

Fetal Alcohol Spectrum Disorder Provincial Roundtable Report

A Report from Parliamentary Assistant Granville Anderson
to the Minister of Children and Youth Services

SEPTEMBER 2015

Fetal Alcohol Spectrum Disorder Provincial Roundtable Report

A Report from Parliamentary Assistant Granville Anderson
to the Minister of Children and Youth Services

1	A MESSAGE FROM THE PARLIAMENTARY ASSISTANT
3	INTRODUCTION
3	About Fetal Alcohol Spectrum Disorder (FASD)
4	About this report
4	Our sustained commitment
5	About the roundtables
9	PARTICIPANT FEEDBACK
9	What We Heard: Awareness and Prevention
13	What We Heard: Screening, Assessment and Diagnosis
15	What We Heard: Programs, Services and Supports
18	What We Heard: Training for Front-Line Staff and Professionals
21	What We Heard: Evidence-Based Service Delivery Models
23	POPULATION-SPECIFIC CONSIDERATIONS
23	What We Heard: First Nations, Métis, Inuit and Urban Aboriginal Perspectives
25	What We Heard: The Francophone Perspective
26	OBSERVATIONS AND REFLECTIONS
28	ENDNOTES

A Message From the Parliamentary Assistant



Granville Anderson

Parliamentary Assistant
to the Minister of Children
and Youth Services
MPP Durham

Prenatal exposure to alcohol is a leading known cause of cognitive and developmental disability in Canada. The statistics for Fetal Alcohol Spectrum Disorder (FASD) are startling.

Approximately one in one hundred Canadians is affected by FASD. This means over 130,000 Ontarians are living with FASD. **What makes the issue of Fetal Alcohol Spectrum Disorder worthy of our commitment is we know that with the right information, programs, services and supports, FASD is preventable.**

Recognizing the importance of the FASD issue in Ontario, the Honourable Tracy MacCharles, Minister of Children and Youth Services, asked me to host province-wide roundtables. The Minister asked me to listen and learn about what is needed to better meet the needs of people with FASD, and their families and caregivers.

From May to August of this year, I hosted roundtable sessions across Ontario in major cities, small towns, and remote regions. Each roundtable brought together a diverse group of service providers, advocates, families, caregivers and individuals whose lives have been changed by FASD. We met with a common goal. As a roundtable participant stated: "We need to build awareness of what it is like to live with FASD every day."

This is what I learned: Public knowledge of FASD is limited at best. Many women and men are unaware of the risks of alcohol use before, during and after pregnancy. Children and youth affected by FASD are more likely to have mental health issues, substance abuse problems, and social and behavioural problems. Those affected have a high likelihood of dropping out of school or facing conflict with the law. Many adults with FASD cannot live independently, and have troubles obtaining and keeping a job. Adults with FASD are also more likely to experience psycho-social problems that increase their chances of getting arrested and going to jail. There are limited supports for adults and seniors living with FASD.

I have heard heart-wrenching accounts of how these challenges have affected people with FASD and their families and caregivers and that these challenges can last a lifetime.

For me, it was apparent from our first meeting that FASD is a complex issue. Participants brought so much passion and dedication to telling their individual stories and experiences. They bravely shared their daily difficulties and frustrations, trying to get help for their children and grandchildren. They told me about the urgency and need for action, and of their desire for Ontario to create positive change. What connected each person was a sense of hope—a hope that individuals affected by FASD in Ontario can reach their full potential if given the right supports.

I am absolutely humbled by, and grateful for, this experience. We came together as parents, caregivers, colleagues, service providers, affected individuals and collaborators—all committed to preventing FASD and improving the lives of those living with this disability. I give a heart-felt thank you to everyone who participated and for sharing your stories. I thank the people in the field for all the wonderful work that you do.

Inside this report, you will find many of the ideas and stories that were shared during the roundtable discussions. We can all play a significant role in the formation of the province's first FASD strategy by keeping the discussion going. As a community, let us continue to help, uplift and encourage each other to integrate new ideas and approaches that raise awareness and ultimately prevent FASD. As one roundtable participant knowingly declared, "People with FASD can succeed if they have the right people in their lives." It is through bravery and integrity that we can pave the way to a more positive future.

Sincerely,



Granville Anderson
Parliamentary Assistant to the Minister
Ministry of Children and Youth Services



IN THEIR OWN VOICES

"FASD is the leading cause of developmental disability in Ontario and it is preventable."

Introduction

About Fetal Alcohol Spectrum Disorder (FASD)

FASD is a term used to describe a range of disabilities that may affect individuals exposed to alcohol in utero. FASD encompasses the following diagnosed conditions: fetal alcohol syndrome (FAS), partial FAS (pFAS), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD)¹.

FASD is brain damage caused by exposure to alcohol in utero. FASD is among the leading causes of cognitive and developmental disability among children in Canada. FASD can affect memory, sensory integration, social communication, language processing, emotional regulation, adaptive functioning and other executive functions such as: planning, prioritizing, organizing, paying attention, and remembering details.

FASD is an invisible disability for the majority of individuals affected. Most individuals who have FASD do not display the physical features associated with the disability. It may appear that the affected individual "won't" comply with expectations, whereas due to the nature of the brain damage, they actually "can't".

FASD is preventable. Although FASD can be prevented by not consuming alcohol during pregnancy, there are many reasons why a woman may drink during pregnancy including: the woman did not know she was pregnant, mental health issues, substance abuse and addictions, coping with violence, physical and/or sexual abuse, a lack of awareness of the risks of drinking during pregnancy, and a lack of a support network (or not feeling supported).

Over 130,000 Ontarians have FASD. The estimated incidence of FASD in Canada is 1:100 live births, or one per cent of the population². FASD can affect every racial, cultural and socio-economic group across Ontario.

FASD cost Canada \$1.8 billion in 2013. A study by the Centre for Addiction and Mental Health found that the overall burden and costs associated with FASD in Canada in 2013 was approximately \$1.8 billion³. The study used the most conservative assumptions, which means that the true costs are likely much higher. Another study indicated that it has been estimated to cost the Canadian economy \$6.2 billion annually⁴.

FASD has a devastating and life-long impact on individuals across Ontario. Many adults affected by FASD cannot live independently, secure and maintain employment, and are more likely to experience psycho-social and behavioural problems that increase their risk of being in conflict with the law and/or correctional facilities⁵.

About this report

In September 2014, Premier Wynne issued a mandate letter to the Minister of Children and Youth Services. The letter included a commitment to develop and implement strategies that will improve the experiences and outcomes for children and youth with complex and special needs (including those who are affected by FASD).

As Parliamentary Assistant to the Minister of Children and Youth Services, my responsibilities include:

“Engaging with families, and as appropriate with affected youth, to listen to the challenges they face, and what they believe is required to better meet their needs in the development of a provincial Fetal Alcohol Spectrum Disorder strategy.”

