



FETAL ALCOHOL SPECTRUM DISORDER (FASD) ACROSS THE LIFESPAN

Alberta's FASD 10-Year Strategic Plan
2007-2017

Year 10 Evaluation

HIGHLIGHT REPORT

Alberta's FASD 10-Year Strategic Plan (the Strategy) provided core strategic direction for the government's response to Fetal Alcohol Spectrum Disorder (FASD) from 2007 to 2017. The Year 10 Evaluation assessed the extent to which the goals of the Strategy were achieved. The evaluation was facilitated by PolicyWise for Children & Families. The *Overview of Key Findings and Recommendations* report summarizes the findings of the evaluation project, and can be found at alberta.ca/fasd.

Thank you to all those
who helped with Alberta's
FASD 10-Year Strategic
Plan. Together we created
a movement.

MYLES HIMMELREICH, MASTER OF CEREMONIES,
2017 NATIONAL FASD CONFERENCE,
CALGARY ALBERTA.

Alberta  Government



Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term that describes the range of effects that can result from being prenatally exposed to alcohol. These effects can include lifelong mental, physical and behavioural difficulties as well as learning disabilities. There is no safe time or safe amount of alcohol to drink when pregnant or when planning to become pregnant.

PRENATAL EXPOSURE TO ALCOHOL IS A POPULATION-WIDE CONCERN

There is no safe time or safe amount of alcohol to drink when pregnant or when planning to become pregnant, and half of all pregnancies are unplanned. A longitudinal study in Calgary of 2,246 women found 49% reported drinking some alcohol prior to and during pregnancy; 13% reported at least one binge drinking episode prior to realizing they were pregnant; only 3% stopped drinking when they learned they were pregnant, with 46% continuing to drink, mostly at low levels (defined as less

than one drink per occasion seven or fewer days per week).

INCIDENCE AND PREVALENCE OF FASD IN ALBERTA

A study by the Institute of Health Economics in 2014 found an incidence rate (percent of new cases per 1,000 births) of between 1.4% and 4.4%, which means every year between 740 and 1,880 babies are born with FASD in Alberta. This study found a prevalence rate of 1.2% of the Alberta population. Based on the 2016 census data, an estimated 48,800 people with FASD were living in Alberta in 2016.



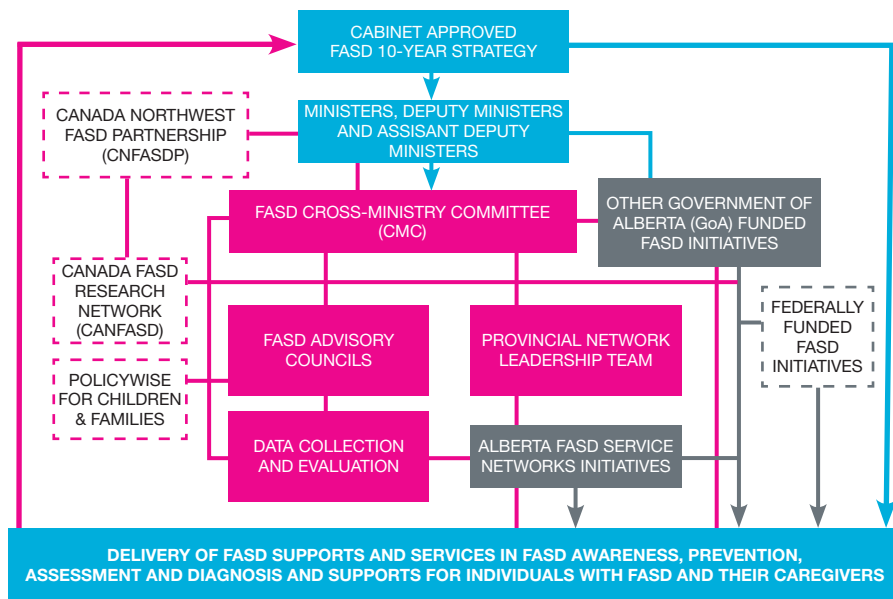
COST OF FASD

A 2017 review of the economics of FASD calculated the total annual cost of FASD in Alberta to be \$1.14 billion. The total annual cost includes \$459 million spent on criminal justice (including police, courts and corrections), \$235 million spent on healthcare, \$188 million on educational services, \$153 million on social services and \$106 million on other services. A 2010 study estimated an incremental lifetime cost per case of FASD of \$800,000, suggesting that one prevented case of FASD results in a cost savings of \$800,000.

