Year 7 Evaluation of the Government of Alberta’s FASD 10-Year Strategic Plan

OVERVIEW OF KEY FINDINGS AND RECOMMENDATIONS
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ABOUT THIS OVERVIEW
This overview presents key findings and recommendations from the Year 7 Evaluation Final Report on the Government of Alberta’s 10-Year Strategic Plan to address Fetal Alcohol Spectrum Disorder (FASD). The Year 7 Evaluation was conducted based on new research compiled by PolicyWise for Children & Families since the Year 5 Evaluation, and is the first evaluation to fully operationalize the new outcome-based management system developed in response to Year 5 recommendations. For complete information see the final report (Abells & Preston, October 2014).

ABOUT FASD
Fetal Alcohol Spectrum Disorder (FASD) refers to a range of physical, neurodevelopmental, and behavioural impairments resulting from damage to the brain of the developing embryo and 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.

ALCOHOL CONSUMPTION IN ALBERTA AND PREGNANCY
The 2011 Canadian Alcohol and Drug Use Monitoring Survey (CADUMS) on alcohol use by women in Alberta in the year prior to the survey indicated 73.7% were using alcohol, 12% were exceeding low risk drinking guidelines, and 13.7% reported heavy monthly use (binge drinking). Albertans and Canadians reported similar prevalence estimates for alcohol use and harmful patterns of consumption (Alberta Health Services, 2013).

There is no safe time or safe amount of alcohol to drink when pregnant or when planning to become pregnant (Canadian Centre on Substance Abuse, 2014), and half of all pregnancies in Canada are unplanned (Public Health Agency of Canada, 2005). An Alberta study of 2,246 Canadian women who consumed alcohol one year prior to pregnancy found that 13% of women reported binge drinking prior to pregnancy recognition; 46% reported drinking after pregnancy recognition; almost all at low to moderate levels (MacDonald et al., 2014).
PREVALENCE AND COST OF FASD IN ALBERTA

Research conducted by the Institute of Health Economics (IHE) using Alberta Health databases found the prevalence of FASD in Alberta was higher than previously estimated (Nguyen et al., August 2013). This research estimates a prevalence rate of 1.2%, indicating there were approximately 46,000 Albertans living with FASD at the end of March 2012, as compared to the previous estimate of 1% prevalence rate and 36,000 affected Albertans. The annual cost per case of FASD is now estimated at $18,000 and the incremental cost per case of FASD over a lifespan is estimated at $784,000, suggesting the social return on investment in the prevention of FASD is $784,000 for each prevented case. Based on this research, the annual cost of FASD is now estimated at $837 million per year (Nguyen et al., November 2013).

ALBERTA’S RESPONSE TO FASD

Alberta’s FASD 10-Year Strategic Plan (2007-2017) continues to prescribe the core strategic direction for the government’s FASD response. The vision is to develop a comprehensive and coordinated response to FASD across the lifespan and a continuum of services that is respectful of individual, family and community diversity. The cornerstone of this plan is the Alberta FASD Service Network Program and its 12 regional networks. Eleven FASD service networks serve geographical regions throughout Alberta and one network serves Métis settlements. Under the direction of the FASD Cross Ministry Committee (FASD-CMC), the networks are developing and implementing an FASD awareness, prevention and service delivery model designed to meet the needs in their region. The networks strive to provide support and mentoring to clients referred to an FASD clinic prior to, during and after diagnostic assessment. Services include helping clients and their caregivers access recommendations made as part of the diagnostic assessment process.

There is no safe time or safe amount of alcohol to drink when pregnant.
YEAR 5 EVALUATION OF ALBERTA’S FASD 10-YEAR STRATEGIC PLAN

The first five years of the FASD 10-Year Plan focused on developing the Alberta FASD Service Network Program. PolicyWise for Children & Families conducted the Year 5 Evaluation (Abells, 2013), and found the networks had increased access to FASD supports and services across Alberta. The Year 5 Evaluation established baseline information and made the following seven recommendations:

1. **Provide clients with assessment for intervention and wraparound services supported by a mentor system:** Creating a continuum of services across the lifespan with planned transitions.

2. **Define sustainability:** Based on a shared understanding of what sustainability means for the population directly affected by FASD and for the delivery system of supports and services.

3. **Clarify outcomes:** Articulate measurable outcomes for individuals affected by FASD (client outcomes) and for the FASD prevention and service delivery model (system outcomes) that demonstrate system effectiveness and efficiency.

4. **Develop a data collection model:** With specified indicators and data collection templates.

5. **Further develop CMC governance structures:** To oversee stakeholder engagement and collaboration, research and evaluation, and knowledge mobilization.

6. **Improve the CMC funding model:** Provide networks with core operating funding on a three-year cycle based on achieving annual objectives described in network business plans.

7. **Increase access to the Alberta FASD Service Network Program:** By increasing funding in order to reach targets identified in the FASD 10-year Strategic Plan.
PATHWAYS TO FASD SERVICES
Responding to recommendation #1, pathway diagrams were developed for each network to illustrate how individuals suspected of prenatal alcohol exposure and their caregivers navigate through Alberta’s FASD system of supports and services once they come into contact with a community agency or health care provider. These diagrams illustrate the FASD system of supports and services in each region, helping to identify systemic barriers or bottlenecks limiting or preventing access to services.

SUSTAINABILITY DEFINED
Responding to recommendation #2, sustainability was defined as “the ability to learn and to adapt to changing circumstances in order to achieve our goals.”

AN FASD OUTCOME-BASED MANAGEMENT SYSTEM
Responding to recommendation #3, the management approach was expanded from a traditional focus on reporting inputs (what is spent), activities (what is done) and outputs (what is produced) to include a focus on outcomes, a life-cycle approach that reports on results (what is achieved), learning (what can be improved) and adaptation (what needs to be changed).

RESPONDING TO YEAR 5 EVALUATION RECOMMENDATIONS
Year 5 recommendations prompted the development of key innovations and adaptations in the management of Alberta’s FASD prevention and service delivery model.

