

Neuropsychological Aspects of Prevention and Intervention for FASD in Canada

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Abstract Fetal alcohol spectrum disorder (FASD) is the leading cause of developmental disability among Canadians. As a result, FASD has emerged as a public health priority in Canada. The current paper provides an overview of FASD in Canada with respect to (1) epidemiology; (2) conceptualizations of FASD by schools, the government, mental health services and the medical community; (3) current research; (4) prevention initiatives; and (5) intervention efforts. Overall, Canada has become a world leader in advancing knowledge about FASD, in part through the establishment of research networks aimed at preventing FASD and improving the lives of individuals affected by the disorder across the lifespan. A nationwide research framework has strengthened the links between research and practice in Canada, and major bodies in Canada appear to be moving towards a more integrated model for conceptualizing FASD, with increased investment in prevention and intervention. Although research and evaluation evidence is emerging, however, the strength of current evidence does not yet allow for prevalence rates or prevention and intervention best practices to be defined with certainty. With quality cross-sectoral research and evaluation that incorporates the lived experiences of parents and individuals with FASD, it will be possible to enhance under-

standing of facilitators and barriers to service delivery, access and utilization with respect to FASD prevention and intervention in Canada.

Keywords Fetal Alcohol Spectrum Disorder · Intervention · Prevention · Diagnosis

Introduction

Fetal alcohol spectrum disorder (FASD) describes the range of deficits in physical, behavioural, emotional, adaptive and neurocognitive functioning caused by prenatal alcohol exposure. FASD is the leading cause of developmental disability among Canadians and places a large economic burden on society through multiple systems of support including the health care system, mental health and substance abuse treatment services, foster care, social services, the criminal justice system, the education system and systems supporting the long-term care of individuals with intellectual and physical disabilities (Abel 1998; Conry and Fast 2000; Credé et al. 2011; Harwood 2000; Lupton et al. 2004; Popova et al. 2014, 2015). The cost associated with FASD in Canada was approximately \$1.8 billion in 2013, with the three largest contributing factors attributed to productivity loss as a result of disability or premature mortality (42 % of total cost), the cost of corrections (30 % of total cost) and health care (10 % of total cost; Popova et al. 2015). The Canadian Federal Government has recognized the substantial costs associated with the care and services required by individuals with FASD. As such, FASD has emerged as a public health priority in Canada, and substantial efforts have been devoted to FASD research, prevention and intervention. The objective of the current paper is to provide an overview of FASD in Canada with respect to (1) epidemiology; (2) conceptualizations of

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FASD by schools, the government, mental health services and the medical community; (3) current research; (4) prevention initiatives; and (5) intervention efforts.

Epidemiology of Alcohol Use During Pregnancy

Accurate epidemiological data is critical for the development of effective FASD prevention and intervention programs and can help to shape public policy and resource allocation (Nanson 1997). Epidemiological research on FASD in Canada has largely focused on (i) risk factors for alcohol consumption during pregnancy, (ii) the prevalence of alcohol consumption during pregnancy and (iii) the prevalence of FASD.

With respect to research regarding risk factors for alcohol consumption during pregnancy, the Maternity Experiences Survey was sponsored by the Public Health Agency of Canada and conducted by Statistics Canada in 2006. This nationwide survey assessed pregnancy, delivery and postnatal experiences of mothers and their children. Walker et al. (2011) conducted an analysis of data from 5882 respondents to this survey with a primary focus on low to moderate levels of alcohol consumption. The authors reported that women who were residents of Eastern Central or Western provinces, women who had partners, women who smoked and women who reported indifferent or unhappy reactions to their pregnancies had an increased likelihood of using alcohol during their pregnancy (Walker et al. 2011). None of the socioeconomic variables investigated by Walker et al. (2011) were predictive of alcohol use during pregnancy. With respect to factors decreasing risk for alcohol consumption during pregnancy, immigrant status appeared to confer a protective effect, with significantly fewer women of immigrant status reporting alcohol consumption during pregnancy (Walker et al. 2011). The authors concluded that interventions for unplanned pregnancies are critical. This is supported by research associating involvement with a general physician or family physician with a decreased risk of alcohol consumption during pregnancy (Thanh and Jonsson 2010).

Overall, there is consensus that high-risk use of alcohol by pregnant women occurs within a complex web of mutually reinforcing influences on their drinking, such as interpersonal violence, socioeconomic status, mental health challenges and isolation (Motz et al. 2006). As is the case with other countries, Canadian research documenting risk factors for alcohol consumption during pregnancy has resulted in findings that are not wholly consistent (Parkes et al. 2008). Accordingly, researchers have emphasized the importance of exploring context-specific risk factors for individual women (Parkes et al. 2008).

