

2019-04-16

Anxiety in Children and Youth With Autism Spectrum Disorder: Perceptions of Implementing the Facing Your Fears Program in Hospital and Community Organizations

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Berlanda, L. (2019). Anxiety in Children and Youth With Autism Spectrum Disorder: Perceptions of Implementing the Facing Your Fears Program in Hospital and Community Organizations (Master's thesis, University of Calgary, Calgary, Canada). Retrieved from <https://prism.ucalgary.ca>.
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Anxiety in Children and Youth With Autism Spectrum Disorder:
Perceptions of Implementing the Facing Your Fears Program in
Hospital and Community Organizations

by

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A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES
IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE
DEGREE OF MASTER OF SCIENCE

GRADUATE PROGRAM IN EDUCATIONAL PSYCHOLOGY

CALGARY, ALBERTA

APRIL, 2019

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FYF IMPLEMENTATION

Abstract

The Facing Your Fears (FYF) program is a family-centered intervention designed to teach children and youth with ASD strategies to reduce co-occurring symptoms of anxiety. The present study explored the process of implementing the FYF program through the perceptions of facilitators and managers in either a hospital setting or community organization, in addition to determining the treatment outcomes for participants who completed FYF. Sixteen facilitators and managers were interviewed regarding their perceptions of the compatibility, complexity, relative advantages, barriers, challenges, and adaptations that arose during implementation. Overall, facilitators and managers from both organizations reported that FYF had good compatibility with their organization, implementation of FYF was not too complex, and members of each organization reported advantages that were related to their setting. Facilitators and managers reported barriers and challenges that were organized into four theme-categories: system-level, intervention delivery, logistics, and individual and family. Adaptation themes directly reflected the barriers and challenges that each organization encountered when implementing FYF, as modifications were needed to be made to the intervention as well as the organization structure to overcome the difficulties of implementing an evidence-based intervention into clinical practice. Despite these modifications, both parent and child reported symptoms of anxiety, in addition to social responsiveness changed post intervention. Factors that may have impacted changes in anxiety symptoms, such as increased understanding or awareness of anxiety, are discussed in more detail. These findings provide foundational knowledge to the understanding of the strengths and challenges of implementing FYF in clinical practice across different settings. Additionally, knowledge gained from the current project may be beneficial and useful for future

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facilitators and managers to consider when preparing to implement and implementing FYF within their organization.

Keywords: implementation research, autism spectrum disorder, ASD, anxiety, Facing Your Fears, intervention

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Preface

This thesis is original, unpublished, independent work by the author, L. Berlanda. The data collected and reported in this study were covered by Review Ethics Board (REB) Certificate number REB17-1711 (Modification 3), issued by the University of Calgary Conjoint Health Ethics Board for the project “Anxiety in Children and Youth with Autism Spectrum Disorder” on March 6, 2018.

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Acknowledgements

I have been fortunate to work with many innovative researchers, but it has been an exceptional pleasure to learn from someone who whole-heartedly dedicates herself to improving the lives of others through research. Dr. Carly McMorris has provided an abundance of inspiration and guidance throughout the process of this study, and I am very grateful for all her support. Dr. McMorris also has a talent for bringing together many brilliant emerging researchers, and I am indebted to the ENHANCE Lab team for their thoughtful discussions, feedback, and suggestions. In particular, I would like to acknowledge the meticulous efforts of Stephanie Howe, Jessica Baraskewich, Rachel Pagaling, and Clare Song for reviewing all the data in this study. Lastly, I recognize that implementation research is not possible without the initial creation of an evidence-based intervention, and so I thank Dr. Judy Reaven and her esteemed colleagues for their hard work in supporting children and youth with autism and anxiety.

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Dedication

This work is dedicated to the health care professionals who have laboured tirelessly to research, organize, and implement the most current interventions and best practices to support families. I hope this information is useful in your endeavours.

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Chapter 1: Introduction

Implementation research is an emerging field that examines how evidence-based interventions are delivered in different settings, and how variables from different contexts impact implementation (Proctor et al. 2009). For example, context-specific variables that support successful interventions, such as program facilitators or resources, may vary across settings and create a gap between optimal implementation and realistic implementation (Proctor et al. 2011). Focusing on the factors that affect implementation can help to minimize the gap between research and clinical practice, and allow interventions to be more versatile when implemented in new settings (Proctor et al. 2011).

The current implementation research study examines Facing Your Fears (FYF; Reaven et al., 2009, Reaven et al., 2012), an evidence-based intervention designed to help children and youth with autism spectrum disorder (ASD) learn to cope with symptoms of anxiety. The study explores how the FYF intervention is implemented within a hospital organization and a community organization through first-hand reports from people who implemented the program. Intervention facilitators and managers were interviewed to understand their perceptions and experiences of FYF implementation. Information gathered from facilitators and managers was structured according to the framework of diffusion of innovation theory (DIT), which examines the compatibility, complexity, and relative advantage of FYF. Participants were also asked to provide their perceptions of the barriers, challenges and mutual adaptations involved in implementing FYF within their organization. These perceptions were then coded into themes and organized by case classifications, such as type of organization, profession, and education level. Additionally, in order to contextualize facilitator perceptions of FYF, the study also includes intervention outcomes for participants related to changes in their social responsiveness and

anxiety symptoms. Post-intervention outcomes measured by the Social Responsiveness Scale – Second Edition (SRS-II; Constantino & Gruber, 2012) and the Anxiety Scale for Children – Autism Spectrum Disorder Version (ASC-ASD; Rodgers et al., 2016) were used to explore the impact of the intervention with the understanding that other factors such as self-awareness may impact participant responses (Ozsivadjian, Hibberd, & Hollocks, 2013; Walsh et al., 2018).

The overall goal of the project was to gather first-hand information about implementing FYF in different settings to understand how FYF was currently used in clinical practice, and explore the advantages, barrier, and challenges for this particular intervention. This information may ultimately serve as a tool for future facilitators and managers when considering their own setting, and help organizations anticipate advantages or challenges of implementing the FYF program within their organization.

Chapter 2: Literature Review

Autism Spectrum Disorder

Autism spectrum disorder (ASD) is characterized by qualitative impairments in the functioning of social communication, as well as the presence of restrictive and repetitive behaviours and interests (American Psychological Association [APA], 2013). Autism spectrum disorder is a neurodevelopmental disorder in the Diagnostic and Statistical Manual of Mental Disorders – 5th Edition (DSM-V), as the disorder becomes present during the developmental period (APA, 2013). There are two primary diagnostic criteria for ASD. First, impaired social interaction and ability to communicate, such as social-emotional reciprocity, nonverbal communication, and maintaining social relationships (APA, 2013). Social interactions require the recognition, understanding and organization of various social cues, and individuals with ASD struggle with simultaneously processing multiple cues in their environment (Cunningham & Schreibman, 2008). The second criterion is restricted and repetitive behaviours and interests, such as repetitive motor movements, insistence on sameness, intense interest in specific topics, and sensory sensitivity (APA, 2013). Some of these symptoms may appear in other neurodevelopmental disorders, such as repetitive behaviours or language impairment within intellectual disability disorder or social communication difficulties, but ASD diagnosis requires evidence of significant impairment affecting function in both symptom areas (Whitten, Unruh, Shafer, & Bodkin, 2018).

According to the Centers for Disease Control and Prevention (CDC; CDC 2018), ASD occurs across all types of racial, ethnic and socioeconomic groups, but Caucasian children are more frequently identified with ASD than African-American or Hispanic children. Furthermore, males are 5 times more likely to be identified than females (CDC, 2018), and the estimated ratio

of prevalence for boys to girls is approximately 5.2:1 (Ouellette-Kuntz, Coo, Yu, & Lewis, 2012). The prevalence of ASD within Canada is difficult to pinpoint as local numbers may vary across communities; however, in a recent report, it was estimated that 1 in 66 school age children in Canada are diagnosed with ASD (Ofner et al., 2018). Globally, ASD is estimated to affect 62 in 10,000 children (Elsabbagh et al., 2012). Prevalence rates of ASD have increased over time (e.g., 123% reported increase in the United States between 2002 and 2012; CDC, 2014), and it is unclear if the increase is due to in-migration and identification, or a true increase in incidence (CDC, 2018; Elsabbagh et al., 2012; Ouellette-Kuntz et al., 2014).

Mental health and other neurodevelopmental disorders often co-occur with ASD, including depression, attention deficit hyperactivity disorder and intellectual impairment (APA, 2013; Grofer Klinger, Dawson, Barnes, & Crisler, 2014); however, anxiety is the most common comorbid mental health disorder, and has been examined extensively in this population over last 20 years (Simonoff, 2008; Vasa, Keefer, Reaven, South, White, 2018). Kerns and Kendall (2012) reviewed the high prevalence of anxiety among children and youth with ASD, and there were no studies in which 100% of participants presented with both ASD and comorbid anxiety, suggesting that anxiety may not be a phenomenological characteristic of ASD. However, other researchers have speculated that some symptoms of ASD, such as repetitive movements may occur as a response to feeling overwhelmed or anxious (White, Oswald, Ollendick, & Scahill, 2009a).

Many types of treatment have been created for children and youth with ASD aimed to support the development and attainment of specific skills. For example, intensive behavioural intervention that incorporates principles of applied behaviour analysis (ABA) can be effective for improving daily living, social, and language skills, especially when implemented as early as

possible for the child (Virués-Ortega, 2010). Behavioural interventions may improve daily functioning, but it does not completely ameliorate the disorder, and so the aim of many treatments is to reduce specific symptoms or comorbid disorders to both reach the optimal outcome. For example, evidence-based social skills programs are commonly used to treat social skills deficits (Kaat & Lecavalier, 2013). Some treatments may include medication, which can have adverse effects, but there are approved pharmacological treatments for symptoms such as irritability and comorbid disorders such as anxiety (Cohen et al., 2013, King et al., 2013). It is important to note that behavioural interventions are led by trained health professionals not primary caregivers, although some interventions may incorporate some caregiver training, such as skill development for managing challenging behaviours (Reaven, 2011). Supporting the development of daily living skills for children with ASD can be very challenging for caregivers, and they seek intervention and treatment assistance through local hospitals, health care agencies, and community organizations (Klinger, Dawson, Barnes, & Crisler, 2014). Lastly, cognitive behavioural therapy (CBT) is also an effective treatment to help children and youth with ASD and comorbid disorders attain skills that can improve their daily functioning (Lang, Regeher, Lauderdale, Ashbaugh, & Haring, 2010; Moree & Davis, 2010; Reaven et al., 2009; Reaven et al., 2012).

Anxiety Disorders in Youth without ASD

Anxiety is one of the most prevalent mental health issues in children and youth, as an estimated 6.5% of children and youth worldwide experience anxiety, and approximately 3.1% of children in Canada access mental health support for anxiety each year (McRae, O'Donnell, Loukine, Rancourt, & Pelletier, 2016; Polanczyk, Salum, Sugaya, Caye, & Rohde, 2015).

Anxiety disorders are characterized by excessive fears and worries that cause impairment in

daily occupational, academic, and social functioning (APA, 2013). Clinically significant anxiety occurs when fear (i.e., feeling of anticipated danger) and worry (i.e., uncontrollable negative thoughts and feelings) are persistent, frequent, and out of proportion with the actual situation, and significantly interferes with daily functioning (APA, 2013). Typical symptoms of anxiety in childhood can be mental (e.g., difficulty concentrating), physical (e.g., muscle tension), or emotional (e.g., irritability; APA, 2013). Children who struggle with internalizing disorders such as anxiety may conceal their symptoms from peers and adults, which contributes to the under diagnosis and lack of support for anxiety disorders, despite a high prevalence (Haller, Cramer, Lauche, Gass, Dobos, 2014; Polanczyk et al., 2015). The impact of these anxiety disorders creates substantial impairment for not only the child in areas such as school performance, social functioning and peer relationships, but can also affect larger systems surrounding the child, such as family relationships, the need for school support, or community resources (Jongerden, Simon, Bodden, Dirksen, & Bogels, 2015; Poole, Van Lieshout, McHolm, Cunningham, & Schmidt, 2017). Childhood anxiety disorders also predict adult anxiety disorders and major depression later in life (Achenbach, Howell, McConaughy, & Stanger, 1995; Shanahan, Zucker, Copeland, Bondy, Egger, & Costello, 2015).

The development of childhood anxiety disorders can be influenced by genetic, temperamental, environmental, neurobiological, psychosocial, and familial factors (Higa-MacMillan, Francis, & Chorpita, 2014). Contextual risk factors in childhood, such as parental psychopathology, poor child-parent attachments, unpredictable living environments, and negative social interactions, can interact with pre-existing biological factors, such as poor hypothalamic-pituitary-adrenal axis regulation (Higa-MacMillan, Francis, & Chorpita, 2014; Pantis et al., 2015). The presence of anxiety disorder in childhood increases the risk of

developing other mental health difficulties such as mood disorders, aggression, oppositional defiant disorder, and substance use disorder (Clark, Rodgers, Caldwell, Power, & Stansfeld, 2007; Dallaire & Weinraub, 2007; Higa-McMillan, Francis, & Chorpita, 2014; Woodward & Fergusson, 2001).

Anxiety Disorders in Youth with ASD

Some children may have a higher risk of developing anxiety, especially if they have existing physical and mental health issues, and developmental issues, including ASD (Strang, et al., 2012). In a review of the comorbidity of ASD and anxiety symptoms (van Steensel, Bogels, & Perrin, 2011), almost 40% of youth with ASD had at least one comorbid anxiety disorder, including specific phobia (29.8%), OCD (17.4%) and social anxiety disorder (16.4%). The impact of anxiety for individuals with ASD is associated with increased difficulties in personal, social, and family functioning (van Steensel et al, 2011; White et al., 2009a; Kerns et al., 2014).

Historically, anxiety symptoms have been observed among children with ASD, as noted by Kanner in his original description of children with ASD (Kanner, 1943). In recent times, the reported prevalence of anxiety among individuals with ASD ranges between 11-84%, although prevalence may be affected by sampling and assessment methods (Kerns & Kendall, 2012). For example, whereas the prevalence of anxiety symptoms in community-based samples of children with ASD was between 11-42%, anxiety symptoms were between 14-59% for samples taken from a clinical or hospital treatment setting (Kerns & Kendall, 2012). Differences between these samples may be due to the use of different assessment or diagnostic measures, or higher severity of symptoms for individuals in treatment settings, and may reflect different service needs between community and hospital settings (Kerns & Kendall, 2012).

The manifestation of anxiety in children and youth with ASD can vary in presentation due to specific characteristics of ASD. For example, some children may appear to be anxious about routines, but others can be more flexible with support, or some children may be distressed about social situations, while others do not appear concerned or interested (Baron-Cohen, 2006; Kerns et al., 2014; White & Roberson-Nay, 2009). Unique phenomenology of anxiety associated with characteristics of ASD includes sensory anxiety, intolerance of uncertainty, and phobias related to the sensory processing abnormalities, restrictive and repetitive behaviours, and impairments in social functioning (Bellini, 2004; Green & Ben-Sasson, 2010; Rodgers, Glod, Connolly, McConachie, 2012; Wigham et al., 2015). Differential diagnosis is necessary to understand if symptoms that appear to be related to ASD (e.g., repetitive behaviours) may be exhibited to reduce anxiety (i.e., coping strategy), or to prevent a feared event (i.e., compulsion), which should be addressed in treatment (Kerns et al., 2014; Leyfer et al., 2006). Additionally, difficulties in differential diagnosis exist as some manifestations of anxiety seem paradoxical according to what we know about ASD. For instance, children who show limited interest or awareness of social interactions can experience distress, nervousness, and avoidance in social situations, thus the social anxiety contradicts the social deficits found in ASD (Kerns & Kendall, 2012; Leyfer et al., 2006; White & Roberson-Nay, 2009).

While there is no consensus on the phenomenology or construct of anxiety and ASD, some researchers suggest that the presentation of anxiety depends on factors such as intelligence, language ability, symptoms or severity of ASD (Kerns & Kendall, 2012; White et al., 2009). Kerns et al. (2014) examined anxiety in children and youth with ASD and found that 17% of families reported traditional anxiety (i.e., consistent with DSM-V definitions of anxiety), 15% reported atypical anxiety (i.e., inconsistent with the DSM-V), 31% reported both traditional and

atypical symptoms of anxiety, and 31% reported no anxiety. Traditional anxiety, such as generalized worries or separate anxiety, appears to be unrelated to symptoms of ASD (Kerns et al., 2014; White et al., 2009). Kerns et al. (2014) found that traditional anxiety is associated with negative cognitive style, language ability, and hypersensitivity, and not intelligence or severity of ASD. Atypical anxiety is related to an underlying worry that manifests in a domain that is salient to the child, such as a core symptom of ASD (Kerns et al., 2014; Kerns & Kendall, 2012). For example, difficulties with interpreting social situations and social cues is a symptom of ASD, and negative social interactions can lead to increased anxiety about social situations, thus creating anxiety related to a symptom of ASD. Kerns et al. (2014) found that atypical symptoms of anxiety are not related to intelligence, language ability or hypersensitivity, but are associated with greater ASD severity and negative cognitive style, supporting the hypothesis that atypical anxiety occurs as a convergence of ASD and anxiety symptoms (Kerns et al., 2014; Kerns & Kendall, 2012). Kerns et al. (2014) highlights that research evidence regarding the unique presentations of anxiety among children and youth with ASD is important for differential diagnosis, but it also provides evidence that researchers and clinicians should target treatment through specialized interventions designed to address both ASD and anxiety symptoms.

