

Environmental Scan of Programs for Fetal Alcohol Spectrum Disorder in Eastern Ontario

Abstract

Fetal Alcohol Spectrum Disorder (FASD) is a leading cause of developmental disability in Canadian children. The majority of Canadians with FASD are not identified: FASD is diagnosed in less than 1% of Canadians, when it may occur in as high as 2–5% of the school-aged population. This discrepancy is due in part to a lack of harmonized policy and service coordination at national and provincial levels. Failure to provide appropriate interventions for individuals with FASD results in the development of debilitating secondary effects that impact individuals, families and communities. Ontario is the most populated Canadian province with an emerging provincial strategy for FASD that is challenged by additional barriers to effective service provision and utilization. The Eastern Ontario region represents a population of 3 million residents that are particularly underserved. This environmental scan used formal and informal sources to explore, summarize, and map out current services for FASD in order to present a comprehensive review of service accessibility. The results inform residents, policymakers, service providers, and program developers on the scope and nature of services for FASD located in the Eastern Ontario region in 2012.

Fetal alcohol spectrum disorder (FASD) is a term used to describe the full range of adverse developmental outcomes directly resulting from prenatal exposure to alcohol. Although preventable, FASD is the leading cause of developmental and cognitive disability among Canadian school-aged children (Public Health Agency of Canada, 2005; Stade et al., 2009). Currently diagnosed in 1 in 100 live births in Canada, emerging evidence suggests that FASD may actually occur in 2–5% of the school-aged population in North America and Western Europe (May et al., 2009; Stade et al., 2009).

FASD is a non-diagnostic hyponym that represents the cognitive, behavioural, neurodevelopmental and physical features associated with a group of clinical diagnoses directly resulting from the teratogenic effects of prenatal exposure to alcohol. In addition to the congenital *primary disabilities* (the direct physiological effects of alcohol on fetal development), FASD is associated with a number of *secondary disabilities* that include problems with executive function, adaptive behaviour and social engagement (Streissguth, Bookstein, Barr, Sampson, O'Malley, & Young, 2004).

Secondary disabilities are considered to be the most debilitating aspect of FASD and are associated with a range of adverse life outcomes (Streissguth et al., 2004). Researchers have identified nine broad categories of secondary disabili-

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ities experienced by individuals with FASD: (1) mental health problems; (2) disrupted school experience; (3) trouble with the law; (4) confinement; (5) inappropriate sexual behaviour; (6) alcohol/drug problems; (7) problems with employment; (8) dependent living; and (9) problems with parenting (Clark, Lutke, Minnes, & Ouellette-Kuntz, 2004; Streissguth & Kanter, 1997). These functional impacts are assumed to arise in individuals with FASD through interactions between individual personality factors and environments; research indicates that they are negatively correlated to the provision of appropriate interventions and support required to address the underlying primary disabilities associated with FASD (Streissguth et al., 2004). In order to prevent the occurrence (or minimize the effects) of secondary disabilities, it is important that individuals affected by FASD have early access to diagnostic services and appropriate interventions and support programs (Streissguth et al., 2004).

For the purpose of this report, we use the terms “program” and “service” interchangeably to refer to the organized provision of specific and ongoing interventions, treatments, screening or diagnostic aids that explicitly target the needs of individuals and families affected by FASD. All system levels of community and government programs providing intangible goods and social support, information support (training and education), and resource supports specifically targeting FASD are included under this definition.

FASD Programming in Canada

There is very little information available to residents, clinicians, and researchers on the availability of provincial resources, programs, and services to assist FASD-affected families in Ontario (Hall, Cunningham, & Jones, 2010; Halloran, 2008; Whyte, 2010). Research links optimal outcomes to protective factors including early detection and intervention (Streissguth et al., 2004), yet the majority of Canadians affected by FASD are undiagnosed or misdiagnosed and do not have access to the supports they require to avoid adverse life outcomes (Koren, Fantus, & Nulman, 2010). This observation is especially applicable to the province of Ontario, the nation’s most populous province. Home to a third of the Canadian population (over 13 million people), Ontario is considered to be well behind the provinces and

territories in western Canada when it comes to functionally addressing the prevention of secondary disabilities associated with FASD (Halloran, 2008; Hall et al., 2010).

Current Program Initiatives in Ontario

In contrast to the longstanding successful approach to collaborative service provision demonstrated in western Canada through the *Canada Northwest FASD Partnership*, the few FASD programs that are available in Ontario have traditionally stood separate from one another, and there has been a provincial call for a more coordinated approach to service delivery (Duquette & Orders, 2010; Hall et al., 2010; Whyte, 2010). Without direct provincial involvement linking the provision of services to people affected by FASD, gaps in service provision are largely unnoticed by service providers and policymakers, and residents affected by FASD have reported that they are unsure of where to turn for help. Provincial reports published by the FASD Ontario Network of Expertise (FASD ONE) indicate that Ontario has some areas of promising or best practice, but there is no coordinated leadership or mandate to advance these beyond local delivery platforms (Duquette & Orders, 2010; Hall et al., 2010; Whyte, 2010).

FASD ONE is a key federally sponsored project in Ontario, composed of an interdisciplinary group of health professionals, researchers, service providers, and family members affected by FASD, working together to address issues relating to FASD in Ontario. Operating out of Central Ontario, FASD ONE is initiating and advocating for a province-wide movement toward a collaborative approach to FASD service provision (Hall et al., 2010); however, Ontario presents several geographical, systematic and cultural barriers to effective program delivery and coordinated approaches to FASD. Covering an area of 1,076,395 square kilometres, the province accounts for 10.8% of Canada’s total area and can be roughly divided into three distinct regions of population density (Chagnon & Milan, 2011):

- Central and Southern Ontario represent the most densely populated region, consisting of over 8 million people surrounding the most populous Canadian city, Toronto (Government of Ontario, 2012);

- Eastern Ontario, spanning the region between Ajax and the Canadian capital city of Ottawa, consists of several urban areas and over 600 smaller communities;
- Northern Ontario consists of few major urban centres and several smaller municipalities, and is sparsely populated.

While the emergence of FASD ONE has resulted in a noticeable increase in collaborative programming approaches for FASD in the most populous region of the province, residents in the eastern and northern regions of Ontario continue to struggle to access programming (Duquette & Orders, 2010; Hall et al., 2010; Whyte, 2010).

The Ontario provincial government has not yet designated a ministry that is responsible for issues related to FASD, and provincial initiatives are primarily focused on programs related to primary prevention (Government of Ontario, 2010). Moreover, the Ontario health insurance program does not offer a universal billing code for physicians to provide care for FASD-specific screening, diagnosis and intervention, deterring physicians from exploring prenatal alcohol exposure as a contributing factor in affected patients (Legislative Assembly of Ontario, 2010). While some progress has been made toward addressing this issue through introducing the 18-month “enhanced well-baby visit” for infants suspected of developmental delay (Williams, Clinton, Prince, & Novak, 2010), this continues to represent a significant systematic barrier to effective program delivery and utilization for individuals affected by FASD. Without renewable provincial funding for FASD-specific programs, many of the health care programs and social services accessed by residents of Ontario can only indirectly address FASD by targeting comorbid disorders and secondary disabilities instead of targeting the primary source of these problems (Legislative Assembly of Ontario, 2010).

Ontario is home to the largest number of Canadians with Aboriginal ancestry, and there are 207 Aboriginal reserves and settlements that operate outside of provincial jurisdiction (Statistics Canada, 2006). Uncertainty over the limits and boundaries of provincial and federal jurisdictional responsibilities pertaining to Aboriginal health care are often associated with a fragmented approach to the provision

of healthcare services for Aboriginal people (NWAC, 2002). Moreover, widespread misconceptions that FASD is a cultural problem primarily associated with people of Aboriginal descent impacts both policy and service provision pertaining to FASD (Tough, Clarke, & Cook, 2007).

May and colleagues (2009) note that the social stigma commonly associated with alcoholism extends into FASD and is credited with causing under-diagnosis in many mainstream populations, and over-diagnosis in minority populations. Active case ascertainment studies are often featured in FASD research on incidence and prevalence, and are mainly conducted in small communities specifically selected for their high risk and heavy drinking populations, thereby creating an over-representation of the prevalence of FASD in minority populations while simultaneously under-representing FASD in mainstream middle-class populations (May et al., 2009). Projecting the results of these studies onto the general population has resulted in the false impression that FASD primarily occurs in socially marginalized and lower class populations (Hannigan et al., 2010; Maguire, 2004; Whaley & O'Connor, 2003). In fact, national surveys have found that Canadian women who are Aboriginal, younger than 35, and/or have lower education levels are more likely to be aware of the danger of alcohol use during pregnancy (Burgoyne, 2007; Environics Research Group Limited, 2006); while it is Ontario women who are older than 35, with higher incomes and university educations who are more likely to believe that low to moderate levels of alcohol consumption are safe during pregnancy, and to report alcohol consumption during their last pregnancy (Burgoyne, 2007; Dell & Roberts, 2006; Health Canada, 2003).

The need for a comprehensive review of FASD services within the Eastern Ontario region initially emerged from informal conversations between participants in a FASD community support group meeting held in September 2010. In the initial stages of the research, feedback from our advisory committee indicated that the results of a comprehensive environmental scan would be most functional if it were contained to broad provincial regions instead of the entire province. The Eastern Ontario region was strategically chosen as the initial focus for this project, representing the underserved region

with the highest population to benefit from a resource that would aid in the development and functional utilization of policies, services, and program evaluation that specifically address the needs of residents affected by FASD.

