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Adolescents with FASD: Education-Based Strategies for Social Skills Development

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Abstract

Fetal Alcohol Spectrum Disorder (FASD) is a permanent neurodevelopmental disorder characterized by physical, mental, and learning disabilities. Despite variability, individuals with FASD consistently struggle with acquiring appropriate social skills. Limited research has explored educational strategies that facilitate or hinder the development of social skills acquisition. The purpose of this study was to evaluate whether secondary schools have or plan to implement social skills training programs, and whether or not they are effectively targeting areas of vulnerability. In addition, the study hoped to produce recommendations for forming a successful social skills program. Nine semi-structured interviews were conducted with caregivers and service providers to identify common themes. Five themes emerged that outline key components of a successful social skills program, which addresses current weaknesses and builds upon current knowledge: Becoming FASD informed, holistic consultation, engaging the zone of proximal development, incorporating dialectical behavioural therapy (DBT) skills, and building a sense of belonging. These themes are discussed in relation to the social challenges faced by individuals with FASD, current gaps within educational programs, and future directions for constructing a formal social skills program.

Keywords: FASD, education, social skills, school, social development, intervention.

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Chapter 1: Introduction

Fetal Alcohol Spectrum Disorder (FASD) is a permanent neurodevelopmental disorder characterized by physical, mental, and learning disabilities (Millar et al., 2017). The disorder is caused by prenatal alcohol exposure (Millar et al., 2017) and results in damage to the central nervous system (Bertrand, 2009). The impact of prenatal alcohol exposure is based on numerous factors including the amount, the timing, and the frequency of alcohol consumption (Public Health Agency of Canada, 2003). In addition, the interaction between genetics, the health status of the mother, and the influence of social, economic, physical, and environmental factors also play a role (Public Health Agency of Canada, 2003). Fetal Alcohol Syndrome was first classified as a medical diagnosis in 1973 (Public Health Agency of Canada, 2003). Currently, the disorder is defined by specific diagnostic criteria set by the National Center on Birth Defects and Developmental Disabilities (NCBDD), Centers for Disease Control and Prevention (CDC), and the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect (Senturias & Asamoah, 2014). Individuals are diagnosed with fetal alcohol syndrome (FAS) when they present with severe symptoms that include abnormal facial features, growth deficits, and abnormalities in the central nervous system (Senturias & Asamoah, 2014; Wilhoit, Scott, & Simecka, 2017). In these cases, documentation of prenatal alcohol exposure is not required. In contrast, documentation is required for other disorders on the spectrum since they do not present with all these characteristics (Senturias & Asamoah, 2014). These disorders include Partial FAS (pFAS), Alcohol-Related Neurodevelopmental Disorder (ARND), and Alcohol-Related Birth Defects (ARBD; Senturias & Asamoah, 2014). As such, the severity of impairment is quite variable.

Despite this variability, individuals with FASD consistently struggle with acquiring appropriate social skills (Schonfeld, Paley, Frankel, & O'Connor, 2006). Consequently, a workshop headed by the Winnipeg School Division suggested that social skills programming be a focus with FASD children / youth in educational institutions (Millar et al. 2017). This recommendation aims to improve educational accommodations for students with FASD; however, little is known about current programming. Therefore, evaluation research is needed to address this research gap.

The Current Study

The aim of the current study is to explore what accommodations in secondary schools facilitate or hinder social skills development in adolescents with FASD. In addition, the current study highlights what additional programming is required to aid in positive social development. Partnership with a network supporting community FASD initiatives has been established. The Network is comprised of community agencies and community members who advocate, educate, and support those living with FASD. These key informants provide insight into the strengths and challenges that exist within current educational programs.

The use of a qualitative design to explore educational experiences is consistent with prior literature. Specifically, qualitative studies have explored school experiences of children with FASD (Jirikowic, Olson, & Kartin, 2008; Koren, Fantus, & Nulman, 2009); however, limited research has explored the experiences of adolescents (Duquette et al., 2006a). Existing research notes that adolescents with FASD frequently experience educational challenges and disruptions (Streissguth, Barr, Kogan, and Bookstein, 1996). A consistent challenge is developing and maintaining adaptive social skills (Schonfeld et al., 2006). Unfortunately, research has failed to evaluate social skills programming within secondary schools. This is largely because social skills

acquisition is considered a latent function of educational institutions. Moreover, targeted interventions are predominately administered at a young age. Often continuity in care is absent, despite the need for the repetition of skills. This is problematic because a negative relationship exists between age and the use of appropriate social skills for individuals with FASD (Åse, et al., 2012; Whaley et al., 2001).

Frequency of FASD in Canada

Health Canada estimates that approximately 1% of the population is affected by FASD (Millar et al., 2017) and it is the leading cause of developmental delay both in Canada and worldwide (Kully-Martens, Denys, Treit, Tamana, & Rasmussen, 2012). The Public Health Agency of Canada (2006) estimates that 3,000 babies annually are born with FASD, and that approximately 300,000 Canadians are currently living with FASD. However, reported prevalence rates likely underestimate true rates of FASD (May et al., 2006; Popova et al., 2014). Specifically, the majority of Canadians with FASD are not diagnosed or are misdiagnosed (Millar et al., 2017). Consequently, individuals affected by FASD do not have access to the support and services that they require (Public Health Agency of Canada, 2003).

Despite being a preventable disorder, FASD is a complex social issue that impacts Canadians across the country (Public Health Agency of Canada, 2003). Unfortunately, Canada's Indigenous communities have higher rates of FASD due to a history of colonization and cultural genocide (Public Health Agency of Canada, 2003). This is largely reflective of an oppressive system, where in effect, substances have been used to cope with intergenerational trauma and a lack of sufficient resources. Similarly, prevalence rates are elevated in vulnerable populations including those in the child welfare system (Lange, Shield, Rehm, & Popova, 2013) and those in

the criminal justice system (Fast & Conroy, 2009). As such, FASD is considered a major public health concern (Rasmussen, Andrew, Zwaigenbaum, & Tough, 2008).

This public health issue causes financial strain on multiple systems within society. Health Canada (2013) estimates that it costs \$1.5 million to support an individual with FASD over his or her lifetime (Duquette, Stodel, Fullarton, & Hagglund, 2006b). In addition, the annual cost of care ranges from \$57.9 to \$198.3 million in the Canadian child welfare system (Popova, Lange, Burd, & Rehm, 2014). Ontario has one of the highest rates of children with FASD in the child welfare system, costing between nine and 33 million dollars annually (Popova et al., 2014). The total direct cost to health care in Canada was approximately \$6.7 million from 2008 to 2009 and this cost is increasing (Popova, Lange, Burd, & Rehm, 2012). In Canada, the financial burden on health care institutions increased 21.6 times in a six-year period from 2002 to 2008 (Popova et al., 2012).

Utility of Findings

Research is one of the most effective ways to inform practice so that service providers are aware of what strategies and programming can effectively address the challenges and needs of adolescents with FASD. It is important that educators, service providers, and law and policy makers are aware of how educational institutions are currently functioning, what accommodations are required, and where gaps in programming exist. However, these are complex questions to answer. As such, information sharing and collaboration among key informants who form a multidisciplinary team are needed. Hearing a diversity of voices allows us to form a comprehensive answer to these questions. Ultimately, educational institutions have the power to help limit the development of secondary disabilities. Secondary disabilities occur as a result of primary disabilities, and can be prevented or reduced through the implementation of

appropriate interventions. Therefore, the present study explores how social skills programming can alleviate suffering and reduce costs. Specifically, we aim to share the knowledge of key informants who can help facilitate the creation of comprehensive social skills interventions.

Counselling. Education poses unique challenges for adolescents with FASD, and teachers struggle to provide appropriate accommodations. Consequently, students with FASD become frustrated, engage in challenging behaviours, and fail to acquire appropriate skills. These difficulties lead to the experience of school disruption, such as suspension, expulsion, or dropping out of school (Duquette et al., 2006b; Millar et al., 2017). Such events are examples of common secondary disabilities experienced by individuals with FASD (Moore & Riley, 2015). Ultimately, adolescents with FASD are more likely to experience lower life-satisfaction and lower overall well-being because of inadequate educational supports. Subsequently, individuals with FASD may choose to seek counseling services; however, counselors face a wide-array of challenges when trying to meet the needs of this population.

A dearth of systematic research has been conducted on providing effective counselling to individuals with FASD (Burd, 2007); however, two primary challenges have been identified (Masotti et al., 2015). The first challenge is a lack of openness to collaborate with services in an individual's circle of care (Masotti et al., 2015). This is largely because many professionals do not feel that they possess the expertise to offer assistance (Masotti et al., 2015). The second challenge consists of having inadequate education and knowledge about providing effective support (Masotti et al., 2015). Unfortunately, these challenges act as barriers to information sharing and to providing a holistic model of support. Consequently, Tremblay et al. (2017) found that when clinical consultation was mandated, greater collaboration occurred. Specifically, when organizations scheduled regular consultation meetings with community partners, had ongoing

internal peer consultation, and had formal monthly meetings, professionals implemented more novel ideas and found more innovative approaches. As a result, services were able to aid one another in professional confidence and skill development (Tremblay et al., 2017).

One way to facilitate clinical consultation and collaboration is by conducting research so that individual services feel competent, and more open to sharing their knowledge. As such, research is needed to better address best practices (interventions, supports, and programs) to help all professionals become more educated, informed, and confident in their interventions and strategies (Masotti et al., 2015). Specifically, by consulting with key informants, secondary schools have the opportunity to use an array of perspectives as a guide in constructing and adapting effective interventions (Pei et al., 2017). In turn, this information can be utilized by counsellors to increase their understanding of how to adapt social skills training programs. Ultimately, this knowledge could create the foundation for FASD-specific protocols.

Education. Educational institutions need to follow best-practices in order to provide appropriate accommodations for students with FASD. Without appropriate strategies and guidelines to structure program delivery, students with FASD lose the opportunity to develop their skills and become more susceptible to developing secondary disabilities (Pei, Baugh, Andrew, Rasmussen, 2017). Unfortunately, the hierarchical organization and professional status of educators can act as a barrier to collaborative advocacy and decision-making (Kalyanpur, Harry, & Skrtic, 2000). Specifically, low caregiver credibility and rigid boundaries between education and community organizations are commonplace. As such, educators need to make an active effort to retrieve information from other key informants (Kalyanpur et al., 2000).

As such, research provides an opportunity for educational institutions to consider the knowledge and experiences of both caregivers and professionals (Kalyanpur, Harry, & Skrtic,

2000). Achieving this partnership requires policy development, continual funding, and educational planning between all stakeholders (Millar et al., 2017). In addition, outcome research facilitates specialized programme evaluation that allows for comparison among groups. For instance, it allows educators to compare academic accommodation and accessibility services within both inclusive and specialized FASD classrooms (Millar et al., 2017). The ultimate aim is to make programming more accessible and effective at addressing individual needs.

Policy. This research can help to inform and support amendments to educational policy that focuses on providing support and accommodations to students with FASD. Fortunately, there has been movement towards greater collaboration in special education decision-making processes. For instance, the Individuals with Disabilities Education Act (IDEA) recommends that professionals consult with caregivers and receive their input on their child's educational needs (Turnbull & Turnbull, 1998). In addition, this US policy recommends that caregivers are informed of their rights and are notified of any changes of placement. This reflects the importance of including key informants in educational decisions and demonstrates that partnership is needed between caregivers, education, and law and policy (Turnbull & Turnbull, 1998).

The use of collaboration is also reflected in Canadian policy. Specifically, the Standing Committee on Justice and Human Rights recommended that the federal government collaborate with the provinces and territories and key stakeholders when conducting best practice research (Canada: House of Commons, 2015). This research aims to improve the understanding of FASD, to inform the public about protective and risk factors, and to support initiatives that improve health outcomes (Canada: House of Commons, 2015). More recently, Bill 191 has been issued and it was introduced in the house on December 13, 2017 (Legislative Assembly of Ontario,

2017). The bill outlines amendments to the Education Act, which includes the stipulation that Ontario school boards develop and implement best practices that promote the success of students who are impacted by FASD (Legislative Assembly of Ontario, 2017). Unfortunately, the Bill did not pass and the promotion of best practices has been placed on hold. The Progressive Conservative Party took leadership following the 42nd Ontario General Election. Consequently, budget cuts were made to education programs. If future funding does get allocated to accommodating the needs of students with FASD, this research can inform the development of best practices.

Chapter 2: Literature Review

In this chapter, effects of prenatal alcohol exposure are reviewed along with ways to target and prevent the formation of secondary disabilities. In addition, social skills acquisition, social skills interventions, and the role of educational institutions are explored.

Effects of Prenatal Alcohol Exposure

FASD is characterized by structural and functional brain damage (Streissguth, 1997), which leads to physical, mental, and learning difficulties (Millar et al., 2017). These difficulties are classified as primary effects since they are directly related to prenatal alcohol exposure. Specifically, individuals with FASD have functional impairment in a variety of behavioural and cognitive domains (Kodituwakku, 2009). The effected cognitive domains include global deficits, executive functioning, verbal and nonverbal learning and memory, language, visual-spatial ability, motor function, and attention and hyperactivity (Kodituwakku, 2009; Mattson, Crocker, & Nguyen, 2011). Extensive neuropsychological research has been conducted to explore these domains and the clinical profile of individuals with FASD (Mattson et al., 2011). In this chapter, research related to behavioural difficulties and global deficits will be explored. In addition, particular attention will be paid to disruptions in executive functioning. These three factors play a critical role in understanding the school experiences of individuals with FASD.