Symptoms of anxiety can vary throughout child development, and can affect how anxiety manifests and how it should be treated (Kerns & Kendall, 2012). The research on development and anxiety for children with ASD is inconsistent, as some researchers have found no relationship with age (Sukhodolsky et al., 2008; White & Roberson-Nay, 2009). However, some anxiety has been reported to start around 3-5 years of age when ASD symptoms begin to appear (Gadow et al., 2005). Anxiety that appears concurrently with ASD may be inherently different from anxiety that manifests later in childhood or elevates as awareness and age increases (Davis

et al, 2011). For example, Gadow and colleagues (2005) found that 12% of children with ASD showed elevated level of social anxiety compared to 5% of toddlers with ASD (Gadow, DeVincent, Pomeroy, & Azizian, 2004), possibly reflecting an increase in social awareness or evaluation concerns. There is evidence that the trajectory of increasing anxiety continues for adolescence, as Kuusikko and colleagues (2008) social avoidance and fear of negative evaluation increased in youth 8-15 years old. Severe social anxiety symptoms including social avoidance, inhibition, and social discomfort characterized youth with high-functioning ASD, as it is speculated that youth are aware of their own impaired social skills, which increases their self-consciousness and behavioural withdrawal. Therefore, treatments for anxiety for this population should consider how age differences might impact the presentation of symptoms, and be able to support children and youth at their specific developmental stage (Alfano, Beidel, & Turner, 2006).

Cognitive Behaviour Therapy (CBT) in Children without ASD

Cognitive behaviour therapy (CBT) is an evidence-based intervention designed to reduce anxiety, and it has been found to be an effective treatment for anxiety disorders in children and youth in the general population (Hollon & Beck, 2013; James, James, Cowdrey, Soler, & Choke, 2013; Olatunji, Cisler, & Deacon, 2010; Reynolds, Wilson, Austin, & Hooper, 2012). CBT commonly involves psychoeducation about the disorder as evidence based coping skills and problem-solving skills (Beck, 2011; Briers, 2015; Kendall et al., 2006). The coping skills are necessary to help clients engage in a process of cognitive restructuring, meaning that they are able to purposefully change their thoughts to improve positive self-talk and reduce cognitive distortions such as exaggerated or polarized thinking (Beck, 2011; Briers, 2015). Cognitive techniques alone are not sufficient to reduce anxiety, thus behavioural techniques such as

graduated exposure to situations that are feared or avoided, are also an important component of CBT, but should not be engaged until the individual has learned adequate coping skills (Beck, 1991; Beck 2011; Briers, 2015; Ellis, 1991; Joyce-Beaulieu & Sulkowski, 2015).

The use of CBT is considered to be the gold standard for treatment of anxiety as several randomized, controlled trials (RCTs) have generated empirical support for the efficacy of CBT over active education (Kendall, Hudson, Gosch, Flannery-Schroeder, & Suveg, 2008), therapy treatment without CBT (Olatunji, Cisler, & Deacon, 2010), and pill placebo (Beidel et al., 2007). Walkup et al (2008) found that approximately 60% of children in their study showed improvement with CBT alone, compared to 55% of children who received medication alone (i.e. sertraline). Although the percentages may appear to be similar, maintenance of these improvements is often greater after CBT is completed than after medication treatment is terminated, as the goal of CBT is for individuals to be able to continue using their coping skills once treatment is complete (Beck, 2011; Briers, 2015). Lastly, CBT treatment for children and youth with or without ASD is available through different settings, such as hospitals and community organizations, but currently there is limited research comparing the quality or delivery of evidence-based interventions across contexts.

CBT for Children with ASD

CBT interventions are often manualized protocols that can be slightly altered as needed to best support individual needs, such as unique characteristics of ASD. There is ongoing research regarding the efficacy of reducing anxiety with CBT for children and youth with ASD, and several RCTs have been conducted with positive results (Chalfant, Rapee, & Carroll, 2007; Reaven et al., 2012; Sofronoff, Attwood, & Hinton, 2005; White et al., 2013; Wood et al., 2015; Storch et al., 2013; Sung et al., 2011). This project focuses on the Facing Your Fears (FYF)

program, a CBT intervention developed by Reaven et al. in 2009, but it is worth noting that there are other CBT programs designed for anxiety and ASD. The *Exploring Feelings* program (McConachie et al., 2013) focuses on recognition of anxiety and somatic feelings, and how to develop physical, social and cognitive coping strategies, but it does not include many other fundamental CBT strategies. Two programs that do include common behavioural CBT techniques such as relaxation training, cognitive restricting, and social skills development, are the *Multimodal Anxiety and Social Skills Intervention* (MASSI; White et al, 2009) and the *Behavioural Interventions for Anxiety in Children with Autism* (BIACA; Wood et al., 2009). Both the MASSI and the BIACA programs use an evidence-based manual to standardize implementation, but the manuals for both programs are only accessed through a training workshop, and are not widely available like the FYF manual (Reaven, Blakeley-Smith, Nichols, & Hepburn, 2011; White et al, 2009; Wood et al., 2009). Only the BIACA and FYF programs include the creation of exposure hierarchies, which allows children and youth to overcome worries through graduated exposure to fears, making it one of the most useful and powerful activities in CBT (Reaven et al., 2009; Wood et al., 2009). Wood and colleagues have found positive results for reducing anxiety using the BIACA program (Wood et al., 2009; Wood et al., 2015), but the program has more sessions than FYF and less accessible due to training restrictions, which can limit the usability and implementation of the program.

Facing Your Fears

Facing Your Fears (FYF) is an adapted CBT intervention for youth aged 7 to 14 years old with ASD and anxiety (Reaven, Blakeley-Smith, Culhane-Shelburne, & Hepburn, 2012; Reaven, Blakeley-Smith, Nichols, & Hepburn, 2011). Depending on the participants, groups are often separated into a younger and older group based on developmental similarities and creating better

group cohesion (Reaven et al., 2009). The program recognizes the role of both parents and youth in learning how to manage anxiety, and is guided by a facilitator over the course of 14 weekly sessions (Reaven et al., 2011). The 1.5-hour sessions initially focus on the basics of CBT and anxiety, and then transition to how parents and youth can effectively use the strategies in everyday life (Reaven et al., 2011). The FYF program also incorporates a booster session 4-6 weeks following the end of the intervention to help participants maintain skills (Reaven et al., 2012) and generalize to other settings (e.g., home and school). Parent involvement is particularly important within the intervention as Reaven acknowledges parenting factors such as psychoeducation, child encouragement, parental anxiety, and communication challenges that can impact the parent-child relationship (Reaven, 2011). Therefore, the sessions are structured to include large-group activities (parents and children combined), small-group activities (parent group separate from child group), and parent-child partner activities (Reaven et al., 2012).

The FYF program was initially developed as a pilot study, and Reaven et al., published the study in 2009. The original study was designed with adaptations to specialize the program for children and youth with ASD (Reaven et al., 2009). Reaven and colleagues (2009) found that although there was a clinically significant decrease in parent reported child anxiety; there wasn't a clinically significant change in child reported anxiety. The authors speculated that children with ASD may report higher anxiety as a result of gaining a better understanding and awareness of their own anxiety through the intervention, and thus more research is needed to understand the long-term impact of FYF (Reaven et al., 2009; Reaven et al., 2012). However, Reaven and colleagues (2012) conducted a RCT study with blinded independent clinical evaluators measuring changes in Clinical Severity Ratings, diagnostic status, and global improvement, and found significant group differences between the FYF group and the treatment-as-usual control

group (Reaven et al., 2012). Reaven and colleagues note in the pilot and RCT studies that group-based, manualized CBT interventions have the advantage of making treatment more readily available by minimizing waitlists for treatments, and incorporating parents increases the likelihood that changes will be sustainable (Reaven et al., 2009, Reaven et al., 2012)

The FYF program was originally created in the United States, but the intervention has also been implemented successfully in Canada (Reaven et al., 2014). Clinicians from a health center in Halifax, Nova Scotia received 2.5 days of training from two authors of the FYF program, and successfully implemented the program with high treatment fidelity, increased knowledge of CBT, and meaningful decreases in participant-reported symptoms of anxiety (Reaven et al., 2014). The researchers found that the FYF program demonstrates initial effectiveness and transportability in new clinical settings (Reaven et al., 2014). Most studies about the FYF program are conducted in a hospital or clinical setting, with the addition of a modified FYF program conducted in a school-based setting (Drmic, Aljunied, & Reaven, 2017), and there is currently no research examining the implementation of FYF in a community setting.

Many FYF facilitators receive formal training through workshops delivered by the authors of the FYF program, but as FYF is a widely available manualized program, facilitators may have a varied level of training or experience, and may provide the program through various types of organizations with diverse resource availability. Recently, Reaven et al. (2018) have found that clinicians who receive FYF training workshops or workshops plus ongoing consultation significantly increased their knowledge of CBT compared to clinicians who did not receive a workshop and relied solely on the manual for the FYF content (Reaven et al., 2018). All clinicians obtained satisfactory treatment fidelity, but clinicians who received workshops had significantly higher fidelity ratings and better quality of implementation (Reaven et al., 2018).

Nevertheless, youth participants reported significant decreases in anxiety symptoms across all groups, indicating that participant improvement is possible regardless of formal training as long as there is sufficient treatment fidelity (Reaven et al., 2018).

Facilitators. Research on the training and background of facilitators has implications for community organizations, as the standards for training and experience may vary in these settings. For example, in a recent study of FYF in Singapore (Drmic, Aljunied, & Reaven, 2017), psychologists trained allied educators (learning and behaviour support staff) to be facilitators for a school-based version of the FYF program. The allied educators had some experience supporting youth with ASD, but very little CBT experience when they initially participated in a 3-day training workshop delivered by the study authors (Drmic, Aljunied, & Reaven, 2017). It is important to note that the allied educators had received the formal FYF training, and were not relying on the manual alone. Adaptations to the manualized program were needed to account for the facilitator, setting, and cultural factors that varied from the original FYF protocol; however, results from the study were promising as students with ASD ($n = 35$) demonstrated a clinically meaningful decrease in anxiety symptoms (Drmic, Aljunied, & Reaven, 2017).

Following the completion of FYF, Drmic, Aljunied, and Reaven (2017) conducted a review session to allow facilitators ($n = 33$) to reflect on their experience and identify successes and challenges when implementing this adapted FYF program. Themes from the session were qualitatively analyzed (Drmic, Aljunied, & Reaven, 2017). The factors that were identified as facilitating the implementation of FYF included: strong and consistent support from stakeholders; joint planning sessions for facilitators; appropriate and meaningful resources adapted to the setting; identification of students who are motivated; optimal structure of FYF sessions (e.g., small group format); and skilled facilitators with prior experience who can help to

carry out the program (Drmic, Aljunied, & Reaven, 2017). Many of the facilitating factors are within the control of facilitators to optimize, such as organizing and scheduling joint planning sessions, and developing appropriate adaptations to ensure the intervention was a good fit for the school setting. It is also interesting that prior experience was identified as a facilitating factor, as this could motivate facilitators to continue building experience and capacity in delivering the FYF program. Understanding the factors that can be actively planned or modified by facilitators can lead to better implementation and problem prevention (Stahmer, Collings, & Palinkas, 2005).

Drmic, Aljunied, and Reaven (2017) also analyzed the themes that arose as barriers to the implementation of the FYF program in this school setting. The seven main barriers included: scheduling difficulties and delays in program delivery; lack of parental support (e.g., parent reluctance to talk about child's fear); child readiness for intervention (e.g., readiness to discuss fear); difficulty selecting fear and creating exposure hierarchy; absence of locally-developed resources; more knowledge and skills required for implementation (e.g., group management and CBT knowledge); and logistics and person power problems, such as needing additional facilitators for school-based exposure practices (Drmic, Aljunied, & Reaven, 2017). Many of these barriers were beyond the control of facilitators, such as school events that disrupted sessions, lack of facilitators for exposures, and parent/child reluctance to participate. Drmic and colleagues (2017) acknowledged and incorporated the feedback about barriers to continue optimizing the FYF program. The findings from this study need to be interpreted with caution, as the feedback and findings from this study may be context specific, as it would be expected that feedback from other settings, such as community settings, could yield different results.

The researchers found that a major component of promoting the long-term sustainability of an intervention is ongoing collaboration with key stakeholders throughout the intervention

process (Drmic, Aljunied, & Reaven, 2017). Furthermore, important factors for initial implementation and sustainability of the FYF program were identified as: ongoing support from administrators and decision-makers; a strong advocate for the program; alignment of FYF with existing organization philosophy, goals, programs, and policies; ongoing consultation and quality professional development; procedures for staff turnover; evident/identifiable treatment outcomes; and appropriate financial resources to support program delivery, such as cost of materials (Drmic, Aljunied, & Reaven, 2017; Forman et al., 2009; Owens et al., 2014).

Limited research is available regarding how facilitator background (e.g., profession, level of education, and years of experience) may impact FYF implementation, although there is promising evidence that suggests adequate treatment fidelity of FYF supports implementation regardless of experience (Drmic, Aljunied, & Reaven, 2017; Reaven et al., 2018). At the time of this study, no research existed (to our knowledge) about how facilitators and organization directors perceive the implementation process, or first-hand reports of the challenges and strengths of the FYF program in various settings. Treatment for anxiety could be more readily available for children and youth with ASD if FYF could be implemented in a variety of settings, such as through hospitals, clinics, and community organizations. More CBT treatment availability could increase accessibility for many families, as Pickard and colleagues (2018) found that families of children with ASD and low socio-economic status or underrepresented racial and ethnic minorities had disproportionately limited accessibility to treatment. Therefore, ongoing implementation research is needed regarding the delivery of CBT interventions such as the FYF program for children and youth with ASD and anxiety (Reaven et al., 2018).

Implementation Research

Interventions can be evaluated for their effectiveness by examining characteristics of the implementation. The success of a CBT intervention depends on how well it is delivered by facilitators in a suitable environment, which requires systematic monitoring and evaluation of the program implementation – otherwise known as implementation research (Proctor et al. 2009). Implementation research aims to minimize the gap between research and practice by evaluating methods and approaches that increase intervention success when it is implemented in different settings (Proctor et al., 2011). Fixsen and colleagues (2009) describe implementation research as examining the process of “Science to Service.” The “Science” and research that goes into creating an evidence-based intervention typically occurs within contrived conditions supported by a university or research institution, and a transition process is needed for the intervention of “service” to maintain its integrity under new conditions, such as in a community-based setting (Fixsen, Blase, Naoom, & Wallace, 2009). The FYF program is an example of an evidence-based intervention that is currently in the process of “Science to Service,” and many of the transition challenges have already been identified by Drmic and colleagues (2017) when the FYF program was implemented in a school-based setting, but more research is needed to understand how to achieve a high quality of “service” in a community-based setting.

Intervention practices for supporting children and youth with ASD in community-based settings have been researched in light of the high demand for family and individual support (Stahmer, 2007). Unfortunately, “youth with ASD do not always receive [evidence-based interventions] in community settings where they most often receive treatment” (Wood, McLeod, Klebanoff, & Brookman-Frazee, 2015, p. 83). The lack of evidence-based interventions in community services can limit the youth’s potential to learn skills that improve their quality of

life (Brookman-Frazee, Taylor, & Garland, 2010; Marriage, Wolverton, & Marriage, 2009; Wood, McLeod, Klebanoff, & Brookman-Frazee, 2015). To address the lack of evidence-based interventions in community settings, Stahmer, Collings, and Palinkas (2005) collected information in focus groups from service providers (e.g., psychologists and special educators) who deliver interventions to children with ASD in community settings. One key finding from the results of the focus group is that service providers had a limited understanding of what can truly be considered “evidence-based practices,” and what is necessary to ensure evidence-based interventions are properly implemented, such as with training and fidelity. Service providers shared that they often use both evidence-based and non-evidence-based techniques in their interventions, as they modify the techniques based on the child, personal strengths, and other external factors like funding and support (Stahmer, Collings, & Palinkas, 2005). It was also noted that adequate training for interventions was not always available, or not available for the assistants or aides who help with interventions, which service providers acknowledged as a possible shortfall in their ability to provide high quality interventions (Stahmer, Collings, & Palinkas, 2005). These experiences could align with the challenges that facilitators may face when delivering FYF in community settings. The FYF program follows a standardized protocol that differs from interventions that allow for adaptation and use of non-evidence-based techniques (Stahmer, Collings, & Palinkas, 2005). Therefore, more evidence is needed to understand if the FYF program can undergo a process of adaptation in order to be successfully implemented in novel settings.

