

Fetal Alcohol Spectrum Disorder (FASD):

Provincial Assessment of FASD PROGRAMS AND SERVICES for Ontario Inuit

September 30, 2018

Report prepared by:



Ottawa Inuit
Children's
Centre

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The Ottawa Inuit Children's Centre (OICC)

The Ottawa Inuit Children's Centre (OICC) was established in August 2005 by parents of children enrolled in the Aboriginal Head Start (AHS) Program at Tungasuvvingat Inuit (TI). OICC serves Inuit children, youth and their families in the Ottawa Region.

In April 2006, the sponsorship of the AHS program was transferred by the Public Health Agency of Canada (PHAC) to the Ottawa Inuit Children's Centre under the leadership of a newly formed Board of Directors. The AHS program became the Sivummut Head Start Program with the aim of keeping the parent-driven philosophy and mandate embedded in the AHS Principles and Guidelines.

Today, the OICC consists of 22 programs throughout 4 locations in Ottawa and employs over 50 full time employees of which the majority are Inuk. In partnership with parents and the community, the OICC fosters strong Inuit children, youth and families by providing a learning environment that will enhance overall well-being, adaptability and strength in a proud Inuit environment. In 2017, the OICC Board of Directors expanded their mandate to include a provincial outreach with a desire to share what they have learned with other urban Inuit, children, youth and families.

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Fetal Alcohol Spectrum Disorder (FASD): Assessment of FASD Services and Programs for Inuit across Ontario

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EXECUTIVE SUMMARY

OICC is a member of the Métis, Inuit and Urban Indigenous Technical Table (MIUI) which provides input to ministry initiatives relating to the Ontario Indigenous Children and Youth Strategy. The Ottawa Inuit Children's Centre (OICC) has written the following independent report which assesses the FASD service provision for Ontario Inuit. This report focuses on the city of Ottawa, and provincial-level service providers located throughout Ontario,

primarily in the Toronto-Scarborough region, with whom OICC has established outstanding relationships.

The following report serves to assess current capacity for FASD service provision for Inuit women, children, youth and their families and caregivers within Ottawa and across Ontario. The purpose of this report is to build culturally relevant foundational FASD supports for Inuit communities.

Key Activities

- Environmental scan capturing FASD programs and services claiming to serve Inuit women, children, youth and families.
- Environmental scan on existing FASD programs and services that exist throughout Ontario significant to Inuit.
- Identification of programs and services that are known to be connected, referred to and/or partnered with that exist for Inuit women, children, youth and families.
- Assessment of gaps and challenges and identification of best-practices or initiatives that could be developed to meet the needs of the Inuit.

Key Findings

- There are service gaps and the needs of Inuit in Ontario are not being met.
- There is a lack of awareness of the Inuit culture amongst service providers.
- There is a lack of awareness of FASD programs and services by community members.
- The stigma of FASD is still a big issue in most communities, whether due to the lack of knowledge, or the defaulting effect of having to blame for the cause of such an 'injury' on the FASD-affected child.
- There is a lack of diagnostic services throughout the province. There are few diagnostic clinics and most of these existing services have waitlists.

- There is also a lack of available FASD-specific services and supports. Most of the specific services require a diagnosis that results in families being stuck in a system that has an outcome of them not getting the help they need.
- Many indigenous programs and services do not adequately reflect Inuit culture.

Recommendations

- **Develop and implement standardized care and supports** to truly get to the members that are the most affected by FASD in the Inuit community.
- **Education and Awareness.** For these services to be accurate and applicable, service providers who support individuals with FASD need to be educated, have knowledge about FASD and most importantly be grounded in Inuit culture.
- **A sense of belonging** is needed on the ground within communities that serve Inuit families, to promote a sense of welcoming support and connection.
- **Provincial conversation and push for implementation.** If FASD is seen as a priority throughout the province of Ontario, a provincial conversation and push for implementation should occur throughout all areas including those 'at risk' populations.
- **Building Capacity.** It is necessary for service providers to develop skills, awareness and cultural capacity to support Inuit children, youth, and families affected by FASD.

INTRODUCTION

Fetal Alcohol Spectrum Disorder (FASD) is a medical diagnosis that describes the range of effects that can occur when a developing baby is prenatally exposed to alcohol (Citizen Advocacy, 2018). Even though FASD is prevalent and can happen to anyone, regardless of race, ethnicity, or socioeconomic status, many individuals living with FASD are undiagnosed or misdiagnosed. In addition to being undiagnosed or misdiagnosed due to the invisibility of FASD, many individuals are stigmatized by judgements and stereotypes that are often linked to culture – including Indigenous people.

The information that follows is based on engagements that have taken place throughout the month of July and August 2018 with various service providers and community members that are directly and/or indirectly affected by FASD. These engagements have been organized and hosted by the Ottawa Inuit Children's Centre's FASD Project Coordination team.

As a follow-up to several roundtable discussions, including the 2015 FASD roundtable with Inuit stakeholders, this independent report is composed of the following themes:

A summary of the methodology used, and communities/service providers engagement;

- An initial environmental scan of existing FASD programs and services, as well as FASD relevant community programs and services throughout the province of Ontario that are available to Inuit children, youth and families.
- An assessment of FASD services accessed by Inuit and Inuit knowledge of current

programs, broken down into five analysis steps (identity, services, knowledge, perspective, and need/insight);

- An environmental scan of current programs and services offered for Inuit women, children, youth and families;
- An overall needs assessment of best practices; and
- A capacity assessment – where gaps may exist and identify practices or initiatives that could be developed to meet the needs of the Inuit;
- An identification of known and highlighted gaps and challenges throughout service provision;
- A summary based on consultation and environmental scan results, and;
- Recommendations for improving FASD service delivery to Inuit in Ontario.

This report aims to build on culturally relevant foundational FASD supports for Inuit communities in Ontario to address FASD prevention and support services for Inuit women, children, youth and families.

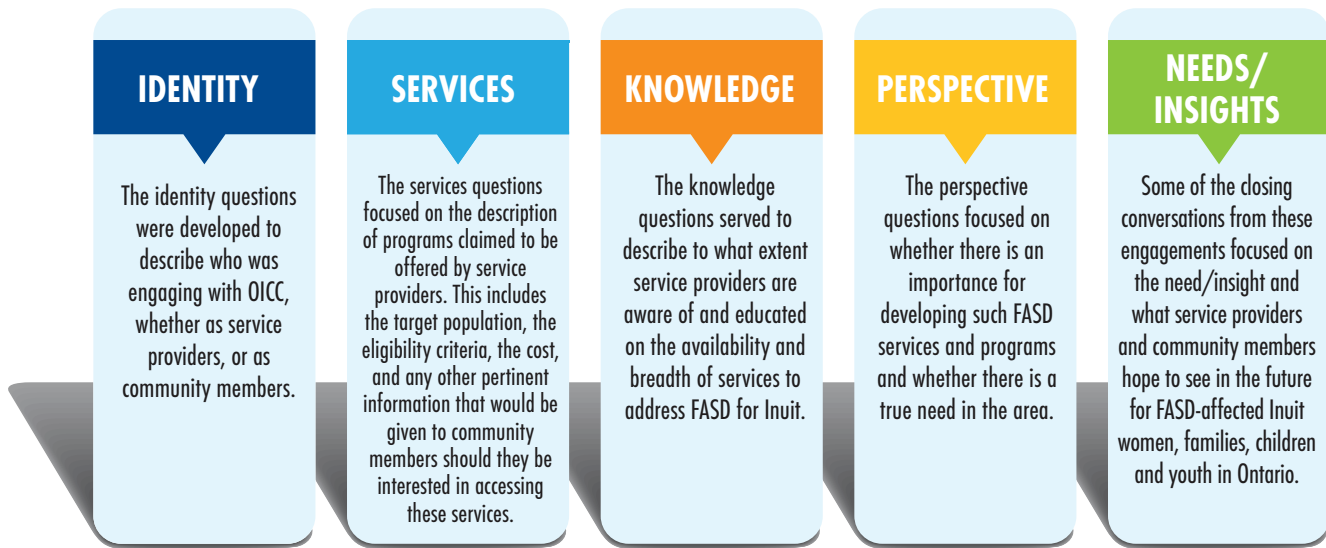
METHODOLOGY

The OICC conducted an initial environmental scan of existing FASD material and available information throughout Ontario that are said to be available to Inuit children, youth and families.