In addition, epidemiological research on the prevalence of alcohol consumption during pregnancy indicates that, although public education campaigns have elevated awareness

of FASD, these campaigns alone are insufficient to change the behaviours of women who are at highest risk for drinking during pregnancy (Clarren et al. 2011). Supporting this assertion, the Public Health Agency of Canada reported that, in 2006, 15 % of pregnant women used alcohol. However, a study conducted in Alberta found that 50 % of women reported consuming alcohol before discovering that they were pregnant, and 18 % continued to consume alcohol after confirming pregnancy (Tough et al. 2006). Other studies have reported still different rates of alcohol consumption during pregnancy, including approximately 25 % of women among a First Nations population in northwestern Ontario (Kelly et al. 2011) and approximately 60 % of Inuit women in Arctic Quebec (Muckle et al. 2011). Alternatively, using data from the 2007/2008 Canadian Community Health Survey, Thanh and Jonsson (2010) estimated the weighted prevalence of women who consumed alcohol during their last pregnancy to be 5.4, 7.2 and 5.8 %, in Ontario, British Columbia and Canada, respectively. Analysis of the Maternity Experiences Survey indicated that 10.8 % of Canadian women report using alcohol during pregnancy (Walker et al. 2011). It is likely that variations in research methods contribute to different estimates of alcohol consumption during pregnancy. For example, Canadian epidemiological data on alcohol consumption during pregnancy generally focuses on small and rural subsets of the country, which may not be widely applicable to Canada as a whole (Walker et al. 2011). In addition, the stigma associated with women's drinking behaviours can impact reporting rates. According to Poole and Dell (2005), pregnant women who use substances experience marked scrutiny in Canadian society, and are met with judgmental, blaming and unsympathetic attitudes.

As is the case with estimating the prevalence of alcohol consumption during pregnancy, estimating the prevalence of FASD is a task that has been characterized by methodological inconsistencies and difficulty. Different researchers' estimates of FASD prevalence are highly varied, at least in part due to different case definition and diagnostic methods, as well as disparate geographical and population factors across settings (Ospina and Dennett 2013). Canadian guidelines recommend a comprehensive multidisciplinary assessment in order to diagnose FASD. However, limited resources and capacity to carry out such assessments inevitably result in an underestimation of the true rate of FASD (Tough and Jack 2011). This is perhaps especially true in correctional settings, where a past history of alcohol exposure may be difficult to document and where diagnostic services are lacking (Burd et al. 2003).

Clarren and Cook (2013) note that meconium screening, offered in some Canadian hospitals, is a potential biomarker for FASD. This involves testing samples of a newborn's first stool for fatty acid ethyl esters, which confirm alcohol exposure during the second and third trimesters of pregnancy. However, meconium testing poses significant logistical, cost

and ethical challenges, and it cannot be used to confirm an FASD diagnosis without subsequent testing (Clarren and Cook 2013). In addition, meconium screening cannot determine alcohol exposure during the first trimester of pregnancy. Concerns have also been raised about the potential of such screening deterring high-risk women from accessing obstetric care for fear of losing custody of their children based on the results (Clarren et al. 2011). In addition to the type of alcohol use screening employed, there are challenges regarding review of file documentation in Canada: there are inconsistent practices across Canada for recording alcohol use in a woman's medical charts and for transferring information on prenatal alcohol exposure to her child's health records (Sarkar et al. 2009). Canadian researchers have also used maternal self-report screening tools for estimating FASD prevalence. In Canada, however, different maternal self-report screening tools are used in different provinces, health-care settings and even across health-care providers (Sarkar et al. 2009).

Despite significant methodological limitations in understanding the prevalence of FASD, Canadian researchers have attempted to estimate prevalence rates. The most commonly cited statistic for the prevalence of FASD in Canada is 9.1 per 1000 births (Health Canada 2006). However, this rate is an estimate based on data extrapolated from studies conducted in the USA. More specific to Canadian data, a recent systematic review on the prevalence of FASD identified nine prevalence studies conducted in Canada (Ospina and Dennett 2013).

Five of these nine studies estimated the prevalence of FASD in Aboriginal communities (Habbick et al. 1996; Kowlessar 1997; Robinson et al. 1987; Williams et al. 1999; Rojas and Gretton 2007), while the remaining four examined prevalence in correctional settings (Burd et al. 2003; Fast et al. 1999; MacPherson and Chudley 2007; Murphy and Chittenden 2005). Sample sizes ranged from 91 to 797, with age ranges between infancy and adulthood. Ospina and Dennett (2013) judged four out of the nine studies to be of low quality, while five were judged to be of moderate quality. Diagnostic methods were highly varied and included vital statistics records, medical records, interviews, chart reviews, dysmorphological assessments, neurobehavioural assessments, medical examinations, case conferences and self-reported diagnosis. Among these studies, rates of partial fetal alcohol syndrome (pFAS) ranged from 0.02 to 18 %, rates of alcohol-related neurodevelopmental disorder (ARND) ranged from 0.13 to 8.79 %, rates of fetal alcohol syndrome (FAS) ranged from 0.008 to 12 % and rates of FASD ranged from 0.26 to 26.9 %.

Clearly, there is a need to advance documentation and data collection processes, as well as to use more consistent diagnostic methods in prevalence studies to enhance understanding of epidemiological information related to maternal alcohol consumption and FASD. Research results are highly

varied depending on methodology, sample characteristics and geography, among other factors. As such, there is not currently a clear understanding of alcohol consumption during pregnancy, as well as FASD prevalence rates, in the provinces and territories of Canada, or in the country as a whole.