Behavioural difficulties. Individuals with FASD exhibit a variety of behavioural problems, which include disruptions in attention, problematic behaviour, poor academic performance, and low social competence (Mattson et al., 2011). Specifically, a meta-analysis revealed that children with FASD exhibit more internalizing (e.g. depression) and externalizing (e.g., hyperactivity, antisocial behaviour) behaviours than children without FASD (Tsang, Lucas, Carmichael Olson, Pinto, & Elliott, 2016). For instance, individuals with FASD have higher rates of mood disorders than their unaffected peers (O'Connor & Paley, 2006). Similarly, rates of

oppositional defiant disorder, conduct disorder, and ADHD are high (D’Onofrio et al., 2007). These problems reflect difficulties with emotion regulation and an increased susceptibility to becoming overwhelmed and overstimulated (Olson & Montague, 2011). Unfortunately, individuals with FASD often struggle to calm themselves down once they reach these states of high affect (Olson & Montague, 2011). As a result, they often react with tantrums and socially disruptive behaviours (D’Onofrio et al., 2007). Similarly, these factors contribute to poor sustained attention and poor maintenance of meaningful relationships (Tsang et al., 2016).

Research evidence suggests that both internalizing and externalizing behaviours exhibited in childhood continue to persist in adolescence and adulthood (Barr et al., 2006). Consequently, individuals with FASD engage in more delinquency and exhibit more aggressive behaviours than their unaffected peers (Tsang et al., 2016). These behaviours place this population at greater risk for adverse life outcomes. As such, these behaviours need to be targeted through effective programming that reflects their intellectual capacity and learning style.

Global deficits. Individuals with FASD experience global deficits when trying to process and integrate information (Kodituwakku, 2009). This is emphasized by their average IQ scores (Rasmussen, 2005). Specifically, they have an average IQ of 70 (Streissguth, et al., 1991) with the majority of individuals with FASD falling between the borderline and low average range on standardized intelligence measures (Howell, Lynch, Platzman, Smith, & Coles, 2006, Kodituwakku, 2009). For instance, difficulties were found in areas of reading and spelling, as well as in mathematics (Howell et al., 2006). Intellectual impairment is consistently found in this population, even in the absence of facial features and diminished growth (Dalen, Bruaroy, Wentzel-Larsen, & Laegreid, 2009). The average IQ of individuals without these features is approximately 80 (Mattson et al., 1997). In contrast, individuals with facial features (e.g. smooth

philtrum, short palpebral fissures, and thin upper lip) typically display more severe intellectual impairment (Mattson, Riley, Gramling, Delis, & Jones, 1997). Therefore, general cognitive function is significantly associated with the degree of growth deficiency and facial dysmorphia (Mattson et al., 1997).

Furthermore, a consistent relationship has been found between an individual's IQ score and the development of psychopathology (Steinhausen, Willms, & Spohr, 1994). Children with FASD who had moderate to severe intellectual difficulties experienced an elevated rate of psychological distress (Steinhausen et al., 1994). As such, education and the development of adaptive skills are required to buffer against this vulnerability. Consequently, functional domains that are amenable to change require special programming.

Disruption in Executive Functioning. One hallmark of FASD is the disruption in executive functioning, which is characterized by problems with self-control and self-regulation (Kodituwakku, 2007; Nash et al., 2015). Specifically, this construct encompasses a variety of higher order cognitive processes, including planning, response inhibition, working memory, and the integration of more basic processes (Pennington & Ozonoff, 1996). Caregiver self-report data has indicated that prenatal alcohol exposure leads to impairment on executive function tasks that measure a variety of skills, including verbal and non-verbal fluency, response inhibition, working memory, and problem-solving (Mattson et al., 2011). In addition, a large body of neuropsychological research on children with FASD highlights a pattern where affected children succeed at simple tasks but display greater difficulty on more complex tasks (Kodituwakku, 2007). This illustrates how prenatal alcohol exposure disrupts the processing and integration of complex information, especially when they are required to hold and manipulate information in working memory (Kodituwakku, 2007). Therefore, it is more difficult to engage in effective

problem solving to achieve future goals (Welsh & Pennington, 1988). This is particularly concerning since a meta-analysis revealed that impairment in executive functioning is significant across development (Khoury, Milligan, & Girard, 2015).

As such, prenatal alcohol exposure is associated with a lower acquisition of life skills. Alcohol effects prevent higher order processes that allow the rest of the population to plan ahead, consider consequences, and respond appropriately to emotions (Mattson et al., 2007). Consequently, individuals with FASD struggle to obtain independence and meaningful relationships. This is illustrated by independent living difficulties, employment difficulties, an inability to learn from mistakes, and problems with socialization (Rasmussen et al., 2008). As such, individuals with FASD are vulnerable to developing secondary disabilities that could include mental health challenges, dropping out of school, issues with deviance and law breaking, as well as substance abuse (Kully-Martens et al., 2012; Millar et al., 2017; Moore & Riley, 2015; Public Health Agency of Canada, 2006). Therefore, a greater understanding of secondary disabilities is required in order to develop programming that can lower this population's susceptibility.

Development of Secondary Disabilities

Secondary disabilities are conditions that develop as a result of other pre-existing vulnerabilities (Moore & Riley, 2015), and hinder individuals with FASD from behaving in socially acceptable ways (Kelly, Day, & Streissguth, 2000). These vulnerabilities are emphasized by the increased prevalence of negative life outcomes in adults with FASD, including higher rates of psychiatric illness and legal problems (Kodituwakku, 2007). For example, Streissguth et al. (2004) noted that 90% of adults with FASD experience some form of mental health problem and 60% have contact with the criminal justice system. Similarly, 45% experience substance use

problems, which can lead to unstable housing and homelessness (Streissguth et al, 2004). In addition, 415 caregivers reported higher rates of inappropriate sexual activity, trouble with the law, disrupted school experiences, and illegal substance use (Streissguth et al., 1996). Moreover, Spohr, Willms, & Steinhausen (2007) explored the vocational and independent living outcomes for adults with FASD. Spohr et al. (2007) noted that 69% of their sample had at least foundational job training, while only 13% held an “ordinary” job at a 20-year follow-up (Spohr et al., 2007). Similarly, only 16% of their sample lived with a partner or had their own family (Spohr et al., 2007). The other two-thirds were in a dependent-living or institutional setting (Spohr et al., 2007). Similarly, a survey with caregivers of adults with FASD revealed that 37% required moderate care, while the other 44% required extensive care (Clark, Minnes, Lutke, & Ouellette-Kuntz, 2008). These findings were surprising considering only 34% had an IQ score that was indicative of a diagnosable intellectual disability (Clark et al., 2008). Given these prevalence rates, and the resulting financial burden it imposes on healthcare, education, social services, and criminal justice systems (Rasmussen et al., 2008), it has become necessary to develop more comprehensive treatment (Pei, Wing SzeWence, Jampolsky, & Alsbury, 2016). Fortunately, such accommodations can help to prevent the process of developing secondary disabilities.

Targeting Secondary Disabilities

One way to target secondary disabilities is by improving the recognition of FASD (Streissguth et al., 2004). Specifically, a diagnosis before the age of six years is associated with a significant decrease in the development of secondary disabilities (Coriale et al., 2013). Early diagnosis allows caregivers to utilize resources that mitigate the effects of prenatal alcohol exposure (Chudley et al., 2005). The literature suggests that maternal self-reports about alcohol

consumption are the most practical and valid methods of identification (Bax, Geurts, & Balachova, 2015). This is largely due to a lack of confidence, skill, and time to effectively screen for prenatal alcohol exposure (Bax et al., 2015). Fortunately, a variety of self-report methods have shown validity, and thus assist in the process of early identification and accessibility to supportive services (Bax et al., 2015).

In addition, the development of secondary disabilities can be prevented by reducing the impact of risk factors. For instance, semi-structured interviews with both service providers and individuals with FASD revealed that biological, psychological, and social risk factors all contribute to the formation of secondary disabilities (Pei et al., 2016). Specifically, poor-decision making, lack of assertiveness, victimization, and limited social support increased the risk of criminal justice system involvement (Pei et al., 2016). As such, proper interventions need to be developed that reduce the impact of primary disabilities and, ultimately, decrease the likelihood that secondary disabilities will emerge (Pei et al., 2016).

More specifically, primary disabilities related to executive functioning can be improved through social skills interventions. In particular, improving social skills shows promise in reducing risk factors since social skills and executive functioning have been linked within this population. Consequently, social skills interventions can be designed to nurture higher order processing. For instance, a study of 98 children with FASD found that executive functioning explained a significant proportion of the variance found in parent- and teacher-rated social skills (Schonfeld et al., 2006). They utilized two measures (the BRIEF and the SSRS), which also found that social skills deficits were consistent in all forms of FASD (Schonfeld et al., 2006). As such, social impairment appears consistent for this group despite the severity of prenatal alcohol exposure (Schonfeld et al., 2006). Similarly, poor adaptive functioning has been linked to

adverse life outcomes in adults with FASD (Crocker, Vaurio, Riley, & Mattson, 2009). Specifically, poor skill acquisition in the domains of communication, daily functioning, and socialization have been linked to the formation of secondary disabilities (Crocker et al., 2009). As such, this impairment discourages the formation of social supports and positive peer relationships (Kelly et al., 2000; Thomas, Kelly, Mattson, & Riley, 1998), which increases this population's vulnerability for future adversity (Crocker et al., 2009). Thus, the development of social skills programming and outcome research is needed.

Social Skills

Social skills refer to one's ability to interact with others, including expressing and recognizing emotion, developing relationships, assisting others, and using social cues to direct behaviour (Kully-Martens et al., 2012). In addition, social skills include responsibility, following rules and laws, and the use of interpersonal skills (Kully-Martens et al., 2012). Unfortunately, individuals with FASD show significant social impairment. Specifically, individuals with FASD are more open to suggestion, have a preference for younger friends, are less mature, have less specified interactions, engage in less suitable initiations, and their adaptive skills are significantly lower than their cognitive potential (Senturias & Asamoah, 2014). Consequently, individuals with FASD struggle to form and maintain healthy relationships and are at greater risk for bullying and victimization (Wilhoit et al., 2017). This social rejection provokes low self-esteem, anxiety, depression, and personal maladjustment (Kully-Martens et al., 2012). Ultimately, this leads them to become further isolated and aggressive, which perpetuates interpersonal issues into adulthood (Wilhoit et al., 2017). These interpersonal issues are well documented and have been measured using a variety of well-established measures.

Significant social impairment has been found to be consistent within this population and has been measured using subscales on the Vineland Adaptive Behaviour Scales (VABS; Ase et al., 2012) and the Child Behavior Checklist (CBC; Whaley, O'Connor, & Gunderson, 2001). For instance, a study of 143 children and adolescents with FASD found poor adaptive behaviour (communication, daily living skills, and socialization) when compared to normally developing controls and IQ-matched individuals with a specific learning disorder (Åse et al., 2012). Similarly, 33 children with FASD were found to show deficits on all aspects of adaptive functioning, and deficits in socialization and social skills were highlighted (Whaley et al., 2001). In both studies, a negative relationship between social skills and age were found for individuals with FASD (Åse et al., 2012; Whaley et al., 2001). This is consistent with research findings that have indicated that adolescents and adults with FASD often continue to have negative peer relationships (Streissguth et al., 1991), which may contribute to future delinquency and school failure (Schonfeld, Mattson, Lang, Delis, & Riley, 2001). As such, early social skills training are required for individuals with FASD to increase their adaptive functioning and their ability to have positive interactions with others (Coriale et al., 2013; Whaley et al., 2001). The literature provides some evidence of social skills programming for children with FASD; however, it fails to explore the effects of social skills training for older populations.

Improving Social Skills Acquisition

Social skills interventions have been successful in addressing social impairment in a variety of disorders; however, few have been developed for individuals with FASD (Kully-Martens et al., 2012). For instance, dialectical behaviour therapy (DBT) skills are a valid and reliable form of intervention for helping adolescents manage intense affective states, cope with

internal and external stressors, and facilitate problem solving (Mazza, 2016). Unfortunately, limited research exists on this intervention's application with individuals with FASD.

The first study to systematically implement social skills training yielded positive results on the Test of Social Skills Knowledge measure (O'Connor et al., 2006). Specifically, they evaluated a child friendship training program at a university that included 100 children with FASD (O'Connor et al., 2006). Those who received the program displayed fewer behavioural problems and improved social skills (O'Connor et al., 2006). Yet, these positive results were only found on child- and parent-measures, while teachers did not report positive gains. Future studies would benefit from measuring social behaviours in a more naturalistic setting to explore the lack of consistency between parent and teacher findings. For instance, implementing the program in their own classroom or home may yield more consistent results. This would help to address this study's methodological issues.

In an attempt to use a more naturalistic setting, a later study was conducted with 85 children with prenatal alcohol exposure in a community mental health center (O'Connor et al., 2012). The children were either assigned to the Children's Friendship Training (CFT) program or the Standard of Care (SOC) program (O'Connor et al., 2012). The controlled trial found that children who participated in CFT showed significant improvements on both child- and parent-reported social skills measures, which included the Test of Social Skills Knowledge (TSSK), the Piers-Harris Children's Self-Concept Scale-Second Edition (Piers-Harris 2), and the Social Skills Rating System-Parent Form (SSRS-P; O'Connor et al., 2012). Surprisingly, children who participated in the intervention showed comparable performance to children without prenatal alcohol exposure (O'Connor et al., 2012). In addition, both children with and without prenatal alcohol exposure benefited from the CFT program (O'Connor et al., 2012). Thus, social skills

programming can be integrated into a variety of treatment protocols and educational institutions since it also benefits individuals without FASD (O'Connor et al., 2012). Educational institutions are therefore a desirable setting to explore social skills programming for this group.