Leonard-Barton’s (1988) framework of implementation highlights that the initial implementation process is important to examine as it is an extension of the original invention process and involves the first steps of mutual adaptation. An intervention created for one setting

undergoes change due to the mutual adaptation that occurs when the intervention has to be slightly adapted to fit a new setting, and the organization has to adapt to accommodate the new intervention (Leonard-Barton, 1988; Pérez, Van der Stuyft, del Carmen Zabala, Castro, & Lefèvre, 2015). As the initial implementation period involves mutual adaptation, it is often a more challenging period for facilitators, and can prevent intervention sustainability if implementation barriers are not addressed (Pérez et al., 2015). Therefore, by examining the perceptions related to mutual adaptation, facilitators in the present study will be providing insight about the barriers and adaptations needed to understand how FYF can best support children and adolescents with ASD and anxiety in both community and hospital settings.

Dingfelder and Mandell (2011) advocate that “researchers should plan for sustainability by examining implementation during the study and determining what supports or modifications are necessary for [the autism intervention] to continue after the study ends” (Dingfelder & Mandell, 2011, p. 606). Currently, there is no research examining the barriers and mutual adaptations of FYF in a community-based setting using both the qualitative report of facilitators and measurable intervention outcomes. Furthermore, there is no research that compares the implementation of FYF between community-based and hospital organizations, to determine how implementation is affected by different settings. This information is essential for community-based organizations whom wish to implement FYF, and can be used to provide accountability and evidence to local boards and stakeholders.

Implementation research involves measuring outcomes that are “conceptually and empirically distinct from those of service and treatment effectiveness” (Proctor et al., 2011, p. 30). Key implementation outcomes are identified by Proctor and colleagues (2011), which include acceptability, adoption, appropriateness, feasibility, fidelity, implementation costs,

penetration, and sustainability. For example, treatment acceptability is commonly measured by researchers in many FYF studies, and is associated with treatment outcomes, as higher acceptability ratings were predictive of lower post-intervention anxiety levels (Walsh et al., 2018). Fidelity would be undertaken and monitored by facilitators, and may depend on the facilitator's level of training. The FYF studies involve rigorous treatment integrity, often with observers monitoring sessions, or video-recordings reviewed by program developers (Drmic, Aljunied, & Reaven, 2017; Walsh et al., 2018). Implementation outcomes highlight the advocacy and management needed by managers, administrators, stakeholders and even regional or provincial boards, as they make many of the decisions around adoption, appropriateness, feasibility, implementation costs, and sustainability (Proctor et al., 2009). Although system-level decisions such as allocation of resources and funding may be at the discretion of organization directors, it is more effective if it is based on the feedback and need specified by facilitators who are front-line service providers (Proctor et al., 2011). Implementation research qualitatively examines the process through the actual experiences of people involved directly (e.g., facilitators) and indirectly (e.g., managers) with the intervention (Palinkas et al., 2011; Proctor et al., 2009; Proctor et al., 2011). This information is essential for understanding how to best deliver an intervention given real-world challenges and barriers (Proctor et al., 2009). In order to collect data on the implementation of the FYF program, it is necessary to address how the research project will conceptualize and evaluate program success (Proctor et al., 2011). Therefore, research on implementation should follow an evidence-based theory, such as the diffusion of innovation theory, to ensure the information is systematic and generalizable within the field, and there are clear indicators of successful implementation (Dingfelder & Mandell, 2011).

Diffusion of Innovation Theory. Diffusion of innovation theory (DIT) examines the process by which a new innovation is shared or communicated across a social system over time (Rogers 2010). The process includes four stages of dissemination, adoption, implementation, and maintenance (Rogers, 2010). These stages reflect the process of “Science to Service,” in which the intervention is disseminated beyond the academic community through modes such as publication, training workshops, and conferences (Rogers, 2010). The intervention is then adopted by community organizations and implemented with some degree of mutual adaptation (Pérez et al., 2015; Rogers, 2010). Finally, the intervention is maintained by the organization if it is sustainable and meets the organization’s standards of a valuable intervention (Rogers, 2010). DIT has been adopted within ASD research to explore why effective ASD interventions are often not implemented in public mental health or education systems (Dingfelder & Mandell, 2011). The underlying theory of DIT is that the adoption, implementation, and maintenance of interventions depend on the “perceived fit between the intervention and the needs and capacities of the setting” (Dingfelder & Mandell, 2011, p. 597). The focus is on the perceptions of the facilitators and organization directors, and what impacts whether an intervention is implemented. Therefore, DIT can be used to explore the perceptions of service providers to better understand the barriers and benefits of particular interventions (Dingfelder & Mandell, 2011).

Some studies about ASD services in the community have started to use the DIT framework. For example, Pickard, Kilgore, & Ingersoll (2016) used DIT in community partnership research to explore the barriers in parent-mediated intervention for ASD in a Medicaid system. Parent and facilitator focus groups were conducted to understand perceptions of compatibility, complexity, and relative advantage of the intervention in under-resourced community settings (Pickard, Kilgore, & Ingersoll, 2016). Participants indicated that they

appreciated flexible program delivery, less complexity in written materials, a strong parent-therapist relationship, involving extended family, and helping families integrate strategies into pre-existing routines (Pickard, Kilgore, & Ingersoll, 2016).

This type of information may also be useful to know in regards to the specifics of the FYF program. Within the four DIT stages, the most influential characteristics are compatibility, complexity, and relative advantage, and they are considered to address “structural determinants of innovation” in health service organizations (Greenhalgh, Robert, MacFarlane, Bane, & Kyriakidou, 2004, p. 591; Rogers, 2010). For example, examining compatibility can help administrators determine if the innovation (i.e., intervention) will be a good fit within the structure of the organization, and compatibility may need to be considered for scheduling, space availability, or client needs (Greenhalgh et al., 2004; Rogers, 2010). The complexity of the program may prevent success in some settings if the intervention is too challenging for facilitators to deliver or too difficult for participants to complete (Greenhalgh et al., 2004; Rogers, 2010). Finally, the relative advantage is a structural determinant as it addresses the degree to which the intervention is perceived as better than those previously implemented or other interventions that are currently available. For example, an organization may consider the relative advantages of implementing the FYF program instead of the BIACA program, and the relative advantage may be the accessibility of the program manual.

Rationale

Research to date has contributed to a strong, evidence-based foundation for the FYF program, but ongoing research is needed to explore new possibilities for implementing FYF. The current research project is designed to explore implementation of the FYF program as guided by the framework of DIT. In addition to the compatibility, complexity, and relative advantages

presented in DIT, information about the barriers and mutual adaptations that occur when implementing the FYF intervention could also contribute to ongoing research regarding FYF. Exploring implementation from the frontline of facilitators and managers who are directly responsible for delivering the FYF intervention can provide information about how to minimize the gap between research and clinical practice. The primary aim of this project is to gather information from facilitators and managers about their experience implementing the FYF program in a hospital organization, as well as a community organization. Treatment outcomes for participants will also be considered in understanding the outcome of implementation. However, the main focus of the present study is to understand the perceptions of facilitators and managers so that future organizations can gain insight when preparing to implement FYF. Implementation research for the FYF program can help organizations increase the availability of services for children and youth with ASD and anxiety.

Chapter 3: Research Methodology

Research Questions

The following research questions will be used to examine the implementation of FYF in a community and hospital setting. Question 1 is guided by DTI and explores perceptions of compatibility, complexity and relative advantage. Question 2 explores the barriers and mutual adaptation that occurs when FYF is implemented in two different settings. Question 3 examines the treatment outcomes of FYF participants.

1. What are the perceptions of facilitators and managers regarding the implementation of FYF as guided by the framework of DIT? Participants will be asked to provide their perception of the compatibility, complexity, and relative advantage of FYF within their organization during the initial implementation period. To minimize research bias, this first question is exploratory, and aims to describe the perceptions of facilitators and managers, rather than compare perceptions between settings. Although exploratory, it is expected that some perceptions will align with those previously reported in the literature by facilitators and service providers (e.g., Drmic, Aljunied, & Reaven, 2017; Pickard, Kilgore, & Ingersoll, 2016)
 - a. What are the differences in perceived compatibility, complexity, and relative advantages of facilitators and managers between community and hospital settings? It is hypothesized that the organization's unique attributes within each setting will impact the perceptions of facilitators, and contribute to unique perspectives on the characteristics of diffusion of innovation.
 - b. How do the perceptions of facilitators and managers differ according to their education level (i.e., undergraduate, graduate, or doctorate), and profession (i.e.,

psychologist, occupational therapist, or social worker)? This question is designed to provide exploratory data based on the composition of facilitators in this study, and it is not associated with previous research findings. It is possible that some commonalities found with subtypes of facilitators (i.e., psychologists vs. other health care professionals) may emerge through exploring secondary data related to education level and profession.

2. What are the barriers that occur during the initial implementation period of FYF in either community or hospital settings? It is hypothesized that mutual adaptation will be necessary in both settings, although the adaptations may differ as barriers are unique in community and hospital settings.
 - a. How do barriers (e.g., resources, funding, etc.) differ between community and hospital settings?
 - b. What barriers were experienced by participants in both community and hospital settings?
 - c. How do facilitators adapt FYF implementation to increase intervention compatibility within the organization and minimize barriers (i.e., mutual adaptation)?
3. Is there a clinically meaningful change in anxiety symptoms for FYF participants in both settings according to treatment outcomes measured by the *Anxiety Scale for Children - Autism Spectrum Disorder Version* (ASC-ASD; Rogers et al., 2016) and the *Social Responsiveness Scale – Second Edition* (SRS-II; Constantino & Gruber, 2012). It is expected that participants will report improvement in anxiety levels and social responsiveness, although results may be varied for some participants. The hypothesis is

based on results from a multi-site study (Reaven et al., 2018), which indicates that positive treatment outcomes are possible in different settings.

Research Design

A mixed methods design was used for this project, which incorporated elements of both quantitative and qualitative data collection and analysis (Palinkas et al., 2011). Mixed methods designs are frequently used in implementation research as it allows researchers to combine quantitative and qualitative approaches, and provides a more comprehensive understanding of the intervention than either approach alone (Robins et al., 2008). In mixed methods designs for implementation research, qualitative methods are used to explore and understand reasons for success or failure during implementation, as well as to identify strategies that increase mutual adaptation (Palinkas et al, 2011; Teddlie & Tashakkori, 2003). Furthermore, quantitative methods can be used to evaluate successful implementation based on treatment outcomes (Palinkas et al, 2011; Teddlie & Tashakkori, 2003). The present study uses qualitative and quantitative methods simultaneously, although the primary method is qualitative (i.e., interview) supported by quantitative (i.e., measured outcomes) to provide a context for understanding the success of implementation (Morse, 1991; Palinkas et al., 2011). There are several functions of mixed method designs, such as convergence (e.g., triangulation), expansion (e.g., explaining results), complementarity (e.g., evaluation), or sampling (e.g., selecting participants); however, the function of the present study is development (e.g., develop measures or interventions) as the results will lead to a better understanding of how to develop FYF in various settings (Green et al., 1989; Palinkas et al., 2011). Finally, the process of combining quantitative and qualitative data will include connecting the data by allowing the quantitative data to elaborate on the context

from which the qualitative data is gathered (Cresswell & Plano Clark, 2007; Palinkas et al., 2011).

Participants

The present study is part of a larger ongoing study: *Anxiety in Children and Youth with Autism Spectrum Disorder*, led by principal investigator Dr. Carly McMorris. All facilitators and managers involved with FYF at the hospital or community organizations were eligible to participate in the interviews as the primary sampling criterion was involvement in the FYF program, thereby creating a purposeful sample limited to facilitators and managers involved in the larger study (Marshall et al., 2008; Palinkas et al., 2013; Patton, 2002). One participant was involved in multiple roles for the intervention, (i.e., both facilitator and manager roles), and thus provided responses according to different roles resulting in a higher number of responses ($n = 18$) than participants ($n = 16$; see Appendix B). None of the facilitators or managers had previous experience implementing the FYF program. While all facilitators and managers had the opportunity to attend 2-day FYF training, one facilitator was present only for the first day, and one manager did not attend the training. The education level varied from undergraduate, graduate, and doctorate, and the professions included psychology, social work, occupational therapy, and epidemiology.

The FYF participants included ten children and youth (8-14 years old; $M = 11.5$, $SD = 2.18$), and eleven caregivers, although data for this study was only received from nine families. Inclusionary criteria for children and youth in the FYF program included: (1) 8-14 years of age; (2) previously confirmed diagnosis of ASD; (3) grade 2 reading proficiency on the Wechsler Individual Achievement Test (WIAT-III CND; Wechsler, 2009); (4) full scale IQ of 80 or higher, as measured by the Wechsler Abbreviated Scales of Intelligence (WASI-II; Wechsler,

2011), (5) significant anxiety impairing functioning at home and school, as measured by parent report on the Anxiety Disorders Interview Schedule – Autism Addendum (ADIS; Kerns et al., 2017); and (6) anxiety as the primary presenting problem. Involvement in the FYF program also required the children or youth to be able to commit to the 14-week program, function independently (i.e., without caregiver) for at least 30 minutes, and self-regulate behaviours (e.g., aggression) in order to participate in the group. Caregivers who provided data for this study (6 female, 3 male) completed an extensive in-take process and committed to participating in each session throughout the FYF program. The demographic background information for facilitators and managers, parent participants, and child and adolescent participants is reported in three tables in Appendix C, D, and E, respectively.

Children and youth participating in the FYF program were divided into three groups and numbered only for ease of reference in this study: Group 1 and 2 were both led by facilitators at the hospital setting, each contained four participants, and were divided by age, as Group 1 contained older youth (12-14 years old) and Group 2 contained younger children (8-11 years old). The results reflect missing data from one family in a hospital group. Group 3 was led by facilitators at the community setting, and initially contained three participants (13-14 years old), but participant dropout is common within new interventions and one family left the community based group after a few weeks. Targeted recruitment was used to initially identify families who may benefit from the FYF intervention based on previous involvement with clinicians at the hospital setting (Groups 1 and 2 participants). A wait list was then created that was made up of families who were not able to participate in Group 1 or 2 due to logistical issues (e.g., schedule conflict). Participants for Group 3 were then recruited from that waitlist.

Procedure

Interview. Approval for the study was obtained from the Conjoint Health Research Ethics Board at the University of Calgary. An email of initial contact was sent to all facilitators and managers by the principal investigator [C.M.] on behalf of the researcher [L.B.], and individual interview times were arranged with each participant. Participants completed a consent form, and the discussion followed the interview structure outlined in the interview guide (Appendix A). Participants also completed a background information questionnaire after the interview was complete to identify the characteristics of facilitators at different organizations, such as profession, education level, and years of experience (Appendix B). Sixteen interviews were conducted with facilitators and managers, and all interviews were conducted in person. Each interview was audio recorded, and an anonymized, verbatim transcript was created for each participant.

Treatment outcomes. Pretreatment data were obtained during a rigorous screening process that included an initial phone interview and a full in-person assessment (3 hours) with parents (e.g., observed ASD symptoms, anxiety and parental stress), children and youth (e.g., behavioural, cognitive, social-emotional, and anxiety), as well as teachers (e.g., classroom functioning and behaviours). In-depth screening was necessary to determine baseline functioning, but it was also used to ensure eligibility for the intervention (as per Reaven et al., 2011; clinically significant levels of anxiety, full scale intelligence quotient above 80, and reading skills at or above a grade 2 level. Some posttreatment questionnaires were administered immediately following the completion of the intervention, including those used in the present study; however, the full battery of measures was readministered six months after the conclusion of the intervention.

Interview

The interview format follows a descriptive, multiple-case study format to gain insight into the perceptions of facilitators and managers who implement the FYF program (Yin, 2014). The format is descriptive because it is used to “describe an intervention or phenomenon and the real-life context in which it occurred” (Baxter & Jack, 2008, p. 548). While DIT and mutual adaptation provide a framework for creating generalizable interview questions, the ultimate purpose of the questions is to allow facilitators the opportunity to describe their experience implementing the FYF program in a real-life context. The goal of multiple-case studies (i.e., multiple interviews) is to replicate findings across similar cases and predict differences between contrasting cases (Baxter & Jack, 2008; Yin, 2014). For example, there may be replicated findings within one of the FYF groups (e.g., similar barriers), but differences between groups (e.g., different resource needs). Gathering information from multiple cases diversifies the data, and increases the likelihood that the results will be applicable to a wider audience (Miles & Huberman, 1994). Each case provides a “subjective understanding” (Seidman, 1998, p. 4) of how facilitators perceived, engaged and responded to the intervention. Therefore, it is the researcher’s responsibility to conduct in-depth interviews that elicit specific opinions, reflections, and details rather than vague global statements (Kvale, 1996). The interviews become a “construction site of knowledge” when the interviewee shares experiences that are transformed into knowledge through the interaction between the interviewer and the interviewee (Kvale, 1996, p. 2).