The resultant research report describes the availability of FASD programming within Eastern Ontario, identifying a comprehensive inventory of current programs in this region that specifically address the needs of individuals and families affected by FASD. It expands upon the initiatives and publications led by FASD ONE with the purpose of identifying the scope and nature of direct services for FASD in this region in order to create a comprehensive resource that clearly identifies gaps in service provision contributing to the occurrence of secondary disabilities in Ontario residents with FASD.

Materials and Methods

In order to address the objectives of this research, we drew on two complementary methodological frameworks. First, we conducted a scoping review (Arksey & O'Malley, 2005) to identify the scope and nature of direct services for FASD. Next, analyses of these results were followed by an environmental scan to clearly identify the gaps in service provision in Eastern Ontario (Graham, Evitts, & Thomas-MacLean, 2008). A scoping review is a systematic exploratory approach used to investigate research areas with little supporting academic literature, and is useful for identifying knowledge gaps by offering a comprehensive picture of what information is available and where it came from (Arksey & O'Malley, 2005). In comparison, environmental scans are emerging as an effective tool to collect evidence pertaining to healthcare service delivery gaps (Graham et al., 2008). By using both the scoping review and the environmental scan methodologies, we have gathered a comprehensive set of data that can be used to understand and illustrate the current status of FASD supports in Eastern Ontario.

Scoping Review Methodology

A scoping review is a literature review technique that is commonly utilized to map key concepts and relevant literature when a research area is complex or has not been

comprehensively reviewed before (Arksey & O'Malley, 2005). Aiming to disseminate all existing information on a broad research question, all gathered information is summarized and afforded the same credence; sources include government literature, personal communication, print media, internet sources, and any available peer reviewed literature. Consistent with other research methodologies, the methodological process is documented in enough detail that it can be replicated by other researchers. Arksey and O'Malley (2005) provide a structured outline of the framework stages for conducting a scoping review, stressing that the following stages are an iterative process that can effectively guide research: (1) identify the research question; (2) identify relevant literature; (3) select relevant literature; (4) chart data; (5) collate, summarize and report results; and (6) consult with key stakeholders (optional).

Scoping reviews do not seek to address specific research questions or assess the quality of the studies that they include. They present an overview of the main findings of related research, and are particularly useful when it is necessary to examine the scope and nature of research on a topic that has not before been comprehensively reviewed. By identifying the sources and types of research evidence available, they are useful in providing an informational platform upon which to build more refined research endeavors (Arksey & O'Malley, 2005; Lavis, 2006).

Scoping Review Data Collection and Analysis

Identify the Research Question

Considering the objectives of the proposed research project, we asked the question: "What is the scope and nature of services for FASD in the Eastern Ontario region currently accessed by resident individuals and families affected by prenatal exposure to alcohol?" We defined the parameters of the term "FASD services" to refer to the organized provision of specific and ongoing interventions, treatments, or direct services which target individuals and their families who are living with, or suspected of having an FASD diagnosis in Eastern Ontario.

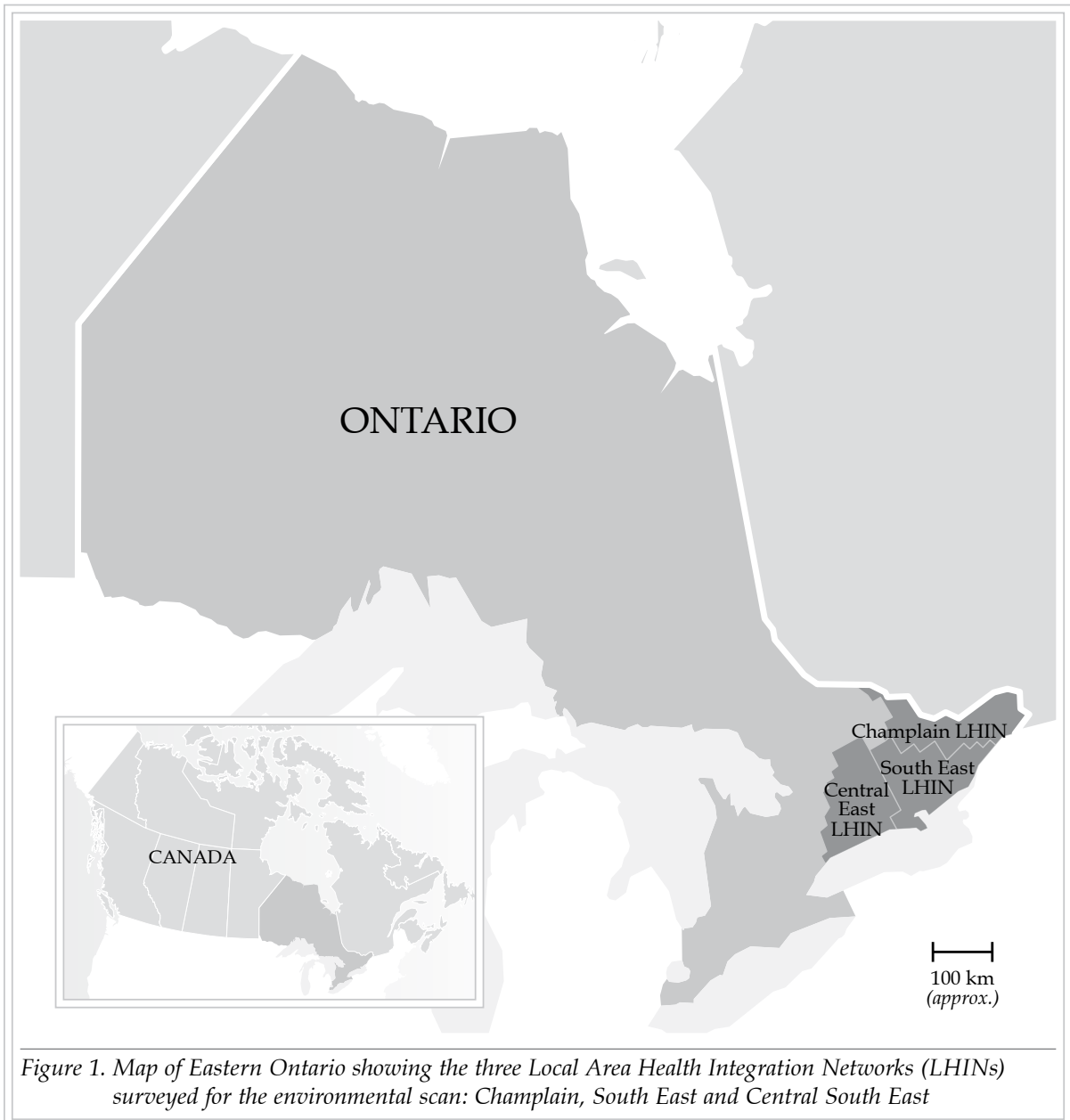
Identify Relevant Literature

Relevant literature considered from this scoping review was drawn from a range of formal and informal sources, and was included for analysis if it identified services that are currently offered within the Eastern Ontario region (See Figure 1). Search results were limited to literature published over a period of 10 years (2001–2011); and data were drawn from both peer-reviewed literature and grey literature (informally and unreviewed media and publications). Other parameters for literature

searches included: English-language articles from peer-reviewed and grey literature, geographic location (Ontario-based), and availability for primary review.

Keywords

Electronic searches combined the following terms: FASD; fetal alcohol spectrum disorder; FAS; fetal alcohol syndrome; alcohol related neurodevelopmental disorder; ARND; and On* (Ontario); and/or programs; services; resources; support; help; group.



Electronic Databases

Peer-reviewed journals were searched using PubMed, ProQuest, Scholars Portal, CINAHL, MEDLINE, and PsycINFO. Non-peer-reviewed scholarly literature (books, unpublished literature) were searched through the Queen's University Library "Summons" search, ProQuest International Theses and Dissertations, Google Books and Google Scholar.

Content-Searching

Reference lists of key articles and key journals were hand-searched for content that might not have been captured by the databases used. Content pages of the following key journals were included: Canadian Journal of Clinical Pharmacology; Journal of Fetal Alcohol Syndrome International; Canadian Journal of Public Health; Journal of Studies on Alcohol and Drugs; Alcoholism: Clinical and Experimental Research; Journal of Fetal Alcohol Syndrome; and Journal of Fetal Alcohol Disorders International.

Grey Literature

Arksey and O'Malley (2005) suggest that researchers undertaking a scoping study utilize an explicitly defined search strategy for gathering the grey literature they will include in the review. For the purposes of this research, we define the term "grey literature" to include all mediums of literature available through existing networks, search engines, websites, organizations, organizations, conferences, government organizations, research institutions, and professional associations (McColl et al., 2009). Grey literature selected for inclusion in the review was limited to Canadian content, and with over 1 million hits, time constraints limited our review of information to include only the first 1000 hits (10 pages of results) for each of the search term combinations (total 8000 hits).

Finally, 17 government websites were searched, and key informants identified in the literature were contacted via email or telephone to ensure the comprehensive nature of our data. Literature searches were conducted by two researchers, spanning a period of 12 months (September 2010 to September 2011). Key websites were identified for individual review.

Through this process, a total of 612 published documents, research articles, unpublished documents, audio-visual resources, websites, newsletters, and resources under development were charted and retained for more extensive review. Key websites were identified and charted for individual review.