Social skills programming has shown sustainable outcomes with younger age groups, and thus shows promise moving forward. For instance, 100 children with prenatal alcohol exposure were randomly assigned to either a Children's Friendship Training (CFT) program or a Delayed Treatment Control group (Keil, Paley, Frankel, & O'Connor, 2010). Those in the CFT program learned elements of good communication, how to exchange information, and how to join play while following basic rules. The study found that children who participated in the social skills intervention exhibited fewer hostile attributions in peer group entry scenarios and these positive gains were maintained at a three-month follow-up (Keil et al., 2010). In contrast, the intervention did not impact provocation scenarios, which suggests that intervention effects are domain specific (Keil et al., 2010). Specifically, the social skills training program focused on teaching these children how to join and talk with peers while engaging in social activities, and how to respond appropriately to both acceptance and rejection of peer entry (Keil et al., 2010). This suggests that children with FASD are responsive to social skills training programs and can continue to implement skills they have acquired (Keil et al., 2010). However, such programming needs to target specific behaviours and skills since gains do not appear to generalize to other situations (Keil et al., 2010).

Thus, targeted social skills programming shows the most promise. Nash et al. (2015) conducted a study where 25 children with FASD were assigned to either an immediate treatment or a delayed treatment group to determine how an Alert program would influence executive functioning. Both questionnaires and executive functioning tests were utilized pre- and post-

treatment, as well as at a six-month follow up to explore maintenance. The Alert program was conducive to improvements in self-regulation; however, no impact was found on parent-rated social skills. These results were surprising considering the established relationship between executive functioning and social skills (Yeates et al., 2007). However, it is likely indicative of the low baseline of social skills and the need for direct instruction of when and how to apply the learned skills (Yeates et al., 2007). More specifically, this is consistent with the finding that individuals with FASD are context-specific learners, which means that it is difficult for them to apply skills learned in one situation to another (Wilhoit et al., 2017). Therefore, individuals with FASD appear to need targeted programming to improve their social skills and to encourage adaptive behaviour (Åse, et al., 2012).

Social Skills Training in Schools

More recently, it has been suggested that schools place a larger emphasis on social skills programming (Millar et al., 2017) since effective education services have been shown to mitigate negative outcomes (Senturias & Asamoah, 2014). Similarly, schools have been targeted as the institution to administer such support since students with FASD are more likely to drop out or be suspended, which in turn provokes the development of secondary disabilities (Duquette et al., 2006b; Millar et al., 2017). In addition, students with FASD already require special consideration in educational institutions to mitigate their unique developmental trajectory and individualized disabilities (Millar et al., 2017). For instance, the most frequent behaviour problems cited in schools were difficulty getting along with peers and regularly being disruptive in class (Duquette, Stodel, Fullarton, & Hagglund, 2006a). Moreover, adolescents with FASD cited their diagnosis as a barrier to relating to peers (Duquette et al., 2006b), and FASD students were found to display greater variability in social communication (Kjellmer & Olswang, 2013). For

example, twelve pairs of children were observed for 20 minutes a day for four days in a classroom (Olswang, Stevenson, & Astley, 2010). Classroom social communication was documented to see if any differences existed between children with FASD and their typically developing matched peers (Olswang et al., 2010). Children with FASD were found to engage in more passive and irrelevant behaviour and exhibited shorter instances of prosocial interactions than their pair-matched peers (Olswang et al., 2010). Therefore, schools need to provide a variety of supportive services especially during transitional periods, such as from elementary school to high school (Wilhoit et al., 2017). As such, multidisciplinary teams have developed specialized strategies and programs to implement in both inclusive and FASD-specific classrooms (Millar et al., 2017). The aim is to facilitate and support academic success, as well as social skills development (Millar et al., 2017). Ultimately, the formation of specialized strategies could aid in addressing secondary disabilities and minimize their impact in the future (Millar et al., 2017).

Specifically, the Winnipeg School Division established one of the first classrooms for students with FASD in Canada in 1995 (Millar et al., 2017). The division has shown national leadership in developing innovative strategies for educating students with FASD. More recently, the Winnipeg School Division offered a workshop that explored the experiences and informed perspectives of 36 key informants across Canada involved in FASD education (Millar et al., 2017). The workshop revealed best practices for accommodating and supporting students with FASD and suggestions for programming moving forward (Millar et al., 2017). A key suggestion for schools was to provide additional programming that focused on executive functioning, and more specifically, social skills programming (Millar et al., 2017). As such, the current study will evaluate whether schools have or plan to implement social skills training programs, and whether or not they are effectively targeting areas of vulnerability.

Current research suggests that negative peer relationships are common within the educational setting. For example, semi-structured interviews were conducted with adults with FASD in urban areas in Western Canada (Knorr & McIntyre, 2016). The purpose of the study was to explore their peer relationships within educational institutions and their community (Knorr & McIntyre, 2016). One theme that emerged was that adults with FASD felt that they did not fit in (Knorr & McIntyre, 2016). As such, these negative school experiences led them to feel greater anger and frustration towards their FASD diagnosis (Knorr & McIntyre, 2016).

These negative experiences were also noted by teachers. A qualitative study exploring education practices was conducted with 20 teachers who worked with children with FASD in either primary, secondary, or special schools (Carpenter, 2011). Semi-structured interviews with the teachers and non-participant observations revealed that one of the top challenges for teachers was the lack of social skills within this group (Carpenter, 2011). Lack of social skills significantly hindered the capacity of the student with FASD to form appropriate relationships with teachers and peers (Kalberg & Buckley, 2007; Roebuck, Mattson, & Riley, 1999). Specifically, group work regularly presented problems since the child with FASD often engaged in irrational and inappropriate behaviour despite longing for peer relationships (Carpenter, 2011). Consequently, teachers tried to implement buddy systems to increase interaction; however, the child with FASD was often found to be verbally or physically abusive towards the other child (Carpenter, 2011). Given these difficulties, it is not surprising to find that 60% of students with FASD are likely to experience suspension, expulsion, or to drop-out before the age of 18 (Streissguth, 1997). Thus, studies have attempted to provide evidence-based suggestions to improve skill acquisition for this population (Carpenter, 2011; Green, 2007); however, further research is required to explore educational strategies that achieve significant improvements in

adaptive functioning. Ultimately, schools need to implement programming that maximizes these students' learning and development (Poth, Pei, Job, & Wyper, 2014). This can only be achieved if practices are evaluated and re-structured to build upon individual strengths.

Summary

A review of the existing literature reveals that individuals with FASD are vulnerable to developing secondary disabilities that negatively impact their well-being. One way to target secondary disabilities is by improving executive functioning through social skills programming. Social skills programming can be delivered through the school system, where students can utilize their acquired skills; however, little research has explored the school experiences of individuals with FASD, and specifically those of adolescents (Duquette et al., 2006a). Similarly, the majority of social skills interventions have targeted children with FASD (Reid et al., 2015). As such, additional research is required to evaluate social outcomes of adolescents who participate in specialized programs (Millar et al., 2017). Adolescents' experiences should be targeted since social skills have been found to decline with age (Åse, et al., 2012; Whaley et al., 2001), and successful interventions could help to reduce the development of secondary-disabilities (Reid et al., 2015). Effective programming may minimize significant risks such as suspension, expulsion, and drop-out. Ultimately, further exploration of current experiences and areas in need of change will facilitate the formation of best practice strategies for adolescents with FASD.

Chapter 3: Method

Participants and Recruitment

The sample of participants was obtained through a partnership with a network supporting community FASD initiatives in a medium sized city and its surrounding area. Access to the Network was gained through a prior relationship that was established between the thesis supervisor and the Network. One of the lead members at the Network partnered with the researcher and granted her permission to conduct semi-structured interviews with anyone wanting to participate. The leadership of the Network gave approval for the guiding questions used in this study. Approval of the use of human participants was obtained prior to data collection from the office of Human Research Ethics on behalf of Western's Research Ethics Boards (REB).

All participants were key informants from the local area. Each participant had to fall into one of three categories: caregiver, young adult with FASD, or service provider (including counsellors, educators, social services staff, and community agency staff). The Network is a group of community agencies, individuals, and service providers whose mission is to enhance the community's capacity for advocacy and support related to FASD in the areas of community awareness, education, diagnostics, justice, parent support, and mutual professional support and collaboration. All individuals connected with the Network were invited to participate if they were over the age of 18. This ensured that all participants had some experience with secondary institutions. In addition, no attention was paid to race, ethnicity, or area of residence. As such, the only demographic information collected was age, sex, and the participant's role in the Network.

A purposive sample was used whereby an administrative assistant at the Network recruited participants through the distribution of flyers via email. In addition, flyers were distributed in-person during monthly meetings. A scripted explanation of the study and its purpose was provided on the flyer where individuals were encouraged to email the researcher if they were interested in participating in the study. All participants were told that the purpose of the study was to gain an understanding of what education-based strategies facilitate or hinder social skills development for adolescents with FASD. In addition, they were asked about what programming or strategies could facilitate greater acquisition of social skills. Data collection began once ethical approval was granted and continued until the point of saturation. As such, data analysis occurred throughout the data collection process.

All participants were given the option to partake in the semi-structured interview either within their home or in an empty classroom on the University campus. If an in-person interview could not be successfully scheduled, the participant was invited to complete a phone interview. In the former case, a letter of information was presented to each key informant, and the researcher provided a verbal summary of each section to ensure informed consent was provided. In the latter case, the letter of information was emailed to the participant and they were asked to fax the signed consent form to the researcher prior to their scheduled phone interview. At the time of the interview, the participant was provided with a brief summary of the letter of information (LOI) and was asked for verbal assent.

A total of nine interviews were conducted. The nine participants included eight female participants (five caregivers and three service providers) and one male participant (service provider). Unfortunately, no young adults with FASD were successfully recruited. Caregiver age range was from 50 to 70 ($M = 58.80$, $SD = 7.71$), and service provider age range was from 47 to

67 ($M = 60.00$, $SD = 6.97$). All service providers had minimum college level education in child and youth work, and no caregiver was a biological parent (all were adoptive parents). In addition, all caregivers indicated extensive involvement in their loved one's educational endeavours.

Data Collection

The phenomenological qualitative approach utilized aimed to understand the experiences and perspectives of key informants via face-to-face or over-the-phone semi-structured interviews. All key informants were asked for permission to audio record as well as permission to use anonymous quotes. Participants were then asked to complete the informed consent form and to indicate whether permission was granted using explicit check boxes. If permission to audio record was denied, case field notes were taken. In the two in-person interviews conducted, both participants consented to audio recording and anonymous quotes. For the seven over-the-phone interviews, the researcher took case field notes throughout the interview. Participants were informed that all answers provided would be kept confidential and that all audio recordings would be transcribed verbatim by the researcher, stored in a lock box at the Faculty of Education during the coding process, and then destroyed after seven years.

Guiding questions were used to facilitate discussion in interviews, which utilized open-ended questions (see Appendix A). These guiding questions aimed to reveal key informant experiences, perceptions, and beliefs about what education-based strategies facilitate or hinder the development of social skills for adolescents with FASD. Additional questions and prompts were subsequently added throughout the data collection processes that were found to initiate relevant data. All participants were asked explicitly about what challenges are experienced in the realm of social skills, and whether or not they feel social skills are important for adolescents with FASD. In addition, all key informants were asked if they thought educational institutions should

be responsible for implementing social skills programming. These questions helped to develop rapport between the researcher and the participant and added contextual information that aided in the researcher's understanding of the participant's views and experiences. The only demographic information collected was age and sex. In addition, each participant was asked to identify whether they were a caregiver or a service provider and what position they occupy. Each individual interview lasted between 23 minutes and 60 minutes. At the end, all participants were asked if they have something they would like to add about their experience.

Semi-structured interviews were conducted to the point of saturation, which was defined as being reached after three consecutive interviews where no new information was provided. Specifically, the last three participants reflected experiences that were already conveyed in the dataset. The study's sample size was characteristic of phenomenological qualitative research and adhered to general guidelines of saturation (Mason, 2010). The same researcher was present for each semi-structured interview. In addition, the researcher attended a few of the Network's monthly meetings. As such, the researcher was familiar with the culture and vision of the Network and gained experience interacting with its members.

