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An Exploration of Service Needs for Adults who Live with Fetal Alcohol Spectrum Disorder

Armush Salahadin
The University of Western Ontario

Supervisor
Dr. Jason Brown
The University of Western Ontario

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Abstract

Families who care for children with disabilities feel that supports are essential. However, little is known about the support needs of adults who live with Fetal Alcohol Spectrum Disorders, and few specialized services exist to meet their needs. This study examined caregivers' perceived support needs for their children when they grow into adults. Sixteen caregivers of children aged 10 years or older with FASD participated in telephone interviews. Participants provided responses to the following two questions: "What do caregivers need to help young adults live as independently as possible?" and "What services would help young adults live as independently as possible?" All responses provided to the interview questions were independently grouped together by caregivers, and their grouping data was analyzed with multi-dimensional scaling and cluster analysis (Trochim, 1989). The first question focused on caregiver needs and resulted in a six-concept map including: 1) Structural Supports, 2) Practical Supports, 3) Caregiver Support, 4) Ideals, 5) Address Long-Term Development Concerns, and 6) Incorporation into Daily Living. The second question targeted service needs and resulted in a six-concept map including: 1) A Slider, 2) Ensuring a Future, 3) Help with the Adulthood Transition, 4) Financial Relief, 5) Encouraging Autonomy, and 6) Legal and Emotional Support. Findings were compared and contrasted with the literature.

Keywords: concept map, fetal alcohol spectrum disorder, caregivers' perceptions

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Chapter 1: Introduction

Fetal alcohol syndrome is caused by alcohol exposure during pregnancy when the structures of the human body and brain are developing (Caley, Kramer, & Robinson, 2005). To be identified as having fetal alcohol syndrome, an individual must display a distinct expression of facial dysmorphia, growth problems in weight and height, and evidence of structural, neurological, and functional central nervous system (CNS) damage (Caley et al., 2005). Alcohol is a teratogen, and through the process of teratogenesis, ethanol crosses the placenta and impacts the developing brain and nervous system (Caley et al., 2005). It is important to note that children who are exposed to alcohol prenatally do not all present the same way as gestational timing, severity, and chronicity affect the fetus in different ways (Caley et al., 2005).

Fetal alcohol syndrome is the leading cause of intellectual disability in North America and is a significant public health issue causing developmental disabilities in those affected (Petrenko, Tahir, Mahoney, & Chin, 2014b; Rasmussen et al., 2012; Stade, Ungar, Stevens, Beyene, & Koren, 2006). Individuals with histories of prenatal-alcohol exposure are at risk for problems with mental health, educational attainment, and deficits in cognitive and behavioral functioning (Riley, Infante, & Warren, 2011). According to Health Canada (2009), 300 000 Canadians live with FASD, and it is therefore a significant public health issue. This health issue is also a prevalent concern in the United States with frequency reports of 1-3 per 1000 live births (Chudley et al., 2005). It is essential to recognize the challenges associated with these chronic conditions that persist throughout adolescence and into adulthood.

History of FASD

In response to critics of alcohol consumption in 18th century London, the committee of the British House of Commons collaborated in 1834 to investigate drunkenness, and in that same

year the Alcoholic Licensure Act was developed (House of Commons, 1834). It was Dr. William Sullivan who investigated female alcoholics of the Liverpool Prison, and documented an increased frequency of early fetal death and early infant mortality among their offspring (Sullivan, 1899). Ladrage (1901) in France reported miscarriages and underdevelopment within children who had alcoholic mothers. French physicians Lemoine, Harousseau, Borteryu, and Menuet (1968, as cited in Streissguth, 1997) reported characteristics of growth deficiencies, physical abnormalities and ‘irritable dispositions’ among 127 children born to alcoholic mothers.

Later in 1973, 11 unrelated children who were all born to different women who drank heavily during their pregnancy displayed similar patterns of altered growth and morphogenesis (Jones & Smith, 1973; Jones, Smith, Ulleland, & Streissguth, 1973). After examining these reports, an understanding was reached that there was a clear association between heavy maternal alcohol consumption and a disorder known as Fetal Alcohol Syndrome (FAS; Jones & Streissguth, 2010). Since these documented studies, the health and impairments associated with children who are exposed to alcohol prenatally have been studied and discussed.

Causes

Alcohol is a teratogen that impacts the developing embryo and fetus (Streissguth, 1994) and since ethanol can cross the placenta easily, this substance is simultaneously delivered to the infant when the mother consumes alcohol (Streissguth, 1997). Drinking throughout pregnancy causes severe neuropsychological effects with binge drinking being more detrimental than casual drinking (Jacobson & Jacobson, 1999; Korkman, Autti-rämö, Koivulehto, & Granström, 1998). The most harmful time for prenatal alcohol exposure is during the first three weeks of gestation when the central nervous system develops (Polygenis et al., 1998).

Alcohol related disabilities are associated with structural, functional and metabolic brain

abnormalities, which cause challenges in physical, behavioural, emotional and cognitive functioning (Kully- Martens, Denys, Treit, Tamana, & Rasmussen, 2012; Manji, Pei, Loomes, & Rasmussen, 2009). Since prenatal-alcohol exposure impacts the brain, awareness must be promoted that individuals with FASD have abnormal brain structure and function (Senturias, 2014).

There are different fetal alcohol spectrum disorders that vary according to diagnostic standards. Criteria in the United States result in four diagnoses including FAS with or without confirmed prenatal alcohol exposure, partial FAS (pFAS), Alcohol-Related Birth Defects (ARBD), and Alcohol-Related Neurodevelopmental Disorder (ARND) (Streissguth & O'Malley, 2000). In Canada, the spectrum of fetal alcohol spectrum disorders consists of Fetal Alcohol Syndrome (FAS), partial Fetal Alcohol Syndrome (pFAS), and Alcohol-Related Neurodevelopment Disorder (ARND; Chudley et al., 2005). It should be noted that the newest Canadian criteria, published in December 2015 (Cook et al., 2015), were not in place at the time of this data collection but represent a shift to the use of FASD with or without Sentinel Facial Features as the diagnostic terminology. Facial features include short palpebral fissures, smooth philtrum and a thin vermilion border of the upper lip (Jones & Streissguth, 2010).

Expressions can include children with prenatal alcohol exposure who have only some characteristics of physical features accompanied by neurobehavioral impairments depicted by pFAS, or individuals who may have no characteristic physical features but are neurobehaviorally affected portrayed through ARND (Stratton, Howe, & Battaglia, 1996). For the purposes of the present study, it is understood that prenatal exposure to alcohol can produce many defects and the term “fetal alcohol spectrum disorders” (FASD) represents a non-diagnostic umbrella term to incorporate a range of outcomes associated with prenatal-alcohol exposure (Jones & Streissguth,

2010; Popova et al., 2013; Riley et al., 2011).

Living with Fetal Alcohol Spectrum Disorder

Individuals with histories of prenatal-alcohol exposure are at risk for severe problems in mental health, school, the justice system, community skills and personal-living (Brown, 2004; Jirikowic, Kartin, & Olson, 2008; Riley et al., 2011). The literature indicates that children with FASD have impairments with both verbal and visual spatial memory, which negatively impacts their information processing speed and academic capabilities (Manji et al., 2009). Unfortunately, in later life, adults with FASD find integrating education, employment and volunteering into their lives challenging and may feel disconnected from their communities (Clark, Minnes, Lutke, & Oullette-Kuntz, 2008).

FASD is often considered an “invisible disability” that presents itself in diverse ways. Many individuals who are impaired with FASD remain highly under-diagnosed in the healthcare system (Brown, Sigvaldason, & Bednar, 2005; Paley, 2009). This health impairment has been found to persist throughout the lifespan, and many caregivers of children with FASD fear for the future of their children as they approach adulthood (Clark et al., 2008; Michaud & Temple, 2013; Watson, Hayes, Radford-Paz, & Coons, 2013). Caregivers express concern with being unable to meet the complex needs of their children and report that FASD often requires lifelong parenting (Michaud & Temple, 2013; Watson et al., 2013).

Development is a marker of health, and the wellbeing of individuals are influenced by not only societal factors but the social organization of health services (Lynam, Loock, Scott, Wong, Munroe, & Palmer, 2010). Individuals with FASD have a range of complex and specialized needs, which requires many different systems of care (Brownell et al., 2013; Jirikowic, Gelo, & Astley, 2010). By tailoring services to the family’s unique needs, intervention programs can

provide social and informational supports that enhance family interaction patterns (Olson, Jirikowic, Kartin, & Astley, 2007). However, there is little research published on the prevalence, natural history, medical and social complications relevant to adults with FASD (Chudley, Kilgour, Cranston, & Edwards, 2007).

Diagnosis

Diagnosis of FASD requires a physical examination, dysmorphology assessment, neurobehavioral assessment and prenatal-alcohol exposure (PAE) confirmation (Popova et al., 2013). The physical examination requires measurements of growth (i.e., head circumference, height, weight) and documentation of anomalies (i.e., heart defects, high arched palate (Popova et al., 2013). The dysmorphology assessment recognizes facial features related to prenatal alcohol exposure, while the neurobehavioral assessment involves an evaluation of domains such as brain structure, cognition, IQ and memory (Popova et al., 2013). Finally, the confirmation of prenatal alcohol exposure is from the mother's report.

A difficulty in diagnosis relates to the variation in amount, timing and frequency of exposure as well as fetal vulnerability, which leads to a range of impairments between children (Pei & Rinaldi, 2004). Moreover, prenatal-alcohol exposure history, and informative birth records may be unavailable or non-existent (Chudley et al., 2007). Additionally, among mental health providers, FASD may not be routinely considered. Many individuals with prenatal-alcohol exposure can present with Attention Deficit Hyperactivity Disorder (ADHD), psychotic or anxiety symptoms, executive functioning abnormalities or social skills deficits (Lockhart, 2001). Finally, there is no widely accepted standardized FASD screening test in Canada because there is not enough evidence concerning validity and reliability (Popova et al., 2013).

Formal diagnosis is a lengthy process requiring different trained specialists to diagnose

FASD, which is expensive (Popova et al., 2013). As it requires a comprehensive and multidisciplinary assessment, an alcohol-related disability is likely under-diagnosed in Canada (Popova et al., 2013). Chudley et al. (2007) stresses that although FASD is relatively common, the resources needed to diagnose are limited.

Frequency of FASD

Internationally, FASD has an estimated incidence between 1 to 67 per 1000 births; and in Western countries, FASD affects 2 to 5 percent of the population (May et al., 2009). The Canadian rates of FASD were estimated by Health Canada to be about 9 per every 1000 live births (Chudley et al., 2005; Popova et al., 2013). The actual prevalence of FASD may be difficult to detect because the physical features are subtle. In addition, the lack of diagnostic expertise and resources among professionals also affects recognition and diagnosis (Jones & Streissguth, 2010).

Cost of FASD

The estimated annual cost of treating FASD in Canada is 198.3 million dollars (Popova, Lange, Burd, & Rehm, 2014). This cost does not take into account the additional team members such as addiction counselors, childcare workers, probation officers, teachers, psychiatrists, neuropsychologists and family therapists who are involved (Popova et al., 2013). Thus, the financial cost for raising a child with a disability is heightened, especially as the child with disabilities may need specified services in medical, educational, and psychological domains (Brown & Rodger, 2009; Reilly & Platz, 2004).

Total cost for Canadian diagnostic services associated with FASD were estimated to be between \$5.0 to \$7.2 million dollars (Popova et al., 2013). The total direct health care costs of

acute care, psychiatric care, day surgery and emergency department services associated with fetal alcohol syndrome in Canada was about 6.7 million (Popova, Lange, Burd, & Rehm, 2012).

In a study by Stade et al. (2006) 149 parents who had children with FASD aged 1-21 years old completed the Health Services Utilization Inventory (HSUI). Medical, education, out-of-pocket and social services costs were calculated. The total annual average cost per child was determined to be \$14, 343, and the severity of the child's condition, age and geographical location increased these costs (Stade et al., 2006).

Services

The lack of available services is especially problematic for adults with FASD, as few services exist for adults with developmental disabilities. Existing services are facilitated through long waiting lists or seem to be a poor fit in terms of appropriateness for young adults with FASD (Petrenko et al., 2014b). In reviewing the literature surrounding this topic, it is evident that there is a lack of knowledge regarding FASD among young adults as the services currently available are aimed at children and adolescents.

