This study found that baseline SDQ scores predicted improvements in emotional and behavioural difficulties following *SibWorks*, such that greater difficulties pre-intervention predicted greater reductions in difficulties post-intervention. As noted earlier, siblings and caregivers who reported poorer psychosocial functioning on the SDQ in the current study reported significant improvements in the current evaluation of *iSibWorks*. Due to mixed results regarding symptom severity on the YSR/CBCL, future studies should consider screening for low versus high symptom severity at baseline and attempt to enrol an equal number of participants from both groups. This may help determine whether the inconsistency between results is due to inherent differences between measures and evoke formal evaluation of other potentially confounding variables (e.g., severity of their sibling's disability) on intervention outcomes.

Since the COVID-19 lockdown, many clinicians have provided clients with an option to receive psychosocial services in-person and/or virtually (Lindsay et al., 2024). However, practitioners are often wary to offer virtual psychosocial interventions to youth and their families (Usluoglu & Balik, 2023). For most interventions, this concern arises because treatment response

has not been compared across modes of delivery (in-person versus virtual), making it difficult to perform an accurate risk-benefit assessment prior to conducting these interventions with families (Krasvosky et al., 2024). Some of these studies investigating the efficacy of virtual interventions relative to their in-person counterparts have implemented a randomized controlled trial design with control groups, in-person treatment groups, and virtual treatment groups to precisely evaluate differences across modes of delivery. While results from our research on the virtual adaptation of *SibWorks* (*iSibWorks*) appear similar to those reported for the in-person intervention (*SibWorks*), the use of multiple groups to directly compare the *SibWorks* (in-person) and *iSibWorks* (virtual) interventions is recommended for future research. By allocating participants to different treatment groups, it can be determined whether psychosocial functioning differs based on engaging with intervention content in-person versus virtually. It may also be useful to determine whether other characteristics (e.g., symptom severity at baseline and sibling disability type; Roberts et al., 2016) predict which siblings do best with the in-person versus virtual intervention to help with resource allocation. Our hope is that conducting this research may augment both interventions in a manner that allows clinicians to provide the most effective support for siblings of youth with disabilities.

Conclusion

This study quantitatively assessed the psychosocial functioning of siblings prior to participating in *iSibWorks,* immediately following the intervention and at 3-months follow-up. Results indicated that both siblings and caregivers reported improvements in sibling psychosocial functioning after the intervention, which was maintained three months later. There was also preliminary evidence that siblings with greater psychosocial difficulties experienced greater psychosocial improvements following the *iSibWorks* intervention. Research must

continue to evaluate *iSibWorks* with a broader range of measures to ensure that siblings receive the support that they have asked for, appreciated, and, ultimately, deserve.

CHAPTER 4. General Discussion

Summary of Main Findings

The work detailed in this dissertation addressed three overarching Objectives: (1) To adapt the *SibWorks* intervention for virtual delivery via *iSibWorks;* (2) To assess the acceptability of *iSibWorks* with siblings and their caregivers; and (3) To determine the effect of *iSibWorks* on psychosocial outcomes over time based on responses from siblings and caregivers. Below, I summarise the findings from both studies and contextualise them within the broader literature.

Study One: Adaptation of the iSibWorks Intervention and Qualitative Acceptability of iSibWorks by Siblings and their Caregivers

The second chapter (Study One) of this dissertation outlines the successful adaptation of the *SibWorks* intervention to *iSibWorks*, which our team tailored for implementation on a videoconferencing platform with siblings in grades three to eight. These adaptations did not interfere with the objectives set forth by the *SibWorks* manual for improving psychosocial outcomes and aligned with research on effective virtual learning strategies (Henriksen et al., 2022; Hongsuchon et al., 2022; McLoughlin, 2001); in fact, siblings reported enjoying and learning from psychoeducational content provided virtually via *iSibWorks* like the *Problem Squashing* activity.

Following six weekly sessions of *iSibWorks*, semi-structured interviews were conducted with siblings and their caregivers to assess the acceptability of this intervention. Overarching themes included satisfaction with the *iSibWorks* intervention, applicability of its content to their lives, and appreciation for the opportunity it provided for them to receive support alongside other siblings. Siblings and their caregivers also offered suggestions for improvement like

incorporating more breakout room activities, extending the intervention's length, including in-person components, and providing caregivers with more opportunities to support siblings by increasing their engagement with the intervention's content. Taken together, these findings indicate that *iSibWorks* began to address important processes for siblings to improve their psychosocial functioning, including emotion regulation, stress management, and communication skills (Compas et al., 2017; McHale et al., 2016; Schumann et al., 2024; Tudor & Lerner, 2015).

Study Two: Quantitative Assessment of Psychosocial Functioning for Siblings Throughout iSibWorks – Perceptions of Siblings and Caregivers

The third chapter (Study Two) of this dissertation describes quantitative findings where both siblings and caregivers reported improvements in psychosocial functioning over time on two validated questionnaires – namely, the YSR/CBCL (Achenbach & Rescorla, 2004) and SDQ (Goodman, 1998) – at three time points (pre, post, follow-up). The YSR/CBCL was more sensitive than the SDQ for detecting changes in psychosocial functioning throughout *iSibWorks*. This is likely due to its comprehensive assessment of symptoms associated with internalising problems via the withdrawn behaviour, somatic complaints, and anxiety or depression subscales (Achenbach et al., 2008). In contrast, the SDQ includes two subscales (emotional symptoms and peer problems) within its internalising score that investigate anxiousness, sadness, fearfulness, friendship difficulties, loneliness, and social exclusion. Given that siblings often express a broad range of psychosocial outcomes (Dempsey et al., 2012; Haukeland et al., 2021; Orm & Fjermestad, 2021; Rixon et al., 2021; Tomeny et al., 2012; Walton & Ingersoll, 2015**)**, recent evidence suggests that the YSR/CBCL may have stronger psychometric properties for an in-depth assessment of psychosocial functioning relative to the SDQ (Dang et al., 2017).