Select Relevant Literature

We included literature published since 2001, outlining treatment, diagnosis, screening tools, education, and intervention or support specifically provided to residents affected by prenatal alcohol exposure and their families. Post-hoc study selection was conducted on abstracts in the database results, with exclusion criteria including: geographical origin of study sample (outside of Eastern Ontario), relevance to programming, language (English only), availability of literature, and originality of article. Sources of information that featured provincial programming in a broad sample that included Eastern Ontario were also included for further analysis.

Services and interventions focused exclusively on primary prevention of FASDs were excluded from this analysis if they did not also provide direct services to residents affected by FASD. Excluded primary prevention services included national or provincial programming that singularly focused on prenatal prevention, including identifying at risk mothers, educating women who abuse substances, prenatal testing, or prenatal screening. However, if a program or service for primary prevention also offered direct services to clientele affected by prenatal exposure to alcohol, these data were included in the analysis. Information sources pertaining to research occurring in Eastern Ontario in the absence of providing a direct service were also excluded from further analysis.

Based on these criteria, 515 sources of information were excluded, leaving 97 remaining data sources pertaining to direct services available to residents in the Eastern Ontario region. This final set of data offered information on programs and services providing: (1) primary prevention of FASD in addition to direct services for individuals and caregivers affected by FASD; (2) services for individuals living with FASD; and/or (3) services for caregivers of people with FASD.

Chart Data

The final 97 data sources were reviewed in detail by the researchers, and the services featured in the data were categorized according to key concepts that they described. Researchers collaboratively identified four different categories of services in Eastern Ontario (See Table 1). In the case that a data source included information on more than one theme, we included this source in our analysis for all applicable areas.

Collate, Summarize, and Report Results

The results of the scoping review are presented in a manner that corresponds with the features of the four categories of direct services available to residents of Eastern Ontario.

Consult with Key Stakeholders

We chose to include this optional stage of the scoping review in our methodological framework. This allowed for the incorporation of stakeholder input and recommendations throughout formation of this project. Following recommendations by Arksey and O’Malley (2005), key opinion leaders identified in the data were contacted over email or telephone for their input throughout the project. These key opinion leaders represented parents, educators, researchers, consultants, committee members, Aboriginal representatives and individuals with FASD.

Environmental Scan Methodology

Originating within the business context as a valuable method for retrieving and organizing needs assessment data, the environmental scan methodology has been growing in use and complexity, recently emerging as a popular method of effectively determining the health care needs of communities (Graham et al., 2008; Scobba, 2010). Similar to the scoping study, both external and internal sources of data are utilized during an environmental scan. External sources of data include corporate media and sources, government data, and academic literature; internal sources include the informal records and knowledge held by individuals or organizations, personal communications, minutes of meetings, memos, and other internal documents. The use of this invaluable internal data allows for researchers to explore the health care experience at the grassroots level through the documentation of informal networking between individual entities. Recently, environmental scans have been utilized by health care researchers to specifically address services for FASD in various Canadian regions and populations; and also to address related areas of: mental health, knowledge transfer, women’s health and Aboriginal health (Clinesmith & Pacey, 2008; Graham et al., 2008; NCCAH, 2006; 2010; NSHPP, 2008; PIWC, 2010).

As methodological frameworks for environmental scans in health care are still developing, we drew from organizational develop-

Table 1. Categories of Services in Eastern Ontario for Residents Affected by FASD

<i>Category</i>	<i>Inclusion Criteria</i>
1. Screening and diagnosis	Provide or propose the provision of screening or diagnostic services that include consideration of the possibility of prenatal alcohol exposure in clientele.
2. Family and community services	Organized provision of services that target the identified needs of families, individuals, and professionals who are affected by FASD; containing explicit reference to service provision for individuals with FASD.
3. Social and education services	Educational programs designed for people with FASD, or programs designed to educate people about FASD; and programs funded through social services, including public and Catholic school boards, and the criminal justice/ corrections system.
4. Aboriginal approaches	Programs and services designed by Aboriginal peoples for Aboriginal peoples, with the explicit purpose of addressing FASD in a culturally appropriate manner.

ment research conducted by Choo (2001) and utilized a modified “conditioned viewing” (i.e., collecting existing knowledge from well-established sources) and “searching” elements into our framework (i.e., actively contacting organizations in the environment) by incorporating search strategies and recommendations from environmental scans previously conducted on issues related to FASD (Choo, 2001; Rowel, Moore, Nowrojee, Memiah, & Bronner, 2005). Our methodology included the four characteristics of environmental scans as outlined by the American Society of Association Executives (ASAE): (1) identify the issue; (2) gather information from a variety of sources; (3) consult with key informants; and (4) study trends in data, while also considering trends in other industries (Blankin & Liff, 1999).

Sample

The broad region of Eastern Ontario, as defined by the Ontario provincial government, was surveyed for the purpose of this environmental scan. This region consists of three provincial local health integration networks (LHINs): (1) Central East LHIN; (2) South East LHIN; and (3) Champlain LHIN (See Figure 1). Together, these three LHINs total an area of 54,146 square kilometres, and represent a population of over 3.1 million Canadians living in over 600 communities (Government of Ontario 2006; 2009; 2011).

Environmental Scan Data Collection and Analysis

Identify the Issue

The purpose of the environmental scan was to collect the evidence required to raise awareness of the state of FASD service availability to residents in Eastern Ontario, explore the experience of FASD at the grassroots level and to identify and illustrate gaps in service delivery.

Gather Information from a Variety of Sources

Search strategies were primarily conducted through the internet, and involved gathering and organizing information from a variety of

sources, including: (1) internet search engines; (2) federal and provincial government websites; (3) email listserves; (4) hospital websites; (5) research registers; (6) existing networks, relevant organizations; (7) conference proceedings; and (8) social media. In addition to this strategy, key informants and school boards were directly contacted and invited to contribute any additional information on programs and services not broadcast on the internet. Search results were limited to literature published within the last five years (2007–2012); and data were drawn from both peer-reviewed literature and grey literature. Other search parameters for literature searches included: English-language articles from peer-reviewed and grey literature, geographic location (Ontario-based), and availability for primary review. Search terms combined the key words used in the scoping review: FASD; fetal alcohol spectrum disorder; FAS; fetal alcohol syndrome; alcohol related neurodevelopmental disorder; ARND; and On* (Ontario); and/or programs; services; resources; support; help; group.

Consult with Key Informants

The previous scoping review phase of this research created an advisory group of key informants residing or practicing within Eastern Ontario to aid in identifying and obtaining potential sources of internal information from primary sources. Many of these key informants continued to contribute to the project during the environmental scan. This advisory group consisted of: two academic researchers, one mental health nurse specializing in FASD, one local FASD service provider, one parent of an individual with FASD, and two special education representatives from regional school boards. Members of the advisory group were consulted throughout the environmental scan and were instrumental in the creation of an inventory of key informants, resources, and literature.

Study Trends in Data

Region-specific services identified in the data collection and literature review were superimposed on a map of Ontario, and included according to their geographical location in the province. This strategy was chosen in order to track the geographical availability of the ser-

vices and services in relation to residents of Eastern Ontario. Under the classifications identified in the scoping review, key characteristics of the available services were identified and data regarding these characteristics were extracted and put into a table format. In instances that programs represented more than one service area, they were listed in all applicable areas.

Results

The results of the scoping review describe the scope and nature of FASD services and a foundation for interpreting the environmental scan, while the results of the environmental scan address the objectives pertaining to service accessibility and gaps in service provision. For ease of interpretation, the results of each methodology are presented separately.

Scoping Review Results

Four themes regarding service provision emerged with rough grouping, and were validated through consultation with key informants (refer back to Table 1 for details on inclusion criteria). These themes included: (1) services for screening and diagnosis of FASD, (2) family and community support services, (3) social and education services, and (4) Aboriginal approaches to service delivery.

Screening and Diagnosis

Emerging research from Ontario universities includes innovative screening techniques like eye-tracking methods that examine oculomotor control of people with FASD (Green, 2008) and meconium testing (MacLeod, 2011); however, these approaches are not common practice as they are subject to further research and are expensive to implement. Other prominent research focuses on policy development that will promote a universal screening method for Ontario FASD diagnostic clinics (PHAC, 2005). The PHAC has partnered with many Ontario researchers to develop and implement an initiative for improving the capacity of communities to screen for FASD. They have created a screening toolkit for FASD that is based on the Canadian guidelines for diagnosis (of FASD), and have made it freely available for download from the *Knowledge Exchange Network* website

found at www.ken.caphc.org (Maynard, 2011). While still under review for national approval, the toolkit includes five screening tools commonly used in widespread screening for FASD in a variety of populations: the *Neurobehavioral Screening Tool (NST)* for children and youth 6–18 years; information on *Meconium FAEE Testing* for newborns and at-risk new mothers; the *Maternal Drinking Guide Fact Sheet and Tool* for at-risk women; the *Medicine Wheel Student Index* and the *Medicine Wheel Developmental History* (developed by Aboriginal populations) for children 4–14 years of age and at-risk mothers; and the *FASD Screening and Referral Form for Youth Probation Officers*, targeting youth in the justice system (Maynard, 2011).