Wheeler, Kenney, and Temple (2013) explored the available interventions for individuals with FASD by systematically reviewing 38 experimental-design abstracts. The information surrounding interventions and services for adults with FASD was found to be minimal (Wheeler et al., 2013). Case management was helpful to parents and individuals with FASD. Relevant interventions focused on addictions and mental health supports as well as employment training (Wheeler et al., 2013).

Summary

Adults with FASD lack appropriate supports outside of family, and thus require specialized services. Understanding the type and nature of services needed to accommodate

individuals with FASD is crucial when assisting individuals who live with these conditions. This review highlights the need for research to examine interventions for the adult population. The present study investigates caregiver's experiences raising a child with FASD. The focus is on understanding the needs and supports to help family members of affected adult children. Results provide an understanding of what caregivers require to help young adults with FASD live as independently as possible, and the services needed when assisting young adults who live with FASD. The findings from this study provide a foundation for the creation of more effective interventions that can better assist the community integration of adults who live with FASD.

This thesis is divided into five chapters. Chapter One situates the issue of FASD providing an overview of history and diagnosis. Chapter Two is a review of the literature that has been examined to date surrounding FASD concerning the experiences of caregivers and those affected, including service implications. Chapter Three describes the method used in the study and steps taken to generate results. Chapter Four includes a detailed description of the results for two questions asked of caregivers. In Chapter Five results of the present study are compared and contrasted with the literature reviewed in Chapter Two.

Chapter 2: Literature Review

Fetal Alcohol Spectrum Disorder (FASD) is a result of prenatal-alcohol exposure which damages the structural and functional aspects of the brain and produces adverse outcomes in the lives of those affected. Considerable literature has been produced concerning the lives of affected children, but there is very little concerning the service needs of affected adults. Specifically, there has been little reported about what caregivers need to help adults with FASD live as independently as they can, and the services that make such arrangements possible.

In order to systematically retrieve the literature surrounding FASD services, relevant search terms were identified. The string of terms included: “FAS”, “FASD”, “prenatal-alcohol exposure”, “fetal alcohol syndrome”, “fetal alcohol spectrum disorders”, “foetal alcohol syndrome”, and “alcohol related disorder”. These terms were combined with the words “service”, “support”, “intervention”, as well as “caregiver”, “parent”, “foster parent”, and “non-biological parent”. The databases included MEDLINE, ERIC and PsycINFO.

Adults with FASD

Adults with FASD are faced with cognitive impairments. However their challenges are often not physically obvious and many live with an invisible disability (Denys, Rasmussen, Henneveld, 2011). More importantly, the demands and expectations for independence within adulthood increase. Such expectations put adults with FASD at an elevated risk because their functioning is diminished due to problems with executive function, employment instability as well as potentially, legal issues. Such challenges require external support to manage (Denys et al., 2011).

The vast majority of studies to date examine experiences of children with FASD. However, when affected children become adults they remain in need of assisted living.

Moreover, adults with FASD often stay connected to their caregivers from their own childhood (Streissguth et al., 2004). The modest amount of research concerning adults with FASD provides evidence that impairments persist in adaptive functioning and risks continue for those affected, as well as their families and communities. However, there is little evidence concerning evaluations, interventions and supports are available or necessary for the adult population affected by FASD (Chudley et al., 2007). More specifically, it is not known if the range of services that FASD children require are suitable and applicable to the services that adults with FASD require. Parents struggle to meet the complicated needs of individuals with FASD, and consequently many of their parental needs go unmet (Green et al., 2014). Individuals affected by prenatal-alcohol exposure struggle as they enter adult roles (Lynch, Kable, & Coles, 2015). Salmon and Buetow (2012) found that individuals with FASD aged 14-37 experienced difficulties with school, the workplace, socialization, and mental health. While there is a wide range of interventions that aim to improve outcomes for early to middle childhood, there is a lack of research outside of this developmental period (Reid et al., 2015). Since there is very little literature on caregiver and service needs of older children and few concerning adults, the literature presented is drawn primarily from studies of children.

Structure of the Review

The present study explores caregivers' perceptions of caregiver and service needs of adults with FASD. The literature, with some noted exceptions, reports on the needs of children and youth. The final analysis, a comparison and contrast between existing needs literature and experiences of caregivers reported in this study is presented in Chapter Five. In this Chapter, the literature is organized in accordance with the research questions. The first question focuses on what caregivers need to help young adults live as independently as possible. Topics from the

literature include the experiences of parents of children with FASD express, effects of this lifelong commitment on caregivers, professional support required as well as the type of planning and responsibility that is suitable. The second question focuses on what services would be needed for adults to live as independently as possible. Topics from the literature include multidisciplinary professional support, interventions to promote adaptive skills and functioning, services for different family types, pathways for obtaining such services and the need for respite care.

Caregiver Needs

Identifying the needs for caregivers of children with FASD is essential. Although there is a considerable literature base for the caregiver needs of young children with alcohol-related disabilities, there is far less on needs when the children grow into adults who require supports from home, as well as services and integration within the community.

Optimism and realism. Parents of children with FASD express a great deal of emotional conflict and describe their anxiety, stress and fear for both themselves and their children as they age (Whitehurst, 2012). Many experience caregiver burden when raising children with disabilities, and the exaggerated demands are time consuming, expensive and physically exhaustive (Green, 2007b). One of the most central goals for parents of children with alcohol-related disabilities is to have them become “good” people (Rutman & Van Bibber, 2010). Parents are concerned about the future of their children as they enter later stages of development, especially when considering the future possibilities for them as adults (Mukherjee et al., 2013).

Watson et al. (2013), found that families who had children with autism expressed hope for their future possibilities, and felt their children would be fully independent, educated and meaningfully employed. In contrast, families of children with FASD recognized their lack of

hope for their child's future, and mentioned the difficulties in establishing independent living, education and employment (Watson et al., 2013). This study substantiates the fears and guilt of caregivers associated with the inability to meet the complex needs of their children who become adults with FASD.

Lifelong commitment. Caring for individuals with FASD becomes increasingly complex over time, including developmental as well as different combinations of environmental risk and protective experiences (Chudley et al., 2007; Michaud & Temple, 2013; Paley, 2009; Sanders & Buck, 2010). Michaud and Temple (2013) interviewed adoptive and biological mothers of individuals with FASD and parents conveyed fear they had for their children's futures as adults, given the need for lifelong support.

Health care, social service needs, community involvement, employment and daily living needs are concerns that parents worry about even if they envision a time where their involvement or influence may not be as great in their adult child's life (Brabender & Fallon, 2013). Parents have expressed the need for ongoing support groups especially with other parents who have more experience caring for children who are older than their own. Such groups also provide the opportunity to discuss feelings about different ways to handle similar experiences children (Brown et al., 2005; Olson, Oti, Gelo, & Beck, 2009; Rowbottom, Merali, & Pei, 2010).

Professional support. Weiner and Morse (1994) indicate that because the presenting problems are diverse, interventions need to incorporate medical, psychological, educational and social domains for children with FASD. In a study of adoptive parents, unmet needs included in-home supports, financial supports, counseling and home placement requests. Discrepancies between perceived need and service support were associated with lower quality of family functioning and parent-child relationship (Reilly & Platz, 2004).

Brown and Bednar (2003) analyzed interviews with nineteen birth, foster and adoptive parents whose children lived with FASD, and found that not only were parents in need of supports from a broad support network, but they also required social services as well as child management skills. Other problems faced by foster parents when raising children with disabilities included maintaining educational placements and having difficulties in obtaining specialized professional services (Brown et al., 2005). Parents who have children with alcohol-related disabilities additionally depend upon collaboration with the school, income support and a strengths-based parenting approach (Brown, 2004).

Interventions for caregivers include psycho-education about the causes, nature and progression of FASD including the behavioral, emotional, physical and cognitive aspects as well as how FASD manifests at different stages (Murthy, Kudler, George, & Mathew, 2009). These parent education and training interventions seem to help parents gain knowledge about FASD and help create more realistic expectations (Bertrand, 2009).

Raising a child with FASD also poses financial challenges. Not only do parents potentially miss out on earnings because of caregiving responsibilities, but uninsured medical and other professional expenses can be significant (Caley, Winkelman, & Mariano, 2009). Financial planning and support for families is necessary for meet basic physical needs as well as educational and social needs as adults (Brown et al., 2005; Brown & Rodger, 2009; Rowbottom et al., 2010; Stade et al., 2009).

When examining parent and family based interventions, a program known as Coaching Families (CF) connects family members of individuals with FASD to mentors that help with access to resources and education (Leenaars, Denys, Henneveld, & Rasmussen, 2012). Evaluation data from 186 families demonstrated a decrease in needs and an increase in

community connection and personal skills management (Leenaars et al., 2012). Another intervention, which is an adaptation of the Alert Program, teaches caregivers ways to recognize characteristics in their child to notice arousal levels and ways to accommodate their children (Wells, Chasnoff, Schmidt, Telford, & Schwartz, 2012). Effects were noted in higher executive functioning and emotional problem solving for children of parents in the treatment groups (Wells et al., 2012). Programs that involve collaboration between services within a particular community are particularly helpful to families (Abrams, 2010).

Planning and shared responsibility. In a study by Pei, Job, Poth and Atkinson (2013), assessment practices for children with FASD were examined. It was noted that child's needs must be understood broadly, to include not only academic, but learning, as well as emotional and social development into adolescence. Assessment results can be used for educational and program planning as well as anticipation of needs in subsequent years. There must also be a willingness and capacity in the school and community to meet those needs. These findings reinforce what is known about the negative impact that a lack of external support can have on caregivers to individuals affected by FASD.

With respect to possibilities for independent living, Whaley, O'Connor, and Gunderson (2001) found that in a group of children with alcohol related disabilities between the ages of two to ten, adaptive daily living skills (ADLs) on the Vineland Adaptive Behavior Scale (VABS) that were two standard deviations below the mean. Jirikowic et al. (2008) compared caregiver reports of adaptive and maladaptive behaviors of 25 children with FASD as opposed to 23 children with typical development. It was noted that children with FASD rated significantly lower in independent behaviors associated with communication, personal-living skills and community-living skills. Burnside and Fuchs (2013) interviewed 20 youth between the ages of 16 and 21

living in the child welfare system about their experiences of transitioning out of care while living with their disability. Youth with FASD were fearful of the responsibilities and challenges that would come with independent living, and acknowledged that foster parents were the most important source of help with their independent living skills (Burnside & Fuchs, 2013). In a rare study concerning adults with FASD, adoptive, foster and biological caregivers noted that their children felt marginalized and had high, unmet needs for social involvement, community-participation, education and employment (Clark et al., 2008).

Service Needs

Many families who care for children with disabilities feel that external support is essential (Wodehouse & McGill, 2009). However, little is known about the support needs of adults who live with FASD, and even fewer specialized services exist to meet their needs. Research concerning the service and support needs of individuals who live with FASD requires attention to adequately assist individuals who experience these conditions. There should be specific focus directed toward adolescent and adult populations.

Primary and secondary disabilities. Clinical descriptions of individuals with fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE) indicate adverse outcomes across the lifespan and into adulthood. Within FASD, primary disabilities refer to the brain damage indicative of CNS functioning, that results in impaired mental functions with general intelligence, reading, spelling, math as well as adaptive functioning (Streissguth, Barr, Kogan & Bookstein, 1996). Secondary disabilities are impairments that are not present at birth, but develop as a result of primary disabilities (Streissguth et al., 1996). For example, secondary disability outcomes include inappropriate sexual behaviors, disrupted school experience through suspension, learning and behavioral problems, trouble with the law through crime against others,

assault, confinement and subsequent alcohol and drug problems (Streissguth et al., 2004). An appropriate diagnosis of FASD and living in a stable environment together has a substantial effect on the prevention of secondary disabilities (Streissguth et al., 2004).

Multidisciplinary professional support. Important supports for alcohol-exposed individuals include psychopharmacological treatment, behavior therapy, proper education placement, speech and language services, parental education and support, social services and vocational services (Lockhart, 2001). However, many parents who have children with FASD report difficulties receiving help, as professionals fail to understand the child's situation, may not take their reports of challenging behavior as problematic, and may even blame the parents for their child's misbehavior (Wodehouse & McGill, 2009).

