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Sib Kinect: supporting siblings of children with disabilities using a telehealth approach

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BOSTON UNIVERSITY
SARGENT COLLEGE OF HEALTH AND REHABILITATION SCIENCES

Doctoral Project

**SIB KINNECT:
SUPPORTING SIBLINGS OF CHILDREN WITH
DISABILITIES USING A TELEHEALTH APPROACH**

by

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Submitted in partial fulfillment of the
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DEDICATION

I would like to dedicate this work to the incredibly special children and families with whom I have the privilege of working.

ACKNOWLEDGMENTS

I would like to thank my family, Dr. Karen Jacobs, and my dear girlfriends for their encouragement, humor, and support. A special thank you to my four fellow MSOT colleagues who have shared this OTD journey with me.

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ABSTRACT

Current evidence-based literature regarding the experiences of siblings of children with disabilities acknowledges that siblings have diverse experiences and that it is unclear to what extent siblings are negatively impacted. (Emerson & Giallo, 2014; Giallo, Roberts, Emerson, Wood, & Gavidia-Payne, 2014; Goudie, Havercamp, Jamieson, & Sahr, 2013; Neely-Barnes & Graff, 2011). Yet the literature also emphasizes that a substantial portion of siblings experience emotional and social difficulties and are in need of clinical services that better address their challenges. The aim of this doctoral project is to create an evidence-based and theoretically grounded program that supports siblings through the use of telehealth.

Telehealth has previously been used with youth, mostly to address chronic conditions, and demonstrated comparable, and sometimes superior, outcomes when using telehealth as opposed to face-to-face treatment (Dougherty, Lipman, Hyams, & Montgomery, 2014; Gettings, Franco, & Santosh, 2015; Letourneau et al., 2012). The objectives of Sib Kinnect, the proposed program, are to use telehealth to increase knowledge about disability, promote development of meaningful interests, improve

coping and problem solving skills, and provide an enjoyable experience in which siblings can connect and learn from each other. The eight-week manual-guided program is designed for siblings, ages 10-12, of children with developmental disabilities and will include fun, age-appropriate activities and discussions that address the desired outcomes in a format that is enjoyable and engaging. In order for this program to be implemented, this project will also discuss important operational components such as the evaluation plan, information dissemination, staffing, and funding.

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CHAPTER ONE: INTRODUCTION

Siblings of children with disabilities have diverse experiences. For some, it is an enriching experience with opportunities for increased personal growth and development of empathy and sensitivity (Williams et al., 2010). Others feel loving and protective toward their siblings, along with resentment, embarrassment, guilt, sorrow and fear. Approximately 60% of studies looking at sibling wellness reported manifestations of increased risk for negative outcomes, 30% reported no increased risk, and 10% reported both negative and positive effects (Williams et al., 2010). Without the mature cognitive or emotional abilities to manage complex emotions and experiences, siblings of children with disabilities may be at risk for developing behavioral, internalizing, or self-esteem problems (Cuzzocrea, Larcan, Costa, & Gazzano, 2014; Emerson & Giallo, 2014; Giallo et al., 2014; McCullough & Simon, 2011). Common factors that impact sibling adjustment are parental mental health, limited parental or adult attention, limited opportunities for personally meaningful activities, isolation from peers in similar circumstances, and lack of information about disability (Giallo et al., 2014; Goudie et al., 2013; Granat, Nordgren, Rein, & Sonnander, 2012; Tudor & Lerner, 2015).

While the potential issues for siblings of children with disabilities are evident, this problem goes beyond the sibling. For families, parental time and attention is devoted to addressing the needs of the child with a disability. It is not parents' intent to deprioritize other children; they are simply trying to manage many demanding aspects of their lives (Gettings et al., 2015; Granat et al., 2012). Unfortunately, parental mental health, particularly maternal depression, is a key determinant of sibling wellness (Tudor &

Lerner, 2015). Compounding this, siblings from families with fewer resources may be exposed to more stressful home environments, which increases the risk of adjustment problems (Cuzzocrea et al., 2014; Emerson & Giallo, 2014; Giallo et al., 2014).

Additionally, siblings are often the future caregivers or overseers of care (Arnold, Heller, & Kramer, 2012). Therefore, the future wellbeing of siblings, impacted by childhood experiences, has a significant effect on overall health of the family and need for external services in the future.

This doctoral project aims to address the key factors of sibling adjustment through the creation of a program, Sib Kinnect, which could be used by clinicians to develop and facilitate a telehealth group for siblings. A comprehensive manual will be created to guide program facilitators on approach and reasoning of the actual sessions. The manual will also include templates and check lists for operational components such as budgets and correspondence.

The target audience for Sib Kinnect is 10-12 year old siblings. A telehealth approach will be used to facilitate the implementation by an occupational therapist and mental health professional. The desired outcomes of Sib Kinnect are increased knowledge about disability, development of personally meaningful pursuits, improved coping and problem skills, and that participants experience joy and have fun, as evidence has shown that all kids like fun, but some may need it for optimal development (Tudor & Lerner, 2015).

Occupational therapy has a distinct value in the development of this program. Occupational therapists (OT) use occupations, or activities, to support health and

wellness (American Occupational Therapy Association, 2014b). In the context of support groups for siblings of children with disabilities, OTs are able to use engaging and preferred childhood activities in a therapeutic manner that does not feel like another medical interaction. For instance, a game can be used to teach about disability in a way that is enjoyable, engaging, and just happens to increase knowledge and problem solving skills. Many current sibling support groups are intentionally structured in a way that is not clinical or therapeutic, as contact with health professionals can lead to increased stress for the family (Tudor & Lerner 2015). Parents should feel that they are making a good decision for the siblings because the experience will be enjoyable instead of pathologizing.

The following chapters will cover the theory and evidence that supports this program, current efforts to support siblings, a thorough description of the proposed program, a three part evaluation plan, and an overview of implementation logistics such as dissemination and funding. Please note that the term ‘sibling’ refers to the typically developing brother or sister throughout this chapter and the following chapters.

CHAPTER TWO: THEORETICAL AND EVIDENCE BASE

Overview of the Problem

Current evidence-based literature regarding the experience of siblings of children with disabilities acknowledges that it is unclear to what extent siblings are negatively impacted as compared to siblings of typically developing children (Emerson & Giallo, 2014; Giallo et al., 2014; Goudie et al., 2013; Neely-Barnes & Graff, 2011). However, the literature also consistently notes that many siblings experience emotional and social difficulties, even if those are due to issues secondary to having a child with a disability such as low socioeconomic status and poor family functioning (Neely-Barnes & Graff, 2011). Tudor and Lerner (2015) combine these sentiments when suggesting that, “Together, the overall risk for sibling maladjustment is not yet well-specified, but the potential for siblings being in need of clinical services remains evident” (p. 2).

The evidence-based literature suggests that the main factors impacting siblings are limited time and attention from parents and other adults, limited social and economic resources, increased family stress, lack of information about disability, and isolation from peers in similar situations (Gettings et al., 2015; Giallo et al., 2014; Goudie et al., 2013; Granat et al., 2012; McCullough & Simon, 2011; Tudor & Lerner, 2015). Figure 2.1. depicts these factors along with potential outcomes.

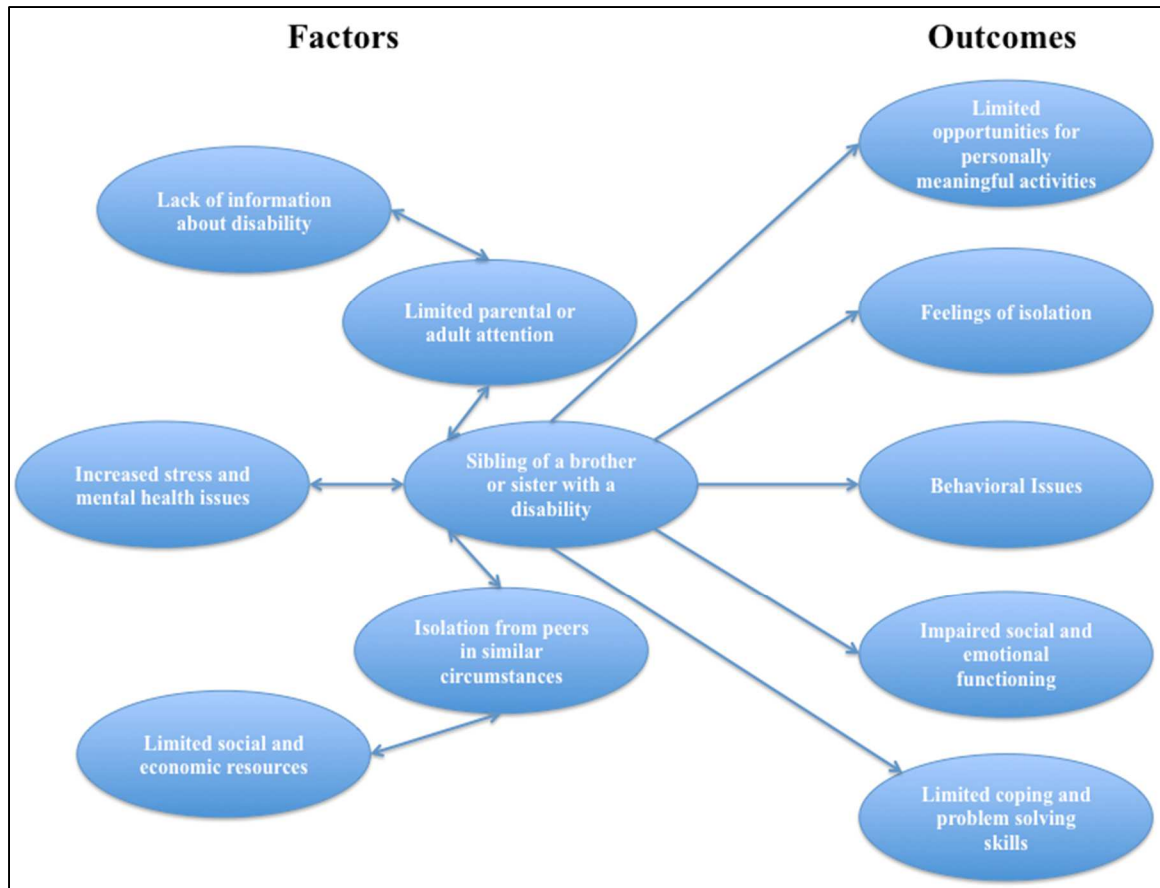


Figure 2.1: Factors Impacting Siblings and Potential Outcomes

Time, resources, and stress are three intertwined factors. When a parent has a child with a disability they spend an increased amount of time and attention on medical appointments, at-home medical procedures and routines, and managing the administrative aspects such as insurance and caregiver instructions. This amounts to significant time and attention that cannot be devoted to other siblings in the family (Gettings et al., 2015; Giallo et al., 2014). Parents report they feel concerned about their ability to provide enough for each of their children, which may contribute to family stress (Goudie et al., 2013). Other sources of stress include concern about the health and functioning of the

child with a disability, plans about the future, marital distress, and stretched financial resources (Neely-Barnes & Graff, 2011).

Limited economic resources can affect basic family needs, but may also impact a sibling's ability to participate in activities that could negate other factors. For example, the literature is clear that siblings have less attention from parents, but also from adults in general. After school clubs, sports teams, and involvement in personally meaningful activities expose children to a range of adults who often provide additional mentorship, fun, or simple attention. These opportunities also provide siblings with something that is meaningful and unique to them, which can be therapeutic in itself, when so much of their family's time and attention must go elsewhere (Angell, Meadan, & Stoner, 2012).

Unfortunately, if a sibling is struggling at school due to subtle or difficult emotional or social issues they may blend with the crowd and receive less attention from adults in the educational setting as well, a place where many children find external support (Goudie et al., 2013).