Diagnostic clinics across Ontario are encouraged to follow the interdisciplinary approach outlined in the Canadian Guidelines for FASD diagnosis (Chudley et al., 2005). Rather than operating as clinics exclusively specializing in FASD diagnosis, emerging Ontario clinics are exploring the efficacy of the inclusion of FASD screening and diagnosis embedded in the scope of practice of existing interprofessional developmental paediatric clinics (Goh, Koren, & Kay, 2007; Guilfoyle, 2006). This reportedly helps to diminish the assumption of a FASD diagnosis, the stigma of a referral, and to decrease disconnect between FASD diagnosis and continued access to broad community-based resources for children with developmental disabilities (S. Burns, personal communication, October 24, 2012). While innovative training opportunities continue to emerge, Eastern Ontario continues to struggle to train healthcare providers on screening and diagnosis, especially in relation to the diagnosis of FASD in adult clientele (Goh et al., 2007). Funding for FASD-related screening and diagnostic services is primarily obtained through unsustainable methods such as donations and grants.

Family and Community Approaches

Respite services are highly valued and sought after by parents and caregivers of children with FASD as they are critical to preventing caregiver burnout, reducing family isolation, and increasing family stability (Whyte, 2010). Families affected by FASD identify the following barriers to obtaining respite services: not knowing where or how to access services, a lack

of services within their area; respite services are unaffordable and children with FASD often do not qualify for funding; and, many respite providers do not know how to care for a child with an FASD (Whyte, 2010). In our study, key informants validated these findings, reporting that respite services are limited within the Eastern Ontario region and that parents tend to require a co-occurring diagnosis in order to be eligible for funded services through developmental service agencies.

In addition to respite services, support groups are found to be extremely helpful to families who are coping with the diverse experience of caring for a person with FASD (Kellerman, 2003). Support groups often develop informally through collaboration between parents and professionals with a common goal within the community, and there are several professional committees and family support groups that have formed in the Eastern Ontario region in order to lead the development of community approaches to FASD.

Ontario also supports many initiatives featuring research on the social impacts of FASD, specifically in terms of the relationships between family involvement and FASD outcomes. Emerging research looks at: developing best practices regarding father involvement in FASD (Gearing, McNeill, & Lozier, 2005); the impact of support groups on non-biological caregivers' experiences of FASD (Porty, 2009); and the effects of a diagnosis of FASD on birth mothers (George et al., 2007).

Social and Education Approaches

FASD is not a recognized exceptionality within the Ontario public education system. Some children diagnosed with FASD may have individualized education plans (IEPs) assigned to them, but they rarely qualify for the educational supports they require for success in the school environment (FASD ONE Intervention and Support Working Group, 2010). As a result, parents will often advocate for special education accommodations on the basis of an ADHD diagnosis rather than FASD diagnosis. Students with FASD reportedly receive similar intervention strategies as students with autism to deal with limitations within the classroom setting (T. Jordan, personal communication, January 13, 2011). Recognizing that a disrupted school experience is a secondary disability

associated with FASD, the FASD Coalition of Ottawa has developed a *FASD and School Working Group* that is leading the movement toward the inclusion of FASD in special education services in Champlain LHIN.

Ontario residents with FASD face similar inequity in other social systems. They are over represented in the foster care system, with over 60% of parents participating in a recent provincial survey identifying as foster or adoptive parents (Whyte, 2010). Children with FASD in the foster care system are more likely to experience multiple placement breakdowns resulting from the behavioural challenges they present with, which results in their early placement in intensive private residential group models of care (Ontario Association of Residences Treating Youth, 2008; Gharabaghi, 2009). Moreover, people with FASD are very likely to become involved with the justice system, both as victims and as perpetrators (Fraser & McDonald, 2009).

While the true prevalence of FASD within the justice system has not been established, several studies indicate that the disorders may affect as high as 50% of some populations in the prison system (Fraser & McDonald, 2009). The FASD and Justice website (fasdjustice.ca) is a resource designed for professionals working within the justice system. In addition to providing information on FASD with regards to case law, legal resources, screening, and strategies for effective intervention, the website offers a current and comprehensive inventory of program developments in the justice system (FASD ONE: Justice Committee, 2010). Recently adopted at the national level, this initiative originated in Ontario and promotes appropriate options for people affected by FASD who are involved in the justice system, in addition to increasing knowledge and awareness of the impact of FASD in the court systems.

In addition to emerging services for FASD in the mainstream justice system, several Aboriginal initiatives are also implementing innovative approaches to effective community-based rehabilitative justice programming that support offenders and youth with FASD. An example of this is the Akwesasne Community Justice Program, a unique program that implements a true community-based rehabilitative approach to offenders, including those affected by FASD (Mohawk Council of Akwesasne, 2012). Bridging

Canada and the U.S., the Akwesasne Mohawk community is in a unique geographical position that imposes several jurisdictional conflicts on community operations. In addition to managing national jurisdiction issues affecting the governance of this community, the Akwesasne Territory also overlaps the Canadian provinces of Ontario and Quebec. In order to address the many jurisdictional conflicts associated with their geographical location, the Mohawk Council of Akwesasne have been granted primary responsibility for their justice system with regards to traffic laws, community laws, band bylaws, and minor criminal code offences (Clairmont & Augustine, 2009). Their traditional approach to conflict resolution provides an alternative to the mainstream court process, and is credited for exceptionally effective rehabilitation for people with FASD involved in the justice system.

Aboriginal Approaches

In agreement with published literature (Hannigan et al., 2010; Maguire, 2004; May et al., 2009; Whaley & O'Connor, 2003), evidence for well-established and effective models of service delivery in Aboriginal communities emerged from this research project. Best practice models for addressing FASD developed by Aboriginal communities are increasingly being recognized in the FASD literature and professional communities for their functional and comprehensive approach to FASD service delivery and interventions (Chudley et al., 2005; George et al., 2007; Maguire, 2004; May et al., 2009). While there is overlap between all Aboriginal services and the other categories, the literature consensus is that Aboriginal approaches represent a distinctive community-based approach to service delivery and intervention that is complicated by systematic barriers to accessing these services (for non-community members). The funding sources and community base supporting service delivery often prevents individuals from outside the host communities from accessing these services. These characteristics supported our decision for separate consideration of Aboriginal approaches to service delivery.

Strategies for supporting the prevention of disabilities associated with FASD that have a strong presence within Eastern Ontario include: Ontario Federation of Indian Friendship Centres (OFIFC), Aboriginal FASD and

Child Nutrition Programs, the Aboriginal Healthy Babies Healthy Children Program, and the Aboriginal Health and Wellness Strategy. In addition to these provincial initiatives, the Community Action Program for Children (CAPC) provides funding to Aboriginal organizations in Eastern Ontario, identifying the provision of family support and developmental screening (explicitly including FASD) as part of the funding allocated for these community based services (PHAC-CAPC 2010).

Environmental Scan Results

The results of the environmental scan were charted according to: (1) the themes that emerged from the scoping review; and (2) geographical region/communities served. These results were subsequently mapped onto a representation of the geographical region, and four distinct areas of activity emerged with few scattered programs outside these areas (see Figure 2). We anticipate separate publication of these details at a later date, for widespread utility by stakeholders and families affected by FASD.

Screening and Diagnosis

Validated through direct contact with service providers, this environmental scan identified 10 diagnostic clinics in the Eastern Ontario region that report following the FASD Canadian guidelines for diagnosis (Chudley et al., 2005). Figure 3 provides a visual representation of the distribution of these FASD diagnostic clinics in Eastern Ontario. In addition, Eastern Ontario currently offers 11 sites for developmental screening that include FASD screening. Four of these provide genetic screening to clientele in order to rule out conditions that share symptoms with FASD; one provides assessment and consultation leading to referral for diagnostic assessment; and the remaining six sites are specific to Aboriginal communities.

Services Targeting Family and Community

The environmental scan identified 17 support groups and professional committees in Eastern Ontario. Of these, 12 were identified as support groups, two as task groups, and three as professional coalitions. Support groups often

