Fetal Alcohol Spectrum Disorder (FASD) Across the Lifespan

FASD Cross-Ministry Committee (FASD-CMC)

FASD Strategic and Operational Plan 2017/2018:
An Outcome-Based Management Plan

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Context: FASD in Alberta

**Fetal Alcohol Spectrum Disorder (FASD)** is an umbrella term that describes the range of effects that can occur in an individual who was prenatally exposed to alcohol. Alcohol exposure during pregnancy results in changes to the developing brain at neurochemical and structural levels. Often, these changes are not detected until a child reaches early or middle school-age when difficulties at school and at home become increasingly problematic. These challenges can include problems in social communication and attention, motor and sensory problems, memory, and difficulty learning from consequences. As a child grows, they are also at increased risk for depression, anxiety and other mental health conditions (CanFASD 2017).

**Incidence and Prevalence of FASD in Alberta**: A study by Alberta’s Institute of Health Economics (Thanh et al., 2014) found an incidence rate (percent of new cases per 1000 births) of between 1.4% and 4.4% depending on the year of study (between 739 and 1,884 people born annually with FASD in Alberta). The authors suggested that incidence of FASD in their study may be underestimated due to the relatively short period of follow-up (10 years), and concluded that if follow-up had been longer, incidence of FASD in Alberta would be at least 4.4% per 1000 birth. The study estimated a prevalence rate of 1.2% of the Alberta population. Based on 2016 census data (Statistics Canada, 2017), an estimated 48,000 people with FASD were living in Alberta in 2016.

**Demographics of FASD in Alberta**: The study by Thanh et al. (2014) also found that more males than females were diagnosed with FASD, and 60% of people diagnosed with FASD were younger than 20 years of age. A profile of 3,025 young Albertans diagnosed with FASD ages 0 to 25 years (PolicyWise for Children & Families, 2017) also found the proportion of males diagnosed with FASD (58%) was higher than for females (42%). The profile also found that young people with FASD were disproportionately overrepresented in neighbourhoods with the lowest socio-economic status (41%) and underrepresented in the highest (7%), compared with those with no FASD diagnosis.

**Cost of FASD in Alberta**: A study by the Institute of Health Economics (Thanh & Jonsson, 2015) estimated the total cost of FASD in Canada to be $9.7 billion per year, with 40% of these costs related to criminal justice, 21% to healthcare, 17% to education, and 13% to social services. By calculating the national cost per capita and applying this to the population of Alberta in 2015, Jonsson (2017) found the total annual cost of FASD in Alberta to be $1.14 billion, with $459 million spent annually on criminal justice (including police, courts, corrections), $235 million spent annually on healthcare, $188 million on educational services, $153 million on social services and $106 million on other services and indirect costs. An economic analysis by Thanh et al. (2010) 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.

The profile of young Albertans with FASD ages 0 to 25 (PolicyWise for Children & Families, 2017) found that 78% were high government service users, compared to 11% of children and youth 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 38 to 41% of 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; 37% (ages 0-17) received Family Support for Children with Disabilities (FSCD); 17-30% (ages 18-25) received Persons with Developmental Disabilities (PDD) services, and 42% received Assured Income for the Severely Handicapped (AISH).

**Background: Alberta’s FASD 10-Year Strategic Plan (2007-2017)**

Recognizing that FASD directly or indirectly affects every Albertan, the Government of Alberta took decisive action in 2003 by launching a cross-ministry initiative to develop a comprehensive and coordinated response to FASD across the lifespan. Three years later, the FASD Cross-Ministry Committee (FASD-CMC) developed Alberta’s FASD 10-year Strategic Plan (2007-2017) to guide programs, services and research. Funding for implementation was received in 2008.

**Achievements:** The FASD 10-Year Strategic Plan provided guidance for Alberta’s leadership and led to tremendous strides forward in FASD awareness and prevention, assessment and diagnosis, and supports for individuals with FASD, their families and caregivers using a community-based and evidence-driven approach. These achievements were realized through the development of innovative models in governance and knowledge mobilization, prevention and service delivery, as well as annual strategic planning and continuous improvement.

**Alberta’s FASD Governance and Knowledge Mobilization Model:** The FASD 10-Year Strategic Plan produced a unique governance model that features knowledge mobilization as a key driver of FASD prevention and service delivery (see Figure 1 below). Green boxes describe the FASD Learning Organization, led by the FASD-CMC. With a focus on evaluation and research, education and training, strategic planning and stakeholder engagement, the model facilitates learning and adaptation to meet strategic goals. Red boxes describe FASD initiatives funded by the FASD-CMC and delivered by the Alberta FASD Service Networks, as well as other FASD supports and services funded by partnering ministries and agencies. Blue and Green arrows signify annual life-cycle planning, where the delivery
of FASD supports and services are influenced by evaluation and research, with knowledge mobilized through the FASD Learning Organization.

**Figure 1: Alberta’s FASD Governance and Knowledge Mobilization Model**

**FASD Prevention Model:** To prevent primary disabilities resulting from prenatal exposure to alcohol (brain damage, physical birth defects, and health problems), strategies are needed to promote abstention from alcohol when pregnant or planning to become pregnant. Strategies are also needed to prevent or lessen the severity of adverse outcomes (secondary challenges not present at birth) to enable individuals with FASD to have improved life outcomes. These strategies include improved access to assessment and diagnosis, leading to appropriate interventions that are proactive and protective to address challenges related to mental health, disrupted school experience, alcohol and drug use, multiple foster care placements, involvement with the justice system, confinement, or inappropriate sexual behaviour (Streissguth et al., 1998). The FASD-CMC adopted a Canadian FASD prevention model
that focuses on providing a continuum of care and support for women, where all strategies are considered preventative (Poole, 2008). This model has four mutually reinforcing strategies that span general and specific practices that focus on assisting women to improve their health and the health of their children with support from family, support networks, services and community:

- **Level 1 Prevention:** Raises public awareness through public campaigns and other broad strategies that advance social support and change to prevent prenatal exposure to alcohol.
- **Level 2 Prevention:** Supports safe discussions with women of childbearing years, with their support networks and healthcare providers about reproductive health, contraception, pregnancy and alcohol use.
- **Level 3 Prevention:** Provides supportive services for women and their support networks that are specialized, culturally safe and accessible for women with alcohol use challenges, histories of violence and trauma, and related health concerns.
- **Level 4 Prevention:** Provides postpartum support for new mothers and their support networks to help them maintain healthy changes made during pregnancy, and/or to continue to help them improve their health, and support the health of their children.

**Alberta’s FASD Prevention and Service Delivery Model:** The FASD-CMC and Alberta’s 12 regional FASD Service Networks have successfully developed and implemented an FASD prevention and service delivery model that is client-focused and results-oriented. FASD-informed supports and services are now accessible to Albertans in every corner of the province, and are focused on providing FASD awareness and prevention, assessment and diagnosis, and supports for individuals with FASD, their families and caregivers.

**Alberta’s FASD Strategic Planning Model:** The FASD-CMC adopted a results-oriented outcome-based planning model. The annual FASD Strategic and Operational Plan (S&O Plan) was introduced after the Year 5 Evaluation to identify strategies and priorities of the FASD-CMC, partnering ministries, Alberta FASD Advisory Councils and FASD Service Networks to address identified gaps and to implement recommendations from evaluations and research to support continuous improvement. Incorporating the FASD prevention model, the S&O Plan is organized under five strategic pillars:

1. Public Awareness and Understanding (Level 1 Prevention)
2. Prevention (Level 2 Prevention: Safe Discussions; Level 3 and 4 Prevention: Supports for Women)
3. Assessment and Diagnosis
4. Supports for Individuals and Caregivers
5. The FASD Learning Organization.
The purpose of the S&O Plan is to:

- Identify goals, targets, client and system outcomes, and performance indicators and measures under each strategic pillar, with priority actions (activities) identified that will contribute to achieving outcomes.
- Identify key direction-setting documents from partnering ministries and other sources, recommendations from which drive program development and implementation.
- Ensure program and system evaluations are embedded to improve knowledge and capacity through data capture and analysis across systems and ministries to inform policy, practice and continuous improvement.
- Strengthen partnerships and enhance shared understanding required to continuously improve service delivery.
- Support effective change management processes by identifying opportunities for collaboration and stakeholder engagement to implement actions and achieve outcomes.
- Ensure a Gender-Based Analysis Plus (GBA+) lens informs the way FASD supports and services are delivered.

**Continuous Improvement:** The Year 5 and Year 7 Evaluations of the FASD 10-Year Strategic Plan confirmed that it was working, and demonstrated the continued positive impact for Albertans of the FASD Service Network Program and of the FASD programs and services provided by partnering ministries. These evaluations enabled the FASD-CMC to identify gaps in prevention and service delivery and to address challenges through its Learning Organization. The FASD 10-Year Strategic Plan concluded March 31, 2017. The results of the Year 10 Evaluation (to be completed in December 2017) will inform strategic planning for Alberta’s FASD system going forward.