To achieve an accurate and high-quality report, an Inuit-specific engagement survey, interview, and focus group questions were developed to ensure cultural representation. These three formats of engagements were developed by the OICC FASD team, based

on consultations and collaboration with Tungasuvvingat Inuit (TI)'s FASD team (Appendix A to D).

These questions were based on five (5) themes: identity, services, knowledge, perspective, and need/insight. Within each theme, questions were asked through qualitative measures as well as a few quantitative measures to capture demographics. The themes were described as follows:



Content based on all five themes was gathered throughout the three types of engagements and are combined and summarized (below) to accurately represent the Inuit and Inuit-serving individuals in Ontario with regards to FASD.

The information and data for this report was collected and captured through various engagements with service providers and community members throughout Ontario, with a focus on Ottawa and OICC's provincial partners. Initially, a list of contact service providers was constructed based on previous engagements and relationships built between OICC and these service providers, as agreed upon with TI. Additionally, the FASD project coordinators were tasked with researching to find a baseline list of service providers that are known to serve Indigenous people, if not more specifically, Inuit (Appendix E). Initial contact was made with service providers to gauge interest in taking part in an engagement to discuss the topic of FASD in the province. The main areas of engagement were in the following regions:

- Ottawa
- Toronto/Scarborough
- Kingston



This initial contact was done either by telephone or e-mail to reach the most appropriate staff. Following this initial contact, the OICC FASD team arranged for a scheduled engagement. These engagements were conducted using one of the formats listed above depending on the knowledge and involvement of the staff with FASD work and Inuit.

Surveys were distributed to the service providers that were known to primarily serve the 'general' population that may or may not include Inuit. Following this, there was also an opportunity for service providers to partake in an interview, consisting of more quantitative measures to complete a more in-depth and specific engagement. Finally, OICC FASD Project Coordinators reached out to service providers known to have a focus on Indigenous work as well as on FASD to take part in an in-person focus group to facilitate more of an in-depth conversation with staff most qualified to speak to the FASD programs and services of the service provider.

To engage with community members in the Ottawa area, the OICC FASD coordination team distributed posters and e-mails to Ottawa's Inuit service providers. Engagements were primarily held in-person at OICC. For all surveys and interviews, the option of filling the surveys out online was offered, through Survey Monkey links, as well as through paper-copies that could be mailed in to OICC once completed. Surveys were available in both English and Inuktitut.

EXAMINATION OF CURRENT FASD SERVICES AVAILABLE FOR INUIT ACROSS ONTARIO

Environmental Scan of Current FASD Programs and Services in Ontario

This initial environmental scan consisted of reviewing and capturing FASD information and materials through service providers that claimed to serve all Inuit women, children, youth and families. Here is a summary of the available material:



Fetal Alcohol Spectrum Disorder Ontario Network of Expertise (FASD ONE) consists of a provincial volunteer collaborative group working on FASD, composed of experts and specialists in research, health promotion diagnosis, justice services, education, community and policy development and service delivery as well as family members who have intimate knowledge of the practical needs of individuals with this disability. Funded by the Public Health Agency of Canada (PHAC), FASD ONE has published a variety of resource documents to promote the development and dissemination of information that will support individuals and their families with FASD. Some of these resources include a

recent brochure (2018) with mention of Indigenous heritage that brings unique opportunities to addressing the needs of individuals with FASD. Additionally, the brochure highlights that culturally-based strategies can ensure programs and services reflect strengths within the community.

Additionally, a publication came out in 2010 from FASD ONE highlighting the brain-based approach. This report listed twelve points regarding FA/NB (Fetal Alcohol/Neuro Behavioural) conditions within the logic model. One of these points mentioned that all systems within culture and community would benefit from a shared understanding of a common language that enhances communication and helps establish and sustain informed, community-based, continuum of care. FASD ONE's work has influenced the advancement of effective educational practices, respite services, and community knowledge on FASD for Ontario.



Best Start consists of Ontario's Maternal, Newborn and Early Child Development Resource Centre. This group has developed information and resources for the community as well as for professionals on the dangers of alcohol use during pregnancy and the prevention of FASD. These resources have narrowed in on populations such as Inuit. Some of the available online documentation includes a facilitator guide that includes information and tools to help service providers run workshops about FASD prevention and skills for change for First Nations women. Despite the First Nations focus, the document also mentioned that the content, with some adaptations, may also be useful for workshops with Inuit women.

In 2012, with a partnership with Health Nexus, Best Start published a 'Be Safe – Have an Alcohol Free Pregnancy' poster with support from the LCBO. The handout answers a variety of frequently asked questions such as "what if I had a couple of drinks before I knew I was pregnant?". A similar brochure was also released with a focus on the effects of drinking, traditional teachings about pregnancy and where to get help in Ontario. In 2009, Best Start released a report on the FASD implications for Ontario – Awareness of FASD that reports that 3% of the respondents reported as being Inuit.

"It takes a community – Framework for the First Nations and Inuit FAS and Fetal Alcohol Effects (FAE) Initiative: A Resource manual

for community-based prevention of FAS" consists of work published by the FAS/FAE Technical Working Group (accountable to the CPNP/FAS/E (FNIC), National Steering Committee, representing the Assembly of First Nations, the Inuit Tapiriit Kanatami, and the First Nations and Inuit Health Branch). This framework serves as a resource manual for community-based prevention of FAS and FAE, now recognized as FASD.

The Ontario based Aboriginal Community Action Plan for Children (CAPC) has a strong FASD component and targets new mothers and their children.



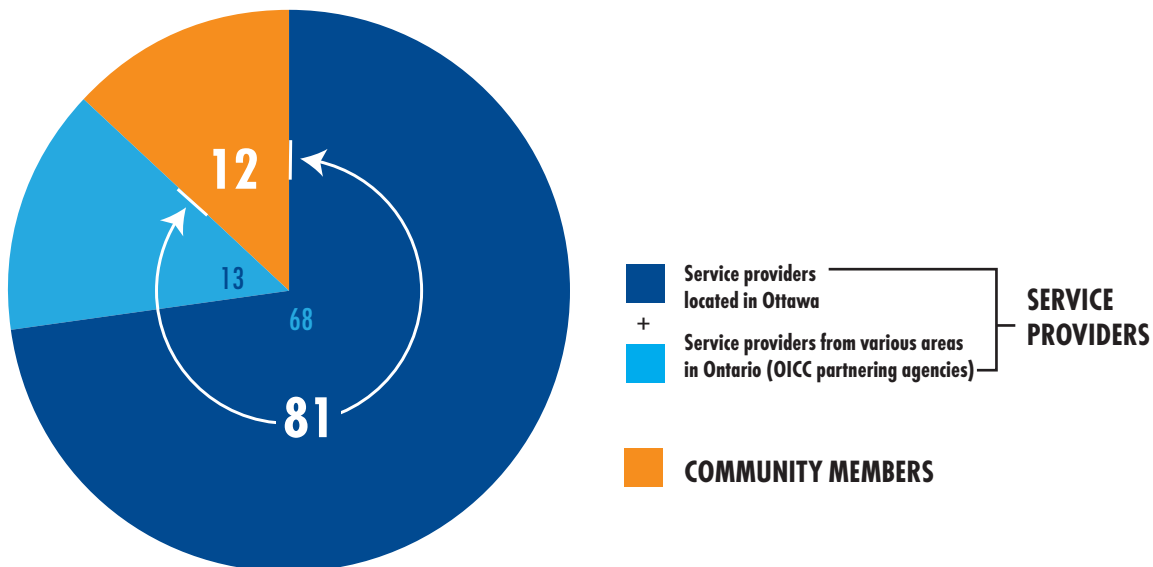
Pauktuutit Inuit Women of Canada, the National representative organization for Inuit Women in Canada, wrote a report with a Five-Year Strategic Plan for FASD (2010-2015). This report highlights the needs for comprehensive, multidisciplinary, holistic, community driven and culturally relevant FASD training to support FASD awareness, diagnosis, prevention and life-long care in a multifaceted and inter-agency manner. Pauktuutit recommends that training must prepare communities to manage FASD throughout the lifespan of the individual, in order to place FASD in the context of substance abuse. The report also emphasizes the need for training to better support education staff to understand and plan for proper care for FASD affected children and youth.