This report provides a summary of what we heard through our engagement. The discussions at our roundtables will help shape a future provincial FASD strategy to increase awareness and prevention—as well as support the needs of those living with FASD and their families and caregivers.

Finally, it is the experiences and insights shared by individuals affected by FASD, their families and caregivers, service providers, and researchers that have made this report possible. I deeply appreciate all of your contributions.

Look for these text features inside this report:



IN THEIR OWN VOICES

What we heard from Ontario



DIGGING DEEPER

Information to deepen your knowledge

Our sustained commitment

The Ministry of Children and Youth Services is committed to supporting children and youth with complex and special needs to ensure that every child in Ontario has the best possible start in life. As part of this commitment, the province is developing an FASD strategy to address the complex needs of individuals affected by FASD across the lifespan so they can participate as fully as possible in community life.

To facilitate the development of an Ontario FASD strategy, the Ministry of Children and Youth Services:



DIGGING DEEPER: READ THE 2014 MANDATE LETTERS

[The Minister of Children and Youth Services' 2014 Mandate Letter.](#)

[The Parliamentary Assistant to the Minister of Children and Youth Services' 2014 Mandate Letter.](#)

MCYS VISION

An Ontario where all children and youth have the best opportunity to succeed and reach their full potential.

- Organized 25 cross-ministry roundtable sessions to facilitate dialogue among service providers, advocates, children’s treatment centres, families, caregivers, and especially individuals affected by FASD. The sessions included insights from Francophone, Aboriginal communities, lived-experience and general attendance audiences. Individuals were also able to send informal and formal written submissions, as well as information and research on FASD.
- Implemented a web-based survey on the Ministry of Children and Youth Services’ website.
- Established an expert group of FASD researchers and clinicians.
- Conducted interviews with a number of other key informants from across Canada to seek evidence-based input and expertise.
- Consulted with partners from the Ministry of Community and Social Services, Ministry of Education, Ministry of Health and Long-Term Care, Ministry of Community Safety and Correctional Services, Ministry of Aboriginal Affairs, Ministry of Citizenship and Immigration and International Trade, Ministry of Training, Colleges and Universities, and the Ministry of the Attorney General. They confirmed the project direction and provided input and participation where feasible.
- Hired a researcher to conduct research to inform awareness, prevention and targeted intervention strategies to support women and their partners to have alcohol-free pregnancies.

There is still more work to be done.

Decreasing the incidence of new FASD cases in Ontario continues to be important. Our stakeholders have called for the development of a FASD strategy for Ontario, including: the Fetal Alcohol Spectrum Disorder Ontario Network of Expertise (FASD ONE), the Ontario Federation of Indigenous Friendship Centres, the Select Committee on Developmental Services, and the Registered Nurses Association of Ontario.

We remain steadfast in our commitment to developing a strategy to give hope to those affected by FASD and their families and caregivers.

ROUNDTABLE PARTICIPANTS:

A complete invitation list of 500+ participants was compiled with input from ten ministries.

FASD participants reflected the diversity of Ontario’s population as a whole.

About the roundtables

In their own voices

From May 2015 to August 2015, the following FASD stakeholder engagement occurred: eight roundtables with First Nations, Métis, Inuit and urban Aboriginal communities; 16 roundtables with service providers, advocates, families, caregivers and individuals affected by FASD—in five Ontario regions; and one dedicated roundtable for individuals with lived experience and their families and caregivers.

The Ministry worked with a professional facilitator with subject matter expertise in FASD to organize, lead, moderate, transcribe, summarize and report on the roundtable sessions across Ontario. Over 400 Ontarians participated. A number of these participants represented organizations from across different sectors (such as: health, education, social services, justice and corrections) and shared their feedback. In doing so, they enriched our work with their perspectives.

Format of roundtable sessions

In each session, a dialogue was facilitated with key stakeholders following a participant guide and set of questions arranged into five FASD roundtable themes. In collaboration with First Nations, Métis, Inuit, urban Aboriginal organizations, and Francophone partners, a customized agenda, participation guide and feedback survey were developed to tailor roundtable sessions to better meet the needs of participants.

Group discussion, small breakout sessions, and an individual exercise were used to stimulate input from session participants. The responses noted down electronically and on a poster board were used to generate this report.

Roundtable themes

Individuals affected by FASD, families, caregivers, service providers, researchers and provincial associations provided feedback in the following five areas:

1. **Awareness and Prevention:** Includes broad awareness building and health promotion efforts, community development, discussion of alcohol use and related risk with all women of childbearing years and their support networks, specialized, holistic support of pregnant women with alcohol and other health/social problems, and postpartum support for new mothers and their children.
2. **Screening, Assessment and Diagnosis:** Includes medical, cognitive, behavioural, communication, adaptive, motor and executive functioning information provided by a multi-disciplinary team trained in the current best practice model and using accepted diagnostic criteria. Diagnosis requires confirmed history of prenatal alcohol exposure and areas of suspected delay.
3. **Programs, Services and Supports for Individuals and Caregivers:** Addresses the needs of individuals with FASD and their families and caregivers. Programs and services in the community, aimed at enabling individuals affected by FASD to reach their potential, as well as supports and assistance to families and caregivers.
4. **Training for Front-Line Staff and Professionals:** Consists of formal education, pre-service and in-service training programs, typically targeted at program/service providers (including health, medical and social and human services professionals) and/or community groups.
5. **Evidence-Based Service Delivery Models:** Evidence refers to basic scientific and applied research leading to increased understanding of FASD, its epidemiology (i.e., incidence and prevalence), leading practices in the prevention of FASD, and development of standards to guide the delivery of FASD clinical services and/or FASD programming.