When raising a child with FASD, adoptive parents feel as though they are not given enough information from professionals like doctors, social workers and educators, and therefore experience increased stress, isolation and difficulty within the family (Mukherjee, Wray, Commers, Hollins, & Curfs, 2013). In fact, although human service professionals are essential in preventing secondary disabilities of FASD, professionals reveal that they have less knowledge of epidemiology of fetal alcohol spectrum disorder and feel less capable of knowing how to work with affected individuals (Caley et al., 2008).

However, when families have adequate support from knowledgeable professionals, community clinics and connections through groups, they have better personal, as well as child and family outcomes (Bailey, 2007). There is considerable evidence that the development and behavior of children with FASD be monitored and the work of caregivers supplemented with adequate supports and interventions (Senturias, 2014). There is a clear need for professionals to

understand FASD, and specialists must be prepared to work with individuals as they approach adolescence and adulthood (Jirikowic et al., 2010).

Interventions to promote adaptive skills and functioning. Adolescents and adults who are affected by FASD will demonstrate deficiencies in social skills, daily living skills and communication as well as attention (Streissguth et al., 1991). Individuals with FASD experience challenges associated with adaptive behavior manifested through lower social competency (Kully-Martens et al., 2012). Children need healthy caregivers. However challenges arise when there is an increase in disruptive behaviors that heighten parenting stress (Brabender & Fallon, 2013). It has been found that impaired sensory processing, deficits in executive functioning, poor adaptive functioning and behavioral problems all increase caregiver stress (Jirikowic, Olson, & Astley, 2012; Paley, O'Connor, Frankel, & Marquardt, 2006). As noted in one study with foster parents of children with FASD, participants considered ending a placement if they felt burned out, and had noncompliance with house rules (Brown, Bednar, & Sigvaldason, 2007).

Specialized aids. Studies have shown that skills can be taught to children with FASD through computer technology. For example, a computerized fire safety skills training found that children with FAS were able to increase knowledge toward the safety skill being taught, and were able to describe the steps to take if a fire occurred (Coles, Strickland, Padgett, & Bellmoff, 2007; Padgett, Strickland, & Coles, 2006). In a computerized progressive attention training (CPAT) developed specifically for children with FASD, there were improvements in selective attention, spatial working memory and reading as well as math fluency (Kerns, MacSween, Vander Wekken, & Gruppuso, 2010). These results suggest the possibility that computerized training may be a useful component for teaching and coaching independence in adults with FASD.

Social skills. An important area of adaptive functioning in social skills is communication, where interventions can help improve social and cognitive skills (Timler, Olswang, & Coggins, 2005). The Children's Friendship Training (CFT) is a manualized evidence-based social skills intervention where focus is given to child and parent behaviors to help build social networks, improve information exchange with peers and promote conflict avoidance, which is taught through modeling, coaching and feedback (Laugeson et al., 2007). Implementation of this program results in social skill improvements among children with FASD (Frankel, Paley, Marquardt, & O'Connor, 2006) and maintenance of these skills after a three-month follow up (O'Connor et al., 2006). In addition, significant improvement of knowledge and engagement in appropriate social behavior, improved self-concept, ability to control impulsiveness, better transitions and decreases in problematic behaviors were also found with the CFT (O'Connor et al., 2012; Schonfeld, Paley, Frankel, & O'Connor, 2009). This intervention teaches important adaptive skills in the social realm through modeling and feedback, and provides insight that such treatments may be helpful to adults who live with FASD.

Cognitive-based interventions. For individuals with FASD, neurophysiological processing deficits are associated with struggles in the areas of memory, social skills and information processing, which endure into adulthood (Hammond, 2012). In a study that included adults with FASD, crucial effects throughout development were found, which included problems with memory and organization, preservation, planning, a lack of using consequences effectively, and impulsivity (Rutman & Van Bibber, 2010).

Rehearsal training interventions allow significant increases in remembering a series of numbers during the posttests and follow ups, and lead to improvements in working memory for individuals with FASD (Loomes, Rasmussen, Pei, Manji, & Andrew, 2008). Raising a child with

FASD includes consistency because any change of routine is extremely challenging (Garnder, 2000; Kalberg & Buckley, 2007). Building structure into a child's day can include decreasing visual and auditory distraction, including a visualized schedule and providing clear instructions, which all promote predictability and assist the child's ability to make transitions (Kalberg & Buckley, 2007; Weiner & Morse, 1994).

Although many of these studies focus on children, they offer the possibility that these competencies are relevant to adults and could be areas to focus on when considering interventions and supports. It is clear that the literature is lacking empirical evidence that would demonstrate effectiveness of interventions for adults diagnosed with FASD. It is therefore important to generate research concerning the range of services necessary for adults.

Services for different family types. Children with FASD are overrepresented within out-of-home care arrangements. While many continue to reside with birth parents and families, others live with foster or adoptive parents. There has been research on the types of service needs that are beneficial to different family structures.

Foster and adoptive parents. Foster and adoptive parents who live with a child that is diagnosed with FASD identify particular struggles. Caregivers have recognized that obtaining a diagnosis is complex, and even with a diagnosis many feel the schools are not equipped to educate their children and challenging behaviors in school increase familial stress at home (Watson, Hayes, Coons, & Radford-Paz, 2013).

At home, externalizing behaviors such as physical aggression, defiance, hyperactivity and peer-related problems in the community are associated with high rates of foster placement disruption (Brabender & Fallon, 2013; Smith, Howard, & Monroe, 2000). In a study by Gardner (2000), mothers living with children with FASD described many challenges including memory

problems, lack of understanding consequences and absence of fear in their children.

Hyperactivity, aggressiveness, and high pain tolerance have also been mentioned as problematic by adoptive and foster parents (Gardner, 2000).

Birth parents. Interventions have focused on birth parents, although largely in a prevention role, by identifying higher risk individuals for giving birth to children with alcohol related disabilities. There are also programs with case managers that work with women who have FASD themselves to increase access to community supports, ensure health care needs are met, allow access to safe housing and meet community service provider recommendations (Denys et al., 2011; Grant, Huggins, Connor, Pedersen, Whitney, & Streissguth, 2004; Rasmussen et al., 2012). However, there is little attention in the research directed specifically to supports needed to help birth parents and families caring for children, youth, or adults with FASD.

Family cohesion. The potential predictors for family intactness for foster, adoptive and birth families include the child's characteristics, the family's characteristics, previous placement(s) and service history (Berry, Propp, & Martens, 2007). In particular, foster parents are motivated to care for children with prenatal-alcohol exposure when they witness positive changes in the children in their care, when they help children focus on their strengths, when they have adequate income and when they help children stay connected to their community (Brown, Sigvaldason, & Bednar, 2006).

Brown and Bednar (2004) interviewed nineteen birth, foster, and adoptive parents, and portrayed that rearing a child with FASD led to challenges with their children's behavior, difficulties with arranging long-term plans, and keeping the child involved in social activities. Ultimately, the challenges and subsequent support needs of adults with FASD is immense. Olson and Montague (2011) suggest that protective factors can be biological such as innate

intelligence, and can also include environmental factors such as having parental warmth, involvement, a supportive family, and connections within the community. Moreover, understanding which stimuli might set off an outburst is pivotal for caregivers to understand when rearing their children (Streissguth, 1997).

Supportive relationships strengthened through caseworkers may lead to better outcomes as well as placement stability for children and youth with FASD (Pelech, Badry, & Daoust, 2013). Casework interventions can be very helpful to foster parents when raising children with FASD. They may also be beneficial to birth and adoptive families, following children with FASD throughout their childhood, into their adolescence and adulthood. Such services could support health and social needs, as well as employment needs or advocacy if there was justice system involvement (Rutman, La Berge, & Wheway, 2002).

Service access. A problematic occurrence is the absence of a clear standardized pathway for accessing services (Mills, McLennan, & Caza, 2006). There are multiple entry points when accessing the systems of care. Delivery systems do not necessarily work in collaboration, thus it is up to individuals to navigate across programs and services (Lynam et al., 2010; Mills et al., 2006). This can become confusing to the caregiver who is trying to obtain services, and many children fall through the organizational ‘cracks’ when seeking suitable interventions (Lynam et al., 2010; Mills et al., 2006). The absence of service results in missed opportunities for prevention, and heightens physical, emotional, and cognitive challenges (Badry, 2009; Mills et al., 2006). To prevent secondary conditions in individuals with FASD, appropriate services must be accessible to support affected adults and their families.

Service barriers. Petrenko et al. (2014b) noted that barriers to receiving adequate services included qualification, availability, implementation and maintenance of services. Brown’s (2004)

findings are consistent with these findings, by suggesting that families of children with alcohol-related disabilities face difficulties related to service availability, appropriateness, adequacy and acceptability. Parents commonly express frustration in being unable to obtain appropriate services for their children (Petrenko et al., 2014b).

Whitehurst (2012) found that parents of children with FASD had challenges receiving supports and services that were appropriate. Service providers who were not FASD-informed were not very helpful (Wodehouse & McGill, 2009). FASD-informed medical and mental health professionals, local agencies, and schools could make a significant difference in the lives of those with FASD (Phung, Wallace, Alexander, & Phung, 2011). Other major barriers included not knowing how to access services, not having services within one's area, and the financial burden when the child did not qualify for a needed service (Naumann, Reynolds, McColl & Smith, 2013; Petrenko et al., 2014b; Whitehurst, 2012; Whyte, 2010). Parents also describe implementation of services as unsuccessful when they do not fit with the strengths and weaknesses of their children (Petrenko et al., 2014b).

Systematic barriers also contribute to difficulties. For example, policy barriers based on eligibility criteria for Community Living resources are IQ-based. IQ has been shown to be a poor predictor for the ability level of individuals living with FASD. Indeed, as average IQ within the FASD population can exceed cut-offs for adult support, a large weight will fall on the parents' shoulders (Sanders & Buck, 2010). Thus, access to developmental services for parents with an adult child who has FASD is limited (Russell, 2003; Rutman & Van Bibber, 2010).

Respite care. Respite is a short-term temporary caregiving arrangement to alleviate the physical and emotional burdens of parents who care for a child who has challenges (Joyce, 1983). One aim of respite care is to provide a “time out” for parents to pursue their own interests,

and it is highly valued by many caregivers of children with disabilities (Joyce, 1983; Whyte, 2010). In a sample of 32 surveyed families, parents agreed that their family got along better when receiving respite care, and that it also relieved stress (Joyce, 1983). Rimmerman, Kramer, Levy, and Levy (1989) examined families who had children with comparable levels of developmental disabilities, and found that families who used home-based respite care over an 18-month period reported reduced levels of stress and better coping, whereas the families that did not use respite care exhibited the opposite effect.

Respite care also reduces social isolation of caregivers and can increase their resiliency (Wikler, Hanusa, & Stoycheff, 1986). Respite is integral to reducing caregiver burnout, decreasing family isolation and increasing family stability (Chan & Sigafos, 2001; Doig, McLennan, Urichuk, 2009; Whyte, 2010). During the FASD Center for Excellence town hall meetings, parents and caregivers repeatedly indicated the need for affordable and appropriate respite care (Ryan, Bonnett, & Gass, 2006). The unavailability of these services is problematic. Many parents feel that there is not enough flexibility or coordination when trying to obtain these supports (Doig et al., 2009; Petrenko et al., 2014b).

Summary

The purpose of the present study is to explore caregivers' perceptions of their own needs and the service needs for children with FASD as adults. It was evident through the review of literature on FASD that the prevention of secondary disabilities is an important outcome of appropriate support at home, and in the community throughout childhood and adolescence. However, there is little about the support needs of adults with FASD in the literature.

Many caregiver and service needs have been recognized in relation to children with FASD. Needed services included multidisciplinary professional support, interventions to

promote adaptive skills and functioning, services for different family types, pathways for obtaining such services, and the need for respite care. Caregiver needs included the experiences of parents of children with FASD, effects of the lifelong commitment on caregivers, professional support, as well as planning and shared responsibility.

Caregivers of older children with FASD were asked about their perceptions of the needs they would have and their adult children would have for community support. The methodology is described in Chapter Three. The results of the study presented in Chapter Four, are compared and contrasted in Chapter Five, to determine which adult needs are similar to, and different from the needs identified from existing research concerning children.

Chapter 3: Methodology

The purpose of the present study was to explore caregivers' perceptions of their own needs and the service needs for their children with FASD as adults. The data from this study was gathered through telephone interview interviews with caregivers of children aged 10 years or older with FASD. This research was conducted in partnership with the FASD Network of Elgin, London, Middlesex and Oxford (ELMO) counties in the Southwestern Ontario region. The ELMO Network includes community agencies, individuals, and service providers whose goal is to improve the support and advocacy related to Fetal Alcohol Spectrum Disorders. The Network seeks to enhance areas of community awareness, education, diagnostics, justice and parental support through professional collaboration.