In the 2015 Truth and Reconciliation Commission of Canada: Calls to Action, there was a call upon the Federal, Provincial and Territorial governments to recognize the need to address and prevent FASD, while collaborating with Indigenous people in culturally appropriate ways. In addition to this recommendation, the recommendation highlights that reforms to the criminal justice system are needed to better address the needs of offenders with FASD. The following report describes such a focus through the following recommendations:

- i. Providing increased community resources and powers for courts to ensure that FASD is properly diagnosed, and that appropriate community supports are in place for those with FASD.
- ii. Enacting statutory exemptions from mandatory minimum sentences of imprisonment for offenders affected by FASD.
- iii. Providing community, correctional, and parole resources to maximize the ability of people with FASD to live in the community.
- iv. Adopting appropriate evaluation mechanisms to measure the effectiveness of such programs and ensure community safety.

Data Collection

A total of ninety-three (93) participants took part in this study. This is broken down to eighty-one (81) service providers and twelve (12) community members. All community members were from the Ottawa and surrounding area. Service providers were primarily located in Ottawa, sixty-eight (68), and the remaining thirteen (13) were from other locations in Ontario.



IDENTITY

The identity questions were developed in order to describe who was engaging with OICC, whether as service providers, or as community members.

Most **service providers** recruited to take part in these engagements were known to either serve Inuit specifically and/or incorporate indigenous culture in their programs and services (such as offering interpretation/translation, safe cultural spaces, etc.). The majority of these service providers either identified as Inuit themselves or recognized that some of their employees identified as being Inuit: 56% identified yes, 21% no, and 23% did not know. The interaction with community members was reported as mostly direct, whether through front line work (46%) or primarily through management and coordination of ongoing programs and services being offered (33%). The majority of the participating staff reported being in direct contact with community members (90%) and this at more than 50% of the time within their role as service providers (overall mean of 63%).

A significant number of service providers reported that they serve Inuit (87%). When asked how they go about learning the cultural identity of Inuit families utilizing their services, most service providers reported that families self-identified (50%). The remaining service providers reported that cultural identity was listed on their intake forms (33%), or through data collection documents (17%).

Service providers reported that a significant amount of community members utilizing their services are either directly or indirectly affected by FASD (72%). When asked how they go about knowing which families are affected by FASD, most service providers reported that families self-identified (50%). The remaining service providers reported that FASD was listed as an area of care on their data collection documents (29%), or on their intake forms (21%).

The majority of the **community members** that engaged reported as being non-Inuk (75%) but most were caregivers for Inuit children/youth (83%) and reported being directly/indirectly affected by FASD (92% directly) – primarily directly affected (82%). The majority of community members reported as being mothers (50%), biological (50%) and adoptive (40%), of three children or more (40%).

SERVICES

The services questions focused on the description of programs claimed to be offered by service providers. This included the target population, the eligibility criteria, the cost, and any other pertinent information that would be given to community members should they be interested in accessing these services.

Approximately half of the overall number of **service providers** reported having FASD services/programs (54%).

These service providers are primarily located in the Ottawa area, in Toronto, as well as a few others including Timmins, Hamilton, Sudbury, Thunder Bay and Kingston.



Citizen Advocacy operates a Fetal Alcohol Resource Program (FARP) in Ottawa that aims to support the large number of people affected by this permanent brain injury. Launched almost four years ago, through education and community leadership development, the program draws together resources, skills and knowledge that exist in Ottawa and provides education workshops for service providers and community navigation for individuals affected by FASD and their families.

Prior to the formation of this program, Citizen Advocacy sent out a survey to over a hundred and fifty (150) service providers in Ontario to assess the need and capacity for FASD clients, knowledge, training, referral, fees, and whether more information and training would be needed. By doing so, FARP has now reached out to over three thousand (3000) service providers within various sectors of service provision including the justice system, education, (mental) health, social work, counselling, employment supports services, housing support services, and more.

“ There is now an FASD worker position created do to the high demand for navigation and support for families affected by FASD throughout Ontario. Service providers within the Ontario regions that recognize the need for training and capacity building, will be or have been getting support from Citizen Advocacy through these various FASD worker positions that are being filled.”

- Citizen Advocacy Service Provider



Some of the **Ontario Indigenous Friendship Centres (OIFC)**, such as Timmins, Hamilton, and Sudbury, reported the Indigenous FASD/Child Nutrition Program (CNP) as one of their main resource programs/services. FASD/CNP is designed and delivered by Indigenous service providers to Indigenous children, youth and families across Ontario. This program provides healthy lifestyle education, personal support, and traditional cultural activities that promote FASD prevention and healthy nutrition. The FASD/CNP staff also produce community resource materials, offer professional development training on prevention and intervention to both Indigenous and non-Indigenous social service providers, educators, justice and medical personnel, and provide training on healthy nutrition to community service providers and families. In addition to the FASD/CNP, the *Thunder Bay Indigenous Friendship Centre* runs an FASD Community Support Program.

This program assists with FASD resources available to urban Aboriginal people and offers both the traditional and contemporary approaches to FASD on-site training.



The **Minwaashin Lodge Indigenous Women's Support Centre**, offers an Elders' Day, where various topics may be addressed between service providers and Indigenous women within the Ottawa community. These topics may at times include alcohol use as well as dependence and the effects of drinking, including FASD.



The **Kids Brain Health Network (KBHN)** is currently funded to move knowledge into implementation, through practice and policies in Ontario.

" This service provider has moved from doing research, having evolved of eight-nine years, to now delivering consultative services to partners within the province who can deliver the services and change to the community members. KBHN also helps give informative talks to community members, moving on to Indigenous lands and within communities where Inuit reside, in order to better inform families that may be affected by FASD."

- KBHN Service Provider

Lastly, KBHN is also partnering with Citizen Advocacy to build on evidence-based knowledge sharing in qualitative ways that can be easily and efficiently distributed to the community members and service providers.



The **Ottawa Inuit Children's Centre (OICC)** makes referrals to Integrated Plans of Care (IPCs) for families to have the best care within multi-disciplinary teams. These teams are often composed of medical, mental health, educational, community and cultural representatives, along with the child's family.

OICC service providers meet women, children, youth and families where they are at in their lives. If there is a suspected diagnosis for FASD, staff support families in

a sensitive nature in order to promote and build strong relationships with the children, youth and families in accepting and non-judgmental ways.