A lack of information about disability, along with isolation from peers in similar situations, are two factors that are also connected to time, resources, and family stress. However, these factors are more personal and internal for siblings. As a brother or sister of a sibling with a disability, they must attempt to manage complex and conflicting emotions (Tudor & Lerner, 2015). Siblings report they have feelings of anger and jealousy along with feelings of concern, pride, and gratitude (Angell et al., 2012). Information about disability in general and the specific diagnoses of their siblings may help to explain why a child acts out in a certain manner, lacks control over responses, or

must adhere to specific treatment regimens (Gettings et al., 2015). In turn, this information can ease sibling concerns or clarify confusing emotions. Siblings want more information about disability, but also how peers in similar situations deal with the unique circumstances they encounter in their daily lives (Gettings et al., 2015). Several studies found that siblings often feel the need to be the ‘good’ child, not create additional work or stress for their family, and refrain from talking about the negative aspects of having a sibling with a disability (Angell et al., 2012; Tichon, 2015; Williams et al., 2010). The opportunity to talk freely and honestly about their experience and hear the experiences of others is highly valued by siblings. When other siblings provide ideas about how they cope with various challenges and enjoy games and activities within a relaxed environment, there is a certain ease because of an unspoken understanding, and perhaps most importantly, the security that one is not alone in their circumstances. The impact of these social interactions is valuable to siblings. There is reassurance about their personal situations along with an opportunity to make changes in their own lives once they feel they have the capability to do so. The theoretical basis for Sib Kinect will guide the program in a manner that empowers siblings to bring about meaningful changes in their lives.

Theoretical Basis and Approach to Problem

The Social Cognitive Theory (SCT) will provide the theoretical basis for the proposed program. SCT describes the dynamic relationship that exists between personal, environmental, and human factors and views self-efficacy, goals, and outcome expectancies as the primary factors that affect one’s inclination to change their behaviors

(Glanz & Rimer, 2005). The theory first began as Social Learning Theory (SLT), which was developed and expanded upon in the 1960's and 70's by Bandura. SLT posits that individuals learn from their own experiences as well as observing the actions and eventual outcomes of others. This tenant remains within SCT, which evolved from SLT, with an additional focus on self-efficacy. Self-efficacy helps to explain personal empowerment; people must believe they have the power to enact change in order for it to come about (Ramirez, Kulinna, & Cothran, 2012). Combined with the other primary determinates of behavior change, the degree of self-efficacy one has impacts their ability to make changes, or meet their goals, because it feeds their positive or negative outcome expectations (Plotnikoff, Costigan, Karunamuni, & Lubans, 2013).

Environmental factors, specifically social support, have a significant influence on one's self-efficacy (Ramirez et al., 2012). Support from others can help to facilitate change and provide a positive foundation for other key constructs of behavior. Perhaps this is why schools are effective environmental settings where social interactions can greatly influence student behaviors. Students learn how to regulate emotions and positively interact with others from observation and personal experience. Effective social interactions in school enhance their outcome expectations for social interactions in other settings. This exchange carries over to many other areas of behavior that impact emotional wellbeing (Harmon et al., 2014).

The primary factors and foundation of SCT are weaved throughout the Sib Kinnect program. The use of technology to bring together siblings who cannot easily access face-to-face sibling support groups or connect with other siblings is the

cornerstone of the program. Similarly, SCT was founded on the belief that learning from others' experiences is a powerful force to change behaviors and the emotions that drive them. Exposure to other siblings and interaction with them and their ideas through games, activities, and discussions provides a forum for social learning to take place. These interactions also facilitate the development of social supports among the siblings, as this is a key environmental influence on one's self-efficacy. According to SCT, self-efficacy is also affected by knowledge that forms one's goals and expectations. Knowledge increases the feelings that one can exercise control over their behaviors (Glanz & Rimer, 2005). In the case of Sib Kinect, knowledge about coping mechanisms, problem solving skills, disability, and the value of engaging in personally meaningful activities are critical tools to make changes or consider approaches that are important to them.

While siblings share common experiences, just like any other sibling, they have personally unique circumstances and desires that form the goals that are relevant and meaningful to them. Research in sibling interventions suggests that effective efforts have focused on fun and general information rather than specific pathology or scenarios (Carter, Cook, Sutton-Boulton, Ward, & Clarke, 2015). With this in mind, siblings will not be asked directly to consider or develop goals. Instead, the use of enjoyable role-playing, leisure time exploration, illusion activities, and silly but content focused problem-solving games will provide program participants with numerous ideas on how to better manage or think about their own situations and relevant changes.

Lastly, siblings' outcome expectations regarding their goals are largely influenced

by the previously discussed elements of social support, self-efficacy, and even fun. Awareness of others' similar experiences is affirming and decreases feelings of isolation (Angell et al., 2012). However, social support also provides helpful parameters for expectations. Some siblings may benefit from hearing or observing the outcomes of other siblings' approaches and ways of managing, which allows them to see greater possibilities than they previously expected. However, others can find it useful to scale back expectations in order to see the significance of what they perceive to be smaller changes or improvements. In this way, SCT advocates for short-term attainable goals, as they are thought to be most effective in enacting behavior changes (Ramirez et al., 2012). When individuals feel confident about the attainability of outcomes, this increases self-efficacy. Regardless of how siblings perceive their current situations, skilled, adult facilitation of Sib Kinnect sessions will assist with the generation and exchange of ideas between siblings and promote an environment that is supportive and positive.

Another role of adult facilitators and one that will be shared with siblings, is the importance of instilling enjoyment and pure fun into the program. As one systematic review noted, "All kids like fun, but some may need it" (Tudor & Lerner, 2015, p. 18). The literature suggests that for some siblings, fun, special activities hold special significance because they may be rare or not expressly for the particular sibling's enjoyment (Carter et al., 2015; Roberts et al., 2015; Tudor & Lerner, 2015). Enthusiasm and participation increase when sibling interventions include many game based sessions (Carter et al., 2015; Jacobson & Hooke, 2015). Therefore it comes as no surprise that school children are more likely to make changes when they enjoy the intervention

(Harmon et al., 2014). Given this information, the Sib Kinect program has a core focus on having fun and intervening through activities that children enjoy and want to be a part of. The activities might include an internet scavenger hunt to learn about ways to spend leisure time or game show style trivia about disability and common misperceptions. The intent is not to downplay the challenges that siblings may face. Instead, the aim is to provide information and support in a way that has the greatest likelihood of leading to important changes while giving siblings time and attention that is enjoyable, positive, and specifically for them.

Previous Attempts to Address the Problem

The two main methods of supporting siblings represented in the literature are asynchronous online support groups and face-to-face support groups (Kryzak, Cengher, Feeley, Fienup, & Jones, 2015; McCullough & Simon, 2011; Roberts, Ejova, Giallo, Strohm, & Lillie, 2016; Tichon, 2015). Tichon (2015) analyzed the content of Sibkids, an online support group, which furthered the finding that siblings highly value the opportunity to share their honest feelings without judgment or guilt. This is particularly true for siblings who find it difficult to express and cope with simultaneous emotions such as love, fear, jealousy, gratitude, and concern for their brother or sister. There are several sibling support organizations that provide a standard methodology and approach that is put into place in many locations throughout a region (Carter et al., 2015; Roberts et al., 2015; Tudor & Lerner, 2015). Sibworks and SIBS are two such organizations that operate in Australia and United Kingdom respectively and Sibshops started in the United States but now is an international organization. Current literature has explored the

experiences of siblings who have participated in these groups, and largely concluded that siblings enjoy and appreciate them, but there is minimal structured research on the significant effects of these programs (Carter et al., 2015; Roberts et al., 2015; Tudor & Lerner, 2015). Perhaps this is because these programs are not designed to be therapeutic or clinical. If a sibling receives therapeutic benefit from participating in the program then that is viewed as positive but not the only purpose for such a group. For instance, on the website for Sibshops under their Frequently Asked Questions they state that, “Sibshops may be ‘therapeutic’ for kids to attend, but they’re not therapy. The Sibshop model takes a wellness perspective. The model includes a celebration of the many lifelong contributions made by brothers and sisters of people with special health and developmental needs” (“Sibshops FAQ”, 2006, About Sibshops). The impact of these programs appears to interest those who study sibling experiences, as more thorough research does exist on support groups that incorporate the methodologies of these organizations (Hartling et al., 2014; McCullough & Simon, 2011; Tudor & Lerner, 2015).

Research on these programs has found positive effects on many outcomes including social skills, coping mechanisms, family relationships, and leisure time (Carter et al., 2015; Gettings et al., 2015; Granat et al., 2012; McCullough & Simon, 2011; Roberts et al., 2015). The most salient outcomes are increased social support, improved emotional and behavioral wellbeing, improved self-esteem, and increased knowledge about disability (Carter et al., 2015; Gettings et al., 2015; Granat et al., 2012; Hartling et al., 2014; Kryzak et al., 2015; Roberts et al., 2015; Tudor & Lerner, 2015). Authors were careful to differentiate between outcomes that showed improvement and potential versus

those that demonstrated statistical significance. For example, in a randomly controlled trial of a program based on Sibworks, parents reported improved emotional and behavioral functioning with medium to large effect size immediately post-intervention and at three months follow-up (Roberts et al., 2015). Siblings themselves reported improvements in self-esteem and coping strategies with a medium to large effect size, but this did not reach significance. Kryzak et al. (2015) found that in a program for siblings of children with autism there was a significant increase in peer networks and self-esteem, but a non-significant decrease in depression and anxiety even though self-reports consistently noted improvements in these areas.

Sibling support groups have employed a range of techniques to address the factors facing siblings, but several aspects emerged that appeared to be effective and/or highly valued by siblings. The characteristic that most consistently appeared in the literature was the siblings' appreciation of fun during the programs and thus the effectiveness of embedding information and discussions into games and enjoyable activities (Carter et al., 2015; Granat et al., 2012; Kryzak et al., 2015; Puttick, 2011; Tudor & Lerner, 2015). Other important aspects of the programs were using icebreakers or informal, casual discussions to build group camaraderie in the early sessions, providing information on disability, exploring and teaching coping mechanisms, and developing ways for siblings to meaningfully utilize leisure time and express their individuality (Gettings et al., 2015; Kryzak et al., 2015; McCullough & Simon, 2011; Roberts et al., 2016). Parent involvement in the overall process, but not in the individual sessions, was also found to be helpful (Puttick, 2011; Roberts et al., 2015; Scelles, Bouteyre, Dayan, & Picon, 2012;

Tudor & Lerner, 2015). Information sessions prior to the group meetings and summaries of topics helped parents get ahead of questions or concerns that might be brought up. Some parents also found that they became increasingly aware of hardships faced by the siblings (Gettings et al., 2015). It was easier to manage these realizations when they had prior knowledge of the emotions and scenarios that could occur.

As mentioned previously, support groups generally take place in face-to-face settings but there is evidence that technology, particularly videoconferencing, can support children and adolescents dealing with various health conditions. This medium has been shown to be a viable approach to treat and manage chronic medical conditions such as Type 1 diabetes and asthma and mental health conditions like anxiety and trauma exposure (Boydell, 2013; Dougherty et al., 2014; Jacobson & Hooke, 2015; Letourneau et al., 2012; Santos et al., 2014). Additionally, it was reported that young people generally prefer treatments offered via technology (Boydell et al., 2014). Similar to studies on siblings, children and adolescents dealing with health conditions felt less isolated when they knew their concerns were shared by others and the burden of the condition was removed (Dougherty et al., 2014; Letourneau et al., 2012). Compared to face-to-face treatment or support groups, children and adolescents showed comparable, and sometimes superior, outcomes when using telehealth. A systematic review looking at English, Spanish, and Portuguese research articles on the use of telerehabilitation for children found superior outcomes (as compared to traditional delivery) for decrease in occurrence of symptoms, improvement in quality of life, greater disease control, greater treatment adherence, and increased physical exercise (Santos et al., 2014).