**Beyond Year 10: Vision, Commitments and Priorities**

As Alberta’s FASD 10-Year Strategic Plan comes to an end, the FASD-CMC continues to set strategic direction for Alberta’s FASD prevention and service delivery model, and is preparing a path forward. A Guiding Document for Beyond Year 10 will be developed by the FASD-CMC, and recommendations from the Year 10 Evaluation of Alberta’s 10-Year FASD Strategic Plan will inform strategic planning and investments going forward.

The **vision** is to continue to move towards FASD-informed supports and services across systems and jurisdictions around awareness and prevention, assessment and diagnosis, and supports for individuals with FASD, their families and caregivers.
The Government of Alberta is committed to continuing its support for Alberta’s innovative FASD prevention and service delivery model and to supporting continuous quality improvement:

- **The FASD-CMC** will continue to lead the Government of Alberta’s FASD strategy, supported by sustained commitment of the partnering ministries to active contribution, collaboration and membership.

- **The FASD Service Network Program** will continue as a leading practice model for service delivery, supporting community-based partnerships of agencies and organizations working together to build capacity for FASD prevention, assessment and diagnosis, and the provision of FASD-informed supports and services. Respect for cultural diversity, and the development and delivery of culturally-informed services in collaboration with Indigenous and immigrant families and communities, will continue to be a key driver of FASD Service Network Program design and operations.

- **The FASD Learning Organization** will continue to support ongoing quality assurance and continuous quality improvement with the support of expert advice from across jurisdictions and sectors. A commitment to expanded data capture will continue to be a key driver to improve prevention and understanding of the needs of Albertans with FASD across the lifespan, and to improve collaboration and coordination of supports and services.

- **Outcome-Based Management**: The FASD-CMC’s annual Strategic and Operational Plan (S&O Plan) will continue to detail goals, outcomes, targets and performance indicators and measures, and to identify priority actions to be undertaken across Alberta’s FASD prevention and service delivery system. It will coordinate the efforts of partnering ministries, FASD Advisory Councils and FASD Service Networks, responding to identified gaps, and implementing recommendations for continuous improvement.

- **Alberta’s FASD Prevention and Service Delivery Model** and its successes will continue to be shared across government ministries and with other jurisdictions and stakeholders through participation in disability, health, mental health, justice, education and other relevant discussions.

**Priorities going forward** for Alberta’s FASD prevention and service delivery model are:

- **Knowledge and Capacity Development**: Expand knowledge and capacity through integrated FASD data collection and analysis.

- **Criminal Justice Supports**: Continue to provide supports in the criminal justice system to offenders with FASD to change their lives during incarceration, to support their transition back to the community and to avoid future involvement with the criminal justice system after release.
• **FASD Education and Training**: Address gaps in FASD education and training through the FASD Workforce Development Framework that provides consistent and adequate training, incorporates FASD knowledge into post-secondary curricula, and supports respect for diversity.

• **Integrated Housing and Supports**: Enhance integrated housing and supports for individuals with FASD that will help reduce the risk of homelessness.

• **Provincial Service Delivery**: Enhance service delivery through the FASD Service Network Program and integration of FASD-informed services across systems and communities, improving access to proven, effective supports and integrated services that promote equitable participation in education, employment and in community.

• **Gender-based Analysis Plus (GBA+)**: To better serve the needs of Albertans, adapt FASD programs and services to ensure they are equally accessible to individuals of all genders and other intersecting identity factors, such as culture, age, education, disability, language, geography and income.

• **Strengthen relationships with partnering ministries**: To support their continued and sustained commitment to FASD prevention and service delivery.

### 2017-2018 FASD Strategic & Operational Plan

The 2017/18 Strategic and Operational Plan (S&O Plan) consolidates what has been learned over the previous year, and emphasizes the life-cycle approach to planning that values results, learning and adaptation. The FASD-CMC will ensure continued alignment of priorities and results with outcomes, performance indicators and measures, and targets.

#### Alignment with Government of Alberta Policy Documents

FASD-CMC partnering ministries will link, where appropriate, FASD-related policies, practices and performance indicators and measures to their key policy and planning documents to better integrate FASD across all ministries that support this population. Government of Alberta reports that have significant implications for individuals with FASD in Alberta include (but are not limited to):

• **Alberta Mental Health Review Next Steps**

• **Creating Connections: Alberta’s Addiction and Mental Health Strategy**

• **Housing and Supports Framework (Alberta Health Services)**

• **Tertiary Care Framework (Alberta Health Services)**

• **10 Year Plan to End Homelessness**
• Poverty Reduction Strategy
• Information Sharing Strategy
• Social Policy Framework
• Common Service Delivery
• Alberta Alcohol Strategy
• The Continuing Care Community Capacity Initiative
• AHS/HS Disability Division Health Services Collaborative
• Affordable Housing Strategy
• Prevention and Early Intervention Framework
• Child Intervention Practice Framework
• Advanced Education Mental Health Strategy

Alignment with Key Direction-Setting Documents

In addition to partnering ministry documents, several direction-setting documents have been developed over the past 10 years. Each provides recommendations that should be considered in the development and implementation of the actions identified in this S&O Plan.

• Year 5, Year 7 and Year 10 Evaluations of the FASD 10 Year Strategic Plan (Government of Alberta). Recommendations from the Year 7 Evaluation are included here as Appendix A.

• Consensus Statement on FASD – Across the Lifespan, 2009 (Institute of Health Economics), provides practical recommendations on how to improve prevention, diagnosis, and treatment of FASD.

• Consensus Statement on Legal Issues of FASD, 2013 (Institute of Health Economics), explores the implications for the justice system and provides recommendations.

• Calls to Action (Truth and Reconciliation Commission of Canada), especially Recommendation #33 (development of FASD preventive programs in collaboration with Aboriginal people and delivered in a culturally appropriate manner) and Recommendation #34 (reform of the criminal justice system to better address the needs of offenders with FASD).

• United Nations Declaration on the Rights of Indigenous Peoples (United Nations), sets out the principles of partnership and mutual respect that should guide the relationship between states and Indigenous peoples, and provides ways to measure and assess implementation of these rights.
• **OCAP®: Ownership, Control, Access and Possession** (First Nations Information Governance Centre), provides standards that establish how data belonging to First Nations clients should be collected, protected, used, or shared.

• **Convention on the Rights of Persons with Disabilities** (United Nations) reaffirms that all persons with all types of disabilities enjoy all human rights and fundamental freedoms, including full and effective participation and inclusion in society.

• **FASD and Access to Justice: Final Report to Federal/Provincial/Territorial Ministers Responsible for Justice and Public Safety** (Justice Canada), provides recommendations focused on clarifying the court’s power to authorize assessments, improving prevention of contact and re-contact with criminal justice system, determining prevalence of FASD in the correctional population, leveraging existing forensic mental health services to provide assessments, identify validated FASD screening tools, among others.

• **Gender-Based Analysis Plus (GBA+)** (Government of Canada), an analytical tool that assesses the potential impacts of policies, programs, services, and other initiatives on diverse populations, considering gender and other intersecting identity factors (such as age, education, language, geography, culture and income), which includes a disability lens.

**FASD-CMC Planning Forum (May 25-26, 2017)**

As part of learning and adaptation, members of the FASD-CMC, FASD Service Networks and Alberta FASD Advisory Councils meet annually to provide direction for the development of the FASD Strategic & Operational Plan. The focus of this year’s meetings was to provide direction and for year 10 and beyond, reviewing commitments and priorities for action.
Strategic Pillar #1: Public Awareness and Understanding (Level 1 Prevention)

**Goal:** Albertans are aware and understand that alcohol use during pregnancy can lead to FASD, that FASD can be prevented, and that FASD prevention is a shared responsibility.

**10-year Target:** 95% awareness and understanding in Alberta among the general population.

**Key Performance Indicators (KPIs):**
- % of Albertans who are aware and understand that FASD is caused by alcohol use during pregnancy
- % of Albertans who understand that babies born with FASD have irreversible brain damage
- % of Albertans who are aware and understand that there is no safe time or safe amount of alcohol to drink when pregnant or when planning to become pregnant
- % of Albertans who support their friend's and family's choice to abstain from alcohol if they are pregnant or planning to become pregnant
- Prevalence of FASD is reduced.

See Appendix B for complete list of performance indicators and measures.

**System Outcome 1.1:** Level 1 Prevention strategy and initiatives are developed, delivered and evaluated using a collaborative and cooperative approach.

**Priority Actions for System Outcome 1.1**

1.1.1 **Review campaign messaging:** Consider adding messaging on desired behaviour change, such as “No alcohol is best when pregnant or planning to become pregnant.”

*Lead:* Alberta Community and Social Services; Alberta Gaming and Liquor Commission; FASD Service Networks; with advice from FASD Awareness, Prevention & Communications Council

1.1.2 **Develop initiatives that focus on stigma** to raise awareness of FASD and how to be inclusive and supportive of individuals with FASD, their families and caregivers.