One prevented case of FASD results in a cost-savings of \$800,000.

A 2017 profile of 3,025 young Albertans diagnosed with FASD ages 0 to 25 years by PolicyWise for Children & Families found that 78% were high government service users, compared to 11% without an FASD diagnosis. At some point during the study period (2005-2011), 31% of those diagnosed with FASD (ages 12 to 25) were charged with a criminal offence; 64% had high cost health use (in the top 5% of estimated costs for their age and gender); only 40% of school students were meeting or exceeding educational expectations, with 69% receiving a special needs code; 74% received mental health services; and 48% were involved with Child Intervention services.

ALBERTA'S FASD MODEL



MAJOR ACHIEVEMENT: CO-DEVELOPMENT OF ALBERTA'S FASD MODEL

Over the past 10 years, Alberta has developed a successful model to respond to FASD. Key to this success were:

1. **Alberta's FASD 10-Year Strategic Plan** that provided sustained funding and a commitment to annual planning and system-wide evaluation in years 5, 7 and 10 of the Strategy
2. Leadership of the **FASD Cross Ministry Committee (CMC)** that includes participation of federal agencies and FASD experts
3. Regional and local leadership of the **Alberta FASD Service Networks** that provide FASD-informed services across the province
4. the **FASD Learning Organization** that mobilizes knowledge based on evaluation and research through every part of the model
5. FASD services that are **culturally-informed by Indigenous leaders and families**

- Government of Alberta
- Learning Organization
- FASD Service Delivery
- Partners

**Color categories are not relative to investment.*



HIGHLIGHTS FROM THE YEAR 10 EVALUATION

STRATEGIC PILLAR #1: Awareness and Understanding of FASD

Target: 95% awareness among Albertans

A survey of Albertans conducted for the Year 10 Evaluation revealed:

- 89.7% were aware of FASD, a 4% increase from the Year 5 survey.
- 47.5% thought they knew someone with FASD, a 12.3% increase from the Year 5 survey.
- While 99.2% indicated that they knew alcohol use during pregnancy can lead to life long disabilities in a child, only 72.3% responded correctly to all four test statements, indicating that 27.7% did not fully understand key facts about FASD.
- Those surveyed living outside of Alberta's two major cities had a greater awareness and understanding of FASD than those living in Edmonton and Calgary.

Challenges: Awareness and understanding of FASD alone is not sufficient to change behaviour.



STRATEGIC PILLAR #2: Prevention (safe discussions with women of child-bearing years)

The Prevention Conversation engages communities in discussions about drinking during pregnancy, including before a woman knows she is pregnant. It also focuses on the unique role healthcare professionals and social service providers can play in engaging women in supportive and non-judgemental conversations about alcohol use and pregnancy.

- Over 14,000 Albertans attended 755 Prevention Conversation events since July 2015. Half of the events were held in rural and remote areas.

- Over 7,800 professionals and 1,500 post-secondary students in health, education, addictions and mental health, child intervention services and justice received Prevention Conversation training.
- FASD Service Networks reported that the Prevention Conversation has had broad community impact. It has contributed to increased community awareness and understanding about FASD, raised the profile of the FASD Service Networks and strengthened community partnerships.

Challenges: Networks reported that they still found it difficult to engage with medical professionals, especially doctors.

PCAP was found to be effective in preventing future cases of FASD.

STRATEGIC PILLAR #2: Prevention (Parent-Child Assistance Program - PCAP)

Target: 75% of women in PCAP reduce or abstain from using alcohol when pregnant

PCAP is a three-year home visitation program for women with a history of alcohol and drug use who are at risk of giving birth to a child with FASD.