Concept Mapping is a method that uses quantitative procedures to analyze qualitative data. Concept Mapping produces a graphic representation of the interrelationships between different responses to a research question (Kane & Trochim, 2007; Sutherland & Katz, 2005; Trochim, 1989). According to Trochim (1989) there are six steps in the Concept Mapping process. The first three steps that were completed prior to the writer's involvement with the project, which included: preparation, generation and structuring (Trochim, 1989). The remaining steps included representation, interpretation, and utilization.

Procedure

Preparation. In preparation for the study, the focal research questions were determined and potential participants identified. Caregivers of a youth with FASD who was at least ten years of age at the time of interview were invited to participate in a telephone interview. Participants were recruited through advertisements via e-mail or in-person using printed flyers. Researchers were connected with potential participants through professional contacts and associates of the

ELMO Network, as well as the London FASD Clinic. Interested individuals were invited to contact the researchers using the telephone number provided. All who consented to participate in the interview were asked if they were caring for a child aged ten years or older who had a diagnosis of FASD. Any caregiver who indicated that they suspected FASD, but did not have a diagnosis, were asked to complete the Neurodevelopmental Screening Tool.

Neurobehavioral Screening Tool (NST). If the child was suspected of having FASD, the NST was administered. The NST was developed by Nash et al. (2006) to help professionals working with children suspected of FASD to determine their likelihood of receiving a diagnosis if formally assessed (Nash et al., 2006). The NST included ten items from the Child Behavior Checklist and was most accurate with children aged 12-17 (Nash et al., 2006). The sensitivity rate of the NST is 86% and the specificity rate is 82% when compared to controls (LaFrance, Nash, Koren, Andre, & Rasmussen, 2006). Moreover, children with confirmed prenatal alcohol exposure without FASD diagnosis were screened positively (36%) when compared to prenatal exposed children (14%) and controls (0%) (Nash, Koren, & Rovet, 2009).

In the present study results of the screen were scored and if a "suspected" child received a positive screen, that caregiver met the criteria for participation. The NST was administered a total of ten times, and four negative screens resulted in the data from those caregivers being excluded from the study.

Generation. Consenting caregivers were asked several demographic questions as well as the focal research questions for this thesis which included: "What do caregivers need to help young adults live as independently as possible?" and "What services would help young adults live as independently as possible?" (see Appendix A for interview form). Each was provided a small honorarium and asked if she or he was interested in participating in the sorting phase. The

researchers kept a list of telephone numbers for the sorting phase.

Sixteen caregivers participated. Fifteen were female. They were birth parents, adoptive, and foster parents as well as aunts and grandparents to children over the age of ten years with FASD. At the time of interview, there had between 1 and 5 children in their homes. **The average age of the oldest children in the home amounted to 16.9 years in age.** Seven of the 16 had annual gross family incomes under \$50,000, and none had a family income greater than \$100,000. Together they had been caregivers to 42 children with FASD.

Structuring. Researchers reviewed responses to the questions. Any unclear responses were edited for clarity, and redundant responses were removed for the analysis. Individuals who consented to participate in the sorting phase of the study were mailed a complete set of responses to each question. Each response was printed on a separate card. For each question, participants were asked to ‘sort’ the responses into groups "in whatever way makes sense to you". Utilizing guidelines developed by Trochim (1989), participants were informed that each response could only be placed in one pile to avoid simultaneous placement. In sum, each participant was asked to read through the cards, and sort the cards into the piles that made sense to her or him. The sort data was collected by telephone.

Representation. The sort data were analyzed with Concept Systems' Global MAX online software (2015). Two statistical analyses were applied to the sort data. Non-metric multi-dimensional scaling placed responses spatially on a point map and cluster analysis organized responses into concepts.

Multi-dimensional scaling. The first step in multidimensional scaling was to construct a proximity matrix (Trochim, 1989). One matrix was created for each participant’s sort, where response ID members were arranged on the top and side, and values entered in each cell where

two responses intersected. If the participant sorted the two responses into the same group, a value of 1 was in the cell. If the two responses were not sorted into the same group by the participant, a value of 0 was entered in the cell. Matrices for each participant were added together and the total for each cell was calculated. From these data, a two-dimensional map was created with distances between responses on the map reflecting the frequencies, with which participants sorted into the same groups. Responses closer together were more likely to be sorted into the same groups more frequently, and responses further apart are more likely to be sorted into different groups more frequently.

Through the process of multidimensional scaling, a bridging index was also produced for each response. The bridging index was a value between 0 and 1. The bridging index reflected the frequency with which each response "bridged" with others near to it on the map. The closer the value was to 1 for a response (i.e. greater than 0.75), the more often the response was sorted into groups with other responses further away on the map, with other points on the map. A value closer to 0 (i.e. lower than 0.25) indicated that the response was typically sorted into groups with other responses near to it on the map.

Cluster analysis. The multidimensional scaling values were analyzed using a cluster analysis procedure (Anderberg, 1973; Everitt, 1980). At the beginning of this procedure each response was considered as its own concept. At each step of the analysis, two concepts were combined. The analysis was complete when all responses were within one concept.

Interpretation. Based on the results of cluster analysis the author made a decision about the most appropriate number of concepts for each map. Both qualitative (i.e. within concept and between concept content) and quantitative (i.e. bridging index values) data were used to make this decision (Kane & Trochim, 2007). For example, a map with concepts where there was

similarity between responses in each concept and differences between concept contents was favored. In addition, a map with concepts that had low average bridging indices (i.e., less than 0.25) reflected greater consistency of participants' groupings, while those with high average bridging indices (i.e., greater than 0.75) reflected less consistent groupings of responses therein. Following this decision, the author labeled each concept to represent the responses contained within it (Kane & Trochim, 2007).

Utilization. Following the decision about the most appropriate number of concepts for a map and the application of descriptive labels, it was used for its intended purpose. The purpose of the concept maps for this study was to reflect the major issues that participants identified in relation to caregiver and service needs for adults with FASD. In the Chapter Four, a detailed description of the maps is provided and in Chapter Five, a comparison and contrast between the maps and available literature is presented.

Chapter 4: Results

The purpose of the study was to explore caregivers' perceptions of their own needs and the service needs for their children with FASD as adults. Caregivers responded to research questions during telephone interviews. Responses were later sorted into groups by participants and the sort data was analyzed using multidimensional scaling and cluster analysis procedures. A concept map was produced for each question. In this chapter the results of concept mapping are presented for the focal questions: "What do caregivers need to help young adults live as independently as possible?" and "What services would help young adults live as independently as possible?"

Caregiver Needs

A total of 51 unique responses were received to the question "What do caregivers need to help young adults live as independently as possible? Sixteen participants sorted the responses. The sort data was analyzed and a stress value was calculated. This value was used to determine validity of the map. The stress value of this map was 0.33. Values of maps below 0.35 are considered valid representations of the sort data (Trochim, 1989).

According to Trochim (1989), the most appropriate number of concepts for a map with less than 100 responses would likely fall between 20 and 3. Evidence of within concept consistency of responses as well as discrepancies between concepts was considered for each map. A map with eight concepts was initially reviewed and reduced to seven concepts. This map appeared more fragmented. A reduction to five and four concept maps were also considered, but in these cases concepts that were different were merged. As a result, the six-concept map was selected because it was the best representation of the data (see Figure 1).

Responses and bridging indices are presented in Table 1. Individual bridging indices were used to identify central responses for each concept to inform the construction of a label for each. Responses with the lowest bridging index values were most central to the content of that concept. Responses with a low bridging index (i.e. between 0.00 and 0.25) were consistently sorted with other responses in the same concept. Responses with a high bridging index (i.e. between 0.75 and 1.00) were also frequently sorted with responses in other concepts. High bridging indices were less central to the content of a concept (Trochim, 1989). An average bridging index was also calculated for each concept. A lower average bridging index reflected greater cohesion of responses within the concept.

Figure 1. Concept Map: What do caregivers need to help young adults live as independently as possible?

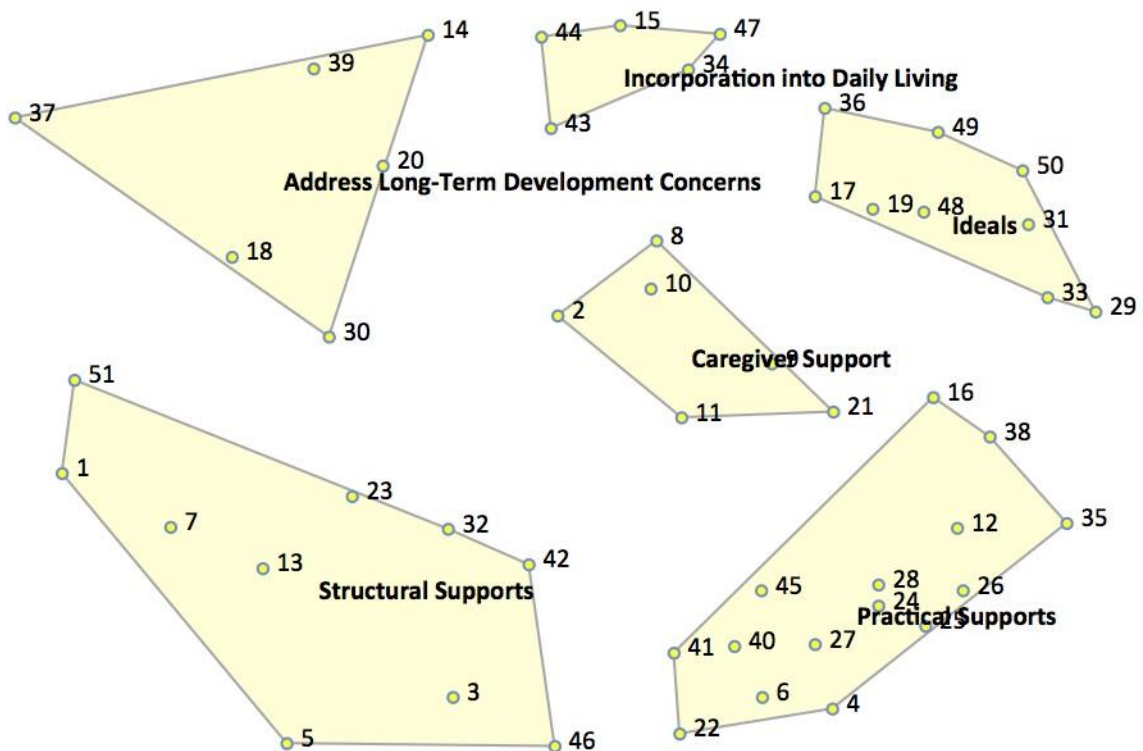


Table 1

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

Concept and Response	Bridging Index
Structural Supports	0.57
42. someone who helps the caregiver understand changes	0.20
32. people that don't think you are a bad parent	0.26
46. support group	0.37
23. look what the family needs	0.38
3. community understanding	0.46
13. group home with appropriate staff	0.61
7. education	0.74
5. don't call the cops on them all the time	0.80
1. assisted living	0.90
51. what colleges offer programs for learning disabilities	0.95
Practical Supports	0.15
45. support from doctors	0.05
24. more one to one workers	0.06
28. need to support caregivers to help adult children be successful	0.08
40. services that have training and understanding	0.10
27. more training options	0.11
12. funding for FASD	0.11
25. more people to help	0.11
41. someone to listen and understood	0.12
16. help to provide emotional and daily living help	0.15
38. respite	0.15
26. more supports and programs that are flexible	0.16
6. don't take services away when child is stable	0.18
4. consistent services	0.22
22. legal systems with flexibility and understanding about FASD	0.28
35. public awareness	0.35
Caregiver Support	0.07
9. financial help	0.00
11. find out what adult supports are out there	0.06
21. know what programs are out there	0.07
10. financial plan	0.09
8. energy	0.09

2. avoid burnout	0.13
Ideals	0.25
17. hope	0.10
19. know the person's challenges	0.16
48. teach life skills	0.20
31. patience	0.23
36. realistic expectations	0.25
49. trust that they can do it	0.26
33. people who understand them	0.32
29. not getting over stressed	0.36
50. understanding	0.37
Address Long-Term Development Concerns	0.62
20. know what needs are in those stages of life	0.45
30. open minded to differences	0.5
14. have him assessed every 3-4 years	0.52
39. security	0.62
18. I am still going to be dealing with problems like I have small children	0.64
37. remember that kids will not be with us forever	1.00
Incorporation into Daily Living	0.33
43. start planning from early on	0.23
34. positive activities	0.31
47. take them places	0.34
44. start things young so it's not a shock when an adult	0.39
15. help him process it and learn from it	0.39

Structural supports. This concept reflected the necessary supports that the individual living with FASD required to function in the larger social structure in which they lived. The need for assistance through social services, peer networks and the community were evidenced by responses such as “group home with appropriate staff”, “support group”, “community understanding”, “look at what the family needs” and “people that don’t think you are a bad parent”. These responses had bridging indices between .25 and .65, indicating that while the responses represented the theme of this concept, they were not strictly sorted with responses in the concept. Most central to this concept was that parents needed “someone who helps the caregiver understand changes”. This response had a low bridging index of 0.20.