*Lead:* Alberta Community and Social Services; FASD Service Networks; with advice from FASD Awareness, Prevention & Communications Council

1.1.3 **Develop targeted, culturally appropriate awareness campaigns:** Partner with service providers working with target populations and provide campaign parameters supported by the
evidence and GBA+ analysis. Support partner-led campaigns that address misinformation and stigma and focus on awareness, understanding and behaviour change.

**Lead:** FASD Service Networks with advice from FASD Awareness, Prevention & Communications Council

1.1.4 **Identify new sources of research and partnerships to collect population data:** Advise the FASD-CMC on the availability of new sources of FASD research on public awareness, understanding and behavioural change, and identify opportunities for new partnerships and data collection opportunities to replace the University of Alberta’s Population Research Lab, such as Kids Brain Health and Saskatchewan FASD Prevention Institute.

**Lead:** FASD Awareness, Prevention & Communications Council; FASD Evaluation & Research Council; CanFASD

**Ongoing Actions for System Outcome 1.1**

1.1.5 **Alberta FASD website:** This website is continually updated and improved to include the latest FASD information, including FASD resources and training.

**Lead:** Alberta Community and Social Services

1.1.6 **Evaluate Level 1 Prevention strategies and campaigns** to support continuous improvement, capturing innovations and implementing adaptations.

**Lead:** Alberta Community and Social Services; Alberta Gaming and Liquor Commission; with advice from FASD Awareness, Prevention & Communications Council

1.1.7 **Fund FASD Service Networks:** Sustain funding to FASD Service Networks to deliver Level 1 Prevention initiatives.

**Lead:** FASD-CMC

**Long-term Actions for System Outcome 1.1**

1.1.8 **Provincial inventory of Level 1 Prevention campaigns** is developed and maintained.

**Lead:** Alberta Community and Social Services, with advice from FASD Awareness, Prevention & Communications Council
Client Outcome 1.2: Albertans are aware and understand that FASD is caused by alcohol use during pregnancy, that babies born with FASD have irreversible brain damage, and that individuals with FASD need supports across their lifespan, as do their families and caregivers.

Client Outcome 1.3: Albertans are willing to inform friends and family about the risks of using alcohol when pregnant and to support women in their effort to abstain from alcohol if they are pregnant or planning to become pregnant.

Long-term Actions for System Outcome 1.2 and 1.3

1.2.1/1.3.1 Population-based survey conducted every 5 years (next survey in 2022): Review survey questions, ensuring concordance with surveys conducted in Year 5 and Year 10 Evaluations and considering other current surveys by, for example, the Society of Obstetricians and Gynecologists of Canada (SOGC), adding additional questions based on current performance indicators and measures.

Lead: FASD-CMC

Strategic Pillar #2: Prevention (Level 2 Prevention: Safe Discussions)

Goal: Alcohol use during pregnancy is eliminated, reducing the profound personal and societal costs of FASD.

10-Year Target: The FASD 10-Year Strategic Plan did not differentiate between FASD awareness and prevention initiatives. There was no target set for Level 2 Prevention.

Key Performance Indicators (KPI):

- Increase in # and types of professionals and post-secondary students trained to deliver Level 2 Prevention
- % of women receiving Level 2 Prevention who report they intend to eliminate alcohol use during current or future pregnancies
- % of women receiving Level 2 Prevention referred to supports and services that can help them eliminate alcohol use during pregnancy
- % of friends and family receiving Level 2 Prevention who report they intend to support women to abstain from alcohol if they are pregnant or planning to become pregnant.

See Appendix B for complete list of performance indicators and measures.
System Outcome 2.1: Level 2 Prevention (Safe Discussions) strategy and initiatives are developed, delivered and evaluated using a collaborative and cooperative approach.

Priority Actions for Outcome 2.1

2.1.1 The Prevention Conversation - A Shared Responsibility: This program is sustained, expanded and enhanced to ensure cultural sensitivity and trauma-informed practice. The development of additional resources focused on having prevention conversations with youth and Indigenous youth are planned for release in the Fall of 2017. Evaluation of Level 2 Prevention initiatives supports consistent reporting.

   **Lead:** FASD-CMC; FASD Service Networks; with advice from the FASD Awareness, Prevention & Communications Council

2.1.2 FASD Treatment Improvement Protocol (TIP): Broadly implement the TIP, incorporating evaluation recommendations from the 2014 pilot program.

   **Lead:** FASD-CMC and CanFASD

Ongoing Actions for Outcome 2.1

2.1.3 Fund FASD Service Networks: Sustain funding to FASD Service Networks to deliver Level 2 Prevention initiatives.

   **Lead:** FASD-CMC

2.1.4 Level 2 Prevention strategy is reviewed annually to support continuous improvement, capturing innovations and implementing adaptations.

   **Lead:** FASD-CMC; FASD Networks; with advice from FASD Awareness, Prevention & Communications Council

System Outcome 2.2: Professionals trained in Level 2 Prevention feel confident in their knowledge of FASD, are willing to engage their clients in safe discussions about FASD, and support their clients’ efforts to abstain from alcohol if they are pregnant or planning to become pregnant.

Priority Actions for Outcome 2.2

2.2.1 Survey professionals trained in Level 2 Prevention: Surveys of professionals and post-secondary students trained in Level 2 Prevention strategies evaluate the effectiveness of their training and report on their intention to implement the strategies.

   **Lead:** FASD-CMC; South Alberta FASD Network; with advice from FASD Awareness, Prevention & Communications Council
Client Outcome 2.3: Women participating in Level 2 Prevention programs know that FASD is caused by alcohol use during pregnancy, have increased knowledge about the range of disabilities that can result from prenatal exposure to alcohol, develop the intention to eliminate alcohol use during current or future pregnancies and are referred to supports and services that can help them.

Priority Actions for Outcome 2.3

2.3.1 Level 2 Prevention data analysis: Data is collected and reported consistently using performance indicators and measures.

Lead: Alberta Community and Social Services

Strategic Pillar #2: Prevention (Level 3 and Level 4 Prevention: Supports for Women)

Goal: Alcohol use during pregnancy is eliminated, reducing the profound personal and societal costs of FASD.

10-Year Target: 75% of women at-risk of giving birth to children with FASD and participating in a prevention program report reducing or abstaining from alcohol use during pregnancy or when planning to become pregnant.

Key Performance Indicators (KPI):

- # of women on waitlists for PCAP
- Reduced incidence of secondary disabilities (adverse outcomes) experienced as a result of primary disabilities associated with FASD) experienced by PCAP clients
- % of women participating in PCAP programs who reduce or abstain from using alcohol during current and subsequent pregnancies*
- % of women participating in PCAP programs who reduce or abstain from using drugs during current and subsequent pregnancies*
- % of women participating in PCAP programs who use an effective family planning method*

1 The Parent-Child Assistance Program (PCAP) is the three-year, home visitation intervention program that has been implemented across the province for women with a history of alcohol and drug use challenges and are at risk of giving birth to a child with FASD. PCAP offers recovery and support services that are specialized and accessible for women who use alcohol and face related mental health/social challenges. While PCAP remains the main Level 3 and 4 Prevention program in Alberta, other programs that meet the criteria for Level 3 and 4 Prevention have been developed and are included here.
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- Decrease in subsequent births of babies born to women in PCAP with prenatal exposure to alcohol.

*Similar performance indicators and measures are included in the Community and Social Services - Performance Management Framework (CSS-PMF). The indicator statements in the CSS-PMF do not include the word “reduce” in the two indicators related to the use of alcohol and drugs, and replaces the word “effective” with the word “appropriate” in the indicator on family planning.

See Appendix B for complete list of performance indicators and measures.

System Outcome 2.4: PCAP and other Level 3 and 4 Prevention programs are available across Alberta and meet community needs.

Priority Actions for Outcome 2.4

2.4.1 Review Level 3 and Level 4 Prevention strategy: The strategy to meet the need for PCAP and other Level 3 and Level 4 Prevention programs (such as the 2nd Floor Women’s Recovery Centre (Lakeland Network) and Alberta Health’s Healthy, Empowered, and Resilient (H.E.R) Pregnancy Program) in communities across Alberta is reviewed to address gaps in availability, access and data collection.

   **Lead:** FASD-CMC; Alberta PCAP Council

2.4.2 Fidelity to PCAP Model: Issues related to fidelity to the PCAP model are identified and addressed, while considering adaptations required to address intersecting identity factors identified through GBA+ (including culture, gender, and disability).

   **Lead:** Alberta PCAP Council

Ongoing Actions for Outcome 2.4

2.4.3 Fund delivery of PCAP and other Level 3 and Level 4 Prevention programs: Sustain funding to FASD Service Networks and other partners so they can continue to deliver PCAP and other Level 3 and Level 4 Prevention programs.