- In March 2017, there were 28 PCAP sites in Alberta. Enrollment in the program increased from 69 in 2008 to 553 in 2017. In 2017, 76% of women receiving PCAP services identified as Indigenous, 33% lived in urban areas, 30% in rural and remote areas, 28% on Reserve and 9% on Métis Settlements.
- Many women in PCAP have a family history of childhood trauma: 58% were in the foster care system; 55% reported involvement with Child Intervention services; and 48% reported that their mother consumed alcohol while they were pregnant.
- After 6 months, 52% of women in PCAP were abstinent from alcohol



for at least one month and, after 30 months, 35% were abstinent for at least one month. After 6 months, 54% were abstinent from drugs for at least one month, and after 30 months, 48% were abstinent from drugs for at least one month. At 6 months, 39% of non-pregnant women were using an effective method of contraception and, at 30 months, 54% were effectively using contraception.

- An analysis of 147 women who had completed three years in PCAP found that 68% were effectively participating in FASD prevention after 6 months and 74% were effectively doing so at 36 months.
- In 2015, a study by the Institute of Health Economics found PCAP was effective in preventing future cases of FASD and resulted in a net monetary benefit for Alberta of approximately \$22 million.

Challenges: It is difficult to recruit qualified personnel in rural and remote areas and PCAP staff in these regions spend a lot of time travelling in poor weather and road conditions to meet with clients, which contributes to higher costs.



STRATEGIC PILLAR #3: Assessment and Diagnosis

Target: 900 assessments annually

- In December 2016, Alberta had 24 clinics providing FASD assessment and diagnostic services. All FASD clinics in Alberta follow the Canadian FASD Guideline for Diagnosis.
- In 2016-17, 1,050 clients had completed the intake process, with 25-31% on waitlists during the year. Of these, 49% were children ages 17 and under, 16% were young adults ages 18-24 and 35% were adults 25 years and older.
- 70% of all clients identified as Indigenous; 31% of all clients lived in urban areas; 45% lived in rural and remote areas; 19% lived on Reserve; and 5% on Métis Settlements.
- In 2016-17, 622 clients (59% of intake) received a diagnostic outcome, of which 55.6% received a diagnosis of FASD, 14.8% received another diagnosis and 29.6% were determined at risk

for neurodevelopmental disorder and FASD, or were deferred (assessments completed by clinics not funded by the FASD Service Networks are not included in this number). Most clients also received additional co-occurring diagnoses: ADHD (36%), cognitive impairment (34%), physical health issues (34%), learning disability (30%), anxiety (22%), communication disorders (22%), depression (18%), sensory issues (13%), post-traumatic stress disorder (9%) and attachment disorders (4%).

Challenges: An FASD diagnosis requires a confirmed history of prenatal alcohol exposure, which can be difficult to obtain. There are a limited number of clinicians trained in FASD to staff multidisciplinary teams. Each clinic has its own definitions and clinic processes to manage their waitlist. Lack of agreement on a waitlist definition and lack of reliable data make it difficult to find solutions to waitlist challenges.

STRATEGIC PILLAR #4: Supports for Individuals with FASD and their Caregivers

Target: 80% of individuals with FASD and their caregivers receive the coordinated services they need and are satisfied with supports received

As awareness and understanding of FASD increases, the role of navigator is emerging as a leading practice to address the increasing number of clients seeking information, assessment and diagnosis and FASD-informed services.

In 2016-17, 2,276 individuals were receiving or waiting for services, of which 7-11% were on waitlists during the year:

- 62% of all clients were under 25 years of age and 60% identified as Indigenous.
- 46% lived in urban areas, 39% in rural and remote areas, 11% lived on First Nations Reserves and 3% in Métis Settlements.
- At intake, 37% had a confirmed diagnosis of FASD.
- 53% accessed one-on-one mentoring, 50% received outreach services and 14% participated in a support group (clients can access multiple services).
- Evaluation of the Wellness Resiliency and Partnership (WRaP) project, which provided coach supports for Alberta school children with FASD, indicated 15 success coaches supported 254 students in 39 schools

in 2015-16. Records for 152 of these students indicated a 90% course completion rate, with 82% completing the school year without suspension.

Challenges: Funding for WRaP has concluded. Students with FASD attending Alberta schools need FASD-informed supports. Young Albertans with FASD transitioning to adulthood also need reassessment and support services. There are few housing and employment supports available for adults with FASD, and there is a growing realization that seniors with FASD are not well-served.