Data Analysis

The researcher transcribed all audio recordings verbatim and typed all case field notes. After the point of saturation was reached, the process of transcribing was completed and all transcripts were checked against the tapes for accuracy (Braun & Clarke, 2006). The process of thematic analysis then began. First, the researcher and thesis supervisor thoroughly read through the data three times to gain an overall understanding and to consider all the data that was present. Both parties also noted any initial ideas (Braun & Clarke, 2006), and considered the data in relation to the two research questions (Crowe, Inder, & Porter, 2015). Next, the researcher and

thesis supervisor individually generated a preliminary list of possible codes (consisting of one to three words per code) for a total of four interviews, two for service providers and two for caregivers. The two lists were compared, discussed, and amalgamated to form one comprehensive list of codes. Subsequently, all transcriptions and case field notes were coded using a chart that included meaning units (quotes from the data) and relevant codes. After this was completed, the researcher and thesis supervisor compared coding to look for agreement. The coding process concluded once both felt that the process was thorough, inclusive, and comprehensive (Braun & Clark, 2006). Finally, the codes were tallied for frequency (see Table 1) and clustered in order to generate potential themes (see Table 2; Crowe et al., 2015). These themes were considered in comparison to each other and in relation to the original data set, which generated a thematic map (Attride-Stirling, 2001; Braun & Clarke, 2006). The researcher and thesis supervisor constructed thematic networks (see Figure 1) and compared basic, organizing, and global themes (Attride-Stirling, 2001). Ongoing analysis occurred until each theme was defined and clearly named (Braun & Clarke, 2006; Crowe et al., 2015), and until refinement of the thematic networks were complete (Attride-Stirling, 2001). Themes were accepted when they were deemed internally coherent, consistent, and distinctive (Braun & Clarke, 2006). Each theme was illustrated by referencing the transcripts through the use of quotes (Crowe et al., 2015). The final phase consisted of synthesizing the findings where the relationship between themes and the socio-cultural context were explored (Attride-Stirling, 2001; Crowe et al., 2015). Specifically, the researcher and thesis supervisor described, explored, and summarized the network until an interpretation was reached (Attride-Stirling, 2001). This interpretation was reflective of the two research questions (Crowe et al., 2015). Finally, all

themes and interpretations were presented to participants and they were asked to confirm or challenge the research findings.

Table 1

Code Frequencies

Codes	Frequency
Need formal learning	52
Need specialized support/programming	49
Collaboration	40
Exclusion	34
Education	33
Individualized needs	31
Strength oriented	28
Emotional regulation	28
Inclusion	26
Life skills	22
Continuity in care	22
Modelling	22
Problematic behaviour management	22
Teaching the average	21
Pervasive problem	19
Belonging	18
Interpersonal effectiveness	17
Emotional intelligence	16
High risk	16

Context is important /consider context	16
Have informal learning	16
Self-esteem	14
Universal program/programming	12
Diagnosis	11
Low accommodation accessibility	11
Negative labelling	11
Communication	10
No standardization	9
Practice	8
Acting out	8
Vulnerability	7
Bullying	6
Workplace	6
Assessment	5
Invisible disability	5
Hands-on learning	5
Repetition	4
Caregiver credibility	4
One-to-one	4
Low comprehension	3
Overwhelmed/overstimulation	3
Team/community	3
Risky sexual behaviour	3
Memory	3

Focused goals/directives	3
Black and white thinking	2
Passing	2
Role play	2
Empathy	2
Mentoring	2
Self-care strategies	2
Confabulation	2
Black and white	1
Literal	1
Delayed response	1
Lower IQ	1
Embarrassing	1
Confirmation bias	1
Mindfulness/relaxation	1
Executive functioning	1
Formal training needed	1
Isolation	1
Boundaries	1
Silos	1
Visual tools	1
Behavioural control	1
Coping	1
Distress tolerance	1
Mental health	1

Rule-oriented	1
Theory of mind	1
Legal problems	1
Physical activity	1

Table 2

Emerging Themes

Themes	<i>Relevant codes</i>
Lack of education	Black and white; delayed response; literal; invisible disability; diagnosis; negative labelling pervasive problem; education;
Secondary disabilities	High risk; vulnerability; legal problems; risky sexual behaviour; bullying; mental health
Current use of ineffective strategies	Problematic behaviour management; acting out; overwhelmed/over-stimulated
Key informants	Collaboration; caregiver-credibility
Wrap-around approach	Continuity in care; life skills; workplace; silos
Restructure curriculum	Individualized need; need specialized support/programming; low accommodation accessibility; need formal learning; have informal learning; universal programming program/programming; teaching the average
Use comprehensive strategies	Low comprehension; lower IQ; memory; strength-oriented; modelling; hands-on learning; practice; visual tools; role-play
Construct an evidence-based program	Interpersonal effectiveness; emotional intelligence; communication; emotional regulation; context is important/consider context; no standardization; mindfulness/relaxation; focused

Develop intimacy

Maintain autonomy

goals/directives

Exclusion; inclusion; belonging;
team/community; isolation

Self-esteem; self-care strategies; coping

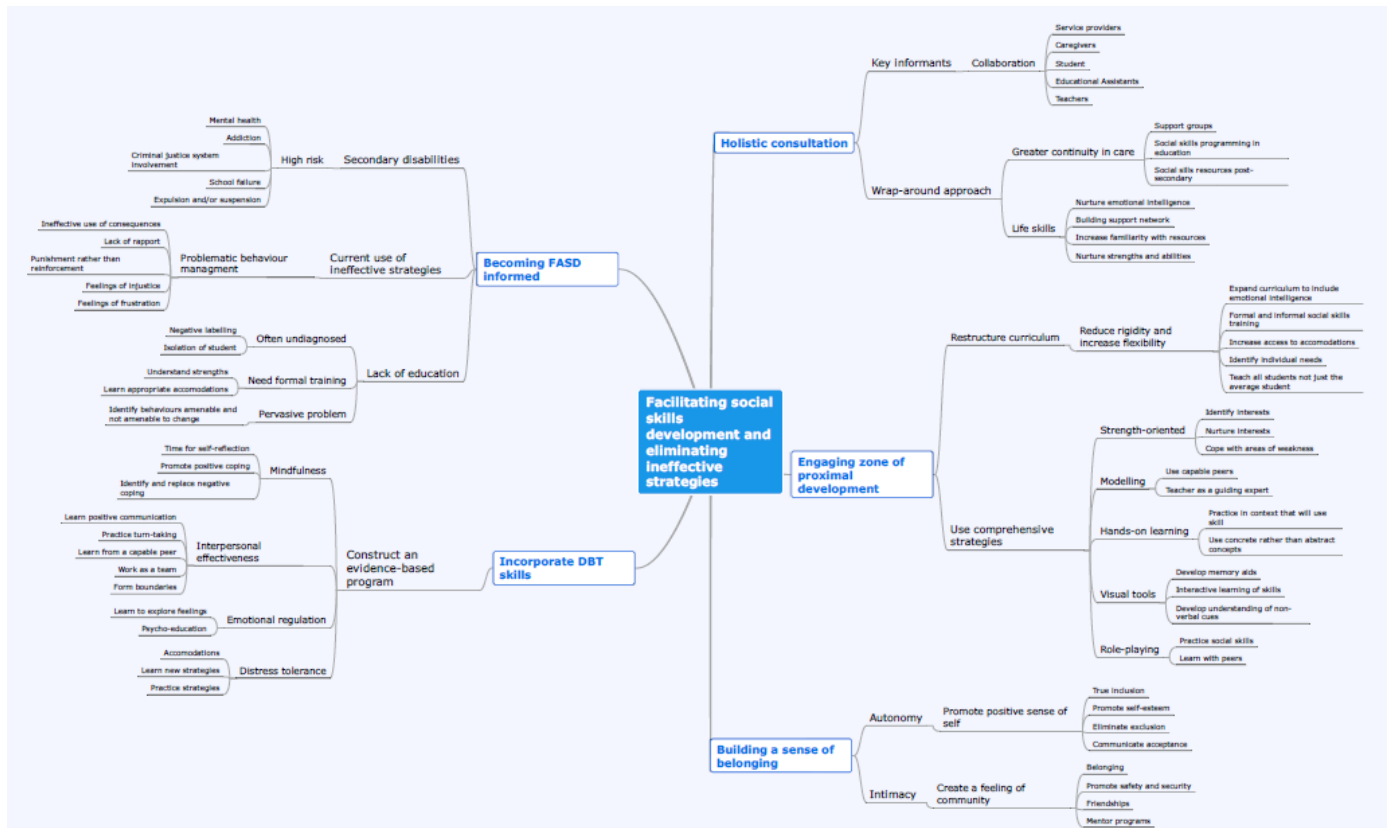


Figure 1. Thematic Network: Facilitating social skills development and eliminating ineffective strategies

Throughout the process of data analysis, ongoing collaboration occurred between the researcher and thesis supervisor to achieve agreement on the process of thematic analysis, the construction of thematic networks, and the interpretation of the data. This collaboration created the opportunity to explore alternative interpretations and contributed to the trustworthiness of this study. Specifically, collaboration helps to minimize individual biases and promotes a comprehensive exploration of various perspectives. In addition, direct quotes are frequently referenced throughout the paper to increase confidence in the results. The use of direct quotes helps illustrate participant meaning and connects interpretations within the context of the original data set. Participants were asked for their input via email. Each participant was presented with the opportunity to clarify their perspective, and confirm or challenge any interpretations made. As such, trustworthiness and confidence in the data was enhanced through the use of verbatim transcripts, member checking, and multiple coders (Merriam, 2009; Patton, 2002).

Chapter 4: Results

This study aimed to identify what educational strategies currently exist within secondary schools that target social skills acquisition, as well as what additional programming could be implemented to aid in positive social development for students with FASD. Interviews were conducted with both caregivers and service providers. Seven of the nine interviews were conducted by telephone, and two were conducted in-person. After data analysis, the results were presented to the same caregivers and service providers to ask for feedback and to give them an opportunity to challenge the themes in the thematic network. This chapter presents the results of the thematic analysis that shares the voices and experiences of caregivers and service providers, which highlight the strengths and challenges of current educational programs. Ultimately, these themes provide insight into current educational experiences, as well as recommendations for constructing formal social skills programming.

Five themes emerged from the data, which outline important strategies to facilitate social skills acquisition in adolescents with FASD, and that reflect how a social skills program can effectively target areas of vulnerability: 1) *Becoming FASD informed*, 2) *Holistic consultation*, 3) *Engaging the zone of proximal development*, 4) *Incorporating DBT skills*, and 5) *Building a sense of belonging* (see table 3). Becoming FASD informed and holistic consultation dominantly represent solutions to current areas of weakness that act as a barrier to the development of social skills. The latter three themes dominantly represent recommendations for constructing formal social skills programming in the future, which reflect positive strategies that have been used or what participants felt would be helpful based on their experience and knowledge-base. Together, these five themes highlight the need for the development of social skills programming.

Table 3

Summarization of Themes

Theme	<i>Explanation</i>
Becoming FASD informed	<p>The majority of teachers and educational assistants have not received formal training or education on students with FASD. Consequently, these students are at high risk for negative school experiences that are characterized by negative labelling and behavioural consequences that hinder rather than facilitate the development of social skills. Educational institutions need formal education on the diagnosis to increase their understanding, as well as strategies that are conducive to social skills acquisition. Difficult behaviours would be understood and addressed through a FASD-lens instead of being met with frustration and negative consequences.</p>
Holistic consultation	<p>Challenges with social skills are pervasive for individuals with FASD. As such, having greater continuity in care is needed throughout the life span. In order to build upon learned skills, teachers and educational assistants need to consult and collaborate with other resources. This includes consulting caregivers and service providers within the community who have learned what strategies successfully meet an adolescent's needs. Social skills are a foundational life skill, which functions as a gatekeeper to independence, positive well-being, and to building a supportive network.</p>
Engaging the zone of proximal development	<p>Individuals with FASD need specialized support and formal social skills programming. Currently, social skills acquisition is not targeted, and educational institutions focus on</p>

meeting the needs of the average student. This model adopts a weakness-based rather than a strength-based approach. Specifically, all students could benefit from the restructuring of the curriculum to include social skills programming that incorporates both informal and formal instruction. In addition, it should use comprehensive strategies, such as modeling of skills, role-playing, mentorship, and the use of hands-on and visual tools. Learners can achieve greater development of skills when they collaborate with their peers and engage in problem solving under adult guidance.

Incorporating DBT skills

Students with FASD would benefit from evidence-based programming that incorporates components from the four modules of dialectical behavioural therapy: mindfulness, interpersonal effectiveness, emotional regulation, and distress tolerance. These skills would help students with FASD to regulate their emotions, communicate their needs, and develop strategies that can be adapted to their environment.

Building a sense of belonging

Secondary students with FASD experience exclusion, which negatively impacts their self-esteem and sense of self-worth. In order to develop social skills, they need to experience inclusion, belonging, and feel that they are part of their school community. Students with FASD thrive when they feel accepted and understood by both their peers and their mentors. Social skills programming needs to facilitate a balance between the development of autonomy and intimacy.

All global themes were generated after basic and organizing themes were established. The thematic network aids in depicting sets of interrelated components that were assumed to formulate the foundation of each global theme. Each individual code or component was assumed to represent a dimension of that theme. The interrelated components that formulated each theme exist on a continuum of representation, with some being more proximal to the global theme, with others being more distal. All components were considered in the appraisal of the data to provide comprehensive understanding. Frequency was used to help identify which components should be more directly related to a particular theme. Discussion of these themes and their underlying components may provide insight and foundational evidence for making social skills programming a greater priority for secondary institutions.

Becoming FASD Informed

The importance of becoming FASD informed was explicitly mentioned by all participants during their interviews. In addition, this global theme was also articulated through the discussion of its component parts that were essential to the overarching theme. These components included: Lack of education and training for professional educators, current use of ineffective strategies, and high risk of developing secondary disabilities. The general consensus was that secondary schools were unable to facilitate social skills acquisition, no formal programming targeted this area of development, and secondary school students with FASD are not well understood.