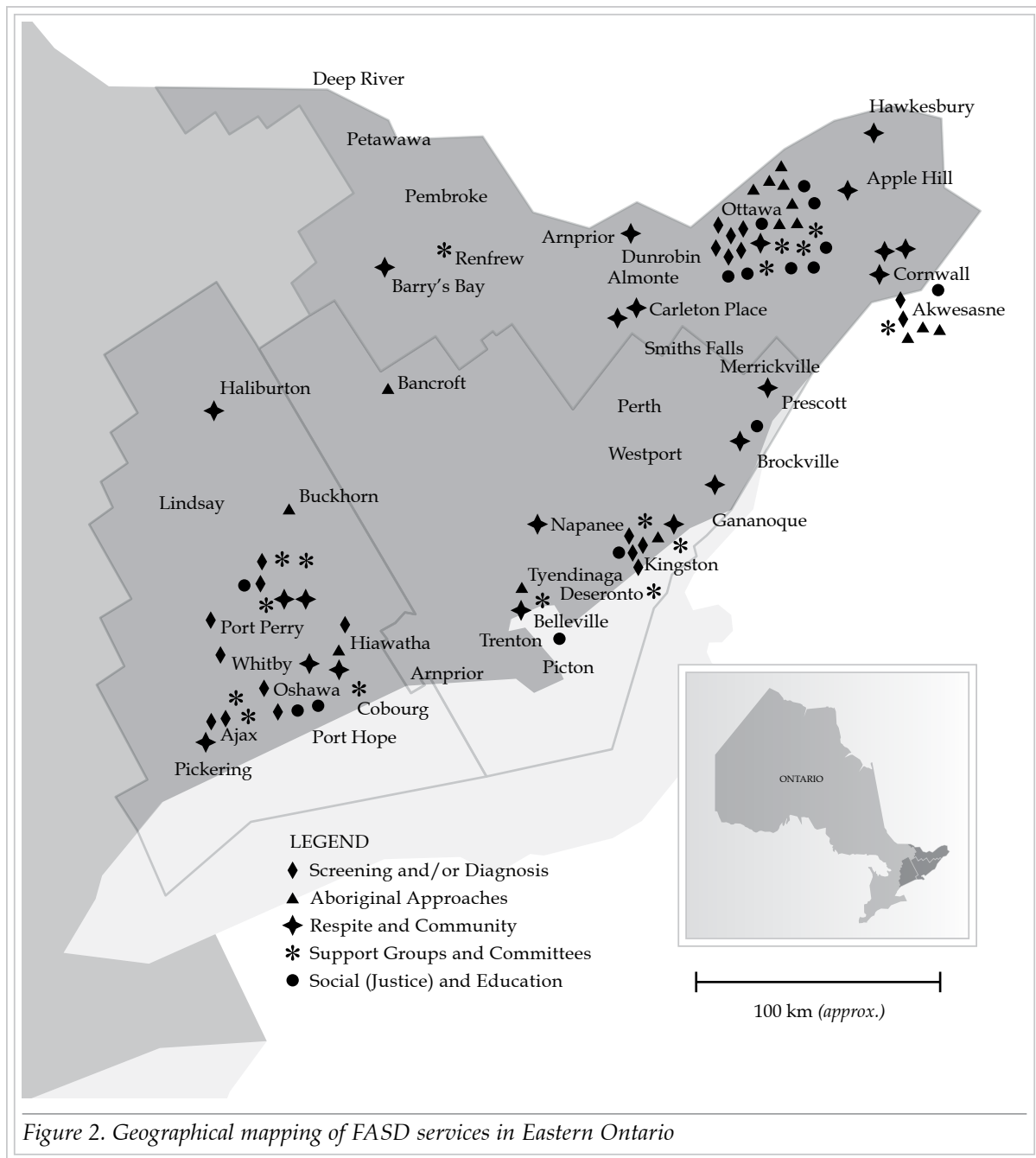


Figure 2. Geographical mapping of FASD services in Eastern Ontario

included service providers as members, fulfilling more than one role; and some support groups specifically served families, Aboriginal people, caregivers, youth, or Inuit clientele.

The environmental scan also identified 21 respite service providers in the Eastern Ontario region that specifically identify serving clientele with FASD. For access to fee-for-service respite services targeting developmental disabilities in general, respiteservices.com is a

valuable online resource for parents throughout the region to connect with independent respite providers in their community. However, families and key informants report that respite service providers are often unaware of best practices for FASD. The Durham region of Eastern Ontario emerged as a leader in the provision of respite services addressing the unique needs of individuals affected by FASD, offering specialized summer camps and fee-for-service respite.

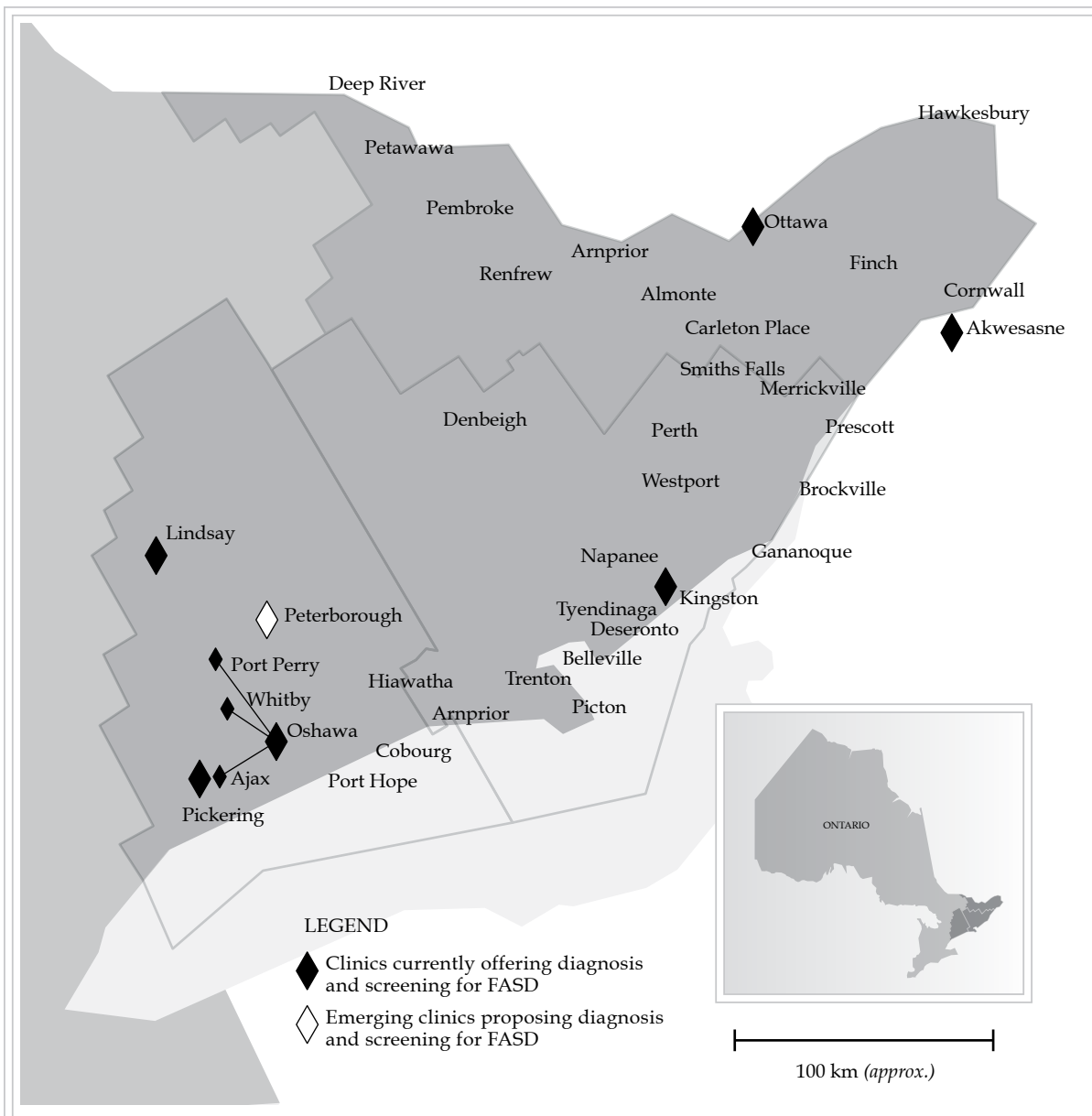


Figure 3. Geographical representation of FASD diagnostic clinics in Eastern Ontario

* Grandview Children’s Treatment Centre in Oshawa has four sites that offer FASD diagnostic clinics.

Social and Education Services

While there are several public school boards in Eastern Ontario that have identified FASD as an area of concern and a priority for consideration, there are currently no formal elementary or secondary public school programs that specifically target the learning needs of children with a primary diagnosis of FASD (C. Deschamps, personal communication, January 12, 2011; A. Marcott, personal communication, January 13, 2011; B. Grandy, personal communication, January 13,

2011; T. Jordan, personal communication, January 13, 2011). Within select school boards, Special Education Advisory Committees (SEACs) reportedly make an effort to include professional development training opportunities for teaching and support staff, but participation in these informal opportunities is often voluntary and is not offered on a consistent basis. Table 2 offers a summary of the education initiatives in Eastern Ontario that target the public school-based educational needs of families and individuals affected by FASD.

Table 2. School-Based Programming and Education Services for Individuals with FASD in Eastern Ontario

<i>Service</i>	<i>Service Provider</i>	<i>Summary of Service</i>
Adult Education	FASTEC: Parrot Learning Centre (613) 961-7112	FASTEC provides clients with a quiet working space, professional support, advocacy, and access to computers in the FASTEC office, facilitating client's engagement in successful return to community-level high school education.
Public School Board (SB) Initiatives for Special Education and FASD	Catholic District SB of Eastern Ontario (613) 283-5007 Ext. 205	Includes a regular member of the Ottawa FASD Coalition on the SEAC. This representative regularly presents/facilitates presentations on FASD to staff during monthly meetings (CDSBEO, 2006; 2012). IEPs focus on strengths instead of diagnosis; interventions similar to those used with autism (T. Jordan, personal communication, January 13, 2011)
	Ottawa-Carleton District SB (613) 596-8713	Plans to address FASD as part of student mental health initiatives, including the provision of specific training on FASD for teaching and support staff (OCDSB, 2011).
	Conseil des écoles publiques de l'est de l'Ontario	Social workers on the SEAC provide training to staff on FASD (C. Deschamps, personal communication, January 12, 2011)
	Upper Canada District SB (613) 342-0371	Historically supported FASD prevention through staff training and student education, including the use of S. Shannon's "FAE - The Million Dollar Baby," and FASD activity kits for students (Guthrie, 2002). No information on activities for FASD since 2005 (Lanark County, 2005)
	Algonquin and Lakeshore Catholic District SB (613) 354-6257 Ext. 482	Services for students with FASD are provided by a speech-language pathologist and a "Special Assignment Teacher for Special Education," who provides support to staff teaching students with FASD or suspected FASD. Developmental assessments are not required for school assessments (A. Thompson, personal communication, January 24, 2011)
	Peterborough Victoria Northumberland & Clarington Catholic District SB (705) 748-4861 Ext. 289	Special Education Consultant for FASD actively liaisons with the local FASD Committee to provide resources to families, teachers, and students diagnosed with FASD. IEPs are developed in collaboration with FASD specialists; Staff participate in workshops on teaching students with FASD (E. Mason, personal communication, January 14, 2011)

(continued on following page)

Table 2. School-Based Programming and Education Services for Individuals with FASD in Eastern Ontario (continued)

Service	Service Provider	Summary of Service
School Authorities	Ottawa Children's Treatment Centre School Authority (613) 737-0871 Ext. 4425	OCTC does not run specific programs for FASD; however, they provide a wide range of supports such as treatment, assessment, intervention, and education services to <i>children who are developmentally delayed as a result of FASD</i> . Support is not identified by diagnosis, but rather by developmental need (B. Grandy, personal communication January 12 2011).
	Campbell Children's School Authority (CCSA) (905) 576-4414	The education partner of Grandview Children's Treatment Centre (GCTC), CCSA serves students with communication and/or multiple disabilities through specialized programs. Students must be GCTC clients; admission is primarily based on students' therapeutic requirements for school readiness, participation, and success.
Private Consulting	Edu-Advocates (Dale Ford) (613) 769-8960	Fee-for-service: Former spec. ed teacher mediates between parents, teachers, principals and school boards to address spec. ed needs.
School Working Groups	FASD and Schools Working Group info@ottawayoungparents.com	A Working Group of the FASD Coalition of Ottawa striving to increase awareness of FASD in schools, act as a resource to improve educational outcomes, and provide guidance on how to support individuals with FASD in the school system.