In 2016-17, 543 caregivers were receiving or waiting for support services, of which 1-4% were on waitlists during the year:

- 76% of caregivers were women; 34% identified as Indigenous; and 11% were 65 years and older. 51% lived in rural and remote areas and 19% lived on Reserve or Métis Settlements.
- 40% were an adoptive parent; 26% were a biological parent; 19% were a kinship caregiver; 11% were a legal guardian; 10% were a foster parent; and 4% were a spouse.
- 11% of caregivers had a confirmed FASD diagnosis.
- 45% of caregivers accessed one-on-one mentoring; 59% participated in a support group; 59% received outreach services; and 10% accessed respite services (clients can access multiple services).

Challenges: Many caregivers struggle to cope with the economic impact, emotional stress and fatigue that come with raising children with complex mental and physical health needs. Best practices for stress management include the use of respite care, peer parent support and counseling services.

STRATEGIC PILLAR #5: The FASD Learning Organization

The FASD 10-Year Strategic Plan helped create a high degree of cohesion within the FASD sector. In-depth interviews with key informants involved in the implementation of the strategy over the last decade indicated that the FASD-CMC was very successful in supporting collaboration, cooperation and coordination among ministries. Stakeholders had multiple opportunities every year to meet, share information, network and access new information. The 12 Alberta FASD Service Networks were described as the eyes and ears of the community.

A large inventory of training and support services demonstrates the diversity of learning needs that must be met, including those of caregivers, PCAP workers, clinicians and service providers. Surveys of participants revealed a high degree of satisfaction with the training and education received:

- The FASD Learning Series provides webcasts on a broad range of topics.

In 2015-16, 10 webcasts were conducted, for a total of 93 archived videos to date. An evaluation of 10 sessions found that 2,249 viewers participated, with 93% indicating it was a valuable learning experience and that their learning objectives had been met.

- PCAP Council has trained 302 PCAP workers since 2013 and 90% were satisfied with their training.

As part of the FASD initiatives, a Workforce Development Framework for Alberta's mental health professionals, child and youth care workers, primary health/healthcare practitioners, educators, probation officers and correctional officers is currently underway.

A culture of evaluation and research was embedded in the 10-Year Strategy. Researchers had many opportunities to directly engage with the FASD-CMC and policy-makers to inform decisions.

Challenges: Resourcing collaboration remains a challenge. Funding is needed to support face-to-face participation from those living in rural and isolated communities, and also for the FASD Advisory Councils to fully capitalize on the highly-valued expertise offered by members. All post-secondary disciplines should include FASD in their curricula. The use of standardized evaluation and data collection tools should be required, and the capacity for FASD data analysis needs expanding.



RECOMMENDATIONS FROM THE YEAR 10 EVALUATION OF ALBERTA'S FASD 10-YEAR STRATEGY

These recommendations build on the achievements and innovations of Alberta's FASD 10-Year Strategic Plan 2007-2017, and address the challenges going forward. Fully addressing these recommendations will secure Alberta's place as a global leader in addressing FASD.

1. To reduce incidence of FASD in Alberta:
 - a. Expand the Parent-Child Assistance Program (PCAP) for women of child bearing age at risk of having alcohol-exposed pregnancies.
 - b. Explore innovative population-based prevention approaches.
2. To prevent adverse outcomes for individuals with FASD and expand access to FASD-informed services.
3. Develop a broad FASD-informed workforce across sectors that can deliver the right information at the right time to prevent alcohol-exposed pregnancies and deliver FASD-informed services.
4. Increase capacity to address waitlists for FASD assessment and diagnosis and for FASD-informed services.
5. Collaborate with Indigenous families and communities to enhance delivery of a culturally-informed response to FASD.
6. Sustain and increase investment in Alberta's FASD governance model.
7. Update FASD strategic goals, outcomes and indicators, implement the use of standardized evaluation and data collection tools and build capacity for cross-system data analytics to inform continuous improvement.
8. Mobilize knowledge regarding the design and implementation of Alberta's model to address FASD.

For more information visit: alberta.ca/fasd

