

Fetal Alcohol Spectrum Disorder (FASD): A Call to Action in Ontario

Presented by: Fetal Alcohol Spectrum Disorder
Ontario Network of Expertise (FASD ONE)
Driving Progress on FASD

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Vision

A province where FASD is prevented and individuals living with FASD have the opportunity to lead full and productive lives as valued and contributing members of their community.

Mission

FASD ONE will be a leader in promoting and encouraging collaboration on FASD to develop a provincial evidence-informed integrated system including prevention, diagnosis, specialized intervention and support.

Contents

- 3 Executive Summary
- 4 Introduction
- 5 Background
 - About Fetal Alcohol Spectrum Disorder (FASD)
 - Michele's Journey
- 8 Why a Provincial Strategy
- 8 A Call to Action
- 9 Recommendations
 - 1. Awareness and Prevention
 - 2. Assessment and Diagnosis
 - 3. Intervention and Support
 - 4. Knowledge Transfer and Capacity Enhancement
 - 5. Research and Evaluation
- 12 References
- 13 FASD ONE Members
- 14 Disclaimers

Executive Summary



Fetal Alcohol Spectrum Disorder (FASD) must be included in Ontario's evolving cross-ministerial response to developmental disabilities.

FASD is an umbrella term describing the range of lifelong brain-based disabilities that can occur in an individual whose mother drank alcohol during pregnancy. In Canada, prenatal exposure to alcohol is the leading cause of developmental disability (Public Health Agency of Canada, 2005), and costs the Canadian economy \$6.2 billion annually (Thanh, et al. 2011).

This submission, prepared by Fetal Alcohol Spectrum Disorder—Ontario Network of Expertise (FASD ONE), calls for a provincial strategy on FASD. A provincial strategy provides an opportunity for the Government of Ontario to take the lead in implementing an action plan that prevents FASD, while ensuring effective services for those affected, resulting in reduced incidence, improved outcomes, and decreased costs.

This document makes recommendations in five areas which are explored in more detail in the full document. They are as follows:

1. AWARENESS and PREVENTION: Ontarians will receive accurate information regarding the risks of alcohol use during pregnancy, together with timely access to the services they require to abstain from or limit alcohol use in pregnancy.

2. ASSESSMENT and DIAGNOSIS: Individuals with prenatal alcohol exposure, regardless of their age, will have access to timely assessment and diagnostic services and a coordinated, informed response that is appropriate, effective, and linguistically and culturally sensitive.

3. INTERVENTION and SUPPORT: Children, youth, adults and their caregivers will have ready access to culturally sensitive resources and services designed to address and accommodate their individual lifelong needs.

4. KNOWLEDGE TRANSFER and CAPACITY ENHANCEMENT: FASD education and training will be made readily available to both current and future families/caregivers and service providers in all service sectors.

5. RESEARCH and EDUCATION: Services and resources will be evidence based, effective, culturally appropriate and inclusive of those affected by FASD.

Introduction

Ontario is in a time of transformation. The government is developing and implementing strategies to address the needs of children, youth and adults across all sectors. These strategies come together around the common aim of enhancing outcomes for Ontario's children, youth and adults by

- i. optimizing health and preventing poor birth outcomes;
- ii. ensuring equitable and accessible services;
- iii. developing evidence-based services that are transparent and accountable.

Fetal Alcohol Spectrum Disorder (FASD) must be included in Ontario's evolving response to developmental disabilities, and to the transformation of the children's mental health, mental health and addictions, early years, child care and child welfare systems. The needs of those with FASD must be addressed in health, social, educational, legal and correctional services.

This submission, prepared by Fetal Alcohol Spectrum Disorder—Ontario Network of Expertise (FASD ONE), proposes recommendations for a strategy to:

1. Prevent FASD by providing evidence-based information and accessible, comprehensive services to pregnant women and all women of childbearing age;
2. Ensure timely access to assessment and diagnostic services to children, youth and adults who may be affected by FASD;
3. Support children, youth and adults who are affected with the disability through evidence-based interventions that stabilize home life and maximize potential.