There are eight federal penitentiaries located in the Eastern Ontario region. While the Canadian Corrections system has implemented several FASD training programs for staff, there are relatively few federally funded community services in the immediate region that have a clear FASD mandate: we identified three sites offering an emerging intensive community rehabilitation that is program designed to support the unique rehabilitation needs of individuals with FASD. This model has been developed to provide intensive clinical and community supports, supervision and crisis management for youth diagnosed with a mental illness or disorder who may be sentenced, and is currently implemented in Ottawa, Kingston, and Oshawa. We also identified three more justice programs that have been designed by Aboriginal people for Aboriginal youth with FASD, two through the Wabano Centre for Aboriginal Health in Ottawa, and the Akwesasne Justice program near Cornwall.

The Akwesasne justice programs are unique to their community and currently include: Diversion; Neh Kanikonriio Council; Youth Court Workers; Youth Reintegration Workers; and Community Service Monitors (Mohawk Council of Akwesasne, 2012).

Aboriginal Approaches to Service Delivery

In addition to the Aboriginal justice programs previously described, the environmental scan identified 17 sites for FASD service delivery in Eastern Ontario. The Aboriginal Healthy Babies Healthy Children programs are currently offered at seven sites in Eastern Ontario; Aboriginal FASD and Child Nutrition is offered at four sites, and the Community Action Program for children is offered at two sites. The remaining services are community-specific, offering services that include: education on FASD, pre and post natal screening/

assessment, training staff on FASD, increasing community awareness, providing family support and providing early intervention. In addition to these, the OFIFC offers a FASD program that has historically provided services, education, and avocations for individuals with FASD; however, it is currently only offered in five Friendship Centres, all within Northern Ontario and only offers intermittent programming events through Eastern Ontario sites (OFIFC, n.d.b). However, employees working at OFIFC Friendship Centres in Ontario receive FASD training, which is then shared with a broad range of individuals and families and community members utilizing the friendship centres (Public Safety Canada, 2010).

Discussion

The objectives of this project were to: (1) inform stakeholders on the scope and nature of FASD services available in Eastern Ontario; (2) present a comprehensive review of service accessibility; and (3) to identify gaps in service provision that contribute to the occurrence of secondary disabilities in residents of Eastern Ontario who are affected by FASD. The results of the scoping study are validated by the results of our environmental scan, illustrating the effects of knowledge gaps on service delivery, specifically in the eastern region of Ontario.

The range of services represented in Eastern Ontario is representative of the scope and nature of services illustrated in provincial literature; however, there are some important points for consideration we will discuss in relation to each classification of services. As depicted in Figure 2, there are often several hundred kilometres between communities and FASD services, representing a significant barrier to service accessibility to families residing outside of urban centers. Moreover, it is important to consider that access to many community services may be contingent on eligibility criteria regarding community membership. While this is especially important to consider in regards to Aboriginal services and programming, it also applies to LHIN-specific initiatives requiring a medical referral and specifying residence within the LHIN catchment area.

Diagnosis and Screening

Our research identified a clear gap in opportunities for a formal diagnosis of FASD within the Eastern Ontario region. The Children's Hospital of Eastern Ontario (CHEO) offers a multidisciplinary approach to screening and diagnosis of FASD for both children and adults residing in their large service area, which includes Eastern Ontario, Western Quebec, Nunavut, and parts of Northern Ontario; resulting in a lengthy wait time for clientele querying a FASD diagnosis (Fox, 2009). The central (Kingston) clinic reportedly assesses fewer than 15 children suspected of having FASD per year, and the Akwesasne screening and diagnostic clinic services are only available to select Aboriginal clientele. The disparity in the availability of diagnostic services to residents of Eastern Ontario is further compounded by the fact that the other major diagnostic clinics (Grandview Children's Centre and Resources for Exceptional Children and Youth) are located at the edge of the western border of the region surveyed, providing services exclusively to residents of the Durham region, nearly 500 kilometres away from communities at the eastern border of Ontario. The current availability of formal diagnostic services in Eastern Ontario is not adequate to serve a region with over 3.1 million people. The results of our study indicated that each diagnostic program in Eastern Ontario outlined specific eligibility criteria based on geographic locations served, and discussion with key informants indicated that while there is sometimes flexibility regarding acceptance of referrals outside of the catchment area, this occurs on a case-by-case basis and referrals from community members are often given priority.

Our results suggest that in order to address the gaps in early screening and diagnostic capacity within Eastern Ontario, the implementation of universal screening procedures are needed along with the creation of additional diagnostic clinics throughout the region. Our analysis of the results of screening initiatives indicate that even within organizations, community sites do not often offer the same screening services. For example, the "Pathways for Children and Youth" site located in Kingston, Ontario offers assessment and consultation for FASD in children up to 18 years of age, but to the best of our knowledge, no other sites in Eastern Ontario offer this service.

There are several provincially funded indirect screening initiatives offered through provincial health units in the region that are in the ideal position to utilize these screening tools, including: the *Ontario Early Years Programming*, the *Healthy Babies/Healthy Children Program*, and the *Aboriginal Fetal Alcohol Spectrum Disorder and Child Nutrition Program*. These multi-site programs were designed to screen for developmental disorders and therefore have the potential to explicitly address screening children for FASD and other developmental disorders in the populations that they serve. In practice, however, they have not consistently included coordinated national screening and education approaches within mainstream communities and do not typically result in consistent FASD screening approaches, with the exception of the Aboriginal-led programming.

Services Targeting Family and Community

Families and individuals affected by FASD in Eastern Ontario face numerous barriers to accessing provincially-funded respite services and community support. They often tend to rely on co-occurring diagnoses to receive respite funding, but report that the respite services they have access to often are not educated on the appropriate approaches to care provision for individuals with FASD. Provision of respite care is vital to combat the burnout and fatigue associated with caring for an individual with FASD, and has been found to be extremely effective in reducing caregiver stress, increasing family stability, decreasing isolation of the family and reducing failed placements in foster care (Gharabaghi, 2009; Whyte, 2010). Considering the prevalence of FASD in the Canadian school-aged population, it is clear that respite providers need to provide education on FASD to their employees.

Social and Education Services

Many individuals and families rely on co-occurring disorders in order to receive intervention services. This seems to be the result of a number of factors, including difficulty and reluctance to seek a FASD diagnosis, policy within the education system, and the lack of a provincial strategy in Ontario to address services (Hall et al., 2010;

Whyte, 2010). This is especially clear in the education system, illustrated in the results of our environmental scan by a lack of educational policy accommodating students with FASD. Reliance on co-occurring disorders to obtain intervention services may result in inappropriate or ineffective interventions for students with FASD.

With regards to the criminal justice system, our results indicate that there are still very few opportunities for individuals with FASD. This is especially apparent in the South East LHIN, which hosts five maximum security federal penitentiaries, yet only offers three small programs for clientele identified as at risk for a FASD diagnosis. Although many probation officers are now receiving training on how to work with clientele affected by FASD, training and education must reach all levels of the justice system including police and prison guards, administration, and policy developers.

Aboriginal Approaches to Service Delivery

Despite emerging professional recognition of the advanced approaches to FASD intervention that are associated with Aboriginal service delivery, externally funded Aboriginal service delivery in Eastern Ontario continue to struggle with the widespread misperception that FASD is a cultural problem, rather than a population problem affecting all Canadians equally. The recent inclusion of Aboriginal approaches into the CAPHC national FASD screening toolkit supports the growing professional recognition that Aboriginal cultures require a distinct and culturally appropriate approach that is sensitive to the historical relationship between Aboriginal people and the Canadian social services system (NWAC, 2002).

Our research indicates that a high proportion of services for FASD in the Eastern Ontario region are offered through Aboriginal communities. When interpreting these results, however, it is important that non-Aboriginal readers are aware that Aboriginal peoples are not a homogenous group. While there are some similarities in terms of worldviews, each community is associated with a distinct culture and membership is not inclusive.

Although it appears that Aboriginal FASD initiatives are well developed and culturally appropriate within Ontario, our research indicates that many of these approaches have not been analyzed in terms of efficacy, and are focused more on primary prevention initiatives than they are on the provision of programs that actively support individuals and families affected by FASD.