   **Lead:** FASD-CMC

2.4.4 PCAP for First Nations: Continue to support implementation of PCAP in First Nation communities.

   **Lead:** FASD Service Networks; Alberta Health; Alberta Community and Social Services; and Alberta PCAP Council
Priority Actions for Outcome 2.5

2.5.1 Use of ORS and Penelope collection models: All Network-funded PCAP programs are required to collect data using ORS and Penelope as a condition of funding. Data collection training on ORS and Penelope is provided.

**Lead:** Alberta Community and Social Services; with advice from Alberta PCAP Council

2.5.2: Expand data analysis: Only clients funded by Networks are tracked by ORS and Penelope. Link key ORS/Penelope performance indicators and measures with other data sources to expand the number of clients included in the data capture.

**Lead:** Alberta Community and Social Services; with advice from Alberta PCAP Council

Client Outcome 2.6: PCAP clients experience improvement in their wellbeing.

Client Outcome 2.7: Subsequent births of children with prenatal exposure to alcohol by women who have used substances while pregnant are reduced.

Client Outcome 2.8: Children of PCAP clients experience improvement in their wellbeing.

Client Outcome 2.9: PCAP clients report satisfaction with the Program.

Ongoing Actions for Outcome 2.4

*Data for Client Outcomes 2.6 and 2.7 is collected through ORS and Penelope (See System Outcome 2.5). For Client Outcome 2.8, ORS only collects data on pregnancy outcomes, and does not collect data on the wellbeing of children of PCAP clients. Some data on children is collected by PCAP sites, but it is not collected using Penelope.*

2.9.1 PCAP and other Level 3 and Level 4 client surveys: Indicators are streamlined and aligned to consistently conduct client surveys and report results.

**Lead:** Alberta PCAP Council
Strategic Pillar #3: Assessment and Diagnosis

**Goal:** Albertans who may be affected by FASD have access to timely and affordable assessment and diagnostic services resulting in recommendations for intervention based on their needs and strengths.

**10-Year Target:** 900 assessments annually.

**Key Performance Indicators (KPIs)**
- # of assessments conducted annually
- # of Albertans on waitlists for assessment
- % of clinics trained to use the standardized assessment tools that conform to Canadian Guidelines
- # of Albertans receiving follow-up assessments at key transition points and crisis periods
- % of clients and/or caregivers who report satisfaction with the assessment services received.

See **Appendix B** for complete list of performance indicators and measures.

**System Outcome 3.1:** Albertans receive timely, affordable assessment and diagnostic services from clinics that use a multidisciplinary approach to assessment and follow Canadian Guidelines for Diagnosis, consistently using standardized assessment tools based on current research and best practices.

**Priority Actions for Outcome 3.1**

**3.1.1 Screening tool(s) for use in the criminal justice system:** Research the merits of using an FASD screening tool(s) for individuals entering the justice system and for recidivist offenders.

*Lead:* Alberta Justice and Solicitor General

**3.1.2 Multidisciplinary assessment and diagnostic services:** Increase the number of FASD-trained multidisciplinary teams to improve access to multidisciplinary assessment and diagnostic services for individuals suspected of FASD.

*Lead:* Alberta Health; Alberta Health Services; with advice from the FASD Assessment & Diagnosis Council

**3.1.3 Reassessment at key transition points across the lifespan:** Increase access to assessments, especially for youth transitioning to adulthood, and at discharge from facilities (such as community-based programs, hospitals, treatment facilities and correctional institutions) to ensure the seamless delivery of a continuum of FASD supports and services.

*Lead:* FASD-CMC
3.1.4 **Funding for assessments:** Provide supplemental funding for the increasing number of referrals.

   **Lead:** Alberta Health

3.1.5 **Family member and caregiver involvement in the assessment and diagnosis process:** Provide advice on how to increase involvement of family members and caregivers (including foster parents) in multidisciplinary assessment and diagnosis processes. Involve them early in the planning process so that they better understand the diagnosis, are more open to receiving services, and learn to advocate on behalf of individuals with FASD needing access to services.

   **Lead:** FASD Assessment & Diagnosis Council

3.1.6 **Support for individual and families on clinic waitlist:** Examine strategies to support individuals and families on clinic waitlists for assessment and diagnosis, such as developing and implementing a pilot project to create a Community Resource Navigator position in clinics to help individuals and families access community-based resources while waiting for assessment.

   **Lead:** FASD-CMC; FASD Service Networks; with advice from FASD Assessment & Diagnosis Council

**Ongoing Actions for Outcome 3.1**

3.1.7 **Fund FASD Service Networks:** Sustain funding to FASD Service Networks so they can continue to fund assessments for individuals needing diagnostic services.

   **Lead:** FASD-CMC

3.1.8 **Communities of Practice support consistency and best practice in assessment and diagnosis:** Continue the current focus on consistency and best practice, and use of assessment tools to support standards of practice. Develop Communities of Practice with physicians and other professionals to support these efforts.

   **Lead:** FASD Assessment & Diagnosis Council; CanFASD

3.1.9 **Develop strong partnerships** among Primary Care Networks, medical clinics, and mental health and addiction treatment centres to improve information sharing and access through coordinated referral to other health strategies and disability programs.

   **Lead:** FASD-CMC; FASD Service Networks; with advice from FASD Assessment & Diagnosis Council

3.1.10 **Alberta physicians billing code:** Monitor the use of billing code 760.71, and provide training to physicians to improve awareness and uptake of the code.

   **Lead:** Alberta Health
Priority Actions for Outcome 3.2

3.2.1 **Link and integrate assessment and diagnosis data** from the ORS database, other ministry databases through the FASD Data Capture and Analysis Framework, and from the CanFASD’s National Database for FASD. Encourage Alberta diagnostic clinics to participate in the National Database project.

*Lead:* Alberta Community and Social Services; Alberta Health; with advice from FASD Assessment & Diagnosis Council; CanFASD

3.2.2 **Report on common assessment recommendations** from diagnostic clinics from all linked data sources to inform policy and guide service provision across all disciplines.

*Lead:* Alberta Health; with advice from FASD Assessment & Diagnosis Council; CanFASD

Ongoing Actions for Outcome 3.2

3.2.3 **ORS data collection:** Develop a standardized data collection process that is aligned with assessment and diagnosis outcomes and performance indicators and that links post-assessment services received to assessment recommendations.

*Lead:* Alberta Community and Social Services, with advice from FASD Assessment & Diagnosis Council

3.2.4 **Inventory of standardized assessment tools:** Develop a standardized inventory of assessment tools, updated periodically to support clinic members.

*Lead:* CanFASD with advice from FASD Assessment & Diagnosis Council

**Client Outcome 3.3:** Clients and/or caregivers have increased understanding of how FASD affects them, the supports and services available to them in their community, and are referred to the post-assessment supports they need.

Ongoing Actions for Outcome 3.3

3.3.1 **Client satisfaction:** Advise on the development of surveys of clients conducted by FASD diagnostic clinics include client understanding of how FASD affects them, and if they have accessed recommended services.

*Lead:* FASD Assessment & Diagnosis Council
Strategic Pillar #4: Supports for Individuals with FASD, their Families and Caregivers

**Goal:** Albertans with FASD and their caregivers receive coordinated access to the supports and services they need, when they need it.

**10-Year Targets:** 80% of individuals diagnosed with FASD are receiving services, and have integrated care plans in place to ensure coordinated service delivery. 80% of caregivers are satisfied with the services they receive and report services are available to meet the identified needs of those individuals in their care affected by FASD.

**Key Performance Indicators (KPIs):**
- % of individuals with a diagnosis receiving recommended supports
- % of clients with an Individualized Service Plan
- # of clients on waitlists for services
- % of clients reporting satisfaction with services received
- % of caregivers who report satisfaction with services received
- % of caregivers who report services are available to meet the needs of individuals in their care affected by FASD.

See Appendix B for complete list of performance indicators and measures.

**System Outcome 4.1:** Every Albertan needing supports receives a case-management plan based on an integrated lifespan approach that manages life-stage transitions and guides the delivery of timely and coordinated services.

**Priority Actions for Outcome 4.1**

4.1.1  **Criminal justice system - Screening:** Screen individuals entering the justice system and recidivist offenders for FASD.

  *Lead:* Alberta Justice and Solicitor General

4.1.2  **Criminal justice system – Supports for youth:** Continue to provide case conferences to connect young offenders with FASD to supports to reduce likelihood of future involvement with the justice system.

  *Lead:* Alberta Justice and Solicitor General; FASD Service Networks

4.1.3  **Criminal justice system - Transitional supports when leaving custody:** Connect offenders screened and suspected of FASD with appropriate supports while still in custody to support effective
transition into the community. Write probation orders in plain language for offenders suspected of FASD to avoid administrative breaches. Once on probation, provide these offenders with access to assessment and diagnosis, and FASD-informed supports.

**Lead:** Alberta Justice and Solicitor General; FASD Service Networks

### 4.1.4 Integrated housing and supports
Provide integrated housing and supports for individuals with FASD by identifying best practices to support chronically and episodically homeless individuals with FASD, and by accessing supports available through other provincial frameworks and strategies, such as the Plan to End Homelessness and Mental Health and Addictions Support Framework.