“ The OICC’s Family Well-Being program is capable of supporting FASD-affected families in order to build on the children’s strengths by providing holistic supports tailored to the unique needs of each family. The programs’ emphasis is on prevention and cultural acquisition and serves Inuit parents children, youth as well as non-Inuk foster and adoptive families.”

- OICC Service Provider

Some of these affiliated services include healing circles, family and youth drop-in groups, culture nights, a parenting program (Inunnguiniq), parent support groups (including some for adoptive/foster parents), the Akwe:go program that works with at-risk children to provide individualized supports to meet their specific needs and identifies children’s needs via an intake, needs analysis and client action plan process. The Akwe:go program worker then strives to involve the parent/caregiver at the onset of receiving services and supports the child by participating in and being a part of the child’s plan through the development and implementation of immediate, short and long term goals. Every three month, the Akwe:go program worker will revisit the client action plan and determine the progress the child has made and where additional services are required.

With training from FASCETS and Citizen Advocacy related to FASD and how to recognize the signs and symptoms; the questions asked are often around what are the circumstances with this child, what are the challenges, and what can the service providers do to best support and assist the child and the family.

“There is no use in painting that kid with that brush. Every child is an individual, despite their abilities.”

- OICC Service Provider

The service provision team reviews the child and family’ background file to get to know the child’s preferences for care. If needed, accommodations and modifications are put into place as needed. In group conversation and consultations with staff, lessons learnt are discussed and then adapted to the child’s care.

OICC’s Bridging the Gap program support Inuit students and their parents and teachers at the primary and secondary level in all four Ottawa School Boards. OICC receives requests for support from other Ontario school boards as well. Program components include classroom presentations, support for Inuit students struggling within the education system and professional development opportunities for school employees.

"This role of student support coordinator is crucial to these Inuit families and children as most teachers are overwhelmed and do not have the time and resources to integrate culture themselves, especially if they are already unfamiliar with it to start with."

- OICC Service Provider

OICC also offers individual supports through court accompaniment, alcohol/addiction-related issues and domestic violence concerns; Children's Aid Society (CAS) support-access visits; one-on-one meetings in their home or elsewhere; and referrals to partnering/external service providers throughout Ontario as well as in Nunavut.



The **Anishinaabe Health Toronto (AHT)** strives to promote the awareness and prevention of FASD as well as early interventions for families and caregivers who are caring for children diagnosed with FASD. Health promotion and prevention activities include community information workshops, support groups, pre-natal circles, school programs, and both one-on-one and group support for families and caregivers. In

addition to these in-house services, AHT has a FASD diagnostic clinic composed of a multidisciplinary team (i.e. doctor/physician, psychologist, speech and language therapist, two social workers, traditional healer and a child/youth counsellor).

" The diagnosis process requires a signed report from the biological mother or a reliable informant confirming maternal alcohol consumption during pregnancy. The FASD multidisciplinary team will recommend aftercare plans across the lifespan and provide follow-up with the family and resources in the family's surroundings in accordance with the final recommendations. From the initial intake to the final recommendations, the duration is around a month and a half."

- AHT Service Provider



The **Aboriginal Legal Services of Toronto** is running a pilot program, now extended for a second year, to support clients who have FASD. With one FASD worker on-site, help is offered with every day services; such as making sure the clients get to their appointments (e.g. court appearances, etc.).

“ With a doctor that comes on-site to the legal clinic, clients are able to get assessed for FASD during two days of testing. The only prerequisite to qualifying for this service is proof that there had been drinking during the mother's pregnancy, whether directly from the mother or from a reliable witness. Approximately, ten to twenty clients are served at a time.”

- Aboriginal Legal Services Service Provider



The **Ontario Aboriginal Head Start Association (OAHS)** frequently request funding from the province whenever there seems to be a significant need for supporting children and families that are affected by FASD.

“ There is an upcoming Indigenous cultural worker position to better assist families that may be facing particular challenges such as FASD.”

- OAHS Toronto Service Provider



Native Child and Family Services of Toronto has two developmental service workers who are employed under the coordination services for FASD work throughout the city of Toronto. Annually, as new staff are hired, there is a mandatory two-day training on FASD in order for all to be aware and educated on the disorder, the prevalence and also on the available services internal and external within Toronto.

“ In terms of services, Native Child can refer to their internal case management team that often takes on cases relevant to a variety of needs such as autism, epilepsy, attention deficits, etc. Work is offered on-site but also within the families' homes to best address the family and children/ youth's needs.”

- Native Child and Family Services
Service Provider



The **Children's Hospital of Eastern Ontario (CHEO)**'s Ottawa Children's Treatment Centre (OCTC), partners with local and northern agencies through a Child in Care Review Committee to repatriate children with their family in Nunavut. CHEO also provides Inuit cultural training through competency modules created with partnering agencies and community members.

" We also provides resources support for workers with four clinicians that travel to northern communities to support families that may need help with various needs such as FASD."

- OCTC Service Provider



The **Toronto Aboriginal Support Services Council (TASSC)** is the leading not-for-profit research, policy, and advocacy service provider that addresses the social determinants of health to improve and enhance the socio-economic prospects and

cultural well-being of Aboriginal peoples living in the City of Toronto. Indirectly, some of the community-based resources are focused on Indigenous service providers. By asking community members about how to better include Indigenous-focused services, recommendations are put forward to service providers in the Toronto area. With regards to FASD, there is a push to help promote other service providers work, through various environmental scans, to support community development and bring Indigenous communities together.



Wabano Centre for Aboriginal Health offers a FASD and Child Nutrition program, known as the "Awashishak" project. It provides services to clients and families impacted by FASD through support groups, group outings, community kitchen & gardens, camps, crafts & traditional crafts, and family friendly activities and events.

" This program also provides child nutrition services to families, through community garden, cooking with kids, and classes to learn to prepare healthy and economical snacks and meals for their family."

- Wabano Service Provider



The **Ottawa Police Services (OPS)** is partnering with Connect Protect, now known as Medic Alert to expand on their vulnerable registry. This registry serves to build individual profiles for vulnerable individuals in the Ottawa area that are susceptible to being involved with the police services. Within the OPS filing system, Medic Alert helps police keep informed about individual diagnosis and best approaches/methods to supporting individuals in times of crisis.

" This is a great opportunity for police staff to collaborate with these vulnerable individuals' family members and caregivers to best understand why they are and act the way they do."

- OPS Service Provider



The Children's Aid Society of Ottawa | La Société de l'aide à l'enfance d'Ottawa

The **Children's Aid Society (CAS) of Ottawa** works with various Indigenous-based service providers in Ottawa in order to best take on child care cases through in-house workers who will assess children and youth based on their suspected needs, such as FASD.

" We host an in-house training on FASD available for foster, kin and prospective parents to best understand the nature and ongoing needs of FASD-affected children and youth. There is also Indigenous training available for staff, in collaboration with a liaison committee for Indigenous people within our Ottawa location as well as 'what to expect' in terms of behaviour for new parents, whether adoptive of foster parents, who may be new to caring for Indigenous children."

- CAS Ottawa Service Provider

KNOWLEDGE

The knowledge questions served to describe to what extent service providers are aware and educated on the availability and breadth of services to address FASD for Inuit.

A majority of participating **service providers** reported being knowledgeable of the Inuit culture (80%), - most reported being 'somewhat' knowledgeable (53%). In terms of knowledge of FASD, out of the 97% that reported being knowledgeable on the subject, most reported being 'considerably' knowledgeable (51%). These same service providers reported gaining their knowledge on FASD through training and education, whether through school or through previous employment (65%).