Roundtable locations



Region	Roundtable Locations	Dates	Target Partner/ Stakeholder Group(s)
West Region	Hamilton	May 4, 2015	All stakeholder groups
East Region	Peterborough	May 5, 2015	All stakeholder groups
North Region	Thunder Bay	May 20, 2015	All stakeholder groups
Central Region	North Cambridge	June 15, 2015	All stakeholder groups
East Region	Kingston	June 16, 2015	All stakeholder groups
East Region	Ottawa (Aboriginal)	June 17, 2015	Aboriginal focus and includes Inuit partners
East Region	Ottawa	June 18, 2015	All stakeholder groups
North Region	North Bay	June 22, 2015	All stakeholder groups
North Region	Sudbury	June 23, 2015	All stakeholder groups
Toronto Region	Downtown Toronto	June 26, 2015	All stakeholder groups
East Region	Ottawa (French)	June 29, 2015	Francophone focus
Central Region	Newmarket	July 3, 2015	All stakeholder groups

Region	Roundtable Locations	Dates	Target Partner/ Stakeholder Group(s)
West Region	London	July 6, 2015	Aboriginal focus and includes Association of Iroquois and Allied Indians and Independent First Nations
West Region	London	July 7, 2015	All stakeholder groups
West Region	Windsor	July 8, 2015	All stakeholder groups
Central Region	Orillia	July 9, 2015	Individuals with lived experience
North Region	Kenora	July 14, 2015	Aboriginal focus and includes Ontario Native Women's Association
Toronto Region	Toronto	July 15, 2015	Dedicated roundtable with Ontario Federation of Indigenous Friendship Centres
Toronto Region	Toronto	July 16, 2015	Dedicated roundtable with Métis Nation of Ontario
North Region	Sudbury	July 21, 2015	Aboriginal focus and includes Union of Ontario Indians
North Region	Thunder Bay	July 23, 2015	Dedicated roundtable with Nishnawbe Aski Nation
Central Region	Toronto	July 27, 2015	All stakeholder groups
North Region	Moosonee	Aug. 5, 2015	All stakeholder groups
North Region	Kenora	Aug. 20, 2015	Dedicated roundtable with Grand Council of Treaty #3
East Region	Durham	Aug. 21, 2015	All stakeholder groups



IN THEIR OWN VOICES

“Ontario needs a cross-government and coordinated FASD strategy that builds on existing programs, services and strategies.”



IN THEIR OWN VOICES

“Many have heard of FASD but they only have a superficial level of understanding of what it is.”



IN THEIR OWN VOICES

“There is so much shame and stigma associated with FASD. People do not want to admit there was maternal drinking.”

Participant Feedback

What We Heard: Awareness and Prevention

The general public does not understand FASD

In Ontario, there is growing awareness about the risks of alcohol use in pregnancy and the specific consequences for the baby. However, participants were quick to point out that there is little awareness about the harm that can be done by consuming alcohol in pregnancy, even small amounts.

TV, radio, social media and public announcements were the most commonly suggested communications methods for FASD awareness campaigns. Participants also mentioned that messaging must be positive and should not blame women or mothers. Messaging should also emphasize the strengths of those living with the disorder.

Working to eliminate the stigma of FASD

Birth mothers of children with FASD face overwhelming stigma. Participants told us that these women often feel guilt, shame, and embarrassment from knowing that prenatal alcohol exposure caused lifelong problems to their own children. The stigma surrounding FASD is a major reason why some people living with the disorder and their families and caregivers may avoid diagnosis and seeking help within their community and health or social care systems. We learned that many adoptive and foster parents of children with FASD also deal with stigma.

We heard that “it is time to change the message”. Participants suggested that FASD be communicated as a brain injury with lifelong challenges and a range of possible “secondary” behavioural symptoms.

FASD awareness strategies are not targeting high risk groups

Participants told us the general public thinks that FASD only affects those of a certain socio-economic status. Participants also believe that FASD awareness strategies in Ontario are not doing a good job of reaching groups at risk for FASD. High risk groups for FASD extend to social drinkers, people with addictions or mental health issues, and sexually active youth.

- Participants identified college and university students as a high risk group due to their propensity for engaging in high risk behaviours, including binge drinking and having unsafe sex while drinking. Some participants believed that FASD awareness and prevention education could be most effective if it became a mandatory part of post-secondary orientation week programs.
- Participants identified professional women in their 30's as another high risk group not being targeted by FASD awareness campaigns. Similarly, FASD awareness strategies do not often target men and partners—even though they can have significant influence helping mothers avoid consuming alcohol while pregnant.
- Participants told us that women struggling with alcohol and substance abuse require a more complex, cross-sectoral response to help them change their alcohol and substance use patterns.
- Participants also said that FASD awareness strategies should be extended to individuals affected by FASD.

FASD awareness should be taught as early as possible in schools

“Start early—before they reach high school” was a resounding theme we heard at the roundtables. Many participants feel the Ontario school curriculum does not include a robust FASD awareness component. Participants believe that teaching students about FASD will help prevent the spread of misinformation, raise awareness, and lower the stigma and bullying associated with individuals affected by the disorder.

- At the elementary level, participants feel that FASD education could take on a greater role in the health and sexual education, and continue on through high school. We also heard that FASD education should be available in college and university.
- Participants also told us that educators require more information, resources and teaching strategies to better support students with FASD. One way participants said this could be addressed is by improving communication between health providers and the education system. Another way is by building customized programs, services and supports for students with FASD.
- We heard that as some children do not go through the Ontario's publicly funded education system, FASD awareness should be taught in federal schools, in communities, and in independent schools (like First Nations schools).



IN THEIR OWN VOICES

“We need to educate both women and men on the dangers of drinking during pregnancy—and the need for using effective birth control if alcohol is being consumed.”



IN THEIR OWN VOICES

“I'm so afraid to send my son to high school because he does not have the necessary support in place. And without these supports, he is at risk of getting involved with the wrong crowd.”



IN THEIR OWN VOICES

“Awareness campaigns should not be targeted just to pregnant women. They need to be targeted to all women of childbearing age and their partners.”



DIGGING DEEPER: SANDY'S LAW

Click [Sandy's Law](#) to read more about the Liquor License Act requiring certain premises to post signs warning women that drinking alcohol during pregnancy can cause FASD.

We need to build on existing FASD awareness campaigns

Participants identified FASD awareness campaigns in Ontario, Alberta, British Columbia, Manitoba, Alaska, France, the United States, Australia and Sweden. Participants stated that there is “no sense reinventing the wheel”. They encouraged the Ministry of Children and Youth Services to look at these campaigns to learn best practices that may be leveraged in Ontario. For example:

- **“Baby Bump” Campaign:** In 2014, LCBO partnered with FASworld Canada to promote the “Baby Bump Campaign” in stores from August 25 to September 12. The goal of the campaign was to help raise awareness about FASD and to promote alcohol-free pregnancy. Virtually all the roundtable participants had seen the Baby Bump FASD awareness posters at a liquor store. Participant opinions with respect to the effectiveness of the campaign varied. Some felt the campaign was effective. Others felt it sent the wrong message and that negative awareness campaigns should be discouraged as they have been shown not to be effective.
- **“Think Before You Drink” Campaign:** Many participants also suggested that we leverage existing campaigns, like: Halton Region’s “Think Before You Drink” campaign, Best Start “Healthy Baby, Healthy Brain” campaign, the Minnesota Organization on Fetal Alcohol Syndrome (MOFAS) campaign, and the Families Affected by FASD “Red Shoes Rock” campaign. Mother’s Against Drunk Driving (MADD) was another successful campaign mentioned by participants.
- **“Bell Let’s Talk” Campaign:** One participant spoke of a TV commercial where a celebrity talked about depression and mental health—and suggested we do the same for FASD.
- **FASD Warnings:** Participants told us that signage in restaurants, bars and clubs, warning about alcohol use in pregnancy, do work. We heard that many places do not have the warning posters up, or that the posters were not visible or that the signage needs to be updated. We also heard about how pregnancy tests have been made available in some women’s washrooms in bars in Alaska. Participants suggested that more efforts could be made to place FASD warnings and labels on: alcohol bottles, contraceptive packages, within liquor stores, and at restaurants (in addition to, or to expand on, Sandy’s Law). Negative campaigns should also be discouraged.

