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Fetal Alcohol Spectrum Disorder and Youth Education: Caregiver Perspectives

Kyle Cleversey

The University of Western Ontario

Supervisor

Dr. Jason Brown

The University of Western Ontario

Graduate Program in Education

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Abstract

The purpose of this study was to identify caregivers' needs in helping youth with Fetal Alcohol Spectrum Disorder (FASD) succeed in school, and services that caregivers believe would help youth with FASD succeed in school. Thirty-two caregivers raising a youth with FASD participated in telephone interviews that included two questions: "What do caregivers need to help youth be successful in school?" and "What services would help youth be successful in school?" Participants then sorted responses to these questions into piles they believed to be a conceptual fit with one another, and the data was analyzed using multi-dimensional scaling and cluster analysis. In response to the question about caregiver needs, five concepts emerged: 1) Working to Meet the Needs of the Individual, 2) Educational Accommodations, 3) FASD-Literate Schools, 4) Resources, and 5) Therapeutic Supports. Six concepts emerged from the question about services, including: 1) Being Heard by Educators, 2) FASD-Informed Educators, 3) Involvement in Child's Education, 4) Resources and Accommodations, 5) Supportive Knowledge Base, and 6) Support and Understanding at Home. These concepts were compared and contrasted with the existing literature.

Keywords: Fetal alcohol syndrome, FASD, education, caregivers, youth, needs, services, concept mapping.

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Chapter 1: Introduction

Fetal alcohol spectrum disorder (or FASD) refers to a range of impairments caused by maternal alcohol consumption during pregnancy (Sokol, 2003). FASD is a highly prevalent disorder, with maternal alcohol consumption being the leading preventable cause of birth defects in North America (Stratton, Howe, & Battaglia, 1996). Prenatal alcohol exposure affects development of the central nervous system, which in turn can cause physical, cognitive, developmental, and behavioural abnormalities (Chudley et al., 2005). In Canada, the diagnosis of prenatal alcohol exposure-related disorders falls along a spectrum including Fetal Alcohol Syndrome (FAS), partial Fetal Alcohol Syndrome (pFAS), and Alcohol-Related Neurodevelopmental Disorder (ARND) (Chudley et al.). Cook et al. (2015) recently released updated guidelines for the diagnosis of prenatal alcohol exposure-related disorders. While some research has focused on caregivers' experiences of raising an adolescent with FASD, little is known about how caregivers engage with and contribute to adolescents' educational experiences.

Present Study

The present study explores caregivers' perceptions of educational experiences for adolescents with FASD, in hopes of understanding of the resources caregivers believe to be necessary to encourage adolescents' educational success. Qualitative studies have been conducted on educational experiences for adolescents with FASD, however few have looked specifically at caregiver perceptions of educational experiences and none have used concept mapping to identify themes.

Although a great deal of research has investigated educational experiences and support systems for children with FASD (Adnams et al., 2007; Jirikowic, Olson, & Kartin, 2008; Koren, Fantus, & Nulman, 2009), research on the educational experiences of older youth and

adolescents is limited. Streissguth, Barr, Kogan, and Bookstein (1996) examined school functioning during adolescence for youth who had experienced pre-natal exposure to alcohol and found frequent educational challenges and disruptions to be the norm for students with FASD. Additional research by Howell, Lynch, Platzman, Smith, & Coles (2006) found that adolescents with FASD showed lower scores on the Wechsler Intelligence Scale and decreased performance on standardized math tests compared to a control group of adolescents from similar socioeconomic backgrounds. Kalberg and Buckley (2007) conducted a systematic review of the available research, identifying several factors contributing to educational success for adolescents with FASD. However, none of these studies focused on caregivers' perspectives on what is needed to ensure adolescent educational persistence.

The purpose of the present study is to bring caregivers' perspectives into the formal literature in hopes of providing a basis for future program planning that more effectively meets the needs of adolescents with FASD. Duquette and Stodel (2005) identified caregiver support as the most important factor contributing to adolescent educational success. Accordingly, the creation of a concept map that identifies themes in caregiver perspectives on adolescent educational experiences will contribute to the creation of programs that facilitate caregiver support, and in turn encourage adolescent educational persistence.

FASD in Canada

FASD is a leading cause of developmental delays and birth defects in Canada (Koren, Nulman, Chudley, & Looche, 2003). The prevalence of FASD places a considerable economic burden on the Canadian child welfare system, with the annual cost of care ranging from \$57.9 to \$198.3 million (Popova, Lange, Burd, & Rehm, 2014). An additional study by Stadel et al. (2009)

found that, including the cost of social services, medical care, and education, prenatal alcohol-exposure related impairments cost Canadian society approximately \$5.3 billion annually.

Fetal alcohol-related conditions are highly prevalent: alcohol-related physical or mental impairments affect nearly 1 in 100 births (Sampson et al., 1997; Stratton, Howe, & Battaglia, 1996). The Public Health Agency of Canada (2003) found that FAS specifically affects between 3 to 5 per 1,000 births. Although these estimates show FASD to be a highly prevalent disorder, it is possible that the actual rate of alcohol-affected births is higher than currently known. May et al. (2006) conducted a detailed physical and psychological assessment of 543 students and estimated occurrences of alcohol-related birth defects to be approximately 35 per 1,000 births. They attributed the discrepancy between their observations and previous estimates to the fact that diagnosis of FASD can be prohibitively costly. Access can be particularly limited for those most in need of a diagnosis, due to the fact that instances of FASD are elevated among lower SES populations (Benz, Rasmussen, & Andre, 2009).

Furthermore, rates of FASD diagnosis are known to be particularly elevated in certain populations, including children in foster care (Lange, Shield, Rehm, & Popova, 2013) and youth involved in the criminal justice system (Fast & Conry, 2009). The Children's Aid Society of London and Middlesex (2013) found that 63.9% of their workers reported suspecting at least one child in their caseload of having FASD. A study by Popova, Lange, Burd, and Rahm (2014) found that between 612 and 2,096 children with FASD are currently in foster care in Ontario, with costs to the foster care system estimated to be between 9 million to 33 million dollars. Despite the prevalence of FASD in Ontario, compared to other provinces Ontario is lacking in programs and services targeted at addressing the needs of children and youth with FASD (Naumann, Reynolds, McColl, & Smith, 2013).

Caregivers' Influences

Caregivers of children with FASD face unique challenges, even in comparison to caregivers of children with other disabilities (Watson, Coons, & Hayes, 2013). A qualitative study by Michaud and Temple (2013) found that caregivers of children with FASD believe “everything we learned as parents does not apply when caring for a child with FASD”. Despite the challenges associated with raising a child with FASD, effective caregiving can have positive impacts on children’s developmental outcomes. A longitudinal study by Jacobson, Jacobson, Sokol, Chiodo, and Corobana (2004) found an enriched home environment to be a mitigating factor in some of the cognitive impairments associated with FASD.

Due to the cognitive and behavioural impairments associated with FASD, education can be an area of particular challenge for children and youth affected by the disorder: Streissguth, Barr, Kogan, and Bookstein (1996) surveyed 473 alcohol-affected youth and found that 70% had experienced disruptions in their education, defined as suspension, expulsion, or dropping out. Furthermore, they found that 60% of alcohol-affected youth had been diagnosed with attention deficit hyperactivity disorder. Despite the challenges associated with education, caregivers can have a strong impact on educational experiences for children and youth with FASD. Duquette and Stodel (2005) identified caregiver support as the most important factor contributing to perceived educational success. Moreover, Duquette, Stodel, Fullarton, & Haglund (2006) showed that caregivers’ perceptions of educational success were correlated with actual educational persistence. Their findings showed that students whose caregivers saw them to be successful were more likely to view themselves as successful, and in turn were less likely to drop out or face expulsion. Streissguth et al. (2004) found that a positive home environment for youth with FASD was associated not only with improved educational persistence, but also with

decreased involvement with the court system, abstinence from drugs and alcohol, and lower risk of developing secondary disabilities.

Potential Impact

Research is vital to ensuring that service providers are aware of the challenges and needs of those providing care to children with FASD. It is important that educators, mental health professionals, and those working in policy development be made aware of caregivers' realities to facilitate the development and implementation of more effective services that directly address caregivers' needs. Research by Brown and Bednar (2004) shows that caregivers often report that being heard by professionals is challenging. Therefore, the present study seeks to bridge the gap between caregivers and professionals by bringing caregivers' voices into the literature.

Specifically, we aim to bring caregiver perspectives on educational experiences for adolescents with FASD into the literature in order to inform educators and policy makers and facilitate the implementation of more effective programs to address the needs of this at-risk population.

Counselling. Education places considerable stress on adolescents with FASD and their caregivers. Gorman (1995) interviewed adolescents between the ages of 15 to 20 and found that a significant majority had experienced educational disruptions such as suspension, expulsion, or dropping out. Because of these challenges, caregivers of students with disabilities often serve as educational advocates for their children (Heyman & Earle, 2000). However, caregivers' interactions with educators and policy-makers can be fraught with tension due to differences in perception about the nature of a student's academic difficulties and the steps needed to address problems (Lawson, 2003; Timler & Olswang, 2001). Therefore, research is needed to provide counsellors with insight into caregivers' experiences of the educational system and facilitate counselling techniques that effectively address their needs.

Some research has focused on the role of counselling in helping adolescents transition from the educational system into the workforce. Shepard and Breen (2007) suggest that counselling based on Social Cognitive Career Theory (SCCT) can help adolescents with FASD overcome low self-esteem, difficulties in establishing routines, information processing challenges, and passive learning styles. SCCT-based counselling focuses on harnessing positive personal attributes, environmental factors, and behavioural factors to facilitate success in transitioning from education into the workforce (Lent, Brown, & Hackett, 2000). However, the existing research focuses on the role of counselling during the transitional period between education and career-focus, and does not address counselling's role in helping adolescents with FASD succeed in education itself. By identifying what caregivers believe is needed to help adolescents with FASD succeed in the context of education, we hope to provide a foundation for future counselling interventions that will more effectively address the educational support needs of this at-risk population.

Policy. This research is beneficial in guiding decisions regarding educational policy focused on youth with FASD. A great deal of progress has been made toward ensuring that caregivers of youth with disabilities are given a voice in their child's education. In many places, legislation requires that parents of students with disabilities be allowed a voice in the educational decision-making process (Kalyanpur, Harry, & Skrtic, 2000). Nonetheless, tension remains between educators and parents in regards to the appropriate degree of control parents should have over educational decisions. Parents and educators often have conflicting views about the nature of students' educational problems and how to best overcome obstacles to educational success (Lawson, 2003; Timler & Olswang, 2001). Policy is needed to guide the educational

decision-making process, and research is a vital tool in bringing caregivers' voices into policy creation.

Although there has been significant progress toward giving caregivers of students with disabilities a voice in education, there is a lack of educational policy regarding FASD specifically (Naumann, Reynolds, McColl, & Smith, 2013). FASD has not been officially recognized as an exceptionality within the Ontario public education system (Naumann et al.). As a result, although many Ontario youth with FASD are assigned individual education plans, they often do not qualify for other resources targeted at youth with disabilities due to the relatively invisible nature of their disorder (FASD ONE Intervention and Support Working Group, 2010). Some Ontario school boards provide educators with FASD-focused learning opportunities during personal development days, but these learning opportunities are typically voluntary rather than mandatory (Naumann et al.). Seeing as caregiver advocacy is key to ensuring educational success for youth with FASD (Duquette, Stodel, Fullarton, & Hagglund, 2006), it is important that caregivers perspectives are given due consideration as educational policy targeted at youth with FASD is implemented. The present study seeks to bring caregiver voices into the literature on FASD education in order to provide a foundation for educational policy-making.

Research. Governments must address the special needs of youth with FASD, and one way in which governments can fulfill this responsibility is by funding research into the disorder. Recent research on FASD focuses on the areas of prevention, diagnosis, and intervention (Canada FASD Research Network, 2015). Research in each of these areas contributes to society's understanding of FASD and improved quality of life for those suffering from the disorder.

Brown (2004) highlights the fact that research and practice need to, “capitalize on what parents of alcohol-affected children have learned about what works for them.” Given that caregiver advocacy is an essential component of educational persistence for youth with FASD (Duquette, Stodel, Fullarton, & Hagglund, 2006), it is particularly important for educational research to incorporate caregiver perspectives. Ultimately, this research brings caregiver voices into the literature on educational experiences for FASD to improve the lives of those suffering from the disorder by ensuring that education and policy decisions are informed by research that considers the perspectives of their strongest advocates.

Structure of the Thesis

Chapter 1 serves as an introduction to the relationship between education and FASD, with a focus on highlighting the importance of research and providing context for the current study. Chapter 2 reviews the relevant literature, and includes a summary of FASD’s history, FASD’s effects and causes, and findings from an analysis of the research on caregivers’ experiences. Chapter 3 outlines the present study’s methodology, and provides a summary of the concept mapping method being used to analyze data. Chapter 4 presents the results of the present study and provides tables and figures illustrating these results. Chapter 5 contains a discussion of the studies results as well as outlining implications and potential directions for future research.