Conceptualizations of FASD in Canada

Recognizing FASD as a primary public health priority, Canadian researchers, in partnership with practitioners and policy makers, released the first version of the Canadian FASD diagnostic guidelines in 2005 (Chudley et al. 2005). This initiative reflected an understanding that a common approach to identification was necessary to establish a prevalence rate in the country, as well as uniform intervention and prevention practices. This initial step allowed for evidence to be gathered on the diagnostic process, intervention practices and prevention directives. Consequently, updated guidelines were published in February of 2016, that were developed using a rigorous evidence-based approach to incorporate this nationally collected data as well as international evidence (Cook et al. 2016). The guidelines provide recommendations weighted in terms of strength and quality of evidence (i.e. effect size) on multiple aspects of identification and FASD diagnosis (e.g. screening, referral and support, medical assessment, maternal alcohol history, physical examination and differential diagnosis, sentinel facial features, neurodevelopmental assessment, nomenclature and diagnostic criteria, diagnostic team composition and special considerations for infants and young children; Cook et al. 2016). An additional change in the new criteria is the inclusion of severe impairment in affect. Researchers in the field consistently report disproportionately high externalizing (e.g. attention deficit hyperactivity disorder) and internalizing disorders (e.g. depression, anxiety) in those affected by FASD (Pei et al. 2011). The inclusion of this neurodevelopmental domain highlights the prevalence of mental health problems in this population and their significant impact on the development and day-to-day functioning of these individuals. Finally, an emphasis on intervention and support beyond the assessment process is included, stressing the importance of ongoing support for individuals with FASD. For example, there is a focus on assisting individuals and their caregivers in accessing resources after the assessment and continuing to support young adults transitioning to independent living situations (Cook et al. 2016).

In addition to establishment of a national identification standard, specific systems of support in Canada have also begun to develop policies to govern practice with individuals with FASD. Several, but not all, provincial education systems in Canada consider school-age children with an FASD

diagnosis within a larger inclusive education context that supports children with disabilities. Identification and funding for children with disabilities is allocated by a provincial/territorial-level funding system where each jurisdiction determines their own funding policies and budget to meet the specific needs and priorities set forth by each province or territory. Due to these differences, identification and subsequent funding allocated to students with disabilities (i.e. FASD) varies across the country. For example, Yukon Territory's Education Act (Yukon Government 2002) states that funding will meet each school board's approved annual operations. Based on school enrolment, a base allocation is granted (e.g. 1.5 educational assistants for every 261 students). Superintendents and principals consider the overall administrative needs of their school(s) in addition to the needs of students with disabilities. In terms of identification, students with FASD are considered to have "exceptional needs" and placed on an Individual Education Plan (IEP) under neurodevelopmental specifications. Categories of neurodevelopmental specifications include gifted and talented, learning disability, intellectual disability, autism spectrum disorder and fetal alcohol spectrum disorder. The preschool and school-age FASD Diagnostic Team can be accessed directly through Yukon Education, a territorial ministry in Canada. Yukon Education has also published a manual aimed at providing educators with resources and tools when working with children with FASD and their families (Yukon 2007).

In Alberta, the Minister of Education, using the province's allocation budget, determines each school board's operating budget. Additional differential funding is awarded to school boards based on the needs of individual school populations. Additional funding is provided for children with disabilities who have received an assessment, meet special education coding criteria and have an Individualized Program Plan (IPP) in place (Alberta Education 2015). Children with FASD are included under Severe Physical or Medical Disability (Code 44; Alberta Government 2014). Children can be referred to multiple diagnostic clinics throughout the 12 FASD Service Networks across the province. In addition to funding, Alberta Education has published multiple documents aimed at supporting children with FASD in the classroom and increasing knowledge of FASD among educators (e.g. Alberta Learning 2004).

In Ontario, funding is allocated on a per-student basis, with the amount of funding a school board receives determined by various grants included in the province's education funding formula. For example, students with disabilities may be funded through the Special Education Grant, the Pupil Foundation Grant and other Special Purpose Grants which are implemented based on the diversity of the student population (Ontario Government 2015). Students are placed under one (or more) of five broad categories of exceptionalities:

behaviour, communication, intellectual, physical and multiple. Currently, the Ministry of Education is working together with other government ministries through the Special Needs Strategy to improve outcomes for students with special needs through early identification and intervention, coordinated service planning and integrated service delivery systems. As part of this strategy, development of an Ontario-wide FASD strategy is underway.

Despite the focus on promoting knowledge and education of FASD across multiple education departments in central and western Canada, the availability of resources and supports are not equal across the country. The Maritime Provinces (i.e. Nova Scotia, New Brunswick and Prince Edward Island) currently provide minimal published resources for educators who work with individuals impacted by FASD. In addition, FASD is not specifically identified in special education policies, which in part, may be due to the non-categorical (i.e. no label) approach to inclusive education. Rather than assigning students to categories in order to access special education services, a non-categorical approach curriculum and services are provided that respond to the needs of all students, regardless of diagnosis (Kanevsky and Clelland 2013). Future directives are needed to ensure that appropriate supports and interventions are offered to students with FASD in these provinces.