FASD ONE is ideally situated to partner with the government to achieve our shared vision of a province in which FASD is prevented, and those individuals living with FASD will have the opportunity to lead full and productive lives as valued and contributing members of their community. FASD ONE is ready, willing and able to inform policy leading to a coordinated, comprehensive, cross-sectoral system of support for Ontarians.

Background

About Fetal Alcohol Spectrum Disorder (FASD)

FASD is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. Prenatal alcohol exposure has its primary impact on brain development and functioning. The effects of prenatal alcohol exposure vary, and are affected by individual maternal and fetal factors, including differences in the amount of alcohol consumed, the pattern and timing of the consumption, and maternal and genetic factors (Canadian Pediatric Society, 2002). Since FAS was first described in 1973 (Jones KL & Smith DW, 1973) it has become apparent that this disorder is actually a spectrum of conditions we now call Fetal Alcohol Spectrum Disorder (FASD). It is complex, with a wide range of expression in those affected—from severe growth restriction, intellectual disability, birth defects and characteristic dysmorphic facial features to normal growth, facial features and intellectual abilities, but with lifelong deficits in several domains of brain function. The neurodevelopmental impacts of FASD are on physical, behavioural, emotional, social and cognitive functioning.

FASD is an invisible disability for the majority of those affected. Most individuals with FASD do not display the physical features associated with the disability, but are affected primarily by brain damage resulting from their prenatal exposure to alcohol. In the absence of identification and diagnosis, it may be assumed that the affected individual “won’t” comply with expectations, whereas the reality is that he/she “can’t”. Expectations of the affected individual may not be congruent with his/her abilities, setting up a cycle of misapplied interventions and supports, frustration and failures for those affected, and risk for secondary disabilities and other adverse outcomes due to inadequate understanding and accommodation.

In Canada, prenatal exposure to alcohol is the leading cause of developmental disability (Public Health Agency of Canada, 2005). FASD is believed to affect 1% of the population (Public Health Agency of Canada, 2005) or 130,000 children, youth and adults in the province. The cost of supporting those affected by FASD in Canada is estimated at \$6.2 billion annually (Thanh, NX, Jonhsson, E, Dennett, L, & Jacobs, P, 2011).

The estimated return on investment in prevention of FASD is significant: “For every \$150,000 dollars spent on prevention we will see \$1.5 million dollars in return” (Thanh NX., & Jonsson E., 2009).

While preventable, FASD is a complex, multi-faceted public health and social issue that affects Ontarians in all walks of life, in every community of the province. While even low to moderate consumption of alcohol can interfere with the normal development of the fetus, heavy or frequent alcohol use increases the risk of delivering a baby with FASD (Chudley, AE, Conry, C, Cooke, JL, Looock, C, Rosales, T, LeBlanc N, 2005). The data indicate that risk factors for prenatal alcohol exposure include higher maternal age, lower education level, maternal use of cocaine and tobacco, custody changes, lower socioeconomic status and paternal drinking and drug use at the time of pregnancy (Sood, B, Delancey-Black, V, Covington, C et al., 2001). Additional conditions of risk include reduced access to prenatal and postnatal care and services, inadequate nutrition and poor developmental environment (e.g. stress, abuse, neglect) (Bingol N, Schuster, D, Fuchs, losoub S, et al, 1987). Prevention of FASD includes attending to the complex biological and social determinants of health, including genetics, poverty, malnutrition, lack of social support networks and personal autonomy, as well as gender-based violence, trauma, stress and social isolation.

The Canadian Guidelines for Diagnosis of FASD clarify and quantify alcohol’s impact on fetal development, and define the criteria for diagnoses that fall under the Spectrum: Fetal Alcohol Syndrome (FAS), partial Fetal Alcohol Syndrome (pFAS) and Alcohol Related Neurodevelopmental Disorder (ARND). The diagnoses under FASD must be given by a physician (paediatrician, family physician, psychiatrist, geneticist) in the context of a multidisciplinary assessment. FASD diagnostic teams often include a psychologist, speech and language therapist, occupational therapist, social worker and case manager. Diagnoses of pFAS and ARND require the confirmation of maternal alcohol use during pregnancy.