Chapter 2: Literature Review

In this chapter, background on alcohol-related effects, diagnosis, caregiver experiences, and educational experiences are reviewed.

Fetal Alcohol Syndrome

In this section, a brief history of FASD as well as its causes and diagnostic criteria are described.

History. Ancient prohibitions against maternal alcohol consumption dating back to Biblical and Greek times point to an early understanding of its negative effects on child outcomes (Jones & Smith, 1973). An 1834 report to the British House of Commons suggested that children born to alcohol-dependant mothers often had a, “starved, shrivelled, and imperfect look” (as cited in Jones & Smith, p. 999). Early scientific inquiry into links between maternal alcohol consumption and birth defects dates as far back as Dr. William Sullivan’s (1899) observation that rates of stillbirth were higher for alcoholic women prisoners than for their non-alcoholic relatives. Sullivan’s observation was in direct contradiction to the prevailing opinion at the time that physical and cognitive defects could be explained purely by hereditary factors (Streissguth, 1997). However, additional contemporary research conducted in France by Ladrage (1901) supported Sullivan’s theory that miscarriages and “idiocy” could be caused by maternal alcohol consumption.

Modern research into birth defects caused by maternal alcohol consumption began when Lemoine, Harousseau, Bortreyu, and Menuet (1968, as cited in Streissguth, 1997) published a study identifying distinctive features in children born to alcoholic mothers. Soon after, Jones and Smith (1973, p. 1000) identified a, “pattern of craniofacial, limb, and cardiovascular defects associated with prenatal onset growth deficiency and developmental delay” associated with

maternal alcohol consumption. Jones and Smith referred to this cluster of symptoms as Fetal Alcohol Syndrome (FAS). Animal research by Clarren & Smith (1978, p. 1064) confirmed that alcohol is a teratogen with the potential to cause, “CNS dysfunctions, growth deficiencies, a characteristic cluster of facial abnormalities, and variable major and minor malformations.” Over time, subsequent research began to point to disparate levels of impairment in children exposed pre-natally to alcohol, and the term Fetal Alcohol Spectrum Disorder (FASD) was created to encompass a variety of conditions associated with maternal alcohol consumption (Buxton, 2010).

Causes. The available research points to several mechanisms by which maternal alcohol consumption may affect children’s physical and neurodevelopmental outcomes. First, maternal alcohol consumption causes ethanol and toxic metabolites to pass freely through the placenta, allowing direct access to the developing fetus (Brien, Loomis, Tranmer, & McGrath, 1983). Due to the fetus’ high sensitivity to ethanol toxicity, exposure can affect the development of almost every aspect of the central nervous system (Brien et al.). Furthermore, the fetal liver is unable to process and detoxify ethanol as efficiently as a fully developed adult liver, thereby prolonging fetal exposure to ethanol and its metabolites (Nava-Ocampo, Velazquez-Armenta, Brien, & Koren, 2004).

While several factors including timing, quantity of alcohol consumed, and maternal factors contribute to maternal alcohol consumption’s effects, research has shown that any amount of alcohol can cause harm to the fetus (Goodlet & West, 1992, as cited in Streissguth, 1997). A meta-analysis of the available research by Polygenis et al. (1998) found that alcohol consumption during the first three weeks of pregnancy posed the greatest risk to development of the central nervous system. However, consistent alcohol consumption throughout pregnancy is associated with a higher risk of severe neuropsychological effects than drinking only during the

first trimester (Korkman, Autti-Ramo, Koivulehto, & Granstrom, 1998). Maternal factors such as smoking, height, weight, and alcohol consumption in the maternal family of origin also contribute to risk and severity of FASD (May et al., 2005).

Diagnosis. North American diagnosis of FASD currently relies on four different systems targeted at diagnosing FAS and other fetal alcohol-related conditions. The first North American standardized diagnostic system for prenatal alcohol exposure was established by the Institute of Medicine (Stratton, Howe, & Battaglia, 1996). Additional diagnostic systems employed in North America include the University of Washington's "4-Digit Diagnostic Code" (Astley & Clarren, 2000), the Center for Disease Control's "Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis" (Center for Disease Control, 2004), and the Canadian Guidelines for FASD Diagnosis (Chudley et al., 2005). Because the present study is Canadian, and concerned specifically with local populations, our focus will be on Canadian guidelines.

All four diagnostic systems include an assessment of four key features of FASD (Chudley et al., 2005). The first point of assessment is growth deficiency, with growth and height ranging from normal to deficient. The second diagnostic measure is FASD-related facial features, including a flattening of the groove between the nose and upper lip, a thinning of the upper lip itself, or shortened eye-width. Third, those responsible for diagnosis look for evidence of central nervous system damage. The final diagnostic measure is a confirmation of prenatal alcohol exposure. Positive findings on all four diagnostic criteria are required for an individual to be diagnosed with fetal alcohol syndrome, however other disorders on the spectrum require as few as two positive findings. The Canadian Guidelines for FASD Diagnosis were the guidelines in place at the time the present study was conducted, and combine and harmonize techniques from existing North American diagnostic systems. Similar to the University of Washington's "4-

Digit Diagnostic Code”, Canadian diagnosis employs a four digit coding system based on Likert scales for each of FASD’s four key features, while combining this feature with diagnostic terminology developed by the Institute of Medicine. Due to significant differences in diagnostic procedures between countries, it is important to note that many studies are conducted outside Canada or North America and may rely on different diagnostic systems than those described above. Furthermore, since the time the present study was conducted, Cook et al. (2015) released revised guidelines for FASD diagnosis. These revised guidelines contained several specific updates, including formalizing the use of FASD as a diagnostic term, the deletion of “growth” as a diagnostic criterion, and the addition of an “at-risk” category targeted at facilitating diagnosis and treatment of individuals who do not meet all of the diagnostic criteria but are still at-risk of FASD.

Effects. FASD is associated with numerous deleterious effects including physical deficits in growth and height (Astley, 2004), observable structural damage to the brain such as agenesis of the corpus collosum or cerebellar hypoplasia (Institute of Medicine, 1996), diagnosable neurological impairments such as epilepsy (Chudley et al., 2005), and softer neurological impairments including impaired motor skills or hearing loss (Center for Disease Control, 2004). Furthermore, FASD is associated with several functional impairments. Individuals with FASD often exhibit deficits in impulse control, social perception, communication, abstraction, cognition, and attention (Institute of Medicine, 1996). FASD-related deficits in executive functioning can cause problems with decision-making, impulsivity, and judgment (Malbin, 2004).

As a result of these deficits, FASD poses several educational challenges. Although a great deal of research has investigated educational experiences for children with FASD (Adnams

et al., 2007; Jirikowic, Olson, & Kartin, 2008; Koren, Fantus, & Nulman, 2009), research on the educational experiences of older youth and adolescents is limited. Children with FASD may present with low math scores or impaired cognitive functioning (Coles, Taddeo, & Millians, 2011), but IQ scores in children affected by FASD have been found to be approximately average (Rasmussen, 2005). Accordingly, educational difficulties are typically ascribed to deficits in functioning in areas such as planning, schedule-adherence, and organization (Siklos, 2008) rather than to low IQ scores.

For adolescents, the effects of FASD often translate into difficult or disrupted school experiences. Streissguth, Barr, Kogan, and Bookstein (1996) found that 70% of alcohol-affected youth had experienced disruptions in their education. Furthermore, they found high rates of co-morbid disorders, with 60% of alcohol-affected youth having been diagnosed with attention deficit hyperactivity disorder. Alcohol-affected youth were also found to place considerable stress on special education resources, with over 65% receiving remedial help in mathematics. Additional research by Howell, Lynch, Platzman, Smith, & Coles (2006) found that adolescents showed decreased performance on standardized math tests compared to a control group of adolescents from similar socioeconomic backgrounds. Taken together, the current research highlights the effects of FASD on adolescents' development and educational experiences and suggests a need to identify effective services, support systems, and other factors contributing to educational success for adolescents with FASD.

Summary. A review of the literature on FASD's history, causes, diagnosis, and effects demonstrates the importance of FASD as an area of research. FASD is an active area of research in which considerable progress is currently being made, leading to an improved understanding of the disorder itself and improvements in the lives of those affected by FASD.

Caregivers' Experiences of Education

A review of the literature was performed, focusing on what caregivers need to support educational persistence when raising an adolescent with FASD. Searching databases in education, health, and social sciences (ERIC, MEDLINE and PsycINFO) using the key words "fetal alcohol spectrum disorder", "caregiver", "developmental disabilities", and "education", relevant peer-reviewed articles, published reports, and dissertations were located. Several themes were identified in the literature regarding the services needed to help youth be successful in school, and what caregivers need to help youth be successful in school.

Services Needed to Help Youth Succeed in School

A review of the existing literature highlighted several areas in which services are needed to help youth with FASD succeed in their education. In terms of service availability, existing research describes the need for FASD-informed services, special education services in general, and individualized services that meet the unique needs of alcohol-affected students. In terms of service delivery, a review of the existing literature highlights the need for individual learning assessments, counselling interventions that could help with educational processes, the implementation of strategies that are known to be effective for alcohol-affected students, and educators who are aware of these service needs.

Availability of services. Despite the prevalence and known impacts of FASD, there are limited services available targeted at improving the educational experiences of youth affected by the disorder. The diversity of learning difficulties faced by students with FASD contributes to the challenging nature of service development and implementation. Furthermore, research into effective educational service delivery for youth with FASD is in its infancy.

FASD-informed services. In recent history, educational institutions have generally acknowledged a duty to support students with complex disabilities by equipping educators with the tools necessary to meet their needs (Ryan & Ferguson, 2006). In attempting to fulfill this obligation, educators face the challenge of navigating a constantly growing array of new and emerging disorders (Blackburn, Carpenter, & Egerton, 2010). Accordingly, there is a need for programs and services that address the needs of specific target populations of students with complex disorders. Furthermore, most North American educational systems recognize a need for students with disabilities to be included in the regular classroom setting along with their peers (Fitch, 2002). Therefore, there is a demand for services that would support students with FASD in functioning and excelling in the regular classroom setting. Despite the demand for services, there has been little progress in service implementation and systematic training of educators targeted at improving educational outcomes for students with FASD (Ryan & Ferguson).

Students with FASD present with unique learning difficulties that necessitate specially designed educational approaches. General theories of learning often fall short in understanding the learning strategies employed by alcohol-affected students (Blackburn et al., 2010). For example, students with FASD often have well-developed short term verbal recall and are able to “parrot back” items that have been taught to them without a full understanding of the item’s meaning (Mattson, Riley, Delis, Stem, & Jones, 1996). This short term verbal recall can make it difficult for educators to ascertain when students with FASD have gained a full understanding of the material. Accordingly, there is a need for services that recognize and address the challenge of assessing learning in students with FASD. Furthermore, students with FASD are often ineligible for general services targeted at students with special needs due to the fact that, despite their disability, testing may find their intellectual ability to be within the average range (Kalberg &

Buckley, 2007). Taken together, the current research highlights the need for services that will address the diverse needs of students with FASD in the context of the regular classroom.

Individualized approaches. Some common factors exist in the learning challenges faced by most students with FASD. Cognitive confusion, difficulty understanding the consequences of actions, and memory impairment represent some of the most common educational challenges for alcohol-affected students (Job et al. 2013). However, research has shown a great deal of diversity in the learning challenges associated with FASD. Abel and Sokol (1987) found no consistent pattern in the learning difficulties faced by alcohol-affected students. Furthermore, depending on the severity and nature of impairment, FASD may have little effect on students' cognitive functioning or learning abilities (Streissguth, Randels, & Smith, 1991). Challenges to educational success often present in other ways such as hyperactivity, poor social functioning, or disruptive behaviours (Blackburn et al., 2010).

As a result of the wide array of educational challenges posed by FASD, services designed to address specific deficits often fail to meet the needs of FASD-affected students as a wider population (Duquette, Stodel, Fullarton, & Hagglund, 2006). Accordingly, research into services for students with FASD must address not only programs targeted at overcoming specific challenges and deficits, but must also aim to develop more general services that can address the needs of FASD affected students at large. Moreover, behaviour modification techniques employed by most educators are often ineffective when used on students with FASD, requiring educators to develop new strategies that respond to the learning abilities of individual students (Malbin, 2007).

Summary. Although considerable progress has been made toward identifying the needs of alcohol-affected students, research into service provision for alcohol-affected students is in its

infancy. Students with FASD face a variety of educational challenges, and require services that address their needs as unique individuals.

Service delivery. Despite the diverse needs of FASD-affected students, some services and interventions have been developed with the intention of addressing common FASD-related educational needs. Recent research has focused on services targeted at delivering comprehensive learning assessments for students with FASD, Cognitive Control Therapy as a means of improving educational outcomes, and professional development for educators.