The impact of FASD on the Canadian criminal justice system has also received considerable attention to date and has emerged as a controversial topic both in adult and youth systems. Currently, there are no specific laws or policies that govern individuals with FASD in Canada. However, efforts are underway to educate those involved in the legal system regarding the impact that FASD can have on offending behaviour, statements, sentencing and corrections. For example, the Canadian FASD Justice Committee, with funding from the Public Health Agency of Canada (PHAC) and the Department of Justice, developed a website aimed at providing evidence-based resources for justice professionals, the Institute of Health Economics has developed a consensus statement on the legal issues of FASD (Institute of Health Economics 2013) and multiple agencies and working groups have developed recommendations aimed at increasing diagnosis, supports and interventions for individuals with FASD involved in the criminal justice system (e.g. Truth and Reconciliation Commission of Canada 2015). Provincial Mental Health Courts (MHC) in Ontario and Quebec additionally have been created where individuals with mental illness (including individuals with FASD) are diverted from the regular system to one that favours a more holistic approach and includes referrals to appropriate services and treatments (Dupuis et al. 2013), while Yukon Territory has developed a therapeutic Community Wellness Court that targets individuals with addictions, mental health problems and/or FASD.

In terms of health-care systems, the Public Health Agency of Canada (PHAC) has developed a federal FASD Initiative that aims to prevent FASD and improve outcomes for those diagnosed as well as their families and communities. Together with Health Canada, the FASD National Strategic Project Fund was established to support knowledge and evidence; knowledge translation and exchange; leadership, coordination and collaboration; systems capacity development; and evaluation across the country. The initiative additionally developed low-risk alcohol drinking guidelines aimed at minimizing individual risk (e.g. pregnant women or women who are planning on becoming pregnant, teenagers), long-term risk (e.g. liver disease) and short-term risk (e.g. acute illness due to overconsumption on a single occasion) to all Canadians from consuming alcohol (Butt et al. 2011).

Linking all of these systems and agencies is The Canada Fetal Alcohol Spectrum Disorder Research Network (CanFASD), a collaborative, interdisciplinary research network of leading organizations and individuals across Canada focused on FASD. It is Canada's first comprehensive national FASD research network and has been in operation since 2005. CanFASD was created as a main focus of a continuing government alliance of the four western provinces and three northern territories called the Canada Northwest FASD Partnership (CNFASDP). This Partnership has been working together since 1998 towards the development and promotion of an inter-jurisdictional approach to diagnosis, prevention, intervention and care, and support of individuals who are affected by FASD. CanFASD creates, nurtures and sustains a collaborative environment and unique partnership able to bring together many scientific viewpoints to address FASD, with a focus on ensuring that research knowledge is translated to community and policy action. It works through four cross-jurisdictional research teams that are focused on the areas of diagnosis, intervention and prevention and connects researchers, graduate students and practitioners from communities and institutions across Canada and internationally.

After 10 years of increasingly successful and high profile operation, CanFASD is now a national Canadian charitable organization whose vision is to support Canada's leadership in addressing the extraordinary complexities of FASD. Its mission is to produce and maintain national, collaborative research designed for sharing with all Canadians, leading to prevention strategies and improved support services for people affected by FASD.

Overall, conceptualization of FASD among major bodies in Canada appears to be moving towards a more integrated model that includes early screening, referral and support for pregnant and postpartum women, early identification, inclusion of both primary neurological impairment and secondary social and environmental dysfunction within diagnostic criteria, and the need for multilevel and

multisystem care and support through the lifespan for individuals with FASD.

FASD Research in Canada

The conceptualization of an integrated approach to FASD would not be possible without the depth and breadth of research taking place in Canada. From a national perspective, CanFASD and NeuroDevNet are two bodies that have established a national capacity for facilitating collaborative research initiatives. These two research groups are comprised of interdisciplinary research teams and are committed to the completion and dissemination of research knowledge to help inform policy and practice and to increase diagnostic, prevention and intervention efforts of FASD across the country.

As previously mentioned, CanFASD's research efforts are comprised of three main research teams, each focused on a specific area of study. The diagnostics team is dedicated to increasing the consistency, clarity and accuracy of the FASD diagnostic process via research focused on three main areas: (i) increasing the reliability and specificity of facial features affected by prenatal alcohol exposure (e.g. Clarren et al. 2010), (ii) clarifying the measurement and assessment process of testing brain dysfunction (e.g. Clarren et al. 2009; Salmon and Clarren 2011) and (iii) redefining the diagnostic and coding terminology in an effort to clearly articulate the levels of brain damage and functional disability of individuals with FASD (e.g. Cook et al. 2016).

The prevention team is made up of a national network of researchers, service providers, policy advisors and community partners who are committed to FASD prevention. The network addresses FASD from multiple levels (see Poole 2008) and aims to increase knowledge of the disorder within health promotion, prevention programs, treatment harm reduction and policy development. Multiple studies have focused on improving and evaluating substance abuse treatment and the evaluation of FASD prevention programs across the nation (e.g. Job et al. 2014; Poole et al. 2013; Rowan et al. 2014; Thanh et al. 2015; Thomas et al. 2014).

