



FETAL ALCOHOL SPECTRUM DISORDER (FASD)

Alberta's FASD Service Network Program: A New Model for FASD Prevention and Service Delivery

Drinking alcohol during pregnancy may cause irreversible brain damage to an unborn child

Fetal Alcohol Spectrum Disorder (FASD) is the umbrella term used to describe a range of disabilities resulting from prenatal exposure to alcohol. While these may include physical birth defects and health problems, FASD may also cause developmental delays, learning disabilities, memory problems, as well as difficulties in communicating feelings and understanding consequences. Secondary adverse effects of FASD often include disrupted school experiences and multiple foster care placements for children and youth in care; and for adults, unemployment, drug and alcohol abuse, crime and homelessness.

THE STATISTICS ARE STARTLING

Alcohol use has become a norm in Alberta. Among women 18 to 44 years of age, 79.9% reported drinking within the past 12 months.¹ Given that 40% of pregnancies are reported to be unplanned,² a significant number of unborn babies are at a high risk of prenatal exposure to alcohol. A recent survey found that of the 87.5% of Albertans who were aware of FASD, 40% reported knowing someone with FASD or someone caring for an individual with FASD.³

There is no safe time or safe amount of alcohol to drink when pregnant or when planning to become pregnant. Yet 9.2% of Alberta women reported drinking during their last pregnancy. The percentage of women who drank while pregnant was markedly higher (40.5%) for women in the highest income group (\$80,000 or more).⁴

PERSONAL, SOCIAL AND ECONOMIC IMPACTS OF FASD ARE PROFOUND

FASD is a lifelong disability that has no cure. But it is preventable. FASD is a complex, multidimensional social and public health issue. While there are no statistics on the prevalence of FASD in Canada or Alberta, research estimates that 9 in every 1000 babies are born with FASD.⁵ In Alberta, this would mean that there are currently more than 36,000 Albertans with FASD, and an estimated 450 babies born with the disorder every year. Using a conservative estimate of 1% prevalence, the Institute of Health Economics⁶ reported:

- The annual total cost of FASD in Alberta is about **\$927.5 million**, which includes the cost of health, social, educational, and correctional services, as well as productivity losses and other costs.
- For each prevented case of FASD, Albertans save about **\$800,000**, which is the incremental or extra cost of FASD.



FUNDING: The FASD 10-Year Strategic Plan has received annual funding of \$16.5 million since 2008/09, supporting 12 FASD Service Networks and Ministry-specific FASD initiatives. Preventing FASD in 10 newborns a year pays for the total current annual amount allocated to the FASD Service Networks.

FASD IS OFTEN CALLED THE “INVISIBLE DISABILITY”

Unlike most other disabilities, medical signs of FASD are often difficult to recognize as the trauma caused by alcohol is inside the brain. This often leads to delays in assessment and access to appropriate interventions. The extent of the damage caused by drinking during pregnancy often goes unrecognized until those born with FASD exhibit cognitive and behavioral problems, and difficulty adapting to society’s expectations.

ALBERTA BECOMES A LEADER IN FASD PREVENTION AND SUPPORT

Recognizing that FASD directly or indirectly touches every Albertan, the Government of Alberta took decisive action in 2003, launching a cross-ministry initiative to develop a comprehensive and coordinated response. In 2006, the Government implemented the FASD 10-Year Strategic Plan (2007 to 2017), which led to the development of the FASD Service Network model. Now in its sixth year, this new system-wide model of prevention and service delivery has made Alberta a leader in the field, in Canada and internationally. In May 2012, Premier Redford announced that FASD is a priority for government action.

CREATING A NEW MODEL FOR FASD PREVENTION AND SERVICE DELIVERY

Twelve (12) FASD Service Networks are now funded to serve geographic regions throughout the province, including one Network serving Métis Settlements across Alberta. Under the direction of Alberta’s FASD Cross-Ministry Committee, these Networks have successfully developed and implemented an FASD prevention and service delivery model that is client focused and results based, enabling individuals with FASD, and their families and caregivers, to access information and services through a single door, the FASD Service Network in their region.

A COMMUNITY-LED AND DELIVERED MODEL WITH STRONG GOVERNMENT OVERSIGHT

Each FASD Service Network is a community-based partnership of agencies and organizations working together to build capacity for FASD prevention and providing needed supports and services. The Networks are responsible for developing, streamlining, and expanding services in three strategic areas:

- **Awareness and Prevention:** With strategies that include **universal prevention** for the general population, **targeted prevention** for women of child-bearing years who use substances, and **indicated prevention** programs for women who are known to be pregnant while using harmful substances, or who have given birth to children with FASD.
- **Assessment and Diagnosis:** With multidisciplinary teams providing children, youth and adults with coordinated access to timely and affordable FASD assessment and diagnostic services.
- **Supports for Individuals and Caregivers:** With community-based programs and services that use inclusive, strength-based approaches to planning, enabling individuals with FASD to reach their full potential across the lifespan, while also providing supports to their families and caregivers.

The FASD Cross-Ministry Committee, supported by government ministries and community-led Councils of experts and stakeholders, provides oversight, ensuring accountability, the standardization of practices, and stakeholder representation.

Examples include the adoption of FASD Canadian Guidelines for Diagnosis led by Alberta Health, the FASD Family Advisory Council and the FASD Training and Education Council.