Learning Assessment. Although it is important for educators to know that a student in their classroom has been diagnosed with FASD, knowledge of a diagnosis is not sufficient for educators to meet the needs of individual students. Rather, due to the diversity of potential impairments associated with FASD, a comprehensive individual learning assessment is necessary to provide educators with the information needed to address the specific needs of a given student (Kalberg & Buckley, 2007). Learning assessments typically garner information about a student from numerous sources including caregivers, educators, and direct observation of the student's learning processes (Olson et al., 1997). Collected information about students' ability to work independently, attentional capabilities, behaviours, strengths, interests, interactional abilities, and general functioning can then be used to develop an individual learning profile for use by educators in developing a learning plan suited to the individual needs of the student (Kalberg & Buckley). However, despite the variance in individual needs for students with FASD, some research has investigated specific strategies and interventions that may address the overarching needs of the majority of alcohol-affected students.

Structured and systematic teaching. A structured and predictable learning environment is an essential contributor to educational success for students with FASD (Streissguth, 1997).

Kalberg and Buckley (2006) explain the need for structure by drawing the analogy of the learning environment as an “external nervous system” for the student. In this analogy, structure in the student’s learning environment can help to compensate for cognitive deficits in the actual nervous system.

Additional research by Kalberg and Buckley (2007) identified three particular types of structure that may facilitate learning experiences for adolescents with FASD: visual, environmental, and task structure. Visual structure was found to be particularly important for youth with FASD, and Kalberg and Buckley recommend taping off sections of the room as activity centres or using containers to separate materials as effective strategies. Environmental structure facilitates learning by establishing clear boundaries for what type of learning occurs in each part of the classroom and minimizes the chances of behavioural problems. For example, an educator could clearly delineate which areas of the classroom are to be used for mathematics, computers, reading, etc. Task structure can also be used to provide a clear system for the child to follow; educators may wish to use colour coding to delineate the beginning, middle, and end of a task. Taken together, Kalberg and Buckley’s evaluation of structure and systematic teaching demonstrates the need for services that enable teachers to organize their classrooms in ways that are conducive to facilitating learning for students with FASD.

Cognitive control therapy. Many children with FASD face significant challenges across a variety of cognitive domains, including working memory, problem solving, executive functioning, and behavioural regulation (Adnams et al., 2001). Accordingly, interventions that address cognitive control strategies have been identified as a potential means of helping students with FASD overcome cognitive deficits (Kalberg & Buckley, 2006). Cognitive control therapy (CCT), “emphasizes the need for reorganizing immature cognitive controls and associated

maladaptive strategies that underlie academic performance” (Riley et al., 2003, p. 365).

Moreover, CCT aims to facilitate students’ learning by improving self-regulation, which is a common deficit area for those affected by FASD (Adnams, Rossouw, Perold, Kodituwakku, & Kalberg, 2003).

Adnams et al. (2003) conducted a randomized controlled trial to evaluate the effects of CCT on learning and behavioural outcomes for students with FASD. Students in their experimental group received CCT for one hour each week over the course of ten school term months. Post-treatment evaluation found that students in the experimental group showed significant improvements in classroom behaviour as evaluated by educators compared to the control group. Furthermore, students in the experimental group showed qualitative improvements in motivation, self-efficacy, school achievement, attitude to learning, and writing as evaluated by therapists and educators. The success of CCT in improving educational outcomes for students with FASD speaks to the need for service delivery in the form of targeted therapeutic interventions that directly address the needs of alcohol-affected students.

Professional development for educators. Due to the complexity of FASD and the highly individualized needs of those affected by the disorder, educators require specialized training to meet the needs of alcohol-affected students (Blackburn, Carpenter, & Egerton, 2010). Although many FASD resources have been made available to educators (British Columbia Ministry of Education, Skills, & Training, 1996; Healthy Child Manitoba, 2009), until recently there had been no evaluation of the effectiveness of available resources. However, an Ontario-based study by Koren, Sadowski, & Scolnik (2013) investigated the effectiveness of the Motherisk FASD Clinic Module, an education resource and professional development session targeted at informing educators about the needs of students with FASD. They found an overwhelmingly

positive reaction to the training module, with 79% of participants reporting that the module will improve their future job performance, 99% reporting that the training module was an important job resource that they would recommend to their colleagues, and 93% reporting increased confidence in their knowledge of FASD. Moreover, 75% of participants reported that this module was their first FASD-focused training experience, demonstrating a clear need for programs and services targeted at raising awareness of FASD among educators.

Summary. Comprehensive learning assessments, structured and systematic teaching, Cognitive Control Therapy, and targeted professional development show promise as methods of improving educational outcomes for students with FASD. The present research suggests that services for students with FASD should focus on addressing the unique needs of individual students.

Caregivers' Needs in Helping Youth Succeed in School

A review of the existing literature revealed several ways in which caregivers contribute to the educational success of students in their care, and several examples of their needs in doing so. In terms of caregivers' contributions to educational processes, the current literature highlighted several examples including support and advocacy roles, minimizing the risk of secondary disabilities, contributing to expectations of success, and contributing to research on education. In terms of caregiver needs in helping youth succeed in their education, a review of the literature yielded several examples including a stable home environment, an understanding of FASD-related challenges, supports in the community, educational supports such as accommodations, and collaboration with educators.

Caregiver contributions to adolescents' educational outcomes. Caregivers' high level of access to adolescents in their care means that their influence is pivotal in helping to determine

educational outcomes for youth with FASD. Caregivers' influences range from providing academic and emotional support to contributing to research on educational outcomes.

Caregivers and educational success. Duquette and Stodel (2005) conducted a qualitative study, interviewing adolescents with FASD and their parents or foster parents. They found that parents and youth identified caring teachers, obtaining a medical diagnosis, support from parents, and appropriate programs and services as the primary contributors to educational success. Additional research by Duquette, Stodel, Fullarton, & Hagglund (2006) expanded on Duquette and Stodel's (2005) study by identifying parental support as the most important factor contributing to perceived educational success. Moreover, Duquette et al. (2006) showed that students' and caregivers' own perceptions of educational success were correlated with actual educational persistence, as students who viewed themselves as successful were less likely to drop out or face expulsion. This finding provides additional evidence that programs targeted at improving educational outcomes for adolescents with FASD should incorporate suggestions from adolescents and caregivers themselves alongside evidence-based interventions such as structured, systematic teaching and cognitive control therapy (Kalberg & Buckley, 2007). Factors contributing to perceived success increase the likelihood that adolescents with FASD will persist in their education, thereby improving the chances that they will continue to have access to evidence-based educational interventions.

Caregivers and educational persistence. Stable and nurturing caregivers play an important role in ensuring educational persistence for adolescents with FASD. Aside from decreasing the likelihood of disrupted school experiences, the presence of supportive caregivers also minimizes the risk of secondary disabilities such as mental health issues, drug use, and criminal activity that could further impact the course of adolescents' education (Streissguth et al.,

2004). Furthermore, caregivers play a vital role as advocates for adolescents: FASD is a heterogeneous disorder, and caregivers are best equipped to understand the unique needs of adolescents in their care (Streissguth, 1997; Child and Youth Working Group, 2007). Duquette, Stodel, Fullarton, & Hagglund (2006) found that caregiver advocacy combines with caregiver expectations of educational persistence to keep students with FASD in school. Duquette et al. identify emotional support, academic support, working to obtain a diagnosis, and communicating needs to educators as ways that caregiver advocacy contributes to educational persistence. Furthermore, Duquette et al. found that when caregivers express an expectation for adolescents in their care to finish school, adolescents pick up on this expectation and are more likely to not only adopt this goal as their own, but also to view themselves as having the potential to succeed. This expectation of success was in turn associated with actual educational persistence.

Caregivers' contributions to research on education. Aside from serving as advocates, caregivers of adolescents with FASD also play an important role in contributing to research on adolescents' educational outcomes. Youth with FASD may not have the cognitive capability, knowledge, or insight into their condition to contribute accurately or completely to research (Jirikowic, Olson, & Astley, 2012). Accordingly, many studies ask caregivers to participate due to their unique insight into the needs of adolescents in their care (e.g., Duquette and Stodel, 2005; Duquette et al., 2006; Streissguth et al., 2004).

Summary. Caregivers fill numerous vital roles in helping youth with FASD succeed in their education. From advocacy, to emotional support, to contributing to research, stable and supportive caregivers are instrumental in ensuring positive educational outcomes for adolescents with FASD.

Caregivers' needs. Due to caregivers' positions of influence over educational success for students with FASD, it is important to investigate factors that support caregivers in their role as educational advocates. The current research shows that stable home environments, an understanding of FASD-related challenges, and strong community and educational supports contribute to caregivers' ability to support students in their education.

Stable home environment. The creation and maintenance of a stable and supportive home environment is vital to minimizing the risk of secondary disabilities and helping adolescents with FASD succeed in school (Streissguth, 2004). Brown (2008) asked caregivers what was needed for a successful foster placement and identified several factors including community support, the right personality and skills, adequate self-care skills, individualized services, and supportive immediate and extended families. Given the heightened challenges of caring for an adolescent with FASD, it is likely that foster parents and other caregivers would require all of these factors and more to ensure the provision of the stable and supportive home environment that is integral to ensuring educational success.

Understanding FASD-related challenges. Foster parents who are unaware that a child in their care has FASD or who lack information on FASD-related impairments often struggle to understand their child's behaviours and have difficulty finding ways of managing those behaviours (Brown, Bednar, & Sigvaldason, 2007). Learning about the nature of FASD helps caregivers to understand the genesis of problem behaviours and can help to assuage guilt and self-blame associated with difficulties managing these behaviours (Weiner & Morse, 1994). Education on FASD can help caregivers to reframe problem behaviours by understanding that they are rooted in neurological impairments, which in turn can help caregivers develop a more positive view of children in their care and to feel more effective in their parenting (Olson &

Montague, 2011). Understanding the etiology of difficult behaviours can help caregivers foster peaceful home environments (Streissguth, 1997), which in turn can help facilitate adolescents' educational success.

Community supports. Social support networks such as family members and neighbours can support caregivers in many ways, including respite care and emotional support (Brown, Sigvaldason, & Bednar, 2005; Parks & Novielli, 2000). Furthermore, professional support networks such as social service teams are instrumental in providing caregivers with the resources needed to care for children and adolescents with disabilities (Brown & Bednar, 2003; Bailey, 2007). Networking with other caregivers who have experience of raising a child with FASD may also help support caregivers by decreasing feelings of isolation and facilitating the sharing of information about FASD (Olson & Montague, 2011). Taken together, the research suggests that strong community supports are integral to providing caregivers with the resources to succeed in creating a supportive environment that facilitates educational success for adolescents with FASD.

Educational supports. For many caregivers of adolescents with FASD, interactions with the educational system can be fraught with difficulties (Brown & Bednar, 2004). School environments that lack adequate support structures can contribute to caregivers' stress by neglecting or actively discriminating against students with FASD (Duquette & Stodel, 2005; Ryan & Ferguson, 2006). Furthermore, caregiver stress and disappointment can be compounded when academic expectations exceed the abilities of students with FASD (Brown & Bednar, 2004). Nonetheless, caregivers identify collaboration with educators as an important need in raising an alcohol-affected child (Brown & Bednar, 2003). Pei, Job, Poth, & Atkinson (2013) conducted interviews with teachers, caregivers, and other professionals in the educational field.

They identified three major themes in the resources that participants believed to be necessary to support students with FASD: responsive assessment processes, a focus on the whole child, and building capacity in the school environment. Working to ensure that these needs are met can help to facilitate positive and impactful relationships between educators and caregivers of students with FASD.

Summary. By enabling caregivers to create a stable home environment, educating caregivers on the nature of FASD, and fostering strong community and educational support systems, caregivers can be empowered to serve as strong advocates for students with FASD and contribute to their educational persistence and success.

Conclusions. A review of the available literature reveals that FASD has significant impacts on adolescents' educational experiences. Cognitive, behavioural, and adaptive challenges create significant risks of drop-outs, expulsions, and other educational setbacks. In turn, there is a need for caregivers to be provided with the resources necessary to provide support for youth with FASD in their roles as educational advocates. Although the current research highlights the educational challenges faced by youth with FASD and their caregivers, little research has been dedicated to investigating caregiver perspectives on what services youth need to be successful in school and what caregivers need to help youth be successful in school.

Chapter 3: Methodology

This study combined qualitative and quantitative techniques by employing semi-structured interviews and statistical analysis based on Trochim's concept mapping (1989). In partnership with the FASD Network of Elgin, London, Middlesex, and Oxford (ELMO), a local London, Ontario caregiver-professional interest group, researchers contacted caregivers of adolescents with either confirmed or suspected FASD. In turn, the present study is beneficial to ELMO as an organization and to the participants involved in that the study's results enhance understanding of FASD and serve as a basis for future advocacy.

A choice was made to contact caregivers of adolescents with FASD rather than adolescents themselves due to the possibility that people with FASD may lack the cognitive ability or insight to respond fully and accurately to interview questions (Jirikowic et al., 2012; Wengel, Hanlon-Dearman, & Fjeldsted, 2011; Streissguth et al., 2004). The present study also investigated caregiver perspectives directly, because of caregivers' influence on educational persistence for adolescents with FASD (Duquette et al., 2006).