An interview guide was created to outline the informed consent process and the interview questions. The research questions that are outlined in the interview guide were used in every interview, although some of the secondary questions may not have been asked if the participants had already addressed the question. A semi-structured interview approach was adopted to allow

the interviewer to pursue or clarify topics instigated by the interview participant, which honours the exploratory nature of qualitative data collection and allows the interviewer to remain open to new themes that may arise (Kvale, 2007). Furthermore, Kvale (2007) notes that the interviewee may also come to realize new themes or issues through the interview process that they had not previously recognized, and a semi-structured format allows the interviewer to explore new topics as they arise.

After the interview, participants completed a background information questionnaire. The participants were informed that their demographic information would not be used to identify individuals, but rather to generally describe the characteristics of groups from different organizations. The background information questionnaire included questions regarding gender, profession, years of experience, highest level of education, training, previous experience with FYF, and number of facilitators present during sessions. These questions were derived from other studies where researchers found that background and experience may influence the implementation, and may also impact facilitator perceptions (Drmic, Aljunied, & Reaven, 2017; Reaven et al., 2018). For example, a health professional without a background in psychology may find explaining the CBT portion of FYF more difficult, which could impact the facilitator's perception of the complexity of the program. Therefore, exploring background variables may offer insight into the experiences of a variety of health professionals.

Measuring Treatment Outcomes

Anxiety Scale for Children – Autism Spectrum Disorder Version. As the primary goal of the FYF program is to reduce anxiety levels among children with ASD, a tool that specifically measures anxiety in this population would be most beneficial, such as the *Anxiety Scale for Children – Autism Spectrum Disorder Version* (ASC-ASD; Rodgers et al., 2016). The ASC-ASD

was adapted for an ASD population from a previous anxiety scale (*Revised Children's Anxiety and Depression Scale*; Chorpita et al., 2000), as Lecavalier et al., (2014) cautioned that tools designed for typically developing children are not adequate for measuring anxiety among children with ASD. Therefore, Rodger et al. (2016) designed a measure to include anxiety symptoms unique to ASD such as sensory anxiety, intolerance of uncertainty and phobias (Rodgers et al., 2016). The self-report and parent forms were used in this study, and both forms contain 24 items with 4-point Likert-type scale responses. The ASC-ASD measures four subscales of anxiety, including Performance Anxiety, Uncertainty, Anxious Arousal, and Separation Anxiety. Total scores higher than 24 indicate the presence of significant levels of anxiety, and are interpreted as a clinical threshold for anxiety in this study (Rodgers et al., 2016). As the measure was designed for youth with ASD, the ASC-ASD demonstrates evidence of good reliability, including strong test-retest reliability and internal consistency with Cronbach's alpha reported to be .94 for both the parent and child version (Rodgers et al., 2016). The subscale alphas for the parent version are reported for performance (.89), separation (.87), arousal (.87), and uncertainty (.91), and the child version produced similar results for performance (.85), separation (.85), arousal (.88), and uncertainty (.88; Rodgers et al., 2016). Researchers have also found the ASC-ASD to demonstrate a strong factor structure supporting the separate subscales, adequate convergent validity, and good consistency with previous parent-reported anxiety diagnosis (Den Houting, Adams, Roberts, & Keen, 2018) making it a valuable scale to measure CBT intervention outcomes (Rodgers et al., 2016).

Social Responsiveness Scale – Second Edition. Difficulty understanding social interactions is common for children with ASD, and can lead to distress and anxiety in social situations (White, Schry, & Kreiser, 2014). The FYF program uses a group structure design to

allow children with ASD to experience novel social situations in a supportive setting that may lead to positive social skill development (Reaven et al., 2009; Reaven et al., 2012). The *Social Responsiveness Scale – Second Edition* (SRS-II; Constantino & Gruber, 2012) is a 65-item scale that measures social deficits related to ASD, and is used in this study to determine the impact of the FYF program on social responsiveness. The School-Age Form (ages 4.0 to 18.0) from the SRS-II was administered, and only the parent version was used although a teacher version is available (Constantino & Gruber, 2012). The measure is based on a 4-point Likert-type scale, and takes approximately 15-20 minutes to complete (Constantino & Gruber, 2012). The SRS-II contains five subscales: Social Awareness (i.e., ability to recognize social cues); Social Cognition (i.e., interpretation of social behaviour); Social Communication (i.e., reciprocal social interactions); Social Motivation (i.e., motivation to participate in social situations); and Restricted Interests and Repetitive Behaviour (i.e., limited interests and stereotypy; Constantino & Gruber, 2012). The raw scores can be converted to T-scores ($M = 50$, $SD = 10$), and standardization for the School-Age Form is based on a normative sample of 1,014 children (Constantino & Gruber, 2012). T-scores above 75 are considered to be severe, and thus act as a clinical threshold for anxiety in this study (Constantino & Gruber, 2012). The internal consistency is not reported for individual subscales, but the total reliability coefficient is reported to be .95 (Constantino & Gruber, 2012). In terms of concurrent validity, moderate to high correlations were found between the SRS-II and other measures of social behaviour and communication, such as the *Social Communication Questionnaire* (Rutter, Bailey, & Lord, 2003), which has been administered in previous studies on the FYF program (Bruni, 2014; Reaven et al., 2009; Reaven et al., 2018).

Data Analysis

Interview data analysis. Verbatim transcripts were created from the audio-recorded interviews, and transcripts were reviewed against the audio recordings. NVivo 12 (QSR International, 2018) is a widely used Computer Assisted Qualitative Data Analysis Software (CAQDAS) program. The software includes features such as character-based coding, rich-text, “edit-while-you-code,” and multimedia capabilities, and is designed to support work with interview transcripts, audio recordings, photographs or pictures, videos, web media, and other types of open-ended surveys and discussions (Kim et al., 2016; Richards, 2002). In general, CAQDAS has increased the accuracy, reliability, transparency and objectivity of qualitative data analysis compared to traditional methods and protocols in which researchers organize the data by hand (Gibbs, 2002; Kim et al., 2016). Within NVivo 12, coding refers to the process of gathering data by topic, theme, or case, which is then organized into nodes, whereby the node represents the containers of topics, opinions, ideas, people, or material that pertains to the relevant qualitative data (Richards & Richards, 2003). The nodes are central to how data are coded, and information can be linked within nodes to other documents or data, which is a unique feature within NVivo 12 as other programs have limited coding procedures or code retrieval functions (Gibbs, 2002; Kim et al., 2016). Cases within NVivo 12 were used to organize the participants by groups and organizations and to record demographic data from the background questionnaire. The intercoder reliability of NVivo is fixed at the character level, and reliability cannot be calculated using words, sentences, or paragraphs (Kim et al., 2016). The present study used only one coder that increased the likelihood of researcher bias, thus multiple reviewers analyzed the coded data to reduce the possibility of bias.

Analysis of the coded qualitative data was based on grounded theory methodology, with the purpose to minimize the gap between theory (i.e., DIT and mutual adaptation) and empirical research (i.e., implementing FYF) using characteristics of the information gathered from participants (Corbin & Strauss, 2008; Glaser & Strauss, 1967; Strauss & Corbin, 1990). Analytic coding for grounded theory is a process of collecting data, coding, and sorting by categories that reveal themes, while remaining open to emerging themes that may not fit pre-existing concepts (Corbin & Strauss, 2008).

The present study applied grounded theory as conceptualized by Charmaz (2006), and followed a process of coding incident-by-incident as reported by the interviewee, allowing codes to emerge from the data rather than forcing the data to fit the codes. The constant comparative method was applied to compare data from different participants and organizations to ascertain analytic distinctions and consistencies (Charmaz, 2006). Focused coding was used to synthesize larger portions of data from the transcripts, and axial coding was completed to connect categories or subcategories (Charmaz, 2006). Finally, themes were identified based on the connections or frame for analytic construction that emerged from the categories (Charmaz, 2006).

Trustworthiness. Trustworthiness and credibility of data collection within qualitative research is guided by six strategies: member checking, triangulation, prolonged engagement, negative case analysis, peer review, and an audit trail (Lincoln & Guba, 1985; Morrow, 2005). The strategies were integrated into each interview, such as providing sufficient meeting times to increase prolonged engagement, and obtaining perspectives from facilitators of all three intervention groups to increase triangulation. Member checking was utilized through reflective listening, asking for clarification or elaboration, and asking for confirmation of my interpretations of participant comments (Marshall & Rossman, 2014). Peer reviewers who are

familiar with ASD and anxiety reviewed the transcripts and shared their perceptions of the themes compared to that of the researcher. Negative case analyses was used by comparing the ratio of barriers and challenges to advantages and adaptations. The transcripts, codes, analysis, and code changes were documented for the audit trail, as well as through project event logging in NVivo 12 (QSR International, 2018).

These strategies contribute to the development of trustworthiness in qualitative research as they align with the qualitative methods of rigor (Cope, 2013; Guba & Lincoln, 1994; Lincoln & Guba, 1985; Morrow, 2005). The criteria for methods of rigor within qualitative research, with the parallel quantitative method, includes *credibility* (i.e., the truth of the data; internal validity), *dependability* (i.e., constancy of the data; reliability), *confirmability* (i.e., the data represents participant views, not researcher bias; objectivity), and *transferability* (i.e., findings are applicable to other settings or groups; external validity/generalizability), which are used in an effort to promote the scientific methodology in qualitative research (Cope, 2013; Guba & Lincoln, 1994; Lincoln & Guba, 1985; Morrow, 2005). However, some researchers argue that promoting scientific methods of rigor in qualitative research diminishes the importance of the human experience that is an intrinsic characteristic of qualitative data, and that strategies should be used to elaborate on emerging findings rather than verify or validate participant experiences (Marshall & Rossman, 2014; Morrow, 2005).

Quantitative data analysis. The reliable change (RC) was calculated in order to examine the magnitude of change that occurs for each participant throughout the intervention, and to determine if this level of change is clinically meaningful (Jacobson, Follette, & Revenstorf, 1984; Christensen & Mendoza, 1986). The RC can be used to investigate if participants experience a change after the invention in terms of (1) how much change has occurred, and (2) if

the participants' overall functioning after the intervention has improved (Jacobson & Truax, 1991). Clinically meaningful change is determined by examining if the participant's posttest score has changed from a clinical range to a more functional range by passing a clinical cutoff point (Jacobson, Follette, & Revenstorf, 1984; Christensen & Mendoza, 1986). The clinical cutoff point can be established one of two ways, depending on the information available to the researcher. The midpoint between the mean of a clinical population (i.e., ASD) and the mean of a non-clinical population (i.e., typically developing) can be used if the authors of the measure have published this information (Jacobson & Truax, 1991). The cutoff point may also be calculated as two standard deviations away from the population's mean; therefore, if a child with clinically significant anxiety demonstrates a clinically meaningful change, it means they now fall within two standard deviations of the mean (Jacobsen & Truax, 1991). The present study will calculate the cutoff point using two standard deviations from the mean, and will also examine if the post-intervention scores fall below the clinical threshold of each scale (i.e., SRS \geq 75; ASC-ASD \geq 24).

In order to determine how much change has occurred, a reliable change index is calculated using the reliability of the measure to determine a minimum value (i.e., index) for statistically significant change. The equation for the reliable change as calculated by Jacobson & Truax (1991, pp. 14) is expressed as:

$$RC = \frac{X_2 - X_1}{S_{\text{diff.}}}$$

The participant's posttest score (X_2) is subtracted by the pretest score (X_1) and divided by the standard error of difference between the two scores. Standard error of difference is expressed as

$S_{\text{diff.}} = \sqrt{2(S_E)^2}$ and standard error of measurement as $S_E = S_1\sqrt{1 - r_{xx}}$. The reliability for the

ASC-ASD and SRS-II outlined in the measures sections will be used to calculate the results for this study. Statistical significance ($p < .05$) is achieved when the RC value is equal to or greater than 1.96, as this indicates that there is less than a 5% chance (i.e., p-value) that the posttest score falls within 2 standard deviations (with error) from the pretest score, thus showing a change of greater than two standard deviations has occurred (Jacobson, Follette, & Revenstorf, 1984; Jacobsen & Truax, 1991). If facilitators report less-than-optimal conditions for implementation, examining the reliable change will reveal if it is possible to achieve clinically meaningful change even when implementation challenges are present.

Chapter 4: Results

The results of this study are presented in three sections that correspond to the research questions. The first section is a description of the qualitative data collected from facilitators and managers regarding the characteristics of DIT, and data from the same participants regarding the barriers, challenges, and adaptations is presented in the second section. The quantitative analysis of the ASC-ASD and SRS data collected from the parent, children, and youth participants is reported in the third section.

Research Question 1. What are the perceptions of facilitators and managers regarding the implementation of FYF as guided by the framework of DIT?

The results of the first research question are presented according to facilitator and manager perceptions of the compatibility, complexity, and relative advantage of the FYF program. The themes and frequency of comments are presented in table format, followed by a detailed overview of theme content.

Table 1
Themes and Frequency of Comments Related to Diffusion of Innovation Theory

Theme	No. of Comments (%)		
	Total	Hospital	Community
Compatibility	119 (10.55)	84 (100)	35 (100)
Population	34 (3.01)	21 (25.00)	13 (37.14)
Staff expertise	34 (3.01)	21 (25.00)	13 (37.14)
Philosophy or mandate	30 (2.67)	21 (25.00)	9 (25.71)
Treatment model	17 (1.51)	17 (20.24)	0 (0.00)
Physical space	4 (0.35)	4 (4.76)	0 (0.00)
Complexity	113 (10.02)	75 (100)	38 (100)
Complex cases	31 (2.75)	19 (25.33)	12 (31.58)
Resources	25 (2.22)	23 (30.67)	2 (5.26)
Manual	22 (2.22)	16 (21.33)	6 (15.79)
Content	21 (1.86)	11 (14.67)	10 (26.32)
Therapy experience	14 (1.24)	6 (8.00)	8 (21.05)
Relative Advantages	294 (26.06)	205 (100)	89 (100)
Intervention advantages	129 (11.44)	84 (40.98)	45 (50.56)
Manualized and structured	25 (2.22)	9 (4.39)	16 (17.98)

Group structure	20 (1.77)	15 (7.32)	5 (5.62)
CBT designed for ASD	20 (1.77)	14 (6.83)	6 (6.74)
Practice and repetition	18 (1.60)	14 (6.83)	4 (4.49)
Exposure-based hierarchies	18 (1.60)	14 (6.83)	4 (4.49)
Multidisciplinary	12 (1.06)	11 (5.37)	1 (1.12)
Behaviour modification	9 (0.80)	0 (0.00)	9 (10.11)
Videotaping	7 (0.62)	7 (3.41)	0 (0.00)
Family advantages	104 (9.22)	85 (41.46)	19 (21.35)
Family-centered	37 (3.28)	32 (15.61)	5 (5.62)
Parent Skills	24 (2.13)	20 (9.76)	4 (4.49)
Social support	19 (1.68)	17 (8.29)	2 (2.25)
Engaging	15 (1.33)	13 (6.34)	2 (2.25)
Individualized care	9 (0.80)	3 (1.46)	6 (6.74)
Clinician advantages	61 (5.41)	36 (17.56)	25 (28.09)
Training	29 (2.57)	22 (10.73)	7 (7.87)
Fidelity	16 (1.42)	11 (5.37)	5 (5.62)
Clinician skill development	16 (1.42)	3 (1.46)	13 (14.61)

Note: Percentage for total is based on total number of all interview comments ($n = 1,128$), and percentage for each organization (hospital or community) is based on total number of comments for each organization per characteristic of DIT.

DIT Characteristic: Compatibility. Many facilitators and managers reported that they found the FYF program to be compatible with their organization because it aligns with the population they serve, as both organizations help children and youth with ASD. Both hospital and community organizations received feedback from the local community regarding the need for intervention to support people with anxiety and ASD, so facilitators noted that FYF program was compatible with the needs of the larger ASD population. Staff expertise emerged as a theme as facilitators shared that FYF was compatible with the background or experience of staff from the organizations. Specific types of staff expertise noted by facilitators included mental health, intervention or therapy, CBT, and experience working with children and youth with ASD. Some facilitators and managers indicated that the FYF program aligned with the philosophy or mandate of both organizations, as a family-centered, strengths-based, and structured program based on core components of CBT. Additionally, every facilitator and manager indicated that

FYF is consistent with their organization's mandate for implementing interventions that have a strong evidence base, and some noted that it has been used in different provinces across the country, supporting the use of the evidence-based intervention in a Canadian context:

"I think the other thing is that it had a really strong evidence-base behind it. It was well known, it had been used in different centers, and so we were able to talk to people who had used it, and it had a really good sort of research foundation. Because again, part of it is assuring that anything we're introducing has that evidence-base as well as a clinical kind of experience that shows it is a good fit for families" (Manager).