Finally, the intervention team is focused on FASD intervention research and knowledge translation. This team focuses on improving the lives of individuals with FASD throughout the lifespan by building research knowledge and improving policy, practice and outcomes associated with FASD. Through innovation, the intervention network action group (iNAT) has prioritized research focused on understanding the functional needs of individuals with FASD to allow for the development of interventions that specifically address these needs across jurisdictions and across the lifespan. Currently, there is a wide range of research taking place across the country including grassroots projects aimed at evaluating existing intervention programs and focusing on the importance of

intervention (Denys et al. 2011; Pei et al. 2013) to large-scale academic and federally funded projects focused on identifying the neurological profiles of individuals with FASD to better inform the kinds of supports and interventions these individuals require (e.g. Loomes et al. 2008; Pei et al. 2008; Rasmussen 2005; Rasmussen and Bisanz 2009). Lastly, through building communication, the team aims to establish a strong online community that can serve as a central place where ongoing discussion and collaboration can help evolve ideas, interventions and research around FASD. A quarterly e-newsletter has been developed to help disseminate new intervention research and help keep stakeholder networks informed regarding the activities of iNAT.

In addition, NeuroDevNet is a Canadian Network of Centres of Excellence (NCE), a large-scale academic-led research centre made up of partners from a variety of disciplines such as academia, government, industry and not-for-profit organizations with the goal of understanding brain development and the causes of neurodevelopmental disorders through high-impact research that challenges and increases current knowledge. NeuroDevNet received \$39.1 million in funding for 2009–2019 to focus on treating and preventing childhood brain disorders, including FASD. Current research is aimed at linking behaviours observed in FASD to brain structures and genetic profiles. For example, Hemington and Reynolds (2014) recently used a single channel EEG recording device to measure EEG activity during an eye movement task probing working memory in children with FASD ($n = 18$) compared to typically developing children ($n = 19$). Results revealed frontal lobe damage in children with FASD, as this group made a larger number and more frequent errors and used more cognitive resources during tasks than the control children. In a related line of research, Paolozza et al. (2014) investigated the relationship between psychometric tests and eye movement tasks in children with FASD. Again, children with FASD ($n = 72$) performed worse than typically developing controls ($n = 139$) on measures of attention and inhibition and on response inhibition during antisaccade and memory-guided tasks. Findings suggest that brain injury due to prenatal alcohol exposure results in poor performance across common brain structures assessed by both psychometric and eye movement measures. Overall, screening for deficits in eye movement control may be an effective tool to identify children affected by prenatal alcohol exposure who would benefit from further multidisciplinary assessment, and is a novel Canadian contribution to the field.

In summary, Canada has become a world leader in advancing knowledge about FASD and supporting knowledge translation through the establishment of both federally and provincially funded research networks aimed at preventing FASD and improving the lives of individuals affected by the disorder across the lifespan. A nationwide research framework that focuses on the prevention of FASD and the development of

interventions to address the specific needs of these individuals guides the work done in this field and emphasizes the importance of looking forward in an effort to strengthen the links between research and practice.

FASD Prevention in Canada

Paralleling advancements in Canada's FASD research landscape, the past decade has involved significant advancements in Canada's FASD prevention efforts, including the development of national and provincial strategic plans, multi-sectoral networks and a framework for FASD prevention (Poole 2011).

This prevention framework was introduced in 2008 by the Public Health Agency of Canada (PHAC) and consists of four levels. The first level of prevention focuses on broad awareness building and health promotion strategies such as campaigns directed towards the general public. The second level of prevention involves discussion of pregnancy, alcohol use and related risks with women of childbearing age along with their support networks. The third level of prevention is increasingly specific and includes specialized, holistic support of pregnant women who have alcohol and other health problems. Level three can also be seen to involve recovery and support services for all women of childbearing age. The fourth level of prevention focuses on support for new mothers to maintain healthy changes made during their pregnancies, as well as ongoing support for women who were not able to stop drinking and need ongoing support and/or treatment. For this latter group, the PHAC prevention framework acknowledges that support is critical in order to continue providing opportunities for the health improvement of new mothers as well as appropriate early interventions for their children. This framework represents an important step forward in understanding and advocating for multiple levels of FASD prevention.

The prevalence of unintended pregnancy in Canada has recently been reported to be 27 % (Oulman et al. 2015; Singh et al. 2010). Canadian researchers have emphasized that FASD prevention should include efforts to prevent unintended pregnancies, in part by improving access to and education regarding birth control for Canadian women (Sanders and Currie 2014). Preconception prevention initiatives have also been proposed in Canada in the form of school-based substance use prevention programs (Baydala et al. 2011) as well as universal screening (Premji and Semenic 2009) and overall practice supported by health policy (Bialystok et al. 2013). As of 2007, only three Canadian provinces (British Columbia, Yukon and Newfoundland) included questions in standard prenatal records regarding pre-pregnancy alcohol use (Premji and Semenic 2009). Clarren et al. (2011) note that this represents a missed opportunity for providing preventive education, counselling and

resources. With the recognition of the stigma associated with women's drinking (Benoit et al. 2014), and the prevalence of gender-based violence and trauma in the lives of many women, opportunities for trauma-informed approaches to discussions with women in preconception and interconception periods are being identified as important (Bialystok et al. 2014). A specialized preconception program in Canada reaches adolescent girls and uses the well-evidenced Project Choices approach of combining support for reducing alcohol use and increasing use of effective birth control (Velasquez et al. 2010). In the Project Choices research, sponsored by the Centers for Disease Control in the USA, evidence was found for brief interventions using a motivational interviewing approach that has a dual focus on alcohol and use of effective birth control, to engage women who are at risk of having alcohol-exposed pregnancies in FASD prevention, by reducing their alcohol use, increasing their use of birth control, or both (Floyd et al. 2007).