Past studies on caregivers of adolescents with FASD have employed telephone interviews with open-ended questions as a data collection method (Brown, Bednar, & Sigvaldason, 2007; Clark, Minnes, Lutke, & Ouelette-Kunts, 2008; Streissguth et al., 2004). Telephone collection is a low cost data collection method, while simultaneously allowing participants the chance to describe their reality in rich detail (Jackson & Trochim, 2002). Interviews also increase the likelihood of accurate responses by allowing participants to respond in whatever manner they

deem appropriate, to elaborate on their responses, and to ask for clarification if necessary (Appleton, 1995).

Concept Mapping

Concept mapping is the quantitative analysis of qualitative data (Trochim, 1989). The final result of concept mapping is an easily-interpretable visual representation of a concept's organizational structure (Trochim, 1989). The creation of a concept map can be used as a foundation for program planning and can help to promote structure and objectivity in qualitative research (Burke et al., 2005). According to Trochim, concept mapping allows for an understanding of participants' lived experiences. Concept mapping uses ideas generated by a sample of participants to draw inferences about the organizational structures of ideas in a larger population. The process of concept mapping consists of six steps: preparation, generation, structuring, representation, interpretation, and utilization.

Procedure

Participants. The present study targeted adult participants who had experience raising a youth age 10 or older with suspected or diagnosed FASD, and who were willing to participate in a telephone interview. Participants were recruited by telephone, in-person, by e-mail, or via printed flyer with the assistance of the ELMO group, a community organization with a focus on FASD serving the London, Middlesex, Elgin, and Oxford areas in Ontario. The ELMO group facilitated this research by connecting the researchers with participants in the community via their professional contacts and associates. Advertisements for participants were issued through the London FASD Clinic by asking professionals in the organization to recruit participants

primarily via e-mail. Caregivers of children with suspected rather than diagnosed FASD were asked to complete an additional screening assessment, the Neurobehavioural Screening Tool.

Neurobehavioural Screening Tool (NST). Nash et al. (2006) developed the Neurobehavioural Screening Tool (NST) in response to the difficulty associated with obtaining a diagnosis of FASD. Numerous caregivers suspect they are raising a child with FASD, but lack access to diagnostic procedures; accordingly, Nash et al. designed the NST to support the suspicion of FASD based on an evaluation of a child or adolescent's behaviour over a six month period. Nash and colleagues created the NST based on ten items from the Child Behaviour Checklist found to predict FASD diagnosis. The NST is particularly suited to the purposes of the present study, because Nash et al. found it to be most accurate for adolescents between 12-17 years of age.

Generation of Responses. Consent to participate was obtained verbally at the beginning of each telephone interview. Participants were offered a small honorarium for each stage of the study in which they chose to participate. Caregivers were asked for demographic information as well as open-ended responses to two interview questions: "What services would help youth be successful in school?" and "What do caregivers need to help youth be successful in school?" (See Appendix for interview form). If the adolescent had been diagnosed with FASD, a copy of the diagnosis was requested. If the adolescent was suspected to have FASD, the NST (Nash et al., 2006) was administered. The NST was then scored by trained researchers, and participants were only included in the study if the NST indicated positive results for FASD. Four potential participants were ineligible to participate because the NST was below cut off. The NST was

administered a total of ten times. Participants also had the option to participate in a second response-sorting phase of the study. If participants chose to continue to this phase, their contact information was collected and stored securely to facilitate additional contact.

A total of 16 interviews were conducted, with 15 females and 1 male participating. Participants were birth parents, adoptive parents, foster parents, aunts, or grandparents of youth over the age of 10 with FASD. Participants had between 1 and 5 children in their households at the time interviews were conducted. Of the 16 participants interviewed, seven had household incomes under \$50,000 and none had household incomes that exceeded \$100,000. Together, participants had been caregivers to 42 children with FASD.

Structuring of the responses. Unclear or redundant responses were edited or removed from the analysis. Participants who volunteered for the sorting phase of the study were asked to organize the responses into groups and that each group would include more than one response. Aside from those two criteria, response sorting was at the discretion of participants themselves.

Representation of responses. After responses had been sorted by participants, statistical software employing non-metric multi-dimensional scaling and hierarchical cluster analysis was used to average the sortings and form distinct concepts. Each open-ended interview question was analyzed individually, producing two concept maps: one for the question on adolescents' needs in school, and one for the question on what caregivers need to help adolescents be successful.

Multi-dimensional scaling. Multi-dimensional scaling using the x-y matrix was employed, and each participant's responses were represented in the matrix. Responses were represented either by a 0, indicating the responses were sorted into the same group by that

individual, or a 1, indicating the response was sorted into a different group. Matrices were then combined into a summary matrix and plotted onto a point map. The distance between points on the map represented the average frequency of each item sorted with each other surrounding item.

Cluster analysis. In concept mapping, concepts that are more closely related to one another appear closer together on the map. Hierarchical cluster analysis was conducted to group individual statements into clusters that reflect related concepts. Cluster analysis was based on the multidimensional scaling values and organized them into concepts based on the frequency of their grouping by participants. At the beginning of the analysis, each response was its own cluster. At each stage of the analysis two clusters were merged until, at the end, all responses were in one cluster. Researchers then decide on the optimal number of clusters for the data by taking into account conceptual similarities/differences and bridging indices (Kane & Trochim, 2007). Bridging indices indicate the cohesiveness of a cluster on a spectrum from 0 to 1, with indices closer to 0 indicating more cohesiveness (responses in the cluster were only likely to be sorted with other responses close by on the map) and indices closer to 1 indicating less cohesiveness (responses in the cluster were likely to be sorted with other responses at varying locations on the map).

Interpretation. In concept mapping, there is no single correct way to determine the appropriate number of concepts. Rather, researchers use past experience and knowledge to determine the optimal number of concepts for the set (Trochim, 1989). A potential disadvantage of concept mapping can be found in the fact that all unique responses are equally represented, which results in researchers being unable to indicate which responses were most common or

which were the highest rated (Brown & Bednar, 2004). However, having participants reflect on and sort the data allows for more accurate participant-generated themes to emerge and helps to minimize the influence of the researcher (Burke et al., 2005). The final product of concept mapping is an easily interpretable visual representation of the organization of ideas.

Utilization. Once a concept map has been created, its potential uses are limited only by the creativity and motivation of its users (Trochim, 1989). One example of a common use for concept maps can be found in their use as foundational bases for program planning; once the relationship between ideas is understood, programs can be planned around the ways in which ideas interconnect (Burke et al., 2005).

Summary

The present study employed concept mapping techniques to analyze the results of interviews conducted with caregivers of alcohol-affected students. Once responses had been generated multi-dimensional scaling and cluster analysis were employed, and researchers then decided on the appropriate numbers of concepts based on conceptual similarity and bridging indices. The resulting concept map can then be interpreted and used as a foundation for future program planning.

Chapter 4: Results

This study aimed to identify services that would help youth with FASD be successful in school, as well as caregivers' needs in helping youth with FASD succeed in school. Interviews with caregivers of youth with FASD were conducted by telephone. These same caregivers were then asked to sort the interview responses into groups similar in meaning or theme. The sorting data was analyzed statistically using the Concept System Global MAX software and the output from this analysis was then used to create concept maps for both interview questions. This chapter presents the results of the concept mapping analysis for each question: "What services would help youth be successful in school?" and "What do caregivers need to help youth be successful in school?"

Services

Participants provided 54 unique responses to the question: "What services would help youth be successful in school?" Thirteen participants sorted the responses. Multidimensional scaling and cluster analysis were used to analyze the sorted responses. The validity of the analysis is measured by a stress value. Trochim (1989) notes that stress values below 0.35 typically indicate that a concept map is a valid representation of the sort data. The present map was found to have a stress value of 0.32.

Trochim (1989) found that, for concept maps with fewer than 100 responses, solutions comprised of between 3 and 20 concepts should be considered. Within-concept consistency of responses and discrepancy between concepts were used as the primary criteria for evaluating the validity of each solution. The default solution of 20 concepts showed clear evidence of fragmentation. Reducing the number of concepts to 10 did not sufficiently reduce this fragmentation. Significant reductions in fragmentation occurred when attempting nine, eight,

seven, and six concept solutions, but the responses were still fragmented. The five concept model represented a good fit with the data. Four and three concept maps were reviewed, but further reduction from five concepts unnecessarily combined conceptually different content and created concepts that were over-generalized. The five concept solution provided the best interpretability (see Figure 1). Responses and bridging indices are presented in Table 1.

The most central responses within each concept were identified using individual bridging indices (i.e., the lowest individual bridging index within a concept represented the response most central to that concept's content). These central responses were then used to provide guidance for concept labelling. Low bridging indices between 0.00 and 0.30 indicated that a response was rarely sorted with responses in other concepts. Bridging indices between 0.31 and 0.69 indicated that responses were sometimes sorted with responses in other concepts. High bridging indices above 0.70 indicated that responses were often sorted with responses in other concepts, thereby indicating a poor conceptual fit with other responses nearby on the map. Responses with high bridging indices are unlikely to reflect the overall content of a concept (Trochim, 1989). Individual bridging indices were then used to calculate an average bridging index for each concept. Lower average bridging indices indicate that responses within a given concept were frequently only sorted with other responses in that same concept.

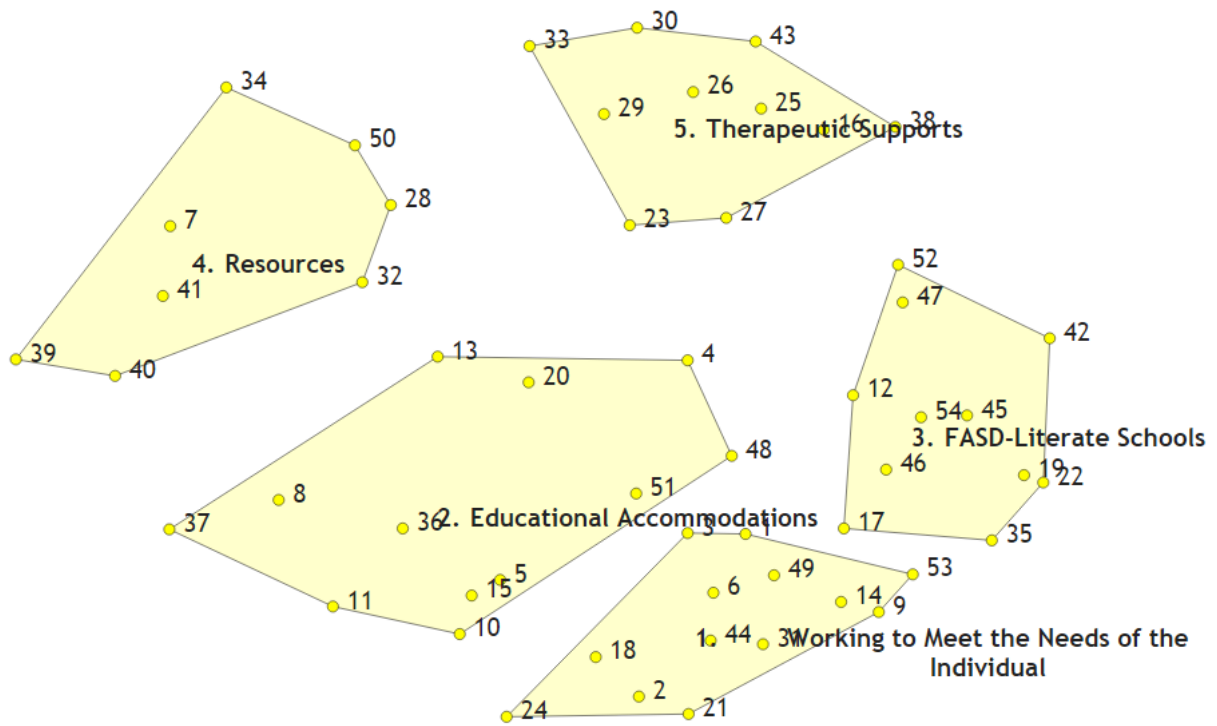


Figure 1. Concept Map: What services would help youth be successful in school?