Occupational therapists are currently using telehealth to deliver services to adults and parents, but are just beginning to use it to directly provide services to children as the primary client (Cason, 2011, 2015). The use of telehealth for early intervention services shows great promise and builds capacity among providers to reach families in rural areas (Cason, 2011). Criss (2013), investigated telehealth in the school setting to improve handwriting in elementary students. In this research study, occupational therapists used a variety of interactive activities that were meaningful to the student and incorporated kinesthetic, biomechanical, and multisensory approaches. Five of the eight students showed at least a 5% increase on their Print Tool assessment and five students showed at least an 11% increase. Parents reported 100% satisfaction with overall quality and those who were indifferent to the delivery method reported surprise in the level of progress made by their children.

Gettings, Franco, and Santosh (2015), study overlaps the areas of technology and sibling support groups. These researchers studied the feasibility of supporting siblings of children with neurodevelopmental disorders using audio-conferencing. Four of the one-hour weekly group sessions were delivered face-to-face and four were carried out over audio-conferencing. The authors reported a reduction in the severity of parents' concerns following psycho-education. The children showed increased coping mechanisms and an improved ability to share their concerns with their parents. Family communication increased and social networks widened. Interestingly, according to parent responses on assessments, the level of their child's psychopathology increased following the program. This may have been because parents became more aware of the issues that siblings face

by going through the program and/or their post-intervention responses were more realistic than their pre-intervention responses. Parents were not aware of some of the challenges faced by their children, which may indicate that the support group provided a safe environment for siblings to share concerns that they were previously reluctant to discuss. Overall, audio-conferencing was reported to be an effective way to facilitate sibling support groups.

Differences in Intervention Effectiveness and Approach

While it appears that technology has the potential to provide comparable treatment outcomes in a manner that is more easily accessible to some siblings, it is imperative to look at which siblings are best suited for which types of intervention. This is an emerging area of interest, but commentary on the impact of severity of disability, general type of disability, and age of siblings are three factors that may help program planners better understand the type of intervention to provide and groups of siblings that may work well together.

Granat et al. (2012), found that response patterns of siblings of children with autism and intellectual disabilities distinctly differed from siblings of children with other diagnoses. Siblings of children with ADHD, Asperger Syndrome, and physical disabilities reported that after intervention they had a less nurturing role and spent less time with their sibling, but enjoyed it much more when they did. Perhaps role playing and group discussion helped them to better problem solve and feel more comfortable setting limits. Siblings of children with autism showed no significant changes in their problem solving abilities. Due to the complexity of autism, these same group activities

may have had little impact because the strategies were too simplistic or general. Post-intervention they also felt that their mothers showed increased favor to the child with autism and the siblings themselves felt increased admiration for the child with autism. These findings might suggest that these particular siblings developed an increased understanding for their own needs as well as those of their brother or sister. Meanwhile siblings of children with intellectual disabilities showed an increase in dominance by a sibling and greater affection for their brother or sister. Similar to siblings of children with autism, these siblings may have realized the significance of the child's disability in a way that increased their empathy while bringing some difficult realities to the forefront.

Interestingly, McCullough & Simon (2011) found that in an intervention targeted to siblings of children with autism, the siblings' favorite activities were 'illusion' activities that attempt to simulate how someone with autism might feel. For instance, a sibling might be asked to do a task that is usually easy for them, such as counting backwards from 50. When they start to count, their senses are bombarded with bright flashing lights, very loud noises, and several people in their personal space. This mimics the challenges of being hypersensitive within an environment that may feel quite typical and comfortable for others who can process sensory input more effectively. Interviews with siblings of children with autism reported that they most valued talking to others who understood, learning about techniques that work for other siblings, and having time for themselves (Angell et al., 2012). These findings may suggest that siblings of children with autism or other disabilities, which present multi-faceted developmental, social, and behavioral symptoms, benefit from more personal and specific interactions with siblings

of children with similar challenges. General problem-solving strategies may not seem relevant to these siblings until they have the opportunity to discuss them in depth with siblings who understand the complexity of the situations with which they are faced. Along these same lines, the severity of a child's diagnosis, particularly if it involves violence to others or themselves, can increase the negative impact on the sibling and the kind of intervention they require (Angell et al., 2012; Gettings et al., 2015). Siblings have a need to share their feelings and experiences free of judgment, embarrassment, or guilt (Carter et al., 2015; Tichon, 2015). It is likely that a social environment that provides this is composed of siblings who empathize and relate.

Alternatively, siblings who have a different experience with disability, potentially one that is not as emotionally fraught, also need a safe place interact with other siblings in similar situations. A systematic review from Tudor & Lerner (2015) suggests that harm may occur when 'sibling' is treated as a diagnosis instead of a characteristic that may or may not bring additional challenges with it. In fact, there is potential for iatrogenic effects to occur if interventions are focused on difficulties with siblings (Kryzak et al., 2015; Tudor & Lerner, 2015). For example, a sibling who is well-adjusted but appreciates socializing and participating in activities with other siblings may view their situation more negatively or with increased anxiety if they are exposed to other siblings' concerns with difficult situations such as fearing that a brother or sister will injure them or a family pet. They may also be content with the time they spend with their parents but begin to view it as insufficient when hearing other siblings discuss their feelings of loneliness. Both groups of siblings have needs and it is unrealistic to think

that siblings will fall neatly into categories, but Tudor & Lerner (2015) interpret their findings to suggest careful consideration of groups. Specifically, they view the experiences of siblings of children with chronic illnesses, developmental disabilities, and physical disabilities as quite different from one another.

Age is another factor that may influence intervention suitability (Boydell, 2013; Jacobson & Hooke, 2015; Santos et al., 2014). Younger children, those under 13 years of age, were found to enjoy support programs more and had better compliance with attendance and outside activities. This may be because younger children like the games and playful activities (that studies have found to be effective) more than adolescents. Even young children have a comfort level with technology that makes it accessible from an early age (Santos et al., 2014). Perhaps adolescents want more in-depth discussion and choice over with whom they communicate and when, which aligns better to other forms of technology such as asynchronous support groups, text messaging, or social media.

Limitations in Current Research

In addition to exploring the characteristics of interventions that are effective for different siblings, it is also important to note the shortcomings in the current research. Many studies note that small sample size, negative biases about sibling functioning, broadly defined study groups, and overall methodological rigor make it difficult to generalize conclusions, determine effectiveness, and understand how characteristics of the participants influence treatment outcomes. (Carter et al., 2015; Emerson & Giallo, 2014; Goudie et al., 2013; Hartling et al., 2014; Neely-Barnes & Graff, 2011; Tudor &

Lerner, 2015) Additionally, across study comparison is difficult because there is minimal overlap of targeted outcomes and the outcome measures. This underscores the importance of Sib Kinnect program planners and interventionists remembering that “sibling is not a diagnosis” (Tudor & Lerner, 2015, p. 17).

Incorporation of Research and Theory

Overall, the evidence-based literature suggests that a younger, more narrow age range and general similarities in type or severity of disability may build a more cohesive group (Gettings et al., 2015; Hartling et al., 2014). However, even with this in mind, each sibling is coming from such a unique family system and school setting. Technology may increase the accessibility of a sibling support group to many children, but this could be for reasons that further differentiate them. For example, some families may choose this delivery method because it alleviates some of the financial burdens from travel and childcare costs (Gibbs & Toth-Cohen, 2011). Other families may live in rural areas where it is not feasible to travel to weekly sessions, and yet others may struggle to find the time or available transportation. Any combination of these reasons is possible. Given this information, it will be important for Sib Kinnect interventionists to be sufficiently trained to build upon similarities, respect the differences of each sibling, and objectively note if there are sibling features that make the program more or less valuable for them so that future groups can meet the diverse needs of siblings.

Although there is limited research on the delivery of services through the use of telehealth to support siblings in a group format, evidence from sibling studies along with the use of telehealth to treat and support children in other areas provides the puzzle pieces

to create a program that effectively connects with siblings and meets their needs.

Fortunately, occupational therapy has distinct value that meshes well with the program characteristics research suggests and is appropriate for the delivery of these services.

Occupational therapy uses meaningful activities (or occupations) as a means to provide treatment, or as a way to increase successful participation in the occupations themselves.

Siblings need information on disability, coping mechanisms, and problem solving via child-friendly activities and assistance with identifying and engaging in more personally satisfying activities that allow for expression of their individuality and time for their own interests. As such, the objectives of Sib Kinnect are to have fun, increase knowledge about disability, improve coping and problem solving skills, and explore personally meaningful pursuits and activities.

SCT will help guide the format of the group so that there is ample time for siblings to share lessons they have learned and interact in various ways to provide more subtle social learning opportunities. A positive environment goes hand in hand with having fun, but it is also an essential element for siblings to build positive expectations through knowledge and social support that will enhance their self-efficacy and therefore likelihood to implement different approaches or behaviors. Figure 2.2 depicts SCT's role in connecting key program components for desired outcomes.

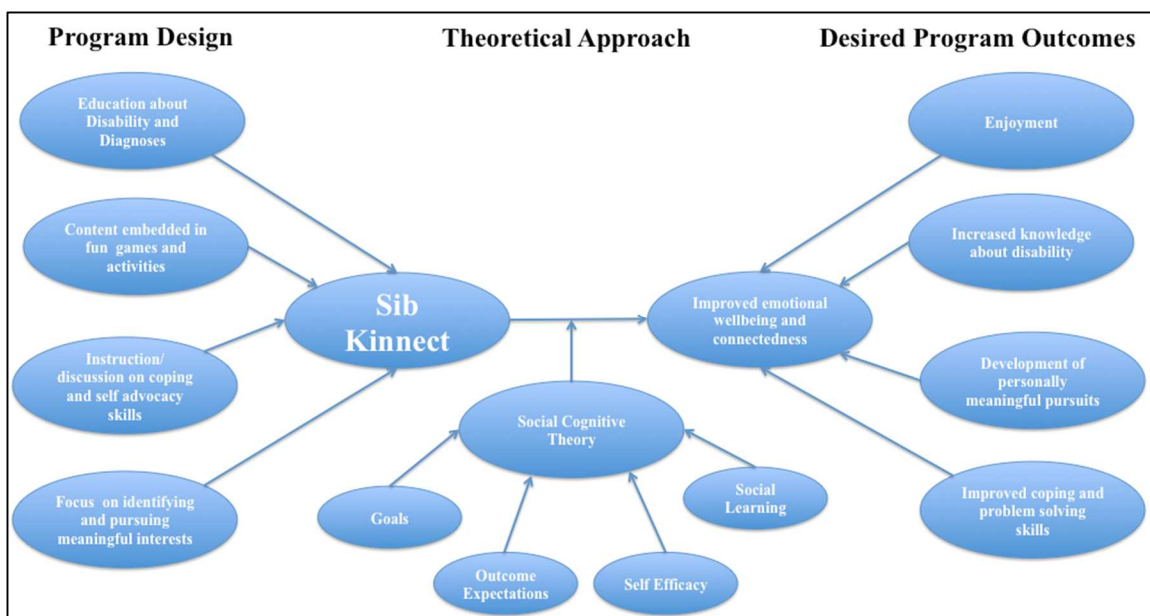


Figure 2.2: Program Components and Theoretical Approach for Desired Outcomes

Parent involvement will be another necessary component, but not a core focus.

Research clearly suggests that siblings value the opportunity to express their thoughts in a forum that is free of guilt or judgment (Angell et al., 2012; Tichon, 2015; Williams et al., 2010). Because of this, parents will not be invited to participate in the sessions, but will have opportunities to ask questions throughout and gather information prior to the start of the program.

In an attempt to build group cohesiveness, community, and peer interactions, Sib Kinnect will focus on supporting siblings ages 10-12 years old who have a brother or sister with a developmental disability. The goal is that siblings will want to participate because they enjoy Sib Kinnect and feel comfortable interacting with peers who have similar experiences and adult facilitators who create a safe space to talk honestly about

their experiences. Ideally this interaction and participation, via telehealth, will give siblings tools and support to better manage their day-to-day lives.