We further assessed if responses differed as per symptom severity for siblings at pre-*iSibWorks*. SDQ results suggested that siblings with greater difficulties at baseline experienced greater improvements from pre- to post-intervention as well as at follow-up three months later. These symptom severity findings were not demonstrated with responses on the YSR/CBCL. However, sample sizes in the high versus low symptom severity groups regarding SDQ analyses were 4 and 21, respectively, whereas analyses for the same participants based on the YSR/CBCL included 10 participants reporting high symptom severity at baseline and 15 endorsing low symptom severity. Although a study by Kovacs and Sharpe (2014) indicated that the SDQ is comparable to the YSR/CBCL and should be implemented in healthcare settings with families, this discrepancy between the YSR/CBCL and SDQ in the number of psychosocial difficulties reported among participants at baseline may support research indicating that the test-retest reliability and criterion validity of the SDQ must be further assessed prior to routinely implementing this questionnaire in clinical settings (Kersten et al., 2016).

Findings in Context: Relationship Between Psychosocial Functioning and Supporting Siblings via the *iSibWorks* Intervention

The findings described in this dissertation demonstrate that the adapted *iSibWorks* intervention was well-received by siblings and their caregivers. Although both studies had conservative sample sizes, the adaptation and accessibility of *iSibWorks* were successful. While modifying the original, in-person *SibWorks* intervention for virtual delivery, it was our goal to maintain the core content and principles of this intervention. Based on the results outlined, the adapted version of *SibWorks* successfully engaged participants and was highly acceptable in its online format. Importantly, our team was able to provide support siblings during a global pandemic and was able to reach families in traditionally underserved geographical areas. At a

time where social isolation was high, *iSibWorks* removed barriers for siblings of youth with disabilities to receive much-needed support. For example, siblings in rural areas with varied access to transportation or time conflicts were able to attend sessions on a weekly basis. Furthermore, many families of medically fragile children were even more isolated, given the high risks the pandemic brought (Jesus et al., 2021; Lee et al., 2024; Sherby et al., 2022; Tomeny et al., 2023). *iSibWorks* provided siblings with the tools to protect their psychosocial functioning during this very challenging time.

Caregivers also indicated notable differences in their children's behaviour after completion of the *iSibWorks* intervention, reporting that siblings were more understanding of the differences between themselves and their siblings with disabilities. They described how the weekly handouts provided to all caregivers allowed them to work with the siblings to apply intervention content, which emphasises the necessity of maintaining a *Whole-Family Approach* even when interventions are aimed directly at the child, such as *iSibWorks* (Dantchev & Zemp, 2021; Feriante et al., 2022; Garbacz et al., 2022; Johnson et al., 2024; Moltrecht et al., 2024; Sutherland et al., 2023). It appears that even though caregivers had limited involvement in *iSibWorks*, it still fostered understanding across all members of the family unit. According to family systems theory, positive changes in one part of the family can influence the entire family system (Fosco & Grych, 2013; Pratt & Skelton, 2018; Cowan & Cowan, 2002). Indirect involvement of caregivers is therefore likely important for reinforcing the skills learned throughout *iSibWorks*. Future research should consider informing caregivers about weekly content in a manner that enhances the core principle of *Whole-Family Approach*. Although measures assessing the effect of this intervention on sibling-caregiver and sibling-sibling

relationships were not used in this research, these constructs could be usefully evaluated when further examining the impact of *iSibWorks* in the future.

Meeting the Needs of Siblings and Caregivers

Through providing a safe environment for siblings to express their emotional and social needs, we noted improvements in psychosocial outcomes and decreased feelings of social isolation. *iSibWorks* facilitators encouraged emotional expression, especially in relation to the challenges faced by siblings of youth with disabilities. Caregivers also reported that their children developed greater empathy and understanding of their siblings with disabilities throughout the program. Perhaps most importantly, participants reported that siblings were better able to apply emotion regulation strategies and cope with distress after completion of the *iSibWorks* intervention. Both quantitative and qualitative results also provided evidence indicating a reduction in overall psychosocial difficulties or problems. Results suggested that fostering community among siblings was valuable because it provided them with a space to feel connected with others in similar situations, which aligns with other literature that describes the importance of peer support through groups settings for siblings (Jones et al., 2020; Meltzer, 2021; Rubin et al., 2018). For example, group discussions encouraged siblings to reflect on their circumstances, demonstrated that they were not alone in their experiences, and validated their emotions. As indicated in previous work (Calio & Higgins-D'Alessandro, 2021; Mallory et al., 2024), this underscores the utility of gathering qualitative feedback alongside administering validated questionnaires to fully capture the effect of a psychosocial intervention implemented with siblings.

Notably, both sibling and caregiver participants mentioned expanding the *iSibWorks* intervention to include a hybrid model. Participants believed that including in-person

components to *iSibWorks* could deepen sibling relationships and enhance their social support systems. Furthermore, increasing the duration of the intervention was recommended to provide more time for siblings to spend together. We suggest that maintaining consistency in a support group format over time may help to reinforce the psychoeducational strategies taught throughout *iSibWorks*. This could be done in tandem with caregiver workshops or meetings meant to educate caregivers on how to best support their children. It may also offer group facilitators more information about how to best support participants throughout *iSibWorks*. During these caregiver sessions, tools should be curated to support them with managing relationships within the family unit, fostering emotional resilience, and strengthening family cohesion.

