FETAL ALCOHOL SPECTRUM DISORDER (FASD) ACROSS THE LIFESPAN

Year 7 Evaluation of the
Government of Alberta's

FASD 10-Year Strategic Plan

PROGRESS REPORT

Alberta Government

Fetal Alcohol Spectrum Disorder (FASD) refers to a range of impairments resulting from damage to the brain of the developing fetus caused by maternal use of alcohol during pregnancy. Brain trauma caused by alcohol is irreparable, lifelong, and devastating for the individual, the family, caregivers and society.

EXECUTIVE SUMMARY

In this progress report, you will find an overview of the Government of Alberta's FASD 10-year Strategic Plan after seven years. This evaluation was facilitated by PolicyWise for Children & Families. The full evaluation data can be found in the "Overview of Key Findings and Recommendations" document at fasd.alberta.ca. In most cases, we are well on our way to meeting our Year 10 targets. For example, 89% of Albertans surveyed indicate a high level of awareness around what causes FASD; 81% of women participating in the Parent-Child Assistance Program for three years, many of whom have dealt with serious addictions, are preventing FASD births. 90% of people are satisfied with their FASD supports—and research from Alberta is guiding best practices in the field.

There continue to be challenges in the area of assessment; more focus on obtaining referrals is needed. There is also a need for residential addiction treatment facilities for specific groups of women as well as more clinics conducting FASD assessments and collecting necessary data. We are also working to address the need for greater housing and respite supports. Addressing these areas for improvement will be important as we plan ahead.

THE PROPORTION OF INFANTS EXPOSED TO ALCOHOL PRENATALLY IS SUBSTANTIAL

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 recent Canadian study of 2,246 women who consumed alcohol one year prior to pregnancy found that 13% reported binge drinking prior to pregnancy recognition, and 46% reported drinking after pregnancy recognition, almost all at low to moderate levels. This study was published in the journal *Alcoholism: Clinical and Experimental Research* in 2014. In this study, low levels were defined as less than one drink/occasion seven or fewer days per week; and moderate levels were defined as one drink/occasion seven or fewer days per week—or two drinks/occasion at three or fewer times per week.

PREVALENCE OF FASD IS HIGHER THAN PREVIOUSLY ESTIMATED

Research conducted by the Institute of Health Economics using Alberta Health databases found a **prevalence rate of 1.2%**, with approximately 46,000 Albertans living with FASD at the end of March 2012, as compared to the previous estimate of 1%. The estimated cost of health, social, and educational services, as well as productivity losses and other costs based on prevalence of 1.2% is **$837 million per year.** For each prevented case of FASD, Albertans save about $784,000.

ALBERTA'S RESPONSE TO FASD

In 2006, the Government of Alberta launched the FASD 10-Year Strategic Plan (2007-2017), with a vision to develop a comprehensive and coordinated response to FASD across the lifespan. The cornerstone of the Plan is the FASD Service Network Program and its 12 regional networks. Under the direction of the FASD Cross Ministry Committee (FASD-CMC), the networks provide support and mentoring to clients referred to an FASD clinic prior to, during and after diagnostic assessment.

INNOVATIONS IN FASD PREVENTION AND SUPPORTS

Responding to PolicyWise for Children & Families' recommendations from the Year 5 Evaluation of the FASD 10-Year Strategic Plan, the FASD-CMC **defined sustainability** as *"the ability to learn and adapt to changing circumstances in order to achieve our goals,"* and then developed:

- An **outcome-based management system** based on five clearly defined strategic pillars and five goals, each supported by measurable outcomes. The FASD Online Reporting System (ORS) was enhanced to support evaluation and report results. This approach is aligned with the government's *Results Based Budgeting* process.

- The **FASD Learning Organization** (the fifth strategic pillar) to increase the capacity of the FASD-CMC and the networks to support: continual stakeholder engagement, education and training, and evaluation and research. The learning organization pillar also facilitates the identification and adoption of new evidence-based leading practices.

HIGHLIGHTS FROM THE YEAR 7 EVALUATION: PROGRESS MADE

Strategic Pillar #1: Awareness

Target: 95% Awareness among Albertans

- 89% of Albertans who participated in network event surveys knew FASD is caused by alcohol use during pregnancy and 83% were aware that children born with FASD have irreversible brain damage.
- 10 FASD Service Networks conducted 1169 post-event evaluations.

Strategic Pillar #2: Prevention (Safe discussions with women of childbearing years)

- 94% of women who participated in network FASD awareness events indicated they intended to eliminate alcohol use during current or future pregnancies.

Strategic Pillar #2: Prevention (Parent-Child Assistance Program - PCAP)

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

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

- In 2012/13, 446 women were provided network-funded PCAP services, an increase of 22% over the previous year, and a 575% increase over the number served in 2008/09.