There are many effective FASD awareness programs in Ontario

Government programs—like **(Aboriginal) Healthy Babies Healthy Children**, **Best Start** and the **Aboriginal Fetal Alcohol Spectrum Disorder and Child Nutrition Program**—are effective programs for sharing information about FASD and educating individuals on the dangers of alcohol consumption during pregnancy.

- **(Aboriginal) Healthy Babies Healthy Children** provides screening and assessment for infants and young children and gives direction to new parents, supports and help finding community programs.
- **Best Start** is a trusted resource for maternal and newborn developmental health providing multi-media resources, consultations and workshops to people across Ontario.
- The **Aboriginal Fetal Alcohol Spectrum Disorder and Child Nutrition Program** provides information, family support and activities related to Fetal Alcohol Spectrum Disorder, offers educational opportunities to the broader community about the dangers of alcohol use during pregnancy, and organizes activities that focus on healthy nutrition.

Participants also spoke very highly of many community-based programs in Ontario, including:

- The **Parent Child Assistance Program** is a home visitation case-management model for mothers who abuse alcohol or drugs during pregnancy.
- Mothercraft's **Breaking the Cycle** program is an early identification and prevention program that enhances the outcomes of alcohol/substance-exposed children by addressing maternal addiction problems and the mother-child relationship through a community based cross-systemic model.



DIGGING DEEPER: BEST START

Click [Best Start](#) to learn more about the Ontario government's Best Start plan for child care, early learning and healthy development.



IN THEIR OWN VOICES

“A diagnosis can provide greater understanding and acceptance. It can also result in more realistic expectations and contribute to positive outcomes.”



DIGGING DEEPER: WHERE DO YOU GO TO GET DIAGNOSED?

[FASD ONE: List of Diagnostic Services in Ontario](#)



DIGGING DEEPER: FASD GUIDELINES

Review them here:
[FASD: Canadian Guidelines for Diagnosis](#)



IN THEIR OWN VOICES

“Ontario needs provincial standards for screening assessment and diagnosis.”

What We Heard: Screening, Assessment and Diagnosis

We should screen for FASD as early as we can

Participants suggested that early post-natal screening take place before the child is six years of age. They also suggested that a teacher, day care worker or social worker could easily screen for FASD in children. We heard that in most instances, once the child is formally diagnosed with FASD, he or she can be linked to a number of beneficial FASD school programs, counseling services and community-based programs. These early interventions will help support the individual and reduce secondary symptoms that are often displayed in individuals with FASD, including: mental health problems, inappropriate behaviours, alcohol and drug abuse, and problems with the law.

A diagnosis can help provide greater understanding and acceptance

Stigma and fear of judgment are the main reasons why women will not disclose to healthcare providers that they drank during their pregnancy. The stigma also prevents individuals from obtaining an FASD diagnosis to access the supports they so desperately need. We heard participants say that a diagnosis is the first step in changing minds and attitudes. A diagnosis can help a person understand that the underlying cause of their issues is a permanent disability. In addition, when others are trained and educated to understand FASD, they will know how to alter their own behaviour towards an individual with FASD in a positive way.

FASD diagnostic clinics and Canadian guidelines

There are 14 diagnostic clinics in Ontario; most of these clinics diagnose children for FASD, not adults. Each diagnostic clinic provides FASD screening, assessment and diagnostic services by a multi-disciplinary team. We learned that a number of community and grassroots organizations are collaborating with the clinics to improve accessibility to Ontarians requiring FASD screening, assessment and diagnostic services.

Revised evidence-based guidelines for FASD screening, assessment and diagnosis will be released in the fall of 2015. Participants hope that the guidelines will be mandated and used by all health and social services organizations to ensure consistency in the screening, assessment and diagnosis process, and to reduce the risk of misdiagnosis.

There are many barriers to screening, assessment and diagnosis

Participants identified the following barriers that need to be overcome to meet the needs of people with FASD, their families and caregivers, and communities:

- **Confirmation of Maternal Alcohol Consumption During Pregnancy is Required to Obtain an FASD Diagnosis:** To get an FASD diagnosis in Ontario, the mother herself does not necessarily need to disclose that she consumed alcohol during her pregnancy; however, there does need to be confirmation by a reliable source (father, grandmother, family members, etc.) that there was alcohol use during pregnancy. The stigma and fear of judgment are reasons that women may not disclose to healthcare providers or others that they drank during their pregnancy. In addition, adults who potentially have FASD may not be able to obtain the corroboration necessary to confirm their mother consumed alcohol while pregnant. Participants suggested a possible solution is to introduce neuro-behavioural testing during pre- and post-natal screening, or to perform meconium testing at birth.
- **Travel and Associated Costs:** Many people with FASD living in remote communities must travel great distances to access screening, assessment and diagnostic services. We heard that the travel expenses and the cost to perform the neuro-developmental assessment may not be covered by insurance. First Nations and Inuit people who live on-reserve are not covered under the federally funded Non-Insured Health Benefits Program. Participants suggested that alternative service models be used to improve access, including: the Ontario Telemedicine Network, Tele-Mental Health, Tele-Psychiatry, and mobile or portable clinics.
- **Lack of Culturally Appropriate Services:** We heard that screening tools are often not culturally appropriate, or do not reflect the diversity of First Nations, Métis, Inuit and urban Aboriginal peoples or other cultures in Ontario.
- **Wait Lists and the Duration of the Process:** Participants told us that they often have to wait a long period of time to get an FASD assessment at one of Ontario's 14 diagnostic clinics. To improve accessibility, participants suggested we expand assessment criteria and open more diagnostic centres, particularly in the North and in remote communities.
- **Lack of Trained Professionals to Provide an Accurate Diagnosis:** Participants highlighted the need for more trained speech language therapists, occupational therapists, physiotherapists, psychologists and other health care providers in Ontario who specialize in FASD screening, assessment and diagnostic services. In addition, we heard that professionals need to be trained to support families and caregivers during, and after, the diagnosis.