As a treatment model, some facilitators highlighted that FYF was compatible with their organization as it provided a framework for introducing treatment to their organization, and helped to shift from an assessment-only model to an assessment-and-treatment model, as it provides a framework for introducing treatment. Finally, it was noted that the FYF program was compatible with the existing physical space of the organizations.

DIT Characteristic: Complexity. Overall, FYF was reported to be a fairly straightforward intervention to deliver if the facilitator was knowledgeable and had experience in the best practice for implementing interventions or therapy. Facilitators reported that the manual was very easy to understand and follow; however, some facilitators noted that following the manual was challenging at times due to the large amount of content to deliver in each session. Similarly, facilitators indicated that it was unclear how much flexibility or consistency with the manual is allowed before treatment fidelity is compromised. Furthermore, they indicated that the content becomes more complex when applied due to complicated family dynamics, and that supporting families to bring the content into practice was not straightforward:

“I don't think that the manual itself or FYF does a nice job of being able to allow for process to happen. When I say process, I mean just families being able to talk about barriers or talk about things that they were struggling with, or where their own parental mental health got in the way” (Facilitator).

It was also noted that the adolescent participants presented with more complex mental health issues than those participants in the younger child group. Consequently, such mental health issues were factored into the treatment and exposure hierarchies, making these treatment components more complex. Therefore, facilitators found that prior therapy experience was an asset when tackling complex issues that arose during treatment sessions. Other areas of complexity reported by facilitators included resources and technology, such as the number of resources needed for the FYF intervention compared to other interventions which do not require props and cameras for exposures. Lastly, the most frequently discussed theme for complexity is that the participants represented a complex population. Many facilitators described the participants as “complex cases” (i.e., both mental health issues and neurodevelopmental disorder), making it hard to target one aspect of functioning without the complexity of other disorders affecting the outcome: *“And as I said, maybe it's more the population than it is the intervention, but I feel like they kinda go hand-in-hand, like you can't parse out the complexity of the population that we're working with from what we need to address in the intervention”* (Facilitator).

DIT Characteristic: Relative Advantages. A large number of relative advantages were reported by the facilitators; therefore, three categories were created to organize the types of themes: 1) relative advantages of the intervention; 2) family advantages; and 3) clinician advantages. Regarding intervention, facilitators who had prior intervention experience spoke

about the advantages of using FYF compared to other CBT interventions. The formatting of the intervention was reported to be an advantage, that is, being a manualized, structured program gave facilitators a step-by-step process to make the CBT concepts more accessible for families. Having facilitators from multiple disciplines was also identified as an advantage, as it provided unique perspectives on content delivery:

“I think the multidisciplinary facilitators does bring some unique perspectives. I wondered at times if it presented us with a little bit of challenge in some ways, but overall, I think it really offers a lot of people seeing things in a different way or from their disciplines lens that I might not have noticed or thought about as much. So I think in the way we delivered it, that has been helpful” (Facilitator).

The group structure of FYF was reported to be more economical than one-to-one therapy sessions for organizations, and provided opportunities for social interactions and peer relationships to develop. The booster session and intensive nature of sessions were identified as advantages for session structure, as well as the amount of practice and repetition built into the sessions. Many facilitators recognized that a major strength of the intervention was that it is specifically designed for children and youth with ASD. This includes the use of behaviour modification strategies and reinforcements, which aligns with many other types of applied behavioural programs that have been shown to be effective in children with ASD. It was also noted that not all CBT interventions focus on exposure-based hierarchies and practicing exposures in session, but the amount of time allotted for practicing and recording exposures was an advantage for FYF. One participant shared their experience with exposures:

“I think compared to other anxiety groups that I've done, there was more opportunities for in-session exposures. So I think we spent five weeks doing in-session exposures, and

so lots of opportunities for the kids to get exposures, for the facilitators to observe the parents coaching their kids through exposures. Lots of opportunities to discuss, developing hierarchies and problem solving with parents and looking forward to the future and developing new hierarchies. So I think that's an advantage, because previous groups you maybe spent two sessions doing in-session exposures” (Facilitator).

A major advantage identified by families was the family-centered approach integrated throughout the FYF program, which allowed for both parent and child skill development. The group format allowed for parents to work with their child/youth, but also for parent-only and child-only groups, creating time to develop relationships with peers who have similar experiences. Many facilitators noted that even though it is a group intervention, there were opportunities to provide individualized care to families, especially with the use of exposure-based hierarchies. Facilitators also reported that the FYF program was very fun and engaging for families, and there was a lot of laughter, peer support, and encouragement in each session. One facilitator described how she felt the program was engaging:

“I think the way it’s designed it’s a really appealing and engaging program where kids and parents are enjoying coming. It makes a huge difference, I don't think it feels as much like sessions. It's hard work but it's wrapped in a lot of fun and excitement and a lot of practical strategies, and I think parents and kids are feeling super proud of themselves for like ‘I can really do, I can get on top of this ’” (Facilitator).

Facilitators shared that the FYF program created opportunities to develop clinical skills directly through implementation as well as in areas such as building therapeutic alliance, which managers noted to be value-added for organizations. Facilitators also shared that the fidelity sessions with the program developer was very beneficial for skill development and helping

facilitators problem-solve unique situations that arose in sessions. Lastly, the in-person training sessions were reported to be very helpful for facilitators, and provided a strong starting point for the facilitators to begin navigating through the program.

Research Question 1.a. What are the differences in perceived compatibility, complexity, and relative advantages of facilitators and managers between community and hospital settings?

DIT Characteristics: Compatibility. Facilitators between organizations reported several differences for compatibility, complexity, and relative advantages. While most facilitators at the hospital indicated that the program was compatible with the population they serve, some facilitators at the community organization shared that they did not feel that the FYF program was compatible with clients that their organization typically serves (preschool age children). However, a manager at the community organization noted that implementing programs for older children can help the organization offer continued support to families as the child grows:

“For us in terms of advantages and benefits to the agency, I think it's another way that we can demonstrate that we're serving ASD across the lifespan” (Manager).

Regarding physical space, the community organization was based out of one building that had sufficient space for the intervention, whereas the hospital setting included facilitators from different health portfolios who were based out of different buildings. Hospital-based facilitators who were not working at the building where the intervention was held indicated that they were required to commute during high traffic times to get to the sessions, which was reported to take more time and resources. Another difference reported between settings was the treatment model. While the community facilitators did not comment about the treatment model, it emerged as a theme for the hospital facilitators and managers. For example, some hospital facilitators had

previously worked in an assessment-only health portfolio, thus the shift to an assessment and treatment-focused model had a larger impact on clinical practice for these facilitators than it did for those who were previously delivering treatment.

DIT Characteristic: Complexity: Complexity regarding the amount of content was reported to be different between organizations. The community group moved quickly through the content whereas the hospital-based facilitators reported more challenges in terms of covering all the session content without going over time. Facilitators from the community organization indicated that while having only two families participate meant that there was less time needed for discussions and weekly reviews, leaving more time to cover the content, they were often required to bolster discussions to ensure the conversation did not quickly taper off. Hospital-based facilitators, who usually had four families participating, did not report this. A difference in the perception of resources is also noticeable between settings, as community-based facilitators reported having many intervention resources on hand, such as prizes and behaviour modification rewards. The hospital-based facilitators indicated that they did not have resources on hand, and it was sometimes difficult to find time to purchase the extra resources before the session, such as cue cards, jars, or prizes.

DIT Characteristic: Relative Advantage. The community organization conveyed a higher frequency of comments regarding the manualized and structured design of the program and the use of behaviour modification compared to the hospital organization. Some facilitators comments on the slower pace and repetition at the beginning of the intervention, and how through the intervention it became evident why so much repetition was necessary:

“We found the pacing of things when the program initially started maybe felt a little bit off in the sense of repetition, and it seemed to take quite a while to get through some of

those initial session concepts. I think it's probably a deliberate choice within FYF because of really wanting to set those core principles in place and build understanding of those concepts. Initially, it felt like you were wondering if you were doing enough” (Facilitator).

Behaviour modification was another advantage more frequently identified by community-based facilitators, as it aligns with their current practices and approaches at their center.

“The program itself talks a lot about using positive reinforcement and using token economies, and token reinforcements, which is like common practice here. So that’s what we’re doing as an agency.” (Facilitator).

Facilitators from the hospital organization more frequently identified the multidisciplinary nature of the program as an advantage, as it helped the organization shift from a compartmentalized and portfolio-based department model to deliver a multidisciplinary intervention. In terms of clinician skills, more facilitators from the hospital organization recognized the FYF training as an advantage, but more facilitators from the community organization identified implementing the program as beneficial for clinical skill development.

Research Question 1.b. How do the perceptions of facilitators differ according to their education level and profession?

The DIT themes are organized by education level of undergraduate ($n = 3$), graduate ($n = 8$), and doctorate ($n = 5$) in Table 2, followed by an explanation of similarities and differences. Rates of all comments are reported in Table 2, and some main themes are outlines for each education level below.

Table 2

Diffusion of Innovation Theory Themes by Education Level

No. of Comments (%)

Theme	Undergraduate	Graduate	Doctorate
Compatibility	19 (100.00)	45 (100.00)	55 (100.00)
Population	8 (42.11)	13 (28.89)	13 (23.64)
Staff expertise	4 (21.05)	10 (22.22)	20 (36.36)
Philosophy or mandate	1 (5.26)	13 (28.89)	16 (29.09)
Treatment model	3 (15.79)	9 (20.00)	5 (9.09)
Physical space	3 (15.79)	0 (0.00)	1 (1.82)
Complexity	19 (100.00)	41 (100.00)	53 (100.00)
Complex cases	8 (42.11)	8 (19.51)	15 (28.30)
Resources	3 (15.79)	10 (24.39)	12 (22.64)
Manual	0 (0.00)	10 (24.39)	12 (22.64)
Content	7 (36.84)	8 (19.51)	6 (11.32)
Therapy experience	1 (5.26)	5 (12.20)	8 (15.09)
Relative Advantages	72 (100.00)	118 (100.00)	104 (100.00)
Intervention advantages	32 (44.44)	60 (50.85)	37 (35.58)
Manualized and structured	9 (12.50)	13 (11.02)	3 (2.88)
Group structure	6 (8.33)	8 (6.78)	6 (5.77)
CBT designed for ASD	3 (4.17)	8 (6.78)	9 (8.65)
Practice and repetition	6 (8.33)	9 (7.63)	3 (2.88)
Exposure-based hierarchies	3 (4.17)	9 (7.63)	6 (5.77)
Multidisciplinary	3 (4.17)	7 (5.93)	2 (1.92)
Behaviour modification	0 (0.00)	5 (4.24)	4 (3.85)
Videotaping	2 (2.78)	1 (0.85)	4 (3.85)
Family advantages	24 (33.33)	42 (35.59)	38 (36.54)
Family-centered	7 (9.72)	15 (12.71)	15 (14.42)
Parent Skills	6 (8.33)	11 (9.32)	7 (6.73)
Social support	7 (9.72)	6 (5.08)	6 (5.77)
Engaging	4 (5.56)	5 (4.24)	6 (5.77)
Individualized care	0 (0.00)	5 (4.24)	4 (3.85)
Clinician advantages	16 (22.22)	16 (13.56)	29 (27.88)
Training	7 (9.72)	10 (8.47)	12 (11.54)
Fidelity	4 (5.56)	3 (2.54)	9 (8.65)
Clinician skill development	5 (6.94)	3 (2.54)	8 (7.69)

Note: Percentages are calculated by education level for each characteristic of DIT.

Some of the undergraduate-level facilitators identified themes within complexity more frequently than other groups. For example, the percentage of comments regarding the complexity of the population is higher than other groups, as well as the complexity of applying the content. Specific complexities with the ASD population were discussed:

“I think because they do have autism, just thinking about their own thoughts is always going to be a challenge, but it’s good that it is a program that’s adapted for that. So they have a lot of concrete examples, and one thing I thought was really helpful was you don’t have to make the kids come up with their own helpful thoughts, you can like give it to them. Say like, think you’re brave. Make it as easy as possible” (Facilitator).

Both undergraduate- and graduate-level facilitators reported the manualized and structured design of the program to be an advantage more often than doctorate-level facilitators. Overall, graduate-level facilitators recognized a higher number of intervention advantages than the other groups. Both graduate- and doctorate-level facilitators more often discussed the compatibility of their program with the philosophy of their organization. Doctorate-level facilitators emphasized staff expertise in their comments compared to other groups and overall they recognized more clinical advantages for the FYF program.

The number DIT themes by profession are reported in Table 3 and some of the most frequently identified themes are subsequently highlighted.

Table 3
Diffusion of Innovation Theory Themes by Profession

Theme	No. of Comments (%)		
	Psychology	Social Work	O.T.
Compatibility	65 (100.00)	28 (100.00)	7 (100.00)
Population	18 (27.69)	9 (32.14)	2 (28.57)
Staff expertise	21 (32.31)	7 (25.00)	2 (28.57)
Philosophy or mandate	20 (30.77)	2 (7.14)	3 (42.86)
Treatment model	5 (7.69)	8 (28.57)	0 (0.00)
Physical space	1 (1.54)	2 (7.14)	0 (0.00)
Complexity	68 (100.00)	24 (100.00)	11 (100.00)
Complex cases	16 (23.53)	10 (41.66)	1 (9.09)
Resources	19 (27.94)	5 (20.83)	0 (0.00)
Manual	15 (22.05)	3 (12.50)	4 (36.36)
Content	7 (10.29)	5 (20.83)	6 (54.55)
Therapy experience	11 (16.17)	1 (4.17)	0 (0.00)
Relative Advantages	133 (100.00)	82 (100.00)	31 (100.00)

Intervention advantages	54 (40.60)	42 (51.22)	19 (61.29)
Manualized and structured	7 (5.26)	9 (10.96)	6 (19.35)
Group structure	8 (6.02)	9 (10.96)	1 (3.23)
CBT designed for ASD	11 (8.27)	4 (4.88)	1 (3.23)
Practice and repetition	6 (4.51)	7 (8.54)	2 (6.45)
Exposure-based hierarchies	9 (6.77)	7 (8.54)	2 (6.45)
Multidisciplinary	4 (3.01)	4 (4.88)	3 (9.68)
Behaviour modification	5 (3.76)	0 (0.00)	4 (12.90)
Videotaping	4 (3.01)	2 (2.44)	0 (0.00)
Family advantages	47 (35.34)	24 (29.27)	9 (29.03)
Family-centered	19 (14.29)	8 (9.76)	3 (9.68)
Parent Skills	8 (6.02)	8 (9.76)	3 (9.68)
Social support	7 (5.26)	6 (7.32)	1 (3.23)
Engaging	6 (4.51)	1 (1.22)	1 (3.23)
Individualized care	7 (5.26)	1 (1.22)	1 (3.23)
Clinician advantages	32 (24.06)	16 (19.28)	3 (9.68)
Training	13 (12.03)	10 (12.20)	1 (3.23)
Fidelity	10 (7.52)	1 (1.22)	0 (0.00)
Clinician skill development	9 (6.77)	5 (6.10)	2 (6.45)

Note: Percentages are calculated by profession for each characteristic of DIT.

The professions of the facilitators and managers include psychology ($n = 7$), social work ($n = 4$) and occupational therapy ($n = 2$). University student ($n = 2$) was not recognized as a profession and epidemiology ($n = 1$) was excluded to prevent the possibility of identifiable information. The psychologists identified a higher percentage of family advantages overall, especially the family-centered approach and parent involvement:

“I think the parent piece was really valuable, just having the little parent group running concurrently was key. That you're bringing the parent in and having them work side-by-side and have that dyad work together where you can look at some of those dynamics and relationships between parent child and then how you can support that” (Facilitator).

The psychologists also made more comments about the importance of therapy experience compared to the other professions. The social workers recognized the advantage of delivering the intervention in a group format, and this provides the opportunity for children to receive peer and

social support. The social workers also discussed the complexity of the population more often than the other groups. Finally, the occupational therapists had a higher percentage of comments regarding the compatibility of the program with their organization's mandate, the advantage of the manualized and structured approach, and the complexity of the content in practice. Compared to the other professions, the occupational therapists more often reported that the use of behaviour modifications aligned with their clinical practice, and noted the advantage of using token reinforcements throughout the entire intervention:

“[We] initially felt that our participants were motivated by social praise . . . then at week six or seven we were like no things are getting hard now, so we had to change that. Even though [the participants] said that they were okay with just that verbal reinforcement, we had to start giving them token reinforcement so that they would buy in a little bit more”
(Facilitator).

Research Question 2. What are the barriers that occur during the initial implementation period of FYF in either community or hospital settings?

A number of themes were identified through facilitator and manager perceptions of barriers and challenges, which are organized in categories of barriers: 1) system-level; 2) intervention delivery; 3) logistics; and 4) families. The themes and frequency of comments are presented in table format, followed by a detailed overview of theme content.