**Lead:** Alberta Community and Social Services; Alberta Health Services; FASD Service Networks

### 4.1.5 Supports for children and youth in schools
Ensure learnings from the FASD Wellness, Resiliency and Partnership (WRaP) project are incorporated into the ongoing work of the ministry.

**Lead:** Alberta Education

### 4.1.6 Inclusive employment supports
Provide resources and training to employers and supports for individuals with FASD to help them transition to employment.

**Lead:** Alberta Community and Social Services with advice from FASD Family Advisory Council

### Ongoing Actions for Outcome 4.1

#### 4.1.7 Funding FASD Service Networks
Sustain funding to FASD Service Networks so they can continue to deliver prevention and support services for individuals with FASD, their families and caregivers.

**Lead:** FASD-CMC

#### 4.1.8 Relationship-based mentoring for children and youth
Continue supporting volunteer mentoring programs for children and youth with FASD in collaboration with the Alberta Mentoring Partnership.

**Lead:** Alberta Education; Alberta Children’s Services; FASD Service Networks

#### 4.1.9 Supports for young children
Partner with Early Childhood Development (ECD) to identify potential programs that support early interventions for young children with complex needs suspected of having FASD.

**Lead:** Alberta Children’s Services; Alberta Health; Alberta Education

#### 4.1.10 Relationship-based mentoring programs across the lifespan
Continue to develop new partnerships for the delivery of mentorship programs for individuals with FASD across the lifespan.

**Lead:** Alberta Children Services; FASD-CMC; FASD Service Networks
**Priority Actions for Outcome 4.2**

4.2.1 **Navigation pilot projects**: Develop pilot projects to support the development of navigator positions to help individuals with FASD, their families and caregivers access services using a coordinated, collaborative and integrated approach. Create an advisory working group to develop a framework for how to navigate the FASD system. Navigators will need training and the authority to work collaboratively with other agencies (requiring shared responsibility), including how to negotiate and navigate Family Support for Children with Disabilities (FSCD) agreements. FASD Service Networks that have created navigator positions are encouraged to share their experience.

*Lead*: FASD-CMC

4.2.2 **Improve collaboration with Family Support for Children with Disabilities (FSCD)**: Families of children with FASD are not accessing disability supports that may be available to them from FSCD. Collaborate with FSCD to improve access for families caring for individuals with FASD. Funding from FSCD is also available to families living on First Nations Reserves. Collaborate with FSCD and First Nations to access funding to develop culturally-sensitive FASD-informed supports.

*Lead*: Alberta Community and Social Services

**Ongoing Actions for Outcome 4.2**

4.2.3 **Caregiver supports and services strategy**: Continue to develop strategies to improve access to respite care, peer and professional support for families and caregivers.

*Lead*: Alberta Community and Social Services; FASD Service Networks with advice from FASD Supports & Services Council

**System Outcome 4.3**: Data is collected consistently.

**Priority Actions for Outcome 4.3**

4.3.1 **ORS data analysis**: Reports are shared on a regular basis with the FASD-CMC, FASD Advisory Councils and FASD Service Networks to inform policy development, resource allocation, program design and service delivery.

*Lead*: FASD-CMC; Alberta Community and Social Services; FASD Service Networks

**Client Outcome 4.4**: Individuals diagnosed or suspected of FASD experience improvement in their wellbeing.

**Client Outcome 4.5**: Caregivers of individuals affected by FASD experience improvement in their wellbeing.

**Client Outcome 4.6**: Individuals and caregivers receiving supports report satisfaction with services received.
Priority Actions for Outcome 4.4-4.6

4.4.1/4.5.1/4.6.1 Data analysis: Data is regularly and consistently analyzed and Information is shared to inform program design, policy development, resource allocation and service delivery.

Lead: FASD-CMC; Alberta Community and Social Services; FASD Service Networks

Strategic Pillar #5: The FASD Learning Organization

Goal: Stakeholders collaborate to develop and mobilize knowledge based on research and best practices to continuously transform Alberta’s FASD system to achieve outcomes and goals.

10-Year Target: The 2006 FASD 10-Year Strategic Plan did not identify targets for activities under this pillar that contribute to the FASD Learning Organization.

Key Performance Indicators (KPIs):

Stakeholder Engagement and Strategic planning
- % of Networks rated excellent in their alignment with operating guidelines in six core areas of funding
- % of stakeholders reporting their networking and information sharing needs are being met

Training and education
- # and types of educational resources and training developed based on research and best practice
- # and type of academic disciplines that include FASD-related knowledge in their curricula
- # and demographics of participants accessing training and educational resources
- % of participants who report that their training, networking and information sharing needs are being met
- % of participants from Indigenous and other cultural communities who report that the training and educational materials are culturally sensitive and meet their needs and the needs of their cultural communities.

Research and Evaluation
- # and types of evaluation/research-based innovations, adaptations, and leading practices identified and adopted in the delivery of FASD programs and services in Alberta.
- Overall social return on investment of Alberta’s FASD Service Networks
- Overall cost of FASD to Albertans.

See Appendix B for complete list of performance indicators and measures.

System Outcome 5.1: The planning and delivery of FASD programs and services are accomplished through a collaborative approach, building the knowledge and capacity of stakeholders through information sharing supported by improvements to data capture and analysis across systems to better inform policy, practice and continuous improvements.
Priority Actions for Outcome 5.1

5.1.1 Guiding Document for FASD Beyond Year 10: Develop a strategy that describes the FASD strategy going forward. This document will consider the policy landscape within government, align with internal ministry directions and be informed by research, evaluation and community. It will respond to the results of the Year 10 Evaluation, as appropriate, and include processes for implementation and evaluation. This guiding document will be used by all ministries to guide the work they do related to FASD for years to come.

   Lead: FASD-CMC

5.1.2 Review goals, targets, outcome statements, and performance indicators and measures: Review these key benchmarks for each strategic pillar of this S&O Plan in light of the Year 10 Evaluation recommendations and the Guiding Document for FASD Beyond Year 10 (Action 5.1.1):
   - Update the wording of goals and outcome statements to accurately reflect current knowledge.
   - Review targets and identify targets where there are none.
   - Review performance indicators and measures in light of current research and resources, such as the Canadian Guidelines for Diagnosis and CanFASD’s National Database for FASD (formerly the Universal Data Form Project).
   - Ensure language used in relation to diagnosis is consistent with the Canadian Guidelines.
   - Ensure the suites of key performance indicators (KPIs) capture all new priorities and areas of focus.
   - Standardize a suite of evaluation frameworks and tools used to evaluate results achieved under each strategic pillar of this S&O Plan.
   - Explore the use of OCAP® agreements, or alignment with OCAP® principles.

   Lead: FASD-CMC

5.1.3 Align FASD with Government of Alberta policy frameworks and strategies: Align FASD with current government-led initiatives by sharing the FASD Prevention and Service Delivery Model and reporting results to inform future planning and decision-making that impact individuals with FASD across jurisdictions and sectors.

   Lead: FASD-CMC and partnering ministries

5.1.4 FASD Organizational Learning supports: Provide funding to support participation in regular face-to-face meetings among FASD stakeholders to facilitate communication, cooperation, networking, information sharing and the development of shared understanding. Fund administrative support to the FASD Advisory Councils. Maintain accountability by annually reviewing and updating each FASD Advisory Council’s Terms of Reference, plans, projects and evaluation tools supporting implementation of the FASD Strategic and Operational Plan.

   Lead: Alberta Community and Social Services

December 21, 2017
5.1.5 **Develop an FASD communications plan:** CanFASD has researched FASD in the media and found that 98% of coverage is negative and is developing a communications plan to tell a different story. Develop a communications plan for Alberta telling a positive story of FASD for use by FASD Service Networks, government ministries and other stakeholders.

*Lead:* Alberta Community and Social Services

5.1.6 **Data Capture and Analysis Framework:** Implement this framework to create a centralized data collection system accessible across ministries that provides reporting to stakeholders to inform future planning, knowledge mobilization and decision-making. Explore the use of OCAP® agreements, or alignment with OCAP® principles.

*Lead:* Alberta Community and Social Services; PolicyWise for Children & Families

5.1.7 **Alberta First Nations Information Governance Centre (AFNIGC):** Engage AFNIGC in discussion regarding the collection of FASD-related data from First Nations clients. Explore the use of OCAP® agreements, or alignment with OCAP® principles.

*Lead:* FASD-CMC; Alberta health; with advice from FASD Evaluation & Research Council and Alberta PCAP Council

5.1.8 **Integrated FASD-informed service delivery models:** Explore partnership opportunities to integrate FASD-informed services into client-centred integrated service delivery models. FASD-CMC members participating on Valuing Mental Health Committees are encouraged to share lessons learned. Explore research partnerships with the Canadian Centre for Substance Use and Addiction (CCSU), Canadian Community Epidemiology Network on Drug Use (CCENDU), and Kids Brain Health.