The primary disability of FASD is diffuse permanent brain damage and includes impacts in the following areas:

- executive functioning (planning/ organization/consideration/moderation);
- adaptive functioning (daily living and self-care);
- social communication (interpretation of meaning; implicit/explicit and verbal/non-verbal within multiple contexts, social rules)
- processing speed/efficiency/accuracy
- areas of memory

The challenges presented by the primary disability of FASD are often compounded by secondary disorders or adverse outcomes that are not intrinsic to the disability.

Secondary disabilities and adverse outcomes arise when the primary disability is not identified or diagnosed, or when appropriate interventions have not been applied. It is in these areas that screening, diagnosis, and effective interventions are most needed to prevent adverse outcomes. In their large seminal study, Streissguth et al (1996) found the following outcomes for individuals (between ages 12 and 51) affected by FASD **who did not receive the services they required:**

- 95% had mental health issues;
- 82% were unable to live independently (between ages 21- 51);
- 80% were raised by someone other than a biological parent;
- 70% had problems with employment (between ages 21-51);
- 68% had “disrupted school experience”;
- 68% experienced trouble with the law;
- 52% exhibited inappropriate sexual behaviour;
- 30% had substance use problems (Streissguth et al.,1996; Streissguth et al., 2004)

It is well-established that individuals with FASD who are not identified and do not receive the services they require face additional challenges as a consequence of their disorder, including breakdown in family relations, disruption of schooling, unemployment, homelessness, alcohol and drug abuse and mental health disorders. Adolescents and adults with FASD are also at high risk for coming into conflict with the criminal justice system, either as offenders or as victims. The legal implications of FASD are complicated.

Streissguth et al, (1996) found that **the following factors protected individuals with FASD** from developing secondary disabilities or adverse outcomes:

- Living in a stable and nurturant home.
- Being diagnosed before the age of 6 years.
- Never having experienced violence against oneself.

Secondary disabilities and adverse outcomes can be reduced or prevented through early diagnosis and interventions that accommodate the disability and result in realistic expectations.