CHAPTER THREE: DESCRIPTION OF PROPOSED PROGRAM

IMPLEMENTATION

Program Components and Participants

Sib Kinect is a program for siblings of children with disabilities that uses a telehealth approach to teach about disability, develop coping skills and personally meaningful interests, and provide an opportunity to have fun with and learn from other siblings who share common experiences. The program will take place on a weekly basis for eight weeks and sessions will run for an hour on weekday evenings. The program will be open to a maximum of eight siblings, ages 10-12 years old, who have a brother or sister with a developmental disability. Previous telehealth programs for children have had six to ten children participate in each group and the only study published thus far that has used a telehealth approach with siblings suggests six in a group (Gettings et al., 2015). Eight participants will hopefully provide an opportunity for each sibling to meaningfully participate while taking into account that conflicting family and social events will cause some participants to miss sessions, naturally decreasing group numbers. The age range of 10-12 years old was chosen because participants should be old enough to independently participate in a group but young enough to find the activities and telehealth approach enjoyable and valuable (Gettings et al., 2015; Hartling et al., 2014). Participants within a similar age group may also help build group cohesiveness.

The program content and guidance in the manual will be geared toward siblings of children with developmental disabilities. Some evidence-based research suggests that within this broad category there are characteristics that make siblings more or less

compatible. For example, siblings of children with autism spectrum disorder, significant behavioral disorders, or severe disabilities may have trouble relating to siblings who they perceive to have less problematic or more unidimensional experiences (Angell et al., 2012; Gettings et al., 2015; Granat et al., 2012). Additionally, siblings whose experiences may be less complicated or traumatic, could feel guilty discussing what they feel are less significant issues, or it could be unnecessarily disturbing to hear stories from siblings with vastly different circumstances (Hartling et al., 2014). Yet, a common theme is that siblings desire to have a space where they can freely speak about their situations without judgment, fear, or isolation (Carter et al., 2015; Roberts et al., 2016; Tudor & Lerner, 2015). Given this information, the Sib Kinnect program and manual will not specify additional diagnostic exclusions for the program, but will advise program managers and facilitators to roughly form sibling groups based on their sibling's type of disability. However, this approach may not always be possible for a number of reasons such as available participants or requests from partners or funder. In any case, it is imperative to continually recognize that having a brother or sister with a disability, even with the same diagnoses, can impact siblings in vastly different ways.

To find appropriate participants, recruitment will be conducted in partnership with children's hospitals and pediatric disability parent support groups. Recruiting efforts will emphasize the 'fun factor' so that parents and siblings understand that the program is designed to support and empower siblings through enjoyable, age-appropriate activities, instead of being another clinical experience.

Delivery Method

The specific telehealth delivery method that will be used is videoconferencing through a web-based platform. A variety of applications have been used in previous telehealth programs such as Adobe Connect, WebEx, and proprietary applications developed within health systems (Cason, 2011; Criss, 2013; Jacobson & Hooke, 2015; McAlpine, Henderson, & Levy, 2014). With the growth of telehealth, there are also many private companies that have developed web applications for this specific delivery method. The application should allow for siblings to connect through the Internet as well as through the phone, as an alternative audio option. The application must also have features that encourage collaboration and sharing such as document sharing, voting buttons, chat screens, and message boxes for communication with the facilitators and other siblings.

The manual for Sib Kinnect will not dictate which application or service to use, but instead provide a list of criteria and available resources to ensure that the application functions in a way that is compliant with the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and the Health Information Technology for Economic and Clinical Health Act of 2009 (HITECH) (Peterson & Watzlaf, 2014). The manual will include information about the importance of complying with standards and guidelines for privacy and security for protected health information (PHI), client informed consent, and patient safety. For example, occupational therapists are considered a health care provider and as such, they are considered a 'covered entity' that must comply with HIPAA and HITECH regulations when dealing with health

information (Peterson & Watzlaf, 2014). If Sib Kinect sessions are recorded for program facilitators to review and critique for future sessions, the actual storage of that recorded content must be done in a way that upholds the participants' security and privacy according to HIPAA and HITECH. It is likely that there will be ongoing changes in telehealth regulations and available technology platforms. For example, the International Journal of Telerehabilitation publishes articles on telerehabilitation interventions as well as best practices and current legal considerations. The American Telemedicine Association is another resource where program planners could better understand application functionality and relevant policy changes.

Program Personnel

The sessions will be co-facilitated by an occupational therapist and mental health professional (psychologist, social worker, etc.) that has experience working with children with and without disabilities. The occupational therapist and mental health professionals must also have a license in whatever state the siblings are located. The role of the facilitators will be to introduce and guide activities, pose questions to further discussions, and maintain an enjoyable and safe web-based environment. The facilitators will also be cognizant of situations in which a sibling would benefit from a referral to other services or if a sibling does not interact well with rest of the group and the overall group dynamics are negatively impacted. Ideally, the facilitators should be involved in the planning process, but are able to rely on the manual for session structures, agendas, and activities. The role of program manager will be held by an occupational therapist or a mental health professional. The roles of program manager and facilitator can be fulfilled either by the

same person or an additional team member. The program manager will be responsible for the administrative and operational aspects of the program such as recruiting participants, developing partnerships, budgeting, and family correspondence. Two research assistants will also be part of the team and will be responsible for working with the program manager to complete the data analysis following the program.

Parent Involvement

Parental involvement is an essential aspect of Sib Kinnect. Involving parents in some manner helped to make previous sibling programs more successful (Puttick, 2011; Roberts et al., 2016; Tudor & Lerner, 2015). Involvement is necessary to help children of this age manage logistics such as computer glitches and signing up for the program, but it is also important in this scenario to provide parents with awareness if questions or concerns arise as a result of their child participating in Sib Kinnect (Gettings et al., 2015; Granat et al., 2012; Scelles et al., 2012). For example, as siblings learn more about disability, they may have questions about their sister or brother's disability or the parents' experience with disability; and in an attempt to discuss frustration or worries with their parents as a coping skill, siblings may discuss things with parents that their parents were previously unaware of or surprised by. To address this, there will be several informational meetings delivered through the chosen web application during the recruitment phase of the program. These will help parents can get an understanding of what it is like to participate in such a forum and better understand the purpose and content of the program. Once the participants are signed up, another introduction meeting will be held for parents to discuss weekly topics and activities, what to expect,

and answer any questions. ‘Checkpoint’ e-mails will be sent to parents on a bi-weekly basis. These e-mails will be sent as a newsletter to review the activities their children participated in and make them aware of themes that emerged from discussions. This allows parents to have awareness without compromising the privacy of siblings.

Program Activities

The activities in the program are designed to support the four outcomes of Sib Kinnect, which were chosen based on their salience in evidence based literature. The outcomes are: increased knowledge about disability, development of personally meaningful pursuits, improved coping and problem skills, and enjoyment of the experience (Carter et al., 2015; Gettings et al., 2015; Granat et al., 2012; Hartling et al., 2014; Kryzak et al., 2015; Puttick, 2011; Roberts et al., 2016). The goal is for these outcomes to bolster an overall enhancement of emotional wellbeing and connectedness. The manual is structured in a way that helps the facilitators understand which activities align with which outcomes and how Social Cognitive Theory (SCT) should guide the facilitation of the weekly sessions and activities. Appendix A. - Sib Kinnect Approach and Appendix B: Key for Sib Kinnect, present the information that the facilitators need in order to understand the foundation and reasoning of the program and how that foundation will flow throughout the manual.

The facilitators will also have access to a set of files that will offer guidance with and supplement each activity. Additionally, before the start of the telehealth sessions, each participant will receive a Sib Kinnect Kit. The kit includes items that will be used during activities such as a small dry-erase board, dry-erase marker, USB drive,

headphones, notepad, and sticky notes. The kit is also a way to welcome the siblings to the group and make them feel that they are part of something that is just for them. Appendix C. and Appendix D. are examples of two activities: “Game Show” and “Emotion in Motion”. These documents include guidance for implementing these activities.

Every session will start with a quick icebreaker activity like playing a silly game or displaying a picture of the sibling doing an activity they enjoy. As the weeks progress, the activities will include more reflection and discussion. None of the activities are designed to evoke strong emotion or discuss intensely personally scenarios. However, over time it is anticipated that the participants will share personal experiences or have valuable discussions if they feel more comfortable and connected with the group. Siblings have a strong desire to have fun and to have a safe place to share their thoughts with others in similar situations (Carter et al., 2015; Kryzak et al., 2015; Tudor & Lerner, 2015). The purpose of the activities is to allow both to happen in a way that best supports the outcomes, and in turn, supports the siblings.

Potential Barriers and Challenges

There are several potential barriers and challenges for the implementation of the program. First, while telehealth is gaining popularity and has become a standard delivery method in some areas of medicine, this program is the first to provide services in a group format to children using telehealth (Calouro, Kwong, & Gutierrez, 2014). Not having an existing template or expectations can be beneficial when thinking of creative approaches and solutions, but it may also bring about challenges with the administration and

recruiting aspects. Internally, the program manager and facilitators will be learning as they go and trying to incorporate newly acquired knowledge as the program is ongoing. It is difficult to plan for unexpected issues, even when the program is based on evidence from research in telehealth and sibling support. There is no previous program to reference for guidance on issues that arise. To mitigate some of these issues it will be important for program facilitators, managers, and potential partners to meet on a weekly basis, particularly in the pilot phase, to discuss any problems that occurred in the previous session and develop a plan to deal with them in future sessions. Selecting a videoconferencing vendor with easily accessible technical assistance, even if this increases cost, will also be beneficial to quickly troubleshoot issues so that participants do not become disengaged. Additionally, setting expectations with parents, participants, and potential partners may help. For participants, they should know that their input and patience with unexpected problems will help improve the experience for future participants and that they are a critical part of improving and developing the program.

Externally, parents may be reluctant for their children to receive services in this manner since it is relatively new and the internet brings with it a host of concerns regarding security and open exchange of information. While parents can be assured that the program abides by HIPAA, they still may feel uncomfortable. It is natural and expected for parents to want to make sure that the program in which their child is involved is safe and valuable. However, it will require some trust on the part of the parents to allow their children to participate in the program in a way that gives them and the other participants a way to openly share their thoughts and feelings without fear of

guilt, shame, or judgment because they are concerned about their family members or those of other participants' hearing their conversation. This is why parent involvement through information sessions and bi-weekly checkpoints is crucial. Striking the balance between parent concerns and participant's privacy will be challenging, but is imperative to make sure all involved feel respected, aware, and comfortable.

Funding and reimbursement is another potential barrier for the program implementation. Currently, occupational therapists are not eligible telehealth providers under the Centers for Medicare & Medicaid Services (CMS) rules. Reimbursement by Medicaid and private insurance varies by state (Cason, 2012). The majority of state regulatory boards do not have any guidance on telehealth regulations and those that do mainly focus on consultation as opposed to direct services (Calouro et al., 2014). However, clinical psychologists and clinical social workers are eligible telehealth providers according to the CMS, with the exception of some current procedural terminology (CPT) codes that are not relevant to the program (American Telehealth Association, 2013). It is unlikely that funding for the initial implementation of Sib Kinnect will depend on Medicare or Medicaid reimbursement, particularly because a pilot program would be free to participants. Yet it could impact the willingness of potential partners to fully support Sib Kinnect if they are thinking of longer term funding issues and how that impacts their involvement. Program managers should be upfront about current regulations but also provide information about the work that organizations like the American Occupational Therapy Association is doing to increase occupational therapy's presence and eligibility in telehealth.