*Lead:* FASD-CMC with advice from the FASD Supports & Services Council and the FASD Evaluation and Research Council

**Ongoing Actions for Outcome 5.1**

5.1.9 **FASD Service Network operating grant policies:** Review Network operating grant policies periodically to support continuous improvement.

*Lead:* Alberta Community and Social Services

5.1.10 **Inclusive Employment Practices for Individuals with FASD:** Develop, pilot and implement an evaluation tool that standardizes a process for evaluating FASD inclusive employment programs. Provide recommendations to government on how inclusive employment outcomes can be achieved.

*Lead:* PolicyWise for Children & Families; CanFASD
5.1.11 **Child welfare practices:** Conduct an updated review and analysis of child welfare practices with respect to children with FASD and foster families, with recommendations provided to government.

*Lead: FASD Family Advisory Council; CanFASD*

5.1.12 **Indigenous Children in Care:** Continue to participate in the Child and Family Services Technical Working Group (a trilateral table).

*Lead: FASD-CMC and Public Health Agency of Canada*

5.1.13 **Single Point of Entry:** Oversee the development and improvement of the FASD Service Networks’ one-stop model of service delivery, helping Albertans affected by FASD to access and navigate a full range of effective programs and services.

*Lead: FASD-CMC; FASD Service Networks*

**Priority Actions for Outcome 5.2**

5.2.1 **FASD Workforce Development Framework:** Develop and implement this framework to equip staff in all sectors to deliver quality FASD-informed supports and services to individuals with FASD. Include models of peer and professional training for all sectors including mental health professionals, child and youth care workers, primary health/primary care practitioners, disability sector workers, educators, probation officers, and correctional officers.

*Lead: FASD-CMC with advice from FASD Education & Training Council*

5.2.2 **Core curriculum for professionals:** Develop a core curriculum for FASD in Alberta that can be incorporated into the teaching of health care and other professions in Alberta’s post-secondary programs that is modeled after the successful Pharmacist’s FASD Training Initiative.

*Lead: Alberta Health; Alberta Community and Social Services; with advice from FASD Education & Training Council*

5.2.3 **Training and education participation statistics:** Advise and recommend a process for gathering participation statistics for all FASD education and training occurring in the province.

*Lead: FASD Education & Training Council*

5.2.4 **Use of diagnostic code:** Monitor use of the 760.71 diagnostic code for FASD and train physicians to improve awareness and uptake of the code to improve monitoring and surveillance.

*Lead: Alberta Health*
Ongoing Actions for Outcome 5.2

5.2.5 Teaching resources to support students with FASD: Develop resources for teachers through the Workforce Development Framework to support students with FASD that align with current programs of study for K-12 education. Provide educators with professional development on how to support students with FASD.

   Lead: PolicyWise for Children and Family; CanFASD; with the advice from the FASD Education & Training Council

5.2.6 FASD Toolkit: Continue to evaluate and update the Toolkit. This Toolkit provides support and educational resources to clinicians, families and communities (http://fasd.alberta.ca/toolkit.aspx).

   Lead: Alberta Community and Social Services, with advice from the FASD Supports & Services Council and the FASD Education & Training Council

5.2.7 FASD Learning Series: Continue to develop and update the Learning Series.

   Lead: Alberta Community and Social Services, with advice from the FASD Education & Training Council

5.2.8 Alberta FASD Conference: Plan and implement the annual conference. Use the conference as an opportunity to identify and source speakers and resources that can add value to other FASD education and training initiatives.

   Lead: Alberta Community and Social Services; FASD Conference Committee

5.2.9 Collect and share stories: Albertans affected by FASD are encouraged to share their stories to bring a deeper awareness and understanding to FASD. The stories are collected and used in training and education, to address issues of stigma, and to enrich the quantitative data with lived-experience.

   Lead: FASD Service Networks; with advice from the FASD Family Advisory Council, the Alberta PCAP Council, the Awareness, Prevention & Communications Council, and the Education and Training Council.

Training to Support Strategic Pillar #1: Awareness and Understanding (Level 1 Prevention)

5.2.10 FASD awareness training for Alberta Government staff and FASD partners: Continue to provide FASD education and training for all frontline staff of partnering ministries and agencies.

   Lead: FASD-CMC; Alberta Justice and Solicitor General; FASD Service Networks; with advice from the FASD Education & Training Council

5.2.11 FASD training in the criminal justice system: Continue to provide FASD education and training for the judiciary, crown attorneys, corrections, probation and parole officers.

December 21, 2017
5.2.12 Training for police and other frontline emergency response personnel: Develop training programs for police and other frontline emergency response personnel to inform them about FASD.

Lead: Justice and Solicitor General; FASD Service Networks; with advice from the FASD Education & Training Council

5.2.13 Level 2 Prevention training: Continue to deliver training for Level 2 Prevention Programs based on training materials developed for the Prevention Conversation. The development of online training for the Prevention Conversation in partnership with CanFASD is planned for release in the Fall of 2017.

Lead: South Alberta FASD Network; CanFASD; with advice from the FASD Education & Training Council and the Awareness, Prevention & Communications Council.

5.2.14 Peer and professional training and supports for PCAP workers: Continue to provide consistent education and training for all PCAP workers (mentors, supervisors and coordinators) to support them in their work and to help them maintain their health and wellbeing.

Lead: Alberta PCAP Council

5.2.15 Penelope PCAP data collection training: Continue to deliver training for PCAP providers to support compliance with all Penelope data collection and entry requirements.

Lead: Alberta PCAP Council

Training to Support Strategic Pillar #3: Assessment and Diagnosis

5.2.16 Training in assessment and diagnosis: Continue to provide training for professional staff in FASD diagnostic clinics. Continue to deliver current information and support to Alberta clinics.

Lead: Alberta Health; Lakeland Centre for FASD and the Rajani Project

5.2.17 Clinical consultation and mentoring: Develop a plan to support clinical consultation and mentoring for clinicians.

Lead: Lakeland Centre for FASD and the Rajani Project, with advice from the FASD Assessment and Diagnosis Council
Training to Support Strategic Pillar #4: Supports for Individuals with FASD, their families and Caregivers

5.2.18 Children in Care - Leading from Within: Continue implementation of this advanced training model in child intervention for caseworkers, foster care supervisors, and Alberta Community and Social Services regional managers.
   Lead: Alberta Community and Social Services; Alberta Children’s Services; with advice from the FASD Community of Practice Council

5.2.19 Training for ORS data collection: Provide training for FASD Service Networks and service providers responsible for data collection and posting to the Online Reporting System (ORS) database.
   Lead: Alberta Community and Social Services

Long Term Actions for Outcome 5.2

5.2.20 Training and educational needs assessment: Conduct surveys to determine the training and educational needs of various target audiences.
   Lead: PolicyWise for Children & Families; CanFASD; Alberta Community and Social Services; with advice from the FASD Education & Training Council

System Outcome 5.3: Evaluation and research informs policy, practice and continuous improvement; and progress made achieving FASD outcomes and goals is reported annually.

Priority Actions for Outcome 5.3

5.3.1 Year 10 Evaluation: Implement the Year 10 Evaluation of the FASD 10-Year Strategic Plan.
   Lead: PolicyWise for Children & Family

5.3.2 FASD stakeholder satisfaction: Evaluate and report on FASD stakeholder satisfaction and their opportunities to participate in information sharing, networking and planning processes.
   Lead: FASD-CMC, with advice from the FASD Evaluation & Research Council

5.3.3 Best Practices for FASD Service Delivery – Guide and Evaluation Tool Kit: Designed for use by agencies and their staff, continue to evaluate this service delivery guide that identifies and describes evidence-based promising practices for working with individuals with FASD, their families and caregivers and support systems.
   Lead: FASD-CMC and University of Alberta ACCERT (Alberta Clinical and Community-Based FASD Evaluation and Research Team)

5.3.4 Patient Journey Mapping and other tools: Alberta Health Services (AHS) has mapped four patient groups, and FASD is found to be a factor in each group. AHS has other evaluation tools that
can identify gaps in patient access. Explore the use of these tools and how these can be used to improve the provision of FASD-informed services.

Lead: Alberta Health Services, with advice from the FASD Evaluation & Research Council

5.3.5 Case management standards and evaluation framework: Advise and recommend an approach to the development and implementation of case management standards.

Lead: FASD Supports & Services Council; FASD Education & Training Council

Ongoing Actions for Outcome 5.3

5.3.6 Longitudinal Study of Albertans with an FASD Diagnosis: Following individuals at key transition points and periods of crisis across the lifespan.

Lead: CMC; PolicyWise; with advice from FASD Evaluation & Research Council

5.3.7 Update inventory of Alberta-based research and evaluation activities: Established as part of the Year 5 Evaluation, this inventory covers four pillars of basic, clinical, population and health services. Continue to update this inventory on a regular basis.