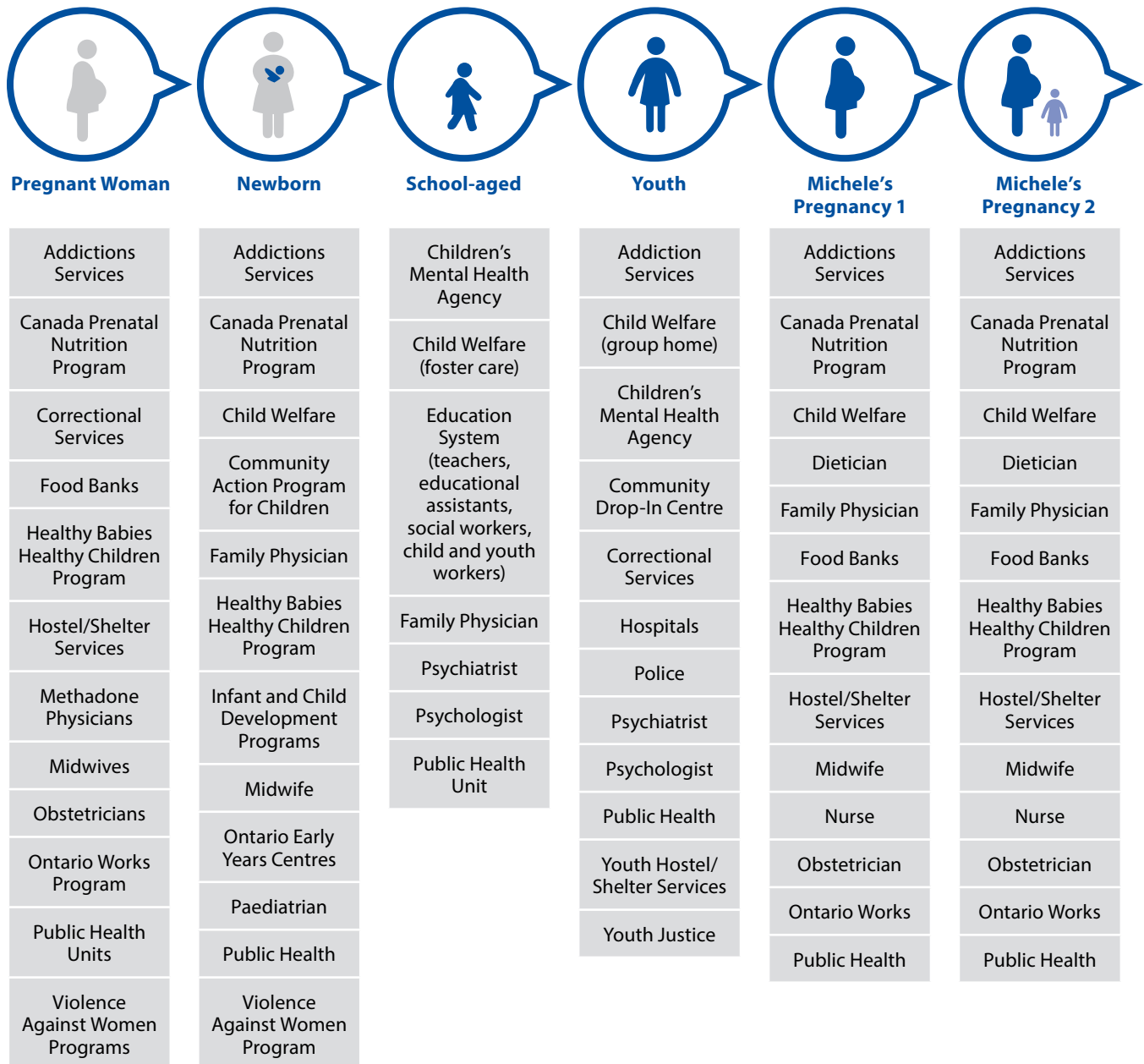
Sadly, a recent study of youth with FASD living in Ontario found that 86% of youth had never been referred to or received any FASD-informed interventions or services, despite high levels of functional impairment across brain domains. Moreover, the majority of youth who had received specialized interventions or services had done so only when participating in research studies (Todorow, M, Moore, TE, Fantus, E, Sorbara, D, & Nulman, I 2011a, b).

Improved outcomes will result in reduced need for expensive, publically funded intervention and supports.



Michele's Journey

Pregnant women at risk for delivering a child with FASD, as well as those individuals affected with the disability, typically have contact with a range of service providers across multiple sectors throughout the lifespan. These contacts offer opportunities for the delivery of interventions that can prevent or reduce the harms associated with prenatal alcohol exposure, and to support children, youth and adults affected with the disability and their caregivers. Michele's Journey identifies the service providers and systems that are typically encountered by those with FASD across various life stages.



Why a Provincial Strategy

A provincial strategy provides an opportunity for the Government of Ontario to take the lead in implementing an action plan that will prevent FASD, while ensuring effective services for those affected with the disability. This will result in reduced incidence, improved outcomes, and decreased costs.

FASD is preventable. The investment in preventing FASD will increase the human potential in Ontario and decrease the cost of supporting those affected with the disability, including fewer secondary disabilities and adverse outcomes.

FASD crosses multiple ministry mandates. Ontario requires a strategy that fosters collaboration across ministries to guide policies, investments, commitments and activities to support pregnant women and all women of childbearing age, as well as children, youth and adults who are affected by FASD.

Collaboration among service sectors is critical. No one ministry and no one sector can provide seamless service

delivery across the lifespan required by individuals with FASD. Ontario requires the implementation of cross-sectoral service strategies that share the load across multiple ministries to address systemic gaps.