Evaluation Plan

In order to evaluate the effectiveness of the Sib Kinnect, it will be important to gather information that is specific to the outcomes of program: increased knowledge about disability, development of personally meaningful pursuits, improved coping and problem skills, and enjoyment of the experience by siblings. All participants, along with their parents, will be invited to provide feedback after the conclusion of the eight-week program. However, quantitative analysis will only include data from participants who attended at least six of the eight sessions, as this reflects a more comprehensive view of the program. Before any information is collected, the program manager will work to obtain approval from an institutional review board (IRB) to assure that the appropriate steps are taken throughout the evaluation process to protect the rights of the participants and their families. The evaluation will have three components: sibling pre- and post-test, a 'knowledge check' that will function as a pre- and post-test specific to disability knowledge of the siblings, and an online survey that will be accessed by siblings and parents following the conclusion of the program. The program manager is free to use the survey tool that best fits their need, but the manual will guide them to use a tool that has secure sockets layer (SSL) data encryption at both the participant and program manager ends of the process and will not permanently store unique user identifications.

The Coping Strategies Inventory (CSI), a self-report measurement tool, will be used as the pre- and post-test for siblings. It will be administered on-line and participants can access the CSI through a link provided through e-mail. The CSI has been used primarily in the United States with children from diverse backgrounds (Blount et al.,

2008). The shortened version, which is most commonly used in pediatrics, is categorized as well-established with strong psychometric properties (Tobin, 2001). The individual whose coping is being assessed describes a stressful event and then uses five-point Likert scales to answer 32 questions that are comprised from the four subscales of problem engagement, emotion engagement, problem disengagement, and emotion disengagement (Blount et al., 2008; Tobin, 2001).

The 'knowledge check' will be administered during the second and sixth sessions. It will consist of 15 questions that cover information about disability in general as well as specific disabilities. Facilitators will use the shared document feature of the videoconferencing application to display the questions and participants will use the vote functionality to respond. The 'knowledge check' is meant to provide additional pre and posttest information but will also be used as an interactive learning tool for participants.

On-line surveys for parents and siblings will be administered one week after the final session so that participants and their families have time reflect, but the experience is still fresh in their minds. These will also be accessed through a link provided through e-mail. They will contain a mixture of fixed choice, Likert-style questions and open ended questions. The fixed choice questions will directly target the four main outcomes while the open ended questions will be more descriptive to gain an understanding of sibling and parent experience with Sib Kinnect. Examples of survey questions are found in Appendix E.. These examples demonstrate how the fixed choice questions correspond with outcomes and how the open-ended questions prompt a broader dialogue. The sibling questions use shorter phrases and simpler language compared to the parent survey

questions. Both sections contain questions about enjoyment, as it will be interesting to compare perspectives, particularly for those siblings who are not able to express themselves as well but whose parents notice their child's engagement.

Data Analysis & Reporting

Once the data is collected, two research assistants will be primarily responsible for compiling and coding the data before it is given to the program manager and facilitators for review. Prior to receiving the data, research assistants will be trained on the survey and coding software. They will also be given a brief overview of the program and why the evaluation is being performed. The program manager will also provide mock surveys, CSI results, and knowledge check data to research assistants for practice. The program manager will establish an acceptable inter-rater reliability and research assistants will review qualitative information during training until that benchmark is met. All quantitative results will be compiled and reviewed by each research assistant. Similarly, both research assistants will code qualitative information and then they will work with the program manager to decide upon the top five themes that emerged from the coded data. Quantitative data from the CSI and knowledge checks will provide data at individual and aggregate levels, while the surveys will provide information primarily at the program level.

Data reporting will be done through an executive summary, formal presentation over videoconferencing, an informal discussion over videoconferencing, and relevant professional publications and community forums. The executive summary will present the quantitative information from the surveys, CSI, and knowledge checks in tables and

charts, as well as brief narratives to explain trends and unexpected findings. The summary will also include the top five themes from open-ended questions. This will be distributed via email to program personnel, parents, and partnership organizations. The formal presentation and discussion will be open to the same audience. While the first two formats (executive summary and presentation) provide one-way, objective information, the discussion is for interested parties to exchange ideas on the results and how they think the results will impact future sessions. Publications such as the American Journal of Occupational Therapy, the Journal of Developmental and Behavioral Pediatrics, and the Journal of Telemedicine and Telecare are all potential channels to report findings and lessons learned. There are also more informal publications that reach professional communities through newsletters, social media, and conferences. Specific to occupational therapy, a poster presentation at the annual American Occupational Therapy Association convention or an article in *OT Practice* magazine are two such possibilities. These provide the community with information about the program but also create enthusiasm and connections to re-create and continue the program with additional practitioners or geographic regions.

Funding Plan

The primary costs to implement Sib Kinect are for personnel and technology. Personnel will be the largest item in the budget. The facilitators and program manager will be paid on an hourly basis, as they will work part-time. The hourly rate will be \$55.00 per hour, which is the hourly rate for limited part-time occupational therapists whose rate is within the 75th percentile of occupational therapists working on a limited

part-time basis (American Occupational Therapy Association, 2014a). Research assistants will be paid an hourly rate of \$20.00, which is roughly the average hourly rate of research assistants across the United States (Glassdoor, 2016). The expense of research assistants could be offset by a partnership with a local university. The university could offer the position as a for-credit internship/independent study, which would remove this cost, or as part of student employment, which may reduce the cost.

The cost of personnel will vary based on the phase of the program and its development. For example, it is estimated that facilitators will need 10 hours per week during the initial planning and implementation phases of the program. However, during year two, their preparation time decreases. It is also likely that the program manager can decrease the hours worked in the second year when facilitators and research assistants are more familiar with the program and less problem solving needs to be done. As personnel is the largest budget item, this is an area where volunteers may be beneficial with work that does not need the skill or familiarity with Sib Kinnect that the program manager has. Volunteer tasks might include tasks such as sending out e-mails, researching contacts at potential partnerships or organizing and mailing Sib Kinnect Kits. The program manager will have access to a dynamic spreadsheet with a pre-loaded budget template to manage costs and see where volunteers could assist. Appendix F. displays the estimated expenses across the first two years along with all other budgeted items.

Technology, the other large budget item, will also be variable depending on partnerships and available resources. The videoconferencing application is the most important part of Sib Kinnect's technology expenditure. Participation and satisfaction

with telehealth programs is impacted by the quality and usability of the videoconferencing application (Boydell et al., 2014; Hepburn, Susan. L; Blakeley-Smith, Audrey; Wolff, Brian; Reaven, 2015; Santos et al., 2014). Therefore, it is necessary to select an application that is user friendly and technically reliable. The program manager will be asked to select an application that provides easy access to technical support for technical glitches and to verify that the application settings support HIPAA. Mainstream videoconferencing applications do not require HIPAA compliance because they are the electronic equivalent of a courier service (Milton, 2013). However, most applications have settings that can be configured and provide assurances to users that their applications do not store transmissions on servers in their clouds or allow personnel to access or view transmissions (Cisco Support Community, 2013).

An average monthly cost for an application that provides sufficient quality and technical support is \$45.00 a month (Adobe, 2016; Cisco, 2016; Citrix, 2016). A partnership with a local children's hospital or pediatric clinic could minimize or remove the cost of a videoconferencing application. Sib Kinnect could utilize their current subscriptions or hold sessions within the organizations own videoconferencing application designed to meet their specific needs. The same considerations would go for a survey tool. A partnership would allow Sib Kinnect to use current tools as long as the program manager is sufficiently trained. Fortunately, Sib Kinnect could also use free services from companies like Survey Monkey and Zoomerang or pay a monthly fee around \$25.00 for increased functionality (Davidson et al., 2009).

Notebook computers for personnel will be a one time fee of approximately

\$2500.00 for five notebook computers at the average cost of \$500.00 (Piltich, 2014). A technology stipend will be given to each member of the team for the months that they are working on the project. The research assistants will receive \$25.00 and the program manager and facilitators will receive \$50.00. This is to be used for additional expenses they may incur for Internet access or telephone usage. Each team member can use his or her discretion for how this is spent. One team member may choose to use their personal phone while another might prefer to use a separate pre-paid phone option.

Notebook computers and internet access is also necessary for the participants and their families. Given that 84% of households in the United States have computers and 73% have high-speed internet access, it is likely that many of the participants will be able to use their household technology (U.S. Census Bureau, 2013). However, in the event that participants do not have access to these resources, Sib Kinnect will provide a notebook computer and technology stipend of \$200.00 for internet expenses. Sib Kinnect will purchase three notebook computers that can be used and returned for future participants who need them. The program will budget for two participant stipends per session.

Supplies for Sib Kinnect Kits, general office needs, and promotional materials will be smaller than the fees for personnel and technology but still need to be accounted for. Each Sib Kinnect kit will be approximately \$25 per participant (Staples, 2016). As all work will be done virtually, the program manager and facilitators will have an annual \$200.00 stipend for any office supplies they require. The cost for promotional materials will be relatively small (approximately \$300.00) since participant recruitment will be

done in partnership with children's hospitals and pediatric disability parent groups. Info sheets will be available but the bulk of promotion will be through online or face-to-face communication channels.

Potential Funding Sources

There is a range of potential funding sources for Sib Kinnect. Because Sib Kinnect involves many areas such as rural health, technology, pediatric mental health, and family-centered care there is a variety of options to consider. In 2014 the U.S. Department of Agriculture (USDA) Rural Development Distance Learning and Telemedicine (DLT) grants were announced to improve health care and educational services in rural communities through telecommunications (Samy & Menner, 2014). The Telehealth Network Grant Program (TNGP), managed by the federal Office for Advancement of Telehealth (OAT), funds projects that use telehealth to improve healthcare services for medically underserved populations in urban, rural, and frontier communities (Office for the Advancement of Telehealth, 2015). Appendix G. provides more specific information on these grants as well as grants funded at the state level. On a smaller scale, there are organizations like the Children's Guild Foundation, Parker's Purpose, and Special Kids whose foundations work to improve the lives of children with disabilities along with their families (Drusback, 2015; Special Kids Foundation, 2013; The Children's Guild, 2014). Smaller grant amounts could be combined or used to cover the costs of items still required with a partnership.

As mentioned previously, a partnership with a children's hospital could be a mutually beneficial way to fund parts of the program using an already existing

infrastructure. Such a partnership would allow the hospital and their staff (pediatricians, social workers, etc.) to offer Sib Kinnect as a way to support a family and invest in family-centered care. Sib Kinnect would have the opportunity to use the hospital's secure videoconferencing tools and other technology. A partnership like this could also save time and money for recruitment and promotion since a children's hospital serves the exact families that Sib Kinnect is looking to help. Another potential funding or partnership source is working with companies in the health information technology or specifically telehealth fields such RespondWell or Care At Hand (Harrison, 2015). These companies may give a donation in return for publicity or find that Sib Kinnect aligns well with their corporate giving strategies. Numerous telehealth applications are competing for business, and providing their services free-of-charge could allow them to demonstrate the flexibility of their application to scale and customize for clients of different sizes with diverse needs.

The funding plan will give program managers a realistic estimate of the funding needed to implement Sib Kinnect as well as ways to minimize larger budget items. The manual and accompanying files will help the program manager financially ground the program in a systematic and organized manner.

CHAPTER FOUR: DISSEMINATION PLAN

In order for Sib Kinnect to be successful, it will be important to provide information to appropriate audiences who have the capacity and interest to engage with the program in various ways. The three main audiences are: families of potential participants, potential partners, and potential funders. Each audience will have different motives for their involvement and the mechanisms to appropriately disseminate program information will be based on their particular interests.

Families of Potential Participants

Families of potential participants will be reached in three ways: through children's hospitals, on-line parent support groups, and in-person sibling groups.