The FASD-CMC Annual Strategic and Operational Plan was re-conceptualized to reflect an outcome-based life-cycle system, with clearly defined and measurable outcomes. While the strategic direction and targets identified in the FASD 10-Year Strategic Plan remain essentially unchanged, how success is measured and evaluated was transformed. The Strategic Plan approved by Cabinet in 2006 described three strategic pillars (Awareness and Prevention; Assessment and Diagnosis; and Supports for Individuals and Caregivers) and four activities (Training and Education; Strategic Planning; Research and Evaluation; and Stakeholder Engagement), with a broad outcome described for each of the three pillars and four activities.
To implement an outcome-based management system, the following key structural adaptations were made to the FASD 10-Year Strategic Plan:

- The broad outcome statements for each of the original three strategic pillars were rearticulated as FASD goal statements. An FASD goal is defined as an overall, long-term result the FASD 10-Year Strategic Plan is intended to achieve.

- The Awareness and Prevention strategic pillar was separated into two pillars, each with its own FASD goal statement.

- The four activities were rolled up into a single strategic pillar called The FASD Learning Organization, with its own goal statement.

- The description of the pillars incorporated the language of prevention. The Four Levels of Prevention (Poole, 2008) reflect an understanding that all strategies are preventative and that prevention is a step along a continuum of care that includes treatment and maintenance. The language of “assessment for intervention” and “coordinated access across the lifespan with planned transitions” was also incorporated into the descriptions.

The result was the re-articulation of the key components of the FASD 10-Year Strategy into five strategic pillars and five goals (see Table 1).
#1: Awareness
- **Level 1 prevention strategies:** Public awareness and education initiatives
  - Albertans are aware that alcohol use during pregnancy can lead to FASD, that FASD can be prevented, and that FASD prevention is a shared responsibility.

#2: Prevention
- **Level 2 prevention strategies:** Safe discussions with women about FASD
- **Level 3 and 4 Prevention:** Parent-Child Assistance Programs (PCAP)
  - Alcohol use during pregnancy is eliminated, preventing the profound personal and societal costs of FASD.

#3: Assessment and Diagnosis
- Assessment for intervention to provide a continuum of supports across the lifespan with planned transitions.
- Diagnosis to support surveillance and research.
  - Albertans who may be affected by FASD have access to timely and affordable assessment and diagnostic services.

#4: Supports for Individuals and Caregivers
- Coordinated access to the right services at the right time, across the lifespan with planned transitions.
  - Albertans with FASD and their caregivers have coordinated access to supports and services that meet their needs.

#5: The FASD Learning Organization
- Includes training and education, strategic planning, research and evaluation, and stakeholder engagement.
  - Stakeholders collaborate to develop and mobilize knowledge based on research and best practice to continuously transform Alberta’s FASD system to achieve outcomes and goals.

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**TABLE 1: FIVE FASD STRATEGIC PILLARS AND FIVE GOALS**

<table>
<thead>
<tr>
<th>Five FASD Strategic Pillars</th>
<th>Five FASD Goals</th>
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<td><em>Level 2 prevention strategies:</em> Safe discussions with women about FASD</td>
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Responding to recommendation #4, the FASD Online Reporting System (ORS) was introduced in 2012 and then enhanced to improve evaluation, learning and adaptation. The FASD unit in Alberta Human Services manages ORS. Criteria used to select Key Performance Indicators (KPIs) align with the Government of Alberta’s Results-Based Budgeting (RBB) initiative. ORS measures the difference made in the lives of clients accessing services under the FASD strategic pillars of prevention (through PCAP), assessment and diagnosis, and supports for individuals affected by FASD and their caregivers. Data collected includes client demographics, assessment and diagnosis results, presenting issues, and changes in the status of presenting issues. ORS captures data and generates reports about clients served by the Alberta FASD Service Network Program. FASD service workers post data in ORS on a quarterly basis (reporting quarters) for each client receiving services funded by the Alberta FASD Service Network Program.

ORS captures data and generates reports about clients served by the Alberta FASD Service Network Program.

THE FASD LEARNING ORGANIZATION

Responding to recommendation #5, the FASD Learning Organization increases the capacity of the FASD-CMC and the networks to support stakeholder engagement, strategic planning, evaluation and research, and education and training. The FASD-CMC developed 12 working groups to engage a broad cross-section of stakeholders and FASD experts, building the capacity of Alberta’s FASD system to learn and adapt. The FASD-CMC, the Provincial Leadership Team, the networks, sub-committees, councils, and communities of practice collectively provide the infrastructure to support organizational learning, and facilitate identification and adoption of new evidence-based leading practices.
Responding to recommendation #6, the grant cycle was lengthened from an annual to a three-year funding cycle, providing networks with more stability and support for long-term planning. An increase in funding for the FASD Service Network Program (recommendation #7) was not received.

**Network Funding**

Figure 1 conceptualizes the component elements of Alberta’s system of FASD prevention and service delivery:

- **Dark grey boxes** describe FASD initiatives funded directly by government ministries or by the FASD-CMC through the Alberta FASD Service Network Program.
- **Light grey boxes** describe The FASD Learning Organization, which includes all FASD working groups that link to the networks and Ministries to facilitate learning and adaptation.
- **The blue and grey arrows** signify how funding and delivery of FASD services is influenced by knowledge mobilized through the FASD Learning Organization.
This evaluation fully operationalizes the new FASD outcome-based management system. Under each of the five strategic pillars, FASD initiatives are identified as provincial and ministry-specific FASD initiatives, or as Alberta FASD service network initiatives. Findings are listed under the outcome to which they contribute. Following is an overview of key findings under each outcome. For complete information see the Final Report (Abells & Preston, October 2014).

