



An Integrated Approach to Address
FASD in Waterloo Region

FASD | WATERLOO REGION

Why is this important?

Fetal Alcohol Spectrum Disorder (FASD) is the term used to describe the range of permanent disabilities caused by alcohol consumption in pregnancy. FASD is a complex and confusing condition that does not look the same in each person. It requires a team of trained professionals to diagnose, furthermore, the full range of disabilities may not be apparent until a child is older. As a result, this makes FASD difficult to recognize and support. However, if individuals receive diagnosis and support early on, they can lead fulfilling and productive lives.

A baby's brain continues to develop throughout pregnancy, and brain damage can occur at any time if alcohol is consumed. Hence, there is no safe time, no safe amount of alcohol to consume during pregnancy. Effects of prenatal exposure to alcohol may include physical, mental, behavioural issues and learning disabilities.

The primary disabilities associated with FASD are difficulties with attention, filtering sensory information, language, memory, planning and initiating activities, regulating emotions and life skills. Often children and youth with FASD have average intelligence (IQ), good expressive language skills and are very social, making them appear more capable than they actually are.

FASD is often referred to as an invisible disability because we cannot see the brain damage like we can with a physical disability. FASD often goes misdiagnosed or undiagnosed. If FASD is not diagnosed, accommodated, and supported those affected can develop secondary characteristics such as poor school experiences, trouble with the law,

drug or alcohol addiction, problems with employment and mental health disorders.

The knowledge we have regarding FASD and how we should address it in a cohesive systematic manner is limited. This Integrated Strategy to Address FASD in Waterloo Region is based on the best evidence available. It is imperative we continue the conversation and incorporate new knowledge and evidence to prevent or reduce the effects of FASD and meet the needs of those living with FASD. This is why it is of utmost importance that we pledge to evaluate all our actions to ensure we are using our limited resources to address FASD in Waterloo Region in the most cost effective evidence based manner.



Who are we?

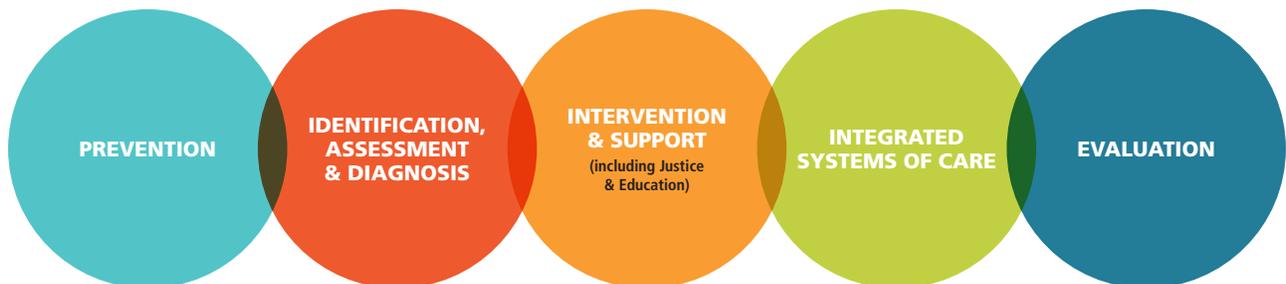
The Waterloo Region FASD Action group is a collaborative of organizations and caregivers whose mandate is to:

1. Develop and advocate for a comprehensive strategy for FASD in Waterloo Region congruent with the Call to Action released by FASD ONE in 2014.
2. Support opportunities in Waterloo Region for FASD evidence-informed prevention, intervention and support initiatives.
3. Seek out and support innovative opportunities for those living with FASD, their caregivers and service providers.

As a community we need your help to implement our plan to prevent FASD and better the lives of those living with FASD. Just as the FASD ONE Call to Action wishes to engage with the Province of Ontario to create opportunities we, in Waterloo Region, need your help to move our plan forward so we are well situated to take advantage of provincial initiatives.



The Waterloo Region FASD Action Group proposes recommendations for action in 5 key areas:





We need **YOUR help**

Who is part of the Integrated Approach to Address FASD in Waterloo Region?

1. Those who work to prevent FASD and those who work with people living with FASD, diagnosed or undiagnosed
2. Leaders/decision makers for agencies and services
3. Policy makers – those who can influence how our region and province work and use our resources
4. People living with FASD

What Can You Do to Support an Integrated Approach to Address FASD in Waterloo Region?

- Be willing to reorient services/systems to prevent/reduce FASD and address the needs of those living with FASD in an evidence based cost effective manner
- Seek out and advocate for funding to better address FASD in Waterloo Region and in Ontario
- Support all staff to work from an FASD informed approach
- Promote reflective practice as a routine part of practice to improve outcomes and reduce burn out
- Be accepting of and understand the benefits of harm reduction strategies to reduce the effects of FASD
- Employ a trauma informed approach when working with our community
- Commit to coordinated evaluation for each action implemented

Benefits of Committing to and Implementing an Integrated Approach to Address FASD in Waterloo Region

- Improve outcomes for those at risk for and those living with FASD
- Engaged satisfied staff
- Better use of resources
- Clients living with FASD diagnosed or undiagnosed will experience less stigma
- Services and systems will be working toward a common goal which will increase the collective impact
- Increase our return of investment
- Decrease the incidence of FASD in Waterloo Region

The Waterloo Region FASD Integrated Approach

Current Developments in FASD

There are positive developments provincially and regionally that have supported progress in the prevention, identification, diagnosis, intervention and support of those at risk of or living with FASD.