Responses such as “education”, “assisted living”, “don’t call the cops on them all the time” and “what colleges offer programs for learning disabilities” implied that access to services and help from social institutions are helpful. The bridging indices of these responses were higher than 0.75, indicating participants frequently sorted these responses with responses in other concepts. However, these responses do suggest the need for assistance through the social structure. The overall bridging value for this concept was 0.57, which indicated that several responses in this concept were sorted by participants with responses in other concepts.

Practical supports. This concept represented the theme of social support, which is necessary to provide opportunities to help the person with FASD positively adjust to daily life. These are practical supports that a typical individual can receive, but are more difficult to achieve by those who are affected by FASD. For example, responses such as “support from doctors”, “more one to one workers” and “need support caregivers to help adult children be successful” reflected the necessity of working professionals to support FASD, especially as these individuals develop into adulthood. These responses had bridging indices of 0.05, 0.06, and 0.08 respectively, indicating that they were central to this concept.

Importantly, caregivers also suggested that supports should include “services that have training and understanding” and “more training options”, which indicated that practical services must be maintained by workers who are qualified through sufficient training. Parents also suggested that in order to help with the functioning of their children, they would need “more people to help”, “someone to listen and understand”, and “help to provide emotional and daily living help”. These responses had bridging indices of 0.11, 0.12, and 0.15 respectively, indicating that these responses were frequently sorted with other responses in the same concept.

Responses such as “consistent services”, “more supports and programs that are flexible” and “don’t take services away when child is stable”, suggested that practical supports need to be provided and maintained into adulthood. Responses such as “funding for FASD” and “respite” also indicated that these practical supports must be sustained through financial support both for caregivers and for individuals with FASD. Caregivers also indicated a need for wide-ranging recognition and understanding of FASD through responses such as “public awareness” and “legal systems with flexibility and understanding about FASD”. This concept had the second lowest bridging index of 0.15, indicating that the responses within it were frequently sorted together.

Caregiver support. The responses in this concept reflected the needs that caregivers required themselves to help young adults with FASD live as independently as possible. The response “financial help” had a bridging index of 0.00, which made it central to this concept. The response “financial plan” was parallel to this response, as both responses indicated the need for financial assistance to help support the long-term needs in the lives of those affected. Caregivers also suggested that an adult with FASD would need awareness and availability of long-term supports, as reflected in the responses “find out what adult supports are out there” and “know what programs are out there”. These responses had bridging indices of 0.06 and 0.07, indicating that they were frequently sorted with other responses specific to this concept. The responses “energy” and “avoid burnout” emphasized the emotional overload and mental exhaustion that caregivers feel when caring for an individual with FASD. This concept had the lowest bridging index (0.07), which indicated that responses within it were sorted only with other responses in the same concept.

Ideals. The theme of this concept reflected the ideals that caregivers uphold to help maintain autonomy for the alcohol-affected individual. The response “hope” had a bridging index of 0.10, demonstrating that this response was central to the concept. It is also essential to assist the affected individual in an encouraging way, as reflected by the responses “know the person’s challenges”, “teach life skills” and “patience”. These responses had bridging indices of 0.16, 0.20, and 0.23, indicating that they were frequently sorted with responses in this same concept. Caregivers also implied the importance of operating in a strengths-based way with an individual who has FASD, as evidenced by the responses “realistic expectations”, “trust they can do it” and “not getting over stressed”. These responses had bridging indices of 0.25, 0.26, and 0.36 respectively, indicating they were occasionally sorted with responses in other concepts. Other notions that coincided with important ideals for the caregiver were “understanding” and “having people who understand them”. The responses within this concept were often sorted with each other, as evidenced by the bridging index of 0.25.

Address long-term development concerns. The developmental concerns associated with FASD were reflected in the responses “know what needs are in those stages of life”, “open minded to differences” and “have him assessed every 3-4 years”. These responses indicated the dissimilarities in the way individuals with FASD develop, and that they must be evaluated with an approach that is ongoing. These responses were central to this concept with moderate bridging indices of 0.45, 0.50, and 0.52 respectively. Parents also reflected that having “security” was important, which was another enduring need both for caregivers and for the person living with a disability. The response “I am still going to be dealing with problems like I have small children” indicated the pressure that is placed on the home when living with someone who has both primary and secondary disabilities. The final response “remember that kids will not be with us

forever” provided insight that caregivers will not always be around, and that this permanent disability needs long-term assistance into adulthood. This response had a bridging index of 1.00, meaning that it was often grouped with responses in other concepts. This concept had the highest bridging index at 0.62, which meant that responses within it were often sorted with responses in other concepts.

Incorporation into daily living. This concept represented the significance of integrating reassuring activities into daily life. Responses such as “start planning from early on” and “positive activities” reflect the importance of such livelihood. These responses had moderately low bridging indices of 0.23 and 0.31. The response “take them places” coincides with the main premise of incorporating activities that encourage a supportive environment for an individual with FASD. As she or he approaches adulthood, caregivers noted that it would be important to “start things young so it’s not a shock when an adult”. This response had a moderate bridging index of 0.39 and highlighted that FASD is an ongoing struggle, which will undoubtedly follow the individual into adulthood. Consequently, it would be important to include activities from early on.

The response “help him process it and learn from it” also parallels the responses sorted within this concept by indicating the significance of allowing the individual with FASD to understand the impact of this disability on their own life both in everyday life, and on a long-term scale. The bridging value for this concept was at 0.33, which indicated that that while responses within it were often sorted with one another and occasionally with responses in other concepts.

Service Needs

A total of 43 unique responses were received to the question “What services would help young adults live as independently as possible?” Fifteen participants sorted the responses. The sort data was analyzed and a stress value was calculated. Validity is signified through a stress value. This value was used to determine validity of the map. The stress value of this map was 0.29. Values of maps below 0.35 are considered valid representations of the sort data (Trochim, 1989).

According to Trochim (1989) the most appropriate number of concepts for a map with less than 100 responses would be between 20 and 3. A map with ten concepts was highly fragmented. Maps with nine, eight and seven concepts did not appreciably reduce this fragmentation. A reduction to four and five concept maps was also considered, but these maps merged responses that were conceptually different. The six-concept map was selected as the most appropriate map for this question (see Figure 2).

Responses and bridging indices are presented in Table 1. Individual bridging indices were used to identify central responses for each concept to inform the construction of a label for each. Responses with the lowest bridging index were most central to the content of that concept. Responses with a low bridging index (i.e. between 0.00 and 0.25) were consistently sorted with other responses in the same concept. Responses with a high bridging index (i.e. between 0.75 and 1.00) were also frequently sorted with responses in other concepts. High bridging indices were less central to the content of a concept (Trochim, 1989). An average bridging index was also calculated for each concept. A lower average bridging index reflected greater cohesion of responses within the concept.

Figure 2. Concept Map: What services would help young adults live as independently as possible?

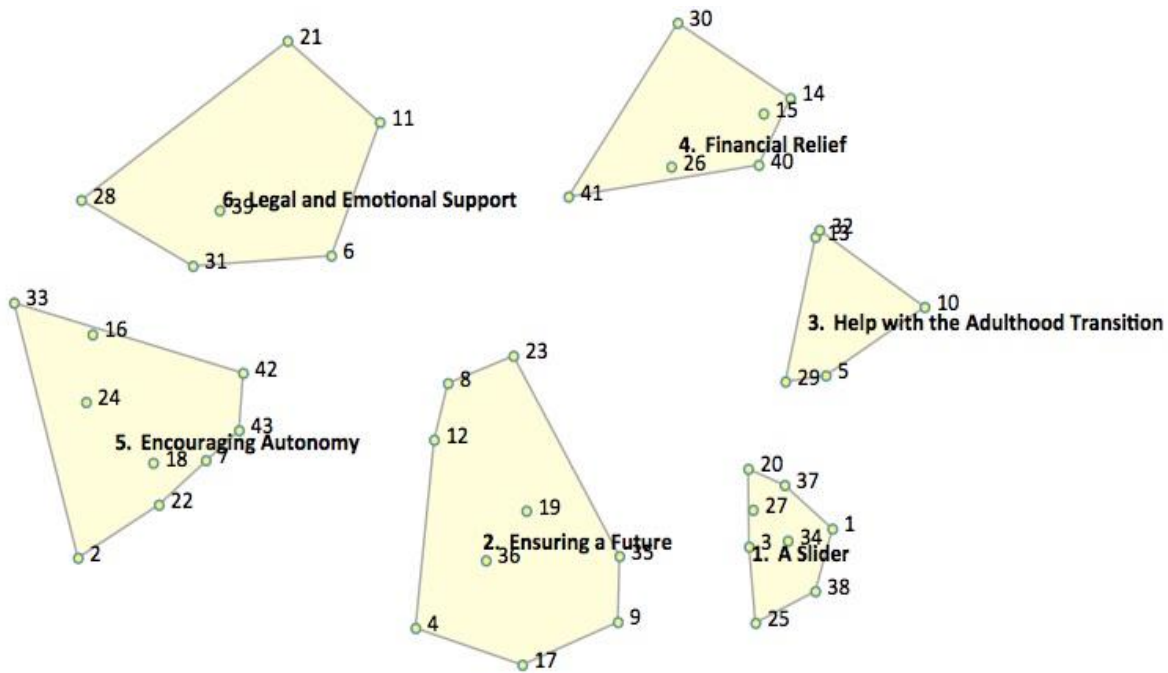


Table 2

Responses and Bridging Values for Concept Map for Question Two: Young Adult Needs

Concept and Response	Bridging Index
A Slider	0.12
3. a lot of supervision	0.02
34. someone needs to take over parent's role	0.05
27. one-to-one worker	0.07
37. someone to help them live day to day	0.07
20. home with supports	0.09
1. 24/7 support	0.16
38. someone with them all the time who knows FASD	0.22
25. need someone all the time	0.28
Ensuring a Future	0.19
8. budgeting	0.01
19. help with daily errands	0.03
35. someone checks in on him consistently	0.06
12. day programming	
17. group home	

23. living skills	0.08
12. day programming	0.20
36. someone to call	0.20
9. co-op living unit	0.24
17. group home	0.42
4. a person to monitor for medical help	0.44
Help with the Adulthood Transition	0.39
29. plan around transitions	0.30
32. services that start at 18 instead of stop	0.31
13. developing services to meet our needs	0.34
5. a trustee	0.41
10. consistent, long term case manager	0.60
Financial Relief	0.38
15. disability services	0.31
26. ODSP	0.34
41. transition from one system to the next	0.37
40. training for caregivers	0.39
14. disability allowance on income tax	0.39
30. RRSP for disability retirement	0.49
Encouraging Autonomy	0.36
43. understand grocery shopping	0.00
42. tricks to stay away from bad things	0.08
7. banking	0.12
18. how to handle systems	0.24
24. navigate and find jobs	0.34
22. life skills coach for parents and children	0.43
16. employment coaching	0.45
2. a dog, his companion	0.78
33. social support group	0.81
Legal and Emotional Support	0.68
6. anger management	0.27
31. safe space to talk about problems	0.55
39. therapy	0.57
11. correctional services for FASD	0.77
28. organization for sports and recreation for FASD	0.90
21. legal services	1.00

A slider. This concept reflected the need to have a person working with an individual affected by FASD on a one-on-one basis to help through difficult situations. The response “24/7 support” and “home with supports” reflected the necessity of on-going supervision for an

individual with FASD to help with a number of cognitive, developmental and behavioral challenges that are associated with their disabilities. The responses “a lot of supervision” and “someone needs to take over parent’s role” specifically addressed the fear parents expressed about taking care of their children long-term. These responses had low bridging indices of 0.02 and 0.05 respectively, indicating that they were central to this concept. The response “need someone all the time” also expressed the concerns that the FASD disabilities are permanent that the alcohol-affected individual would need consistent support.