The service providers that reported having a lack of specific FASD services were aware of few external service providers that offer more specific FASD services. This partnership or awareness of external services was reported primarily through word of mouth or promotional material from other service providers (62%) as well as through the community members themselves reporting on other services (35%). When asked about limitations/ challenges that may limit service providers from knowing about external service provider's FASD programs and services, most reported a lack of time (45%) and also not being sure where to turn (i.e. in the case of a community member seeking an official diagnosis in their community) (11%).

As mentioned above, OICC was responsible for reviewing existing programs and services within Ontario, with a focus on the Ottawa area as well as other areas within the province. In addition to the above-mentioned service providers in Ontario, there was also mention of external services in the region, with whom service providers refer community members for FASD services. These include the following:



Tungasuvvingat Inuit (TI)'s Family Well-Being program is designed to deliver prevention-focused, culturally-responsive supports to promote healthy communities by supporting families to heal from the effects of intergenerational trauma, reduce violence, and address the over-representation of Indigenous children and youth in child welfare and youth justice systems. The program supports Indigenous children, youth and their families in diverse communities regardless of where they live with increased access to prevention-based services and supports. This program has also been known to support families affected with FASD.

Akausivik Inuit Family Health Team Medical Centre consists of a culturally appropriate, interdisciplinary primary health care team with a focus on the Ottawa Inuit population, as well as on health priorities – FASD being one of them. Research and evaluations take place based on the Urban population's needs as well as access to specialized care as needed.



*Odawa
Native
Friendship
Centre*

The **Odawa Native Friendship Centre** runs the Akwe:go program for at-risk children, from ages seven to twelve. The goal of the program is to provide urban Indigenous children with supports, tools and healthy activities that will build upon and foster their inherent ability to make healthy choices. One of the program objectives highlights the following:

"Increase support for children with FASD and/or disabilities and their families by providing access to tutoring and mentoring, supervised physical activities and incorporating parent support component"



Adopt4Life consists of Ontario's adoptive parents association with lived experience of adoption that strengthens and empowers

parents to achieve permanency for children so that they reach their full potential. Within the service providers' programs around FASD, Adopt4Life offers parental and family support, advocacy and guidance with an openness and awareness for culture, such as for Indigenous people.

The **FASD Group of Ottawa** is known as a support and education group for families and professionals on the effect of FASD on people of all ages and the importance of prevention. Elspeth Ross, facilitator of the group, allows for an open discussion and circle of support for these families using an Indigenous lens.

With a focus on the Ottawa area, in terms of the knowledge of **community members** on FASD, most reported having 'considerable' knowledge (50%). When asked about their knowledge of available services and programs for FASD in their community, 50% reported having 'some' knowledge, followed by 25% stating 'very little' knowledge.

This community member awareness of external services was reported primarily through consultation/recommendations from other service providers (63%) as well as through search engine (i.e. Google) (37%). When asked what types of challenges could limit or prevent community members from accessing these types of services/programs, most community members reported either a lack of knowledge of existing community services, the presence of stigma/emotional barriers as well as the location/transportation issues for the community members to get to the services.

PERSPECTIVE

The perspective questions focused on whether respondents felt there is an importance in developing such FASD services and programs and whether there is a true need in this area.

Almost all **service providers** highlighted the importance of incorporating Inuit culture in their services and programs (91%). There was a reported need for culturally specific materials and resources in the work that these service providers do with community members throughout their individual service providers (96%). Most services providers suggested the need for either on-site training for staff, such as through elders, Indigenous leads or educators; or through hand-out/online material (e.g. training modules that can be consulted on the service providers' own time).

Some of the feedback from service providers touched on the positive outcome of collaboration with other service providers in the community to bring specializations and strengths together. More specifically, the various Indigenous Friendship Centres throughout Ontario seemed to have been a key resource for service providers that did not have the specialization or capacity to take on FASD affected families. Other service providers highlighted the importance of research and regular scans of their community to then report back to service providers. This has proven to keep services up to date and accurate with what the Inuit

community's current needs are with regards to FASD. In terms of training, 83% of service providers reported a 'very' important benefit to having such an educational aspect incorporated into their service provider (cultural sensitivity and awareness) to better develop programs and supports for Inuit families affected by FASD.

Finally, some service providers had the opportunity to have on-site training as well as on-site specialized consultative services, such as through occupational therapists, speech and language, specialized counselling, etc. Although often short-term, these specialized services were very beneficial to the service providers that do not have this capacity on a regular basis.

Some providers reported experiences that have been well adapted for Inuit children and their families. These include hearing first-hand from the family of what needs are to be met first and which approach would be best suited for them. A recurring statement in this section of the engagements narrowed in on the positive impact of having one-on-one sessions with families, and/or within a familiar context (i.e. in the family home, in an Inuit-specific service agency, child in a 'playful' environment, serving country food, etc.).

Additionally, it was mentioned that the Inuit way seems to benefit individuals with FASD given that most Inuit children love the outdoors, and this is something that resonates with FASD-affected children/youth. Having one-on-one supports and experienced school teachers who find strategies that work without the label so

that the judgment on parents with FASD children is reduced, with an understanding of the context and of FASD is of importance.

Service providers reported whether these programs and services included culturally appropriate information and services for Inuit specific to FASD. The Indigenous-focused service providers primarily reported on their training available for new staff. The focus is primarily on intergenerational trauma, cultural beliefs and practices using a strength-based approach.

When asked about the level of importance about incorporating culture, the majority of service providers thought it was important (89%). Additionally, more than half of service providers reported that Inuit families, children and youth directly or indirectly affected by FASD in their community are not well supported (68%). When asked about their perspective on the level of knowledge of service providers about FASD in their community, 48% think that service providers are 'not really' knowledgeable.

"It is through trial and error that the service providers find what works best for the child and the family. This is aside from culture and any diagnosis of a particular condition. Every child is different and deserves to have accommodations. This avoids singling out children and labeling them as 'problem' children.

The key is to build relationships with the families. Service providers should not assume that anything will be/is to be 'fixed'. The parents are most likely not going to tell the service providers that they are struggling, especially not the Inuit families – this is not in their culture. Most workshops do not work to spread awareness for community members. The key is to host social events and over time, service providers learn to build trust and positive rapport by getting to know the families and their children. Once trust is shaped, some families feel comfortable enough to come forward with specific concerns, including the challenges they may be facing with regards to their child(ren)."

- OICC Service Provider

The **community member** voice primarily focused on the need for a more standardized way of diagnosing FASD thereby allowing for more standardized access to services for all affected, whether directly or indirectly, by FASD. Community members spoke of the 'very' high importance (75%) of including culture in these services.

The most helpful information on FASD supports and services for Inuit have been found in the welcoming feeling experienced when entering a service provision centre or support group that has helpful and accessible information (whether online or paper-copy), and the transitional and multidisciplinary work that is done between various service

providers, such as between school and community-based services. Additionally, when asked about what experiences were best adapted for FASD-affected families, the community members reported on the importance of the specificity of services. An example was given with regards to summer camps being tailored to welcome and include children and youth with different abilities, such as FASD.

Community members do not believe that they are well supported by service providers to support FASD (100%). According to the community, service providers are 'not really' knowledgeable about FASD in Ottawa. The majority of community members reported that based on their experiences, their community is 'not really' knowledgeable about FASD (75%). Lastly, 75% of community members support the fact that it is very important to incorporate Inuit culture in services and programs, more specifically towards FASD.

NEEDS/INSIGHTS

Some of the closing conversations from these engagements focused on the need/insight and what service providers and community members hope to see developed for FASD-affected Inuit families, children and youth in Ontario.