**THE YEAR 7 FASD SERVICE NETWORK EVALUATION**

The Year 7 FASD Service Network Evaluation (Wirzba & Cameron, 2014) was the largest of the evaluation projects. Conducted in 2013, the analysis was based on the Service Network Evaluation Framework developed in 2012. Network outcomes and indicators used in the evaluation were linked to outcomes and Key Performance Indicators (KPIs) in the FASD Strategic and Operational Plan for 2013/14. The analysis was based on data collected through ORS; through client, caregiver, and stakeholder surveys; and through a new reporting tool developed to track pregnancy outcomes and alcohol use for clients participating in PCAP.

Total number of clients served by the networks: According to ORS, 2,423 unique clients accessed services through the Alberta FASD service networks in 2012/13, an increase of 83 clients (3.5%) over the previous year (an increase of 157% from 2008).

**Waitlists for services:** Following an ORS database enhancement, information on the numbers of clients waiting for each type of service is now available. The first available waitlist information was for January to March 2014 (Quarter 4 of fiscal 2013/14). A total of 297 clients were waiting for network services across Alberta in this period: 197 were waiting for diagnostic assessment, 70 were waiting for FASD supports, and eight clients were waiting to access PCAP.
**Pillar #1: Awareness**

**FASD GOAL #1:** Albertans are aware 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 in Alberta among the general population

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

**Key Provincial and Ministry-Specific FASD Initiatives:** In September 2013, Alberta’s Institute of Health Economics (IHE) hosted the First International Conference on Prevention of FASD in Edmonton. An International Charter on the Prevention of FASD was endorsed and adopted by the 700 delegates from 35 countries who attended the conference. The Charter echoes the view of Alberta’s FASD 10-Year Strategic Plan: “Prevention of FASD is a shared responsibility of all stakeholders.”

**Alberta Gaming and Liquor Commission (AGLC)** introduced changes to regulations requiring Class A licensees (restaurants, bars, nightclubs, etc.) and Class D licensees (liquor stores) to post FASD prevention signage. AGLC provides a link to the latest FASD Awareness poster and information so licensees can access, print and post the copies they need to meet regulations.

**Key Alberta FASD Service Network Initiatives:** The survey of network stakeholders indicated that 90% agreed their network was proactive in increasing awareness of FASD, 80% said that networks were responsive to the needs of a diverse population, and 75% thought their network facilitated collaboration between members.
Client Outcome 1.2: Albertans are aware that FASD is caused by alcohol use during pregnancy, that babies born with prenatal exposure to alcohol may have irreversible brain damage, and that individuals with FASD need supports across their lifespan, as do their families and caregivers.

Key Alberta FASD Service Network Initiatives: 10 FASD networks conducted post-FASD awareness event evaluations (N=1169), and found that 89% of participant respondents were aware that FASD is caused by alcohol use during pregnancy, that there is no safe amount of alcohol to drink when pregnant or when planning to become pregnant, and that individuals with FASD need supports across their lifespan, as do their families and caregivers. 83% were aware that babies born with FASD have irreversible brain damage.

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.

Key Alberta FASD Service Network Initiatives: Post-FASD awareness event surveys (N=1169) found that 95% of respondents were aware that they had a responsibility to inform friends and family about the risks of using alcohol when pregnant or planning to become pregnant, and that they were willing to support friends and families to abstain from drinking alcohol if they are pregnant or planning to become pregnant.

These findings suggest that funding networks to conduct FASD awareness initiatives is a cost-effective, collaborative way to educate Albertans about FASD.
Pillar #2: Prevention

LEVEL 2 PREVENTION: SAFE DISCUSSIONS WITH WOMEN

FASD GOAL #2: Alcohol use during pregnancy is eliminated, preventing the profound personal and societal costs of FASD.

10-YEAR TARGET: The 2006 FASD 10-Year Strategic Plan did not differentiate between FASD awareness and prevention initiatives. There was no target set for Level 2 prevention.

System Outcome 2.1: Level 2 prevention strategy and initiatives are developed, delivered and evaluated using a collaborative and cooperative approach.

Key Alberta FASD Service Network Initiatives:
FASD Prevention Conversation: A Shared Responsibility. This new initiative addresses the need to engage women of childbearing age (18-45), their partners and families in conversations about the use of alcohol before and during pregnancy. It also engages the broader community in discussions around how to best support women to make healthy decisions regarding alcohol and pregnancy.

Evaluation of the training component for Prevention Conversation facilitators revealed that participants felt more comfortable, prepared and confident in their ability to answer questions posed by clients and to deliver core FASD prevention messages post-training.

System Outcome 2.2: Women who drink alcohol use safe and effective birth control methods and abstain from alcohol while pregnant or when planning to become pregnant. (Note: Evidence for this outcome is not collected under Level 2 prevention, but is measured for clients in Level 3 and Level 4 prevention through PCAP. See Outcome 2.9.)

Client Outcome 2.3: Participants know that FASD is caused by alcohol use during pregnancy, and have increased knowledge about the range of disabilities that can result from prenatal exposure to alcohol. (Note: See evidence collected under Strategic Pillar #1, Client Outcome 1.2.)

Client Outcome 2.4: Women participating in Level 2 prevention programs develop the intention to abstain from alcohol use during current or future pregnancies and are referred to supports and services that can help them.

The network post-event survey (N=1169) found that 94% of respondents indicated they intended to eliminate alcohol use during current or future pregnancies.
Pillar #2: Prevention

**FASD GOAL #2:** Alcohol use during pregnancy is eliminated, preventing 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.

**Parent-Child Assistance Program (PCAP)** is the evidence-based strategy for Level 3 prevention (recovery and support services for women with alcohol problems) and Level 4 prevention (postpartum supports for new mothers and early intervention for children who may have FASD). PCAP is a three-year, home visitation program implemented across Alberta for women who have a history of alcohol and drug use and are at-risk of giving birth to a child with FASD. Participants are pregnant or up to six months postpartum, self-report alcohol and/or drug use during their pregnancy, and are ineffectively engaged with community service providers.