Physicians, health care providers and social workers play a critical role in screening for alcohol use

Participants said that many health care providers and social services providers avoid asking their clients and patients questions about drinking patterns and habits. “Ask all mothers if they consumed alcohol during their pregnancy”—participants felt this is a message that all health care providers and social services workers should be trained to ask without judgment or offence. When the questions are asked, we heard that it is not always done in a manner that is culturally appropriate for some groups.



IN THEIR OWN VOICES

“Individuals with FASD need to be supported with programs and services even if they do not have a diagnosis.”



IN THEIR OWN VOICES

“Once a diagnosis is given, then what? There is a lack of programs, services and transitions after diagnosis.”



IN THEIR OWN VOICES

“Too many individuals with FASD have been misdiagnosed or not diagnosed at all.”



IN THEIR OWN VOICES

“You can get wrap-around for one year, or respite for six weeks—but FASD is a lifelong disability.”



IN THEIR OWN VOICES

“Parents need to be advocates; they need to share their stories in order to raise awareness.”



DIGGING DEEPER: FASD AND ONTARIO'S JUSTICE SYSTEM

FASD among the inmate population may be 28 times higher than in the general population.

Youth with FASD are 19 times more likely to be confined in a young offender's facility than their non-affected peers.

[FASD ONE - FASD and Justice: Summary of Activity in Ontario](#)



DIGGING DEEPER: FASD RESOURCES

[FASlink](#)

[Strongest Families](#)

[FASD ONE](#)

[Wabano Centre for Aboriginal Health](#)



IN THEIR OWN VOICES

“There are no supports for seniors with FASD.”

What We Heard: Programs, Services and Supports

People with FASD and their families and caregivers need lifelong support

Across Ontario, there is a network of FASD research organizations and community outreach programs that provide invaluable support to people with FASD and their families and caregivers. The following programs are making a difference to people living with FASD:

- **Reach For It**, the **Compass Program**, **Big Brothers-Big Sisters**, **Aboriginal FASD/Child Nutrition Program**, **Healthy Babies, (Aboriginal) Healthy Children**, **Camp Unity** and Mother Craft's **Breaking the Cycle** are just a few well-established programs offering supports and services for those with FASD.
- **Respite** is another support program mentioned in the roundtable sessions. Respite provides temporary support to parents and caregivers who need a break. It can help decrease the stress of raising a child with FASD.
- Outside of Ontario, some participants pointed to the British Columbia **FASD Key Worker Program**, which provides a specialized family support worker to enhance support of children and youth, families and caregivers, parents and families affected by FASD.
- The **Choice Program** from the United States was also cited as an example of a well-established program that helps at-risk youth build resiliency by promoting protective factors to mitigate risk in their daily lives.
- **Youth Justice Diversion Programs** divert youth affected by FASD who have committed a “less serious” criminal offense from the court system into the community for rehabilitation. While participants applaud these supports, many commented that it is too bad that many of the FASD programs and supports are not readily available to adults in the justice system.
- As is so often the case, the best experts are those who live with, or care for, someone with FASD—and **support groups and networks** in Ontario make good use of this first-hand resource.
- A number of evidence-based **information resources** have also been developed. Some are community, population or sector specific, while others are for the general public. Examples mentioned at the roundtables include: the **Fetal Alcohol Syndrome Information Network**—an online resource that gives insight into the family and caregiver perspective of living with the disorder; the **Strongest Families FASD Parent Training Program**—a pilot study to develop an internet-based program for families and caregivers; **FASD ONE's diagnostic resources**—resources that provides information about FASD assessment and screening best practices in Ontario; and the **Wabano Centre for Aboriginal Health**—which provides educational programming for Aboriginal families on child nutrition and FASD.
- Many parents and caregivers want to ensure their children with FASD are taken care of in later years. For adults affected by FASD, access and availability to employment services, affordable housing, and financial supports that have the flexibility to accommodate the unique needs of individuals with FASD will go a long way to providing the necessary lifelong supports for people with the disability.

Services need to be tailored to the person with FASD

FASD has a spectrum of symptoms. As a result, participants told us that FASD programs and services are most effective when they are tailored to the person with FASD.

- We heard that FASD services are often provided based on an individual's chronological age. Participants feel it would be more effective if services were provided based on the individual's developmental age.
- For many people with FASD and their families and caregivers, there is a need to have programs, services and supports available outside of the normal business hours of 9:00 a.m. to 5:00 p.m. We heard from many families and caregivers that there is very little to no immediate crisis supports. Many participants stressed that this issue could be addressed by introducing 24/7 supports for specific services to assist individuals living with FASD and their families and caregivers during times of need for immediate assistance.
- We heard from participants that families and caregivers either do not have access to sufficient respite supports. The availability of respite varies across the province and some families have access while others do not. Some families and caregivers choose not to access respite because there is a lack of trained workers who do not have the experience to work with an individual with FASD. The need for respite increases when the individual with FASD completes school and, in particular, if there are no alternative programs or activities in place (e.g., postsecondary education, work, day activities). We also heard from families that one of the biggest supports they have is when their child is supported in the school system. Many families and caregivers indicated that school is a form of respite that provides them with a temporary break and allows them to focus on other areas of their lives.
- Many parents at the roundtables voiced their frustrations with Ontario's service system. They indicated that the system is fragmented and not responsive to the needs of individuals with FASD. We learned that many people with FASD who are particularly vulnerable (e.g., homeless, suffering from addictions, or are in the justice system) cannot access current programs, services and supports. Integration and communication are key factors in helping people navigate the FASD care continuum. Participants suggested a multi-disciplinary approach would improve communications between the health, social services and the education systems.
- Families and caregivers often worry that services may be taken away when their child is "doing well". Some service providers do not understand that the services are needed 24/7.



IN THEIR OWN VOICES

"The one-size-fits-all approach does not work with individuals living with FASD."



IN THEIR OWN VOICES

"Parents and caregivers cannot take all the burden with no supports. We need respite services."



IN THEIR OWN VOICES

"I want my child to have the appropriate supports and services in school so that he can succeed."



**IN THEIR
OWN VOICES**

“Every agency should have at least one person who is knowledgeable about FASD.”

Communities need access to more FASD supports

The programs, services and supports that are available to people with FASD vary across the province. Supply of these services is not keeping up with demand in many Ontario communities.

- We heard that when a service provider with knowledge in FASD leaves a rural or remote community, the knowledge leaves with them. To fill the service gap, health care providers must fly in a few times a year to provide FASD specialized services because these services are not available locally.
- Participants mentioned that building community capacity to meet the needs of the individuals affected by FASD is key to ensuring the programs, services and supports we develop are equitable and culturally appropriate.
- It is also important to understand that each community has its own unique circumstances and realities that must be taken into consideration when developing programs, services and supports. For example, while providing services through alternative models (like the Ontario Telemedicine Network and mobile supports) may improve access, participants told us that we should keep in mind that some communities prefer a person-to-person service delivery method.
- Participants suggested that a regional hub model—providing access to training, multidisciplinary teams and system navigators who can leverage the Ontario Telemedicine Network and mobile supports—would help build community expertise.