Specifically, both caregivers and service providers noted that secondary schools have yet to develop programming that specifically targets social skills development. Despite the current literature, secondary schools seem apprehensive about targeting social skills. This apprehension was highlighted by a caregiver's experience who stated, "I specifically asked about social skills

training approximately 2 years ago, and the school said flat out that they do not have time for any kind of social skills training program”. Similarly, another caregiver noted:

No one is specifically trying to teach this group these skills, no one addresses the fact that they don’t relate well to others, nor do they see the ramifications of not addressing them and making them a priority.

This resistance is echoed by a general negative attitude toward learning about FASD and addressing the needs of this student population. For instance, a service provider stated that many teachers label students with FASD as unfit for their classroom because they do not want to change their lesson plan or re-structure their classroom. This perspective was reiterated by a service provider who stated, “If you have it, the response is deal with it, they don’t accommodate it. There is no consistency in how we respond to this diagnosis within secondary schools.” An additional level of difficulty arises since the majority of adolescents with FASD remain undiagnosed. One service provider stated: “A lot of kids are struggling without having a diagnosis, because then they don’t even get that FASD lens nor some form of intervention.” Without adopting a FASD lens, these students are at a higher risk for school failure. A caregiver conveyed concern over self-fulfilling prophecies since educational institutions can instill the belief that students with FASD only express negative behaviours.

Lack of education. Students with FASD are often undiagnosed, negatively labelled by teachers and support staff, and suffer from pervasive challenges that are beyond their control. Consequently, when teachers and educational assistants are uninformed, they are unable to understand what areas to target. One caregiver stated: “Social skills are the biggest issue with students with FASD. They need these skills so they can trust people, but if teachers don’t understand the disability, they cannot expect to teach them the skills that they need.” As such,

many caregivers and service providers mentioned the need for greater training and education on a variety of invisible disabilities: “All teachers colleges should have pre-service training under developmental challenges.” The hope is that with greater education and understanding, more teachers would be willing to accommodate their needs. A caregiver noted, “You can’t “fix” kids with FASD. It’s a permanent brain injury. As such, you need to create a positive environment so that they can learn new skills.” Without this level of understanding, student with FASD are labelled and lose the opportunity to participate in their education. A caregiver noted:

To them it’s not FASD, it’s acting out, it is violence, and it is mischief. It’s not that they see it’s a lack of ability to understand, to control their emotions, and this absence is rooted in the damage that occurred in their brain. It’s not really just behaviour, it is an effect of an assault that occurred to their body –one that they didn’t ask for nor had control over.

By adopting a FASD lens, teachers have a greater opportunity to respond with empathy and acceptance, rather than frustration and contempt. Many service providers have noted that FASD is a disability that is treated quite harshly, and this needs to change:

Generally, what happens, in my experience anyways, in a regular classroom when you’ve got a couple kids with a physical disability, this population is very accepted and supported. But when you can’t see it, like with a lot of cases with FASD, you are the freak, so they do not buy into it. That’s my experience.

Use of ineffective strategies. Often, methods of behaviour management are used. This includes the use of negative consequences to try and control behaviour. Unfortunately, these methods have proven to perpetuate a negative cycle for students with FASD. This neurodevelopmental disorder prevents students from connecting consequences to behaviour.

Often, the student with FASD is left feeling frustrated, unaccepted, and confused by the teacher's response. A service provider stated:

Kids with FASD may not have any insight into why they did something or be able to analyze their decisions. It was coming from a place where the brain was not working properly at that time you know. So, it is not fair to put that on the kid. Because that pushes them into a corner and then they're going to lie, and then they're going to suffer consequences, which will negatively impact the relationship and so on and so forth.

Caregivers also noted several issues with employing a behaviour management model.

Specifically, one caregiver stated that schools are "Always correcting and punishing poor behaviour; however, correction should be strength-based. They need to adopt a teaching of skills philosophy, not a punishment or corrective philosophy." Ultimately, behaviour management strategies have proven to be ineffective time and time again for this population. One caregiver reflected on her son's experience of secondary school and stated: "Teachers have too high of expectations for him behaviourally. I would describe his school experience in high school as very traumatic for him." The major issue is that "No one from the school explores the antecedent or what precipitated the behaviours that were displayed". The biggest barrier to social skills acquisition was identified by caregivers as the punishment model:

The school environment is not one that I would label as safe or welcoming to students who don't fit the typical model. They are not willing to adjust the rigidity of school to meet our kids where they are at . . . the punishment model is the problem because it only further ostracizes and isolates them from their peers and from full participation in the school community.

Secondary disabilities. Educational institutions need to become FASD informed in order to successfully reduce the risk of secondary disabilities. Social development is particularly challenging for this population; however, it is often ignored. Without targeted programs, students will likely suffer life-long repercussions. One caregiver spoke to this level of risk:

Social skills difficulty is a life-long thing. Students with FASD don't know how to handle strong emotions, how to relate to others, or how to respond in developmentally appropriate ways. This makes them very vulnerable to bullying, to being labelled the bad or troubled kid, and to be given up on by peers and teachers.

Similarly, another caregiver noted the long-term consequences of not adopting a FASD lens and targeting areas of risk:

If they don't experience positive interactions with peers, or if they never learn social skills, their behaviours and impulse control won't improve. This increases the probability that they will have contact with the criminal justice system or that they will develop poor mental health and well-being. It is a dangerous slope.

These issues were also noted by service providers. Many professionals noted high rates of expulsion, suspension, and dropping out of school. When they expanded on the cause of these negative outcomes, many cited behavioural issues that were responded to very harshly. As a result, the student felt isolated, frustrated, and defeated. One service provider stated:

These behavioural issues are the types of things that cause students to get suspended, expelled or to frustrate them to the point that they drop out and throw their hands in the air that they don't care about education anymore.

The sum of these challenges highlights the need for professionals to become more FASD informed, and to target social skills acquisition. If these areas of difficulty remain unaddressed,

students with FASD will continue to be labelled negatively by teachers, to be met with inappropriate responses, and to be at greater risk for developing further challenges that act as additional barriers to living a successful and healthy life.

Holistic Consultation

The need for holistic consultation was another global theme that was described by all nine participants. Both caregivers and service providers recognized that educational institutions need to consult with experts on students with FASD. Currently, the response to adolescents with FASD is fragmented and uncoordinated. One service provider noted that “When it comes to a coordinated and collaborative response...I don’t think we are there yet.” Adopting a holistic consultation approach ensures greater information sharing, provides an additional source of expertise, and helps to identify individual differences. FASD is a spectrum disorder, meaning that there is a great deal of variability between individuals; however, challenges with social development have been consistently identified. Therefore, teachers and educational assistants could benefit from learning what triggers have been identified, what strategies have been effective, and what challenges should be the current area of focus. This learning could be facilitated by key informants and from adopting a wrap-around approach. Both of these factors were organizing themes and will thus be discussed.

Key informants. Many caregivers and service providers noted that experts on FASD do exist in every community. Typically, these experts are the individuals who spend every day with an individual with FASD – the caregiver. Unfortunately, caregivers are a widely underutilized resource. One caregiver noted:

Parents are commonly labelled the problem Such as, why do you not discipline your child or you are a poor parent. They ask about rules and expectations at home rather than understanding the FASD diagnosis and how their brain has been impacted.

As such, “Caregivers aren’t labelled as experts on their children or the diagnosis of FASD.” This stigma hinders social skills development, and limits communication between stakeholders. A greater emphasis on caregiver credibility is needed since they can have a wealth of information. Similarly, teachers and educational assistants often do not have time to focus on developing and implementing specialized programming. As such, many participants mentioned collaborating with external agencies to run additional programming:

If the school can’t do it then maybe being open to outside agencies coming in. There are a lot of community resources in town that would be happy to run a program on skills for living independently or those kinds of things.

Many service providers identified the need for a social skills program that is evidence-based.

Specifically, one service provider stated:

We should be adopting a similar toolbox to those with a Master in Social Work. Using those evidence-based strategies; however, teachers and principals usually don’t have this kind of training. It should also be at the macro level, and yes, I mean the teachers should teach social skills to everyone.

Similarly, another service provided stated,

If we are going to deliver a true social skills program that is the gold standard, it should be administered by someone with superior qualifications and superior training. . . . Life skills need to be a focus and enter the educational realm.

Ultimately, the majority of service providers expressed the benefits of utilizing professionals in the community to facilitate social skills programming. One service provider even suggested utilizing professionals or students from child and youth care or social work. She noted the positive impact of having extra professionals in the room that could target social development.

The service provider stated:

[They could] do their mindfulness and provide support. They could help kids with test anxiety and talk to kids about their relationships so that they can flag hey you're going to the back of the woods and doing what? You don't have to be doing this Also saying like hey you don't shower let's talk about that. Or you don't even give anybody eye contact when they are talking to you, like social skills and all those things to help them in the workplace too.

In sum, there are a variety of professionals who would be qualified to administer social skills programming and who could help assist with a proactive approach to reduce risk and increase social development. Participants expressed great value in utilizing key informants in the community who could share their knowledge and help this population to acquire the skills they need.

Wrap-around approach. Adopting a wrap-around approach was alluded to in the majority of the conducted interviews. Many of the participants mentioned the importance of having greater continuity in care and increasing the accessibility to social skills programming throughout the life span. For instance, one service provider stated: "Social skills is needed to open the doors to society." Another stated, "You need that repetition that wrap around, many people working with them doing the same thing". This point was re-iterated by a service provider who said:

I think we have a long way to go. Any work that we do is in silos, no one shares information, and there is not a large amount of collaboration between different sectors. So, families who have FASD are bumped from one service to the next. They have support and then it ends, then they struggle to find a new service to pick up where the other one left off. Warm transfer isn't really occurring right now, and this approach does not work. We need to integrate services.

This fragmented approach seemed to be the rule rather than the exception for families with FASD. A caregiver spoke about her experience, and how she needed to seek out social skills programming for her daughter. The caregiver noted that it was fee for service, and that it would not be accessible to all families. Specifically, the caregiver stated:

My daughter was in a segregated classroom when she started out because she was born deaf. She started socializing through a program called "onward" where social skill development took place. However, this was a fee for hire service. Therefore, we needed to seek out specific social skills programming since it was not automatically available through the school system.

Accessible social skill programming is largely unavailable. Consequently, one caregiver noted why educational institutions are the appropriate setting for administering continuous programming:

They need social skills throughout their lifetime, thus it needs to be embedded in all educational institutions. Continuous programming and continuity in care that does not have a start – stop – long pause orientation that we are currently experiencing now.

This start – stop orientation places students with FASD at the risk of not gaining the appropriate skills and losing the opportunity to live independent and fulfilling lives. One caregiver noted:

If they cannot socialize in school, they probably will struggle to socialize with others in their community or at a place of employment. This furthers their struggle and puts up additional barriers for future success.

The majority of interviews communicated the need for greater continuity in service. In addition, all participants identified secondary schools as the appropriate setting to administer such programming. Specifically, one service provider stated: “What we need is greater continuity in care, where there is life-long support and easy transitions. They need to maintain social skills programming access throughout their lifetime. Yes, we need social skills programming in high school.”

Engaging the Zone of Proximal Development

Engaging the zone of proximal development was another global theme that emerged during interviews with caregivers and service providers. The zone of proximal development (ZPD) is understood as the difference between what a learner can do without help and what he or she can do with help. It is believed that a greater level of development of skills and strategies can be achieved when problem solving occurs under adult guidance or in collaboration with a more capable peer. Ultimately, many educational professionals believe that the role of education is to provide learners with experiences that are within their zone of proximal development, thus encouraging their individual learning. As such, this theme reflects the need for a formal program to be developed within educational institutions that restructures the curriculum and that incorporates comprehensive strategies. These strategies will allow each individual student to achieve more than they could without help or guidance. Specifically, one caregiver describes why such programming would be beneficial for all students:

Unfortunately, a lot of services are a fee for service, which can make them inaccessible to a lot of families. In educational institutions, they can get skills and life skills for free.

This increases the accessibility of programming and services. It just makes sense since they spend the majority of their time in school. Parts of education go beyond literacy and numeracy skills. They need to teach all individuals to be productive members in society.

They need to create a space where they can learn to be involved positively in their community and they need exposure to daily interactions with others.

Caregivers noted that “There’s a propensity for people at the high school level to think that peers will correct their peers, but this is not necessarily a positive or gentle way to do this”. Many caregivers noted that their children have experienced bullying or have bullied others. Therefore, informal learning of social skills is not adequate, and schools miss the opportunity to make a difference for all students. One caregiver identified guidance and support as crucial elements of social skills programming:

Opportunities become less and less available as they enter adolescence The basic level of social skills and knowledge just isn’t there. They mostly just engage in trial and error and unfortunately they don’t always pick up on what works and what doesn’t without that guidance.

As a result, participants made several recommendations in how secondary schools could restructure their curriculum to include social skills, and how they could employ comprehensive strategies that would ensure that all students, including those with FASD, can acquire social skills.

Restructure the curriculum. An organizing theme that emerged during the interviews was the need for schools to implement a universal social skills program. Many participants

mentioned the importance of focusing on emotional intelligence and expanding the curriculum to nurture these skills. A caregiver stated:

We really need to think of both formal and informal programming that can be instituted in a way that everyone benefits so that skills are being taught and learned Where the school environment really works on building up their strengths and capabilities.

Many participants noted how social skills improve all students' resiliency, as well as their readiness to enter the workforce and develop greater autonomy. One caregiver noted the following:

All students could benefit from a greater focus on social skills and inclusion. Schools teach academics yes, but they also have the opportunity to prepare all their students for the real world, and a big part of that is making sure that they are good people, who are nice to others, and who care for others in their community.