Implications of Psychosocial Improvements After iSibWorks

The importance of providing social support applies to clinical and non-clinical populations alike. It is well known that engaging in social support groups can help to mitigate negative emotions associated with loneliness, such as sadness, feeling overwhelmed, and emotion dysregulation (Dodd et al., 2009; Lovell & Wetherell, 2016; Siman-Tov & Sharabi, 2024). As such, facilitators maintained a group-based environment that emphasised practising skills like empathy, patience, and understanding. According to study participants, these skills were helpful in two important ways. First, because siblings were able to form a community that supported one another. In Study One, participants commented that coping strategies offered throughout *iSibWorks* – specifically those related to stress management and problem-solving – provided siblings with the necessary tools to manage difficulties at home and in their external environments. Second, the peer support component of this intervention appeared to have a profound impact on the sense of belonging for siblings. The *iSibWorks* intervention provided siblings with an environment to receive emotional validation and reassurance. Siblings were

encouraged to practise communicating their feelings in a space that felt safe and supportive. These skills were not only applied within the group environment, but facilitators provided tools that could improve family dynamics and enhance communication for siblings when they were developing relationships separate from those with family members.

Psychosocial Functioning and Family Dynamics. Literature suggests that individuals within a family unit must engage in healthy communication to foster family cohesion, especially for families with children with disabilities (Bogdan et al., 2023; Vermaes et al., 2012; Walsh, 1996). The interviews in Study One probed participants for improvement in family dynamics, and siblings and their caregivers reported more supportive family environments following the *iSibWorks* intervention. On the other hand, Study Two offered quantitative evidence outlining that sibling participants applied the skills learned after the completion of *iSibWorks*. This is indicated by their improvements in psychosocial outcomes over time. As a reminder, the questionnaires offered to siblings and their caregivers assessed a wide range of constructs associated with psychological, behavioural, emotional, and social functioning.

In tandem with siblings attending weekly sessions, caregivers described that the weekly handouts provided them with strategies to reinforce within the family unit. These handouts also provided them with tools to decrease tension among family members and increased their confidence to navigate familial challenges. Due to the modest sample size in Study Two, we were unable to assess differences based on subscales within the *YSR*/*CBCL* and *SDQ* questionnaires. Future studies should assess if there are facets of functioning that improved to a greater degree than others. Researchers may also consider assessing response to the intervention for caregivers through measures that evaluate caregiver stress, parenting skills, and family cohesion or tension.

The Major Strength: Fostering Psychosocial Stability. Responses to the semi-structured interviews in Study One with siblings and their caregivers suggest that *iSibWorks* helped strengthen siblings' psychosocial functioning following the intervention. With this population, fostering psychosocial stability may help to ameliorate the depression and anxiety symptoms that commonly affect their functioning and well-being (Dew et al., 2008; Houtzager et al., 2004; Orsmond & Seltzer, 2007; Smith et al., 2018; Taylor et al., 2008). This work demonstrates that strategies learned through this program may help to build their resilience, which is important for their educational attainment, ability to engage in flourishing relationships, and application of adaptive or active coping strategies in the long-term (Rosenthal et al., 2021; Wolff et al., 2022a).

Recent literature suggests that promoting psychosocial stability and offering youth tools that help them handle their ongoing family stressors is crucial to forming a concrete foundation for their mental wellbeing. Consequently, implementing the *iSibWorks* intervention with siblings may support their long-term psychosocial functioning and facilitate their personal psychological, emotional, behavioural, and social development as well as strengthen siblings in future family roles. Through offering siblings coping strategies that support their psychosocial functioning in childhood, we can promote positive outcomes into adulthood and help those who would like to support their siblings with disabilities as caregivers feel equipped to take on this role in the future.

Limitations and Future Directions

Although the findings from the two studies suggest that *iSibWorks* was helpful for siblings, there are several limitations to conducting this research that must be taken into consideration for future iterations of the intervention.

Modest Sample Sizes

It is essential to interpret findings with caution due to the limited number of participants in both phases of the intervention evaluation. Given the global context during the pandemic, many researchers aiming to assess psychosocial interventions with youth and their families report challenges recruiting youth and their caregivers for studies (Skeens et al., 2022). However, our team recruited separate groups of sibling and caregiver participants for each of the two studies: a total of 6 siblings and 4 caregivers participated in Study One (n = 10), whereas another 12 siblings and 13 caregivers were included in Study Two (n = 25). Therefore, taken together, this research is based upon the perspectives of 35 sibling and caregiver participants. It is difficult to ascertain whether results presented in this work are truly generalizable to the broader population of siblings with disabilities. An important goal for future work should be to implement recruitment strategies that are tailored to caregivers of youth with disabilities and emphasise the importance of supporting their children who do not have disabilities (i.e., siblings). Successful recruitment strategies may include posting targeted social media advertisements, offering healthcare professionals – such as pediatricians, child and youth workers, social workers – information about the *iSibWorks* intervention and evidence of its potentially positive impact on psychosocial outcomes. This may help increase their comfort level when referring families in need of psychosocial support for siblings of those with disabilities to participate in the *iSibWorks* intervention.

Issues with Participant Diversity

We noted that participants from our qualitative acceptability research (Study One) only included siblings of youth with disabilities considered neurological and/or neurodevelopmental in nature. This contrasts with sibling and caregiver participants from Study Two, which had a

broader sample regarding sibling disability type. For instance, diagnoses ranged from medical disorders like asthma and ulcerative colitis to neurodevelopmental differences like learning difficulties.

Unfortunately, we were unable to assess relationships between sibling disability type and psychosocial outcomes throughout *iSibWorks* due to limited diversity of disabilities within Study One. Although siblings with disabilities varied in Study Two, the wide range of disabilities also posed an issue for combining data into representative samples for different sibling disability types (e.g., neurodevelopmental, physical, etc.). It is suggested that researchers are intentional about gathering this information about participants to elucidate the effect of predictors on intervention response for siblings and their caregivers in the future.