There is a need for additional funding for FASD supports

The consensus among participants is that cases of FASD in Ontario are most likely under-reported. This under-reporting suggests that there is a greater need for additional funding for FASD programs, services and supports.

Participants pointed out that this lack of funding also contributes to gaps in service, especially in cases whereby the funding is only short-term. It was suggested that long-term funding be committed for FASD services, even if it means fewer programs are funded. Participants also called for more funding for respite services so that families and caregivers have the supports they need to cope with the stress that can be experienced when raising a child with FASD. Additional funding should also be provided for the development of programs, services and supports geared to adults and seniors who do not have family support.

What We Heard: Training for Front-Line Staff and Professionals

All front-line staff and professionals would benefit from FASD training

FASD is a sensitive topic for families and caregivers living with the disorder. This often makes it difficult for many front-line staff and professionals to talk about FASD with their clients. Many say they do not want to stigmatize the birth mother, her family and caregivers, or the child.

Participants emphasized the need for front-line staff to be trained to communicate with individuals with FASD and their families while: limiting judgment, acting with empathy and managing the family's grief, anger and denial.

Below is a list of the groups, as identified by participants during the roundtable sessions, which should be the primary audiences for mandatory training on FASD. It includes the most commonly suggested groups, all of whom have an impact on the life of an individual with FASD and their family and caregivers.

Family/Caregivers/ Foster Parents

Health Care Providers

- Doctors/Obstetricians/
Gynecologists
- Nurses/Nurse Practitioners
- Psychologists/
Neuropsychologists
- Midwives
- Occupational Therapists
- Physical Therapists
- First Responders

Social Service Providers

- Therapists
- Child Welfare Workers
- Case Workers
- Social Workers

Educators

- Childcare Workers
- Teachers
- Principals/Directors
- Education Assistants
- Early Childhood Educators

Justice System

- Police
- Lawyers
- Judges
- Probation Officers
- Corrections Officers
- Court Workers

Other

- Employers
- Landlords
- Financial Managers/
Bank Employees



IN THEIR OWN VOICES

"It is difficult for service providers to ask a woman whether she drinks alcohol."



IN THEIR OWN VOICES

“Service providers are often unaware of the daily struggles of individuals living with FASD and their families and caregivers.”

FASD training needs to be broad in scope

Participants agreed most people do not understand that people with FASD have brain damage. Participants told us that:

- There should be a **consistent level of training** across all front-line staff so there is a common understanding that FASD is a spectrum disorder that affects individuals differently.
- Front-line staff should be trained to **recognize the possible symptoms of FASD** including: behavioural issues, sensitivity to sensory stimulation and learning disabilities.
- Front-line staff should be trained in **effective strategies** on how to support individuals with FASD.
- There is a lack of **consistent information being delivered by front-line workers and professionals** to clients about the risks of alcohol consumption during pregnancy. We heard that training should emphasize this FASD message: There is no safe amount, no safe time, and no safe type of alcohol can be consumed during pregnancy.

Training should also include information about strategies, programs, services and supports available in Ontario to support people with FASD and their families and caregivers and participants stressed that ongoing training is paramount to translating the most current FASD research thinking and best practices to front-line support workers.

There are many ways to deliver FASD training

When asked what methods of training are effective, participants suggested:

- **FASD Champions:** In mentorship programs, front-line staff are connected to FASD Champions—who are people with FASD and/or their families and caregivers. This allows for the sharing of lived experience and gives the front-line staff new insight into effectively working with people with FASD. Some individuals with lived experience indicated their interest in becoming a champion, coordinator or advocate for FASD in Ontario.
- **Train-the-Trainer Programs:** Another effective method of training suggested by participants is to have one expert in the community, who has previously received formal training, train other individuals in the community.
- **Professional Training:** FASD is currently included in some professional training curricula, but it is limited. We heard that FASD education and training must also be included in the curricula of professions that work with individuals with FASD and their families and caregivers. Some of these professions are:
 - Doctors, nurses, nurse practitioners, first responders and midwives
 - Teachers, principals and teaching assistants
 - Social workers and social services workers
 - Child welfare workers
 - Police, probation officers, lawyers and judges

These professionals have a major role in the awareness and prevention of FASD. FASD education and training will give these professionals a greater understanding of the disability and the programs, services and supports available in Ontario.



IN THEIR OWN VOICES

“There needs to be a way to train educators that goes beyond the textbook.”

What We Heard: Evidence-Based Service Delivery Models

People with FASD need consistency of care throughout their lives

Participants were asked what supports do people with FASD need to better access FASD programs, services and supports.

- **Case Coordinator:** Participants agreed that it is important to have a case coordinator or support worker to help people with FASD navigate the system on a consistent basis. Individuals affected by FASD have indicated that having a champion, coordinator, or advocate with lived experience would be helpful for others living with FASD. We also heard that we should build on the existing Special Needs Strategy—in particular the coordinated service planning processes and the integrated delivery of rehabilitation services.
- **One-Stop Source:** Participants described the difficulties people with FASD encounter in their daily lives—and how these difficulties are compounded as they try to navigate the FASD continuum of care. Participants said it would be extremely helpful if there was a one-stop, 24/7 source where they could go to get up-to-date and accurate information about FASD services and supports. Participants suggested that the province could build on an existing website or 1-800 number. A similar information source exists in Manitoba, British Columbia, Saskatchewan and Alberta.
- **No Wrong Door:** The idea of a “No Wrong Door” is a notion mentioned by participants. People with FASD and their families and caregivers will always be given or directed to the appropriate services they need. This may involve referrals to other organizations, collaboration, or connection to a navigator to access appropriate programs, services and supports.

People with FASD need help transitioning from child to adult public support services

Adults with FASD face tremendous challenges and are an underserved population. Participants explained that adults with FASD have fewer services available to them. We heard from participants about the need for better transition processes from the children services system to the adult services system. Families voiced their concerns about their child moving into the adult sector in particular because there is no transition planning or supports available. We learned that in Ontario, many support services that help children with FASD are no longer available once the child reaches the age of 18. Families and caregivers must apply for adult support services. This can be a very frustrating and stressful experience because families have to tell their story again, it is a new and unfamiliar process—and there is no guarantee that helpful services will be available.



IN THEIR OWN VOICES

“I struggle every day and worry about what will happen to my child when I am no longer around.”

Measuring Success – What Would it Look Like?