**System Outcome 2.5:** PCAP programs are available across Alberta and meet community needs.

**Key Provincial and Ministry-specific FASD Initiatives:** There are 25 provincially funded PCAP programs operating in Alberta (as of December 2013), some of which are delivered by the FASD networks. Health Canada funds seven PCAP programs in First Nations communities (Enoch, Ermineskin, Saddle Lake, Samson Cree Nation, Blood Tribe, O’Chiese and Tsuu T’ina). Partnerships between First Nations, Alberta Health, Human Services, and the networks are being established to expand PCAP to six other First Nations communities.
Key Alberta FASD Service Network Initiatives:
All 12 networks provided clients with access to PCAP services. Three networks deliver their own PCAP services, and nine networks contracted 21 other organizations to deliver PCAP services in their regions. A total of 446 women were provided network-funded PCAP services, an increase of 22% over the previous year (a 575% increase over the number served in 2008/09). Networks often work in partnership with First Nations and Métis communities to provide PCAP services in their communities.

Challenges: While the number of women accessing PCAP services through network-funded programs increased every year since 2008/09, networks reported that it is difficult to find residential addiction treatment facilities for pregnant women, women who have children in their care, and women who are affected by FASD. As a solution, the Lakeland FASD Society has developed a new residential treatment program open exclusively to pregnant women. Networks in regions with high levels of oil and gas development experienced high staff turnover. Demand for PCAP exceeds availability of services, especially in remote and rural areas, where there is a lack of transportation and a scarcity of affordable, safe housing and childcare. There were eight clients on a waitlist for access to PCAP in the first quarter of 2014.

System Outcome 2.6: Data is collected using Penelope Integrated Case Management Software.

PCAP programs voluntarily collect data through the Penelope Integrated Case Management Software (Penelope). Advocated for use by the PCAP Council, it promotes fidelity to and comparability with the PCAP originally developed by the University of Washington. Staff members in 17 programs were trained to enter data into Penelope. An examination of the Penelope data (El Hassar, et al. June 2014) analyzed 112 variables on 211 clients over the course of their participation in the 3-year program, in six-month increments from 2011 to 2013. (For results see Outcome 2.9 on the next page.)
System Outcome 2.7: PCAP workers receive supervision, training and mentoring to support their health and wellbeing.

All network-funded PCAP workers take advantage of supports offered by the PCAP Council and acknowledge the positive impact of the training and networking opportunities offered by the Council. Siksika Health Services indicated that while their PCAP mentors are supposed to have caseloads of 15 clients to avoid burnout, all of their mentors had higher caseloads.

System Outcome 2.8: Adverse outcomes experienced by individuals with FASD are reduced. See Client Outcome 2.10 and Client Outcome 2.12 on next pages.

System Outcome 2.9: Women who drink alcohol use safe and effective birth control methods and abstain from alcohol while pregnant or when planning to become pregnant. Subsequent births of children with prenatal exposure to alcohol by women who have used substances while pregnant are reduced.

According to ORS (analyzed over five reporting quarters from June 2012 to September 2013), over 70% of pregnant women admitted to the PCAP program were drinking during their first quarter in the program, and 54% used drugs. Alcohol and drug consumption decreased to 18% for that group after they had been in the program for three reporting quarters. The percentage of women accessing health services and birth control increased from 10% to 36% over four quarters. The new PCAP-ORS reporting tool (N=285 women in PCAP) found the percentage of women effectively preventing new births affected by prenatal alcohol exposure (by abstaining from alcohol or using birth control) was 65% for women enrolled in the PCAP program for one year or less, 65% for women in their second year of the program, and 81% in their third year.

The Penelope analysis (over a 3-year period) found that abstinence remained a challenge for many women in PCAP. However, clients reported a significant increase in the use of birth control the longer they were in the program. While less than 30% of the clients reported using birth control during the first six months in PCAP, that
increased to 70% by the end of the 36-month period. This increase in use of birth control, especially among those not abstaining from alcohol, has led to a decrease in the number of children potentially born with FASD.

**Client Outcome 2.10: PCAP clients experience improvement in their wellbeing.**

ORS data (analyzed over four reporting quarters from July 2012 to June 2013) suggests women in PCAP experience improvement in their wellbeing. The most common presenting issues faced by women admitted to PCAP were: addictions (66%), housing (60%), mental health (45%), finances (44%) and custody of children (34%). Analysis of trends (Figure 2) over one year suggests an initial increase in the prevalence of most issues followed by a decrease.
FIGURE 2: CHANGES IN FREQUENCY OF PRESENTING ISSUES BY LENGTH OF TIME IN PCAP BASED ON ORS DATA (JULY 2012-JUNE 2013)
The Penelope data analysis confirmed some of these trends over a three-year period, demonstrating encouraging results in finance and employment. This analysis showed a decrease in welfare as the main source of income and an increase in client employment. Clients who reported using welfare as their main income source decreased from 60% during their first six-month period in PCAP to 20% by the last six-month period of the program, and employment increased from 5% to 30% for those same periods. The biggest change in client employment status was engagement in full time work. Less than 5% of clients were working full time during their first 18 months in the program. This increased to 30% by the end of 36 months.

**Client Outcome 2.11:** Children of PCAP clients experience improvement in their wellbeing.

Service networks are currently not required to report on children’s outcomes and the ORS database does not track information about the wellbeing of clients’ children.

**Client Outcome 2.12:** PCAP clients report satisfaction with the program and complete the full three-year term.

Responses to the PCAP Advocate-Client Relationship Survey suggest a high degree of satisfaction with the program. For example, 93% said their advocate “motivates me to protect my baby’s health” and “encourages me to succeed in daily life.” Also, 85% said their advocate “helps me learn how to solve my problems.”
Pillar #3: Assessment and Diagnosis

FASD GOAL #3: Albertans who may be affected by FASD have access to timely and affordable assessment resulting in recommendations for intervention based on their needs and strengths.