This point was also reflected by a caregiver who stated:

Everyone –literally all students –could be a part of receiving the emotional intelligence programming. That's why it's an appropriate program for schools. With the increasing dependence on technology, social skills aren't built into school teachings as much as they used to be. And you will notice . . . more and more students have anxiety and depression, and they struggle to communicate effectively and to regulate their emotions.

In addition to the benefits of a universal program, many participants noted that a focus on emotional intelligence helps all students to succeed, not just the average student. Programming that targets emotional intelligence helps students who struggle with academics, and it helps to nurture their abilities and strengths. A service provider described the flaws of the current rigid system:

The school system is designed to allow the gifted children and the average children to move through the educational system, acquire some academic skills, and move on. But people who are slightly different, have some barriers that other students don't have, and they don't get accommodated in the ways that they need. Many of their needs go unmet. This is why many students with FASD find it very difficult to succeed. For instance, one service provider noted, "90% of students with FASD have had negative experiences in school.... They have difficulty communicating with teachers and peers." The key to a successful curriculum is flexibility. This fact was illustrated by a service provider who said:

Any program that is not individualizing expectations, that is not modifying programming, or that is not looking at exceptionality is concerning. So if we expect everybody to you know read this handout, follow these steps, that is going to be problematic.

Unfortunately, the current curriculum is limited in its flexibility. One service provider stated that "most teachers are sticking to a regimented model of what educational delivery looks like without modification or education on special needs." Similarly, another service provider echoed this point by stating the following: "Teachers themselves don't have the flexibility and time to develop programming that goes outside the academic realm, which means that those who may require focus in another more practical realm won't get that addressed sufficiently."

Consequently, the voices of both caregivers and service providers highlight the need to amend the current curriculum to include a focus on emotional intelligence and social skills programming. In addition, there needs to be more openness to change so that information can be delivered in a variety of ways that accommodate students with exceptionalities.

Use comprehensive strategies. An organizing theme that emerged during interviews was the need for more comprehensive learning strategies. Both caregivers and service providers made

recommendations for key components of a successful social skills program. In addition, they also identified areas of weakness in current education delivery. For instance, one service provider noted that “Schools focus on abstract thinking, theory and ideologies, but students with FASD need concrete learning, something that is more hands-on and visual in nature.” One service provider outlined her idea of a comprehensive social skills program:

A good program would be basic in that it is very visual and hands-on. It could include role-playing, modelling of desirable and appropriate behaviours, where this is ongoing support. This would allow any issues that arise to be addressed right then and there and would give them the opportunity to then practice these skills in a more natural setting. They need to understand what they have, that it is a permanent brain injury that affects some of their abilities, and that now they can work on social skills to re-engage their brain in these areas. They need to be taught emotional regulation, behavioural control, and positive coping with peer rejection, emotional discomfort, and frustration.

A caregiver also noted several of the same components:

It should include hands-on learning, modeling, and reinforcement rather than punishment and consequences. The program would need to be FASD-informed and modified to their abilities. They need ongoing support that produces an environment that is conducive to skill building rather than one conducive of being taken advantage of and labelled negatively.

In addition to utilizing a more hands-on approach, many participants identified the importance of a strength-based program. Specifically, one caregiver noted:

There should be lots and lots of assessments around where their strengths lie because there are a lot of strengths. There are pockets of brilliance in most kids with FASD. So

they need to find those, and tap into those. . . . They might have a dream that could become a reality and then a lot of those social skills stuff would be around job readiness and communication and whatever.

In order to help assist with this learning and nurturing of strengths, many caregiver and service providers mentioned the use of mentorship and supervision. One caregiver stated: “People who are enlightened about these challenges can offer support through a mentorship and supervision approach.” Another caregiver also mentioned adopting a mentorship model:

They could easily use peers from the school without disabilities. It could be a win-win to train individuals who want to pursue leadership, teaching, or ECE roles in the future to get educated in FASD and then act as a peer mentor to these students. . . . Again, I really advocate for a peer mentor model – peers ultimately have the biggest influence on these kids when they are in the pre-teen and teen age. This is who they want to spend their time with and who they relate to the best.

This use of mentorship illustrates the need for both informal and formal components of a social skills program. It also highlights the premise that students can achieve a higher degree of development when they receive assistance from a more capable peer or when they have some kind of guidance.

Incorporating Dialectical Behavioural Skills (DBT) Skills

Constructing an evidence-based program. Incorporating DBT skills was another emerging theme. All participants mentioned the importance of developing one’s emotional intelligence. Many participants specifically mentioned nurturing skills of positive coping, communicating well with others, managing difficult emotions, and tolerating negative internal and external events. These components largely reflect the four modules of dialectical behavioural

therapy. As a result, it was identified as the global theme. In addition to being an evidence-based program, it successfully incorporates all the organizing themes and codes that were directly mentioned by both caregivers and service providers. Specifically, one service provider explained what she meant by focusing on nurturing students' emotional intelligence:

When I say emotional intelligence, I am really referring to the awareness of other people's emotions and the way that they are communicating. In addition, it's about having control over one's emotions, and managing relationships in a way that communicates that they care and that they have empathy for another individual.

This service provider also noted that this emotional intelligence should be targeted for all students:

We understand that educational institutions focus on the academic side of learning; however, they are just not working enough with the emotional IQ piece. Individuals with FASD, as well as students in the general population, are not developing positive relationships, positive emotional regulation, and behavioural control.

Consequently, using the modules of DBT could successfully target each area of concern in a social skills program.

Mindfulness. Mindfulness was mentioned by a service provider who spoke about her experience supervising and teaching child and youth care students. She noted that they were able to successfully implement components of mindfulness training and positive coping in their placements. Specifically, the service provider stated:

Students were doing special programming on Fridays where they were going to all the classes. All the kids in the school, including kids with FASD, were benefiting from this. They were doing mindfulness, so different strategies around that since everybody gets

wound up especially kids who are frustrated with their day to day experiences. So this is teaching that self-care and mindfulness.

This proves that mindfulness-based strategies can be a part of a universal program. It helps students develop and practice skills of positive coping and self-care strategies. Evidence-based methods can easily be adapted to the education realm.

Interpersonal effectiveness. Interpersonal effectiveness incorporates understanding one's self, and stress management. Many caregivers and service providers noted the importance of learning to cope with stressful peer situations, while also not internalizing one's weaknesses. For instance, one caregiver noted:

It would be helpful for someone to coach them through peer rejection so they can learn to cope with it, and to not internalize it and take it to heart. . . . If she had someone to model behaviour, coach, and support her through the difficult interactions, and give her better skills to use, I think she would feel a lot better about herself, be happier, and have more friends.

Another caregiver described the biggest challenge for her child as the communication delay, "They struggle to initiate social interaction, interacting with peers, and using proper language or speech that is developmentally appropriate". Similarly, another caregiver noted difficulties with self-reflection:

It's the self-awareness piece of how do they come off to their peers, and how well are they actually communicating their wants and needs in a way that other people can be receptive to those wants and needs –often, they just aren't able to successfully communicate this.

As such, learning how to maintain positive relationships despite these challenges could be helpful. It provides the opportunity to explore methods of communication, as well as ways to maintain self-respect. Such teachings could help decrease their vulnerability.

Emotional regulation. Emotional regulation consists of being able to understand one's emotions, to reduce emotional vulnerability, and to decrease emotional suffering. Participants frequently mentioned students with FASD struggle to understand both their own and other people's emotions. In addition, many noted that difficult emotions prompted negative behaviours, which negatively impacted their relationships. One service provider stated that "They need to start building those soft skills. They need help working on anger management, regulating those emotions so that they don't get kicked off the job." Similarly, a caregiver stated: "They need to learn how to work with others, but people with FASD struggle with empathy and perspective taking. This creates challenges. Theory of mind can be a challenge. Therefore, debriefing, monitoring, and coaching are key." Another caregiver noted that her son struggles to manage his emotions. She described a behavioural profile, which included a lower level of impulse control, difficulty with delaying gratification, more fidgeting behaviours, and less fluid expression of self. She noted that "this causes problems socially with peer acceptance and understanding. Typically peers and other adults within the educational system believe that he knows these things." As such, emotional regulation was identified as an area of concern, and one that could be targeted within a social skills program.

Distress tolerance. Distress tolerance consists of being able to accept reality as it is and learning to tolerate pain. Many caregivers and service providers indirectly described components of distress tolerance and mentioned that individuals with FASD would benefit from assistance in this area. Specifically, one caregiver described difficulties that her daughter experiences. She

stated: “Sometimes she responds with aggression when she experiences social rejection and cannot successfully initiate play with others”. Another caregiver noted that “social situations evoke a lot of frustration since her peers don’t identify with her and she experiences rejection. If students are aware of her behavioural difficulties, this sometimes acts as a barrier to future social interactions”. Similarly, a service provider stated:

Instead of taking a moment to reflect on their frustration or disappointment, they engage in behaviours out of impulse –which unfortunately can lead to aggression, which obviously creates even greater challenges when they’re trying to make friends, or receive understanding from others.

As such, the same service provider suggested that “If they acquire some basic social skills, we will see the behavioural issues decline and that in and of itself is better for their engagement and ultimately their learning”. Therefore, targeting distress tolerance is one way to increase social development for this population.

Building a Sense of Belonging

Building a sense of belonging was a reoccurring theme during interviews with participants. Both participant groups discussed the importance of building a sense of competency and self-esteem, as well as feeling accepted and part of a community. These positive feelings help to facilitate school success, and are conducive to building positive relationships in the future. Both the organizing themes of autonomy and intimacy will be discussed.

Autonomy. It is important for all students, including those with FASD, to have personal autonomy. They need to build a sense of self-worth and have self-esteem. This can be facilitated by having positive interactions with others, where they feel capable and practice their skills of

positive communication. One caregiver spoke to the importance of social skills in building this sense of autonomy and stated:

It's huge –it needs to be done. I want to see my daughter happy and productive, have peers to hang out with, be a part of the community, and be independent. This is all social stuff. Then they're adults with so many expectations but they're screwed right now because they have no social skills and no self-esteem.

Another caregiver spoke about her son's experience in school, and noted: "My son needs to feel liked, accepted, and appreciated. This is a pre-requisite to building his self-esteem and the foundation for social skills." As such, students with FASD need a sense of belonging before they can feel competent and trust their own capabilities. Without this positive self-perception, they are at a higher risk for both negative internal and external experiences. One caregiver noted the consequences of feeling isolated and unaccepted. She spoke about the secondary disabilities that she has noticed: "All I see is a decline in my daughter's self-esteem, self-confidence, and I even see depression and anxiety slowly creeping in. This is obviously very distressing to see and I don't know what I can do to stop it." Moreover, another caregiver stated:

These kids are not really included, and they end up isolated from their classmates. They are missing the critical function of school – which is socialization. Without that critical piece, they are bullying others or are bullied, which never has good consequences.

Ultimately, participants expressed that half the battle is improving a student's perception of themselves. This point was reiterated by a service provider who stated: "If you can make them feel better about themselves, you are half way in. You've got them." This belief was supported by the idea that social skills can promote acceptance within a community. Specifically, a caregiver stated that social skills "Prevent mental health issues from developing. It has the

opportunity to increase their self-esteem, and to increase their inclusion in their community and school.” As such, nurturing self-esteem and a sense of autonomy can act as a protective factor.

Intimacy. A major component of developing a sense of belonging is fostering feelings of intimacy and closeness in relationships. Participants noted that students with FASD benefit from feeling that they are part of a team or that they are part of a larger community. One caregiver explained the benefits that followed after her son joined a sports team at school. She stated:

My son is on the football team, which has been a huge help. He has made great friends at school and it has increased his self-esteem. This in and of itself improves his success in school because he is an accepted peer, feels better about the environment and his peers, feels safe, and exhibits less issues behaviourally.

Ultimately, social skills are a prerequisite to building a sense of belonging and closeness in one’s community. This understanding was expressed by a caregiver who stated: “It is pretty imperative because again, we are hoping that people leave secondary school with the ability to participate in their community and broader society. They need social skills to navigate any system out in the community.” As such, a caregiver suggested the following idea for a program to help facilitate these skills:

We need empathy-based programs with social skills programming all the way through school. They need to focus on empathy and understanding with individuals who consistently run it and who understand the FASD diagnosis. Mentoring should also be a part of the program to create a sense of community and belonging.

Ultimately, parents believe that students with FASD need a forum that facilitates discussions about relationships. One caregiver stated that “They need a safe space to discuss challenges and to foster relationships that are fun. They need to foster fun and a sense of community in these

spaces.” Again, this reflects the importance of feeling part of a larger community, where there are internal feelings of acceptance and belonging.

Chapter 5: Discussion

The purpose of this phenomenological qualitative study was to understand what current educational strategies and programs exist within secondary institutions that facilitate or hinder social skills development for students with FASD. In addition, the study aimed to identify what programming or strategies could facilitate greater acquisition of social skills. Interviews were conducted with five caregivers and four service providers. Seven interviews were over-the-phone, and two were conducted in-person. The data was analyzed using a thematic analysis, where each theme emerged through an inductive process. These themes included: *Becoming FASD informed*, *holistic consultation*, *engaging the zone of proximal development*, *incorporating DBT skills*, and *building a sense of belonging*. None of the participants could identify any formal social skills programming within secondary schools. As such, no participant felt that social skills were comprehensively being acquired within the current education system. Moreover, all participants noted that they felt social skills programming was crucial to facilitate positive development. Consequently, the themes discussed outline key components for improving social skills acquisition by addressing current weaknesses and building upon strengths. These results highlight future directions that could help produce an educational environment that is more conducive to social development and that targets areas of risk for secondary disabilities. In effect, the present chapter will compare the results of this analysis to the existing literature.