Table 1

Responses and Bridging Values for Concept Map for Question One: Services

Concept and Response	Bridging Index
Working to Meet the Needs of the Individual	0.21
1. One on one support	0.00
49. The right curriculum	0.02
3. Academic supports	0.03
14. Consistent educational assistant for the year	0.11
6. Advocacy for their needs	0.12
44. Staff who know exactly how to look after her	0.18
18. Flexible and individualized	0.23
24. Warnings about supply teachers and changes in class	0.24
9. Awareness by everyone	0.25
31. Principal leadership	0.25
2. A “go to” person at school	0.35
21. High supervision	0.40

24. Look at child's values	0.58
Educational Accommodations	0.40
51. Transition services for adolescents	0.10
48. Different form of testing	0.11
4. Access to special classroom	0.26
5. Accommodations	0.26
20. Safety plan	0.33
10. Body breaks to move around	0.35
15. Consistent staffing	0.41
36. Sensory training for self management, self soothing, and self	0.43
13. Community services should follow child into school	0.46
11. Child can excuse self if knows that going to have a meltdown	0.58
8. Alternative program	0.73
37. Separate entrance time	0.77
FASD-Literate Schools	0.32
17. Educational assistants who are not only into behaviour modification and understand FASD	0.09
46. Tailor school to them	0.17
12. Community professional involvement	0.23
54. Individualized education plan	0.26
19. Formal recognition of FASD by system	0.32
45. Study skills that make more sense for them	0.33
35. Sensitive to differences within the disorder	0.35
22. In-house training in FASD	0.36
47. Teaching social skills	0.40
52. Tutor in school	0.49
42. Special services for FASD	0.56
Resources	0.83
32. Resource classroom	0.57
28. Ongoing supports	0.63
50. Training for parents	0.77
41. Special pencils	0.78
40. Special desk	0.92
34. Rural community resources less than city	0.99

7. After school program	1.00
39. Special classroom	1.00
Therapeutic Supports	0.55
27. Occupational therapist assessments	0.42
23. Life skills	0.45
43. Speech therapy	0.49
30. Physiotherapy	0.51
25. Mental health class	0.56
29. Outdoor activities	0.58
16. Counsellor	0.59
26. Mental health support	0.60
38. Social worker	0.62
33. Respite care	0.68

Working to meet the needs of the individual. This concept represented the need for professionals in the education system to work toward meeting the unique and complex needs of individual students with FASD. Responses such as “one on one support”, “the right curriculum”, “advocacy for their needs”, “staff who know exactly how to look after her”, and “flexible and individualized” reflected the need for educators to focus on the individual and avoid the assumption that students with FASD can learn from a standardized curriculum, or that they all share similar needs and challenges. In addition, responses such as “academic supports”, “consistent educational assistant for the year”, “warnings about supply teachers and changes in class”, “awareness by everyone”, and “principal leadership” reflected the high level of demand and resources required to meet unique individual needs.

Responses such as “a ‘go to’ person at school” and “high supervision” also reflected the need for schools to devote considerable resources to meeting the needs of individual students. However, these responses had bridging indices of above 0.30 and were therefore not as central to the concept. It is possible that these responses may also have been sorted with responses in the

concept of Educational Accommodations. Similarly, the response “look at child’s values” reflects the need to recognize students’ individuality but has a bridging index of 0.58, indicating that it was often sorted with responses from other concepts. This response may also have been grouped with responses in the category of Therapeutic Supports due to its focus on the child’s beliefs and value system.

This concept’s overall bridging value was 0.21. This bridging value suggests that overall, responses within this concept were consistently sorted together and represented a similar idea.

Educational accommodations. This concept reflected the need for educational accommodations that meet the needs of students with FASD. Responses such as “transition services for adolescents”, and “access to special classroom” represented examples of specific accommodations that could help students with FASD succeed in their education. The response of “accommodations” spoke more generally to the need for educational services that are tailored to students’ needs.

Responses such as “safety plan”, “body break to move around”, “consistent staffing”, “sensory training for self management, self soothing, and self regulation”, “community services should follow child into school”, and “child can excuse self if knows that going to have a meltdown” also reflected the need for specific accommodations that can help to make the educational environment safer and more conducive to learning for students with FASD. However, these concepts had bridging values between 0.33 and 0.58, indicating that they were not necessarily central to the concept and may sometimes have been sorted with responses in other concepts. For example, “sensory training, self soothing, and self regulation” may have fit conceptually with responses in the Therapeutic Supports concept because of its focus on an accommodation that would require therapeutic training on the part of the educators delivering it.

The responses “alternative program” and “separate entrance time” had high bridging indices of .73 and .77 respectively, indicating that they were frequently sorted with responses in other concepts and may be a poor conceptual fit for other responses within this concept.

This concept had an average bridging index of .40, indicating that responses within it were sometimes sorted with responses in other concepts.

FASD-literate schools. Most central to this concept was the response “educational assistants who are not only into behaviour modification and understand FASD”. This response speaks to the need for training that would allow educators to understand that traditional behaviour management and educational techniques do not typically work for students with FASD, and to adapt their approach accordingly. Responses such as “tailor school to them” and “individualized education plan” speak to the practical educational adaptations that could result from FASD-literacy. The response “community professional involvement” spoke to the need to bring community experts on FASD into the education system to provide a supportive knowledge base.

Responses such as “formal recognition of FASD by system” and “in-house training in FASD” also spoke to the need for those involved in the education system to understand the nature of FASD. However, these responses had bridging indices of 0.32 and 0.36 respectively, indicating that they were sometimes sorted with responses in other concepts. Similarly, “study skills that make more sense to them”, “sensitive to differences within the disorder”, “teaching social skills”, “tutor in school”, and “special services for FASD” reflected changes that would likely follow from increased FASD literacy in schools, but had bridging indices between 0.33 and 0.56 indicating they were frequently sorted with responses in other concepts. It is possible these responses may have frequently been sorted with responses in the Educational

Accommodations concept because of their practical value in meeting the needs of students with FASD.

Resources. Most central to this concept was the idea of a “resource classroom”, reflecting the need for an educational environment that is equipped to meet the needs of students with FASD. Several responses such as “special pencils”, “special desk”, “rural community resources less than city”, and “special classroom” reflected the need for specific, tangible resources that could improve the educational experience. Responses such as “ongoing supports”, “training for parents”, and “after school program” spoke to the need for resources that are not necessarily as tangible as others included in this concept, but which would nonetheless require considerable funding to implement.

This concept had the highest bridging index at 0.83, indicating that responses within it were often sorted with responses from other concepts. This concept may have reflected more than one main idea aside from Resources.

Therapeutic supports. This concept reflected the need for therapeutic supports that could help support students psychological, physical, and social well-being. Central to this concept was the idea of “occupational therapist assessments”, a concrete example of a practical therapeutic support. Responses such as “speech therapy”, “physiotherapy”, “mental health support”, and “counsellor”, and “social worker” also represented specific forms of therapeutic support that may be advantageous to students with FASD. Other responses such as “life skills”, “mental health class”, and “outdoor activities” reflected the need for supports that, while not necessarily therapeutic interventions, could serve to support students’ holistic well-being. The idea of “respite care”, having the highest bridging index at 0.68, demonstrated the need for mental health supports that not only target the needs of students but also of their caregivers.

This concept had an average bridging index of 0.55, indicating that responses within it were sometimes grouped with responses in other concepts. It is possible that responses in this concept may also have been sorted with responses in the Working to Meet the Needs of the Individual concept due to their focus on ensuring individual well-being, or with responses in the Resources concept due to the cost implications of implementing adequate therapeutic supports.

Caregiver Needs

Participants provided 59 unique responses to the question “What do caregivers need to help youth be successful in school?” Sixteen participants sorted the responses. Multidimensional scaling and cluster analysis were used to analyze the results. Stress values were used to measure the validity of the final concept map. Trochim (1989) states that concept maps with a stress value below 0.35 are considered to be valid representations of the sort data. The present concept map had a stress value of 0.31.

Within-concept consistency of responses and discrepancy between concepts were used as the primary criteria for evaluating the validity of each solution. The default solution of 20 concepts showed clear evidence of fragmentation. Reducing the number of concepts to 10 did not sufficiently reduce this fragmentation. Significant reductions in fragmentation occurred when attempting nine, eight, and seven concept solutions, but the responses were still fragmented. The six concept model represented a good fit with the data. Five and four concept maps were reviewed, but further reduction from six concepts unnecessarily combined conceptually different content and created concepts that were over-generalized. The six concept solution provided the best interpretability (see Figure 2). Responses and bridging indices are presented in Table 2.

The most central responses within each concept were identified using individual bridging indices (i.e., the lowest individual bridging index within a concept represented the response most

central to that concept's content). These central responses were then used to provide guidance for concept labelling. Low bridging indices between 0.00 and 0.30 indicated that a response was rarely sorted with responses in other concepts. Bridging indices between 0.31 and 0.69 indicated that responses were sometimes sorted with responses in other concepts. High bridging indices above 0.70 indicated that responses were often sorted with responses in other concepts, thereby indicating a poor conceptual fit with other responses nearby on the map. Responses with high bridging indices are unlikely to reflect the overall content of a concept (Trochim, 1989). Individual bridging indices were then used to calculate an average bridging index for each concept. Lower average bridging indices indicate that responses within a given concept were frequently only sorted with other responses in that same concept.

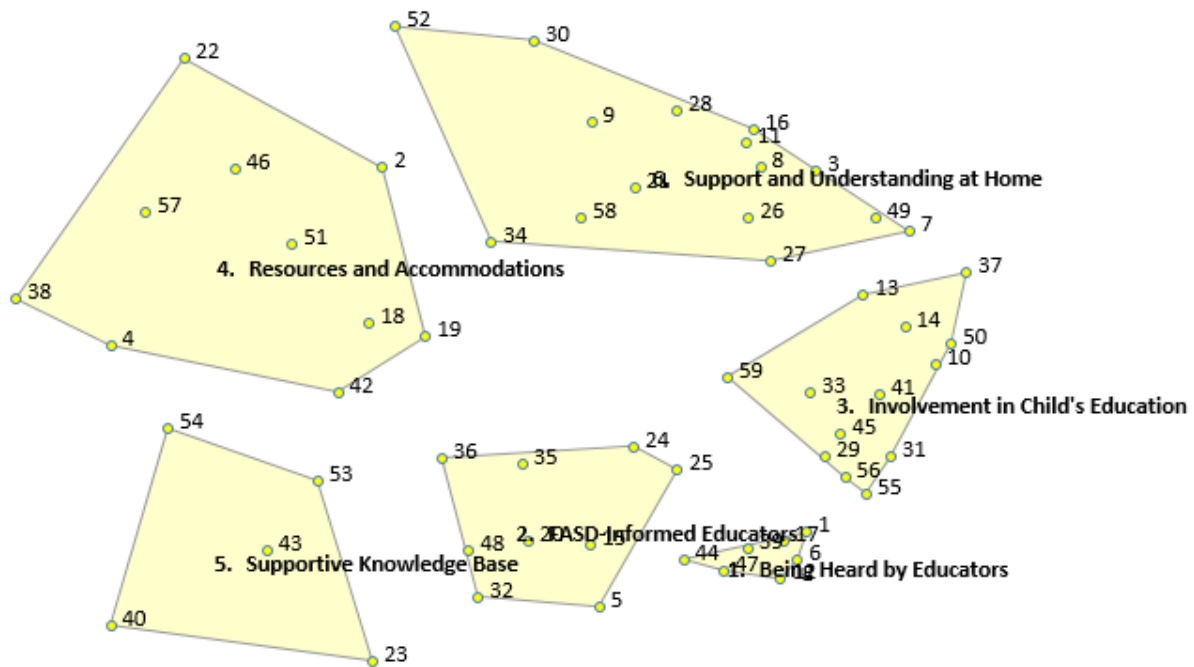


Figure 2. Concept Map: What do caregivers need to help youth be successful in school?

Table 2

Responses and Bridging Values for Concept Map for Question Two: Caregiver Needs

Concept and Response	Bridging Index
Being Heard by Educators	0.05
17. Communication between school and parents	0.00
39. Listen to our suggestions about how to teach them	0.01
44. Openness to listening to parents	0.03
1. A good team	0.05
6. Administration that is on board	0.08
47. People who listen to parents who know the needs of the kids	0.09
12. Be respected as partners	0.12
FASD-Informed Educators	0.17
20. Education so can educate staff	0.00
24. Education on FASD-related issues	0.02
15. Clear understanding of challenges and triggers	0.12
35. Know when to remove child from class	0.13
20. Coping at school so don't always need parent to come in	0.17
36. Learn about the brain	0.21
48. Professionals who understand FASD	0.24
5. Accommodations	0.31
32. Knowhow to diffuse situation	0.34
Involvement in Child's Education	0.09
56. Talk to teachers before school starts	0.00
41. Make yourself known to teachers	0.01
29. Help school see kids in a positive light	0.03
59. Understand what supports are available in school system	0.03
33. Know school resources and options	0.04
45. Part of all planning about programs or routines	0.04
55. Teach staff about youths' sensitivities	0.06
31. Keeping in touch with the school and teachers	0.07
14. Check that IEP is being followed	0.11
50. Remember that parents have rights too	0.20
37. Learn what is expected at school and help with it at home	0.26
Resources and Accommodations	0.52
19. Computer programs for learning	0.24
42. More resources	0.32

18. Community resources	0.33
51. Sensory equipment	0.43
2. A lot of help with their studies	0.48
46. Peer support system	0.51
57. Tutoring	0.54
4. A special school	0.68
22. Don't think university is an option	0.70
38. Let the school handle it	1.00
Supportive Knowledge Base	0.58
43. Obtain professional knowledge	0.45
53. Someone on your side of the table	0.50
23. Educate about intergenerational trauma and colonial effects	0.58
54. Support groups	0.58
40. Lots of training and information	0.81
Support and Understanding at Home	0.27
27. Flexibility	0.11
8. Appropriate life goals for kids	0.18
26. Encourage focus on social skills building	0.18
21. Create what isn't available	0.22
58. Understand brain changes during adolescence	0.22
7. Advocate for child	0.24
34. Know there is a purpose to what is being taught	0.24
11. Be realistic	0.25
28. Have hope but not so much that it sets them up for failure	0.27
49. Realistic conversations	0.27
3. A lot of patience	0.29
16. Coming home to a safe place	0.30
9. At home preparation for school	0.35
30. If they wind up on disability it is OK	0.48
52. Set finishing high school as a goal	0.48

Being heard by educators. This concept represented the need for educators who were willing to recognize that caregivers had special insight into the unique needs of children in their

care and listen to them accordingly. Responses in this category spoke to the need for openness on the part of educators when communicating with caregivers of children with FASD.