Provincial strategies have proven effective in other jurisdictions to facilitate coordination of efforts, shifts in policy, and the advancement of FASD-informed practices in all sectors. This is consistent with services available for other neurodevelopmental disabilities in Ontario.

Provincial models exist for the coordination of activities that could infuse knowledge of FASD into systems transformations and improve service outcomes (e.g. LIHNs; the Human Services and Justice Coordinating Committees).

Provincial leadership and action is required to build on and extend existing local, community-based initiatives. The investment in addressing this disability has a ripple effect across multiple systems.

A Call to Action

Action on the prevention of FASD, and effective interventions for those affected with the disability, is urgently needed in Ontario.

In the forty years since FASD was first identified little action has taken place in the province. Stigma associated with alcohol use during pregnancy and FASD is one cause for inaction. The voices of families who so often drive social change are lost to addiction, grief and misinformation. This has meant that opportunities to inform, support and prevent FASD in all sectors of society have been missed.

Not addressing the impact of FASD on the health, education, child welfare, early years, mental health, developmental services, and legal systems will embed chronic failure into the current platform of services for individuals with this neurodevelopmental disability. Because FASD can mimic or co-occur with other common neurodevelopmental disorders like Autism, ADHD, and/

or mental health disorders, diagnosis becomes complicated. If the brain function vulnerabilities are missed, resources are misdirected from appropriate services. The cost is generations of individuals whose primary needs have been missed; this has resulted in a loss of individual, family and community potential and misapplied resources.

Developing a provincial strategy to address FASD will ensure that investments meet the needs of citizens by providing appropriate and efficient services. The benefit would be immediate. It would allow service providers and families to begin to address the chronic issues associated with the disability and stabilize lives. Individuals with FASD could contribute their skills and talents to community. Resources would be more aptly and efficiently applied, reducing reliance on expensive crisis services and ensuring those with this (and other) developmental disabilities live with dignity.

Recommendations

1. Awareness and Prevention

Ontarians will receive accurate information regarding the risks of alcohol use during pregnancy together with timely access to the services they require to abstain from or limit alcohol use in pregnancy.

- 1.1 Ensure that all Ontarians receive ongoing evidence-informed knowledge about the effects of alcohol use during pregnancy using broad-based, community driven, linguistically and culturally appropriate communication channels, resources and materials.
- 1.2 Ensure that all pregnant women and women of childbearing age have the opportunity to discuss their alcohol use, the risk of alcohol exposed pregnancy, and pregnancy planning, in a safe environment with well-informed practitioners.

- 1.3 Ensure that pregnant women who are using alcohol or are at higher risk of alcohol use in pregnancy have priority access to holistic, culturally appropriate, women-centred services that reflect the social determinants of health—addiction treatment, mental health services, health care, prenatal care, safe housing, income stability, food security.
- 1.4 Ensure that new mothers receive postpartum support to assist them to maintain healthy changes made during pregnancy, to prevent future alcohol exposed pregnancies, to support the development of their children and to prevent secondary disabilities related to prenatal alcohol exposure.

2. Assessment and Diagnosis

Individuals with prenatal alcohol exposure, regardless of their age, will have access to timely assessment and diagnostic services and a coordinated informed response that is appropriate, effective, and linguistically and culturally sensitive.