The responses “one-to-one worker” and “someone to help them live day to day” both had bridging indices of 0.07, indicating they were consistently grouped with other responses in this concept. These responses expressed the idea of a slider; wherein a worker who helps with the FASD-affected assists with day-to-day issues, but is sensitive enough to know when to slide in and out of each situation as they occur. The response “someone with them all the time who knows FASD” also reflects the theme of a slider, by indicating that this support should be someone who knowledgeable about FASD and could slide in to help out in everyday situations as they arise. This response held a bridging index of 0.22 indicating that it was frequently sorted with other responses in this concept. This concept had the lowest bridging index of 0.12 indicating that the responses were consistently sorted with other responses in this concept.

Encouraging a future. This concept identified the areas where ongoing support was needed. The responses “budgeting” and “help with daily errands” had low bridging indices (0.01 and 0.03, respectively), which indicated that they were central to this concept. These responses evidenced the continual help that individuals with FASD would require with their everyday routine, even after their caregivers were gone. Similarly, the response “living skills” expressed the concern parents had for future capabilities when caring for an individual with a permanent

disability. This response had a low bridging index of 0.08 indicating it was frequently sorted with other responses in this concept. The responses such as “someone checks in on him consistently” and “someone to call” reflected the needs of having a guardian to help an individual with FASD with persisting problems. These responses also had low bridging indices of 0.06 and 0.20 respectively, indicating they were consistently sorted with responses in this concept. Similarly, the response “a person to monitor for medical help” highlighted the enduring demand of a constant support to help meet unique needs. The bridging index for this response was 0.44, which indicated that while it was sorted both with responses in this concept and occasionally with responses in other concepts as well.

The responses “co-op living unit” and “group home” indicated the need for long-lasting living arrangements and expressed the idea of safeguarding a stable future. Finally, the response “day programming” indicated the need for activities to encourage positive adjustment both in the community as well as in their personal lives over the long-term. This response had a bridging index of 0.20 indicating that it was frequently sorted with other responses in this concept and not often with responses in other concepts. The main ideas in this concept highlighted the types of constant support that were needed through routine tasks, one-on-one support and living arrangements. The overall bridging index of this concept was the second lowest (0.19), indicating responses were rarely grouped together with responses in other concepts.

Help with the adulthood transition. Another way caregivers believed young adults could live as independently as possible with an FASD was through long-term assistance to help with the longevity of their disability. Most central to this concept was the response “plan around transitions” which illustrated that caregivers of a person with FASD needed help with smoother transitions between childhood and adulthood. This response had a bridging index of 0.30

indicating that it was occasionally sorted with other responses in other concepts. Responses such as “services that start at 18 instead of stop” and “developing services to meet our needs” reflected the heightened need of services that grow and change as individuals and their situations develop over time. These responses shared moderate bridging indices of 0.31 and 0.34.

The response “a trustee” expressed parents’ concerns about helping an individual with FASD with lifelong assistance by providing a guardian that would be reliable and trustworthy. Similarly, the response “consistent, long-term case manager” reflected that due to the permanence of associated disabilities, affected individuals would need a trustee who could help them transition into adulthood. These responses had bridging values of 0.41 and 0.60 respectively, indicating that they were sorted with responses in other concepts as well. A bridging index of 0.39 was found for this concept. This value indicated that participants occasionally sorted responses within this concept with responses in other concepts.

Financial relief. Material support through finances was reflected in this concept as necessary for assisting a young adult with FASD to live as independently as possible. Responses such as “disability services” and “ODSP” reflected the need for financial assistance to help with essential living expenses both through income support and benefits. These responses had bridging indices of 0.31 and 0.34 respectively, indicating that they were occasionally sorted with responses in other concepts. The response “disability allowance on income tax” paralleled the need to gain access to material resources. Similarly, the response “RRSP for disability retirement” indicated that long-term financial assistance would be a concern. This response had a moderate bridging index (0.49) indicating that it was sorted with responses in other concepts as well as this one. Combined, these responses reflect the need for FASD to be considered a permanent disability in which government support and financial assistance is warranted.

Other services seen as important included “training for caregivers” and help to “transition from one system to the next”. These responses indicated that the disability could become demanding on the caregiver, making training and help with navigating systems essential supports. These responses had moderately high bridging indices of 0.39 and 0.37 respectively, indicating that while they reflected the theme of this concept, they were occasionally sorted by participants with responses in other concepts. This concept had a bridging index of 0.38 indicating that responses were occasionally sorted with responses in other concepts.

Encouraging autonomy. Fulfilling meaningful life choices through self-management was a theme throughout this concept. The response “understand grocery shopping” was most central to this concept. This response had a bridging index of 0, indicating that it was only sorted with other responses in this concept. The response “banking” was also central to this concept, which had a low bridging index of 0.12. These responses reflected that engaging in activities which promoted livelihood were seen as necessary supports to promote autonomy. The response “tricks to stay away from bad things” had a low bridging index of 0.08, also indicating that this response was frequently sorted with other responses in this concept. This response indicated that being able to recognize social cues could help the young adult prevent negative implications. Similarly, the response “how to handle systems” represented the need to learn how to navigate services, systems and policies that are part of the larger community is difficult but important.

The response “life skills coach for parents” also represented the need for self-determination. Responses such as “navigate and find jobs” as well as “employment coaching” indicated the need for vocational services to gain work opportunities. These responses had bridging indices of 0.34 and 0.45 respectively. The need for independence was also salient through the idea of social participation. Responses such as the need for “a dog, his companion”

and “social support group” indicated that building social engagement through meaningful relationships could encourage autonomy. These responses had bridging indices of 0.78 and 0.81, indicating that they were frequently sorted with responses in other concepts. The bridging value for this concept was 0.36, which indicated that responses were occasionally sorted with responses in other concepts.

Legal and emotional support. This concept addressed the concerns caregivers shared when considering issues of legality and emotion-regulation. Responses such as “anger management,” “safe space to talk”, and “therapy” represented the need for expressing emotionality through safe outlets. These responses had bridging indices between 0.27 and 0.57, indicating that they were occasionally and often grouped with responses in other concepts. Similarly, the response “organization for sports and recreation for FASD” further exemplified the need for children to express emotionality through an interactive and physical activity. This response had a bridging index of 0.9 indicating that it was often sorted with responses in other concepts.

The response “correctional services for FASD” reflected the supports required when their deficits would lead to trouble with the law. The response “legal services” coincided with the necessity of supports through the criminal justice system. These responses had high bridging indices of 0.77 and 1.00 respectively, indicating that they were frequently sorted with responses in other concepts as well. The highest bridging index (0.68) was found for this concept, indicating that some responses within it were often sorted with responses in other concepts.

Results Summary

Sixteen caregivers to alcohol-affected youth provided 51 unique responses to the question: “What do caregivers need to help young adults live as independently as possible?” The

sort data was analyzed using multidimensional scaling and cluster analysis. The six concept solution included the following: 1) Structural Supports, 2) Practical Supports, 3) Caregiver Support, 4) Ideals, 5) Address Long-Term Development Concerns, and 6) Incorporation into Daily Living. Structural Supports focused on helping the adult with FASD integrate within her or his community and included the examples of “support group” and “community understanding”. Practical Supports reflected the need for different modes of social support to assist with everyday living, as evidenced by responses “support from doctors”, “respite” and “consistent services”. Caregiver Support reflected the needs that parents shared for themselves, evidenced by the responses “financial help”, “find out what adult supports are out there” and “avoid burnout”. Another need caregivers expressed was Ideals, exemplified by the responses “hope”, “patience” and “realistic expectations”. Responses in Address Long-Term Development Concerns such as “know what needs are in those stages of life” and “have him assessed every 3-4 years” represented the ongoing developmental challenges that caregivers focus on. Finally, responses in Incorporation into Daily Living such as “start planning from early on” and “positive activities” highlighted the importance of normalizing and incorporating the permanent disabilities associated with FASD into everyday life.

There were sixteen caregivers who provided 43 unique responses to the second question: “What services would help young adults live as independently as possible?” The responses were categorized into six concepts including: 1) A Slider, 2) Ensuring a Future, 3) Help with the Adulthood Transition, 4) Financial Relief, 5) Encouraging Autonomy, and 6) Legal and Emotional Support. The responses “someone needs to take over parent’s role” and “someone with them all the time who knows FASD” exemplified the idea of having a long-term support worker to help individuals with FASD through everyday living assistance and troublesome

situations as they arose. Ensuring a Future included “budgeting” and “co-op living unit” reflecting security concerns associated with long-term needs. Examples of responses in Help with the Adulthood Transition included “plan around transitions” and “services that start at 18 instead of stop” which reflected concerns associated with the shift into adulthood. Financial Relief reflected the importance of economic and material support such as “disability services”, “ODSP” and “RRSP for disability retirement”. Encouraging Autonomy was evidenced by responses such as “understand grocery shopping”, “tricks to stay away from bad things” and “banking”, reflecting the importance of fostering independence. Finally, Legal and Emotional Support highlighted the importance of legal and emotional support as evident through the responses “anger management”, “therapy” and “correctional service for FASD”.

In the following Chapter, the results are compared and contrasted with the literature reviewed in Chapter Two.

Chapter 5: Discussion

The purpose of the study was to explore caregivers' perceptions of their own needs and the service needs for their children with FASD as adults. Participants answered two questions via telephone interview including: "What do caregivers need to help young adults live as independently as possible?" and "What services would help young adults live as independently as possible?" Sixteen caregivers with youth aged 10 years or older participated in the interview and sorted responses into groups. The sort data was analyzed through multidimensional scaling and cluster analysis using Concept System Global MAX software (2015). In this Chapter results are compared and contrasted with the literature.

Caregiver Needs

The question "What do caregivers need to help young adults live as independently as possible?" resulted in a map with six concepts. The concepts included: 1) Structural Supports, 2) Practical Supports, 3) Caregiver Support, 4) Ideals, 5) Address Long-Term Development Concerns, and 6) Incorporation into Daily Living. There were both similarities and differences between the existing literature and responses provided by participants.

Structural supports. Participants identified the need for social and community supports for the affected individual to adjust to the social realities of the broader community. Caregivers in the present study identified the need for support groups and community understanding. These needs have been discussed in prior research. Adults with FASD have required support through groups and programming to promote their own involvement in their communities (Clark et al., 2008; Hubberstey, Rutman, Hume, Van Bibber, & Poole, 2015). Caregivers in the present study also expressed the need for assistance through education and a helpful advisor. Duquette and Stodel (2005) similarly found that elements of a successful school experience for an alcohol-

affected person included caring teachers that worked alongside supportive programs and services.

Different from the literature was the need for colleges to offer programs geared toward individuals with learning disabilities. While some college-based programming for students with autism spectrum disorders (ASD) have become an option (Zager & Alpern, 2010), the literature has not explored the possibility of education services for adult students with FASD. Duquette (2013) found that the symptoms associated with FASD such as deficit in memory, difficulty with independent work, and the need for slower paced instruction, affected academic integration in college-level programs. It has also been noted that IQ for individuals with FASD may be high enough for college level study (Sanders & Buck, 2010), but that the cognitive profile, behavioral and adaptive challenges pose barriers (Jirikowic et al., 2008). These challenges may be addressed through education specific to their needs. Indeed, many post-secondary institutions have worked to meet the transitional and support needs of students with learning disabilities via modified evaluation and academic instruction based on their learning processes (Dalke & Schmitt, 1987; Morningstar, Lombardi, Fowler, & Test, 2015).

Caregivers also expressed the need for group homes and assisted living when preparing for the future of their children. These responses were not reflected in the literature. While it has been noted in the childhood literature, in relation to need for placement stability in foster care (Brown et al., 2007) and the need for transition planning for youth with FASD aging out of care (Burnside & Fuchs, 2013), there was no attention to the needs of young adults who were not in care nor to the housing needs specifically.