ESTABLISHING MEASURES OF SUCCESS ACROSS THE LIFESPAN

The Year 5 Evaluation of the FASD 10-Year Strategic Plan has established baseline performance measures against outcomes and targets, providing a sound foundation for subsequent evaluations. Following are key performance measures and results for fiscal year 2011/12:

- **Access to services:** 2,340 Albertans accessed services through the Alberta FASD Service Networks in 2011/12, an increase of 148% since 2008/09.
- **Access to prevention programs:** 366 clients enrolled in a Network-funded Parent Child Assistance Program (PCAP), an increase of 430% since 2008/09. PCAP is the evidence-based indicated prevention strategy selected for expansion across Alberta.
- **Access to assessment and diagnosis** (target: 900 annual assessments): 659 Albertans accessed assessment services, an increase of 231% from 2008/09.
- **Access to supports:** 1,770 Albertans accessed supports, an increase of 162% since 2008/09.

A POSITIVE RETURN ON INVESTMENT

The Institute of Health Economics prepared an economic assessment of the potential impact of the FASD Service Networks⁷ using a cost benefit analysis focused on savings from reduced occurrence of secondary adverse effects associated with FASD, including school disruption for children, unemployment for adults, mental health problems, crime and homelessness.

- Total monetary benefit for these reduced occurrences was estimated to be between \$8.87 to \$17.73 million per year at a cost of \$6.12 million (based on actual annual spending of the FASD Service Networks on assessment/diagnosis and supports, excluding costs of PCAP, the indicated prevention program).
- Overall social return of the FASD Service Networks is estimated at \$1.5 to \$2.9 for every \$1 invested.

THE ALBERTA FASD STRATEGY IS DEMONSTRATING RESULTS

Vulnerable Albertans with FASD were once lost to the system, left undiagnosed, untreated, and disconnected from society. They are now finding hope by accessing the services they need.

Alberta's new FASD model of prevention and service delivery is a case study of how to address complex needs.

The FASD 10-Year Strategic Plan is broad in scope, but focused on outcomes. Funding has resulted in more integrated and coordinated services delivered in the community.

PLANNING FOR SUSTAINABILITY

The FASD 10-Year Strategic Plan has been thoroughly evaluated at mid-point. Outcomes align with the Government of Alberta's new Social Policy Framework, and have performance measures consistent with the demands of Results-Based Budgeting.

The first five years of the Strategic Plan were focused on developing FASD Service Networks that are well managed and accountable, ensuring that funding received is directed towards service delivery.

The next five years will be focused on responding to the recommendations of the Year 5 Evaluation, increasing levels of supports and service, and increasing community participation in planning, evaluation, research, training and education. Sustainability will be achieved by developing a responsive, knowledge-based FASD Service Network Program capable of adapting to changing circumstances while maintaining its focus on achieving outcomes.

The story of Mr. K

Mr. K heard about FASD on the radio and went to the FASD Service Network in his region because he had always felt that something might be wrong with him. His father had told him that his mother drank throughout her pregnancy with him, and he wanted to know if this had anything to do with his problems.

Mr. K had very limited support in his life, and so the Network coordinator linked him with a mentor who helped him throughout the assessment process.

The clinic team found that Mr. K was facing many barriers: learning difficulties; depression, anxiety and anger; difficulty following through on medical recommendations; financial and housing issues; and addictions.

The team worked with Mr. K, his family, and his mentor to develop a plan of supports that would help him build on his strengths by accessing needed services and disability income.

His mentor continues to provide him with support and advocacy.

When last contacted, the mentor reported that Mr. K:

- Has, for the first time in his life, lived successfully on his own for almost 9 months
- Is receiving Assured Income for the Severely Handicapped (AISH)
- Is receiving one-to-one tutoring through a literacy program
- Has been referred to a new family doctor in his neighbourhood
- Has been spending more time with family and friends
- Has decreased the amount he uses alcohol and smokes
- Gets more exercise and eats better
- Is better able to manage his money.

For more information please visit: www.fasd.alberta.ca



- 1 Alberta Alcohol and Drug Abuse Commission. (2004). *Windows of opportunity: A statistical profile of substance use among women in their childbearing years in Alberta. Executive Summary.*
- 2 Public Health Agency of Canada. *Why is it important to address Fetal Alcohol Spectrum Disorder (FASD)?* http://www.phac-aspc.gc.ca/hp-ps/dca-dea/prog-ini/fasd-etcaf/publications/fs-fi_02-eng.php
- 3 Government of Alberta. (2012). Year 5 Evaluation of the Government of Alberta's FASD 10-Year Strategic Plan.
- 4 Ibid. Alberta Alcohol and Drug Abuse Commission. (2004).
- 5 Public Health Agency of Canada. *Alcohol Use and Pregnancy: An Important Canadian Public Health and Social Issue.* <http://www.phac-aspc.gc.ca/publicat/fasd-ru-ectaf-pr-06/4-eng.php>
- 6 Institute of Health Economics. (January 25, 2013). Presentation to Alberta Children and Youth Initiative, Meeting of Assistant Deputy Ministers.
- 7 Thanh NX, et al. (Updated: Feb. 7, 2013). *An Economic Analysis of the Impact of the Alberta FASD Cross-Ministry Committee: Social Return on Investment - Addressing Secondary Disabilities.* Alberta: Institute of Health Economics.