The majority of **service providers** reported that more training and education is needed in the relevant service provision fields that touch on FASD-related matters as well as funding designated for Inuit-

specific services. When asked about what types of culturally specific materials/resources would be best seen as additions to their service providers, staff seemed to focus on training (e.g. from elders, Indigenous leaders and educators), as well as through the distribution of paper/online training materials (e.g. training modules, booklets, etc.).

The vast majority of participating service providers emphasized that the priority should be on training/education (through service provision but also through the community at large) (47%), as well as funding for Inuit-specific services (27%) for all to better understand FASD.

Based on their direct/indirect experiences with FASD as service providers, it was primarily recommended (37%) that the focus be on cultural and FASD awareness and training to break the stigma within service provision but also throughout the community at large. The awareness should be spread from a clinical standpoint as well as through a trauma-informed and culturally aware perspective that would allow for service providers to reach the Inuit population that may feel hesitant to coming forward for help on such a 'sensitive' matter.

This was followed by 33% of providers recommending that the focus be on better supports and treatments for Inuit children and families affected by FASD. These supports include education-based programs to help prevention and treatment for families at every stage of FASD

(pre-natal, post-natal, and later in the child/youth's life). It was also mentioned that it is important to meet families where they are at on the spectrum. 19% of service providers highlighted the importance of developing better diagnostic tools and services, as well as various systematic changes to standardize care within Ontario. There is a need for consistent and accurate information, as much from the clinical standpoint, but also through the Inuit perspective. With better awareness and proper training, service providers can better address FASD-related matters and share accurate and consistent information to community members that will also help reduce the ongoing stigma that is felt by community members, such as within the Inuit population. To reduce the stigma in communities, service providers recommend that the messaging around FASD be changed to a positive, strength-based approach that is not only adapted to Inuit communities but to all that wish to access care and community services. To maintain consistent knowledge sharing within service providers, a standardized approach should be taken by putting service providers in the shoes of community members.

To standardize care, some service providers recommended that more collaboration take place between the more clinically focused service providers and those that have the first-hand knowledge of the Inuit culture. Every service provider has a role to play, whether as part of the medical services, through the justice system, as community-based workers, or teachers,

etc. If all Inuit-serving staff can gain a basic level of knowledge and awareness on FASD and available services in their community, families would have a better experience navigating the various systems to find FASD-focused services.

Autism Spectrum Disorder (ASD) was brought up during some of the service provider engagements as being primarily well addressed in the community.

This is a result of the consistency of knowledge sharing, research, and ongoing implementation of services within the different areas of care. It was repeatedly suggested that similar steps be taken to incorporate FASD into these same services and programs. A network could be developed to link programs and services that have been successful for ASD as well as for Attention Deficit Hyperactive Disorder (ADHD), to meet the need for FASD.

Lastly, in terms of existing FASD services and programs, it was mentioned that some service providers within the province are doing great work and are spreading awareness to the best of their abilities. It was reported that the starting point should be capacity building to ensure that there are enough individuals to support and help grow these educational and intervention initiatives throughout the province. With capacity and relationship building, this reduces the need of starting new programs from the ground up, and instead builds on what the province already has in place in the areas that have a need for FASD services and programs.

Community members would like to feel more supported by available services in their communities that surround them and their children – such as through school, community service providers, municipal and provincial leaders and to have a more consistent level of awareness and education, and support for their families. When asked about how to add consistency to services, more community members suggested that services providers build on their ongoing services for families, children and youth and add a cultural component that would best serve the members that need these supports.

Overall, the feedback received from community members was quite similar to the suggestions raised by service providers, noted above. An additional component was mentioned during the engagements with community members about the growing need for respite care for FASD-affected children and youth. When referring to respite, most parents/caregivers made references to available services customized for FASD-affected children. The recommendations given were supporting the need for more of this care, whether through day programming and/or cultural day/weekend programs.

In terms of terminology given and used to describe FASD, the majority of community members agreed that the terms 'fetal' and 'alcohol' seemed to put a lot of blame on the mother rather than emphasizing the current impact on the child/youth's brain, known as a life-long injury that does not heal, and should not be reassessed over the

course of the individual's life. Rather than reassessing the child/youth's inabilities, parents want more support to build on their child/youth's abilities and strengths. For such changes to be heard and made possible, community members would like to see better adaptation and recognition for FASD in schools and through the justice system, primarily.

The need was focused on seeking a proper diagnosis for (potentially) FASD-affected children/youth. There needs to be a more streamlined and efficient manner for getting children diagnosed at a young age to set them up with the proper supports and services throughout their lifespan.

GAPS AND CHALLENGES IN ADDRESSING INUIT-SPECIFIC FASD NEEDS

It was reported that there is lack of knowledge of FASD, both on the service provision side as well as throughout the community at large

" Efforts to spread knowledge and awareness are made yet families affected do not always participate and engage. The challenge becomes that there is a lack of commitment and involvement, whether due to a lack of time or other reasons."

- Ottawa Service Provider

It was reported more than once through the service provider and community member engagements that the stigma is still a big issue in most communities, whether due to the lack of knowledge, or the defaulting effect of blaming the cause of such an 'injury' on the FASD-affected child.

There is a lack in diagnostic services in the province. There are few diagnostic clinics and most of these existing services have waitlists that do not allow for a quick turnover for families that are coming from rural areas. Another barrier is having to establish parental consent and/or the presence of a witness to the prenatal alcohol consumption – realistically, this is not always possible,

especially if the Inuk child/youth is from outside the region.

Often because of the lack of diagnostic services, there is also a lack of available FASD-specific services and supports. Most of the specific services require a diagnosis that results in families not getting the help they need.

During the service provider discussions, the following was raised with regards to the transition between cultural programming and school services:

"The biggest challenge with regards to transitions for children, is the drastic differences that are often seen in terms of care – from OICC to other services that do not have the same level of care or attention for individuality or integration of culture. That is why it is very important to state and integrate the culture in more 'main stream' settings such as within the classroom."

- OICC Service Provider

Many indigenous programs and services do not adequately reflect Inuit culture. Inuit are often not 'welcomed' by the appearance of these services and therefore do not end up accessing them.

" FASD is currently under-funded within Ontario, considering the need and the number of families affected. Also, in terms of re-assessment for funding, this should not be applicable for FASD as it consists of a brain injury that does not vary or heal like other conditions."

- Ottawa Community Member

SUMMARY & RECOMMENDATIONS

Summary

The majority of **service providers** were front line workers. The workers that took part in this study reported serving Inuit, primarily in a direct way (i.e. having contact with them on a regular basis, on average 65% of the time spent at work).

Service providers recognized that some of these families are directly or indirectly affected by FASD. Both Inuit status and FASD were reported primarily through self-identification from the community members and their families. Almost half of these service providers indicated that they offer FASD services and programs to the community.

When asked about knowledge, the majority of service providers indicated that they had some knowledge on FASD as well as of Inuit culture. These service providers reported primarily learning about FASD through alternate training and education from their current or previous position(s).

When asked about limitations that could impact community members' access to services, a lack of knowledge and awareness was the primary reason reported.

Most service providers that reported as not having FASD/Inuit-specific services, were mostly aware of external services in their community, to which they refer when applicable. When asked about how they learned about these external service providers, it was reported as acquired through networking and relationships with other service providers. Time was the main limitation reported when service providers were asked about what challenges could limit them from knowing about external service providers.

Almost all service providers agreed with the importance of having Inuit culture incorporated in their services and programs as well as mentioning the need for Inuit specific materials/ resources. Most mentioned the benefit that would come with having access to training on cultural sensitivity and awareness to appropriately develop and deliver on Inuit-specific services and programs with an FASD context.