Lead: FASD Evaluation & Research Council

5.3.8 Inventory of Alberta-based FASD programs: Advise and recommend an approach to the development of an inventory of Alberta-based FASD programs to support the expansion of successful programs and partnerships across the province.

Lead: FASD Supports & Services Council; FASD Education & Training Council

5.3.9 Implications of FASD on programs, practices and policy: Provide advice and recommend research that should be undertaken on how FASD differs from other developmental disabilities across the lifespan, and what this means for programs, practices and policy.

Lead: FASD Evaluation & Research Council
Works Cited


Appendix A: Year 7 Evaluation Recommendations

Overarching Recommendations

1. **Increase funding to the Alberta FASD Service Networks:** The FASD-CMC has successfully initiated an outcome-based management system and FASD learning organization to sustain and continuously improve Alberta’s FASD initiative. 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 of $16.5 million (39% of the $42 million requested by 2013/14 to implement the FASD 10-Year Strategic Plan) is insufficient to achieve targets and address identified challenges.

2. **Streamline FASD outcomes, indicators and key performance indicators (KPIs) and continue to enhance the Online Reporting System (ORS):** Expand ORS to capture contributions made to outcomes by all provincial and ministry-specific FASD initiatives, making data collection and reporting of all FASD initiatives a requirement of funding. Continue to enhance the ORS data collection system to track improvement in client wellbeing for all those receiving FASD-related services in Alberta.

Recommendations under each Strategic Pillar

**Strategic Pillar #1 - Awareness (Level 1 Prevention):**

3. **Fund Alberta’s FASD Service Networks to deliver awareness (Level 1 Prevention) initiatives at the local and regional levels:** The findings suggest that funding Networks to conduct awareness activities is a cost-effective, collaborative way to educate Albertans about FASD.

4. **Differentiate between Level 1 Prevention and Level 2 Prevention initiatives:** Evaluate initiatives under each level of prevention separately.

**Strategic Pillar #2 - Prevention (Level 2 Prevention – Safe Discussions):**

5. **Implement and evaluate The Prevention Conversation:** The investment has been made to develop this program, which is designed to reach women of child bearing age and their families, helping them understand the consequences of consuming alcohol when pregnant or planning to become pregnant. This program is needed to reach the goal of eliminating alcohol use during pregnancy.

**Strategic Pillar #2 - Prevention (Level 3 and Level 4 Prevention - PCAP):**

6. **Expand the Parent Child Assistance Program (PCAP):** Particularly into First Nations communities, through partnerships with Alberta Health, Alberta Community and Social Services, and Alberta’s
FASD Service Networks. This evidence-based FASD prevention program has proven to be cost-effective, providing a significant net monetary benefit for Alberta as it improves client wellbeing and prevents future cases of FASD.

7. **Require all Alberta PCAP programs to contribute data to ORS and Penelope databases:** These databases are making significant contributions to our understanding of how to improve client wellbeing and prevent future cases of FASD.

**Strategic Pillar #3 - Assessment and Diagnosis:**

8. **Require all Alberta assessment and diagnostic clinics to report results to ORS:** ORS only reports on Network-funded diagnostic assessments, which is only 30% of the target of 900 assessments per year.

9. **Increase access to diagnostic assessment for those suspected of FASD, especially in rural and remote areas:** The longest FASD waitlists are currently for diagnostic assessment services (197 identified in the first ORS reporting quarter of January-March 2014).

10. **Increase access to diagnostic assessment for offenders in the justice system suspected of having FASD:** Access to FASD clinical services helps guide the Court in providing FASD-informed services that appropriately reflect the developmental functioning of an individual with FASD.

11. **Increase access to (re)assessment at key transition points across the lifespan:** These assessments are especially needed for youth transitioning to adulthood to ensure ongoing delivery of the right support services at the right time.

**Strategic Pillar #4 - Supports for Individuals and Caregivers:**

12. **Conduct a longitudinal study of assessment recommendations given and supports received:** To identify systemic issues related to service availability and access.

13. **Track reasons for file closure in the ORS database:** To determine the percentage of clients for whom outcomes were met and differentiate these clients from those who left the program for other reasons.

14. **Increase access to relationally-based supports (mentors and coaches):** Especially for adults and youth transitioning to adulthood who are diagnosed or suspected of having FASD: The evidence suggests that relationally-based supports provide coordination/cooperation/collaboration between services, creating the “wraparound” supports needed by individuals with FASD to access a continuum of supports of services.
Strategic Pillar #5 – The FASD Learning Organization:

15. **Provide administrative support** to FASD Councils and subcommittees to improve communication and cooperation among these expert-led volunteer teams.

16. **Continue to support knowledge mobilization and continuous improvement** through evaluation/research and education/training in leading evidence-based FASD practices.

17. **Deepen the interconnection** (collaboration/cooperation/coordination) between FASD Network-funded programs and services delivered at the local and regional levels and Government of Alberta ministries and their provincial and ministry-specific initiatives to improve effectiveness and efficiency of Alberta’s FASD response.

**Recommendations from ADM Executive Committee**

The Assistant Deputy Minister (ADMs) on the Child, Youth and Family Executive Committee (CYFEC), who are the partnering ADMs of the FASD-CMC, supported the 17 recommendations of the Year 7 Evaluation in principle and recommended they be the foundation for activity should funding become available for FASD. They also added the following recommendations.

18. Utilize case management for service delivery as described in the Year 7 Evaluation of the South Alberta FASD Network.

19. Post-secondary data and support: (a) Track individuals with FASD attending post-secondary institutions; (b) Review post-secondary programs for those working in the field of FASD.

20. Model of Plateau: Develop a model demonstrating when we might expect to see plateau in cases of FASD.

**Recommendations from the Consensus Statement on Legal Issues of FASD**

The CYFEC-ADMs also agreed to focus on the following five recommendations from Institute of Health Economics’ (IHE’s) 2013 Consensus Development Conference on Legal Issues of FASD:

21. Where at all possible, those affected by FASD should be kept out of the criminal justice system, [with] support for community-based housing and transition housing programs; community education program starting with children and youth; and community support and intervention programs that are evidence-based in supporting individuals affected by FASD through their lifespan, particularly in key transition periods. (See IHE’s Recommendation #6)

22. Undertake research to establish a defined score on the Asante Centre’s FASD Screening and Referral Tool for Youth Probation Officers screening tool that would trigger a formal FASD
assessment. (See IHE’s recommendation #15)

23. Federal, provincial and territorial governments should continue to support research that provides estimates of the incidence and prevalence of persons with FASD in correctional settings and in child protection care. (See IHE’s recommendation #18)

24. Special attention [should] be paid to the use of the various forms of temporary or conditional release reviews for youth as well as temporary absence, day parole, parole, etc. for adults designed to reintegrate the offender safely into society... these offenders are, eventually, going to be [released] back in the community and it is in the public interest to use special efforts to develop and implement release strategies for these offenders that will be most effective in the long run. (See IHE’s recommendation #41).

25. Provide transition planning for FASD-affected youth moving into adult services, with consideration for an extension of the original care agreement. (See recommendation #47).
Appendix B: FASD Performance Indicators and Measures

All FASD performance indicators and measures are listed here. Those highlighted in bold were selected as Key Performance Indicators (KPIs).

**Strategic Pillar #1: Public Awareness and Understanding (Level 1 Prevention)**

**Performance indicators and measures by outcome**

**System Outcome 1.1:** Level 1 Prevention strategy and initiatives are developed, delivered and evaluated using a collaborative and cooperative approach.
- # and types of Level 1 Prevention (awareness) initiatives undertaken and evaluated per year
- Distribution (reach), engagement (interactions) and influence of Level 1 Prevention campaigns
- Prevalence of FASD is reduced.

**Client Outcome 1.2:** Albertans are aware and understand that FASD is caused by alcohol use during pregnancy, that babies born with FASD have irreversible brain damage, and that individuals with FASD need supports across their lifespan, as do their families and caregivers.
- % of Albertans who are aware and understand that FASD is caused by alcohol use during pregnancy
- % of Albertans who understand that babies born with FASD have irreversible brain damage
- % of Albertans who are aware and understand that there is no safe time or safe amount of alcohol to drink when pregnant or when planning to become pregnant.

**Client Outcome 1.3:** Albertans are willing to inform friends and family about the risks of using alcohol when pregnant and to support women and their effort to abstain from alcohol if they are pregnant or planning to become pregnant.
- % of Albertans willing to inform friends and family about the risks of using alcohol when pregnant
- % of Albertans willing to inform friends and family about abstaining from drinking alcohol if they are pregnant or planning to become pregnant
- % of Albertans willing to support women to abstain from alcohol if they are pregnant or planning to become pregnant.
Strategic Pillar #2: Prevention (Level 2 Prevention: Safe Discussions)

Performance indicators and measures by outcome

System Outcome 2.1: Level 2 Prevention (Safe Discussions) strategy and initiatives are developed, delivered and evaluated using a collaborative and cooperative approach.
- Increase in # of stakeholder groups participating in the delivery of Level 2 Prevention initiatives
- Increase in # and types of Level 2 Prevention initiatives delivered
- Increase in # and types of professionals and post-secondary students trained to deliver Level 2 Prevention
- Increase in # of Level 2 initiatives evaluated.