Self-Selection Bias

An issue with conducting this work is self-selection bias. It is possible that caregivers with prior interest in facilitating support for the siblings of their children with disabilities may have more readily participated in the *iSibWorks* intervention, relative to siblings from families who are not aware of this type of support or who do not see its value. For example, one recruitment site was Kinark Child and Family Services, which is a mental health organisation in Toronto, Ontario that supports autistic youth and their families, offers community-based mental health services for youth with a broad range of presenting mental health concerns, and engages with youth and their families within the justice system. Families from there may have felt more inclined to participate in this research to enhance their children's outcomes. Moreover, families receiving support from the Holland Bloorview and Kinark Child and Family Services organizations often experience similar socio-economic backgrounds, cultural contexts, and geographical locations. Although we did not assess these variables, future work should consider

collaborating with organizations across Canada to ensure that results are more generalizable for siblings of children with disabilities within a Canadian context.

Conclusion

This work demonstrates that a virtual, CBT-based intervention holds promise for supporting siblings and improving psychosocial outcomes, which were maintained at three months. Larger sample sizes and more nuanced analyses will be important for moving our understanding of how to provide the best possible support and which siblings may benefit most. It is critical to continue developing this work to help siblings step out of their role as a *glass child* and to feel *seen*. As *iSibWorks* evolves, our hope is that it will continue to empower siblings, foster resilience and enhance emotional well-being, extending into adulthood. Through interventions like *iSibWorks*, we can ensure that siblings, who are often overlooked in the family dynamic, are seen, heard, and valued as essential members of their families.

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Appendices

Appendix A: Demographic Form (Siblings)

1. Initials: _____

2. Date of Birth: Day:_____ Month:_____ Year:_____

3. Current age: _____

4. What is your gender?
   - □ Male
   - □ Female
   - □ Prefer not to specify
   - □ Other: _____

5. Current school grade level: _____

6. Are you currently receiving additional social support services?
   - □ Yes
   - □ No

7. Have you ever attended a group program (i.e. with other youth) to support you in managing your mental health?

   - □ Yes
   - □ No

Appendix B: Demographic Form (Caregivers)

Study ID: _____

2. How many adults are living in your household? _____

3. What is the ethnic background of your child who is participating in i-SibworkS?
- White
- Black
- Latin American
- South Asian (e.g. East Indian, Sri Lankan, etc.)
- West Asian (e.g. Iranian, Afghani, etc.)
- Southeast Asian (e.g. Vietnamese, Cambodian, etc.)
- Arab
- Filipino
- Chinese
- Korean
- Japanese
- Aboriginal (e.g. Indigenous, First Nations, Métis, Inuit, etc.)
- Multiple Ethnic Identities: _____
- Other: _____
- Prefer not to answer
- Do not know

4. What is your average family income?
- Less than 30,000
- 31,000-50,000
- 51,000-70,000
- 71,000- 90,000
- 91,000-100,000
- Greater than 100,000

5. Are you receiving social support services? □ Yes □ No

Questions 6-10 are related to your child with special needs:

6. What is the diagnosis of your child? _____

7. What is the gender of your child? _____

8. What is the age of your child? _____

9. What is the birth order of your child?

10. Is your child receiving social support services? Yes or No

Appendix C: Informed Consent Form to Participate in a Research Study

Study Title:
Left in the waiting room: A digital intervention feasibility study for siblings of children with disabilities

Principal Investigator:

- Dr. Shannon Scratch, PhD, C. Psych., Clinician Scientist and Clinical Neuropsychologist, Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital
- Dr. Alex Elkader, PhD, Kinark Child and Family Services

Co-investigator(s):

- Dr. Kelli Phythian, Research and Evaluation Advisor, Kinark Child and Family Services Dr. Mary Desrocher, Associate Professor, York University
- Kate Strohm, Author, SibworkS
- Victoria Rombos, Sibling with Lived Experience, Holland Bloorview Kids Rehabilitation Hospital Shona Casola or Vincent, MSW, Parent with Lived Experience
- Marie Hooper, PhD Student, Holland Bloorview Family Leader

Study Coordinator/Research contact:

- Hiba Al Hakeem, thenovellab@hollandbloorview.ca

Sponsor/Funder(s):

- Mental Health Research Canada (MHRC) and Ontario Centre of Excellence for Child and Youth Mental Health (OCECYMH).

There are no conflicts of interest to declare related to this study.

Dear Participant,

Introduction
As your child's Substitute Decision Maker, you are being asked to provide informed consent on behalf of your child. If your child gains the capacity to consent for themselves, consent will be sought from them and your consent for them will end. Throughout this form, first and second-person pronouns (e.g., "I", "me", "my", "you") means the person you are representing, "we" represents the BRI researchers.

You are being asked to participate in this research study because your guardian or yourself informed us that you are the sibling of a child or teenage with disabilities.

Why is this study being done?
We know that there are both positives and negatives to having a sibling with a disability. This study is being done because we want to know whether a group peer support program for siblings of youth with disabilities is beneficial to you. We know how important your mental health is. We also know that kids like yourselves don't always feel comfortable talking about things that may be going on for you. Our hope is that you will find this group to be a safe space to talk every week and meet other kids like you.

Specifically, we want to learn feedback on the program to see if a program like this would be helpful for other kids like you.

How many participants will be in this study?
At Holland Bloorview, up to 12 siblings (age 6-16) and their parents are expected to participate in this study. This study is being completed online at Holland Bloorview Rehabilitation Hospital and Kinark Child and Family Services.