Participants described the need for “communication between school[s] and parents” that includes “listen[ing] to our suggestions about how to teach them” and “openness to listening to parents”. They described qualities that would help to enable such communication, such as “a good team”, “administration that is on board”, and “people who listen to parents who know the needs of the kids”. Communication and openness on the part of educators would help caregivers know that they can “be respected as partners”.

Responses in this concept all had low bridging indices between 0.00 and 0.12, with an average bridging index of 0.05 for the concept as a whole. This indicates that responses in this category were frequently only sorted with other responses in the same category, thereby indicating a strong conceptual fit for all within-concept responses.

FASD-informed educators. Responses in this category reflected the need for educators who are both aware of the complex individual needs of students with FASD, and are ready and willing to meet those demands. Responses such as “education so can educate staff”, “education on FASD-related issues”, “clear understanding of challenges and triggers”, “learn about the brain”, and “professionals who understand FASD” spoke to the need for FASD-specific training targeted at ensuring educators understand how FASD affects their students’ educational experience. Other responses such as “know when to remove child from class”, “coping at school so don’t always need parents to come in”, “accommodations”, and “knowhow to diffuse situation” reflected the practical changes that could arise as a result of improved FASD-literacy on the part of educators.

This concept had an average bridging index of 0.17, indicating that responses in this concept were frequently only sorted with responses inside this same concept and were a good conceptual fit for one another.

Involvement in child's education. This concept spoke to the need for caregivers to be actively involved in ensuring their child's education is tailored to their unique needs. Responses in this concept reflected the demands inherent to advocating for a child with complex needs.

Many responses in this concept highlighted the need to communicate directly with educators to ensure the child's needs are being met, e.g. "talk to teachers before school starts", "make yourself known to teachers", "teach staff about youths' sensitivities", and "keeping in touch with the school and teachers". Other responses spoke to caregivers' responsibility to familiarize themselves with the educational resources at their disposal, e.g. "understand what supports are available in school system", "know school resources and options", and "check that IEP is being followed". Responses such as "part of all planning about programs or routines" and "learn what is expected at school and help with it at home" reflected caregivers' responsibility to actively engage in ensuring their child's need are met. In order to feel empowered to take such a role, it is imperative that caregivers "remember that parents have rights too". Caregivers who feel empowered to actively engage in their child's education can "help [the] school to see [their] kids in a positive light".

This concept had an average bridging index of 0.09, indicating that responses in this concept were frequently only sorted with other within-concept responses and generally had a good conceptual fit with one another.

Resources and accommodations. This concept included responses that highlighted the need for practical resources that could help reassure caregivers that schools are equipped to meet

their child's complex needs. Responses such as "computer programs for learning", "sensory equipment", "peer support system", "tutoring", and "a special school" represented specific examples of resources and accommodations that could be beneficial for students with FASD. Other responses including "more resources", "community resources", and "a lot of help with their studies" spoke more generally to the need for resources in schools and the community at large that meet the needs of students with FASD.

The responses "don't think university is an option" and "let the school handle it" had high bridging indices of 0.70 and 1.00 respectively, indicating that they were frequently sorted with responses in other concepts and may not be a good conceptual fit with other responses within this concept.

This concept had an average bridging index of 0.52, indicating that responses within it were sometimes sorted with responses from other concepts.

Supportive knowledge base. Responses included in this concept reflected the necessity of generating knowledge about FASD and then using that knowledge to inform supportive efforts targeted at ameliorating students' educational experiences. Responses such as "obtain professional knowledge", "educate about intergenerational and colonial effects", and "lots of training and information" referred to the process of generating and sharing FASD-specific knowledge. "Support groups" represented a potential source of such knowledge, as information could be shared between those with lived experience of caring for someone with FASD. "Someone on your side of the table" highlighted a potential benefit of sharing FASD-related knowledge, in that those who are equipped with such knowledge could then join FASD-focused advocacy efforts.

This concept had an average bridging index of 0.58, indicating that responses within it were sometimes sorted with responses from other concepts.

Support and understanding at home. Responses in this concept spoke to the needs for caregivers to simultaneously adapt their skillset to provide the best support possible for their child's unique needs, and to recognize and respect their child's FASD-related limitations. Responses such as "flexibility", "be realistic", and "a lot of patience" represented qualities or attributes that could help caregivers to adapt and respond to their child's needs. "Understand brain changes during adolescence" and "know there is a purpose to what is being taught" spoke to the need for knowledge that could help parents develop supportive qualities and attributes.

Once parents have sufficient knowledge to adequately support their child, practical supportive steps must be implemented. Responses such as "encourage focus on social skills building", "create what isn't available", and "advocate for child" represented examples of such supportive steps. Similarly, "coming home to a safe place" and "at home preparation for school" reflected the need for caregivers to use their knowledge to create a supportive home environment. However, caregivers who are knowledgeable about FASD must also respect their child's limitations and respond appropriately. Responses such as "appropriate life goals for kids", "be realistic", "have hope but not so much that it sets them up for failure", "if they wind up on disability it is OK", and "set finishing high school as a goal" reflect the need for hopes and expectations that respect the realistic implications of FASD for children's futures.

This concept had an average bridging index of 0.27, indicating that responses within it were rarely sorted with responses in other concepts and generally represented a good fit with one another.

Results Summary

Thirteen participants sorted 54 unique responses to the question “What services would help youth be successful in school?” Multidimensional scaling and cluster analysis were used to analyze the sorting data, revealing five concepts: 1) Working to Meet the Needs of the Individual, 2) Educational Accommodations, 3) FASD-Literate Schools, 4) Resources, and 5) Therapeutic Supports.

Working to Meet the Needs of Individuals included responses representing the need for professionals in the education system to work toward meeting the unique and complex needs of individual students with FASD and included responses such as “the right curriculum” and “one on one support”. Educational Accommodations reflected the need for the education system to make the necessary adjustments to meet the needs of students with FASD, represented by responses such as “transition services for adolescents” and “access to special classroom”. Responses such as “tailor school to them” and “in-house training in FASD” in the FASD-Literate Schools concept spoke to the need for educators to understand that traditional behaviour management and educational techniques do not typically work for students with FASD, and to adapt their approach accordingly. Responses in the Resources concept including “resource classroom” and “special desks” reflected the need for resources to be dedicated to creating an educational environment equipped to meet the needs of students with FASD. Finally, responses in the Therapeutic Supports concept including “speech therapy” and “mental health supports” reflected the need for formalized therapeutic support systems that could help support students psychological, physical, and social well-being.

The second question: “What do caregivers need to help youth be successful in school?” included 59 responses sorted by 16 caregivers raising children with FASD. Analysis revealed that these responses were best sorted into six concepts: 1) Being Heard by Educators, 2) FASD-

Informed Educators, 3) Involvement in Child’s Education, 4) Resources and Accommodations, 5) Supportive Knowledge Base, and 6) Support and Understanding at Home.

Being Heard by Educators included responses reflecting the need for educators who are willing to recognize that caregivers have special insight into the unique needs of children in their care and listen to them accordingly, including “listen to our suggestions about how to teach them” and “people who listen to parents who know the needs of kids”. Responses including “education on FASD-related issues”, “professionals who understand FASD”, and “know when to remove child from class” in FASD-Informed Educators spoke to the need for educators who are both aware of the complex individual needs of students with FASD, and are ready and willing to meet those demands. Involvement in Child’s Education included responses such as “talk to teachers before school starts” and “teach staff about youths’ sensitivities”, which reflected the need for caregivers to be actively involved in ensuring their child’s education is tailored to their unique needs. The Resources and Accommodations concept spoke to the need for practical resources that could help reassure caregivers that schools are equipped to meet their child’s complex needs and included responses such as “computer programs for learning” and “a special school”. Responses in the Supportive Knowledge Base concept included “obtain professional knowledge” and “lots of training and information”, reflecting the necessity of generating knowledge about FASD and then using that knowledge to inform supportive efforts targeted at ameliorating students’ educational experiences. Finally, Support and Understanding at Home spoke to the need for caregivers to simultaneously adapt their skillset to provide the best support possible for their child’s unique needs, and to recognize and respect their child’s FASD-related limitations. This concept included responses such as “be realistic” and “advocate for the child”.

Chapter 5: Discussion

This study aimed to identify what services caregivers of youth with FASD believe are needed to help youth succeed in school, as well as caregivers' needs in helping youth with FASD succeed in their education. Participants were asked two questions: "What services would help youth be successful in school?" and "What do caregivers need to help youth be successful in school?". Thirty-two caregivers provided responses by telephone. Sixteen caregivers who participated in the interviews sorted responses to the question "What services would help youth be successful in school?" into groups, and 15 caregivers sorted responses for "What do caregivers need to help youth be successful in school?". Sort data was then analyzed using The Concept System (2014) to conduct multi-dimensional scaling and cluster analysis. The present chapter compares the results of this analysis to the existing literature.

Services

The questions: "What services would help youth be successful in school?" resulted in a map with five concepts. The concepts included: 1) Working to Meet the Needs of the Individual, 2) Educational Accommodations, 3) FASD-Literate Schools, 4) Resources, and 5) Therapeutic Supports. There was a considerable amount of overlap between the concepts generated by participants in the present study and the ideas present in the existing literature. However, some notable differences were also found.

Working to meet the needs of the individual. Responses within this concept focused on the need for educators and caregivers to work together to meet the unique needs of individual students with FASD. Many of the responses within this concept were consistent with findings from previous studies, but some specific strategies emerged that were unique to the present study.

Previous studies have addressed the highly individualized nature of FASD-related educational deficits. Abel and Sokol (1987) found no consistent pattern in the learning difficulties faced by alcohol-affected students. Furthermore, Duquette, Stodel, Fullarton, and Hagglund (2006) found that as a result of the wide array of educational challenges posed by FASD, services designed to address specific deficits often fail to meet the needs of FASD-affected students as a wider population. Responses within this concept such as “flexible and individualized”, “staff who know exactly how to work with her”, “the right curriculum”, and “look at child’s strengths” spoke to the need for educators to recognize the uniqueness of each student’s educational needs.

Although the general concept of meeting individual needs was consistent with the existing literature, the present study identified several specific strategies for meeting those needs that had not been addressed in previous studies. Responses such as “1 on 1 support”, “a go to person at school”, “high supervision”, and “consistent educational assistant for the year” spoke to the need for a single individual dedicated to understanding the needs of a specific student. Due to the complicated and diverse needs of students with FASD (Duquette et al., 2006), it is possible that a teacher tasked with educating an entire classroom of students could be unable to understand or meet the needs of a student with FASD, and therefore more individualized attention may be necessary. Furthermore, responses such as “principal leadership” and “warnings about supply teachers and changes in class” highlighted examples of practical steps that educators could take to ensure students’ individual needs are met.

Educational accommodations. This concept focused on specific examples of educational accommodations that could help students with FASD succeed in the classroom. Although responses in this concept were consistent with the existing literature in that they

recognized the need for specially tailored educational accommodations, this concept included several new examples of specific accommodations that were not explored in previous studies.

Most central to this concept was the idea of “transition services for adolescents”. In the context of being sorted with other responses within this concept, it is apparent that this response highlights the need for educational accommodations that recognize the changing educational needs of adolescents as compared to children. Although a great deal of research has investigated educational experiences and support systems for children with FASD (Adnams et al., 2007; Jirikowic, Olson, & Kartin, 2008; Koren, Fantus, & Nulman, 2009), research on the educational experiences of older youth and adolescents is limited (Kalberg & Buckley, 2006). Accordingly, the present study highlighted several specific educational accommodations that recognize the increasing autonomy and resulting shift in educational needs that accompany the transition into adolescence, including “child can excuse self- if going to have a meltdown”, “sensory training for self-soothing, self-management, and self-regulation”, “body breaks to move around”, “community services that follow the child into school”, and “separate entrance time”. Taken together, these responses highlight the fact that youth with FASD not only have unique individual needs, but may have more insight into their own needs and be capable of some level of self-regulation.

Streissguth (1997) highlighted the need for a structured and predictable learning environment. Kalberg and Buckley (2006) explain the need for structure by drawing the analogy of the learning environment as an “external nervous system” for the student. In this analogy, structure in the student’s learning environment can help to compensate for cognitive deficits in the actual nervous system. The response “access to a special classroom” in this concept may speak to the need for such accommodations, or may also encompass additional accommodations

that may be present in a FASD-equipped classroom such as “different form of testing”, “safety plan”, “consistent staffing”, or “alternative program”. Taken together, the responses in this concept represent several examples of potential educational accommodations that could help adolescents with FASD succeed in school, and which were not present in a review of the existing literature.