10-YEAR TARGET: 900 assessments annually.

System Outcome 3.1: Albertans have access to timely functional assessment.

Key Provincial and Ministry-specific FASD Initiatives: FASD Assessment and Diagnostic Clinics: Multidisciplinary teams trained in the current leading practice model provide FASD diagnosis and functional assessment to inform intervention. Referrals require a suspected history of prenatal alcohol exposure with areas of suspected dysfunction. Alberta’s FASD clinics all have different funding models with funding coming from different sources. In September 2013, there were 25 FASD assessment and diagnosis clinics in Alberta, and two under development.

The Consensus Statement on Legal Issues of FASD (Institute of Health Economics, 2013): The Statement calls on the legal system to provide individualized, context-specific diagnoses, and to formulate criteria to guide sentencing and provision of services to individuals affected by FASD.

Treatment Improvement Protocol (TIP) for FASD: Developed by Canada FASD Research Network (CanFASD), the TIP is focused on the Canadian approach to diagnosis, and consists of comprehensive information resources, screening and referral tools. The TIP was piloted in Alberta with four service provider agencies. A total of 121 caseworkers participated in the three-hour training program. Training evaluations revealed over 90% of respondents felt they could now recognize FASD as a concern, they were satisfied with the training, and they found the training materials to be culturally sensitive. Respondents indicated they wanted more information on the referral process and more information on specific strategies to improve support provided to clients suspected of FASD in their practice.

The TIP was piloted in Alberta with four service provider agencies.
Key Alberta FASD Service Network Initiatives:

FASD Assessment and Diagnosis: All networks fund access to FASD diagnostic assessment. Three networks managed their own FASD clinics. Nine networks contracted clinical services, with 16 clinics receiving partial or full funding from the networks in 2012/13. Lakeland FASD Network, Northwest Region and Mackenzie Network were contracted to provide diagnostic assessment services to the Métis Settlements FASD Network. South FASD Network completed a pilot project with the Kainai Nation on the Blood Reserve to assess women with FASD.

- **Number of clients in 2012/13 referred for diagnostic assessment:** 315 new clients were entered in ORS in 2012/13, and 270 clients completed the assessment process during that year.

- **Time required to complete the diagnostic assessment process:** Of 212 clients who completed the process over five ORS reporting periods (July 2012 and September 2013), 76% were completed within three months of admission, 15% within four to six months, and 9% within seven to 15 months.

- **Waitlist for network-funded assessment:** 197 clients were referred and waiting for assessment and diagnosis in the reporting quarter of January to March 2014.

Challenges: Current leading practice requires a confirmed history of prenatal alcohol exposure before an FASD diagnosis can be made. However, women and their families were often reluctant to disclose drinking patterns during pregnancy and adult clients were often unable to confirm the use of alcohol by their mothers during pregnancy. There are a limited number of clinicians trained in FASD diagnostic assessment available to staff multidisciplinary teams, and funding to increase access to these teams is limited. There is limited access to diagnostic assessment services for adults and for youth transitioning to adulthood, particularly in remote areas.
FASD assessment and diagnosis for offenders: The Alexis Restorative Justice Committee in partnership with the Northwest Central Network (NWCFAN) provided clinical services to adult offenders suspected of FASD to guide the Court in providing FASD-informed services. In the first two years (2011-2013), the partnership provided services to 11 clients. Central Alberta FASD Network received funding from Alberta Health Services to provide diagnostic assessment clinical services to six federal inmates in 2011/12. This project has been expanded to provide these clinical services to inmates suspected of FASD in provincial correctional institutions.

System Outcome 3.2: Albertans have access to affordable functional assessment.

Alberta Physician Billing Code for FASD: In May 2013, a fifth digit was added to the Alberta Physician billing code (760.71) to indicate prenatal alcohol exposure. Alberta Health Services reported 42 claims were made for 38 patients since the code was introduced (May 1, 2013 to April 30, 2014). Network-funded adult assessments were limited due to lack of funding. Clients may choose to pay for it themselves, however those who would benefit from a diagnosis do not usually have the resources to pay for a multidisciplinary team assessment.

System Outcome 3.3: Multidisciplinary teams in Alberta use a standardized inventory of assessment tools, updated annually, based on research and best practice.

All Alberta FASD clinics follow the FASD Canadian Guidelines for Diagnosis (Chudley et al., 2005) and the national common data set developed by the Canada FASD Research Network (CanFASD). All diagnostic clinics are required to follow the guidelines, as well as the principles of the Prevention & Diagnosis of Fetal Alcohol Syndrome (Alberta Medical Association, 1999).

System Outcome 3.4: Data is consistently collected based on a template of common recommendations that is linked to services received.

Common data collection templates were not used at the time of this evaluation. However, ORS collects data on the number and type of FASD diagnosis, number and type of presenting issues, and number and type of secondary diagnoses. Of 555 clients in ORS between April 2012 and September 2013 (6 ORS reporting quarters), 332 (60%) completed the diagnostic assessment process. Of these 332, 86% were known to have had prenatal alcohol exposure. Of these 332 clients, 47% were assigned a diagnosis of FASD, 24% were diagnosed with Alcohol Related Neuro-developmental Disorder (ARND), 5% with partial Fetal Alcohol Syndrome (pFAS), 1% with full Fetal Alcohol Syndrome (FAS), and 22% had no indicated diagnosis.

Prevalence of presenting issues: Based on the 332 clients for whom the assessment process was completed, the most common presenting issues were behaviour (64%), education (61%), social skills (58%), adaptive/life skills (53%), and mental health (47%), followed by health (28%), housing (27%), finance (24%), employment (23%), addictions (20%), legal (10%), custody of children (8%), and family violence (7%).
Prevalence of secondary diagnoses: For the same 332 clients, some were also diagnosed with ADHD (39%), anxiety (19%), depression (16%), post-traumatic stress disorder (5%), and attachment disorder (3%).