How long will the study take?
This study should take 8 months to complete and the results should be known in about one year. Your participation in this study will be for 8 weeks. All sessions will be conducted virtually through the video conferencing platform, Zoom. Each study visit is expected to take about 6o minutes.

What will happen in this research study?
This research is called a "feasibility study" and is done to test the study plan and to find out whether a bigger study is possible. This type of study involves a small number of participants and so it is not expected to prove safety or effectiveness. Knowledge gained from pilot or feasibility studies may be used to develop future studies that may benefit others. Participation in a pilot study does not mean that you will be able to participate in a future larger study.

What is the study intervention?
SibworkS is a six-week program and will be held in the evenings and/or weekends online. i-SibworkS will run four different programs based on grade. So, we will offer groups based on what grade you are in at school. All groups will contain six weekly sessions, totalling around 60 minutes. For this study, each group will include a group of 2-3 siblings. The groups will be

facilitated by a research staff member who is trained in the intervention delivery and has experience working with children. They will be assisted by research assistant who will provide technology and Zoom support. Prior to running the groups, the research assistant will complete training offered by the principal investigator and group facilitator. Some of the topics that will be learnt during program are: Exploring Differences, Friendly & Not-So-Friendly Feeling, Problem Solving and Coping Skills. The weekly sessions will be done through the video conferencing platform Zoom.

To use Zoom videoconferencing we need to send you an email. This email will include the instructions for how to log-in. For the session, please try to find a quiet place where you will not be disturbed and use earphones if you can. It's a good idea to test out the system a few minutes before the session to make sure the connection and sound are working. Please do not communicate personal sensitive information by e-mail. Email is not routinely monitored outside of work hours. Please do not use e-mail to communicate emergency or urgent health matters – please contact your clinician or family doctor. If it is a medical emergency, call 911.

What are the study procedures?

Questionnaires
You will be asked to fill out some questionnaires about your thoughts and feelings twice. You will be asked to fill the questionnaire once before the start of the program (week 1) and after the group program ends (week 8). This will take about 70 minutes. The purpose of the questionnaire is to learn about your demographic information. The information you provide is for research purposes only. Total questionnaire time will be around 70 minutes. You may want to ask a member of your family to help you get set-up to participate on zoom.

Group Program
Once the questionnaire session is complete; we will assign you to a group to join other siblings that are your age. The i-SibworkS program will take about 60 minutes a week for six weeks. You may want to ask a member of your family to help you get set-up to participate on zoom

Study Interview
You will be asked to participate in one interview. The interview will be done over Zoom. Each interview will take about 30 minutes to complete and will be scheduled with a member of our research team.

The interview will be done after you have completed the program. During this interview, you and you will be asked about the following:

- How helpful you found the program
- Barriers you encountered while in the program
- How you would change the program
- If you would recommend the program to other kids like you

This following study procedure is only relevant for youth aged 14-16 years: Rapid Group Interview Session

We will ask youth who between the ages of 14-16 years old for an additional 15-20 minutes of their time after each i-SibworkS session (hence, total session time commitment is: 1 hour and 20 minutes weekly for six weeks). The additional twenty minutes will involve group interview questions to get your feedback on each session. We hope to use the information gained in these group interviews to improve experiences for teens with i-SibworkS. Some examples of the questions asked:

What topic/strategy did you find most helpful in the session?

- In today's session different strategies were used to share information with you and to help you
- be engaged.
- How did those strategies work for you?
- What changes would you want made to the information/topics that we talked about to better meet your needs?
- What will happen during study visits?

In the first and last visit:

- We will ask you to complete electronic demographic questionnaire. Questions include age,
- gender, school level… (first visit)
- We will ask you to complete a questionnaire about your everyday living, productivity and leisure.
- We will ask you some health-related questions as well as questions on your quality of life.
- Also, we will ask you questions related to your self-confidence and behavior routine.
- Finally, we will invite you to participate in an interview so you can give us your feedback on i- SibworkS. Your parents will also be invited to participate in a separate interview.
- All youth will participate in i-SibworkS.
- There will be 6 sessions, one session each week (total of six weeks). This will occur in a group setting using Zoom.
- Each session will take 60 minutes. It is recommended you check your internet connection.
- You may take breaks during the program session.
- A PhD student in Clinical Psychology will run the sessions. She is a part of this study's research
- team.

What are your responsibilities in this study?

- Complete questionnaires (70 minutes)
- Participate in 6 weekly sessions for the i-SibworkS intervention (60 minutes each session)
- Participate in an exit semi-structured interview (~ 30 minutes)
- Ask your study team about anything that worries you
- Tell the study staff if you change your mind about being in this study

What other choices are there?
You do not have to take part in this study.

What are the risks, harms or discomforts of the study?
You might experience some side effects and discomfort while participating in this study. Some of the interview questions about your experiences might make you feel distressed or uncomfortable. If this happens, please let one of the research team members know and we will help support you through this experience. You don't have to answer any questions you do not want to answer. The questions we ask you in the interview may show that you have a lot of stress or feelings of extreme sadness or anxiety If you are a youth aged 14-16 years old, the rapid group interview session may have additional risks: we will work hard to keep your information private, but other youth in the group may repeat things that were said in the meeting. Please note that we will ask everyone to respect each other's privacy and not repeat what is said in the interview group to others.

If you reveal feelings that suggest harm your well-being, then a member of the i-SibworkS program team will let you know about ways to get help for these problems. Our team will also work with psychologists at Holland Bloorview Children's Rehabilitation Hospital and Kinark Child and Family Services who can suggest ways for you to get help. If you suddenly log of the zoom session and we are unable to reach you, the program lead or research assistant will call your caregiver to ensure your safety and provide appropriate assistance. If immediate harm is identified, we will refer you to the Emergency Department for immediate evaluation. You will also be given a list of resources in the community that you can use.