Global Themes

Becoming FASD informed. This global theme reflects the need for greater education and training for educational professionals. The majority of the responses within this theme were consistent with the existing literature; however, greater specificity emerged with regards to what areas of knowledge should be targeted.

Prior research noted that the majority of teachers and educational assistants have had limited knowledge and understanding of FASD (Carpenter, 2011). Consequently, secondary students with FASD are often misunderstood, negatively labelled as troubled kids, and their individualized needs go unmet (Tsang et al., 2016). As a result, many students with FASD have negative school experiences that hinder rather than facilitate social development (Streissguth, 1997). Specifically, secondary students with FASD are at a greater risk of dropping-out, being suspended or expelled, and having greater contact with mental health and criminal justice agencies (Kully-Martens et al., 2012; Millar et al., 2017; Moore & Riley, 2015; Public Health Agency of Canada, 2006). Consequently, greater education and training is needed so that this group of students has a higher probability of school success.

Although the global theme of becoming more FASD-informed was consistent with prior research, the present study identified regular errors made by educational institutions. Specifically, what was coded as “problematic behaviour management” is a particular strategy that hinders social development for this population. All participants noted that when students with FASD respond inappropriately or exhibit difficult behaviours, teachers default to applying negative consequences. The application of negative consequences does not teach students with FASD new skills, nor does it facilitate the acquisition of positive social skills. A behaviour management model is ineffective with this group because they are unable to connect cause and effect. As such, greater education is needed to facilitate the implementation of more effective strategies that allow them to learn positive ways of coping. In addition, greater understanding of their social challenges would increase empathy in educational staff, as well as provide them with successful tools and strategies that are more conducive to social skills acquisition. These tools and strategies are further discussed by the latter three themes.

Holistic consultation. The global theme of holistic consultation reflects responses that have highlighted the need for greater collaboration and consultation among key informants, as well as greater continuity in service throughout the lifespan. These responses were largely consistent with the existing literature.

Several studies mentioned the importance of including caregivers in the educational process. For instance, a study that examined school persistence for students with FASD identified caregiver support and advocacy as the most critical factor contributing to educational success (Duquette, Stodel, Fullarton, & Hagglund, 2007). Similarly, Millar et al. (2017) noted that multidisciplinary teams have developed specialized strategies and programs to implement in classrooms in Manitoba. As such, other provinces in Canada have recognized professionals in the community as key stakeholders who can facilitate the implementation of more specialized programs. Finally, research on the experiences of caregivers and professionals has created an additional resource for educational institutions to learn about the needs of students with FASD.

Unfortunately, this study revealed that in practice many caregivers have to fight for their voices to be heard. Specifically, both caregivers and service providers noted that many educational institutions do not feel that parents have credible knowledge or know strategies that could be helpful in the classroom. Many caregivers noted that their child's IEP was ignored. In addition, one caregiver noted that she provided helpful documents that outlined triggers and successful ways to cope with behaviours that were never consulted. Similarly, professionals in the community noted that they have not been invited to run programs or seminars on FASD. Consequently, these key informants are often recognized in research, but are largely an underutilized and undervalued resource in practice. Additional funding for staffing would be one solution to increase access to school social workers and psychologists.

Regarding greater continuity in care, all participants directly or indirectly alluded to the need for a wrap-around approach in services where there is a warm transfer between agencies and supportive networks. Ultimately, both caregivers and service providers recognized that educational institutions are only one piece of the puzzle when it comes to addressing social skills acquisition. The challenges in this realm are pervasive, and thus need to be continuously targeted and addressed. Each agency or institution needs to build upon learned skills, and thus, teachers and educational assistants need to consult and collaborate with other resources in the community. Participants felt that this needed to be communicated because social skills are a foundational life skill. In particular, social skills function as a gatekeeper to independence, positive well-being, and to building a supportive network. The importance of social skills was consistently communicated in the literature (e.g. Åse, et al., 2012; Whaley et al., 2001); however, previous literature did not directly highlight the need for greater continuity in care to nurture this development.

Engaging the zone of proximal development. The global theme of engaging the zone of proximal development reflects responses that communicated the need for specialized support and formal social skills programming. This theme was consistent with the existing literature that stated the importance of social skills; however, only one study specifically mentioned social skills programming within education institutions (Millar et al., 2017). Moreover, this study's results add to the current literature since participants were able to identify key components of a successful social skills program for adolescents with FASD.

Several studies in the existing literature reported that social skills decline with age for individuals with FASD (e.g. Whaley et al., 2001); however, few studies have been conducted on implementing social skills programs for this population. In particular, Millar et al. (2017) was the

only study that referenced the need for social skills programming within schools and that suggested a standard protocol for how teachers and educational assistants support students with FASD. Comparably, responses in this study reported that social skills acquisition is not specifically targeted, and educational institutions focus on meeting the needs of the average student. As a result, many adolescents with FASD miss the opportunity to participate in social activities, and only learn some skills informally. Many of these students, therefore, are unable to acquire the latent function of education – positive socialization.

Subsequently, a central component of this theme was the conclusion that a universal social skills program should be constructed to better meet the needs of students with FASD. Specifically, participants noted that all students could benefit from the restructuring of the curriculum to include social skills programming that incorporates both informal and formal instruction. This would aid in developing the emotional intelligence of all students, while also specifically nurturing the abilities of students with FASD. This conclusion was not reflected in the literature that was consulted. In fact, no research study referenced a specific program that targeted adolescents with FASD (Duquette et al., 2006a). Meanwhile, prior research does suggest that children with FASD are responsive to social skills training programs and that they can continue to implement skills they have acquired (Keil et al., 2010). As such, there appears to be limited momentum in the creation of preventative interventions. Miller et al. (2017) appears to be the only study that is informing practice. In particular, the Winnipeg School Division has recognized that educational institutions are an appropriate site to administer specialized programming since they are responsible for providing special consideration to students with unique developmental trajectories and individualized disabilities (Miller et al., 2017).

Adding to the existing literature, responses highlighted core components of a specialized social skills program. Specifically, participants mentioned the need for comprehensive strategies, where students with FASD would have the opportunity to learn from their peers, a mentor, or receive assistance from a teacher or educational assistant. This point reflects the concept of engaging the zone of proximal development. For instance, students with FASD would be able to acquire more social skills when they learn with the help of a more capable peer. Working with at least one other individual, helps students with FASD to acquire skills both formally and informally. This repetition facilitates learning for this population since they are often context-specific learners. More specifically, responses consistently noted the use of modelling, role-playing, hands-on learning, and the use of visual tools. Many participants felt that these strategies could be facilitated by a mentorship model. Again, this reflects the idea that learners can achieve greater development of skills when they collaborate with their peers and engage in problem solving under adult guidance.

Incorporating DBT skills. This global theme reflects an evidence-based treatment modality that targets areas of social development that were mentioned by participants. This theme was consistent with the existing literature since many studies described a behavioural profile of individuals with FASD that included difficulties with emotional regulation, acting out, and communication. In contrast, no study specifically mentioned the use of DBT skills as a form of intervention for this group.

Previous research consistently noted difficulties with emotional regulation and an increased vulnerability to becoming overwhelmed and overstimulated (Olson & Montague, 2011). Individuals with FASD generally struggle to calm themselves down when they feel intense emotions, which can lead to outbursts or aggressive behaviour (Olson & Montague,

2011). As a result, individuals with FASD struggle to maintain meaningful relationships (Tsang et al., 2016). These points were re-iterated by both caregivers and service providers, who noted that friendships are consistently ruptured when adolescents with FASD respond to intense emotions in developmentally inappropriate ways (Mattson et al., 2007). As such, responses reflected the need for social skills programming to include modules on communication, emotional regulation, positive coping with peer rejection, and healthy boundaries in relationships. Again, this reflects existing literature that notes disruption in executive functioning that often is illustrated by challenges with self-control and self-regulation (Kodituwakku, 2007; Nash et al., 2015).

The specific labelling of this theme reflected responses that mentioned the need for an “evidence-based” program. The four modules of dialectical behavioural therapy: mindfulness; interpersonal effectiveness; emotional regulation; and distress tolerance, addressed all the components that were emphasized by participants. Indeed, these skills would help students with FASD to regulate their emotions, communicate their needs, and develop strategies that can be adapted to their environment. In addition, DBT skills have been found to benefit a variety of at-risk groups, and therefore would be valuable in both a universal and a FASD-specific program. As such, the four modules of DBT are recommended as a core component of a social skills program for secondary institutions.

Building a sense of belonging. The global theme of building a sense of belonging reflects the idea that adolescents with FASD have a greater probability of thriving in school when they feel accepted and understood by both their peers and their mentors. As such, social skills programming needs to facilitate a balance between the development of autonomy and intimacy. This theme reflects a solution to negative school experiences, which are described in

the literature. In addition, developing this sense of belonging will also reduce the risk of developing secondary disabilities.

Secondary students with FASD often experience exclusion, bullying, and negative labelling. Prior research noted that adolescents and adults with FASD consistently experience negative peer relationships (Streissguth et al., 1991), and that this is a predictor of school failure and future contact with the law (Schonfeld, Mattson, Lang, Delis, & Riley, 2001). Social rejection provokes low self-esteem, anxiety, depression, and personal maladjustment (Kully-Martens et al., 2012). Ultimately, this leads them to become further isolated and aggressive, which perpetuates interpersonal issues into adulthood (Wilhoit et al., 2017). These interpersonal issues have been documented in several studies. As such, the implementation of social skills training has been suggested to increase adaptive functioning and the probability of developing positive interactions with others (Coriale et al., 2013; Whaley et al., 2001). This was reflected in responses, where participants mentioned feelings of “exclusion” and “isolation”, as well as the development of “low self-esteem”. In contrast, participants noted greater resiliency in adolescents with FASD when they had feelings of “inclusion”, “belonging” and when they felt “part of a team”. Consequently, responses communicated the need for intimacy or connectedness in partnership with a sense of autonomy and feelings of self-worth. As such, responses expressed the need for building a sense of community and belonging within the education realm. Responses reflected that this could be directly incorporated into a formal social skills program through empathy-based components or the use of team-building exercises. In addition, responses tended toward including opportunities to reflect on personal strengths and the achievement of individualized goals.

Discussion Summary

The aim of the current study was to explore what educational strategies facilitate or hinder the development of social skills acquisition. The study intended to evaluate whether secondary schools have or plan to implement social skills training programs, and whether or not they are effectively targeting areas of vulnerability. Five global themes emerged from the data, including: 1) *Becoming FASD informed*, 2) *Holistic consultation*, 3) *Engaging the zone of proximal development*, 4) *Incorporating DBT skills*, and 5) *Building a sense of belonging*. Overall, the results from the present analysis were consistent with the existing literature. Previous research consistently reported that individuals with FASD struggle with social skills acquisition, and that targeting this area of development would reduce the risk of developing secondary disabilities. In congruence with these findings, responses consistently reported challenges with social development and the need for greater support and training to facilitate the development of these skills. Similarly, previous studies reported negative labelling and limited accessibility to accommodations for students with FASD in educational institutions. Several studies have reported limited knowledge of the diagnosis, a lack of appropriate accommodations, and negative attitudes towards this student population. These results were echoed in the present study where responses highlighted negative school experiences where individualized needs were unmet. Consequently, responses explicitly noted the need for additional training and education so that educational professionals could adopt a FASD-informed lens. This included utilizing strength-oriented strategies that support learning rather than implementing behaviour management strategies that are ineffective and that perpetuate feelings of isolation and self-doubt.

Although the existing literature noted the benefits of collaborating with caregivers and a multidisciplinary team, student advocacy and accommodation planning appeared to occur in

isolation rather than in concert with credible resources. Specifically, responses emphasised the benefits of utilizing the knowledge and experience of key stakeholders and building upon previously learned skills. An area of disparity from the literature was that in practice, key stakeholders were often undervalued and underutilized in the education realm. As such, there appears to be a discrepancy between research and practice in that a holistic consultation model is not valued or adopted in day-to-day operations.

Granted that there was substantial overlap between the existing literature and the findings of the current study, numerous innovative recommendations also materialised as a result of the emerging themes and analysis. Notably, responses outlined key components of a successful social skills program. Participants identified the necessity of re-structuring the current curriculum to include a universal social skills program that utilized comprehensive strategies. These strategies included the use of a mentorship model where students with FASD could learn from their peers or be guided by capable adults. This reflected the notion of engaging the zone of proximal development, where appropriate skills would be modelled, role-played, and practiced through repetition. These strategies would facilitate greater generalizability of social skills. In addition, the acquisition of these skills was believed to be supported through the use of hands-on learning and visual tools. This was only recently mentioned by a study that communicated the results of a consensus-generating workshop run by the Winnipeg School Division. As such, the implementation of social skills programming within secondary schools seems to be a novel idea that is being supported by research and policy.