System Outcome 2.2: Professionals trained in Level 2 Prevention feel confident in their knowledge of FASD, are willing to engage their clients in safe discussions about FASD, and support their clients’ efforts to abstain from alcohol if they are pregnant or planning to become pregnant.
- Increase in # of professionals and post-secondary students who feel confident in their knowledge of FASD
- Increase in # of professionals and post-secondary students who intend to engage their clients in Level 2 Prevention
- Increase in # of professionals and post-secondary students who intend to support their clients in their efforts to abstain from alcohol if they are pregnant or planning to become pregnant.

Client Outcome 2.3: Women participating in Level 2 Prevention programs know that FASD is caused by alcohol use during pregnancy, have increased knowledge about the range of disabilities that can result from prenatal exposure to alcohol, develop the intention to eliminate alcohol use during current or future pregnancies and are referred to supports and services that can help them.
- # of clients (women of childbearing years, their friends and family) participating in Level 2 Prevention
- % of clients reporting that they understand FASD is caused by alcohol use during pregnancy
- % of clients who have increased knowledge about the range of disabilities that can result from prenatal exposure to alcohol
- % of clients reporting increased knowledge about supports and services available to individuals with FASD, their families and caregivers
- % of women receiving Level 2 Prevention who report they intend to eliminate alcohol use during current or future pregnancies
- % of women receiving Level 2 Prevention referred to supports and services that can help them eliminate alcohol use during pregnancy
- % of friends and family receiving Level 2 Prevention who report they intend to support women to abstain from alcohol if they are pregnant or planning to become pregnant.
**Strategic Pillar #2: Prevention (Level 3 and Level 4 Prevention: Supports for Women)**

**Performance indicators and measures by outcome**

**System Outcome 2.4:** PCAP and other Level 3 and 4 Prevention programs are available across Alberta and meet community needs.
- # of clients in PCAP programs
- # of women on waitlists for PCAP programs
- % of First Nations communities with PCAP programs.

**System Outcome 2.5:** Data is collected consistently using both ORS and Penelope Integrated Case Management software.
- Increase in # of PCAP programs reporting all clients to ORS, and that report both Network and non-Network funded clients
- Increase in # of PCAP programs reporting using Penelope
- Increase in # of PCAP programs reporting using both ORS and Penelope.

**Client Outcome 2.6:** PCAP Clients experience improvement in their wellbeing.
- Reduced incidence of secondary disabilities (adverse outcomes experienced as a result of primary disabilities associated with FASD) experienced by PCAP clients
- % of women participating in PCAP programs who use an effective family planning method
- % of women participating in PCAP programs who reduce or abstain from using alcohol during current and subsequent pregnancies
- % of women participating in PCAP programs who reduce or abstain from using drugs during current and subsequent pregnancies.

**Client Outcome 2.7:** Subsequent births of children with prenatal exposure to alcohol by women who have used substances while pregnant are reduced.
- Decrease in subsequent births of babies born to women in PCAP with prenatal exposure to alcohol.

**Client Outcome 2.8:** Children of PCAP clients experience improvement in their wellbeing.
- % of “target” children living with their PCAP client mother
- Decrease in foster care placements of “target” children
- % of children involved in early childhood education.

**Client Outcome 2.9:** PCAP Clients report satisfaction with the Program.
- % of “target” children living with their PCAP client mother
- Decrease in foster care placements of “target” children
- % of children involved in early childhood education.
Strategic Pillar #3: Assessment and Diagnosis

Performance indicators and measures by outcome

System Outcome 3.1: Albertans receive timely, affordable assessment and diagnostic services from clinics that use a multidisciplinary approach to assessment and follow Canadian Guidelines for Diagnosis, consistently using standardized assessment tools based on current research and best practices.

- # of assessments conducted annually
- # of Albertans on waitlists for assessment
- % of clinics trained to use standardized assessment tools that conform to Canadian Guidelines
- # of Albertans receiving follow-up assessments at key transition points and crisis periods
- # of clinics conducting longitudinal assessments.

System Outcome 3.2: Data is consistently collected based on a template of common recommendations that is linked to services received.

- % of clients receiving assessments with a single intake process
- Increase in the # of clinics reporting to ORS.

Client Outcome 3.3: Clients and/or caregivers have increased understanding of how FASD affects them, the supports and services available to them in their community, and are referred to the post-assessment supports they need.

- % of clients and/or caregivers who report increased understanding of how FASD affects them or their dependent
- % of clients and/or caregivers who report they understand the assessment process
- % of clients and/or caregivers who report satisfaction with the assessment services received
- % of clients and/or caregivers who report satisfaction with the time waited for an assessment (time between assessment request and completion).

Strategic Pillar #4: Supports for Individuals and Caregivers

Performance indicators and measures by outcome

System Outcome 4.1: Every Albertan needing supports receives a case-management plan based on an integrated lifespan approach* that manages life-stage transitions and guides the delivery of timely and coordinated services.

- % of clients with an Individualized Service Plan
- % of clients who receive functional assessments to inform case management plans
• % of clients with a mentor, and caseload per mentor
• # and types of services recommended and # and types received
• % of clients with a diagnosis receiving recommended supports
• # of clients on waitlists for services
• # and types of post-assessment services unavailable in the community.

System Outcome 4.2: Caregivers receive respite care, peer and professional support.
• % of caregivers receiving respite care
• % of caregivers on waitlists for respite care
• # and types of peer and professional supports available for caregivers
• % of caregivers receiving peer and professional supports
• % of caregivers on waitlists for peer and professional supports.

System Outcome 4.3: Data is collected consistently.
• increase in # of Networks and service providers that report data consistently and regularly to ORS.

Client Outcome 4.4: Individuals diagnosed or suspected of FASD experience improvement in their wellbeing.
• Reduced incidence of adverse outcomes such as crime, employment, homelessness and re-housing (for adults) and school disruptions and foster care placements (for children)
• % of clients reporting increased knowledge of and access to community resources.

Client Outcome 4.5: Caregivers of individuals affected by FASD experience improvement in their wellbeing.
• % of caregivers reporting positive changes in their stress levels (increased sense of hope for dependents; ability to cope)
• % of caregivers reporting increased knowledge of FASD and how to care for a person with FASD
• % of caregivers reporting increased knowledge of and access to community resources
• % caregivers reporting receiving the services they need when they need them both for their dependent and for themselves
• % of caregivers reporting increased ability to care for themselves and for their dependents.

Client Outcome 4.6: Individuals and caregivers receiving supports report satisfaction with services received.
• % of clients reporting satisfaction with services received
• % of caregivers reporting satisfaction with services received
• % of caregivers reporting services are available to meet the needs of their dependents.
Performance indicators and measures by outcome

**System Outcome 5.1:** The planning and delivery of FASD programs and services are accomplished through a collaborative approach, building the knowledge and capacity of stakeholders through information sharing supported by improvements to data capture and analysis across systems to better inform policy, practice and continuous improvements.

- # and types of FASD planning Committees, Councils and Roundtables at the provincial, regional, and local levels
- % of Networks conducting needs assessments in their regions
- % of Service Networks including stakeholders in their business planning activities
- % of Networks rated excellent in their alignment with operating guidelines in six core areas of funding
- % of stakeholders reporting their networking and information sharing needs are being met
- % of stakeholders reporting that they are satisfied with their engagement in the FASD planning process.

**System Outcome 5.2:** FASD stakeholders have access to training and educational resources about FASD that are based on research and leading practices.

- # and types of educational and training resources developed based on research and best practice
- # and type of academic disciplines that include FASD-related knowledge in their curricula
- # and demographics of participants accessing training and educational resources
- % of participants from Indigenous other cultural communities accessing FASD training
- % of participants from Indigenous other cultural communities accessing educational resources for their communities.
- % of participants who report that their training, networking and information sharing needs are being met
- % of participants from Indigenous other cultural communities who report that their training, networking and information sharing needs are being met.
- % of participants from Indigenous and other cultural communities who report that the training and educational materials are culturally sensitive and meet their needs and the needs of their cultural communities.

**System Outcome 5.3:** Evaluation and research informs policy, practice and continuous improvement; and progress made achieving FASD outcomes and goals is reported annually.

- # and type of evaluation and research projects undertaken annually
- # of new evaluation/research partnerships created per year
- # and types of evaluation/research-based innovations, adaptations, and leading practices
adopted in the delivery of FASD programs and services in Alberta

- Overall social return on investment of Alberta's FASD Service Networks
- Overall cost of FASD to Albertans
- Annual publication of key performance indicators and measures
- Outcome-based Strategic and Operational plan reviewed and updated annually, operationalizing recommendations for continuous improvement
- All FASD Councils, Committees and Networks report annually using performance indicators and measures identified in the annual Strategic and Operational Plan relevant to their areas of operation.