Practical supports. Responses in this concept reflected the practical support needs of young adults with FASD. Responses were consistent with the literature. Participants identified

the need for training. Training for professionals and service providers has been identified, such as the need to train public school educators about FASD (Koren, Sadowski, & Scolnik, 2013). Participants also identified the need for consistent services and effective interventions, which has been reported in the literature (Bertrand et al., 2009; Senturias, 2014; Wheeler et al., 2013). Interventions cited in the literature range from specialized aids (Coled et al., 2007), to social skills (Laugeson et al., 2007; Timler et al., 2005) as well as cognitive-based treatment (Loomes et al., 2008; Rutman & Van Bibber, 2010). However, unique to this study was the contention that services be continued, even after stability is achieved.

Participants in the study also identified the need for one-to-one support workers and increased support from primary care physicians. Support practitioners trained in FASD to be working with families were also indicated (Scott & Dewane, 2007). Brown and Bednar (2003) noted that access to health professionals would be essential for success into adolescence. Following a diagnosis, there was still a need to shadow families over the long haul to help them manage challenges (Olson & Montague, 2011).

Participants in this study highlighted the need for respite care. Support through respite has been reported in the literature to reduce stress, increase coping, reduce social isolation and increase family stability (Doig et al., 2009; Joyce, 1983; Rimmerman et al., 1989; Wikler et al., 1986; Whyte, 2010). The literature has also referenced challenges for families trying to access these supports (Petrenko et al., 2014).

Caregiver support. This concept related to needs that caregivers themselves had to help them raise children with FASD. Participants indicated that financial help to ease the caregiving burden would be beneficial. The financial challenge associated with FASD was consistent with previous research (Caley et al., 2009). Stade et al. (2008) demonstrated that due to the annual

costs associated with FASD per child, caregivers were expected to carry a long-term economic burden. The lack of financial assistance when caring for an FASD was also recognized as a reason to end a foster placement (Brown et al., 2007). Participants in the present study also identified their own energy levels as essential to maintain to be good caregivers. This was clearly referenced in the literature in the research linking caregiving and FASD to parenting stress and burnout (Olson et al., 2009; Rowbottom et al., 2010).

Caregivers in other studies have identified the importance of daily extra-familial support for those living with FASD throughout childhood (Rutman & Van Bibber, 2010; Sanders & Buck, 2010). In addition, caregivers noted the need for their own and others' advocacy for youth with FASD through education, parental support, and political action (DeVries & Waller, 1997). Participants indicated their own increase in knowledge about programs and supports were available for adults with FASD. There has not been attention in the research literature to particular resources that adults with FASD could access. This was a difference between participants in the present study and the existing research.

Ideals. In this concept, caregivers identified a perspective about their children that was important to their sense of tolerance for an unpredictable future. Hope was central to the participants in the present study. In contrast, Watson et al. (2013) noted that families with children who had FASD actually lacked hope for their child's futures because of the anticipated difficulty with employment, education, and interpersonal connections.

Participants also described principles consistent with a strength-based approach. For example, participants' understanding of individual challenges with trust and patience were viewed as important approaches to take. Similarly, Brown (2004) also found that a strengths-based approach was a helpful framework. Caregivers also reflected that realistic expectations

were necessary to guide their efforts for supporting as much independence as possible. Such modifications in expectations and possibilities have been identified by caregivers in other studies (Clifford, 2013).

Interestingly, teaching life skills was described as important for participants in order to prepare and assist their child. This was not expressed in the existing literature. Moreover, participants indicated that not getting ‘stressed out’ was important for promoting independence. Conversely, the evidence of poor adaptive functioning, behavioral problems, and few family resources were noted as major sources of stress for parents of alcohol-affected individuals (Paley et al., 2006). The different perspective evident by participants illustrated a contrast in both outlook and stress management.

Address long-term development concerns. This concept reflected concerns about adaptive functioning for the child into adolescence and adulthood. Nash et al. (2006) indicated that in many cases of FASD, facial features and maternal history were absent, making diagnosis challenging. It was also noted that since FASD was comorbid with many other disorders, there was an increased likelihood that children would be improperly diagnosed and receive the wrong treatment (Greenbaum, Stevens, Nash, Koren, & Rovet, 2009; Nash et al., 2006). Caregivers in this study expressed similar needs for accurate and thorough assessment. However, a challenge reported by participants that was not evident in the literature was the frequent need for assessment, specifically every 3 to 4 years. Assessments, to be useful, would need to be completed at different stages of development to appreciate how needs and strengths would shift.

Kalberg and Buckley (2007) suggested that intervention methods such as building external supports into the learning environment were helpful for children with FASD. Additional challenges evidenced in the research included the range of their functional capacity, the age at

which they entered out-of-home placement, if applicable, as well as effects of traumatic experiences (Koponen, Kalland, & Auti-Ramo, 2009). Participants did not report these challenges, focusing instead on the need for open-mindedness and recognition that additional challenges were introduced when there was more than one child in the home.

The need to understand requirements and strengths at different stages of development was noted by participants in the study but not indicated in the literature. Participants identified the importance for security needs of their children to be addressed through long-term care, as they recognized that they would not always be able to provide such a high level of support. In a study by Keiver, Bertram, Orr, and Clarren (2015), it was reported that the long-term effects of prenatal-alcohol exposure on the hypothalamic-pituitary-adrenal (HPA) system could increase vulnerability of mental health issues and diseases in later life. While this recognition of developmental changes is important, there has been little attention to the relationship between developmental changes and adaptive needs for youth with FASD as they age into adulthood. The research was silent on supports, services, and programming that should be available over the long-term to help young alcohol-affected adults.

Incorporation into daily living. Responses in this concept reflected the importance of integrating FASD-related challenges and capacities into needed supports for daily life. Research has highlighted that planning for individuals with FASD should include social aspects, healthcare, education, and vocational needs (Breen & Burns, 2012). Caregivers also identified the need for planning in their children's lives to begin early in their development. Participants expanded on this by indicating that they had to start planning at a very early point in order to prepare for transitions for themselves as well as their child, later in life. These specific ideas of early planning are nuanced considerations for individuals with FASD from participants who

noted that early attention helped both themselves, and their children prepare for eventual transitions.

Brown et al. (2005) found that the knowledge and skills associated with disabilities associated with FASD were important for foster parents to provide to their children. Caregivers in the present study also noted the importance of helping their children process and learn from their own challenges. In addition, participants noted that positive activities also provided learning opportunities. Jirikowic et al. (2008) also noted that children with FASD, if provided with guidance and support, engaged in and enjoyed social activities. Participants noted that taking their children places was helpful to normalize their lives and help the children see that they had a rightful place in their communities. Hubberstey et al. (2015) described activities including family outings, cultural, and land-based activities.

Service Needs

The question “What services would help young adults live as independently as possible?” resulted in a map with six concepts. The concepts included: 1) A Slider, 2) Ensuring a Future, 3) Help with the Adulthood Transition, 4) Financial Relief, 5) Encouraging Autonomy, and 6) Legal and Emotional Support. There were both similarities and differences between the existing literature and responses provided by participants.

A slider. Responses in this concept described the long-term support and supervision needs of youth with FASD throughout adulthood. Dr. Sterling Clarren developed the idea of the ‘external brain’, which necessitated long-term support to assist with emotion regulation or behavioral control by knowledgeable others in the person’s environment (as cited in Boulding & Brooks, 2010; Green, 2007a). The focus is not on changing the person with FASD, but rather, changing the approach by shifting the environment, providing ongoing supervision, and

promoting self-monitoring (Green, 2007a).

Findings from the present study expanded on the notion of an ‘external-brain’, and posed additional suggestions for what it could be. For example, participants stated that their youth would require wide-ranging supervision including support that was twenty-four hours a day, seven days a week. The permanent deficits associated with FASD require support that is not only constant but also consistent. Caregivers reflected on these needs by affirming that their children would need someone at all times who had knowledge on FASD.

Caregivers carry the heavy burden until they are no longer able to do so. Participants stated that they needed someone who would take over their role. Such a person would ideally be a one-to-one worker able to help with day-to-day activities. The ideas shared by participants converge on the notion of “a slider,” who could slide in and out of the situation as needed. This person could be a support worker trained and experienced with FASD constantly accompanying that person. “A slider” is someone willing to promote independence, but also acting as a support by sliding into potential conflicts as they arise, and sliding out of these situations once they have been handled. This suggestion and term is unique to the present study.

Ensuring a future. Responses in this concept centered on personal needs of a youth with FASD into adulthood. Caregivers reflected on specific supports as well as necessary arrangements. Long-term case management for adults with FASD would require a multidisciplinary team of professionals who could treat both mental health and developmental disabilities (Burd, Klug, Martsof, & Kerbeshian, 2003). Atchison (2007) noted that a referral to appropriate professionals would be essential to providing needed support for an adult with FASD. Participants in the present study expanded on the need for professionals, stating their children would require monitoring for day-to-day as well as specialized resources as needed.

They also noted that adults would need someone to call on as needed and someone to check on them regularly and often.

Ryan et al. (2006) suggested that the systems of care in place for living arrangements did not extend to the permanent brain damage associated with FASD. Participants in the present study reported that a group home or co-op living unit would be a beneficial living arrangement for youth living with FASD. It has also been noted that the increasing number of children who live with FASD will end up transitioning out of care and end-up in their communities (Fuchs, Burnside, Marchenski, & Mudry, 2010). Participants identified day programming as an important component to maximum independence. This was a nuanced response, providing additional detail to what is already documented in the literature about how to incorporate daily planning and activities in the lives of adults who have FASD.

Alcohol-affected children experience deficits in life skills (Whaley et al., 2001). In a study by Gardner (2000), foster parents noted that any change in daily routine resulted in difficulty, and that because of this they feared the future of their children. The present study parallels these responses, indicating that living skills were a pivotal concern by participants about the future of their youth. Specifically, caregivers in this study reported that help with budgeting and daily errands were central to promoting the independence within their children who lived with FASD. These considerations offer additional detail about the day-to-day concerns that will inevitably impact a young adult with FASD.

Help with the adulthood transition. This concept included responses concerning service needs as well as professional support required to help youth with FASD transition into adulthood. The need for smoother transitions between children's services and adult services for individuals with FASD has been identified in the literature (Burnside & Fuchs, 2013; Michaud &

Temple, 2013). In addition to service needs, developmental changes accompany this transition as well (Petrenko et al., 2014a). Participants in the present study similarly reflected on the need for planning to support transitions for youth with FASD.

Caregivers of children with FASD worry about them becoming adults who no longer qualify for support services (Michaud & Temple, 2013). Participants in the present study identified the need for services that start at age 18 instead of end at that age. This particular suggestion for long-term services was not been referenced in other research. Participants also noted that it was important to develop services to meet the caregiver's needs. This was also not identified in the existing research, which tended to focus instead on caregivers' needs when they had young children with FASD and not when those children became adults.

Caseworkers have been found to be helpful to individuals with FASD (Denys et al., 2011). Increased contact with families affected by FASD helped caseworkers to understand the children better which facilitated more supportive relationships (Pelech et al., 2013). Participants in the present study reported a consistent need for a caseworker, but extended the timeframe into adulthood. In addition, participants identified the need for a trustee who had legal status in the adult's life.

Financial relief. This concept focused on the need for financial support. The need for income support to caregivers has been reported in the literature (Brown, 2004; Ivanova & Brown, 2010; McKee, 1997), however, less attention has been paid to the need for income support for the individual with FASD in adulthood. Many adults with FASD who have an IQ above the cutoff for funding due to developmental disability are not eligible for income support, despite the permanence of their impairments (Chudley et al., 2007; Sanders & Buck, 2010). Caregivers in the present study indicated that disability services, which in this province is the

Ontario Disability Support Program (ODSP), would be helpful to support young adults with FASD to live as independently as possible. Participants added that a disability allowance for income tax purposes, as well as an RRSP for disability retirement, were necessary to provide financial support for their children into adulthood and old age.

Encouraging autonomy. Responses in this concept centered on the importance of supporting independence as much as was viable and appropriate for the individual affected by FASD. Unsupported transitions into adulthood leaves individuals entitled to, and presumed to be responsible for, the management of their own financial affairs (Temple, Ives, & Lindsay, 2015). In the present study participants noted that assistance in the area of banking was of great importance. Related to this was the need for supported daily life skills such as grocery shopping as a way to promote independence. These responses had not been reported in the literature.