Children's Hospitals

Due to specialized care needs, it is likely that families with children with disabilities visit children's hospitals for specialist appointments and routine follow-ups. Additionally, they are connected to the hospitals through newsletters, email updates, and social media. A partnership with a children's hospital, or a clinic within one, would help promote the spread of information about Sib Kinnect. A formal partnership could help to facilitate this in a more organized fashion, but even without one, information can still be shared directly with office managers, physicians, family advocates, and social workers. With permission, information sheets about Sib Kinnect can be posted and available in the hospital and featured on the hospital's social media accounts and e-newsletters.

On-line Parent Support Groups

On-line parent support groups for parents of children with various developmental disabilities will also be helpful because they reach a similar audience to that of children's hospitals, but may be able to target even more parents who would have difficulty getting their siblings to in-person groups because of rural locations or limited resources. Ideally, the facilitators or managers of online parent support groups would be contacted so they can distribute to the group in the most appropriate manner.

In-person Sibling Programs

In-person sibling programs affiliated with hospitals or stand-alone organizations will be another way to reach potential participants. The managers of these programs may have information about siblings who wanted to participate in their groups but found it difficult due to distance or other limitations. In-person sibling programs likely have shared goals to that of Sib Kinnect and connecting with them could prove useful for participants, programming, and problem solving. Information for potential participants, disseminated through these three avenues, will focus on the four main outcomes, with an emphasis on fun, and the opportunity get more information through the information session or by contacting the program manager via email. It will also be useful to clarify that Sib Kinnect is designed for siblings of children with developmental disabilities, as opposed to acute or chronic illnesses.

Potential Partners

Potential partners of the program are another audience to contact in an attempt to create partnerships that are mutually beneficial. Potential partners may be children's

hospitals, in-person sibling groups, and universities. Unlike sharing information with potential participants, which was quite transactional, the process to share information with potential partners will be more relational. Sib Kinnect will work to identify the appropriate contact people and then meet in person to discuss the goals of Sib Kinnect and how a partnership could presumably work. It will be beneficial for the Sib Kinnect program manager to identify specific needs of each potential partner so that the advantages are clear to each party. For instance, if a children's hospital has a strategic objective to provide family-centered care, then the conversation should include how the partnership would help them come closer to meeting that objective. Likewise, if an occupational therapy or social work department at a university is hoping to provide students with additional research or volunteer opportunities in less common areas of practice, the Sib Kinnect program manager would relate those needs to what a partnership with Sib Kinnect could provide. Additionally, while there are certain areas that would be of highest financial benefit to Sib Kinnect (use of videoconferencing application, volunteer hours for mailing, etc.) the program manager will share a variety of ways in which the potential partner could assist and collaborate. Ideally, the Sib Kinnect program manager and the partner contact could brainstorm together about how the partnership could work so that it feels more like a reciprocal partnership and both parties are being represented. For example, if Sib Kinnect forms a partnership with an in-person sibling group, Sib Kinnect could benefit from guidance about how to form appropriate groups, while the in-person sibling group can take advantage of the information gleaned from Sib Kinnect evaluations.

Potential Funders

The last audience is potential funders. This could be in the form of grants, foundation giving programs, community organizations, small businesses, or corporations. Formal applications or interviews may be required, or it could be a situation in which the Sib Kinnect program manager asks to meet with relevant individuals for an informal discussion about Sib Kinnect. Regardless, the information disseminated will focus on the current problem and how current efforts are not able to address it. To further this, the program manager will make clear parallels between the problems that siblings may encounter and how that fits with the mission of the organization or foundation. This is something that can be done for the initial implementation as well as following sessions. Information and testimonials from actual Sib Kinnect participants and parents provide first hand information about their experiences as siblings and how Sib Kinnect helped them to handle challenges or feel less isolated. Overall, the dissemination plan should endeavor to provide information that is relevant to the audience and clearly defines how each audience fits with bringing about the goals of Sib Kinnect.

CHAPTER FIVE: CONCLUSION

Sib Kinect is a program that offers siblings of children with developmental disabilities an opportunity to connect with other siblings while having fun and acquiring relevant skills and knowledge, all through telehealth. It uses telehealth, specifically videoconferencing, as a medium to bring together a group with similar experiences but limited access to services. Sib Kinect is designed according to evidence-based literature, with a focus on what siblings report they want and need in a program and uses an occupational therapy lens to support overall wellness and positive changes.

In-person sibling groups and asynchronous online sibling discussion boards have provided support to siblings who can access those groups and have the resources to participate (Carter et al., 2015; Roberts et al., 2016; Tudor & Lerner, 2015). The Sib Shops model in particular has helped to form other in-person sibling groups and stress the need for enjoyment and connectedness over intensely therapeutic programming (Tudor & Lerner, 2015). Sib Kinect utilizes the lessons learned and successes of other sibling support efforts, but also uses the delivery method of videoconferencing, in an attempt to reach siblings who may not have the opportunity to participate in other siblings groups because of geographic location or limited financial and social resources. Research suggests that having a child with a disability often contributes to limited resources due to medical costs and the time and travel associated with appointments and every day caregiving (Cuzzocrea et al., 2014; Emerson & Giallo, 2014; Gettings et al., 2015). Additionally, families living in rural communities often have limited access to quality health care due to poor infrastructure and a smaller health care workforce (National

Advisory Committee on Rural Health and Human Services, 2011). Sib Kinnect aims to lessen the burden on siblings and allow them access to information and connection with other siblings they might not have otherwise.

Sib Kinnect incorporates components from successful in-person sibling groups as well as telehealth programs that have addressed chronic pediatric conditions. For example, using games and role-playing to convey information and develop skills is a method that was found to be useful in many studies (Carter et al., 2015; Granat et al., 2012; Kryzak et al., 2015; Puttick, 2011; Tudor & Lerner, 2015). There is also an emphasis on including features that siblings value based on their first-hand experiences. The three most commonly reported needs or desires of siblings are: a need to have a safe place, free of guilt and judgment, to discuss their thoughts and feelings with those who share a common experience, a desire to understand how other siblings cope with challenging situations, and fun (Carter et al., 2015; Dougherty et al., 2014; Gettings et al., 2015; Kryzak et al., 2015; Letourneau et al., 2012; Puttick, 2011; Roberts et al., 2016). Sib Kinnect is structured in terms of participants and strategic parent involvement to provide an environment where siblings feel comfortable and secure sharing and receiving information about their distinct challenges and personal perspectives. Fun is paramount to the success of Sib Kinnect. Most activities are meant to be enjoyable and interactive. Some activities are more serious or contemplative, but these will be introduced later in the program when participants are more familiar and comfortable with each other.

In addition to designing Sib Kinnect around major themes from the evidence-based literature, the program is also theoretically guided by Social Cognitive Theory

(SCT), and uses an occupational therapy lens to support siblings' wellness and behavior changes. Occupational therapy has distinct value that is appropriate for delivering services to siblings through a telehealth delivery method. The incorporation of meaningful activities as a means to learn a related skill or perform the actual skill through supported practice, as opposed to structured discussions or presentations, is the main approach that occupational therapists use (American Occupational Therapy Association, 2014b). For example, in an illusion activity, participants may be asked to complete a task while each of them is hindered in some way. One participant must wear a blindfold and another can only speak two words each minute. Through participation in the activity, participants gain a deeper understanding of the frustrations their brothers or sisters might encounter when trying to accomplish a seemingly simple task. Improved sibling relationships may then help them cope with challenging situations involving their siblings because they are less likely to internalize problems (Morgan, Shaw, & Olino, 2012). Alternatively, participants may be given a scenario and asked to choose a coping skill, and then role play how they would use the skill in such a scenario. In this activity, they are improving their coping skills by actually using the skill in a situation where the skill would be realistic and relevant. Participation in activities (or occupations) is a foundational element of occupational therapy that is prominently embedded within Sib Kinnect to help siblings increase their skills and knowledge.

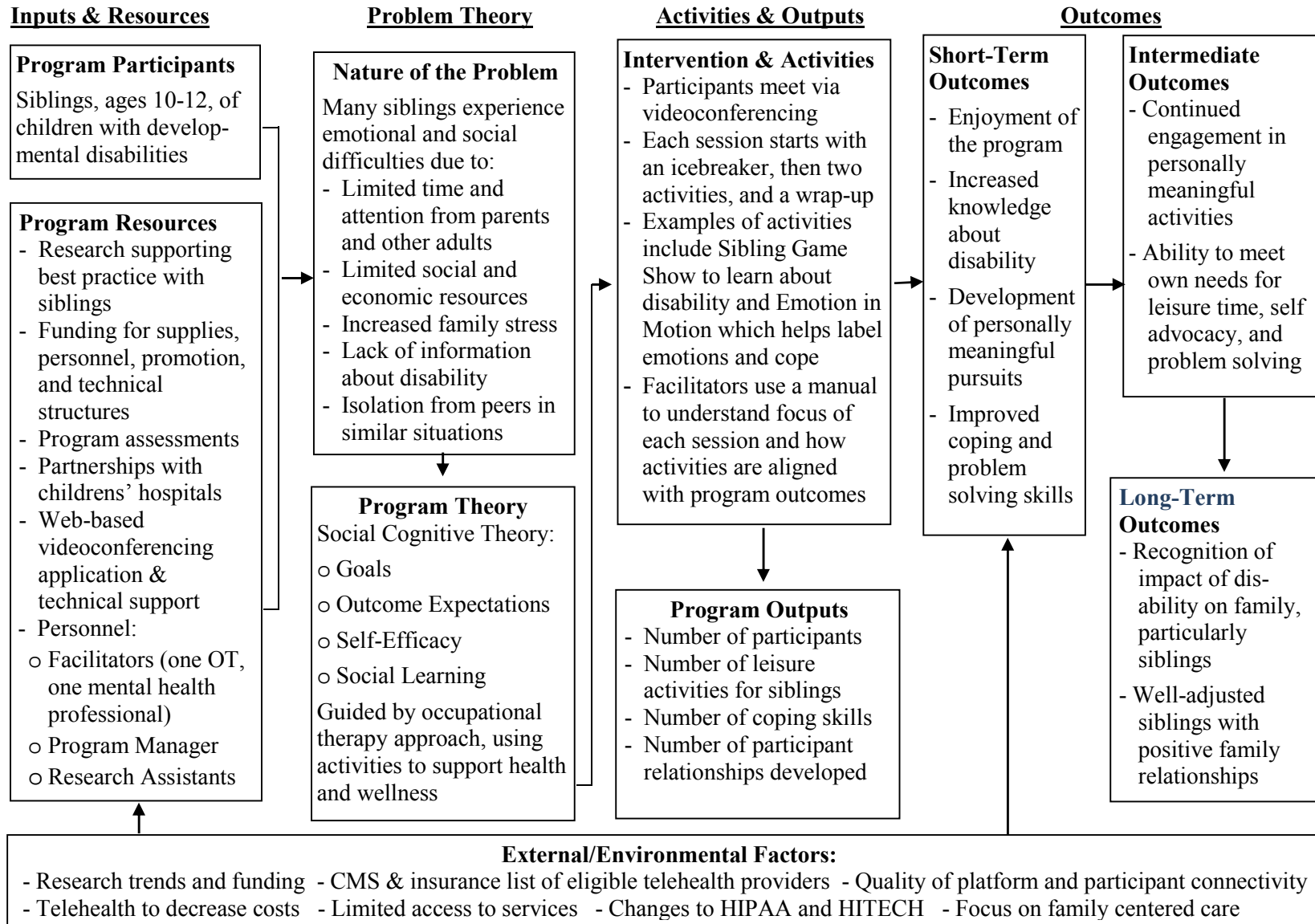
In order to effectively implement Sib Kinnect, the program personnel will use a manual that provides detailed explanations of each session along with the reasoning behind the activities and how they fit with the theoretical and evidence base. Each

activity focuses on a particular outcome and uses a variety of methods such as role playing or trivia to impart the concepts. The manual will also provide guidance on operational aspects of bringing about Sib Kinnect such as the financial plan, funding, and dissemination of program information. The financial plan is based on a budget template for the first two years, with personnel and technology being the largest expenses. Ways to offset costs of the program include using volunteers for basic administrative work and partnering with organizations who share common goals. There are several potential funding options including government grants, private foundations, and technology donations. Disseminating information about the program is imperative to recruit appropriate participants, attract potential partners, and share lessons learned and successes from Sib Kinnect. Messaging will be tailored to audiences to address their respective concerns and priorities. For example, parents of potential participants may want to know the level of commitment required and the format of the program while potential funders may want to understand how the goals of Sib Kinnect match with their organization's mission and current objectives.