Table 4
Themes and Frequency of Comments Related to Barriers and Challenges

Theme	No. of Comments (%)		
	Total	Hospital	Community
Barriers and challenges	362 (32.09)	261 (100.00)	101 (100.00)
System-level	122 (10.82)	92 (35.25)	30 (29.70)
Resources and funding	46 (4.08)	33 (12.64)	13 (12.87)
Organization buy-in	30 (2.67)	25 (9.58)	5 (4.95)
Facilitator time allotment	24 (2.13)	16 (6.13)	8 (7.92)

Compartmentalization	12 (1.06)	12 (4.60)	0 (0.00)
Sustainability	10 (0.89)	6 (2.30)	4 (3.96)
Intervention delivery	109 (9.66)	82 (31.42)	27 (26.73)
Planning exposures and hierarchies	30 (2.67)	20 (7.66)	10 (9.90)
Indirect time	29 (2.57)	22 (8.43)	7 (6.93)
Session preparation	27 (2.39)	24 (9.20)	3 (2.97)
Content amount	12 (1.06)	12 (4.60)	0 (0.00)
Technology and videos	7 (0.62)	4 (1.53)	3 (2.97)
Lack of Experience	4 (0.35)	0 (0.00)	4 (3.96)
Logistics	91 (8.07)	65 (24.90)	26 (25.74)
Recruiting and screening	27 (2.39)	15 (5.72)	12 (11.88)
Coordinating and scheduling	27 (2.39)	21 (8.05)	6 (5.94)
Eligibility	24 (2.13)	18 (6.87)	6 (5.94)
Physical Space	13 (1.15)	11 (4.21)	2 (1.98)
Individual & Family	40 (3.55)	22 (8.43)	18 (17.82)
Child resistance	16 (1.42)	6 (2.30)	10 (9.90)
Parent cooperation	16 (1.42)	10 (3.83)	6 (5.94)
Comorbid disorders	8 (0.71)	6 (2.30)	2 (1.98)

Note: Percentages for total are based on total number of all interview comments ($n = 1,128$), and percentages for organizations are based on total number of comments by each organization.

Facilitators and managers identified many barriers and challenges from a top-down, systems-level perspective within their organization. Funding and resources were merged into one overarching theme as funding was needed for resources and were often discussed interchangeably by participants. Specific resources that required funding were identified as FYF workbooks, snacks, prizes/positive reinforcements, videomaking technology such as video cameras, USB drives or external hard-drives, and incidental intervention supplies such as markers, pens, paper, photocopies, envelopes, post-it notes, cue cards and jars. However, given that it was the first time running FYF, facilitators noted that the resources were more challenging to manage, and expected that time spent obtaining the various resources would decrease with more familiarity with the program:

“I think once the program was up and running, there's not much once you have all the tools you need and the snacks it's similar, but I think that the beforehand preparation is

something that they would have or do find challenging to integrate into the current system” (Facilitator).

Trained facilitators were also identified as a resource for the organization, that is, it was noted that even though FYF is a group intervention, the ratio of four facilitators to four families is essentially individual client work. Facilitators reported that running FYF with fewer facilitators could create challenges if one facilitator is unable to attend a session, and although the parent group could be led by one facilitator, the child group requires two facilitators or one facilitator and a volunteer. Therefore, the facilitators reported that it was optimal to run FYF groups with at least 3-4 facilitators. It was also reported that the timing of the intervention in the evenings was more difficult for some facilitators who work daytime hours. Facilitator time allotment is a system-level theme to emerge because managers reported that they had to shift responsibilities, provide a time allotment specifically for intervention services, back-fill pay with external funding sources, or provide flex hours (i.e., time in lieu) for facilitators to be able to build the intervention into their work schedules. Managers reported that handling and negotiating time and pay for the FYF intervention is impacted by the norms and practices of the health care system at a societal or national level:

“[Our provincial health care system] in general doesn't have a climate that allows me to just have a pot of peripheral or added resources to add services. Especially in a world that's now being driven by activity-based budgeting and operational best practices, I'm funded for the actual activity that clinicians partake in which is compared to national benchmarking standards, and those formulas are outside of my control” (Manager).

Managers indicated that an initial system-level challenge to occur was organization buy-in, or the willingness of the organization to try a new intervention. Questions around the

community need, feasibility, evidence-base, and cost were the first to emerge from organization boards and managers. Sustainability of the FYF program was also an issue that arose during the pre-intervention stage:

“Again, there is just no appetite for starting pilot studies without that really rigorous sustainability thinking. I think there's just been too many experiences in the health system where we just do pilot after pilot and pilot that when the funding's over it goes nowhere and there's not a lot of appetite to do that anymore, and I think that's a good thing”

(Manager).

Once an organization approved the implementation of FYF, managers reported it was challenging to decide who would be responsible for the program. This was particularly challenging for the hospital organization that is divided between different health portfolios, such as child neurodevelopment or child and youth mental health. Facilitators and managers reported that compartmentalization within the health system made it difficult for different health portfolios to collaborate, and communication between departments was challenging, such as scheduling meetings times that worked for every facilitator.

Facilitators and managers recognized several different themes relating to intervention delivery. Facilitators reported that the amount of content and activities are challenging to deliver within the session time limit while still allowing time for family to discuss and apply the content to their situation. The amount of indirect intervention time was a barrier for some facilitators who were not given a sufficient time allotment to plan and prepare outside of direct intervention time. Some facilitators had to cancel clients prior to intervention, refrain from booking clients on intervention days, or stop client meetings early to prepare for FYF, which has an impact on the workload at the organization. Several facilitators noted that FYF requires more preparation time

than other interventions, and requires extra planning and creativity before sessions to ensure exposures are possible:

“There were days where we literally had facilitators looking for worms in their backyard garden, and we had facilitators stopping at the store to get different foods to try, and making scavenger hunts in the building where kids could get lost. We certainly had facilitators doing indirect work that was amazing but would be hard to include and account for if you only get thirty minutes of indirect time per one hour of intervention time” (Facilitator).

Facilitators shared that planning the exposures with the families was challenging in a few different ways. Families often had a hard time breaking down a fear into graduated steps that can be used for exposures, and it was also challenging to brainstorm ways that exposures could be feasibly enacted and filmed during sessions. One facilitator shared that preparation prior to the first session is not possible as you do not know what fears families will want to address, and it is hard to know which fear participants are ready to face:

“For some kids [exposures were] what was their absolute biggest fear and they could work on it right away from the beginning. Other kids just couldn't get there, and we had to find a fear they could face with success” (Facilitator).

Filming the exposures was described to be a challenge and sometimes a barrier if the video equipment was not ready to use, for example if the camera battery is dead, or if the camera could not be connected to a screen for viewing. Lastly, it was reported that although having a range of disciplines involved in the FYF intervention created a diverse service delivery team, some facilitators noted that it was challenging to explain anxiety and CBT without prior training and experience, and understanding comorbid disorders is challenging without a background in mental

health. Lack of experience across areas such as ASD, anxiety, or mental health made implementation more difficult, especially for the adolescent group: *“I think that having the experience of CBT and mental health and family dynamics from a therapeutic perspective was essential, especially in older adolescents who are psychiatrically complex”* (Facilitator).

The logistics of organizing the time, resources, and people needed to make the FYF intervention possible posed some challenges and barriers for facilitators. During the pre-intervention stage, the recruiting, screening, and eligibility of participants was an initial barrier until the research team became involved:

“I think another big barrier was once we decided that yep we're gonna do this is kinda like ok who is going to be doing all of the planning, all of the organizing, all of the screening. And again, I don't think this would have happened if we didn't have a research component involved because not clinic or service would be willing to take on screening. Well, I guess [they were] taking referrals, reviewing files, screening patients and identifying whether or not they were appropriate for the group” (Manager).

Facilitators shared that having good group cohesion with the participants contributes to the success of the intervention, so rigorous screening and determination of eligibility is important for the is essential:

“Recruiting and screening for the right types of participants is very time consuming. . . All the time you're taking to sort out what kids could participate and not and you're interviewing a family and they turn out not to be the right fit for the group, it's time that's lost, that's really hard to find a way to account for in your hours and statistics if that's how your agency works” (Manager).

Coordinating the facilitators to meet together as a group was at times reported to be a barrier as schedules often conflicted. For examples, some facilitators indicated that they would have liked to learn more about the participants through a meeting before the group starts, but time limits and scheduling issues prevented sufficient time availability. Coordinating families was also a challenge, and the day and time presented a barrier for some families who were not able to attend during the predetermined session time. Lastly, a few facilitators stated that aspects of the physical space of the organizations presented challenges. Some families had to travel a long distance to get to the FYF intervention, so children were taken out of school early. The main room for the intervention session had to be large enough to accommodate families and facilitators, and some facilitators reported that children indicated that they were uncomfortable if they were situated too close to others. The program also requires additional rooms nearby for when parent and child group separate, as well as different spaces to accommodate the exposures and filming.

The final category of barriers and challenges to be identified by facilitators was related to the families. Facilitators reported that there were varying levels of child resistance throughout the intervention, which was initially expected given that the intervention is designed to put children in uncomfortable situations. Facilitators gave reports of children refusing to participate, parent-child arguments in session, resistance to accept the need for change, and in some cases child drop-out after the program started. One facilitator noted that drop-out after the intervention started meant that group dynamics changed and the group became smaller, impacting the social experience in the group. Parents also played a role in the success of the intervention according to facilitators, but there was resistance from parents at times, which led to challenges with parent cooperation. Areas identified by facilitators included parent resistance to change, engagement

during sessions, parent support with homework, parent capacity and parent mental health. Lastly, facilitators recognized that the presence of comorbid disorders presented barriers as they interfered with the child's ability to learn how to cope with anxiety and may be related to the anxiety:

“I think something that we repeatedly ran into was parsing out a skill deficit from an actual fear. So that was something that facilitators had to spend a lot of time outside of group going back and forth about and saying this kid has an LD in this but also has fear about this so how do we address that or do we address that in group. So we're trying to figure out, trying to conceptualize all their challenges and trying to figure out what we can address and what would best be addressed elsewhere” (Facilitator).

Research Question 2.a. How do barriers (e.g., resources, funding, etc.) differ between community and hospital settings?

Barriers at the system-level differed according to the internal administration structure within the organization. Both of the organizations had a system of board members, managers, and facilitators, but the process of communication and approval differed across these systems for each organization. For example, the community organization reported good organization buy-in as the board members did not create a barrier: *“We're fortunate to have a board that allows us to drive the ship clinically, and I know the business folks on our board like the arrangement in terms of [the research team] providing us with the training”* (Manager). The experience of the community organization was very different from the hospital organization where the system is more complex, and hospital managers reported that they had to be persistent:

“When we took this program initially to our steering committee and said we have this opportunity to address a significant persistent need in a mental health area, we were shut

down pretty quickly. There wasn't a lot of support for us to be introducing a new intervention, so we right away hit some initial barriers. The onus was on us to really persist and demonstrate, before we ever got started, that this could be done. I think with the partnerships and collaborative approach we needed to demonstrate how many groups were on board, because I think that started to let people know that this was something that we could actually achieve” (Manager).

Managers reported that coordinating schedules is more challenging at the hospital organization because communication and collaboration between different health portfolios is not as simple as coordinating among facilitators who are working at the same building and have prior experience working together. Thus, the compartmentalization of the hospital setting created a challenge that did not exist at the community organization. Facilitators from the community organization reported fewer difficulties organizing meetings and space as everyone worked onsite, and they also reported fewer time management difficulties. Lastly, content amount was not reported as a challenge, and it was noted by one community facilitator that this may be related to the small group size (i.e., only two families).

Research Question 2.b. What barriers were experienced by participants in both community and hospital settings?

Funding was identified as a barrier by both organizations without the assistance of the research team. Managers reported that they valued the opportunity to get training and access to fidelity checks through the research pilot initiative, as funding would have been a barrier:

“I think in terms of community agencies, that's probably the biggest impediment to evidence-based practice is the fact that we really have to eat the cost of all of that training. . . That's really been our challenge in terms of spending that money which we

know is money well spent in terms of getting people up to speed on an evidence-based intervention, but we have difficulty if we don't know for sure that the community is gonna embrace that program and over time will be able to theoretically pay ourselves back for the training” (Manager).

Funding impacts the ability for the FYF program to be sustainable, which was discussed by both organizations. Different ideas about how to plan for sustainability were presented by facilitators and managers from both organizations, such as a fee-for-service model, provincial funding provided to families for support with ASD, and reaching out the local school boards to explore their interest in supporting the intervention. The community organization reported that using a fee-for-service model in the future may have some added advantages:

“We found that with the programs, when there's not charge associated with the program sometimes people don't have skin in the game. Sometimes attendance isn't as great. . . Once they put some money up, then I think it spoke to dedication and how much they valued the service and how much of a priority they were gonna make it for their family” (Manager).

Parent cooperation, engagement and capacity were reported to be a challenge for both organizations. Facilitators reported that capacity and readiness for parents to support their child with anxiety was present to varying degrees depending on the family's understanding of anxiety and parental mental health:

“I think it was easy for [families] to label the anxiety, but then when it was like specifically what, it was really hard to break it down into those smaller components and get to what the actual root is rather than just like I don't like big crowds, I'm anxious in

big crowds, but like I can do it here and I can do it here and I can do it here, but not here, so why is that one different and what about that makes it harder?” (Facilitator).

Building exposure hierarchies and completing the exposure activities was a challenging process according to both organizations. The time and effort needed for the exposures to be successful were demanding and required collaboration with the facilitators as well as indirect time before and after the intervention to problem-solve how to make the exposures feasible.

Research Question 2.c. How do facilitators adapt FYF implementation to increase intervention compatibility within the organization and minimize barriers (i.e., mutual adaptation)?

Facilitators identified many ways in which they tried to minimize the impact of the barriers and find create solutions to overcome challenges. The themes and frequency of comments regarding adaptations are presented in Table 5, followed by a closer examination of theme content.

Table 5
Themes and Frequency of Comments Related to Adaptations

	No. of Comments (%)		
	Total	Hospital	Community
Adaptations	240 (21.28)	177 (100)	63 (100)
System-level	113 (10.02)	89 (50.28)	24 (38.10)
Research team	48 (4.26)	41 (23.16)	7 (11.11)
Facilitator time allotment	20 (1.77)	10 (5.65)	10 (15.87)
Advocacy and funding	18 (1.60)	13 (7.34)	5 (7.94)
Organization meetings	15 (1.33)	13 (7.34)	2 (3.17)
Project-based initiative and pilot	12 (1.06)	12 (6.78)	0 (0.00)
Intervention delivery	75 (6.65)	51 (28.81)	24 (38.10)
Facilitator communication	24 (2.13)	16 (9.04)	8 (12.70)
Fidelity	17 (1.51)	9 (5.08)	8 (12.70)
Flexibility	15 (1.33)	13 (7.34)	2 (3.17)
Content	11 (0.98)	5 (2.82)	6 (9.52)
Collaboration and partnerships	8 (0.71)	8 (4.52)	0 (0.00)
Logistics	39 (3.46)	31 (17.51)	8 (12.70)
Booster session	19 (1.68)	14 (7.91)	5 (7.94)

Session length and timing	17 (1.51)	14 (7.91)	3 (4.76)
Child care	2 (0.18)	2 (1.13)	0 (0.00)
Paid parking	1 (0.09)	1 (0.56)	0 (0.00)
Individual & Family	13 (1.15)	6 (3.39)	7 (11.11)
Individual needs	9 (0.80)	2 (1.13)	7 (11.11)
Parent follow-up	4 (0.35)	4 (2.26)	0 (0.00)

Note: Percentage for total is based on total number of comments ($n = 1,128$), and percentage for organizations are based on total number of comments by each organization.

System-level mutual adaptations are themes identified by facilitators and managers in which changes were required at the organizational level to implement the intervention. A significant change recognized by facilitators was the introduction of the research team to support the implementation. Not only was there ongoing support from the research team throughout the intervention, but many of the pre-intervention set-up tasks were managed by the research team and students from the research lab, such as screening:

“Again, I don't think this [intervention] would have happened if we didn't have a research component involved. Because not clinic nor service would be willing to take on screening, well I guess taking referrals, reviewing files, screening patients and identifying whether or not they were appropriate for the group” (Facilitator).

The research team also brought funding for resources and covered the cost of training and treatment fidelity. The research team formed a pilot study with the hospital organization through a project-based initiative, which served as an entry point into the organization. Managers involved in the pilot study at the hospital recognized that it was about 18 months of prior work and collaboration, such as proposals for committees and board members, presentations to the organization, awareness days, and training, before the FYF program was ready to commence. Managers reported that additional funding was used by the project-based initiative to bring in extra help to sustain the workload of facilitators while they focused on the FYF program.

The mutual adaptations recognized for intervention delivery themes relate to changes made to the intervention or delivery to better suit the organization. Facilitators shared that they had to make minor changes to the intervention in order to suit the needs of the families, such as spending more time on certain topics that the families found more challenging. As a result of the changes and accommodations that needed to be made, facilitators noted that appropriate communication and flexibility is necessary during the intervention. This includes weekly communication between facilitators, and flexibility in terms of logistics, resources, family problem-solving, and even flexibility on the part of the organization to try a new intervention: *“Some persistence and flexibility helps, I think if people see you're creative and that there's room people want to see innovation, you just have to do it in a really responsible and respectful way”* (Facilitator).