Prevention campaigns have been developed in Canada to either directly reach women or others who can influence a woman's alcohol use (for example, parents, family members, friends or the larger community). A wide variety of universal prevention campaigns have been developed by governments and non-profit organizations across Canada and include resources such as fact sheets, websites, posters, brochures, videos, handbooks, radio and television advertisements, and workshop kits (Cismaru et al. 2010).

A recent environmental scan resulted in the development of an inventory with 262 primary FASD prevention resources and/or campaigns in northwestern Canada (Thurmeier et al. 2011). Only three of these campaigns were formally evaluated. These included the Born Free Campaign initiated by Alberta Children Services, the Mother Kangaroo Campaign developed by the Saskatchewan Prevention Institute and the With Child/Without Alcohol Campaign developed by the Manitoba Liquor Control Commission. Thurmeier et al. (2011) note that, although evaluation of each campaign highlighted an increased knowledge and awareness of FASD among the general public, evaluations did not shed light on the extent to which messages reached different target groups, or whether these campaigns effected actual behaviour change. Prevention campaigns are important awareness raising tools in FASD prevention efforts, but without reinforcement from other levels of prevention, they have not been found sufficient to change behaviour (Clarren et al. 2011; Thomas et al. 2014).

Distinct from universal approaches to FASD prevention, selective prevention efforts reach subgroups of women who are at risk of having children with FASD (Ospina et al. 2011). Selective FASD prevention combines brief interventions using motivational interviewing approaches and wholistic community support programming which address alcohol use and wider determinants of health. In several Canadian

provinces, education for health professionals is offered to promote brief intervention approaches that are grounded in evidence for motivational interviewing and trauma-informed practice. For example, the FASD Prevention Conversation initiative, developed and delivered in Alberta, focuses on training health-care and social service providers to support and facilitate non-judgmental, supportive conversations with women of childbearing age (Pei et al. 2015). In addition, there are over 800 community-based pregnancy outreach programs across Canada, with nutritional support goals, which are increasingly taking a role in support for alcohol, tobacco and related health issues. In a number of communities, enhanced versions of this community-based programming promote the use of motivational interviewing, trauma-informed and harm-reduction-oriented approaches, found to be effective in engaging women at highest risk (Nathoo et al. 2013). The Alberta Alcohol and Drug Abuse Commission's Enhanced Services for Women has incorporated these techniques into services provided to this population of women (Clarren et al. 2011).

Indicated FASD prevention is geared towards supporting women at the highest level of risk for having children with FASD and includes treatment of alcohol use problems in women who are pregnant or likely to become pregnant (Ospina et al. 2011). Among the most widely researched programs at this level of prevention in Canada is the Parent Child Assistance Program (PCAP), originally developed in Washington, USA (Grant et al. 2005). The PCAP has been replicated across western Canada, with demonstrated cost-effectiveness and success in reducing alcohol-exposed births (Thanh et al. 2015). An important contribution that PCAP findings and evaluations of the specialized community-based outreach programs make to the field of prevention is the recognition that FASD prevention efforts must take into account the social determinants of health such as socioeconomic status and access to social support networks (Clarren et al. 2011).

In 2011, a systematic review was conducted on the effectiveness of universal, selective and indicated prevention approaches for FASD (Ospina and Dennett 2013). No Canadian studies of selective or indicated prevention met inclusion criteria for the review, and only two Canadian studies of universal prevention approaches met criteria. Clearly, there is a wide range of universal, selective and indicated prevention efforts being undertaken across Canada. There remains a pressing need to understand the ways in which these approaches effect meaningful change in preventing FASD. Significant effort is currently underway to promote the use of a comprehensive evaluation framework, developed in collaboration with researchers, evaluation specialists and community-based services across the country (Hubberstey et al. 2015; Rutman et al. 2015).

Furthermore, Clarren et al. (2011) note that, even where prevention campaigns are successful in urging women to seek help to prevent and reduce alcohol consumption during

pregnancy, Canadian health-care systems are often unprepared to serve these women. Pregnant women who are facing multiple and complex issues during pregnancy often bounce between uncoordinated systems of care (Clarren et al. 2011; Marcellus et al. 2015). This points to the need for a more systemic approach to FASD prevention characterized by strong linkages between the multiple levels of prevention efforts, and increased interagency cooperation to best meet the needs of mothers, children and families (Salmon and Clarren 2011).

FASD Interventions in Canada

There is a general consensus that individuals with FASD living in Canada require targeted interventions and supports to live healthy, successful lives (Wheeler et al. 2013). Required supports span multiple sectors including health, education, the corrections system, as well as social and family services (Thanh and Jonsson 2010). Without early diagnosis and appropriate intervention, individuals with FASD are at a heightened risk of adverse outcomes such as conflict with the law and development of mental health problems (Streissguth et al. 2004). Recently, there has been an increase in efforts to design and test interventions for individuals with FASD (Paley and O'Connor 2009). In a review of services and interventions for individuals with FASD, however, Wheeler et al. (2013) discovered few interventions that had been tested using experimental designs, and even fewer that had been developed or tested in Canada. Peadon et al. (2009) have also concluded that there is a lack of good quality evidence for specific interventions for children with FASD. As a result, interventions are often provided based on general wisdom and eclectic models that are not based in solid evidence (Paley and O'Connor 2009).