Are there benefits from being in the study?
You may not benefit directly from being part of this study. However, what we learn from this study may help other siblings of children with disabilities. This study will hopefully lead to improvements in your healthcare delivery, too.

Can I choose to leave the study?
It is your choice to take part in this study, participation is voluntary. You can change your mind at any time during the research study. The study team may ask why you are withdrawing for reporting purposes, but you do not need to give a reason to withdraw from the study if you do not want to.

Withdrawal from the study will not have any effect on the care you or your family will receive at Holland Bloorview or Kinark Child and Health Services. If you decide to leave the study, you can contact the Principal Investigator or a member of the study team to let them know.

Will it cost me anything to be in this study?
Participation in this study will not involve any additional costs to you or your private health care insurance.

Will I be paid and/or reimbursed if I join this study?

You will be given a $25 gift card for participating in this study. You should not expect to have any additional personal expenses by participating in this study. You may receive a certificate of recognition for volunteer hours towards participation in the study.

How will my privacy be protected?
Since this a group program, we will ask everyone in the group to keep the conversations confidential but we cannot guarantee this confidentiality. However, all the information we collect about you and your responses will be always kept private. Throughout the study, your name will be replaced with a number. The number is also private and only people who have access to it are the research study team. All information will be in a locked filing cabinet in Holland Bloorview. When data is placed onto computers, a protected password will be applied. No information identifying you will be allowed off site in any form without your consent. For the interview process (exit interview and rapid group interview), we will record the session with an audio-recorder. The audio recorder will allow us to review what your experience and your feedback in more detail after the session. Only members of the research team will listen to what you say during this interview. The research assistant will transcribe the audio recording and destroy the recording once it has been transcribed. Quotes from the interviews may be used in publications, but it will not be possible to identify their source. The data we collect about you will be kept private. We will not use your real name. We will not make anything public that might identify you unless legally required to do so (for example: law requires disclosure of information if health/welfare of client or someone else is at risk) or if we think someone might get hurt (for example: if client threatened to harm others or themselves).

Authorized representatives of the following organizations may look at your original (identifiable) research records at the site where these records are held to check that the information collected for the study is correct and follows proper laws and guidelines:

- The Holland Bloorview Research Ethics Board who oversees the ethical conduct of this study
- Holland Bloorview representatives, for verification of research procedures and/or data and compliance with relevant
- If the results of the study are published, your name will not be used and no information that discloses your identity will be released without your prior agreement. We must keep the research data we collect for 7 years after study completion as required by Holland Bloorview.

What if I am injured during/in this study?
If you suffer an injury from participation in this study, medical care will be provided to you in the same manner as you would ordinarily obtain any other medical treatment. In no way does signing this consent form waive your legal rights or release the study doctor(s)/investigator(s), sponsors or involved institutions from their legal and professional responsibilities.

How will I be informed about new information?
We may learn new information during the study that you may need to know. We may also learn about things that might make you want to stop participating in the study. If this happens, you will

be notified about any new information in a timely manner. You may also be asked to sign a new consent form that describes these new findings if you decide to continue in the research study.

What are my rights when participating in a research study?
You have the right to receive all information that could help you make a decision about participating in this study. You also have the right to ask questions about this study at any time and to have them answered to your satisfaction. Your rights to privacy are legally protected by federal and provincial laws that require safeguards to ensure that your privacy is respected.

By signing this form you do not give up any of your legal rights against the study doctor/investigator, sponsor or involved institutions for compensation, nor does this form relieve the study doctor/investigator, sponsor or their agents of their legal and professional responsibilities.

If the i-SibworkS program works well, a company may decide replicate the model to make money. We might even get some money by letting a company use it. However, you and your family will not be entitled to any product rights or money from the sale of this product.
You will not waive your legal rights in the event of research-related harm if you decide to take part in this study.

Will I receive study results?
If you would like to be informed of the results of this study, please let the study doctor/investigator know

Parent/Guardian Participation in the Study
As part of this study, we will be asking your parent/guardian to participate as well. i-SibworkS involves both siblings and their families and we want to know what your parent/guardian thinks about the program. All parents/guardians will be asked to consent for themselves. Your parent/guardian's decision about the study will not affect your participation.

Your parent will be asked to fill out questionnaires about you before, during, and after the program. Your parent will also be asked to participate in a parent interview after you complete the program as well.

Who can I call if I have questions about the study?
If you have any questions during your participation in this research study you can contact the Study Doctor/Investigator, Dr. Shannon Scratch at sscratch@hollandbloorview.ca

Research Ethics Board Contact information
This study has been reviewed by the Holland Bloorview Research Ethics Board (REB). The REB is a group of people who oversee the ethical conduct of research studies. The REB is not part of the study team. If you have any questions regarding your rights as a research participant, you may contact the Research Ethics Office at 416.425.6220 ext. 3161 or researchethicsboard@hollandbloorview.ca during business hours.

Future Contact

This study includes procedures which need to be completed before, during and following participation in the i-SibworkS program. There are no specific plans for additional follow-up visits. However, if we get future funding, we would like to contact you and invite you back for additional follow-up interviews/procedures. This is optional. If you consent now to be contacted in the future, you can change your mind later on. Just let a member of the study team know.