Participants were asked to provide the measures of success for a provincial FASD strategy. Despite the varying participant backgrounds, the majority of the responses followed these themes:

- **Reduction of the Prevalence of FASD:** We will know that an FASD strategy is successful when we see a reduction in the prevalence of FASD. This would mean that there is a greater awareness of the risks of drinking alcohol while pregnant and prevention efforts are successfully reaching Ontarians.
- **Services are More Accessible:** A successful FASD strategy will address the lack of accessible services for remote communities and for people living in urban centres. Efforts to increase capacity, to better integrate services, to leverage the Ontario Telemedicine Network, and to improve navigation will lead to improved programs, services and supports that are more accessible to people with FASD and their families and caregivers.
- **Increased Capacity to Diagnose FASD:** We will know an FASD strategy is successful when we see sufficient diagnostic clinics in the province, trained professionals to do the diagnosis, a decrease in the number of misdiagnoses—and there will no longer be a wait list for individuals waiting to be diagnosed.
- **Fewer People with FASD within the Justice System:** Due to lack of screening, lack of transition supports and general lack of advocacy, many people with FASD end up in the justice system. We will know that an FASD strategy is successful when we have fewer people with FASD entering the justice system—as well as more supports for people with FASD already within the justice system.
- **Reducing Stigma:** The negative opinion that many people have towards FASD has been detrimental to the improvement of FASD awareness, prevention, programs, services and supports in Ontario. Reducing stigma towards FASD would be a major success factor of an FASD strategy.
- **Live a Successful Life:** With adequate programs, services and supports in place, individuals with FASD will be able to lead a successful life within their community. They will have the basic requirements like housing and employment, or access to money, along with all the unique social, psychological and health supports required. The result will be a lower level of stress on individuals with FASD, their families and caregivers.
- **Better Data on FASD:** An FASD strategy will create the necessary systems to monitor FASD prevalence in Ontario. Some participants felt that an FASD diagnosis code in the Ontario Health Insurance Plan (OHIP) could help us obtain statistics on the prevalence of FASD in Ontario. This data could then help inform our targeted prevention efforts. In addition, participants believe that physicians would be more likely to assess FASD if a billing code existed.



IN THEIR OWN VOICES

“I am a student at a community college and my disability counsellor really understands me and helps me.”



DIGGING DEEPER: ABORIGINAL CHILDREN AND YOUTH STRATEGY

Ontario is developing an [Aboriginal Children and Youth Strategy](#) in collaboration with First Nations, Métis, Inuit and urban Aboriginal partners to improve outcomes and opportunities for Aboriginal children and youth by transforming the way that services are designed and delivered.



DIGGING DEEPER: ABORIGINAL FASD/CHILD NUTRITION PROGRAM (CNP)

The Aboriginal FASD/CNP is delivered to 180 Aboriginal communities both on- and off-reserve.

Front-line workers provide healthy lifestyle education, personal support and traditional cultural activities that promote FASD prevention and healthy nutrition.

Program staff produce community resource materials and offer professional development training on prevention/ intervention to Aboriginal and non-Aboriginal social service providers, educators, justice and medical personnel.



IN THEIR OWN VOICES

“Services and service delivery need to be developed using the traditions and culture of Aboriginal people.”

Population-Specific Considerations

We engaged with First Nations, Métis, Inuit and urban Aboriginal partners and Francophone community through a number of dedicated roundtables. The feedback we received echoed many of the same themes and issues raised at the other roundtables. Below are additional comments that were uniquely voiced by First Nations, Métis, Inuit and urban Aboriginal partners and the Francophone community.

What We Heard: First Nations, Métis, Inuit and Urban Aboriginal Perspectives

We must acknowledge the history and trauma of Aboriginal People

Participants stressed the need for sensitivity and understanding of the impacts of history on the present state and the challenges of Aboriginal children, youth, and their families. Aboriginal communities continue to be affected by, and are recovering from, the intergenerational impacts of historical assimilationist policies and program approaches. These approaches removed children from their families and communities, and resulted in the loss of cultural connections and traditional child-rearing practices (e.g., *Indian Act*; forced relocations of Inuit families in northern Canada).

The resulting intergenerational effects emerge as socio-economic challenges for children, youth, and families—including high levels of addictions and substance misuse, mental health issues such as post-traumatic stress and suicides, loss of traditional parenting skills, and loss of attachment and pride in cultural identities, traditional ceremonies and governance systems.

Culturally-based and culturally-specific FASD support services

Cultural knowledge building and retention of culture are essential for Aboriginal people in developing positive self-esteem and pride in their identities. Participants mentioned that culturally-based and culturally-specific programs, services and supports that are preventative, family-centred, holistic and strength-based are needed to support those affected by FASD. Programs, services and supports also need to be available in the language of the specific community. Participants said service providers should be trained to work with Aboriginal children, youth, adults, families and caregivers, and communities.

FASD programs, services and supports: designed and delivered by Aboriginal People, for Aboriginal People

We heard from participants that enhanced Aboriginal control over service design, delivery and system governance is key to improving outcomes. Participants said that Aboriginal communities and organizations are best positioned to understand and determine the needs of their own communities. In addition, it was noted that greater control by First Nations, Métis, Inuit, and urban Aboriginal peoples to develop and deliver culturally appropriate programs, services and supports will promote family preservation and cultural connection.

Some First Nations participants told us that the provincial and federal governments need to resolve issues of jurisdiction and funding so that FASD programs, services and supports can be made available both on- and off-reserve.

Northern and remote communities need better access to FASD services

Participants said that funding additional FASD diagnostic clinics in the northern and remote communities will minimize the cost of travel. Increasing service capacity will also limit the disruption and sense of disconnection many feel when traveling outside their communities to get the help they need. This also applies to building capacity within communities to provide FASD programs, services and supports.

Aboriginal communities support culturally appropriate, evidence-based FASD programs and supports

This includes supporting research and evaluation developed by Aboriginal people for their communities to measure the effectiveness of these programs, services, supports and resources. In addition, we heard the need to track progress through culturally and contextually appropriate monitoring, and evaluation approaches, including data collection to measure the prevalence of FASD in Aboriginal communities in Ontario.

We need to continue the conversation as the provincial FASD strategy is developed

Continuing the conversation will assist in improving relationships and partnerships between Ontario and First Nations, Métis, Inuit, and urban Aboriginal partners. Successful implementation of actions under an FASD strategy is contingent on an ongoing commitment and partnership. An FASD strategy responds to the diversity within and among First Nations, Métis, and Inuit cultures and communities in terms of histories, and priorities, and approaches to family care.



IN THEIR OWN VOICES

“To ensure that FASD supports are culturally and linguistically appropriate, there needs to be self-determination and development from the grassroots; not, ‘here it is, now adapt to it.’”



IN THEIR OWN VOICES

“Aboriginal peoples understand the needs of our communities better than anyone else.”