Evidence from previous efforts to support siblings, theoretical guidance, and well designed activities are all key pieces of Sib Kinnect. Operational considerations such as budget, staffing, and targeted communications are necessary to bring the ideas and approaches of Sib Kinnect to fruition. The value of Sib Kinnect is that it reaches those whose needs are often unaddressed in a manner that is accessible and largely based on actual sibling experience. It is the first of its kind to bring together a group of siblings using telehealth services (videoconferencing technology). The aim of Sib Kinnect is to

provide siblings with services they might not otherwise encounter in a way that respects their needs and gives them support, skills, and joy in their current family scenarios and future experiences as a sibling of a child with a disability

APPENDIX A: Sib Kinect Approach (Logic Model)







APPENDIX B: Sib Kinect Outcomes, Theoretical Approach, and Connection to Activities

Sib Kinect is a program designed to support siblings of children with disabilities through a telehealth approach. The program is designed to help siblings enhance their overall emotional wellbeing and feeling of connectedness through four main outcomes: enjoyment, increased knowledge about disability, development of personally meaningful pursuits, and improved coping and problem solving skills.





Sib Kinect uses the Social Cognitive Theory (SCT) as the guiding theoretical approach to bring about these outcomes. SCT suggests that people are more likely to make changes in their behavior if they have more positive expectations about potential outcomes and their ability to enact those changes (self-efficacy). Social learning is another important part of SCT that posits that observing the actions and eventual outcomes of others can positively influence one's views about outcome expectations and their own self-efficacy.

As you go through the manual you will notice that each activity is aligned with specific outcomes and aspects of SCT. Every activity has the potential to support every outcome, but aligning the activities with primary outcomes helps facilitators to understand why certain activities are included and where facilitators should focus their attention. The following key will denote the outcomes and SCT focuses.

Outcomes

-  Enjoyment
-  Increased Knowledge About Disability
-  Development of Personally Meaningful Pursuits
-  Improved Coping and Problem Solving Skills

Aspects of Social Cognitive Theory




-  Goals
-  Self-Efficacy
-  Outcome Expectations
-  Social Learning

APPENDIX C: Week 2 – Activity 2: Game Show!

Description:

There will be three ‘Game Show ‘ activities throughout the eight-week program and week 2 is the first of those. This ‘Game Show’ will be about disability in general, as opposed to specific diagnoses of the siblings’ brothers and sisters, which will be featured in a later session.

Outcome & Approaches:

-  Enjoyment
-  Increased Knowledge About Disability
-  Social Learning

Set Up:

1. Before the session begins, upload the ‘Game Show Week 2’ power point to your computer and/or the web application.
2. By clicking through the power point you will be able to play the game. The questions and answers are in the correct order.

During the Session:

Playing the Game

1. Group the participants into two teams and have each team develop a team name and spokesperson by using the group chat windows.

2. Explain that this game is about disability in general and simply for fun. Everyone will have the opportunity to learn and participate regardless of team outcome.
3. Once a question is posed to the two teams, the teams will have the opportunity to type in their chat window and decide on the answer. The team that is the first to answer correctly gets the point.
4. There are 20 questions. Check in with the team scores after every five questions. You can make the last few questions part of a bonus round to increase the fun and even up the scores.

Discussion Following Game

1. What was something new that you learned?
2. Was anything surprising to you?
3. Do you disagree with any of the 'correct' answers?
4. How did you feel when you read these questions? Happy, sad, or frustrated? Did any questions make you feel stronger than the others?

Facilitation Focus:




- This is the second week of the group. Participants are very new to each other still. Therefore the discussion may be superficial or slow – that's okay!
- Use the participants' own comments to facilitate further conversation. Make sure everyone feels comfortable and included. Be ready to provide examples or supporting comments to make sure that siblings who share personal stories feel safe.

APPENDIX D: Week 4 – Activity 1: Emotion in Motion

Description:

Using the dry-erase board and markers from the Sib Kinnect Kit, the siblings will respond to stories about siblings like themselves at home and school. This is a chance for siblings to name the emotions they feel and then discuss how they would handle the situation if they were unsatisfied with the story.

Outcome & Approaches:

-  Improved Coping and Problem Solving Skills
-  Self-Efficacy
-  Social Learning

Set Up:

1. Before the session begins, post a message to remind the participants to have their Sib Kinnect Kits available during the session.
2. Open up the power point labeled Week 4_Activity 1. There is only one slide in this power point, which provides a list of emotions. This can be shared on the side screen throughout the activity.
3. Open up the Word document labeled Week 4_Activity 1. This document has the four brief stories that the facilitator will use along with directions on where to pause.

During the Session:

Playing the Game

1. Read the first part of the story and have the participants right down three emotions (on the white board) that come to mind after hearing the first part of the story. Instruct participants to hold up their boards so everyone can see.
2. Read the second part of the story that details how the sibling in the story handled the situation.
3. Again, have the participants right down three emotions (on the white board) that come to mind after hearing the second part of the story.
 - a. If they are positive emotions, discuss why the solution worked. Help label the coping skills and problem solving skills used.
 - b. If they are unhappy with the outcome, have each sibling right down a short phrase that describes what they would do. Discuss their ideas and label the coping skills and problem solving skills used.
4. Repeat this process for the next three stories as well.

Facilitation Focus:

- These are the first discussions to go into more personal scenarios. Help siblings to label the emotions and strategies so they can be referred to at a later time. To further the discussion, ask others if they have tried a strategy posed by another sibling. Make sure to discuss the outcomes to further social learning.
- The second activity of this week will focus on developing leisure activities. It is possible that a sibling will mention that they handle their frustration or another

challenging emotion by doing something they enjoy. If not, bring that up as an example or ask who has used such a strategy.

APPENDIX E: Example Survey Questions

Sibling Questions:

1. I enjoyed attending Sib Kinect sessions.

Circle one: Strongly Agree, Agree, Undecided, Disagree, Strongly Disagree

2. I now know more about my sibling's disability.

Circle one: Strongly Agree, Agree, Undecided, Disagree, Strongly Disagree

3. What would you have liked to talk more about?

Parent Questions:

1. I noticed a change in the way my child deals with challenging situations

Circle one: Strongly Agree, Agree, Undecided, Disagree, Strongly Disagree

2. I enjoyed seeing my child participate in the program.

Circle one: Strongly Agree, Agree, Undecided, Disagree, Strongly Disagree

3. Given your observations and conversations with your child, what parts of the program were most beneficial? Least beneficial?

APPENDIX F: Sib Kinnect Budget for Years One and Two

	Month 1	Month 2	Month 3	Month 4	Month 5	Month 6	Month 7	Month 8	Month 9	Month 10	Month 11	Month 12	Year 1
Personnel													
Facilitator: OT				2200	2200	2200				2200	2200	2200	13200
Facilitator: Mental Health				2200	2200	2200				2200	2200	2200	13200
Program Manager	4400	4400	4400	4400	4400	4400	4400	4400	4400	4400	4400	4400	52800
Research Assistant 1							800	800	800				2400
Research Assistant 2							800	800	800				2400
													84000
Technology													
Videoconferencing	40	40	40	40	40	40	40	40	40	40	40	40	480
Personnel Notebook Computers (5)	2500												2500
Participant Notebook Computers (3)	1500												1500
Survey Tools	25	25	25	25	25	25	25	25	25	25	25	25	300
Personnel Technology Stipend	50	50	50	150	150	150	100	100	100	150	150	150	1350
Participant Technology Stipend				400			400			400			1200
													7330
Supplies													
Sib Kinnect Kit (8 participants)				200					200				400
Office Supplies	400												400
Promotional Materials	300												300
													1100
Total Expenses	9215	4515	4515	9615	9015	9015	6565	6165	6365	9415	9015	9015	92430

	Month 1	Month 2	Month 3	Month 4	Month 5	Month 6	Month 7	Month 8	Month 9	Month 10	Month 11	Month 12	Year 2
Personnel													
Facilitator: OT	1100	2200	2200			1100	2200	2200		1100	2200	2200	16500
Facilitator: Mental Health	1100	2200	2200			1100	2200	2200		1100	2200	2200	16500
Program Manager	4400	2200	2200	4400	2200	4400	2200	2200	4400	4400	2200	2200	37400
Research Assistant 1				800	800				800				2400
Research Assistant 2				800	800				800				2400
													75200
Technology													
Videoconferencing	40	40	40	40	40	40	40	40	40	40	40	40	480
Survey Tools	25	25	25	25	25	25	25	25	25	25	25	25	300
Personnel Technology Stipend	150	150	150	100	100	150	150	150	100	150	150	150	1650
Participant Technology Stipend	400					400				400			1200
													3630
Supplies													
Sib Kinect Kit (8 participants)	200					200				200			600
Office Supplies	400												400
Promotional Materials	300												300
													1300
Total Expenses	8115	6815	6815	6165	3965	7415	6815	6815	6165	7415	6815	6815	80130

APPENDIX G: Potential Sources of Grants

Grant Name	Purpose	Contact Details	Range of Awards
U.S. Department of Agriculture Rural Development Distance Learning and Telemedicine Grants (United States Department of Agriculture and Rural Development, 2016)	Helps rural communities use the unique capabilities of telecommunications to connect to each other and to the world, overcoming the effects of remoteness and low population density.	<ul style="list-style-type: none"> • dltinfo@wdc.usda.gov • (202) 720-0800 	<ul style="list-style-type: none"> • Grant-only funds, awarded through a nationally competitive process – 15% match required • Awards can range from \$50,000 to \$500,000
Telehealth Network Grant Program (Office for the Advancement of Telehealth, 2015)	Demonstrate how telehealth programs and networks can improve access to quality health care services in rural, frontier, and underserved communities.	<ul style="list-style-type: none"> • Carlos Mena • cmena@hrsa.gov • 301-443-3198 	<ul style="list-style-type: none"> • Seeking innovative applications that meet new and emerging needs in a changing health care delivery system • 20 grants totaling \$6,000,000
Community Responsive Grant Program (The Wellmark Foundation, 2016)	Support nonprofit organizations or community groups in Iowa that develop, implement and enhance local wellness and prevention projects with a focus on long-term sustainability.	<ul style="list-style-type: none"> • Wellmarkfoundation@wellmark.com 	<ul style="list-style-type: none"> • Three different grants offering \$10,000, \$25,000, and \$75,000 • Project duration from 12-24 months
Oregon Health Authority Telehealth Pilot Project Grants (Oregon Health Authority, 2014)	Fund innovative projects that support the State's health care system transformation efforts.	<ul style="list-style-type: none"> • Meredith Guardino • guardino@ohsu.edu 	<ul style="list-style-type: none"> • Project period of 15-16 months • Budgets of up to \$75,000
The California Wellness Foundation Bridging the Gaps in Access and Quality Care (California Wellness Foundation, 2016)	All Californians, particularly those most vulnerable, should have access to quality health care services. To achieve this, our health care systems and organizations must be strong, equitable and effective.	<ul style="list-style-type: none"> • Info@calwellness.org • (818) 702-1900 	<ul style="list-style-type: none"> • Organizations may submit more than one application for different geographic areas • The average grant amount is between \$120,000 and \$200,000 over three years

APPENDIX H: Executive Summary

The evidence-based literature clearly states that being a ‘sibling’ should not be treated as a diagnosis with a universal set of experiences and outcomes (Angell et al., 2012; Emerson & Giallo, 2014; Giallo et al., 2014; Tudor & Lerner, 2015). Siblings of children disabilities have a wide range of experiences. Some siblings and their parents report that having a brother or sister with a disability helped them to develop empathy, achieve personal growth, and improved familial relationships (Williams et al., 2010). Others report negative manifestations such as feelings of isolation and inequity, difficulty in school, and behavior problems, or a complex combination of positive and negative outcomes and emotions (Goudie et al., 2013; McCullough & Simon, 2011; Tichon, 2015).