System Outcome 3.5: Clinics conduct longitudinal assessments, following Albertans with an FASD diagnosis at key transition points and periods of crisis across the lifespan.

The Year 7 Service Network Evaluation created the baseline for a future longitudinal study. A total of 2,887 diagnostic recommendations were recorded for the 332 clients who completed the assessment process, with an average of 8.7 recommendations per client: 96% of clients received recommendations for cognitive delays and deficits supports; 31% for performance delays and deficits supports; and 32% for learning disabilities supports. Between 50 and 60% of clients received recommendations for behaviour management supports, ranging from parenting, to addiction services, to housing supports.

System Outcome 3.6: Clinics cooperate and communicate to facilitate access to client information in compliance with privacy legislation.

Following the Year 5 Evaluation, the FASD-CMC funded training on privacy legislation for all networks, which was managed by the Northwest Central Network. Data was not collected regarding access to information and compliance with privacy legislation.

Client Outcome 3.7: 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.

Post-clinic surveys of network-funded assessments revealed that 95% of parents/caregivers and 85% of clients indicated they had a better understanding of how FASD affects them after their diagnostic assessment; 88% of parents/caregivers and 90% of clients indicated they had increased knowledge of the supports and services available to them in the community after their diagnostic assessment; and 81% of parents/caregivers said they received help accessing community services for their child/dependent during the diagnostic assessment.
Pillar #4: Supports for Individuals and Caregivers

**FASD GOAL #4:** Albertans with FASD and their caregivers receive coordinated access to the supports and services they need, when they need it.

**10-YEAR TARGET:** 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.

**System Outcome 4.1:** Every Albertan needing supports receives an Individualized Service Plan based on an integrated lifespan approach that guides the delivery of timely and coordinated services.

**Key Provincial and Ministry-specific FASD Initiatives:** Human Services provides a range of supports to vulnerable Albertans including employment supports. Human Services funded three FASD projects in 2012/13 to assist individuals with FASD. Fifteen participants in High Prairie received job coaching and work placement; Lakeland Centre for FASD supported 62 clients with career readiness programs, job placement, and transition planning for youth with FASD; an employment placement service in Calgary supported 41 clients with FASD with skills training, job placement and on-the-job supports.

**Supports for students with FASD:** Schools are recognizing positive outcomes by providing relationally-based supports (such as coaching) to junior and senior high school students. An evaluation of Alberta Education’s Wellness, Resiliency and Partnerships Project (WRaP) (Cormier, et al. 2013) found that most students participating in WRaP were not engaging in problem behaviour leading to out-of-school suspension (79% by Year 2), and the majority of students were receiving satisfactory grades and working towards high school completion. Since 2013, the TRY School Initiative (Transformational Relationships to reclaim Youth) has used success coaches to serve 98 students, 60% of which were in junior high and 40% in senior high school. Of these 98 students, 19 with confirmed or suspected FASD were “reclaimed” and re-engaged back into the school community.

Schools are recognizing positive outcomes by providing relationally-based supports.
Supports for offenders with FASD: Alberta Justice and Solicitor General funded programs in 2012/13 for offenders living with FASD, including an Aboriginal Female Mentoring Program for 100 women at the Lethbridge Correctional Centre and a Life Skills and Employability Program for 110 individuals at Peace River Correctional Centre. Alberta Human Services funded a Specialized FASD Mentoring Program delivered by Catholic Social Services in Edmonton assisting 40 justice-involved youth with transition programming.

Key Alberta FASD Service Network Initiatives:
Two networks (Mackenzie and Lakeland) directly provided all network-funded front-line FASD Services, including prevention (PCAP), assessment and diagnosis, and support services in their region. Eight networks contracted all network-funded front-line FASD Services to other community agencies, and two networks (Central and Northwest) contracted some and provided other services directly. A total of 37 organizations received funding from the networks to provide FASD support services in 2012/13.

Number of clients served: In 2012/13, a total of 1,526 clients received support services, including 488 parents/caregivers. Of the 1,038 clients suspected of having FASD, 571 (55%) had a confirmed FASD diagnosis. Seventy clients were referred and waiting for supports in January to March 2014. (Note: The number of network-funded clients reported is lower than the previous year (1,770 in 2011/12) due to the introduction and enhancement of ORS, which is a more rigorous reporting system with consistent definitions for data input.)

Individualized Service Plans: Networks are not required to collect this information. However, four networks reported conducting systematic case management and case consultations to coordinate services. South Alberta FASD Network reported that by implementing a formal case management system, their contracted support agency was able to increase the caseloads of their mentors without affecting the quality of service provided. This is an example of a success. Ideas are often shared with other networks to explore whether they’re a fit in other areas.
Challenges: Housing was identified as a major issue facing individuals diagnosed or suspected of FASD, particularly for Aboriginal persons and youth transitioning to adulthood. There is no funding to help individuals with FASD to maintain housing, and persons with FASD were often not deemed eligible for homelessness programs. Housing agencies were often not fully aware of the unique housing issues faced by persons with FASD. There are very few FASD-specific community living supports or transitional housing options. The Mackenzie FASD Network is planning for a large supportive housing project. Other challenges include:

- Clinics do not collect data linking recommendations to service access to help identify access issues.
- There are not enough resources to provide supports and services across the lifespan.
- There is concern about referring teenagers and adults to addiction/mental health residential treatment services due to staff lack of awareness of and training for FASD.

System Outcome 4.2: Caregivers receive respite care, peer and professional support.

Key Alberta FASD Service Network Initiatives: The survey of network-funded caregivers receiving support services (N=196) found 89% of caregivers said they received assistance accessing help in the community for their child/dependent while working with the agency, 91% said that their support network had increased since working with the agency, but only 47% said their access to respite care had increased since accessing support services. Networks reported that families have limited access to support services and difficulty finding trained respite care.

System Outcome 4.3: Data is collected based on intake Interviews and regular client progress interviews.