Limitations and Concluding Remarks

The methodologies utilized for this report were an ideal fit with the objectives of this project, as it provided an alternative method of transparently mapping out services available to a specific region; however, it is important to draw attention to the limitations of our approach. The research methodologies used do not control for the quality of the data included in the study, providing a descriptive review of the breadth of available data instead of synthesizing data that is reliably accurate. Moreover, the scope of the media included in data analysis was largely dependent upon effective networking between the researchers, service providers, key informants, and the search terms utilized.

When considering the results of this study, it is important for the reader to be aware of the cultural misconceptions often associated with FASD. The positive contributions of Aboriginal populations on FASD research and intervention services are officially recognized in several literature sources; however, there remains a widespread misconception that these populations experience higher incidence and prevalence rates of FASD, which is reinforced by the amount of research featuring small subsets of Aboriginal populations (Chudley et al., 2005; George et al., 2007; Maguire, 2004; May et al., 2009). Researchers, service providers, and policymakers building on the results of this study will need to practice in a culturally competent manner that includes members of Aboriginal populations as equal partners with a unique expert opinion on the community health and sociocultural effects of FASD on their communities.

The results of this environmental scan clearly identify that both FASD services for individuals

and FASD services for families are scarce in the Eastern Ontario region. There is very little information available on the specific nature of interventions offered in Eastern Ontario. The current system seems to “piggy-back” FASD services onto services provided for disorders that commonly co-occur with FASD. While this approach complements a model of service provision that is emerging in Ontario, the data we collected echoes the consensus that this approach is only effective if service providers are educated on FASD and clearly include FASD within their mandate.

Services are also provided within the parameters of interventions targeting secondary disabilities, and these interventions seem to do little to address the underlying primary disabilities and adaptive functioning issues associated with FASD. Service approaches that are emerging from Aboriginal communities and service providers within the justice system show some promise in terms of proactive approaches. It is important to consider that often these services are only offered to clientele after secondary disabilities have already developed. Broad-based services provided within the parameters of interventions targeting secondary disabilities seem to do little to address the underlying primary disabilities and overall functional issues associated with prenatal exposure to alcohol. We hope that the results of this scan will serve as a functional tool for individuals, families, policy-makers, researchers, service providers, and health care providers to maximize existing program use and reduce the effects of secondary disabilities.

Key Messages From This Article

People with disabilities: Ontario has some strong areas in FASD services, but it is difficult to access these if you live in the Eastern Ontario region.

Professionals: Network with clients and colleagues in order to stay informed of changes to services. Most FASD services in Ontario emerge from the community level, and Ontario continues to face many barriers to service coordination.

Policymakers: The unique support needs of individuals with FASD need to be explicitly

identified in all levels of policy in order to minimize the occurrence of costly secondary disabilities. Existing developmental disabilities services are effective vehicles for supporting individuals with FASD and their caregivers; however, policies need to recognize FASD as an eligible disability.

References

- Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Research Methodology*, 8, 19–32.
- Blankin, R. L., & Liff, A. (1999). Facing the future: preparing your association to thrive: Emerging trends from the ASAE Foundation's ongoing environmental scan research. Washington: American Society of Association Executives (ASAE).
- Burgoyne, W. (2007). *Implications for Ontario: Awareness of FASD*. Ottawa: Public Health Agency of Canada.
- Chagnon, J., & Milan, A. (2011). *Population growth: Canada, provinces, and territories, 2010*. Ottawa: Statistics Canada. Retrieved from <http://www.statcan.gc.ca/pub/91-209-x/2011001/article/11508-eng.htm>
- Choo, C. W. (2001). Environmental scanning as information seeking and organizational learning. *Information Research*, 7(1). Revised and updated version retrieved from <http://choo.fis.utoronto.ca/fis/respub/chooimreader.pdf>
- Chudley, A. E., Conry, J., Cook, J. L., Loock, C., Rosales, T., & LeBlanc, N. (2005). Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. *Canadian Medical Association Journal*, 172(5 Suppl.), S1–S21.
- Clairmont, D., & Augustine, T. (2009). *Advancing the strategic justice plan in Elsipogtog: The relevance of First Nation and other initiatives for increased effectiveness and community ownership*. Halifax: Atlantic Institute of Criminology, Dalhousie University. Retrieved from the Polit Research – Aboriginal Policing & Justice Website at <http://pilotresearch.ca/aboriginal-policing-and-justice>
- Clark, E., Lutke, J., Minnes, P., & Ouellette-Kuntz, H. (2004). Secondary disabilities among adults with fetal alcohol spectrum disorder in British Columbia. *Journal of FAS International*, 2(e13), 1–12.
- Clinesmith, J., & Pacey, M. (2008). *Healthy choices in pregnancy for Aboriginal peoples in British Columbia: An analysis and recommendations*. British Columbia: Aboriginal Act Now. Retrieved from <http://www.aboriginalactnow.ca/downloads/AHCIP%20paper%20%20March%202009.pdf>
- Dell, C. A., & Roberts, G. (2005). *Research update. Alcohol use in pregnancy: An important Canadian public health and social issue*. Ottawa: Public Health Agency of Canada. Retrieved from <http://www.addictionresearchchair.ca/wp-content/uploads/Alcohol-Use-and-Pregnancy-An-Important-Canadian-Health-and-Social-Issue.pdf>
- Duquette, C., & Orders, S. (2010). Towards a provincial strategy: Advancing effective educational practices in fetal alcohol spectrum disorder (FASD). Retrieved from Intervention and Support Working Group, FASD ONE, Online via <http://www.fasdontario.ca/pdf/Toward%20a%20Provincial%20Strategy%20-%20Advancing%20Effective%20Educational%20Practices%202010.pdf>
- Environics Research Group Limited (2006). *Alcohol use during pregnancy and awareness of fetal alcohol spectrum disorder: Results of a national survey*. Ottawa: Public Health Agency of Canada.
- Fetal Alcohol Spectrum Disorders Ontario Network of Expertise (FASD ONE). (2012). Retrieved from <http://www.fasdontario.ca/groups/diagnosticClinics.htm>
- Fetal Alcohol Spectrum Disorders Ontario Network of Expertise (FASD ONE): Intervention and Support Working Group. (2010). *Advancing effective educational practices in fetal alcohol spectrum disorder*. Retrieved from <http://www.fasdontario.ca/pdf/Toward%20a%20Provincial%20Strategy%20-%20Advancing%20Effective%20Educational%20Practices%202010.pdf>
- Fetal Alcohol Spectrum Disorders Ontario Network of Expertise (FASD ONE): Justice Working Group. (2010). Retrieved from <http://www.fasdjustice.on.ca>

- Fox, D. (2009). *Legislative Assembly of Ontario court hearings, September 9, 2009*. Retrieved from http://www.ontla.on.ca/web/committee-proceedings/committee_transcripts_details.do?locale=en&Date=2009-09-09&ParlCommID=8915&BillID=&Business=Mental+Health+and+Addictions+Strategy#P1137_327579
- Fraser, C., & McDonald, S. (2009). *Identifying the issues: Victim services' experiences working with victims with fetal alcohol spectrum disorder*. Ottawa: Department of Justice Canada.
- Gearing, R. E., McNeill, T., Lozier, F. A. (2005). Father involvement and fetal alcohol spectrum disorder: Developing best practices. *Journal of Fetal Alcohol Syndrome International*, 3(e14), 1-11.
- George, M. A., Masotti, P., VanBibber, M., Loock, C., Fleming, M., McDiarmid, T., et al. (2007). Bridging the research gap: Aboriginal and academic collaboration in FASD prevention: The Healthy Communities, Mothers and Children Project. *Alaska Medicine*, 49(Suppl.), 135-137.
- Gharabaghi, K. (2009). Private service, public rights: The Private Children's Residential Group Care Sector in Ontario, Canada. *Residential Treatment for Children and Youth*, 26, 161-180.
- Goh, I., Koren, G., & Kay, J. (2007). The inaugural meeting of Ontario FASD clinics March 15, 2007, Toronto. *Journal of FAS International*, 5(e6-July 23, 2007). Retrieved from http://www.motherisk.org/JFAS_documents/JFAS7005_e6_V2.pdf
- Government of Ontario. (2006). *A framework for community engagement and local health planning*. Central East Local Area Health Integration Network (LHIN). Retrieved from http://www.centraleastlhin.on.ca/uploadedFiles/Home_Page/Integrated_Health_Service_Plan/Framework.pdf
- Government of Ontario. (2009). *Finding local solutions to local health care challenges: 2010-2011 annual report*. Champlain Local Area Health Integration Network (LHIN). Retrieved from http://www.champlainlhin.on.ca/publicationandreports.aspx?ekmense1=e2f22c9a_72_206_btnlink
- Government of Ontario: Ministry of Government Services. (2010). *Q's & A's - Sandy's law. News releases*. Retrieved from http://www.mgs.gov.on.ca/en/News/STEL02_047207.html
- Government of Ontario. (2011). *Clinical Services Roadmap: Community Engagement Report, Version 1.1*. Retrieved from http://www.southeastlhin.on.ca/uploadedFiles/Home_Page/Report_and_Publications/TAB%2011%20-%20CSR%20External%20Engagement%20Report%20July%2027%202011.pdf
- Government of Ontario. (2012). About Ontario: People and culture - population densities. Retrieved from http://www.ontario.ca/en/about_ontario/EC001035.html
- Graham, P., Evitts, T., & Thomas-MacLean, R. (2008). Environmental scans: How useful are they for primary care research? *Canadian Family Physician*, 54, 1022-1023.
- Green, C. R. (2008). *Saccadic eye movements and executive function in children with fetal alcohol spectrum disorders: Results from a multi-centred study*. Unpublished doctoral dissertation, Queen's University, Kingston, Ontario, Canada.
- Guilfoyle, G. (2006). Creating a foundation for FASD diagnostic capacity. *FASD Stakeholders for Ontario Diagnostic Working Group*. Retrieved from <http://www.fasdontario.ca/pdf/FASD%20Diagnostic%20Capacity.pdf>
- Hall, N., Cunningham, M., & Jones, S. (2010). *Towards a provincial strategy: Advancing effective service provider practices in fetal alcohol spectrum disorder (FASD)*. *Fetal Alcohol Spectrum Disorder Ontario Network of Expertise: Intervention and Supports Working Group*. Toronto: Ontario. Retrieved from <http://www.fasdontario.ca/pdf/Toward%20a%20Provincial%20Strategy%20-%20Advancing%20Effective%20Service%20Provider%20Practices%202010.pdf>
- Halloran, S. (2008). *Moving forward and supporting families affected by FASD*. *Intervention and Support Working Group, FASD Stakeholders for Ontario*. Rockwood, Ontario. Retrieved from <http://www.fasdontario.ca/pdf/Moving%20Forward%20Report%20Mar%2008.pdf>