Similarly, the analysis reflected the appropriateness of implementing DBT modules to help facilitate learning of emotional regulation and distress tolerance through positive coping and effective problem solving. The literature spoke more narrowly about challenges with these skills;

however, it neglected to suggest an evidence-based solution to address this area of difficulty. As such, this analysis presents a strength-based approach, where individual strengths are supported and students with FASD are taught how to manage difficult events. Finally, the analysis of this study revealed the importance of including both elements of intimacy and autonomy in a social skills program. Responses illustrated that adolescents with FASD excel in an environment where they feel that they belong and are part of a community. These feelings aid in the development of self-esteem and self-worth. Prior research noted that students with FASD are commonly classified as “the other”. In effect, educational programs need to strive towards a community orientation, where everyone feels accepted and individual differences are celebrated rather than condemned.

Implications

Results from the present study add to the existing literature by furthering our understanding of how well some secondary schools are currently functioning in meeting the needs of adolescents with FASD. The resulting analysis identified current strengths and limitations in the school curriculum and makes recommendations for constructing a formal social skills program. This study highlights a gap in programming, where secondary schools have the opportunity to facilitate social skills acquisition and minimize the risk of developing secondary disabilities. Participant voices outlined several unique recommendations and strategies that could form the foundation of a successful social skills program. These recommendations will likely warrant further research; however, they do suggest foundational components for inclusion.

Future research in the area of accommodating adolescents with FASD could explore the perspectives of teachers and students with FASD. Unfortunately, the current study failed to recruit young adults with FASD. Hearing additional voices, especially those of teachers and students, would provide additional information that could highlight practical considerations, as

well as strategies that would encourage engagement. In addition, future research could explore the impact of a mentorship model that implements comprehensive strategies in the area of social development. This would further evaluate the notion of engaging the zone of proximal development, as well as facilitating elements of intimacy and autonomy within schools. In addition, future research could also explore how to successfully implement DBT modules in an educational setting. Ultimately, a pilot study may be warranted in order to evaluate a social skills program for adolescents in secondary schools.

Educational practices need to reflect current research in order to test and evaluate novel ideas, address gaps in learning, and to implement innovative strategies. Research and practice need to hear the voices of key stakeholders who can speak to educational experiences and outcomes. Evaluating outcomes of both the formal and latent functions of education is needed to assess whether all students, not purely the average student, are learning the skills and strategies they need to live fulfilling and functional lives. Limited research has been conducted in Ontario that thoroughly explores current educational strategies, challenges, and successes. Education policy is reflective of provincial standards, and thus needs to be independently evaluated. By implementing a comprehensive social skills programming, educators can improve the adaptive functioning of all students, while also promoting a more positive school experience for students with FASD. As such, explorative research and pilot studies are key components of forming best practice guidelines for this population.

In sum, the current study supports working towards a more comprehensive curriculum where students with FASD have more opportunities for educational success. Previous research has demonstrated that educational success is a key predictor of future outcomes (Millar et al., 2017). As such, presenting the voices of key stakeholders will contribute to a greater

understanding of the educational needs of adolescents with FASD, and suggests potential strategies to facilitate greater social development. Ultimately, greater acquisition of social skills has the potential to reduce the risk of developing secondary disabilities and promoting greater well-being and continuity in care into adulthood.

Counselling. The global themes that emerged in this study identified the importance of incorporating and utilizing therapeutic interventions with students with FASD. Responses indicated that adolescents with FASD are at an elevated risk for experiencing poor mental health, lower self-esteem, and lower life-satisfaction. These responses were congruent with the literature that noted that students with FASD often become frustrated, experience school disruption (Duquette et al., 2006b; Millar et al., 2017), and experience lower overall well-being due to inadequate educational supports (Moore & Riley, 2015). As such, this study supports the idea of collaborating with internal and external counselling services to offer assistance. This will require educational institutions to adopt a more collaborative attitude and an openness to consult with counselling professionals (Masotti et al., 2015). Moreover, clinical consultation was suggested in the literature to improve the competence of both educational and counselling professionals (Tremblay et al., 2017). This point was reiterated by the responses in this study, where both groups of participants noted that becoming FASD-informed is a pre-requisite to providing effective support.

Moving forward, the results from this study could be a resource for both education and counselling staff who need further information on how to effectively support adolescents with FASD. This will facilitate the utilization of a FASD-lens and increase professional competence in implementing successful interventions and strategies. Considering an array of perspectives can help guide professionals in adapting evidence-based intervention to this population. This

knowledge can help form the foundation of FASD-specific protocols when implementing social skills programming and incorporating DBT skills.

Education. The analysis of the present study highlighted the need for appropriate strategies and guidelines when structuring educational delivery. Specifically, responses connected poor school experiences with future negative outcomes for adolescents with FASD. This is consistent with the literature that reported ineffective program delivery increases a student's susceptibility for secondary disabilities (Pei, Baugh, Andrew, Rasmussen, 2017). As such, teachers and educational assistants need greater understanding of the diagnosis, and appropriate interventions. This was highlighted by the general theme of becoming FASD-informed. Greater interconnections between schools and community services would remove a barrier to collaborative advocacy and decision-making (Kalyanpur, Harry, & Skrtic, 2000). This was reiterated by this study's theme of holistic consultation. Formal education and training on FASD is needed, along with ongoing consultation with caregivers and professionals in their community.

Policy. The conclusions of the present study suggest numerous future directions for upcoming policy decisions. Specifically, these findings correspond with the recommendation that the federal government collaborate with the provinces and territories and key stakeholders when conducting best practice research (Canada: House of Commons, 2015). As such, the responses in this study could be considered when creating a best practice protocol for supporting adolescents with FASD in schools. In particular, the theme of holistic consultation highlights the importance of considering this study's findings when making future policy decisions and when providing evidence-based support.

Moreover, the general themes of becoming FASD informed, engaging the zone of proximal development, implementing DBT skills, and building a sense of belonging all represent the importance of understanding the FASD diagnosis, as well as implementing evidence-based strategies to encourage school success. Several longitudinal studies (Streissguth et al., 1996) have shown that the majority of students with FASD are unsuccessful in school due to multiple school disruptions. As such, it is imperative that all schools understand the importance of addressing the needs of all students, and that they are aware of effective education strategies. These global themes can inform and support amendments to education policy that focus on accommodations. Specifically, if Bill 191 is ever passed, or analogous legislation, Ontario school boards will need to develop and implement best practices for students with FASD. In this case, the results from this study can advise the development and implementation of a social skills program that can be piloted, evaluated, and amended based on the knowledge available.

Limitations

This study utilized purposive sampling when recruiting participants. As such, some biases were introduced into this study's results because of voluntary participation. Voluntary research selects individuals who are more willing to participate, and thus are individuals who may have firm beliefs, opinions, or perspectives on the topic being explored. Similarly, interviews were semi-structured, meaning that some participants may have been more open to expand on their thoughts, ideas, and experiences. This would cause some participants to make a greater contribution to the dataset than others.

Furthermore, there were additional methodological limitations to this study. In particular, this study implemented a phenomenological qualitative design, where all participants resided in southern Ontario. Consequently, there is a high probability that school experiences were only

reflective of two or three districts. Similarly, educational institutions will likely differ in their daily practices and policies depending on their geographic location. Moreover, semi-structured interviews were conducted both over-the-phone and in-person. This variability may add additional bias or error into the results since the study environment was not consistent. Lastly, despite firm adherence to the process of thematic analysis and the construction of thematic maps, the potential for researcher bias cannot be completely eliminated. Only two researchers were involved in the production of codes, and the subsequent generation of thematic networks; however, triangulation strategies were used to minimize risk.

Despite these limitations, this study significantly adds to the existing literature since only preliminary research has been conducted to identify possible solutions for the pervasive challenges experienced by students with FASD. This study's findings largely reflect prior research, where several school challenges have been identified. Ultimately, caregivers and service providers can aid in the development of evidence-based interventions that focus on social development and minimizing future risk. If these findings are replicated, and supported by additional key stakeholders, such as teachers and young adults with FASD, then this information could be used to justify funding for the restructuring of the current curriculum, the implementation of specialized strategies and formal social skills programming, and the utilization of external professionals to deliver evidence-based protocols. Implementation of these recommendations could increase the number of adolescents with FASD who have positive school experiences, graduate from high school, and who transition into adulthood with superior adaptive functioning and capabilities. Educational institutions are the main infrastructure for learning about oneself and others, acquiring positive socialization, and for building healthy relationships. Thus, schools require special attention when it comes to addressing the needs of

students with FASD. They need to have an informed, comprehensive, and coordinated response to this public health concern.

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Appendix

Guiding Questions

ID_____

Sex_____

Group_____

- What challenges are experienced in the realm of social skills for adolescents with FASD?
 - Do you think these challenges are slowly being addressed?
- Do you think social skills are important for adolescents with FASD? Why or why not?
- Do you think social skills for adolescents with FASD should be addressed in educational institutions?
 - If yes –why?
 - If no –why?
- What programs and strategies have facilitated the development of social skills for adolescents with FASD?
 - What about those programs/strategies made them effective?
- What programs and strategies have hindered social skills development for adolescents with FASD?
 - What about those program/strategies made them hinder social skills development?
- What could be implemented to further develop social skills for adolescents with FASD?
 - What are key components of the suggested program/strategy?
- Do you think social skills are being acquired within the current system for adolescents with FASD? If so, how? If not, how could we better facilitate this development?

- How important do you think social skills training is within educational institutions for adolescents with FASD?
- Is there anything else you would like to add?



Date: 17 January 2018

To: Dr. Jason Brown

Project ID: 110640

Study Title: Adolescents with FASD: Education-Based Strategies for Social Skills Development

Application Type: NMREB Initial Application

Review Type: Full Board

Meeting Date: 08/Dec/2017 12:30

Date Approval Issued: 17/Jan/2018 17:42

REB Approval Expiry Date: 17/Jan/2019

Dear Dr. Jason Brown

The Western University Non-Medical Research Ethics Board (NMREB) has reviewed and approved the WREM application form for the above mentioned study, as of the date noted above. NMREB approval for this study remains valid until the expiry date noted above, conditional to timely submission and acceptance of NMREB Continuing Ethics Review.

This research study is to be conducted by the investigator noted above. All other required institutional approvals must also be obtained prior to the conduct of the study.

Documents Approved:

Document Name	Document Type	Document Date	Document Version
Email Script for Recruitment	Recruitment Materials	20/Dec/2017	
Flyer for Email	Recruitment Materials	20/Dec/2017	
Interview Guide	Interview Guide		
LOI-caregivers	Written Consent/Assent	20/Dec/2017	
LOI-service providers	Written Consent/Assent	16/Jan/2018	
LOI-young adults with FASD	Written Consent/Assent	20/Dec/2017	
Reminder email	Recruitment Materials	20/Dec/2017	

No deviations from, or changes to the protocol should be initiated without prior written approval from the NMREB, except when necessary to eliminate immediate hazard(s) to study participants or when the change(s) involves only administrative or logistical aspects of the trial.

The Western University NMREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the Ontario Personal Health Information Protection Act (PHIPA, 2004), and the applicable laws and regulations of Ontario. Members of the NMREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB. The NMREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000941.

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

Sincerely,

Katelyn Harris, Research Ethics Officer on behalf of Dr. Randal Graham, NMREB Chair

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).

Curriculum Vitae

Samantha L. Wiendels

EDUCATION

Masters of Arts (Counselling Psychology) **September 2017 – April 2019**

Western University – Faculty of Education

London, Ontario

- Graduate Student Assistantship Contract (2017)
- Ontario Graduate Scholarship (2017)
- Ontario Graduate Scholarship (2018)

Bachelor of Arts **September 2013 – April 2017**

(Honours Specialization in Psychology, Major in Criminal Justice)

Western University – Brescia University College

London, Ontario

- School of Behavioural & Social Sciences Merici Award (2017)
- Dr. Pat Devolder Award (2015)
- Dean's Honour List (2014, 2015, 2016, 2017)
- Family Studies Award (2014)

RELATED EXPERIENCE

Personal, Academic, and Career (PAC) Counselling Intern **September 2018 – Present**

Fanshawe College

London Ontario

Co Facilitator **September 2018 – Present**

London Family Court Clinic Inc.

London Ontario

Withdrawal Management Counselor **September 2017 – Present**

Salvation Army

London, Ontario

Graduate Research Assistant **September 2017 – Present**

Western University

London, Ontario

Co Facilitator **June 2018 – August 2018**

St. Joseph's Hospice

London, Ontario

Wait-List Clinic Counselor Volunteer **October 2016 – August 2017**

CMHA

London, Ontario

Student Researcher **September 2015 – April 2017**

Centre of Hope Withdrawal Management (Salvation Army)

London Ontario

Call Volunteer September 2014 – Nov 2016
London and District Distress Centre (LDDC)
London, Ontario

Youth Engagement Counsellor (summer contract) July 2016 – August 2016
WAYS
London, Ontario

Peer Mentor Volunteer September 2011– June 2013
Community Living Program: Medway High School
London, Ontario

RESEARCH EXPERIENCE

Master Thesis September 2017 – Present
Supervisor: Dr. Jason Brown
Adolescents with FASD: Education-Based Strategies for Social Skills Development
Western University
London, Ontario

Undergraduate Thesis September 2016 – April 2017
Supervisor: Dr. Riley Hinson
Best Practices: Managing Methamphetamine Withdrawal
Western University
London, Ontario

Undergraduate Independent Study September 2015 – April 2016
Supervisor: Dr. Riley Hinson
Exploring the Need for Post-Detox Stabilization
Western University
London, Ontario