DIGGING DEEPER: TRUTH AND RECONCILIATION COMMISSION OF CANADA: CALLS TO ACTION

The [Truth and Reconciliation Commission of Canada](#) has called on all governments to recognize FASD as a high priority and to develop, in collaboration with Aboriginal people, culturally appropriate FASD preventive programs.



IN THEIR OWN VOICES

"We want to design and deliver our own programs, services and supports for our communities."

What We Heard: The Francophone Perspective

There is a negative view towards FASD in Francophone communities

We heard that the stigma associated with FASD prevents some Francophones with FASD and their families and caregivers to reach out for help. In smaller communities, some families are reluctant to access programs, services and supports because of their connections in the community and concerns with privacy and confidentiality.

Culturally appropriate FASD supports are required in French

Often times, Francophone workers have to adapt an existing program on their own, or they simply cannot offer programming. In addition, screening, assessment and diagnosis tools are not culturally appropriate for the Francophone community. French speaking Ontarians have also indicated that often media is translated from English to French without being conscious of the differences between Québécois and French speaking Ontarians. Participants told us that FASD campaigns, programs, services and supports should be created by Francophones for Francophones.

More evidence-based research and data collection is required to support the Francophone community

Participants told us that Francophones affected by FASD do not participate in research studies. As a result, the long-term impact of FASD within the Francophone community is not fully understood. This lack of data also makes it challenging to provide culturally appropriate FASD programs, services and supports to individuals living with FASD, their families and caregivers in the Francophone community.

Observations and Reflections

The roundtables have been a journey into FASD and the rich diversity of Ontario, from Moosonee to Windsor. Each time we came together, we each brought our own unique perspectives with us: families, caregivers, health care providers, affected individuals, social service providers, educators; they all came and shared their stories with us.

The roundtables strived to be inclusive of every individual affected by FASD. What we learned from each other will most certainly play a significant role in the formation of an FASD strategy—and yet it also enhanced each of us personally. For me, these roundtables afforded a privilege that few are able to experience. I am grateful for this opportunity to listen and learn from the many voices across this province. As I reflect back on this experience, I would like to share some of my observations:

Support for an FASD strategy is high

Without exception, there is a great demand for an integrated Ontario FASD strategy. Participants have waited a long time for action, and they are very pleased to see that the provincial government is moving forward with an FASD strategy.

The people of Ontario are not aware of FASD

Awareness was an overarching theme I heard throughout the sessions. The effects of this range from: increased prevalence of FASD, to misinformation fueling the stigma around FASD that is felt by individuals with the disability and their families and caregivers. Sadly, this stigma continues to be perpetuated, highlighting the importance and need for raising awareness of FASD.

We need to start talking about FASD

There is a need to broaden FASD awareness campaigns to target the public in the hopes of preventing new cases—while removing the stigma for people currently affected by FASD. We need to start talking about FASD and how we can decrease its prevalence in Ontario.

FASD prevention efforts are needed

FASD prevention work is complex. It involves more than providing information about the risk of alcohol use during pregnancy. It also includes discussion of alcohol use, specialized holistic support for pregnant women with alcohol and other health and social issues, as well as postpartum support for new mothers and their children. These supports contribute to improving women's health and reduce the risk of having a child affected by FASD.

There are many effective programs and services we can leverage

I learned of many effective programs and services available in Ontario that are helping people with FASD. These need to be leveraged and better supported to improve outcomes for individuals affected by FASD. For example, we could build on the success of the following initiatives: the Aboriginal Children and Youth Strategy, the Special Needs Strategy, the Mental Health and Addictions Strategy, and the Long-Term Affordable Housing Strategy.



IN THEIR OWN VOICES

“Without a provincial strategy, individuals with FASD are falling through the cracks.”

It is time to break down the silos and collaborate

From our many conversations, it is clearly high time to break down the silos that are limiting our success in helping those with FASD. I heard silos exist between sectors such as health, justice, education and social service, as well as between organizations and ministries. An FASD system does not yet exist, and what we do have is fragmented. I believe that FASD programs, services and supports need to be supported by an appropriate accountability structure and funding model.

We need to help people who need it

Who needs our help? I learned that there are certain high risk groups that are falling through the system, including: adults and seniors with FASD, people who live in rural and remote locations, and people who speak different languages or are part of a different culture. Participants were supportive of an FASD strategy that took a holistic approach to expanding programs, services and supports to all high risk groups.

Needs are not being met

It is a commonly held opinion that there is not enough support overall for individuals affected by FASD and their families and caregivers. Participants highlighted the lack of capacity, supports and/or funding for awareness and prevention, screening and diagnosis, programs, services and supports, training, and effective delivery of services. I heard that the delivery of FASD programs, services and supports must reflect and respect the differences and diversity within and across Ontario communities.

Care is required across the life span

Although programs, services and supports exist, many are not available to adults and seniors and there is little support for transition between what programs, services and supports there are.

There is a huge need for earlier diagnosis

In addition to the lack of screening, there is a huge need for early diagnosis to address the extra support needed for children with FASD before they enter the education system.

We need to move forward in a measured way

Finally, we need to evaluate the impact of programs, services and supports new and old—and the prevalence of FASD—to ensure we steer our planning efforts in the right direction.

Thank you to all who participated on this stage of the journey. As the roundtables have come to a close, our collective efforts now begin to pick up steam as we address the comments, feedback, insights, and every day realities that participants shared with us. While there is much work left to do, I do know that together, we will be there—leading, learning, innovating, creating and achieving. Together, we will help people affected by FASD grow and be the best version of themselves.

Endnotes

- ¹ 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), 1-21.
- ² Fetal Alcohol Spectrum Disorder (FASD). (2005). Retrieved from <http://www.phac-aspc.gc.ca/hp-ps/dca-dea/prog-ini/fasd-etcaf/faq/pdf/faq-eng.pdf>
- ³ Popova, S., Lange, S., Burd, L., & Rehm, J. (2015, February). The Burden and Economic Impact of Fetal Alcohol Spectrum Disorder in Canada. Retrieved from http://www.camh.ca/en/research/news_and_publications/reports_and_books/Documents/Burden_and_Eco_Costs_FASD_Feb_2015.pdf
- ⁴ Thanh, N.X., E. Jonsson, J. Kogan, and P. Jacobs. "Cost of FASD." *Fetal Alcohol Spectrum Disorder: Management and Policy Perspectives of FASD*. 1st ed. Weinheim: Wiley-VCH Verlag GmbH & Co KGaA, 2011. Print.
- ⁵ Streissguth, A., Barr, H., Kogan, J., & Bookstein, F. (1996). Understanding the occurrence of secondary disabilities in clients with FAS and FAE: Final report to the centers for disease control and prevention. 96-106: University of Washington, Fetal Alcohol and Drug Unit.