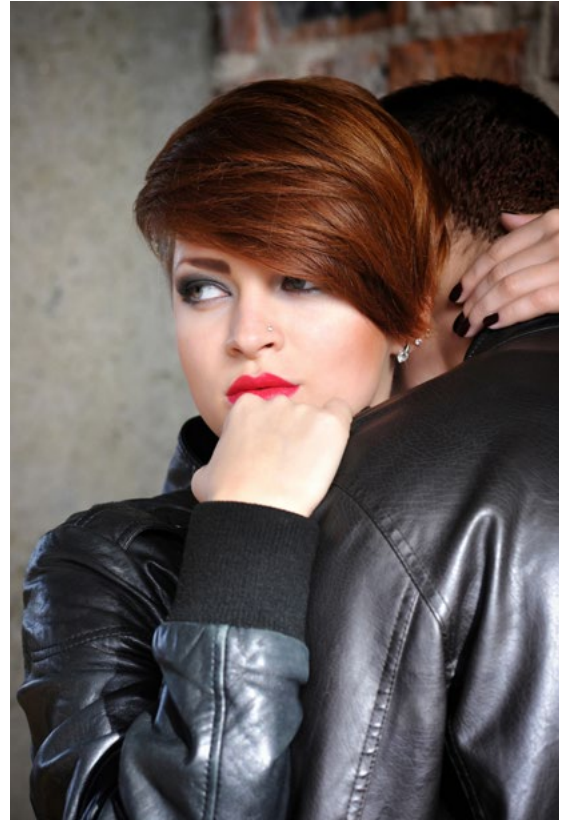
- 2.1 Build capacity to assess for and diagnose FASD as part of the assessment of neurodevelopmental disabilities.
- 2.2 Ensure access to equitable and timely assessment that considers all brain domains affected by prenatal alcohol exposure; ensure diagnosis at the earliest age possible, following up across the lifespan when needed.
- 2.3 Encourage the integration of FASD identification, assessment and diagnosis into all support services for children, youth and adults.
- 2.4 Provide a discrete FASD OHIP code so that the prevalence of FASD diagnoses in Ontario can be tracked.
- 2.5 Provide comprehensive case management support to facilitate referrals.
- 2.6 Develop a protocol to ensure the transfer of a child's medical history from the prenatal to the postnatal period to facilitate assessment, diagnosis and referral.



3. Intervention and Support

Children, youth, adults and their caregivers will have ready access to culturally sensitive resources and services designed to address and accommodate their individual lifelong needs. Elements of effective practice inform service provision across a range of sectors—child welfare, education, justice, housing, income security, employment, health, mental health, and addictions—in ways that stabilize lives and maximize potential.

- 3.1 Define service pathways to ensure those affected by FASD have access to the services they need across multiple sectors.
- 3.2 Expand service interventions to include effective practices so that individuals living with FASD have access to the services that contribute to optimal outcomes.
- 3.3 Integrate the expansion of collaborative family-centred service coordination to include respite, case management, education, parenting support, supportive housing and employment, and income security.
- 3.4 Facilitate the addition of Fetal Alcohol Spectrum Disorder (FASD) as a neurodevelopmental exceptionality in the special education system of Ontario and provide effective programming to support students with this brain-based disorder.



- 3.5 Support cross-sector, lifelong FASD services that are seamless, personalized and feature ongoing and transitional support.
- 3.6 Ensure that all families have access to timely, affordable, tailored, strengths-based supports and resources.
- 3.7 Ensure access to FASD-informed custodial and non-custodial programs and services for victims, accused and offenders with this brain-based developmental disability.
- 3.8 Establish protocols to ensure the protection of the rights of witness, the accused, offenders and victims with FASD in the legal system



4. Knowledge Transfer and Capacity Enhancement

FASD education and training will be made readily available to both current and future families/caregivers and service providers in all service sectors.

- 4.1 Facilitate awareness of and access to FASD education and training for families and caregivers, as well as those in all sectors serving individuals affected by FASD and their families.
- 4.2 Ensure the inclusion of FASD-specific content in the curriculum of College and University programs including medicine, nursing, midwifery, early childhood education, education, child and youth, occupational therapy, speech and language pathology, physiotherapy, social work, psychology, police, corrections and law.

- 4.3 Knowledge transfer should include cross-sector collaboration to explore potential opportunities in programming and coordinate and align policies to enhance effectiveness of service delivery and mitigate adverse outcomes.
- 4.4 Facilitate knowledge transfer and communication among Ontario's local community FASD networks.



5. Research and Evaluation

Services and resources will be evidence-based, effective, culturally appropriate, and inclusive of the voice of those affected by FASD.