If future follow-up visits are conducted, do you give us your permission to be contacted for more information? Choosing "yes" below does not mean you have to participate in any more follow-ups, but simply means that you give us permission to contact you in the future to ask if you are interested. You can choose to participate or not at that time:

Initials. Yes, I agree to be contacted

Initials. No, I do not agree to be contacted

Consent to Participate in a Research Study

Study Title: Left in the waiting room: A digital intervention feasibility study for siblings of children with disabilities

By signing this research consent form, I understand and confirm that:

- All of my questions have been answered,
- I understand the information within this informed consent form,
- I allow access to my/my child's medical records and specimens as explained in this consent form,
- I do not give up any of my or my child's legal rights by signing this consent form,
- I understand that my/my child's family doctor/health care provider will/may be informed of my participation in this study
- I have been told I will be given a signed and dated copy of this consent form.
- I agree to allow the person for whom I am responsible to take part in this study.

For participant consent:
I consent to participate in this study.

Printed Name of Participant	Participant signature & date (DD/MMM/YYYY)

Printed Name of person who obtained consent	Role of person obtaining consent	Signature & date (DD/MMM/YYYY)

For parent/guardian consent:
I consent on behalf of (name of child) to participate in this study.

Printed Name of Parent/Guardian	Parent/guardian signature & date (DD/MMM/YYYY)

Printed Name of person who obtained consent	Role of person obtaining consent	Signature & date (DD/MMM/YYYY)

Appendix D: Assent to Participate in a Research Study

Study Title: Left in the waiting room: A pilot study of a digital intervention for siblings of children with special needs

Principal Investigator:

- **Dr. Shannon Scratch, PhD, C. Psych.**, Clinician Scientist and Clinical Neuropsychologist, Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital
- **Dr. Alex Elkader, PhD,** Kinark Child and Family Services

Co-investigator(s):

- Dr. Kelli Phythian, Research and Evaluation Advisor, Kinark Child and Family Services
- Dr. Mary Desrocher, Associate Professor, York University
- Kate Strohm, Author, SibworkS
- Victoria Rombos, Sibling with Lived Experience, Holland Bloorview Kids Rehabilitation Hospital
- Shona Casola or Vincent, MSW, Parent with Lived Experience
- Marie Hooper, PhD Student, Holland Bloorview Family Leader
- Sponsor/Funder(s): Mental Health Research Canada (MHRC) and Ontario Centre of Excellence for Child and Youth Mental Health (OCECYMH).

Research contact: Hiba Al Hakeem, halhakeem@hollandbloorview.ca

There are no conflicts of interest to declare related to this study.

What is a research study?
Research can help us learn new things. It can help us learn more about disabilities. In a research study we can test new ideas and ask new questions to try to find answers. This may help us make treatments and technology better for kids and youth.

Why am I being asked to be a part of this research study?
You are being asked to take part in this research study because we are trying to learn about mental health needs for siblings of youth with special needs. We are asking you to be in the study because study because your parent or guardian has informed us that you are the sibling of a child or teenage with special needs. We want to learn about your feedback and opinion on the peer support program and see if it will be helpful for you and other children. We will first ask you to complete questionnaires in three different visits, then we will invite you to participate in the –SibworkS program.

If I join the study what will happen?
If you decide to be in the study:

- You will be asked to complete questionnaires two separate times. This will take about up to 70 minutes. The purpose of the questionnaire is to learn more about your background.

- Then, you will be invited to participate in 6 weekly sessions for the iSibworks intervention. Before you join the group, you will be asked to do the same questionnaires again as well as one more time after the program is done. After three months of i-SibworkS, we will invite you to do a final questionnaire session as well.
- In i-SibworkS, you will join a group with other youth that are your age. You will learn about topics such as problem solving, coping skills and other fun activities. Weekly sessions will last about 60 minutes each.
- Ask your study team about anything that worries you
- Tell the study staff if you change your mind about being in this study
- You will receive a gift card to thank you for your participation and time

Will any part of the study hurt?
You might be uncomfortable while participating in this study. We will ask you questions about your experience that might make you feel stressed. If this happen, please let one of the research team know and we will help support you.

Will the study help me?
We don't know if this study will help you. You may not benefit directly from being part of this study. This study will hopefully lead to improvements in your healthcare.

Will the study help other people?
What we learn from this study may help other siblings of children with special needs.

Do I have to be in the study?
You do not have to be in the study. It's up to you. No one will be angry or upset if you don't want to do this study. If you join the study, you can change your mind and stop being part of it at any time. All you have to do is tell us, nobody will be upset.

What choices do I have if I say no to this study?
This study is extra, so you don't have to participate if you don't want too.

Do my parents/guardian know about this study?
This study was explained to your parents/guardian and they said that we could ask you if you want to be in it. You can talk this over with them before you decide.

Who will see the information collected about me?
The information collected about you during this study will be kept safely locked up. The study information about you will not be given to your parents. Nobody else will know it except the people doing the research. The researchers will not tell your friends or anyone else.
There is a chance that we may find out something that makes us worried about your safety. If this happens we will share this information with people who can help you.

What if I have questions?
You can ask any questions you want about the study. If you think of a question later, you can call or have your parents call Dr. Shannon Scratch at sscratch@hollandbloorview.ca.

I, _____ (name of participant) have been explained this study and agree (assent) to participate.

Participant Name	Signature	Date (DD/MMM/YYYY)

Assent (for the study team to complete):

I have discussed this research study with _____ using language which is understandable and appropriate for the participant. I believe that I have fully informed him/her of the nature of the study and its possible risks and benefits. I believe the participant understood this explanation and assented to participate in this study.

Person obtaining Assent (DD/MMM/YYYY)	Signature	Date

Appendix E: Sample Parent Information Sheet

Day 1

The aim of sibling groups is to meet other children in a similar situation to share feelings and experiences in a safe and supportive environment. Siblings will explore their strengths as well as the strengths of their brother or sister with a disability, look at various feelings they may have about being a sibling, and look at problem-solving some of the challenges they may face.