Provincially, a report from the Select Committee on Developmental Services pointed out the need for a strategy to address FASD. As a result, the Ministry of Children and Youth Services was directed to address FASD within their 2015 mandate. The Fetal Alcohol Spectrum Disorder Ontario Network of Expertise (FASD ONE) published a Call to Action advocating for an integrated provincial strategy in March 2014. In response to these actions, the Ontario government conducted FASD Roundtable discussions across the province and has produced the "Fetal Alcohol Spectrum Disorder Provincial Roundtable Report". This report is a first step to create an integrated strategy to address FASD in Ontario.

Regional Gaps

While progress has been made addressing FASD in Waterloo region, there are continued and anticipated gaps in:

- Prevention
- Identification and timely diagnosis
- Appropriate and adequate supports for children and young adults in schools

- Respite for families
- Ongoing recreational services for children
- Support for young adults with FASD.

Integrated Approach for FASD for Waterloo Region

The Waterloo Region FASD Action Group has developed a foundation for an Integrated Approach for FASD. The purpose of the Integrated Approach is to provide a framework to address FASD in a coordinated and cohesive fashion in Waterloo Region. This will be a working document to present to organizations and regional planning tables. The plan will be informed by provincial and national initiatives (e.g., Special Needs Strategy, FASD ONE Call to Action, MCYS FASD Roundtables, Truth and Reconciliation Committee Report, Moving on Mental Health, etc.) and the input of local stakeholders.

The Plan currently consists of five goals. Each goal includes a statement of the desired outcome along with a number of key milestones in support of the goal. The Plan will be further developed to include specific and measurable outcomes, roles and responsibilities, and timelines through consultation with agencies and organizations throughout Waterloo Region.

A recent study in the U.S. found that 2.5-4.8% of children in the school system have some form of FASD.



Goals:

Prevention

The incidence of babies who are exposed to alcohol in pregnancy is reduced.

- A. Everyone will be aware of the risks of drinking alcohol in pregnancy.
- B. Girls and women of childbearing age will be screened and be provided brief counselling regarding the need to use reliable birth control if alcohol is used.
- C. All pregnant women will have priority access to specialized prenatal supports if they are struggling with remaining alcohol/substance free.
- D. All mothers who have struggled with alcohol/substance use in their pregnancy will have access to support for themselves and their children.
- E. Supportive alcohol policy will be practiced.

Identification, Assessment & Diagnosis

Children and Youth (0-17yrs) who have been prenatally exposed to alcohol will have access to identification, assessment and diagnosis.

- A. Every baby who has been substance exposed will be referred to infant development services.
- B. Communication between prenatal and postnatal supports will increase.
- C. Documentation in the infant/child/youth file will occur when a professional confirms that a pregnancy was exposed to alcohol.
- D. Those assessing infant, children and youth will have increased understanding of FASD and how it presents and affects daily living.
- E. Pathways of referral for assessment of FASD will be clear and open to all.
- F. Diagnostic capacity will increase with ongoing funding and trained professionals.

Intervention & Support (including Justice & Education)

Families and caregivers will have access to evidence informed and/or innovative interventions and supports in their homes, schools and community.

- A. Interventions for infants and young children will support social development, physical growth (with or without a diagnosis) and social determinants of health. This will occur as early as possible and will be easy and accessible.
- B. Families will have access to respite services.
- C. Children/Youth will have access to accommodated recreational opportunities.
- D. Children/Youth will have success in positive school environments and when their need outweighs resources they will have access to specialized FASD informed school placements.
- E. Targeted interventions will be piloted and evaluated.
- F. Housing, job training and life skills for transition to adulthood will be developed.
- G. Justice services will become increasingly aware of FASD and alter practices when addressing matters involving witnesses, offenders and victims.

Integrated Systems of Care

Families and caregivers will have easily accessible pathways to care.

- A. FASD will be considered when key service delivery models are developed (Special Needs Strategy, FASD ONE Call to Action, MCYS FASD Roundtables, take our Truth and Reconciliation Committee Report, Moving on Mental Health, etc.)
- B. Agencies and professionals will continue to develop an FASD-informed approach by participating in the Waterloo Region FASD Community of Practice.

Evaluation

Evaluation will be funded, purposeful and used as a tool to inform future services.



Social stigma, lack of awareness and lack of diagnostic services results in many FASD cases in our community not being identified.

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A woman in a white long-sleeved shirt is shown from the chest up, looking out a window. The background is a bright, slightly blurred outdoor scene. The image is partially covered by a teal overlay on the left side where the text is located.

Did you know?

FASD is the leading cause of developmental disability in Canada.

FASD causes strain on health-care, educational, community and criminal justice services.

FASD costs Canadians an estimated 5.3-6.8 billion dollars every year.

Services for an individual with FASD costs 1 to 3 million dollars over their lifetime.

Investing 150,000 dollars on FASD prevention saves 1.6 million dollars in specialized supports.

Individuals with FASD are 10-19 times more likely to be incarcerated and 95% struggle with mental illness.

Caregivers report social isolation caused by a lack of understanding of their child's disability from family, educators, health and social service providers.

The lack of respite care for families causes increased stress and family breakdown.

For More Resources

www.fasdwaterlooregion.ca offers a collection of information, strategies, tips and community resources developed and assembled by professionals and parents.

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