- Hannigan, J. L., Chiodo, L. M., Sokol, R. J., Janisse, J., Ager, J. W., Greenwald, M. K., et al. (2010). A 14-year retrospective maternal report of alcohol consumption in pregnancy predicts pregnancy and teen outcomes. *Alcohol*, 44, 583–594
- Health Canada (2003). *Canadian Perinatal Health Report 2003*. Ottawa, Ontario: Author.
- Kellerman, T. (2003). *Start a local FASD support group*. Retrieved from <http://www.come-over.to/FAS/SupportGroup.htm>
- Koren, G., Fantus, E., & Nulman, I. (2010). Managing fetal alcohol spectrum disorder in the public school system: A needs assessment pilot. *Canadian Journal of Clinical Pharmacology*, 17, 79–89.
- Lavis, J. N., (2006). Research, public policymaking, and knowledge-translation processes: Canadian efforts to build bridges. *The Journal of Continuing Education in the Health Professions*, 26, 37–45.
- Legislative Assembly of Ontario (2010). *Select Committee on Mental Health and Addictions: Interim Report*. Ottawa: Author. Retrieved from http://www.ontla.on.ca/committee-proceedings/committee-reports/files_pdf/SCMHA-InterimReport-March2010.pdf
- MacLeod, S. (2011). Understanding the epidemiology of FASD: The role of meconium testing. Retrieved from <http://www.motherisk.org/FAR/fas10.jsp>
- Maguire, D. (2004). Voices from the field: An Aboriginal view on FAS/FAE. Revised Edition. In R. E. Tremblay, R. G. Barr, & R. DeV. Peters (Eds.), *Encyclopedia of early childhood development*. Montreal, QC: Centre of Excellence for Early Childhood Development (pp. 1–9). Retrieved from <http://www.child-encyclopedia.com/pages/PDF/MaguireANGps.pdf>
- May, P. A., Gossage, J. P., Kalberg, W. A., Robinson, L. K., Buckley, D., Manning, M., et al. (2009). Prevalence and epidemiologic characteristics of FASD from various research methods with an emphasis on recent in-school studies. *Developmental Disabilities Research Reviews*, 15, 176–192.
- Maynard, D. (2011). National screening tool kit for children and youth identified and potentially affected by FASD. Ottawa: Canadian Association of Paediatric Health Centres. Retrieved April 18, 2011, from <http://www.ken.caphc.org/xwiki/bin/view/FASDScreeningToolkit/>
- McColl, M. A., Shortt, S., Godwin, M., Smith, K., Rowe, K., O'Brien, P., & Donnelly, C. (2009). Models for integrating rehabilitation and primary care: A scoping study. *Archives of Physical Medicine and Rehabilitation*, 90, 1523–1531.
- Mohawk Council of Akwesasne. (2012). *Akwesasne community justice program*. Retrieved from <http://www.akwesasne.ca/Akwesasne%20Community%20Justice%20Program.html>
- National Collaborating Centre for Aboriginal Health (NCCAHA). (2006). *Landscapes of indigenous health: An environmental scan by the national collaborating centre for Aboriginal health*. Retrieved from http://www.unbc.ca/assets/nccah/english/papers/environmental_scan_nov_2006.pdf
- National Collaborating Centre for Aboriginal Health (NCCAHA). (2010). *Landscapes of First Nations, Inuit, and Métis health: An updated environmental scan, 2010*. Retrieved from http://www.nccah-ccnsa.ca/docs/1747_LandscapesofHealth_final_web.pdf
- Native Women's Association of Canada (NWAC). (2002). *Aboriginal Women and Health Care in Canada. A submission to the Commission on the Future of Health Care in Canada*. Retrieved from <http://www.nwac.ca/sites/default/files/reports/AboriginalWomenandHealthCareinCanada.pdf>
- Nova Scotia Health Promotion and Protection (NSHPP). (2008). *Fetal alcohol spectrum disorder (FASD) stakeholder forum: Towards a coordinated approach to FASD in Nova Scotia*. Retrieved from <http://www.gov.ns.ca/hpp/publications/fasd-2008.pdf>
- Ontario Association of Residences Treating Youth (2008). *Partners in care III: Information about our children*. Toronto, Canada: OARTY
- Ontario Federation of Indian Friendship Centres (OFIFC). (n.d.a). *Fetal alcohol spectrum disorder programme*. Retrieved from http://www.ofifc.org/programmes/Fetal_Alcohol_Spectrum_Disorder.php
- Ontario Federation of Indian Friendship Centres (OFIFC). (n.d.b). About the OFIFC. Retrieved from <http://www.ofifc.org>
- Pauktuutit Inuit Women of Canada (PIWC). (2010). *Inuit five-year strategic plan for fetal alcohol spectrum disorder 2010–2015*. Ottawa: Pauktuutit Inuit Women of Canada. Retrieved from http://pauktuutit.ca/assets/FASD_5yrPlan_English1.pdf

- Porty, S. (2009). *Non-biological caregivers' experiences of fetal alcohol spectrum disorder (FASD) support groups*. Unpublished master's thesis, Wilfrid Laurier University, Waterloo, Ontario, Canada.
- Public Health Agency of Canada (PHAC). (2005). *Alcohol use and pregnancy: An important Canadian public health and social issue*. Ottawa: PHAC.
- PHAC-CAPC. (2010). *CAPC Projects Directory Online*. Retrieved from <http://capc-pace.phac-aspc.gc.ca/index-eng.php>
- Public Safety Canada. (2010). *Fetal alcohol spectrum disorder and the criminal justice system*. Ottawa: Aboriginal Corrections Policy Unit, Aboriginal Peoples Collection. Retrieved from http://publications.gc.ca/collections/collection_2012/sp-ps/PS4-85-2010-eng.pdf
- Rowel, R., Moore, N. D., Nowrojee, S., Memiah, P., & Bronner, Y. (2005). The utility of the environmental scan for public health practice: Lessons from an urban program to increase cancer screening. *Journal of the National Medical Association, 97*(4), 527-534.
- Scobba, V. (2010). The environmental scan, a valuable community health research tool. *Clinical Medicine and Research, 8*, 184-185.
- Stade, B., Ali, A., Bennett, D., Campbell, D., Johnston, M., Lens, C., Tran, S., & Koren, G. (2009). The burden of prenatal exposure to alcohol: Revised measurement of cost. *Canadian Journal of Clinical Pharmacology, 16*, 91-102.
- Statistics Canada. (2006). *Aboriginal identity population by age groups, median age and sex, 2006 counts for both sexes, for Canada, provinces and territories - 20% sample data, October 2010*. Retrieved from <http://www12.statcan.ca/census-recensement/2006/dp-pd/hlt/97-558/pages/page.cfm?Lang=E&Geo=PR&Code=01&Table=1&Data=Count&Sex=1&Age=1&StartRec=1&Sort=2&Display=Page>
- Streissguth, A. P., & Kanter, J. (1997). *The challenges of fetal alcohol syndrome: Overcoming secondary disabilities*. Seattle: University of Washington Press.
- Streissguth, A. P., Bookstein, F. L., Barr, H. M., Sampson, P. D., O'Malley, K., & Young, J. K. (2004). Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Developmental and Behavioral Pediatrics, 25*, 228-238.
- Tough, S. C., Clarke, M., & Cook, J. (2007). Fetal alcohol spectrum disorder prevention among Canadian physicians by proportion of Native/Aboriginal patients: Practices during the preconception and prenatal periods. *Maternal and Child Health Journal, 11*, 385-393.
- Whaley, S. E., & O'Connor, M. J., (2003). Increasing the report of alcohol use among low-income pregnant women. *American Journal of Health Promotion, 17*, 369-372.
- Whyte, L. B. (2010). *Towards a provincial strategy: Advancing effective respite services in fetal alcohol spectrum disorder (FASD)*. Ottawa: PHAC.
- Williams, R. C., Clinton, J., Prince, D. J., & Novak, N. E. (2010). Ontario's Enhanced 18-Month Well-Baby Visit: Program overview, implications for physicians. *Ontario Medical Review, 23-27*.