- 5.1 Encourage the expansion and support of systemic evaluation processes to measure the effectiveness of FASD services and programs in Ontario.
- 5.2 Encourage the expansion and support of a systematic data collection process to measure prevalence of FASD in Ontario.



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FASD ONE Members

- Action on Women’s Addictions – Research and Education (AWARE), Kingston, ON
- Associated Youth Services of Peel, Mississauga, ON
- Best Start Resource Centre at Health Nexus, Toronto, ON
- Sheila Burns, FASD Consultant, M.S. & Associates, Ajax, ON
- Canadian Mental Health Association, Sault Ste. Marie, ON
- Children’s Aid Society of Toronto, Toronto, ON
- Elaine Cousineau, FASD Independent Educator/Consultant, North Bay, ON
- Lynn Cunningham, Ryerson University, Toronto, ON
- Mary Cunningham, FASD Consultant, Kitchener, ON
- Durham District School Board, Whitby, ON
- FASD Durham
- FASD Coalition of Ottawa, Ottawa, ON
- FASD E.L.M.O. Network, London, ON
- Judith Ferguson, FASD Consultant, Georgian Bluffs
- Georgian College, Orillia Campus, Orillia, ON
- Girls Incorporated of Durham, Ajax, ON
- Hotel Dieu Hospital, Child Development Centre, Kingston, ON
- Jane Hoy, Huron County, ON
- Keystone Child, Youth and Family Services, Owen Sound, ON
- KidsLINK, Waterloo Region, Kitchener, ON
- Kathy Layte, Parent, Kitchener, ON
- Middlesex-London Health Unit, London, ON
- Mothercraft/Breaking the Cycle
- Motherisk Program, Hospital for Sick Children, Toronto, ON
- Cheryl Neave, FASD Consultant, Vice-Chair FASD ONE, Unionville, ON
- Niagara District School Board, St. Catharines, ON
- North Bay Indian Friendship Centre, North Bay, ON
- Norwest Community Health Centre, Thunder Bay, ON
- Peel Infant and Child Development Services, Mississauga, ON
- Peel Region FASD Diagnostic Team, Mississauga, ON
- Peterborough FASD Committee & Caregiver Support Group, Peterborough, ON
- Ramsey Lake Health Centre, Sudbury, ON
- Region of Waterloo Public Health, Waterloo, ON
- Regional Support Associates, Walkerton, ON
- Sharron Richards, Community Volunteer, Chair FASD ONE, Toronto, ON
- Rideauwood Addiction Services, Ottawa, ON
- Dr. Scott and Associates, Paris, ON
- St. Michael’s Hospital, FASD Clinic, Toronto, ON
- Southern Ontario Network of Specialized Care, Thorold, ON, ON
- Southwest Ontario Aboriginal Health Access Centre, London, ON
- Surrey Place Centre, Toronto, ON
- Thames Valley District School Board, London ON
- Michelle Todorow, Toronto, ON
- Union of Ontario Indians, North Bay, ON
- Roxana Vernescu, Ph.D., Nipissing University - Muskoka Campus

Disclaimers

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About FASD ONE (Fetal Alcohol Spectrum Disorder Ontario Network of Expertise)

FASD ONE is a volunteer collaborative comprised of Ontario practitioners, parents/caregivers, community volunteers and specialists committed to the prevention of Fetal Alcohol Spectrum Disorder and the development and dissemination of evidence-based information that will support practitioners, as well as individuals affected by FASD, and their families. FASD ONE members represent communities across Ontario, as well as the health, child welfare, justice, early intervention, addiction and mental health, education, and corrections sectors.

FASD ONE has sought province-wide input to inform recommendations for action on FASD. The 2013 Blueprint for Action symposium, which was attended by 180 stakeholders representing community, regional and provincial organizations, identified priority issues. Priorities focused on prevention, education, early intervention, child welfare, assessment and diagnosis, and legal issues. These priorities reflect the sectors and ministries touched by FASD, the need for coordination of a response, and the value of that effort to communities, stakeholders, and families across the province.

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For more information, see www.fasdontario.ca