Increase in network-funded PCAP Participation

2008-2009: 69 women

2009-2010: 144 women

2010-2011: 247 women

2011-2012: 366 women

2012-2013: 446 women

- Over the three-year program, the percentage of women effectively preventing births affected by alcohol (by using birth control or by not consuming alcohol) was 65% for women enrolled in the PCAP program for one year or less, and 81% for women completing their third year of the program.
- PCAP prevented an estimated 31 FASD-affected births between 2008 and 2011. According to an economic evaluation of PCAP data by the Institute of Health Economics, this led to a net cost savings of about $22 million in the cost of services (as compared to a scenario had these children been born with FASD).

Challenges: There are few residential addiction treatment facilities for pregnant women, women who have children in their care, and women affected by FASD. Not all provincial PCAP programs collect data for inclusion in this analysis. Some women accessing PCAP live in rural, remote communities where access to residential treatment facilities may not be available. It may also be due to lack of resources in the area. PCAP programs also may need some support to gather data.

Strategic Pillar #3: Assessment and Diagnosis

Target: 900 assessments annually

- In 2012/13, 315 network clients were referred to clinics for diagnostic assessment.
- 197 clients were on waitlists for diagnostic assessment in the first quarter of 2014.
- Of 212 completed assessments, 76% were completed within three months, 15% within six months, and 9% within 15 months.
- Of 332 completed assessments over 18 months, 86% of clients were known to have had prenatal alcohol exposure and 77% received an FASD diagnosis. In total, 2,887 recommendations for supports were made for these clients. These will form the baseline for future longitudinal studies linking recommendations given to supports received, to improve understanding of barriers to service access.
- Offenders suspected of FASD were provided with access to diagnostic assessments to guide the Courts in providing FASD-informed sentencing and correctional services.

Challenges: Referrals for assessment require a suspected history of prenatal alcohol exposure, which is difficult to obtain because women and their family members are often reluctant to disclose drinking patterns during pregnancy and adult clients are often unable to confirm the use of alcohol by their mothers during pregnancy. There are a limited number of clinicians trained in FASD to staff multidisciplinary teams. All networks reported limited access to diagnostic assessment for adults and for youth transitioning to adulthood, particularly in remote areas. Not all clinics conducting FASD assessments collect and report data to ORS. More clinicians need to be trained in FASD assessment and diagnosis. More consistency in gathering FASD data is also needed among the clinics involved.

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.

- In 2012/13, a total of 1,526 clients received support services, including 488 caregivers.
- Improvements in client wellbeing were measured according to changes in 13 presenting issues. Early trends suggest overall improvement in wellbeing over time.
- Over 90% were satisfied with supports received.
- Education initiatives supporting students with FASD reported success using relationally-based supports (coaches and mentors).

Challenges: Housing is a major issue facing individuals with FASD, particularly for Aboriginal persons and youth transitioning to adulthood. There are not enough resources to provide supports across the lifespan. Only 47% of caregivers received respite care.

Strategic Pillar #5: The FASD Learning Organization

Experts on FASD Councils conducted research on best practices, developed inventories of supports and services, and a core FASD curriculum. They also developed education and training programs, including public awareness and prevention programs, training in FASD screening and referral, and training in advanced case management for children in care.

- Over 87% of stakeholders believed their network facilitated sharing of FASD information with partners and the public.
- Over 91% of those receiving education and training were satisfied with the program.
- 89% of network leaders understand research and evaluation is being used to guide the work of their network.

Challenges: Expert-led volunteer Councils lack administrative support, which would improve their effectiveness and efficiency and deepen their interconnection (collaboration, cooperation and communications) with stakeholders.

> We are learning about FASD, and we are able to apply this knowledge to other situations and benefit those communities too.
>
> - Probation Officer

BROADER APPLICATIONS FOR THE FASD PREVENTION AND SERVICE MODEL

The two innovations of an outcome-based management system and the FASD Learning Organization have been successfully initiated. Enhancements made to the ORS are beginning to effectively measure outcomes, and data collected can be used to conduct longitudinal research on client-wellbeing. These efforts in support of individuals with FASD and their families will inform efforts to improve services to all Albertans with disabilities and their families.

OVERARCHING RECOMMENDATIONS

To build on progress made over the last seven years implementing the FASD 10-Year Strategic Plan, and to address ongoing challenges:

1. **Increase funding to the Alberta FASD Service Networks:** Most networks have evolved into well-managed organizations with deep roots in their communities capable of delivering effective and efficient FASD services to Albertans in their regions. Current annual funding is $16.5 million and therefore, a review of the 10-year targets is needed.

2. **Streamline FASD outcomes, indicators and key performance indicators and continue to enhance the ORS:** Expand ORS to capture contributions to outcomes made by all provincial and ministry-specific FASD initiatives, making data collection and reporting a requirement for all funded FASD initiatives.

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