Themes related to logistics emerged from comments about the timing and facilities required to get all the families and facilitators to the same place at the same time. Facilitators reported adaptations such as postponing the start time of the intervention due to low participant numbers, and staying late after sessions due to extra time needed to cover content. The extra time needed to complete participant forms encroached on facilitator time allotment as parents did not want to stay later after sessions. Facilitators also commented on needing to adopt more rigorous time management strategies to keep the session timing in check:

“This isn't so much the beginning or one month, but around week five or six it did get a bit content heavy and that's where we had more struggles with time management in terms of how to manage our time effectively, I think it was when we started the check-ins, you spend extra time doing check-ins” (Facilitator).

Available facilities through the organizations, such as childcare and parking, were also noted by managers.. The hospital organized access to a child care area for participant siblings, and the research team provided compensation for parking fees, whereas the community organization was able to provide free parking at their location, and had to organize child care based on family need. Timing was also challenging in terms of planning the booster session one-month after the final intervention session:

“We had a really hard time scheduling our booster session because it runs into the summer months, and so a lot of our families are away, and so we had to change the number of weeks, not by a lot, I think it's only one week difference of when our booster session will be delivered. That's something to think about, like you wouldn't want to have a booster session that falls over Christmas, but in a fourteen-week intervention, you really have to plan it right” (Manager).

The last category of adaptations themes emerged from facilitator and manager comments was related to the specific changes that were needed to make the intervention more meaningful for the individual participants and their families. Adapting to individual needs included individualizing content or activities within FYF, such as designing exposure hierarchies to target specific fears identified by the family. Participants with complex profiles (i.e., comorbid disorders like obsessive-compulsive disorder) also required a more individualized exposure plan that accounted for possible complications that arose due to comorbidity. Facilitators in some groups found it helpful to follow-up with families through a phone call or email between sessions to help parents problem-solve any issues that arose during homework activities:

“I guess we were in contact more with the parents, especially via email, like checking in on them throughout the week, because our kids were so complex, so being in contact with

them throughout the week to see that everything's going according to plan. Because that did eat up a lot of time in group, trying to problem solve some things in group and then we weren't able to get to the exposures. Towards the end we moved more towards doing that outside of group time and just focusing on trying to get some exposures done in group” (Facilitator).

Research Question 3. Determine if there is a clinically meaningful change for FYF participants in both settings according to treatment outcomes measures for the ASC-ASD and the SRS-II

The results of the treatment outcomes for the SRS are reported in Table 6 and the ASC-ASD is reported in Table 7. Differences are reported for each group as well as per participant as statistical analysis between groups was not possible due to the small sample size.

Table 6
Reliable Change Values for the Social Responsiveness Scale

Organization and Group	Below Clinical Threshold	Social Responsiveness Scale						
		Total	Awr	Cog	Com	Mot	RRB	SCI
Group 1	Yes	1.40	1.00	1.30	1.30	0.40	2.20	1.20
	Yes*	0.80	1.60	0.80	0.60	0.20	0.80	0.80
	No	0.70	0.90	0.70	0.40	2.00	0.00	1.00
	No	0.50	1.30	0.90	-0.10	0.20	0.70	0.50
Group 2	Yes*	0.30	-0.60	-0.40	0.90	0.40	0.00	0.30
	No	0.40	-0.30	0.40	0.90	0.40	-0.60	0.60
	No	-0.50	-2.20	-0.70	-0.20	-0.30	0.30	-0.70
Group 3	No	0.50	0.30	0.60	0.30	0.70	0.90	0.40
	No	-0.80	-1.60	-0.70	-0.40	-1.00	-0.30	-0.50

Note: * signifies scores below clinical threshold on both pre- and post-intervention measures. Awr = Awareness, Cog = Social Cognition, Com = Social Communication, Mot = Social Motivation, RRB = Restricted, Repetitive Behaviours, and SCI = Social Composite Index

Table 7
Child and Parent Reliable Change Values for the Anxiety Scale for Children - ASD Version

Organization and Group	Below Clinical	ASC-ASD			
		Total	Performance	Arousal	Separation Uncertainty

		Threshold				
Child/Youth						
Group 1	Yes*	-0.21	-0.24	0.00	-0.97	0.25
	Yes	1.54	0.72	0.84	1.94	1.49
	Yes*	1.03	0.24	2.51	1.94	-0.25
	Yes*	0.41	0.24	-0.84	0.97	0.74
Group 2	Yes	0.31	1.20	-1.26	0.00	0.25
	Yes	1.03	0.00	2.09	0.00	1.24
	Yes*	0.82	0.24	-0.42	-0.49	2.23
Group 3	Yes*	0.51	0.48	0.00	1.46	0.00
	No	-0.72	0.24	-0.42	0.74	-0.49
Parent						
Group 1	Yes	1.47	0.79	1.22	1.15	1.53
	Yes*	0.16	-0.26	0.00	0.23	0.44
	No	0.39	0.00	-0.61	0.46	1.09
	No	0.85	-0.26	1.22	0.69	1.09
Group 2	No	-0.54	-0.52	0.31	-0.46	-0.87
	Yes	0.70	1.57	0.92	0.23	-0.22
	Yes*	-0.08	-0.52	0.00	0.00	0.22
Group 3	Yes	1.63	1.05	0.61	1.39	1.96
	No	0.08	0.79	0.00	0.00	-0.44

Note: * signifies scores below clinical threshold on both pre- and post-intervention measures.

There were no reports of clinically meaningful changes (i.e., reliable change values greater than 1.96) indicated through the total scores of the ASC-ASD or the SRS. However, there were some subscales in which participants reported clinically meaningful change, such as arousal and uncertainty in the ASC-ASD and social motivation and restricted interests repetitive behaviours in the SRS. One reliable change value in the social awareness subtest of the SRS indicated a negative value that exceeds 1.96. Total values below clinical cut-off were reported for each measure. Three parent participants (33%) reported subclinical totals on the SRS, eight child and youth participants (89%) reported subclinical totals for the ASC-ASD, and five parent participants (56%) reported subclinical totals for the ASC-ASD after the FYF intervention.

Chapter 5: Discussion

Anxiety is a highly prevalent disorder among children and youth with autism spectrum disorder (ASD). (McRae, O'Donnell, Loukine, Rancourt, & Pelletier, 2016; Polanczyk, Salum, Sugaya, Caye, & Rohde, 2015; van Steensel, Bogels, & Perrin, 2011). Anxiety among children and youth with ASD may present as traditional symptoms (i.e., consistent with DSM-V definitions of anxiety), or atypical anxiety (i.e., inconsistent with DSM-V) (Kerns et al., 2014; Kerns & Kendall, 2012). The FYF program is a CBT-based, manualized intervention specifically designed for children and youth with ASD and anxiety, and has shown to be successful in teaching this population to reduce symptoms of anxiety (Reaven et al., 2009; Reaven et al., 2012). Strong, evidence-based interventions such as FYF could be beneficial for a wider range of families if it is accessible in different settings (Pickard et al., 2018). Currently, there is limited research on how the FYF program is implemented in various settings, such as hospitals and community organizations. Insider perspectives from those who have delivered the FYF intervention provides practical information about how bring a research-based intervention into clinical practice.

The research conducted on the FYF program in the current study was designed to explore facilitator and manager perceptions of implementing the FYF intervention in community and hospital settings. A mixed-methods research design was incorporated, and perceptions were explored qualitatively through interviews and supported quantitatively through treatment outcomes collected on the SRS and ASC-ASD. The theoretical framework used to build the interview focuses on the characteristics of diffusion of innovation (DIT), which included compatibility, complexity, and relative advantages. The organizations both reported that the FYF program was compatible within their organization, and noted that the intervention manual is not

complex to follow, but it is more complex to apply the content in practice and work with complex cases (e.g., neurodevelopmental disorder and mental health concerns). The relative advantages presented by facilitators and managers were unique to the organization's system, and each organization had their own process of introducing and implementing the FYF program. In addition to the DIT characteristics, facilitators and managers reported on the barriers they faced before and during implementation, as well as creative ways to overcome challenges through adaptations. Other organizations whom are initiating the implementation of FYF may want to consider how the barriers and adaptations may be relevant in their situation, especially in a Canadian context. Further consideration of the most frequently reported themes for each organization are explored to provide deeper insight for future directions and implications in practice.

Diffusion of Innovation

Compatibility. Facilitators and managers discussed the compatibility in terms of elements that made the FYF program a good fit for their organization. The population, staff expertise and the philosophy or mandate were the top three most frequently identified themes in compatibility for both the hospital and community organization. Given that both organizations specialize in working with children with ASD, each organization's mandate is to serve clients with ASD using population-specific programs, in addition to staff having expertise in working with this population. Consistent with this, Drmic and colleagues found that staff expertise facilitated the implementation of FYF in a school setting (Drmic, Aljunied, & Reaven, 2017). Compared to the organizations in the present study, staff at a school setting are more likely to see children and youth with more diverse needs, such as ADHD, intellectual disability, and learning disability (Wood, McLeod, Klebanoff, & Brookman-Frazee, 2015). As a result, broader

adaptations may be required in the future to deliver FYF in an organization where there is less compatibility with the client population.

Complexity. Facilitators and managers identified themes regarding both high and low complexity. Facilitators from the hospital organization identified the FYF manual as straightforward to follow as the progression of the sessions creates a sequence that builds on knowledge and practice from prior sessions. Facilitators and managers from the community organization noted that prior psychotherapy experience made implementation less complex and was very useful for understanding how to deliver the FYF program. This theme is consistent with data from a previous FYF study (Reaven et al., 2018) in which facilitators with therapy experience but no FYF training (i.e., only following the manual) were able to successfully support participants in reducing their symptoms of anxiety (Reaven et al., 2018).

Facilitators from both organizations identified the complex nature of the population as being quite challenging to serve, as the intervention must account for ASD symptoms while simultaneously addressing symptoms of anxiety. Some children and youth may also have other comorbid disorders such as ADHD or OCD, making their intervention process even more complex (White et al., 2009). Managing disruptive behaviours associated with ASD or comorbid disorders adds to the complexity of the group, so there have been suggestions that FYF training should include specific information about how to manage a complex group (Reaven et al., 2018).

Securing resources was also identified by facilitators from the hospital organization as being a complex process within the health system where separate health portfolios have different budgets, clinician work-hour allotments, and require approval from different managerial systems. Facilitators from the community organization recognized that the content is more complex in practice, and helping families apply the steps and strategies in practice is more complex than

teaching directly from the manual, which emphasizes the need for good parent-therapist rapport (Pickard, Kilgore, & Ingersoll, 2016).

Relative Advantage. Unlike compatibility and complexity, there is no overlap across the top themes for relative advantages identified by both organizations. Facilitators and managers from the community organization valued the structured and manualized design of the intervention, the opportunity for clinician skill development, and the use of behaviour modification techniques. The community organization recognized the added value of offering a specialized intervention that is not available at other community organizations, especially as they have seen many of their own clients with ASD struggle with anxiety. Professional development through the in-person training and consultation with the FYF developers was reported to be an advantage, as these learning opportunities to learn were viewed as very exciting and motivating to facilitators. A unique advantage noted by the community organization was the use of behaviour modification techniques integrated within the FYF program. Facilitators from the community organization reported that they use behaviour modification in their daily practice when working with clients with ASD, and so it was a natural transition to use it in the FYF program. Given that FYF was designed for use with children and youth with ASD, rather than adapting an existing intervention designed for typically developing children, the incorporation of ASD-specific techniques (e.g., behaviour modification, concrete strategies and examples, video-modelling) was essential to ensure efficacy in this population (Reaven et al., 2009; Reaven et al., 2012). Therefore, other organizations who are utilizing existing anxiety interventions with children with ASD may want to consider if the use of ASD-specific techniques is important for their facilitators and participants.

The main advantage reported by facilitators and managers in the hospital organization was related to the family-centered approach of FYF. Specifically, facilitators and managers from the hospital organization valued the in-person training session as they recognized that it is rare to have intervention developers directly teach and interact with facilitators. The parent component of the FYF was identified as a unique aspect in which facilitators from the hospital organization rarely experience in their practice unless is it family therapy. Parent involvement during FYF sessions allowed for parent skill development through the coaching that facilitators provided to parents on how to support the child, something that is not typical for hospital-based programs. While the family-centered approach was noted as a major advantage for the program, organizations hoping to implement FYF may need to consider if the family-centered approach is appropriate for their setting or if adaptations are needed. For example, Drmic and colleagues adapted the school-based version of FYF so that parent sessions were conducted independent versus simultaneously, from youth sessions (Drmic, Aljunied, & Reaven, 2017). Families in the school-based study reported positive outcomes at the end of the FYF program, demonstrating that parent involvement and a family-centered approach is an advantage that can be adapted to fit the organization's needs (Drmic, Aljunied, & Reaven, 2017; Stahmer, Collings, & Palinkas, 2005).

As hypothesized, there were themes that overlapped with those reported previously in previous studies. Compatibility and complexity were two areas in which there was more overlap of top themes between organizations, which indicates that themes from these DIT characteristics are relevant across settings. The top reported relative advantages were unique to each organization (i.e., no overlapping themes), which aligns with the hypothesis that different intervention settings may impact facilitator perspectives. This suggests that relative advantages

are more dependent on the organization's system in which the intervention is being implemented and will thus vary between settings. The differences between education levels and professions were less prominent than between organizations. By profession, there were some differences in that the psychologists more frequently noted the importance of therapy experience, the social workers valued the group structure, and the occupational therapists appreciated the behaviour modification techniques, which may be influenced by individual practices in each respective field. Unique perspectives across professions can lead to a rich multidisciplinary intervention team. Education levels were similar to professions in that there were many overlapping themes, but there were also differences between the education levels. Of interest, themes from undergraduate and doctorate level facilitators and managers did not overlap, suggesting the two groups have differing perspectives. Although it is good to have unique perspectives on a team, this may have implications for implementation if the intervention team is composed of undergraduate and doctorate level facilitators, as there may be varied perspectives that impact decisions or approaches.

Barriers and Adaptations

Some barrier and challenges occurred for the organizations before the intervention sessions began. Both organizations recognized resources and funding as the primary barrier for starting, maintaining and sustaining interventions, including FYF. The organizations received approval to implement the FYF program largely based on external research funding or specialized project funding, which minimized financial barriers and increased organization buy-in. Problem-solving financial issues was approached differently by each organization, as the hospital organization noted they would consider community partners and government funding, and the community organization shared they would introduce a fee-for-service model. The

hospital organization reported that organization buy-in and approval is essential for initiating and sustaining the FYF program, which aligns with feedback from facilitators in a school-based setting who reported that support from stakeholders is a key facilitating factor when implementing the FYF program (Drmic, Aljunied, & Reaven, 2017), which is also highlighted in implementation research (Proctor et al., 2009). Facilitators in the school-based setting (Drmic, Aljunied, & Reaven, 2017) also recognized that appropriate identification of children is an important facilitating factor for FYF, which relates to the challenge of recruiting and screening children to ensure participants are appropriate for the group. The community organization found that it was hard to find participants for the intervention group due to lower-than-expected recruitment numbers despite hearing there is a need for this intervention in the community. Recruitment and screening require time and resources, which can be wasted on identifying children who are not a good fit for the group. Organizations in the future may need to consider if there is a discrepancy between local interest in an intervention group and the number of families who are ready to commit to the intervention and are available during session times.

Facilitators also noted that some barriers and challenges occurred after the intervention started. The hospital organization reported that session preparation was one of their main challenges. This may be partially related to the added challenge of facilitators meeting from different sites, making communication more challenging than it was for the community organization who all worked in one building. Even if there is physical space available, location needs to be considered as a possible barrier because it may introduce other challenges, such as session preparation or parent availability if there are greater travel times. The community organization recognized in-session challenges such as child resistance and planning exposures and hierarchies, both of which were also identified as barriers by facilitators implementing FYF

in a school-based setting (Drmic, Aljunied, & Reaven, 2017), as well as in other implementation studies (Stahmer, Collings, & Lawrence, 2009). Community facilitators noted that one participant dropped out after the sessions began, and this was reported to have a significant impact on group dynamics. Intervention drop-out may be inevitable in some cases, but it also highlights the importance of screening for both goodness-of-fit for the group as well as participant readiness. Planning exposures and hierarchies may be more challenging for families and facilitators if children are not ready to participate, and there is a risk that the exposure will not be successful if it is too overwhelming. Facilitators at the community organization reported that they were surprised to find how difficult it was for families to break down a fear into smaller parts so that fears can be tackled in small, manageable steps. Adapting the exposures to fit the families' needs is consistent with evidence from Wood and colleagues that flexibility in evidence-based interventions promotes implementation success (Wood, McLeod, Klebanoff, & Brookman-Fraee, 2015). In the future, organizations may consider giving extra time for planning and preparing exposure sessions based on the challenges identified by facilitators.