FASD-literate schools. Responses contained in this concept focused on the need for educators to be aware of how FASD affects students’ ability to function in school, and to actively use that knowledge to improve students’ educational experiences. Ideas in this concept were largely consistent with the existing literature, but also included several novel responses.

Most central to this concept was the idea of “educational assistants who are not only into behaviour modification and understand FASD”. This idea is consistent with Malbin’s (2007) finding that behaviour modification techniques are often ineffective for students with FASD. However, responses in this category identified alternate strategies for managing the behaviour of students with FASD that were not present in the existing literature, including “teaching social skills” and “community professional involvement”. By consulting community professionals with expertise on FASD in an effort to improve their own FASD-literacy, educators may be able to recognize and employ alternate strategies such as working on children’s social skills that could help to manage maladaptive behaviours without relying on behaviour modification techniques.

Because of the diverse nature of FASD-related impairments, some knowledge about FASD must be generated on the individual level. Although it is important for educators to know that a student in their classroom has been diagnosed with FASD, knowledge of a diagnosis is not sufficient for educators to meet the needs of individual students. Rather, due to the diversity of potential impairments associated with FASD, a comprehensive individual learning assessment is

necessary to provide educators with the information needed to address the specific needs of a given student (Kalberg & Buckley, 2007). The responses “individualized education plan”, “tailor school to them”, and “sensitive to differences within the disorder” highlighted ways in which knowledge of a student’s specific needs could result to educational plans that are tailored to the individual.

FASD has not been officially recognized as an exceptionality within the Ontario public education system (Naumann et al., 2013). As a result, although many Ontario youth with FASD are assigned individual education plans, they often do not qualify for other resources targeted at youth with disabilities due to the relatively invisible nature of their disorder (FASD ONE Intervention and Support Working Group, 2010). The response “formal recognition of FASD by the system” spoke directly to this deficit in recognition. The inclusion of this response within the concept of FASD-Literate schools implies that increasing FASD literacy in Ontario’s education system may help to facilitate formal recognition of the disorder as an exceptionality.

Resources. In this concept, caregivers described specific resources that could help to improve educational experiences for youth with FASD. Some responses contained within this concept were congruent with the existing literature, but several new ideas emerged as well.

Most central to this concept was the idea of a “resource classroom”. Research by Kalberg and Buckley (2007) describes several ways in which classroom settings could be adjusted to provide visual, environmental, and task structure for students with FASD. The responses “resource classroom” and “special classroom” contained within this concept are consistent with the idea of adapting classrooms to meet the needs of alcohol-affected students, but several other responses in this concept provide examples of resources that have not been described in the existing literature. “After school program”, “special pencils”, and “special desk” are examples of

resources that were not found in a review of the current research. These ideas are notable for their specificity, possibly suggesting that caregivers' unique insight into the needs of youth in their care allowed them to identify classroom resources that were not readily apparent to researchers in the past.

Also present within this concept was the idea of "training for parents". Research by Olson and Montague (2011) suggests that education on FASD can help caregivers to reframe problem behaviours by understanding that they are rooted in neurological impairments, which in turn can help caregivers develop a more positive view of children in their care and to feel more effective in their parenting. Furthermore, Brown, Bednar, and Sigvaldason (2007) found that foster parents who are unaware that a child in their care has FASD or who lack information on FASD-related impairments often struggle to understand their child's behaviours and have difficulty finding ways of managing those behaviours. The findings of the present study in regards to educating caregivers are congruent with the existing research.

Also present within this concept was the idea that "rural community resources [are] less than city [resources]". This is a novel idea which was not found in a review of the existing literature, and suggests that rural communities may not be as well-equipped as urban communities when dealing with the educational needs of youth with FASD. This idea may have emerged in the present study due to caregivers' direct insight into their children's educational experiences in urban and rural settings.

Therapeutic supports. Responses contained within this concept spoke to the need for various forms of therapy and related supports that may improve educational experiences for alcohol-affected youth. Although the general idea of therapeutic support was present in the existing literature, several specific forms of therapy emerged as novel responses.

Several potential forms of therapy for youth with FASD have been addressed in past studies. Shepard and Breen (2007) suggest that counselling based on Social Cognitive Career Theory (SCCT) can help adolescents with FASD overcome low self-esteem, difficulties in establishing routines, information processing challenges, and passive learning styles. Furthermore, Adnams et al. (2003) found that Cognitive Control Therapy resulted in improvements in motivation, self-efficacy, school achievement, attitude to learning, and writing as evaluated by therapists and educators for youth with FASD. Responses within this concept including “counsellor” and “mental health support” spoke to the need for psychotherapeutic interventions that could help youth with FAS succeed in their education.

Several additional forms of therapeutic supports also emerged as responses, including “occupational therapist assessments”, “speech therapy”, “mental health class”, “physiotherapy”, and “social worker”. Although past research has focused on ways in which similar therapeutic supports could be beneficial for those with FASD (Jirikowic, Kartin, & Olson, 2008; Popova et al., 2014; Stark, Schönau, Semler, & Hoyer-Kuhn, 2015), none of these studies focused specifically on how these therapeutic supports could be beneficial in an educational context. This suggests that future studies may seek to explore the impact of various therapeutic supports on educational experiences for youth with FASD.

Caregiver Needs

The question: “What do caregivers need to help youth be successful in school?” resulted in a map with six concepts. The concepts included: 1) Being Heard by Educators, 2) FASD-Informed Educators, 3) Involvement in Child’s Education, 4) Resources and Accommodations, 5) Supportive Knowledge Base, and 6) Support and Understanding at Home. There was a considerable amount of overlap between the concepts generated by participants in the present

study and the ideas present in the existing literature. However, some notable differences were also found.

Being heard by educators. This concept was largely consistent with the existing literature. For many caregivers of adolescents with FASD, interactions with the educational system can be fraught with difficulties (Brown & Bednar, 2004). Nonetheless, caregivers identify collaboration with educators as an important need in raising an alcohol-affected child (Brown & Bednar, 2003). Responses in this concept including “communication between school and parents” and “openness to listening to parents” reflected the need for caregivers and educators to collaborate to ensure students’ academic success. Furthermore, Brown (2004) highlights the fact that research and practice need to, “capitalize on what parents of alcohol-affected children have learned about what works for them.” The response “listen to our suggestions about how to teach them” is congruent with the idea that caregivers have unique insight into the individual needs of children in their care, and that this insight should be shared with and respected by educators.

The lack of responses in this concept focusing on deficits or difficulties in communication between caregivers and educators is notable. The existing research indicates that caregivers’ interactions with educators and policy-makers can be fraught with tension due to differences in perception about the nature of a student’s academic difficulties and the steps needed to address problems (Lawson, 2003; Timler & Olswang, 2001). However, the phrasing of the question (“What do caregivers need to help youth be successful in school?”) may have biased participants toward highlighting needs rather than deficits. Implicit in the responses to this question is the idea that each response is a need that has gone unmet at times. For example, “be

respected as partners” suggests that caregivers may have experience being disrespected by educators, and therefore recognize that this is a problem in need of correction.

The existing research indicates that educators and legislators are working toward ensuring caregivers’ voices are heard. In many places, legislation is being enacted requiring that parents of students with disabilities be allowed a voice in the educational decision-making process (Kalyanpur, Harry, & Skrtic, 2000; Turnbull & Turnbull, 1998). Furthermore, learning assessments typically garner information about a student from numerous sources including caregivers (Olson et al., 1997). Additionally, supportive research is being generated that indicates caregiver advocacy is key to ensuring educational success for youth with FASD (Duquette, Stodel, Fullarton, & Hagglund, 2006). Taken together, the existing research shows that responses contained within this concept are beginning to be recognized by educators, researchers, and legislators, and that steps are being taken to ensure caregivers’ voices are heard in the education process.

FASD-informed educators. Responses in this concept reflected the need for educators who are informed about FASD and who are capable of translating that knowledge into educational services that meet the diverse needs of alcohol-affected students. The ideas contained within this concept were mostly congruent with the existing literature.

Most North American educational systems recognize a need for students with disabilities to be included in the regular classroom setting along with their peers (Fitch, 2002). However, students with FASD present with unique learning difficulties that necessitate specially designed educational tools; general theories of learning development often fall short in understanding the learning strategies employed by alcohol-affected students (Blackburn et al., 2010). Due to the complexity of FASD and the highly individualized needs of those affected by the disorder,

educators require specialized training to meet the needs of alcohol-affected students (Blackburn, Carpenter, & Egerton, 2010). This need for specialized training was reflected in responses such as “education on alcohol related issues”, “learn about the brain”, and “professionals who understand FASD” contained within this concept.

Most responses in this concept did not speak directly to deficits in educational accommodations for students with FASD. However, responses such as “accommodations” and “know-how to diffuse situation” spoke to practical outcomes that could result from educators understanding FASD’s effects on students’ educational experiences and working to meet students’ unique individual needs. Due to their moderate-to-high bridging indices, these responses were not central to the concept and may have been a better conceptual fit with responses in other concepts.

Involvement in child’s education. Responses within this concept were largely consistent with previous studies, but also included new ideas that did not emerge from a thorough review of the existing literature. Several existing studies spoke to the importance of caregivers’ involvement in the educational process. Gorman (1995) interviewed adolescents between the ages of 15 to 20 and found that a significant majority had experienced had experienced educational disruptions. Because of these challenges, caregivers of students with disabilities often serve as educational advocates for their children (Heyman & Earle, 2000). In fact, Duquette, Stodel, Fullarton, & Hagglund (2006) identified parental support and advocacy as the most important factor contributing to students’ educational success. Responses in this concept identified specific ways in which caregivers can serve as supportive figures or advocates in their child’s education, including “check that IEP is being followed”, “keeping touch with the school

and teachers”, “make yourself known to teachers”, and “part of all planning about programming or routines”.

One response within this concept, “help school see kids in positive light”, was not reflected in the existing literature. Several existing studies highlighted caregivers’ roles in helping their children avoid negative educational outcomes: Duquette, Stodel, Fullarton, & Hagglund (2006) found that caregiver advocacy lowers the risk of dropout for students with FASD; Streissguth et al. (2004) found that the presence of supportive caregivers minimizes the risk of secondary disabilities such as mental health issues, drug use, and criminal activity that could further impact the course of adolescents’ education; Streissguth (1997) found that caregiver advocacy is essential to ensuring educators understand individual students’ unique learning challenges. However, none of these findings spoke to caregivers’ roles in helping educators recognize students’ strengths. Caregivers’ unique access to their children provides them not only with insight into their children’s needs, but also into the ways in which their children can make positive contributions in a classroom setting. The fact that this finding emerged in the present study and not in the existing literature may be due to the fact that this study asked caregivers themselves to reflect on their role as educational advocates.

Resources and accommodations. In this concept, caregivers’ responses were focused primarily on the resources needed to meet the needs of students with FASD and accommodations that could help ensure equal access to education. Responses in this concept tended toward a narrower and more practical focus than resources and accommodations described in the current research.

The majority of the current research on accommodating students with FASD focuses on creating a structured and predictable learning environment (Kalberg & Buckley 2006; Kalberg,

2007; Streissguth, 1997). Kalberg and Buckley (2006) describe the learning environment as an external nervous system that must be organized in a way that compensates for deficits in students' own organizational abilities. However, these studies do not speak to specific in-classroom resources that could help to ameliorate the educational experience for students with FASD. Responses in this category including "computer programs for learning", "a lot of help with their studies", "sensory equipment", "peer support system", and "a special school" identify specific examples of steps that could be taken to make classrooms more accessible to students with FASD.

Supportive knowledge base. Responses within this concept spoke to the need to generate and communicate knowledge that could help educators better understand and address the complex needs of students with FASD. Most responses within this category were congruent with the existing research, however the concept's central response focused on an idea that has not yet been integrated into the literature on FASD in the educational context.

Several recent studies have spoken to the impacts of intergenerational trauma and colonialism on elevated rates of FASD diagnoses in First Nations communities (Badry & Felske, 2013; Choate, 2013; Totten, 2010). However, these studies have not spoken to how experiences of intergenerational trauma and colonialism interact with FASD to impact students' educational experiences. The response "educate about intergenerational trauma and colonial effects" was central to this concept, and spoke to the need for educators to be knowledgeable and understanding of the interaction between intergenerational trauma and FASD-related educational deficits. Considering the heightened stigma directed toward First Nations people with FASD (Badry & Felske, 2013), this response highlights the need for educators to be aware of how

cultural-specific factors interact with FASD's effects on the educational experience and suggests a potential direction for future research.

Additional research on the supportive knowledge base needed to ensure educational success for students with FASD speaks to the importance of professional development for educators. Blackburn, Carpenter, and Egerton (2010) found that educators require specialized training to meet the needs of students with FASD. Moreover, a study by Koren, Sadowski, and Scolnik (2013) found that not only did 99% of educators respond positively to FASD-specific training, they identified training as important to filling a gap in the knowledge base provided to them during teachers' college. The responses "lots of training" and "obtain professional knowledge" in this concept were congruent with this existing research.