ORS data collection: Caseworkers who deliver network-funded FASD services are responsible for entering and updating each client’s service information on a quarterly basis. Data is entered based on case notes or other information. All networks met data collection requirements, which is a condition of their funding.

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

Key Alberta FASD Service Network Initiatives: Improvement in client wellbeing was measured according to changes in 13 different presenting issues. Cohorts of newly admitted clients were created for each quarter. Evaluators examined changes in presenting issues for clients receiving services over subsequent reporting periods. The analysis of wellbeing was based on 1,849 clients newly admitted to ORS between July 2012 and September 2013 (five ORS reporting quarters). See the Year 7 Evaluation Final Report for complete details on trends for each group of clients analyzed. Figure 3 is an example of trends in presenting issues for young adults (ages 18-24).
FIGURE 3: EXAMPLE OF TRENDS IN PRESENTING ISSUES OF YOUNG ADULTS (AGES 18-24)
Children and youth ages 0 to 17: Data from three separate groups of clients were analyzed: children (ages 0-12); youth (ages 13-17); and children in care (ages 0-17). The most common presenting issues in these three groups related to social skills, education, behaviour, and adaptive/life skills issues. The frequency of these issues remained high over all five reporting quarters. Children in care faced higher rates of housing and custody issues.

Young adults ages 18 to 24: Overall, young adults presented with the largest number of issues at admission compared to any of the other client groups. As illustrated in Figure 3, their most prevalent issues related to adaptive/life skills, finances, housing, employment, social skills, and mental health. Most presenting issues appeared to increase, followed by a decrease in some issues by the fourth quarter.

Women at risk of giving birth to a child with FASD: A large percentage of these women presented with adaptive/ life skills issues, followed in prevalence by addiction, finance, mental health, and employment issues. Most presenting issues appeared to increase, followed by a decrease in some issues by the fourth quarter.

Adults over 25 presented with fewer issues overall at admission. The highest frequencies of issues were adaptive/ life skills, mental health, and finance. For most adults, there appeared to be a decrease in the percentage of clients experiencing most issues over time, however, those experiencing behaviour and social skills issues rose sharply in the fourth and fifth quarters.

Parents/caregivers: Similar to adults over 25, parents/caregivers receiving services experienced similar sharp increases in behaviour and social skills issues in the fourth and fifth quarters.

In all cases, more data over a longer period of time is required to confirm these trends and to better understand why presenting issues increase and decrease over time.

Overall, young adults presented with the largest number of issues at admission compared to any of the other client groups.
Client-reported results from services received:
The network evaluation survey of parents/caregivers (N=183) found that 64% reported their child/dependent had improved relationships with family and friends, 58% reported their child/dependent was doing better in school, and 55% reported their child/dependent was taking better care of themselves.

The survey of clients 13 years and older who were capable of filling out the survey (N=384) found that 68% reported the agency helped them to take better care of themselves, 51% said the agency helped them with their relationships with family and friends, 39% reported the agency helped them deal with alcohol and/or drugs, and 29-34% said the agency helped them take care of their money, access a new source of income, find a job, and find a place to live. This survey also found that 86% said they knew where to look for the help they needed, and 76% said someone at the agency helped them to get new supports and services.

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

The network evaluation survey of parents/caregivers on behalf of their child/dependent (N=183) found that 96% of caregivers knew where to look for help for their child/dependent, 90% said they learned about things they needed to change or do differently, and 84% said the supports received helped them find other programs that could help them.

The survey of parents/caregivers receiving support services (N=196) found that 96% said the support they received from the agency helped them increase their understanding of FASD, 92% said the help they received made them feel more capable to parent or care for their child/dependent, 89% said their family life had improved, and 83% said their stress level decreased.

Client Outcome 4.6: Individuals and caregivers receiving supports report satisfaction with services received.

Overall, individuals and parent/caregivers were very satisfied with the services they received (91-93%), and the majority (78-86%) said they were involved in planning the services received. Over 98% said that agency staff treated them with dignity and respect.

Caregivers of individuals affected by FASD experience improvement in their wellbeing.
10-YEAR TARGETS WERE NOT IDENTIFIED FOR THIS PILLAR.

System Outcome 5.1: The planning and delivery of FASD programs and services is accomplished through a collaborative approach, with mechanisms in place to facilitate stakeholder engagement, providing opportunities for networking and information sharing.

Key Provincial and Ministry-specific FASD Initiatives: The role of expert-led FASD working groups (Councils, subcommittees and teams) is proving increasingly valuable, as they develop new tools to mobilize knowledge, such as inventories of supports and services and reviews of the latest Alberta-based research. Experts on FASD Councils also conducted research on best practices, developed a core FASD curriculum, and developed FASD education and training programs ranging from public awareness and prevention programs to improved FASD screening tools and advanced case management for children in care.

Key Alberta FASD Service Network Initiatives: Governance: Since the Year 5 Evaluation, nine of the 12 networks have become societies. Eleven of the 12 networks have strong leadership with diverse representation (culturally, geographically and by discipline). The Métis Settlements FASD Network was in a period of transition, and hoped to have their new leadership in place by early 2014. In six non-service delivery management areas, eight of the networks have fully addressed all recommendations from the Year 5 Evaluation, three are in the process of addressing their recommendations, and one (the Métis Settlements FASD Network) is in transition.

Human Resources: Networks reported relative stability in supervisory positions. However many networks, especially rural ones, had difficulty recruiting and retaining front-line staff. They reported their wages and benefits were not competitive, and housing options were limited and expensive, especially in small communities affected by oil and gas industry expansion. Smaller networks had difficulty ensuring clients received uninterrupted services due to staff turnover and vacant positions. Networks that provide services directly have developed staff retention strategies.
**Collaboration:** All networks contracting FASD service providers had regular meetings with their stakeholders. Networks provided opportunities for service providers and community partners to contribute to strategic planning. Networks actively participated in local interest groups (prostitution, pregnancy, parenting youth, youth justice, immigrant, Safe Communities, crime reduction, addiction, affordable housing, homelessness, education, complex needs, and early childhood development). Networks actively sought to engage and work in partnership with Child and Family Services (CFS) in their region, and with Aboriginal organizations, including Tribal Councils, Friendship Centres, and Aboriginal Health Centres.