With most service providers stated that Inuit families and children and youth directly/ indirectly affected by FASD in their community are not well supported, and that service providers in their region are 'not really' knowledgeable about FASD. There is a need for better training and education initiatives throughout service provision for Inuit in Ontario.

The majority of **community members** did not identify as Inuit, but almost all of them identified as being a caregiver for one or more Inuk child/youth. The community members that took part in this study identified as being either a parent (mostly mothers, some fathers and grandparents) or caregiver, through a biological, adoptive or foster relationship (primarily biological), and caring for an average of 2 to 3 children per family. The vast majority of these community members reported as caring for one or more child/ren affected by FASD, primarily with a direct impact (i.e. the individual/s with FASD live/s with the community member).

When asked about knowledge, the majority of community members indicated that they had considerable knowledge on FASD. When asked about their knowledge of available FASD service providers in their community, most indicated that they had 'some' knowledge.

Most community members found out about alternate service providers through other agencies, whether through a mention or an official referral process.

When asked about limitations that could impact community members' access to services, a lack of knowledge and awareness was the reason reported. All participating community members stated that Inuit families and children/youth directly/indirectly affected by FASD in their community are not well supported.

A significant number of community members indicated that there is a very important need to have Inuit culture incorporated into service providers' programs, and that it would be very beneficial for service providers to have access to training on cultural awareness to appropriately develop Inuit-specific material for FASD families.

Recommendations

For **service providers**, most gaps and challenges were recognized and discussed over the course of these engagements. The awareness is there – it is now about moving forward with implementation of standardized care and supports to truly get to children, youth and families most affected by FASD in the Inuit community. More conversation and knowledge sharing needs

to be implemented into existing programs and services that serve Inuit families, children and youth.

Service providers who support Inuit affected by FASD, need to be educated and made aware of FASD programs and services in their community and ensure supports are culturally appropriate.

A sense of belonging is needed on the ground within communities that serve Inuit families, to welcome and support them. Such a baseline then promotes the reduction of stigma, especially in the cases where the biological mother is present and involved in the diagnostic process of the child/youth as well as to seek appropriate services and supports for herself and her FASD-affected family.

If FASD is seen as a priority throughout the province of Ontario, a provincial conversation and push for implementation should be communicated throughout the various areas, whether rural or urban, that have the most 'at-risk' populations, including all Indigenous groups. In addition, it was recommended that basic clinical training should be offered to service providers that work with families, children and youth; and an Inuit specific cultural component be integrated throughout all training.

Another reappearing topic was capacity building. It is necessary for service providers to develop skills, awareness and the cultural capacity to support Inuit children, youth, and families affected by FASD.

A 'team' approach is needed to support Inuit families – through the school system, the medical and mental health systems, judicial system (if applicable), and applied consistently throughout the province.

“ Such a systematic re-work would allow for a provincial standard of care for all community members, no matter their location in the province. This would avoid re-location, and lengthy wait lists and being sent from one service to the next due to a lack of awareness and communication between service providers.”

- Ontario Service Provider

APPENDICES

Appendix A. Community Member Engagement (Survey)

1. Do you identify as Inuk?
 - No
 - Yes

2. Are you a caregiver for an Inuk child or Inuit youth?
 - No
 - Yes (please specify)
 - How many children: _____
 - Role(s) (e.g. mother, father, grandmother, etc.): _____
 - Relationship(s) (e.g. biological, adoptive, foster, etc.): _____

3. Are you directly/indirectly affected by FASD?
 - No
 - Yes (please specify)
 - Directly affected
(e.g. The person with FASD lives in my household/receives my care on a regular basis.)
 - Indirectly affected
(e.g. The person with FASD lives outside of my household/does not receive my care on a regular basis.)

4. Rate your knowledge of FASD:
 - None
 - Very little
 - Some
 - Considerable

5. Rate your knowledge of available FASD services in your area?
 - None
 - Very little
 - Some
 - Considerable

6. How important is it to you that service providers incorporate Inuit culture in their services/programs?
- Not really
 - Somewhat
 - Very

Refer to your response to Question 3 (Affected by FASD, directly or indirectly)

If you answered 'Yes': Please proceed to Question 7a

If you answered 'No': Please disregard the remaining questions and submit your survey.

7. (a) Do you access or know of services/programs for FASD in your area?
- No
 - Yes (please specify)
 - Name: _____
 - Location: _____
 - Available Language(s) of Service (select all that apply)
 - English
 - French
 - Inuktitut
 - Other (Please specify): _____

Inuit-specific?

- Yes
- No
- I don't know

How did you find out about this service/program?

- Friend
- Family Member
- Other service provider
- Search engine (i.e. Google)
- Other (please specify): _____

(b) What are some challenges that limit or prevent you from accessing FASD services/programs:

- No known challenges
- I don't know

- Knowledge of existing community services
- Finances/Cost
- Stigma/Emotional

- Location/Transportation
- Hours/Availability
- Eligibility
- Waitlist/Systematic issues (e.g. programs closing)
- Language
- Other (please specify): _____

Refer to your response to Question 7a (access to FASD services)

If you answered 'Yes': Please proceed to Question 8.

If you answered 'No': Please disregard the remaining questions and submit your survey.

8. Referring to the service(s)/program(s) mentioned in Question 7a, please respond to the following three (3) questions:
- a. Did you find the resources helpful for you and your family?
 - No
 - Yes

 - b. Did you notice any evidence of Inuit culture throughout these services within the organization?
 - No
 - Yes
 - I didn't notice

 - c. Does this organization refer community members to Inuit-specific supports available in the area (either other programs within their organization, or within other organizations)?
 - No
 - Yes
 - I don't know
9. (a) Are you aware of other FASD programs and services that you have not (yet) accessed?
 - No
 - Yes (please specify)
 - Name: _____
 - Location: _____

- Available Language(s) of Service (select all that apply)

- English
- French
- Inuktitut
- Other (Please specify): _____

-Inuit-specific?

- Yes
- No
- I don't know

- How did you find out about this service/program?

- Friend
- Family Member
- Other service provider
- Search engine (i.e. Google)
- Other (please specify): _____

(b) Challenges that limit or prevent you from accessing FASD services/programs:

- Knowledge of existing community services
- Finances/Cost
- Location/Transportation
- Hours/Availability
- Eligibility
- Waitlist
- Language
- Other (please specify): _____

10. Based on your direct or indirect experience with FASD (if applicable), do you have any recommendations as to how to strengthen FASD supports and services for Inuit families, children and youth in Ontario?
11. From your perspective, how could organizations in your area adapt their FASD services/programs for Inuit families, children and youth?
12. How beneficial would it be for you and your family to have access to Inuit-specific services and programs run by culturally sensitive staff (e.g. with Inuit specific knowledge), who are directly or indirectly affected by FASD?

Appendix B. Community Member Interview/Focus Group

1. Are you aware of any programs or services in your community that support or assist Inuit who may be directly or indirectly affected by FASD?
 - a. What types of services/programs or information have been the most helpful in terms of FASD supports and services for Inuit? Why?
 - b. Have you experienced any FASD approaches or practices that are well adapted for Inuit children and their families?
 - c. Do those programs or practices include culturally appropriate information and services for Inuit? Specific to FASD? If so, please elaborate.

2. Would you say that Inuit families, children and youth directly or indirectly affected by FASD in your community are well supported? If so, in what way?
 - a. How could organizations in your community adapt their FASD services/programs for Inuit families, children and youth?
 - b. How important is it to you that service providers incorporate Inuit culture in their services/programs? How about with FASD services specifically?