The responses "someone on your side of the table" and "support groups" were less central to this concept, but spoke to additional ways in which knowledge could be generated and shared. "Someone on your side of the table" suggests having a FASD-informed advocate facilitate discussions between caregivers of children with FASD and educators, an idea which was not represented in the existing literature. "Support groups", although often sorted with other responses, may fit within this category due to the supportive knowledge shared between caregivers in a group context.

Support and understanding at home. Responses within this concept spoke to the need for caregivers to maintain a home environment that is supportive of students' needs and understanding of the educational challenges that arise as a result of FASD-related deficits. Responses within this concept were largely consistent with the existing literature.

A review of the existing research highlighted several areas in which youth with FASD are at risk for potential negative outcomes: Streissguth, Barr, Kogan, and Bookstein (1996) found

that 70% of alcohol-affected youth had experienced disruptions in their education including suspension, expulsion, and dropping out; rates of FASD diagnosis are elevated among youth involved in the criminal justice system (Fast & Conry, 2009); deficits in areas such as planning, schedule-adherence, and organization often result in educational setbacks for youth with FASD (Siklos, 2008). Several responses within this concept spoke to caregivers' awareness of these potential negative outcomes and the need to adjust expectations accordingly, including "appropriate life goals for kids", "be realistic", "a lot of patience", "flexibility", "have hope, but not so that sets them up for failure", "if they end up on disability, it's OK", "realistic conversations", and "set finishing high school as a goal". Accordingly, responses such as "advocate for child" suggested that caregivers recognized their role as advocates in working to help students avoid these negative outcomes, which is congruent with Streissguth et al.'s (2004) finding that caregiver advocacy and a positive home environment for youth with FASD was associated not only with improved educational persistence, but also with decreased involvement with the court system, abstinence from drugs and alcohol, and lower risk of developing secondary disabilities. Responses such as "coming home to a safe place" and "at home preparation for school" also spoke to the need for a supportive home environment that may help to counteract the potential for negative outcomes, while "create what isn't available" and "encourage focus on social skills building" provided examples of specific steps that could be taken at home to improve students' educational experiences.

The response "understand brain changes during adolescence" was not central to this concept, but spoke to the importance of caregivers recognizing the medical and behavioural implications of FASD's neurological effects. This finding was congruent with Brown, Bednar, and Sigvaldason's (2007) finding that foster parents who are unaware that a child in their care

has FASD or who lack information on FASD-related impairments often struggle to understand their child's behaviours and have difficulty finding ways of managing those behaviours. This finding highlights the importance of educating caregivers on FASD's effects as a way of empowering them to create a home environment that meets the unique needs of a student with FASD.

Discussion Summary

In response to the question: "What services would help youth be successful in school?" five concepts emerged including: 1) Working to Meet the Needs of the Individual, 2) Educational Accommodations, 3) FASD-Literate Schools, 4) Resources, and 5) Therapeutic Supports. Results of the present analysis were mostly congruent with findings in the existing literature. Past studies have also spoken to the need for educators to work toward meeting the diverse needs of individual alcohol-affected students rather than adopting a "one-size-fits-all" approach. There was also considerable overlap between the present study's findings and past research on the necessity of educational accommodations that meet the needs of youth with FASD. Similarly, the idea of ensuring that those involved in the education system are FASD-literate has been noted in past studies. Lastly, the ideas of ensuring adequate resources are available in the classroom and providing therapeutic supports to students with FASD emerged in both the existing literature and the present study.

Although there was considerable overlap between the existing literature and the findings of the present study, several novel ideas also emerged from the present analyses. Caregivers' idea of a single, consistent individual dedicated to assisting with an alcohol-affected student's education throughout the school year had not been noted in previous studies. Additionally, caregivers in this study provided specific examples of resources such as "special desks" that had

not been noted in past studies, which mostly focused on broader ideas of resources. Furthermore, the idea of incorporating therapeutic supports such as occupational therapy and physiotherapy in the context of students' education emerged in this study. Although past studies have explored the therapeutic benefits of such supports for individuals with FASD, these supports have not been studied as a means of supporting students with FASD to succeed in their education.

One topic that emerged in a review of the existing literature but was not identified by caregivers in the present study was the idea of specific psychotherapeutic interventions such as Social Cognitive Career interventions or Cognitive Control Therapy. Caregivers in the present study spoke more broadly to the need for psychotherapeutic supports as well as other types of supports such as speech therapy and physiotherapy. It is possible that, although caregivers are generally aware of the need for psychotherapeutic support, many may not be aware of specific therapeutic modalities that have been found to be effective and may instead rely on experts in the field for direction in this area.

Responses to the question: "What do caregivers need to help youth be successful in school?" resulted in six concepts including: 1) Being Heard by Educators, 2) FASD-Informed Educators, 3) Involvement in Child's Education, 4) Resources and Accommodations, 5) Supportive Knowledge Base, and 6) Support and Understanding at Home. The results of the present study were mostly congruent with findings from the existing literature. The importance of communication between caregivers and educators was reflected in both the findings of the present study and a review of the existing literature. Similarly, the idea of ensuring educators are FASD-informed was congruent with the findings of past studies. Caregivers in this study noted the need to be actively involved in the education process for children in their care, an idea which had been noted in past studies. Lastly, the ideas of ensuring adequate resources and

accommodations are provided, and of generating and using a supportive knowledge base, were congruent with the existing literature.

Despite the overlap between the existing literature and the findings of the present study, some new ideas also emerged from the question on caregiver needs. Responses within the Involvement in Child's Education concept spoke to the need for caregivers to help educators see students with FASD in a positive light. The idea of caregivers being actively involved in taking a strengths-based approach to education had not been noted in past studies. Furthermore, caregivers in this study noted the need to understand how intergenerational trauma and colonial effects interact with the educational process for First Nations students with FASD, a concept which had not emerged in a thematic analysis of the literature.

Implications

The results of the present study add to the existing literature on caregiver needs and service needs in helping youth with FASD succeed in their education. While many caregiver needs and service needs were similar to those found in the existing literature, caregivers provided several unique ideas and strategies that may aide educators and families looking for ways of ensuring educational success for students with FASD. These novel ideas may warrant further research targeted at broadening professional knowledge of FASD.

Future research in the area of FASD could explore the impact of having a single, consistent educational assistant work with students with FASD throughout the school year. Although educational budgetary concerns have been noted in several past studies, future research could explore costs and benefits of having a dedicated educational assistant. Future research could also capitalize on the examples of specific classroom resources provided by caregivers in the present study, such as "special desks" to further explore the impacts of adapting the physical

education environment to students' needs. Furthermore, future research may seek to investigate the impact of involving caregivers in taking a strengths-based rather than a deficits-based approach to education. Lastly, due to the lack of understanding around the interaction between colonial effects, intergenerational trauma, and impacts on the educational process for First Nations students with FASD, future research may wish to address this gap in the existing literature.

Research and practice need to capitalize on caregivers' unique insights into the educational needs of children in their care. Research in the area of educational needs of students with FASD has most frequently been conducted in the United States. Although Canada and the United States share many similarities, culture differences and differences in educational systems create the necessity to understand differences in Canadian students as a unique population. By learning more about the educational needs of students with FASD, educators and caregivers can better prepare themselves to understand and meet the needs of this diverse and challenging population.

Overall, the present research aids in working toward positive outcomes for students with FASD. Past research has shown educational success to be an important contributing factor to long-term outcomes for individuals with disabilities (Turnbull, Turnbull, Wehmeyer, & Park, 2003). Adding to the knowledge on educational experiences of youth with FASD will contribute to meeting the educational needs of this population, assisting youth with FASD to move successfully into adulthood, and creating a stronger community of service and support for families affected by FASD.

Policy implications. The findings of the present study suggest several potential directions for future policy decisions. A consistent theme found throughout many of the responses in this

study was the importance of recognizing FASD-affected students as individuals with unique needs, and providing individualized support that meets those needs. Future decisions on policy could seek to recognize the diverse needs of students and avoid the assumption that a one-size-fits-all approach is appropriate for alcohol-affected individuals. Furthermore, participants in the present study spoke to the need for educators who are FASD-informed. Policies may need to be developed to ensure that information on FASD is included in educators' curriculums, or in professional development opportunities. Additionally, responses in this study highlighted the disparity between rural and urban resources when dealing with students with FASD. Future policy could target rural education specifically in order to alleviate this disparity. Lastly, responses in this study spoke to the importance of caregiver involvement in youths' education. Policy-makers could institute policies targeted at increasing caregiver access and involvement in educational decision-making processes.

Counselling implications. Responses in the present study identified several therapeutic supports that could be beneficial to students with FASD. One idea contained in this study that was not present in the existing research was the idea of a "mental health class". Classroom work targeted at improving mental health or mental health awareness could serve as an adjunct to individualized counselling for students. Furthermore, responses in this study spoke to the need for therapeutic supports such as physiotherapy and speech therapy that could help to improve educational experiences for youth with FASD. Lastly, responses such as "counsellor" and "mental health support" reinforced the importance of counselling in ensuring educational success.

Limitations

All voluntary research is biased in that it selects for people with knowledge, characteristics, or lifestyles which make them more willing to participate compared to those who do not. It is also possible that selecting one caregiver in a household over another as a participant may result in a bias. Different caregivers within the same household may hold opposing views on caregivers' needs in helping youth succeed in school or what services would help youth succeed in school. For example, men and women often have different parenting styles (Stephens, 2009), and therefore selecting for one caregiver over another may result in different opinions on matters related to caregiver roles in ensuring educational success. Furthermore, participants in this study had prior contact with FASD supports and services. The fact that these families are aware of the disorder and have been in contact with services in their community may differentiate them from other caregivers of children with FASD who are unaware that children in their care have the disorder, or who have not engaged with resources in their communities. Lastly, all participants in the present study resided in southern Ontario. This focus on a particular geographic location may mean that these results do not generalize to caregivers of youth with FASD in other areas. Willingness to participate in a study, the caregivers selected as participants, and prior contact with FASD supports and services are all features of the present study's sample.

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Appendix: Interview questions

ID# _____

Caregiver sex _____

Number of Children current/past with suspected or confirmed FASD _____/_____

Relationship with Child(ren) suspected or confirmed FASD _____

Years as primary caregiver to current _____

Other caregivers in home

Average Yearly Family Income (less than \$50,000) (50,001-100,000) (100,001+)

Occupation _____

Total current # children in household _____

Current children with FASD

Alcohol-Related Diagnosis received? Yes No

On waitlist for Diagnostic service? Yes (how long _____?) No

Other diagnoses received _____

Ages of child _____

Sexes of child _____

Grades of child _____

Ethnicities of child _____

Children Suspected of FASD Screening Form

*Child Behavior (of oldest current child aged _____ suspected of FASD, *2* years or older)*

- | | |
|--|--------|
| 1. Does the child act too young for his/her age? | Yes/No |
| 2. Does the child have difficulty concentrating, and can't pay attention for long? | Yes/No |
| 3. Is the child disobedient at home? | Yes/No |
| 4. Does the child lie or cheat? | Yes/No |
| 5. Does the child lack guilt after misbehaving? | Yes/No |
| 6. Does the child act impulsively and without thinking? | Yes/No |
| 7. Does the child have difficulty sitting still/is restless/hyperactive? | Yes/No |
| 8. Does the child display acts of cruelty, bullying or meanness to others? | Yes/No |
| 9. Does the child steal from home? | Yes/No |
| 10. Does the child steal outside of home? | Yes/No |

Open-Ended Questions:

- 1) What do caregivers need to help youth be successful in school?
- 2) What services would help youth be successful in school?

Curriculum Vitae
KYLE CLEVERSEY

Education

Master of Education in Counselling Psychology

Anticipated Convocation: June 2016

The University of Western Ontario, London, ON

Bachelor of Science with Research Specialization in Psychology

June 2014

The University of Toronto, Toronto, ON

Counselling Related Experience

Personal, Academic, and Career Counselling Intern

Sept. 2015 – May 2016

Fanshawe College Counselling and Accessibility Services, London, ON

Partner Assault Response Counsellor

Oct. 2014-Dec. 2015

Changing Ways, London, ON

Intake Counsellor

Jan. 2012 – Jan. 2014

McDowall Counselling and Consulting Group Toronto, ON

Inpatient Creative Arts Counsellor

Sept. 2011 – April 2012

Centre for Addiction and Mental Health Toronto, ON

Research Related Experience

Research Assistant

May 2015 – April 2016

Dr. Jason Brown's Laboratory, Department of Counselling Psychology, University of Western Ontario

Assistant Lab Manager

May 2013 – Aug. 2013

Dr. Allison Chasteen's Laboratory, Department of Psychology, University of Toronto

Research Assistant

Sept. 2012 – May 2013

Dr. Penelope Lockwood's Laboratory, Department of Psychology, University of Toronto