Caregivers also noted that a dog could be a helpful companion in the promotion of independence. Although this particular response was frequently sorted with other concepts as indicated by its high bridging index, this specific recommendation was not associated with needs for independence by adults. There are several references to the use of service dogs in the literature on children with FASD. For example, a case study by Fry-Johnson, Powell, and Winokur (2009) found that the introduction of a service dog was helpful to a child with FASD, and Allen and Blascovich (1996) found that participants in their study who received assistance from service dogs showed significant improvement in self-esteem, internal locus of control and social interaction. In addition, studies have found that individuals with impairments who had service dogs experienced more freedom and less loneliness (Valentine, Kiddoo, & LaFleur, 1993), as well as positive impact on their day-to-day living (Rintala, Matamoros, & Seitz, 2008).

Difficulties associated with vocational support have been reported both by participants in

the present and the literature. Families affected by FASD worry about the lack of community support for vocational assistance (Watson et al., 201). Streissguth et al. (1996) also found that problems with employment impacted 80% of the adults with FASD. Caregivers in the present study noted that employment coaching and vocational support would be necessary to help young adults with FASD live as independently as possible.

Legal and emotional support. The responses in this concept centered on legal and therapeutic support for adults with FASD. Specifically, participants in the present study highlighted the need for anger management support. There is a considerable base of literature about emotional regulation difficulties among children and youth with FASD reflected in the areas of anger, aggression and impulse-control which also contribute to social and behavioral difficulties (Miller, 2006). Interventions directed to recognition of environmental cues to assist awareness and regulation or adaptive behavioral responses have been noted in the research as crucial conduct strategies for young adults with FASD (Burd, Selfridge, Klug, & Juelson, 2003).

Famy, Streissguth, Unis (1998) found, in one of the few studies concerning adults with FASD, that they were at high risk to struggle with mental health challenges such as depression, psychotic disorders, alcohol and drug dependence. Lemoine et al. (2003) also reported mental health problems and Pei, Denys, Hughes and Rasmussen (2011) found high rates of internalizing and externalizing disorders among children. Participants in the present study alluded to these issues by indicating that counselling, including a safe space to talk about problems, were essential supports.

Other services that caregivers reported as useful to help young adults live as independently as possible included correctional and legal supports. There is a considerable literature base on the deficits associated with FASD in relation to an increase risk of criminal

behavior (Brown et al., 2015; Fast & Conry, 2009; Streissguth et al., 1996). McLachlan, Roesch, Viljoen, and Douglas (2014) reported that 90% of the individuals within their study who had FASD experienced impairment with at least one psycho-legal ability, such as knowing their rights or understanding criminal proceedings. Participants in the present study and in other research have recognized the importance of specialized services or need for high sensitivity among professionals involved to the issues associated with FASD.

Discussion Summary

In response to the question “What do caregivers need to help young adults live as independently as possible?” a map with six concepts was constructed. The concepts included: 1) Structural Supports, 2) Practical Supports, 3) Caregiver Support, 4) Ideals, 5) Address Long-Term Development Concerns and 6) Incorporation into Daily Living. Experiences of participants overlapped considerably with findings in existing research. For example, researchers have noted that interpersonal support, educational concerns, and living arrangements are important areas of concern. The need for professionals, trained services and respite were also consistent between participants in the present study and in the literature. Caregivers referenced in existing studies as well as the present study have highlighted concerns about their own energy levels for raising a child with FASD and the need for daily support. Attitudes such as understanding, trust, hope and patience were recommended by caregivers in the present study and reflected a strengths-based perspective. Participants in the present study, and existing research, identified the need for assessments. Finally, daily living needs were indicated in the literature and as well as by caregivers in the present study, by encouraging the use of positive activities.

There were also some differences. Participants in the present study identified considerations that had not been reported in the literature. For example, in the concept that

discussed structural supports, caregivers wanted to access college programs directed toward individuals with learning disabilities. Prior research has not examined how to tailor post-secondary programs specifically for individuals with FASD. The idea of service needs has been thoroughly cited, however the notion of ongoing services that continue even after the child is stable is specific to this study. Participants also queried the existing services available for adults. Surprisingly, there is a wide gap in the literature when considering adult services for FASD other than the criminal justice system. Participants also suggested that assessments should be recurrent and be performed at different developmental stages because the permanent effects of FASD will require supports but the nature of those supports may change. Finally, participants suggested that planning and preparation should begin early in their lives and the lives of their children with FASD.

An area that was highlighted in the literature but not by participants in this study concerned systems of care for individuals with FASD. Although participants noted that transitioning in and out of systems would occur in late adolescence and early adulthood, there was no mention of how their children would transition between caregivers. It has been identified that the difficulties in physical, behavioral and social domains often evidenced among children with FASD in care, may make it difficult to place them (Jones, 2004). Brown et al. (2007) cited that foster care breakdown could occur if the child had serious behavior problems or caused harm to another person in the home. Research has also provided evidence in support of the major benefits of stable foster homes for consistent school and community life that led to better opportunities for them as adults (Burnett & Allen-Meares, 2000).

In response to the question “What services would help young adults live as independently as possible?” a map with six concepts was constructed. The concepts included: 1) A Slider, 2)

Ensuring a Future, 3) Help with the Adulthood Transition, 4) Financial Relief, 5) Encouraging Autonomy and 6) Legal and Emotional Support. There was a great deal of similarity between the concepts identified by participants and the literature. Participants in the present study noted that helping professionals were necessary supports, expanding on this idea by identifying the importance of a case manager. Participants and the literature referenced the need for planning for transitions. Participants as well as the literature on children with FASD highlighted the use of a service dog. The requirement for employment and vocational services was also apparent in the literature and in responses by participants in the present study. Participants identified the need for financial support through ODSP, which was consistent with the need for financial support indicated by other studies. Finally, participants in the present study and in other research have represented the needs for therapy and legal services.

The major difference between the participants and existing literature concerned the need for supervision. Participants considered the need for constant supervision and a one-to-one worker to support their life skills and daily interactions. While the ideas of consistency and long-term support were similar to the notion of an ‘external brain’ for children the adult version of this idea, represented by the experiences of participants in the present study was of “a slider” who could enter and exit situations as they arose and facilitate when needed to promote both autonomy with necessary assistance.

Other differences, largely based on the relative lack of research concerning adults with FASD, were apparent in the need for services to be life-long, provided by individuals knowledgeable about FASD and starting at the age of 18 years. These ideas represent the need identified by caregivers in the present study for services that are continuing and responsive. The need for help with day-to-day living has been identified. However, caregivers in the present

study identified particular tasks such as grocery shopping and banking as well as day programming.

Implications

The findings of the present study supplement existing research on caregiver needs and service needs to assist young adults with FASD with living as independently as possible. While some of the participants' experiences have been reflected on in the literature, responses in the present study offer some new considerations and detail that may be useful.

Areas of consistency between the literature and participants' experiences in this study indicate that there are continuous needs for caregivers and their youth with FASD. The literature has focused extensively on childhood needs of FASD. There is relevance to these findings for adults, as participants in this study identified similar needs for their children as adults. The consistencies between the findings of the present study and existing research lend more credibility to quantitative studies of children's issues and caregiver's needs when discussing FASD. Undoubtedly, the present results suggest that there is no one size fits all approach when preparing for the needs of the FASD population. Rather, each caregiver's parenting style, income range and proximity to community resources will influence the needs. Further research into the specific type caregiver needs, as well as service requirement is necessary, with variables contemplating the child's age, developmental stage and transitional circumstance. The developmental differences that are characteristic of FASD will require sensitivity concerning the transitional setting for children, youth and adults.

Future research must also consider the voices of adults with FASD. Prior research has documented the outcomes for many adults with FASD such as homelessness and involvement in the justice system. However, little is known about what services or needs adults believe

themselves to help with their day-to-day living. Further research should also explore structural supports that youth and adults need should they have contact with the justice system. With respect to policy, supports that are life-long and well-informed are essential to the positive adjustment of youth and adults with FASD. The specialized assistance for FASD services should extend past childhood and instead consider services that are needed at the life-stages of adolescence and emerging adulthood. Children with FASD will inevitably transition out of their systems of care, but there is a major lack of support or formal systems to transition into.

Finally, the implications for professional counsellors from this study indicate the potential benefit to incorporating FASD awareness into their training. Beyond this, future practitioners should be able to access screening measures, be aware of differential diagnoses and, as appropriate, facilitate approaches that focus on changes that are environment-based rather than client-based. Effective practitioners must alter their lens to resemble a strengths-based approach. FASD is a consequence of brain damage and we must view individuals with FASD as having a neurological-based disability, rather than a character flaw or misbehavior. The importance of family, stability and community support will lay the groundwork for a successful transition into adulthood.

Limitations

There are several limitations that should be considered. Results attained from voluntary responses are susceptible to bias, as individuals who are willing to participate may express a certain viewpoint that motivated them to become involved in the study. Choosing to interview one caregiver, when there are additional caregivers in a household, may have also posed different knowledge toward what services are required to support family members affected by FASD. The population of this study was directed to families who were connected with services and supports.

This may misrepresent families impacted by FASD who are unable to achieve similar supports, and have different awareness of service needs.

While gender was not mentioned as a response set by caregivers in this study, past studies suggest different standpoints on the gender-specific effect of FASD. A study by Burd et al. (2003) indicated that males with fetal alcohol spectrum disorder had triple the risk for developing comorbid mental disorders, and were at a slightly higher risk than females. In contrast, another study determined that the association between alcohol-exposure and later problems was more pronounced in girls rather than boys (Sayal et al., 2009). These results might suggest the different considerations associated with service needs of the alcohol-affected person and is another avenue for potential FASD research.

The location and geographic area of this study could cause misrepresentation, as the local families in Southern Ontario have voiced their outlook in this research. However, these results may not always generalize to caregivers or families affected by FASD in other communities. The willingness to participate, combined with location, services and type of caregivers selected, contributed to a unique sample within this study.

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Appendix A: Interview

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 challenges do you face in making your household function well?
- 2) What strengths do you have to make your household function well?
- 3) What do alcohol-affected youth need to be successful in school?
- 4) What do caregivers need to help youth be successful in school?
- 5) What services would help youth be successful in school?
- 6) What do you want for them as adults?
- 7) What kind of adult life do you think they will have?
- 8) What do caregivers need to help young adults live as independently as possible?**
- 9) What services would help young adults live as independently as possible?**

Curriculum Vitae
ARMUSH SALAHADIN

Education

Master of Arts in Counselling Psychology

Anticipated Convocation: June 2016

Western University, London, ON

Bachelor of Arts in Honours Social Psychology

June 2014

McMaster University, Hamilton, ON

Honours and Awards

Province of Ontario Graduate Scholarship <i>Western University</i>	2015-2016
Graduate Admission Scholarship <i>Western University</i>	2014-2015
University Senate Scholarship Award <i>McMaster University</i>	2012-2013
Deans Honour List <i>McMaster University</i>	2011-2014
Golden Key International Honour Society <i>McMaster University</i>	2011-2014
Entrance Award <i>McMaster University</i>	2010

Counselling Related Experience

Counsellor Intern <i>Western University Psychological Services, London, ON</i>	Sep. 2015-April 2015
Pediatrics Mentor <i>Chedoke Hospital, Hamilton, ON</i>	Apr. 2013-May 2014
Speech-Assistant <i>St. Peter's Hospital, Hamilton, ON</i>	Apr. 2013-May 2014

Research Related Experience

Research Assistant <i>Department of Counselling Psychology, Western University</i>	Apr. 2015-August 2015
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Presentations

Salahadin, A. (February 24, 2016). Public Speaking Anxiety. *Laura Evans Lecture Series*.
Lecture conducted from Western University, London, ON.

Salahadin, A. (February 8, 2016). Mindfulness and Meditation. *Laura Evans Lecture Series*.
Lecture conducted from Western University, London, ON.

Salahadin, A. (October 9, 2015). Mindfulness and Meditation. *Laura Evans Lecture Series*.
Lecture conducted from Western University, London, ON.

Salahadin, A. (October 23, 2015) Public Speaking Anxiety. *Laura Evans Lecture Series*. Lecture
conducted from Western University, London, ON.

Salahadin, A. & Brown, J. (April 2015). An Exploration of Service Needs for Adults who Live
with Fetal Alcohol Spectrum Disorder. Round table presentation, Robert Macmillan Graduate
Research in Education Symposium, Western University, London, Canada.

Salahadin, A. & Scott, B. (October 6, 2015). Healthy Relationships. *Laura Evans Lecture Series*.
Lecture conducted from Western University, London, ON.