Not surprisingly then, the extent to which siblings of children with disabilities are negatively impacted, as compared to siblings of typically developing children, remains unclear (Emerson & Giallo, 2014; Giallo et al., 2014; Goudie et al., 2013; Neely-Barnes & Graff, 2011). However, the evidence-based literature consistently notes that many siblings experience emotional and social difficulties, even if those are due to issues secondary to having a sibling with a disability such as low socioeconomic status and poor family functioning (Neely-Barnes & Graff, 2011). Tudor and Lerner (2015) combine these sentiments when suggesting that, “Together, the overall risk for sibling maladjustment is not yet well-specified, but the potential for siblings being in need of clinical services remains evident. Converging evidence shows that, many (though not all) siblings may experience an elevated rate of specific problems, such as behavioral and

psychological impairments” (p. 2). This is where Sib Kinect comes into play.

Sib Kinect is a program designed to support siblings, ages 10-12 years old, of children with developmental disabilities using a telehealth approach, specifically videoconferencing. The program is designed according to evidence-based literature on sibling needs and desires, current and previous efforts to support siblings, and the use of telehealth with pediatrics. Social Cognitive Theory (SCT) provides theoretical grounding for the program. SCT posits that individuals learn from their own experiences as well as observing the actions and eventual outcomes of others. Additionally, people must believe they have the power to enact change, or self-efficacy, in order for it to come about (Ramirez et al., 2012). The degree of self-efficacy the sibling has impacts their ability to make changes, or meet their goals, because it feeds their positive or negative outcome expectations (Plotnikoff et al., 2013).

Regarding sibling needs, they most commonly report a desire to have a safe place, free of guilt and judgment, to discuss their thoughts and feelings with those who share a common experience, a desire to understand how other siblings cope with challenging situations, and have fun (Carter et al., 2015; Dougherty et al., 2014; Gettings et al., 2015; Kryzak et al., 2015; Letourneau et al., 2012; Puttick, 2011; Roberts et al., 2016).

Research suggests that the main factors negatively impacting siblings are limited time and attention from parents and other adults, limited social and economic resources, increased family stress, lack of information about disability, and isolation from peers in similar situations (Gettings et al., 2015; Giallo et al., 2014; Goudie et al., 2013; Granat et al., 2012; McCullough & Simon, 2011; Tudor & Lerner, 2015). Sib Kinect aims to

address these needs and decrease the financial and emotional burden on families by using videoconferencing to host a group of siblings who can participate in enjoyable activities that support them and provide a unique experience, just for them.

The two main methods of supporting siblings represented in the literature are asynchronous online support groups and face-to-face support groups (Kryzak et al., 2015; McCullough & Simon, 2011; Roberts et al., 2016; Tichon, 2015). Siblings highly valued the opportunity to share their honest feelings without judgment or guilt in online support groups (Tichon, 2015). The most salient outcomes from participation in face-to-face support groups are increased social support, improved emotional and behavioral wellbeing, improved self-esteem, and increased knowledge about disability (Carter et al., 2015; Gettings et al., 2015; Granat et al., 2012; Hartling et al., 2014; Kryzak et al., 2015; Roberts et al., 2015; Tudor & Lerner, 2015).

Telehealth, particularly the use of videoconferencing, has been effective in providing support to children and adolescents dealing with various health conditions (Dougherty et al., 2014; Jacobson & Hooke, 2015; Letourneau et al., 2012; Santos et al., 2014). Young people generally prefer treatments offered via technology and showed comparable, and sometimes superior, outcomes when using telehealth as compared to face-to-face treatments (Boydell et al., 2014; Dougherty et al., 2014; Letourneau et al., 2012).

The activities in Sib Kinect are designed to support the four outcomes of the program, which are gleaned from this compilation of evidence-based literature. The outcomes are: increased knowledge about disability, development of personally

meaningful pursuits, improved coping and problem skills, and enjoyment of the experience (Carter et al., 2015; Gettings et al., 2015; Granat et al., 2012; Hartling et al., 2014; Kryzak et al., 2015; Puttick, 2011; Roberts et al., 2016). The goal is for these outcomes to bolster an overall enhancement of emotional wellbeing and connectedness. The facilitation of the activities will be done by two program facilitators, an occupational therapist and a mental health professional. The program facilitators, along with a program manager, who will handle the operational components, will use a manual that details the reasoning behind the program's approach, participant selection, activity focuses, and how SCT guides session outcomes.

The manual will also include guidance and templates for operational components such as budgeting, funding sources, approaches to partnerships, and evaluation plan. The effectiveness of the program will be assessed by an evaluation plan with three components: administration of the Coping Strategies Inventory (CSI) which will be used as a sibling pre- and post-test, a 'knowledge check' that will function as a pre- and post-test specific to disability knowledge of the siblings, and an online survey that will be accessed by siblings and parents following the program.

Sib Kinnect is for the siblings whose needs can go unnoticed or become deprioritized when a family is dealing with the challenges that disability may present (Gettings et al., 2015; Giallo et al., 2014; Goudie et al., 2013). Weekly meetings over an eight week period allow them to participate in activities that provide education about disability and coping skills, opportunities to discuss their concerns and thoughts with those who understand, exploration of interests and pursuits that are meaningful to them,

and perhaps most importantly, fun. Sib Kinect aims to support siblings in a forum that is meaningful and accessible to them so that they are better prepared to manage and confidently engage in the unique experiences that make up their lives.

APPENDIX I: Sib Kinnect Fact Sheet

Please see following page.



Sib Kinnect

Using telehealth to support the unique needs of siblings of children with disabilities

Leslie Hill, MS, OTR/L, OTD Candidate

“Together, the overall level of risk for sibling maladjustment is not yet well specified, but the potential for siblings being in need of clinical services remains evident. Converging evidence shows that, many (though not all) siblings may experience an elevated rate of specific problems, such as behavioral and psychological impairments” (Tudor & Lerner, 2015, p. 2).



Image credit: wallpaperscraft.com

Sibling Reported Needs and Desires:

- Safe place for honest discussion
- Connection with other siblings
- Time for their interests and fun!

(Carter et al., 2015; Dougherty, Lipman, Hyams, & Montgomery, 2014; Gettings et al., 2015; Kryzak et al., 2015; Letourneau et al., 2012; Roberts et al., 2016)

Main Factors Influencing Sibling Adjustment:

- Limited time/ attention from parents and adults
- Limited social and economic resources
- Increased family stress
- Lack of information about disability
- Isolation from peers in similar situations

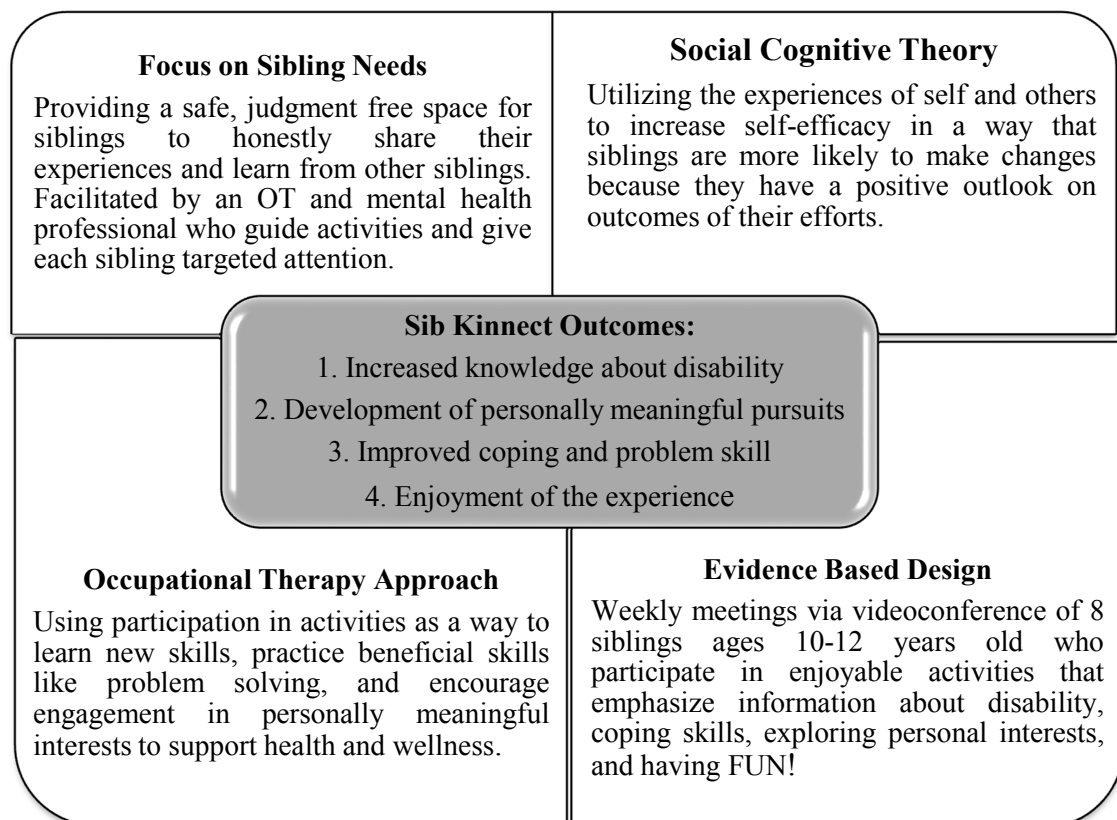
(Gettings, Franco, & Santosh, 2015; Giallo et al., 2014; Goudie et al., 2013; Granat, Nordgren, Rein, & Sonnander, 2012; McCullough & Simon, 2011)



Image credit: <https://www.gov.mb.ca>

Approximately 60% of studies looking at sibling wellness reported manifestations of increased risk for negative outcomes, 30% reported no increased risk, and 10% reported both negative and positive effects. (Williams et al., 2010)

Sib Kinect Program Approach



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CURRICULUM VITAE

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FORMAL EDUCATION

O.T.D.	Doctor of Occupational Therapy Boston, University, Boston MA	September 2016
M.S.	Master of Science in Occupation Therapy Boston University, Boston MA	May 2014
B.S.	Bachelor of Science in Business Administration Kansas State University, Manhattan, KS	December 2003

CREDENTIALS

Crisis Prevention and Physical Interventions Perkins School for the Blind	August 2015 - present
Registered Occupational Therapist National Board for Certification in Occupational Therapy	February 2015 - present
Therapeutic Crisis Intervention Concord Area Special Education Collaborative	October 2014 - present
Adult and Pediatrics First Aid/CPR/AED American Heart Association	May 2014 - present

LICENSED

Licensed Occupational Therapist Commonwealth of Massachusetts Division of Professional Licensure	April 2015 - present
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POSITIONS HELD

Occupational Therapist August 2015 - present
Perkins School for the Blind, Lower School Program

- Responsible for evaluation and intervention for students ages 5 – 15 years old who have multiple disabilities and medical conditions, including visual impairments.
- Provide interventions that support participation in school day activities including academics, self-care skills, and social interactions.
- Collaborate with teachers and other related service providers to facilitate student progress and independence.

PROFESSIONAL SOCIETY AND ORGANIZATION MEMBERSHIPS

American Occupational Therapy Organization
Phi Theta Epsilon, Omicron Chapter

HONORS AND AWARDS

Graduated with honors from Boston University Master of Science in Occupational Therapy.