Despite these limitations, evidence is beginning to emerge in Canada, through both direct research as well as evaluation of existing programs. Many direct intervention research initiatives target the core deficits and symptoms of FASD. For example, impact of the Alert Program for Self-Regulation has been tested for children with FASD in Canada. Nash et al. (2015) reported significant improvements at 12-week follow-up for children who had participated in the program relative to a control group. Improvements were specifically noted with respect to inhibitory control, social cognition, behavioural and emotional regulation, and externalizing behaviour problems.

Research is also being conducted in Canada to investigate the impact of the Math Interactive Learning Experience (MILE) program on children with FASD. Although the MILE program has been developed and evaluated in the USA (Coles et al. 2009; Kable et al. 2007), Canadian researchers have replicated evaluations of the MILE program

and demonstrated encouraging results. In particular, a study replicating and extending the MILE program in Canada with 17 children demonstrated significant changes in math achievement relative to a control group, although significant changes in other cognitive functions were not observed (Kully-Martens 2013). This marks an important international partnership as researchers work across borders to seek solutions.

Other researchers in Canada have examined the impact of interventions on cognitive and executive functioning. In particular, Loomes et al. (2008) reported a positive impact of rehearsal training for 33 children with FASD with respect to working memory performance. Other Canadian researchers have investigated gaming platforms as a way to manage and improve FASD symptoms. Researchers at the University of Victoria reported positive results after testing the Computerized Progressive Training (CPAT) program with ten children who had an FASD diagnosis (Kerns et al. 2010). Several measures of attention, spatial working memory, math fluency and reading fluency showed significant improvement (Kerns et al. 2010). In addition, Cognitive Carnival is a computerized process-approach training program developed by the University of Victoria that provides training for aspects of attention, working memory and inhibitory control (Pei and Kerns 2012). While completing training, children receive individualized support and coaching from a trained interventionist who helps generate metacognitive strategies. A pilot evaluation of Cognitive Carnival demonstrated improvement on tasks of memory, attention, inhibition and metacognitive strategies, with many improvements sustained 12 weeks post-intervention. In addition, Diffusion Tensor Imaging results revealed neural differences in the intervention group relative to controls.

In addition to interventions targeting the core symptoms of FASD, family-based interventions have also been delivered and evaluated in Canada. Breaking the Cycle (BTC) has been identified as one of Canada's first early identification and intervention programs for drug- and alcohol-dependent women and their young children (Motz et al. 2006). Based in Toronto, BTC uses a holistic approach to deliver services including addiction counselling, parenting programs, early childhood intervention, basic needs and medical services, among others (Yazdani et al. 2009). Results of a pilot study conducted by Yazdani et al. (2009) suggest that early intervention such as that offered by BTC to mothers and children can mitigate neurocognitive effects in children less than 3 years of age who were prenatally exposed to alcohol. More recently, an evaluation of the BTC program was undertaken with the use of a comparison group (Pepler et al. 2014). Women in the comparison group received outreach services at a separate site that did not provide direct service to children and was not relationship-focused. Pepler et al. (2014) demonstrated that women in the BTC program decreased their substance use to

a greater extent than women in the control group, that more women from BTC improved their mental health and relationship capacity compared to women in the control group and that attached and secure mother-child relationships formed in the BTC program appeared to protect children from social, emotional and mental health problems.

The Catholic Social Services (CSS) agency based in Edmonton, Alberta provides a number of programs that serve children and adults with FASD in Canada. Aside from prevention programs based on the PCAP model, CSS offers a Step by Step program that matches parents with FASD to mentors. Mentors help parents strengthen community connections, manage crises and access a wide range of resources including housing, addictions supports, as well as respite and recreation resources with the ultimate goal of stabilizing clients with FASD and their families (Denys et al. 2011). An evaluation of the Step by Step program involving 24 participants identified decreases in client need scores and an overall increase in goal scores, attributable to the benefits of the mentor-client relationship (Denys et al. 2011). CSS also offers a Coaching Families program that works with families raising children who have an FASD diagnosis. An evaluation of data from 186 families who participated in the program showed a significant decrease in needs and increase in goal attainment from pre- to post-program, as well as a significant decrease in caregiver stress (Leenaars et al. 2012).

As another example of a community-based intervention approach, the Wellness, Resiliency and Partnership (WRaP) program has been developed and delivered in Canada. WRaP employs success coaches in Alberta schools to support students diagnosed with FASD. Evaluation of the WRaP program has demonstrated promising results in terms of student suspension rates, attendance and course completion, although evaluation of the WRaP program has not included a control group (Tremblay and McLean 2015). Evaluation of WRaP has also demonstrated expressly positive feedback from stakeholders with respect to improvements in school and community capacity to serve students with FASD, as well as school staff observations of behavioural improvements. Qualitative evaluation findings confirm the importance of a relational, strength-based approach to providing services for students with FASD (Tremblay and McLean 2015). This is in line with other qualitative research in Canada that points to the need for building on personal strengths when working with individuals who have an FASD diagnosis rather than employing punitive consequences (Pei et al. 2016).