3. From your perspective, how knowledgeable are service providers about FASD in your community?
 - a. Ideally, what information would help you the most with FASD (e.g. training, books, programs, support groups, etc.)?
 - b. Is there anything that you wish you had known earlier in order to find Inuit-specific supports and services in the area?
 - c. Do you have any recommendations as to how to strengthen or adapt FASD supports and services for Inuit families, children and youth in Ontario?

4. Do you have other comments, concerns or discussion points that are relevant to our FASD discussion?

Appendix C. Service Provider Engagement (Survey)

1. Do you identify as Inuk?
 - Yes
 - No

2. Do people in your organization identify as Inuit?
 - Yes
 - No
 - I don't know

3. What organization do you work/volunteer for?

4. What is your primary role within this organization?
 - Front line
 - Research
 - Management/Coordination
 - Executive Direction
 - Policy/Program Development
 - Other (please specify): _____

5. Do you interact with community members directly?
 - Yes (Please estimate the percentage of time spent with community members)
 - 20%
 - 40%
 - 60%
 - 80%
 - 100%
 - No

6. Do you provide services to Inuit community members?
 - Yes (Please specify)
 - How do you identify whether community members identify as Inuk or not?
 - Community members come forward (if and when they are willing to)
 - Cultural identity is a section on our intake forms
 - Data collection, through forms and questionnaires given by our service providers
 - Other (please specify): _____

- Are these community members directly or indirectly affected by FASD?
 - Yes (Please specify)
- How do you identify whether community members are directly/indirectly affected?
 - Community members come forward (if and when they are willing to)
 - FASD is a section on our intake forms
 - Data collection, through forms and questionnaires given by our service providers
 - Other (please specify): _____

- No
- I don't know

- 7. Do you have knowledge of Inuit culture?
 - Yes (please specify)
 - Rate your level of knowledge:
 - Very little
 - Some
 - Considerable

 - No

- 8. Do you have knowledge of FASD?
 - Yes (please specify)
 - Rate your level of knowledge:
 - Very little
 - Some
 - Considerable

 - No

- How did you learn about it?
 - I am directly or indirectly affected by FASD
 - I know someone who is directly or indirectly affected by FASD
 - Training/Education
 - Other (please specify): _____

- 9. How important is it to you that service providers incorporate Inuit culture in their services/programs?
 - Not really
 - Somewhat
 - Very

10. (a) Does your organization provide FASD services/programs?
- Yes (If so, please specify)
 - Name: _____
 - Language of Service (Select all that apply)
 - English
 - French
 - Inuktitut
 - Other (Please specify): _____
 - Inuit Specific?
 - Yes
 - No
 - I don't know
 - No
- (b) Can you think of any challenge(s) that could limit or prevent community members from accessing this service/program (Select all that apply)?
- Yes (if so, please select those that apply)
 - Knowledge of existing community services
 - Finances/Cost
 - Location/Transportation
 - Hours/Availability
 - Eligibility
 - Waitlist
 - Language
 - Other (please specify): _____
 - No challenges
 - No
 - I don't know
11. Are you aware of any other/external services in your region for FASD?
- Yes (please specify)
 - Name: _____
 - Location: _____
 - Available Language(s) of Service (select all that apply)
 - English
 - French
 - Inuktitut
 - Other (Please specify): _____

-Inuit-specific?

- Yes
- No
- I don't know

-How did you find out about this service/program?

- Friend
- Family Member
- Other service provider
- Community member
- Search engine (i.e. Google)
- Other (please specify): _____

- No (please specify – select all that apply to you)

-Challenges that may limit or prevent you, as a service provider, from knowing about these external services/programs:

- Time
- Not relatable/applicable to your services/programs
- Not sure where to start
- Finances/Cost
- Language
- Other (please specify): _____

12. What is needed to better understand FASD from a service provider's perspective?

- Better training and education
- More funding for Inuit-specific services
- Creation of more regional/local centres and programs that are Inuit-specific
- Other (please specify): _____

Please feel free to add comments/suggestions:

13. Based on your direct or indirect experience with FASD as a service provider, do you have any recommendations as to how to strengthen FASD supports and services for Inuit families, children and youth in Ontario?

14. From your perspective, how could organizations in your area adapt their FASD services/programs for Inuit families, children and youth?

15. How beneficial would it be for you and your organization to have access to training (cultural sensitivity/awareness) in order to develop Inuit-specific services relevant to FASD?

Appendix D. Service Provider Engagement (Interview/Focus Group)

Sign-in Questions

Questions 1-9 from Service Provider Survey (see Appendix C)

1. Does your organization provide programs or services in your community that support or assist Inuit who may be directly or indirectly affected by FASD?

If Yes: Information on program(s)

If Yes / If No: Are you aware of any external organizations that do?

Information on program(s)

- a. What types of services/programs or information have been the most helpful in terms of FASD supports and services for Inuit? Why?
 - b. Have you experienced any FASD approaches or practices that are well adapted for Inuit children and their families?
 - c. Do those programs or practices include culturally appropriate information and services for Inuit? Specific to FASD?
If so, please elaborate.
2. Would you say that Inuit families, children and youth directly or indirectly affected by FASD in your community are well supported?

If Yes: In what way?

If No or I don't know:

- a. How could organizations in your community adapt their FASD services/programs for Inuit families, children and youth?
- b. How important is it to you that service providers incorporate Inuit culture in their services/programs? How about with FASD services specifically?

3. From your perspective, how knowledgeable are service providers about FASD in your community?

Specify:

- a. What information would help service providers to better assist Inuit who may be directly or indirectly affected by FASD? (e.g. training, books, programs, support groups, etc.)?
 - b. Do you have any recommendations as to how to strengthen or adapt FASD supports and services for Inuit families, children and youth in Ontario?
 - c. What changes are required for such approaches to be used more consistently when collaborating with Inuit children and their families?
4. Do you have other comments, concerns or discussion points that are relevant to our FASD discussion?

Appendix E. Contact List of Service Providers

Contact List of (Participating) Service Providers

OTTAWA

Children's Aid Society of Ottawa
Children's Hospital of Easter Ontario (CHEO)
Citizen Advocacy
Community-Based Residential Facilities (CBRFs)
Eastern Ottawa Resource Centre
Gignul Non-Profit Housing Corporation
Inuit Non-Profit Housing Corporation
John Howard Society of Ottawa
Larga Baffin – Ottawa Region
Main Street Community Services
Makonsag Aboriginal Head Start Inc.
Minwaashin Lodge
Nepean, Rideau, Osgoode Community Resource Centre (NROCRC)
Odawa Native Friendship Centre (ONFC)
Ottawa Inuit Children's Centre (OICC)
Ottawa Public Health
Ottawa-Carleton District School Board (OCDSB)
Ottawa Distress Centre
Ottawa Health Service Network Inc. (OHSNI)
Ottawa-Carleton Association for Persons with Developmental Disabilities (OCAPDD)
Partners in Parenting
Pauktuutit Inuit Women of Canada
REACH Canada
Rideauwood Addictions and Family Services
Vanier Community Service Centre (VCSC)
Wabano Centre for Aboriginal Health
Youth Services Bureau of Ottawa

PROVINCIAL

Aboriginal Legal Services of Toronto

Anishnawbe Health Toronto (AHT)

Kids Brain Health Network (KBHN)

Native Child and Family Services of Toronto

Ontario Aboriginal Head Start Association (OAHS)

Ontario Association of Children's Aid Societies (OACAS)

Ontario Federation of Indigenous Friendship Centres (OFIFC)

The Hospital for Sick Kids

Toronto Aboriginal Support Services Council (TASSC)

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Fetal Alcohol Spectrum Disorder (FASD):
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AND SERVICES
for Ontario Inuit**

September 30, 2018