Today, siblings spend time getting to know each other. They also explore the similarities and differences with a brother or sister with a disability as well as with others in our community. The issue of 'being different' is explored and each sibling can share their knowledge about their brother's or sister's disability. We also do some activities around how it might feel for those with a disability.

We also look at activities that siblings enjoy doing with and without their brother or sister with a disability. Some siblings feel frustrated when they try to do something together, but their brother or sister finds it difficult. It is good to think about what things a brother or sister can do more easily, i.e. what are their strengths and how can these strengths be used to play games or participate in other activities? This can often make the activity more enjoyable for your child with a disability and help them feel better about themselves and can also make siblings feel proud. It is also important to explore the things that siblings enjoy doing without their brother or sister with a disability.

We also talk about feelings. Siblings can experience many different feelings about having a brother or a sister with special needs – happy, content, proud, tolerant, important, protective, understanding, responsible, confused, frustrated, angry, lonely, guilty, resentful, sad, worried... All of these feelings are normal. However often siblings do not express the more difficult feelings, especially at home for fear of worrying their parents even more, getting into trouble, or feeling guilty about feeling that way. The message for this week is that it is OK for siblings to have 'friendly and not so friendly' feelings, but it is very important that they are expressed in an appropriate way.

Parent Tips:

- When appropriate try to include siblings in family discussions
- Arrange for siblings to do some of the things that they enjoy doing by themselves or with family or friends
- Truly listen to what a sibling says and acknowledge their feelings
- Try to put yourself in their shoes, recognize that it can be difficult for them
- Give them 'permission' to express the difficult feelings
- Set an example by showing it is ok to share difficult feelings
- When possible, spend 'one on one' time with siblings
- Find books/websites that provide information for siblings or tell stories about other sibling

Appendix F: Interview Guide (Sibling)

The purpose of this interview is to learn about your experience with the *i-SibworkS* program you participated in. The questions will be open-ended to allow you the chance to raise the issues that you feel are important to your experience with the *i-SibworkS* program. You do not have to answer any question you feel uncomfortable with, and you can stop the interview at any time. This will in no way affect the care that you receive at Holland Bloorview or Kinark. Your responses will be confidential and anonymized in any findings we may publish. Quotes from the interviews may be used, but it will not be possible to identify their source.

Throughout the interview process, I will talk to you about your experience with the *i-SibworkS.* program. You will be asked open-ended questions about certain topics, but you are encouraged to talk about any topic that is important to you. Please remember that you can share as much or as little as you like because the goal is to collect your feedback. Please note the interview will be audio recorded so that the research team can keep a record of the interaction. This will enable the team to review and analyse the interview responses along with other participants' feedback to help with our research study. And I will be happy to answer any questions you might have on the interview process. Do you have any questions for me before we begin?

I am interested to learn your feedback on *i-SibworkS.*

Now that the program is done, can you describe your experience with the program? Can you tell me more about that?

I want to learn your thoughts on the structure of *i-SibworkS* sessions.

In each session, was there something that you liked about the session?

Anything you didn't like?

Do you have any suggestions to improve the program?

Did you like learning about the topics discussed in the sessions (such as problem-solving skills, coping with stress, etc.)?

Do you feel that it is important to talk about such topics? Why or why not?

What topic did you feel was the most helpful to you? Can you tell me more about that?

Is there any other topic(s) you feel should be added to the program?

Do you have any suggestions to improve the educational component of the program?

I am interested to learn about how you felt meeting other people your age with similar experiences in the program.

Did you like that this program was done online?

Did you like that it was in a group setting?

How did you feel about the pace of the group?

What did you like about the group?

Is there anything you didn't like about the group format?

What were your initial expectations signing up for this i-SibworkS?

Now at the end of i-SibworkS, did your initial expectations change? If yes, how so?

After reflecting on *i-SibworkS* during this interview, I'm wondering if you have anything else to add in terms of describing your experience with the program?

What did you like about the *i-SibworkS* program?

What did you dislike about the *i-SibworkS* program?

What improvements or changes to the program would you suggest?

Is there anything that we haven't spoken about today that you'd like for me to know?

Do you have any questions for me about the research?

Appendix G: Interview Guide (Caregivers)

The purpose of this interview is to learn about your experience with the i-*SibworkS* program which your child has participated in. The questions will be open-ended to allow you the chance to raise the issues that you feel are important. You do not have to answer any question you feel uncomfortable with, and you can stop the interview at any time. This will in no way affect the care of your child at Holland Bloorview Kids Rehab or Kinark Child & Family Services. Your responses will be confidential and anonymized in any findings we may publish. Quotes from the interviews may be used, but it will not be possible to identify their source.

Throughout this interview, I want to talk to you about your experience with the *i-SibworkS* program. I will ask you few questions but feel free to talk about what is important to you as a parent/guardian. Please remember that you can share as much or as little as you like because I wish to get your relevant feedback. Please note the interview will be audio recorded so that the research team can keep a record of the interaction. This will let the team review and analyse the interview responses along with other participants' feedback to help with our research study. And I will be happy to answer any questions. Do you have any questions for me before we begin?

I'd like to get your opinion on the i-*SibworkS* program your child participated in.

Did you feel that this program was worth your time? Can you tell me more about that?

Did you notice any changes in your child (in terms of behaviour, socioemotional…?) Can you tell me more about that?

What were your initial expectations of signing your child up for this program?

Now at the end of program:

Did your initial expectations change? If yes, how so?

What did you think was the best feature of this program? Why?

What did you like the least about the program?

Overall, did you find the program to be useful?

What did you like / not like about the program's usefulness?

What would you change about the program to enhance its usefulness?

Is there anything that we haven't spoken about today that you'd like for me to know?

Do you have any questions for me about the research?