Overall, it is clear that there are a number of interventions in Canada that target the core functional needs of FASD, as well as broader family and community-based initiatives that offer wraparound supports. Research and evaluation evidence is emerging to support the impact of these interventions on children and families with FASD. However, the strength of the evidence for interventions in Canada does

not yet allow for best practices in intervention to be identified with certainty. Some of the challenges in researching interventions are similar to the challenges in researching the epidemiology of FASD, discussed above. In addition, it can be difficult to engage families identified with FASD in intervention studies (Suchman et al. 2006). With a wide range of deficits that span multiple sectors, there is clearly work to be done in identifying interventions that best meet the needs of children and families with FASD in Canada, although the work completed thus far certainly offers a promising way forward.

Call to Action

In Canada, although FASD prevalence is estimated at 9.1 per 1000 births (Health Canada 2006), prevalence rates vary widely with different research methodology, sample characteristics and geography, among other factors. Consequently, FASD prevalence rates in Canada are not currently well defined, and our understanding of women's knowledge of the effects of alcohol, and of risk factors for alcohol consumption during pregnancy is still emerging. We recognize that women consuming alcohol during pregnancy are not a homogeneous group. Therefore, to best support women to have healthy pregnancies, there is a need to more fully understand the patterns and trends of women's alcohol use overall, and the influences and risk factors related to alcohol consumption for women from different backgrounds and populations. There is also a need to advance documentation and data collection processes, employ more consistent diagnostic methods in research and make use of representative, population-based samples in order to enhance epidemiological knowledge related to maternal alcohol consumption and FASD. Steps to doing this include establishing a national data form for diagnostic information—currently in progress, and continuing to develop national research collaborations, with shared data collection strategies, through groups such as CanFASD and NeuroDevNet.

With regard to conceptualization of FASD, major bodies in Canada appear to be moving towards a more integrated model that includes increased investment in prevention initiatives including support for women planning pregnancies as well as pregnant and postpartum women, early screening and identification of FASD, inclusion of both primary neurological impairment and secondary social and environmental dysfunction within diagnostic criteria, and the need for multilevel and multisystem care and support through the lifespan for individuals with FASD. Although recognition of issues related to FASD exists federally and by some territories and provinces, current initiatives include movement towards consistent and integrated efforts in terms of research efforts, prevention and intervention across the country. For example, access to multidisciplinary FASD diagnostic teams in some jurisdictions

continues to be difficult or not yet available, while disparity in the availability of FASD resources and supports publicly, as well as within school systems, health-care systems and legal systems, is evident across the country. Moving towards this integrated model on a nationwide scale will require all provincial and territorial governments to prioritize FASD as a public health concern and dedicate resources to increasing awareness of this disability across sectors and supporting prevention and intervention efforts. Future directives are needed to ensure that appropriate supports are offered to individuals with FASD across the country. Towards this aim, accurate cross-sectoral resource directories could be developed. Similarly, across the country, there is a need for a more systemic approach to FASD prevention with strong linkages between multiple levels of prevention efforts as well as increased interagency cooperation and knowledge sharing (Poole et al. 2016). That said, this appears a very viable goal in Canada given the history of resource sharing and partnership development in the country. Specifically, development and ongoing evolution of the Canada FASD Research Network, built upon political partnerships between provinces and territories, represents some of the efforts being employed to achieve these integrative goals.

Meeting these needs will also require high-quality research and evaluation of current FASD prevention and intervention initiatives. To date, Canada has become a world leader in advancing knowledge about FASD, in part through the establishment of research networks aimed at preventing FASD and improving the lives of individuals affected by the disorder across the lifespan. A nationwide research framework has strengthened the links between research and practice in Canada. However, although research and evaluation evidence is emerging to support the impact of prevention and intervention initiatives on children and families with FASD, the strength of the evidence does not yet allow for best practices to be identified with certainty. As a result, there remains a pressing need to understand the ways in which prevention and intervention efforts being undertaken across Canada are approaching meaningful change. To this end, significant effort is underway to promote the use of a comprehensive evaluation framework (Hubberstey et al. 2015; Rutman et al. 2015) that allows for consistent and rigorous approaches to evaluation across the country. Investing in training and education that is linked to these frameworks will likely support both the incorporation of evaluation within programs as well as implementation of practice improvements that are based on evidence gathered. Additionally, within the more specific research initiatives, as the evidence gathered in pilot and small-scale studies grows, increased investment in large-scale efficacy studies will be necessary. This will include moving to larger trials, comparisons with other clinical groups and randomized control trial studies and will help to advance understanding and practice, particularly in intervention work. It will be critical to develop research and evaluation capacity within and around

intervention and prevention programs to capitalize on this work. With quality cross-sectoral research and evaluation that incorporates the lived experiences of parents and individuals with FASD, it will be possible to achieve a better understanding of facilitators and barriers to service delivery, access and utilization with respect to FASD prevention and intervention.

Compliance with Ethical Standards This article does not contain any studies with human participants performed by any of the authors.

Conflict of Interest The authors declare that they have no conflict of interest.

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