A survey of network stakeholders (N=343) revealed that 80% of respondents believed their network was responsive to the needs of a diverse population; 78% believed that network leaders were respectful of all members’ culture and beliefs (21% said they did not know). As well, 73% thought their network supported collaborative initiatives with Aboriginal communities (18% did not know). The survey also indicated that 88% of stakeholders, 87% of professionals and 100% of parents/caregivers believed their network facilitated the sharing of FASD information with partners and the public.

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

Many education and training opportunities were offered in 2012/13:

- Leading from Within provided advanced training in complex case management for children in care for 22 staff from nine CFS regions;
- 121 caseworkers were trained in the new FASD TIP;
- 23 staff from the Youth Empowerment and Support Services (YESS) received front-line FASD training;
- Over 340 new youth workers, sheriffs and correctional peace officer recruits were provided FASD awareness and behaviour management training during their respective induction programs;
- 50 new probation officers received FASD awareness training during their induction program;
- Seven webcasts of the FASD Learning Series reached 717 participants; 109 FASD tool kits were distributed; and
- The annual FASD conference attracted 610 participants.

The survey of network stakeholders (N=343) revealed 83% believed the training and education resources offered through their network was based on research and leading practices. Of those who completed post-training surveys, 95% of professionals and 91% of parents/caregivers were satisfied with the training received.

Smaller networks had difficulty ensuring clients received uninterrupted services due to staff turnover and vacant positions.
**Challenges:** Northern networks reported that training was expensive because they had to send newly recruited staff to larger urban centres. Networks also identified there was limited information about best practices in FASD support strategies for front-line workers.

**System Outcome 5.3:** Research informs strategic planning, FASD prevention activities and FASD-related programs and services.

Networks reported they were involved in research projects that had an impact on their practice, including: standardization of diagnostic assessment clinic forms, research on mobile FASD diagnostic assessment clinics that may increase accessibility of services, and research on supports for adults with FASD. The survey of network stakeholders (N=343) revealed 62% of all stakeholders and 89% of Leadership Team members believed that research findings were used to guide the work of their network.

**System Outcome 5.4:** Evaluation informs strategic planning, FASD prevention activities and FASD-related programs and services.

The network stakeholder survey (N=343) revealed 61% of all stakeholders and 89% of Leadership Team members agreed evaluation findings were used to guide the work of the network, and 60% of all stakeholders and 82% of Leadership Team members agreed that community needs assessments were used to guide the work of the networks.

**System Outcome 5.5:** The cost of FASD to Albertans is reduced.

The Institute of Health Economics conducted an economic evaluation of the PCAP program to estimate cost savings attained by preventing FASD compared to the cost of delivering the program (Nguyen, et al., 2013). This study of 366 PCAP clients from 2008 to 2011 found that approximately 31 cases of FASD were prevented by PCAP services, at an incremental $97 thousand per case. This resulted in an estimated total cost saving of $22 million over the lifespan of these 31 prevented FASD cases. These findings demonstrate that PCAP is cost-effective and produces a significant net monetary benefit for Alberta.
OVERARCHING RECOMMENDATIONS

1. Increase funding to the Alberta FASD service networks: Most of the 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. Align and streamline FASD outcomes, indicators and key performance indicators (KPIs) and continue to enhance the Online Reporting System (ORS): Align all network-funded program evaluations with the FASD-CMC’s outcome-based management system. Expand ORS to capture contributions to outcomes made by all provincial and ministry-specific FASD initiatives, making data collection and reporting a requirement of funding. Continue to enhance the ORS data collection system to track improvement in client wellbeing for all clients receiving FASD-related services in Alberta.

RECOMMENDATIONS UNDER EACH STRATEGIC PILLAR

Strategic Pillar #1 - Awareness (Level 1 prevention):

3. Fund networks to deliver Level 1 FASD awareness initiatives, as the findings suggest this is a cost-effective, collaborative way to educate Albertans about FASD.

4. Differentiate between Level 1 and Level 2 prevention initiatives, evaluating initiatives under each level separately.

Strategic Pillar #2 - Prevention (Level 2 prevention):

5. Implement and evaluate The Prevention Conversation: A Shared Responsibility.
Strategic Pillar #2 - Prevention (Level 3 and 4 prevention - PCAP):

6. Expand the Parent-Child Assistance Program (PCAP), particularly into First Nations communities, through partnerships with Health, Human Services, and the 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 prevents future pregnancies impacted by alcohol consumption and improves client wellbeing.

7. Require all PCAP programs to participate in ORS and Penelope data collection, as these databases are making significant contributions to our understanding of FASD and the effectiveness of associated supports and services.

Strategic Pillar #3 - Assessment and Diagnosis:

8. Require all Alberta assessment and diagnostic clinics to report results to ORS, as ORS currently captures only 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, as the longest FASD waitlists are currently for diagnostic assessment.

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, especially for youth transitioning to adulthood, to ensure seamless delivery of a continuum of supports and services.

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 client file closure in the ORS database** to determine the percentage of clients for whom outcomes were met, differentiated from files closed for other reasons.

14. **Increase access to relationally-based supports (mentors and coaches),** especially for youth transitioning to adulthood, as the evidence indicates these supports improve outcomes and create the experience of an uninterrupted continuum of supports and services.

**Strategic Pillar #5 – Organizational Learning:**

15. **Provide administrative support to the FASD Learning Organization** 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.

PCAP programs are available across Alberta and meet community needs.
APPENDIX A: KEY RESEARCH AND EVALUATION REPORTS


Chudley et al. (2005). *Fetal Alcohol Spectrum Disorder Canadian Guidelines for Diagnosis.* Ottawa: CanFASD.