As hypothesized, many adaptations differed between organizations as they faced unique barriers. However, one adaptation shared by both organizations is effective facilitator communication. Each organization created their own system of communication between facilitators to ensure that everyone was prepared for the session, roles and responsibilities were organized, and topics from the break-out groups were shared back to all facilitators. In addition to pre-session meetings, phone-calls or emails throughout the intervention, facilitator debriefing, case conceptualization, and consultation also increased when exposures and hierarchies were introduced. Future facilitators may want to consider how they will establish their own

communication system before the intervention is implemented as both organizations found it useful to adapt their own communication arrangements.

Facilitators from the community organization reported that regular consultation is helpful for understanding how to make appropriate adaptations for the organization while maintaining treatment fidelity. This is contrary to data from the FYF clinician training study (Reaven et al., 2018) in which researchers found that supervised consultation did not have a significant impact on facilitators or groups. However, facilitators from the Reaven et al. study (2018) were clinicians working in university clinics and may have a higher level of applied clinical skills and specialized knowledge (e.g., anxiety and ASD) than a multidisciplinary team from a community organization. Therefore, supervised consultation with experienced clinicians (e.g., in CBT or FYF) may be more beneficial for multidisciplinary teams who are seeking more clinical knowledge and guidance on adaptations. Facilitator communication and consultation both require additional time beyond direct intervention time, which create a necessary adaptation of facilitator time allotment. Facilitators in the community recognized that they were responsible for managing their time between booking client appointments and scheduling time for the intervention. As time conflicts arose, the community facilitators found that they needed to allot extra time before sessions to prepare, especially once exposures began.

The hospital organization used structured facilitator time allotments that could not be changed, but they did identify adaptations around session timing. Specifically, facilitators reported some difficulty around managing time (e.g., sessions going over time, activities taking too long), so time adaptations include designating a timekeeper, giving frequent timing reminders, and limiting time on activities. Some facilitators were not able to stay after the sessions, so any additional tasks, such as filling out forms on the first and last session, had to be

fit into the session timing, which took away time from intervention content. Another timing-related adaptation was the change to the booster session as it needed to be pushed forward to accommodate families on summer vacation. Lastly, the main adaptation noted by the hospital organization is the inclusion of the research team in supporting the implementation of the FYF program. Many facilitators noted that having the additional support of the research team was very beneficial for initiating implementation as the researchers were responsible for time-consuming start-up tasks like participant screening. One hospital-based facilitator noted that the research component was a necessary adaptation in order to make the intervention feasible:

“I don't think [that FYF] would have been feasible for any portfolios, mental health or ASD, to do this without the research component, so ensuring that research clinical relationship I think was really important to overcoming some of the barriers”

(Facilitator).

Treatment Outcomes

The treatment outcomes in this study were used as secondary data to contextualize the qualitative information gathered through interviews with facilitators and managers. Group analysis was not possible because of the small sample size, but there were some general trends that appeared in the individual treatment outcomes. None of the parents or children reported a total score on the SRS or ASC-ASD that exceeds 1.96, thus there was no evidence of clinically significant reliable change for any participant immediately following the intervention. However, data collected at 6-month follow-up may indicate a greater difference in pre-intervention and follow-up scores. It is possible that post-intervention data collected immediately following the intervention may be too soon to allow for families to practice using the intervention in their daily life, and thus the families may not notice or report benefits. Total scores below clinical threshold

at post-intervention varied between the measures. The lowest number of parent participants (33%) reported subclinical levels for social responsive, compared to 56% of parents who indicated subclinical levels for anxiety. Child and youth participants had the highest rate (89%) of reports for subclinical anxiety. This evidence is exploratory and based on a small sample size, thus no outcomes can be accurately attributed to the FYF intervention. However, it is interesting to note that children and youth reported the highest rate of subclinical anxiety at post-intervention given that this is the population and symptoms targeted in the FYF program.

An interesting outcome is that children and parents sometimes rated anxiety at a higher level following participation in FYF. It is possible that the anxiety levels may have increased due to the situational discomfort of confronting fears in exposure exercises, and so children may be reporting on the anxiety they felt during exposures. Alternatively, lower pre-intervention scores may be impacted by social desirability (e.g., parental desire to appear supportive), poor of awareness or understanding of anxiety symptoms (Mazefsky, Kao, Oswald, 2011), and misattribution of anxiety and ASD symptoms (Walsh et al., 2018). Youth with ASD in other FYF studies have also under-reported their level of anxiety, and it has been suggested that this is associated with limited insight regarding emotional experiences (Blakeley-Smith et al., 2012; Walsh et al., 2018). Higher post-intervention scores may be related to the increased awareness, understanding, or acceptance of anxiety symptoms (Ozsivadjian, Hibberd, & Hollocks, 2013; Walsh et al., 2018; White et al., 2009). Lastly, it is also important to recognize that not all children and families respond to CBT as the process and strategies of CBT may not suit the family's needs, values, or cultural background (Beck, 2011; White et al., 2009).

Limitations

The present study has some limitations that may impact the generalizability of the findings. A major limitation is the sample size of the groups and the response rate. The size of each group is designed to be small because it is family-centered, so each child participant also brings a parent, which instantly doubles the size of the groups and prevents larger numbers of child participants. Although there were three groups, participant drop-out and challenges with post-intervention data collection significantly impacted data collection. Comprehensive statistical analysis and between group comparison would be possible with a larger sample size. There is limited capacity for identifying group trends with individual pre- and post-intervention data. The study does not include a control group, such as a waitlist or treatment-as-usual group, which limits the possibility of between-group comparison and minimizes confounding variables and researcher bias. For example, a control group would be useful for understanding if the impact of low emotional awareness in children with ASD affects both groups when reporting anxiety symptoms or just the intervention group. Furthermore, only two measures were used for understand the treatment outcomes immediately following treatment, which only provide information about social responsiveness and anxiety. Although these measures are validated for use with the ASD population, there are large gaps in understanding how the intervention impacts other areas for the child, such as quality of life or types of functioning like behavioural, social-emotional, or daily living.

The qualitative data also has some limitations as it is confined to facilitator and manager perspectives. Furthermore, not all of the facilitators involved with the groups in this study participated in an interview, and so the results are limited to facilitators and managers who volunteered to be interviewed. Understanding the experience of the children and youth, as well

as the parents may provide a more comprehensive study of the implementation. Interviews with parents could provide insight into the aspects of implementation that families found successful or challenging. The parents may also offer new perceptions on the compatibility, complexity, and relative advantages of the FYF program from a family-systems perspectives which may contrast the organization-systems perspective. Lastly, the family demographics indicate that the groups were fairly homogeneous in regards to family income and cultural background, making the results less generalizable to diverse groups. Future FYF implementation research may include families from a wider range of socio-economic and cultural backgrounds.

Future Directions

There are both short-term and long-term possibilities of continuing implementation research on the FYF program. Short-term future directions include additional analysis of implementation data from the current pilot project initiative in which data from this study was collected. For example, a comprehensive analysis of the treatment outcomes could be conducted by a blinded clinician examiner using the *Clinical Global Impressions Scale-Improvement* (CGIS-I; Busner & Targum, 2007; Wood et al., 2006; Wood et al., 2009). The CGIS-I is a comprehensive assessment of pre- and post-intervention data from multiple raters and clinical tools that informs a holistic understanding of improvement, thereby providing a dynamic examination of intervention outcomes. It may also be beneficial to incorporate the CGIS-I as it has been used by researchers in past studies of FYF and thus aligns with previous FYF program data (Reaven et al., 2015; Reaven et al., 2018). The CGIS-I may be useful to use with the 6-month follow-up treatment data as a broader range of measures is administered at that time. Information from the 6-month follow-up data collection may also be helpful in further examining the impact of treatment outcomes reported in this study.

Long-term future directions include examining implementation in different contexts. The FYF program may be implemented at different sites across Canada, providing more information about implementation at a provincial and national level. Funding and resources can be impacted by provincial standards of support, thus implementation research in different provinces may help organizations understand how to access provincial support to aid initial implementation and program sustainability. Longitudinal data from the organizations in this study can also provide information about sustainability, especially as the system or context of the organizations may change internally with the fluctuation of facilitators or managers. Organizations may wish to document their process of sustainability for the FYF program so that strategic processes may be adapted for other programs within the organization or shared with other organizations. One way to document this process is to build on the qualitative data of this project by conducting interviews with facilitators and managers after each round of FYF or on a yearly basis. All FYF program data from community organizations is particularly important as this was not previously explored, and more information from the community is needed to make the data more generalizable. Future implementation research could explore perceptions from community organizations who are not affiliated with a university or research team, as the implementation process may be different for a community organization who must overcome initial implementation barriers without additional funding and resource support.

Conclusion

The present study explored the implementation of the FYF program in hospital and community organizations. Through the DIT framework, facilitators and managers shared their perspectives on the compatibility, complexity, and relative advantages of implementing the FYF program. Overall, FYF was reported to have good compatibility in both hospital and community settings. Facilitators and managers from both organizations indicated that the FYF intervention manual and delivery was straightforward, although working with children and youth with ASD and anxiety was reported to make practice more complex. The reported relative advantages were unique to each organization, suggesting that advantages may relate to contextual factors specific to the organization. For example, the top relative advantage for the community organization was the manualized and structured approach of FYF, whereas the hospital organization valued the family-centered approach, and thus each organization reported advantages that were important and meaningful to their individual context.

The barriers and adaptations explored in this study have the potential to be used by organizations hoping to implement FYF in the future. Knowing barriers in advance can help organizations begin to tackle the challenges that may prevent successful implementation. For example, facilitators and managers may be more prepared to tackle system-level barriers such as access to resources and funding if they recognize that this is a potential barrier. Each organization faced barriers that they were able to overcome with adaptations. The adaptations are based on the setting and challenges faced by each organization, but they may serve as useful adaptations for future implementation in new settings. This is the first study to include a community organization in the implementation research on FYF, and so many of the themes from the community interviews may be generalized to other community organizations, and can

help to preclude or reduce challenges pre-emptively. Information from the hospital organization can contribute to our understanding of FYF in a Canadian context, and can offer insight about how to build sustainability through community and provincial partnerships. Understanding how to overcome intervention barriers based on implementation research will hopefully aid other organizations in exploring possible interventions. Supporting organizations in delivering effective, evidence-based interventions, such as the FYF program, will in turn support wellness in the community, family, and child.

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Appendix A

BACKGROUND INFORMATION QUESTIONNAIRE

Anxiety in Children and Youth with Autism Spectrum Disorder (ASD)

The following information will be used to describe the characteristics of your organization as a whole, not individual participants. Please complete the following background information questions:

1. I am a (Check one):

Male Female Other _____ Prefer not to say

2. What is your profession?

3. How many years of experience do you have in your profession?

4. What is your highest level of education (i.e., type of degree)?

5. Did you receive Facing Your Fears training? When did the training occur?

6. Have you previously implemented Facing Your Fears? If yes, how many times?

7. How many facilitators are present during the Facing Your Fears intervention? Do you have additional assistance (e.g., volunteers)? If so, how many people?

Thank you for completing the questionnaire!

Appendix B

Interview Guide

Anxiety in Children and Youth with Autism Spectrum Disorder (ASD)

I. INTRODUCTION AND INSTRUCTIONS:

Hello, my name is Laura, and I'm a graduate student in the School and Applied Child Psychology at the University of Calgary. Thank you for agreeing to participate in this interview. I'll be asking you questions about the Facing Your Fear intervention, which I will refer to as FYF. Just as a reminder, the purpose of the questions is to understand your perception of FYF and your experience implementing the initial stages of FYF.

If not yet completed:

Review informed consent form and answer any questions about it.
Collect signed consent form.

Confidentiality: [READ ALOUD] - Before we begin our discussion, I want to spend a few moments talking about confidentiality and to go over some basic ground rules for our interview today:

- You are welcome to share any views you hold, as your information will remain confidential and anonymous.
- The information I collect will be attributed to your organization's group, not you as an individual.
- No identifying quotes or ideas will be attributed to an individual.
- You may end the interview at any time.
- After the interview, I will invite you to fill in an anonymous "background information questionnaire" to us help generally describe the kind of people who were part of your organization.
- You can expect this interview to last about 30 minutes.

Use of Tape Recorder

- As you will recall, this interview will be recorded to increase accuracy and to reduce the chance of misinterpreting what is shared.
- All tapes and transcripts will be kept under lock and key by the researcher.
- Names will be removed from transcripts. Participants will have coded numbers attached to their name which only we will know.
- Only I and my research supervisor will have access to transcripts (with your personal names removed) of this interview.
- I'll also ask that when using abbreviations or acronyms, you say the full name at least once to aid transcription.
- I may also write down key points during the focus group and take notes.

Do you have any questions before we begin?

II. INTERVIEW

Interview begins by asking the first question.

1. How compatible do you believe the FYF intervention is within your organization? In other words, do you believe that FYF is a good fit for your organization?
 - a. Please state any reasons that support your belief.
 - b. If possible, please provide an example of how FYF is compatible with your organization.
2. How do you view the complexity of the FYF intervention? For example, how challenging is the FYF intervention to implement?
 - a. Please describe how the complexity of FYF affects your organization.
 - b. If possible, please provide an example of how the complexity of FYF affects your organization.
3. What is the relative advantage of using the FYF intervention? In essence, what strengths does FYF have as an intervention?
 - a. Please state any characteristics of FYF that align well with your organization.
 - b. If possible, please provide an example of a relative advantage of FYF for your organization.
4. Please describe any barriers or challenges that occurred during the initial implementation period of FYF. This includes anything that occurred before the intervention or up to one month after the intervention started.
5. How did you respond to barriers that occurred during FYF implementation?
 - a. Please describe any adaptations or changes that had to be made to the intervention to make it a better fit at your organization.
 - b. Please describe any adaptations or changes that had to be made within your organization to better accommodate the intervention.

Is there anything you would like to include that I have not asked about?

III. CONCLUSION

- Introduce the background information sheet and have the participant complete and leave the sheet face down.
- Thank the participant.

Appendix C

Table 8
Demographic Background of Facilitators and Managers

	<i>n (%)</i>
Total No. of participants	16 (100.00)
Total No. of responses	18 (100.00)
Sex	
Male	1 (6.25)
Female	15 (93.75)
Settings	
Hospital	13 (72.22)
Community	5 (27.78)
Groups	
Group 1 (Hospital: Adolescent)	4 (22.22)
Group 2 (Hospital: Child)	5 (27.78)
Group 3 (Community)	3 (16.67)
Manager (Hospital)	4 (22.22)
Manager (Community)	2 (11.11)
Level of education	
Undergraduate degree	3 (18.75)
Master's degree	8 (50.00)
PhD	5 (31.25)
Profession	
Psychology	7 (43.75)
Social Work	4 (25.00)
Occupational Therapist	2 (12.50)
University Student	2 (12.50)
Epidemiology	1 (6.25)
Years of Experience	
0-5 years	8 (50.00)
6-10 years	2 (12.50)
10+ years	6 (37.50)
Received FYF Training	15 (93.75)
First Time Implementing FYF	16 (100.00)

Note: One participant was involved in multiple roles and provided responses for each role separately, thereby creating a higher number of responses.

Appendix D

Table 9
Demographic Background of Parent Participants

	<i>M (SD)</i>	<i>n (%)</i>
Total No. of participants		9 (100.00)
Age	44.44 (3.36)	
Sex		
Male		3 (33.34)
Female		6 (66.67)
Marital Status		
Married or common law		8 (88.89)
Divorced or separated		1 (11.12)
Level of education		
High School		1 (11.12)
Some college/university		1 (11.12)
University undergraduate degree		5 (55.56)
Master's degree		1 (11.12)
Doctorate		1 (11.12)
Average Household Income		
\$50,000-\$75,000		3 (33.34)
\$100,000 and over		5 (55.56)
Not Specified		1 (11.12)

Appendix E

Table 10
Demographic Background of Child and Adolescent Participants

	<i>M (SD)</i>	<i>n (%)</i>
Total No. of participants		9 (100.00)
Age	11.89 (2.15)	
Sex		
Male		7 (77.78)
Female		2 (22.23)
First Language		
English		9 (100.00)
Ethnicity		
White, Caucasian, Anglo, or European		8 (88.89)
Chinese, Vietnamese, Cambodian, or Japanese		1 (11.12)
Age at ASD Diagnosis	9.78 (3.11)	
Primary Diagnosis ASD		9 (100.00)
Secondary Diagnosis		
Anxiety (GAD and SAD)		7 (77.78)
Attention Deficit-Hyperactivity Disorder		4 (44.45)
Developmental Coordination Disorder		2 (22.23)
Depression		1 (11.12)
Obsessive-Compulsive Disorder		1 (11.12)
Learning Disability		1 (11.12)
Current Medication		
Anxiety		5 (55.56)
Attention Deficit-Hyperactivity Disorder		6 (66.67)