FETAL ALCOHOL SPECTRUM DISORDER (FASD) ACROSS THE LIFESPAN

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

Year 10 Evaluation

OVERVIEW OF KEY FINDINGS AND RECOMMENDATIONS

Alberta Government

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ALBERTA'S FASD 10-YEAR STRATEGIC PLAN 2007-2017

Alberta's FASD 10-Year Strategic Plan (the Strategy) provided core strategic direction for the government's response to Fetal Alcohol Spectrum Disorder (FASD) from 2007 to 2017 (Government of Alberta, 2008).

The vision was to develop a comprehensive and coordinated response to FASD across the lifespan with a continuum of services, including awareness, prevention, assessment and diagnosis, and support services, that is respectful of individual, family and community diversity. These services were to be delivered through a collaborative approach supported by stakeholder engagement, strategic planning, education and training and research and evaluation. Formal evaluation of results and impacts were required in years 5, 7 and 10 of the Strategy, with continuous improvement of services supported by the research.

> This overview highlights key achievements, lessons learned, innovations and trends.

THE YEAR 10 EVALUATION

The Year 10 Evaluation is a summative evaluation of Alberta's FASD 10-Year Strategic Plan 2007-2017. It builds on the formative evaluations undertaken in Years 5 and 7 of the Strategy's implementation. The Year 10 Evaluation assessed the extent to which the goals of the Strategy were met using a balance of quantitative and qualitative research and analysis (Abells & Wirzba, 2017).

This overview highlights key achievements, lessons learned, innovations and trends. The 2016-17 FASD Strategic and Operational Plan identified outcomes and indicators that form the basis of this evaluation. Since 2013-14, the outcome-based management planning tool used by the FASD Cross-Ministry Committee (FASD-CMC) has guided the implementation of Alberta's FASD 10-Year Strategic Plan (Government of Alberta, 2016a). The following questions guided the implementation of the Year 10 Evaluation:

- **Reflection:** How has Alberta's response to FASD evolved over the last 10 years? What lessons have been learned that can inform Alberta's response to FASD going forward?
- **Results:** To what extent have stated outcomes and goals been achieved?
- **Effectiveness and efficiency:** To what extent did the model and processes currently in place support the implementation of Alberta's FASD 10-Year Strategic Plan?

Key sources of information included:

- Annual reports from Alberta's FASD Service Networks
- Parent-Child Assistance Programs (PCAP)
- Projects funded by the FASD-CMC from 2014 to 2017
- Data collected through the Government of Alberta's FASD Online Reporting System (ORS)
- Data collected through Penelope Case Management System (Penelope) used to monitor outcomes for PCAP clients
- Findings from evaluation projects funded as part of the Year 10 Evaluation; and other relevant research and evaluation projects

PolicyWise for Children & Families was responsible for overseeing the Year 10 Evaluation, selecting and contracting with researchers and evaluators.

1 During the Year 10 Evaluation, the Government of Alberta was in the process of building a flexible reporting environment for its FASD Online Reporting System (ORS). Any data elements that had not completed the validation process were not available for inclusion in this report.

ABOUT FASD IN ALBERTA

Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term that describes the range of effects that can occur in an individual who was prenatally exposed to alcohol. These effects can include lifelong mental, physical and behavioural difficulties as well as learning disabilities.

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 with 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, 2017b).

ALCOHOL CONSUMPTION IN ALBERTA

Scientific evidence has conclusively shown that alcohol consumption during pregnancy can cause fetal harm. There is insufficient scientific evidence to define any threshold for safe low-level drinking during pregnancy or when planning to become pregnant. The safest choice for a woman[2] who is pregnant or planning to become pregnant is not to drink alcohol (CanFASD, 2017b).

The latest results from the 2015 Canadian Tobacco Alcohol and Drugs Survey (CTADS) (Health Canada, 2017) found that 77% of Canadians reported consuming an alcoholic beverage in the past year, a prevalence unchanged from 2013. 73% of Canadian women reported past-year alcohol use. The rate of alcohol use among young adults aged 20-24 (83%) was higher than among youth aged 15-19 (59%) and adults aged 25 years and older (78%). 20% of those who reported drinking in the last year (aged 15 years and older) exceeded the Low-Risk Drinking Guideline 1 (risk of long-term harms); 15% reported exceeding Guideline 2 (risk of short-term harms)[3].

CTADS results for Alberta (analyzed by age, but not by sex) indicated that prevalence of past-year alcohol use in Alberta was 77%. 17% of those who reported drinking exceeded the Low-Risk Drinking Guidelines 1 and 14% exceeded the Low-Risk Drinking Guidelines 2 for acute effects (Health Canada, 2017).

2 People with diverse gender identities can become pregnant and therefore experience the birth of a child with FASD. The research reviewed as part of the Year 10 Evaluation of Alberta's FASD 10-Year Strategic Plan did not examine the experiences of gender diverse individuals who were consuming alcohol when pregnant or planning to become pregnant.

3 Guideline 1 (to reduce the risk of long-term alcohol related harms) for women states: *no more than 10 standard drinks per week, with no more than 2 standard drinks per day*; Guideline 2 (to reduce the risk of short-term alcohol-related harms) for women state: *drinking no more than 3 drinks in one day* (Canadian Centre on Substance Use and Addiction, 2017).

ALCOHOL CONSUMPTION AND PREGNANCY IN ALBERTA

Half of all pregnancies in Canada are unplanned (Public Health Agency of Canada, January 2016).

A University of Calgary longitudinal pregnancy study of 2,246 women (McDonald et al., 2014) found that 49% of the women reported drinking some alcohol during pregnancy, including before they realized they were pregnant, with average drinking levels prior to pregnancy recognition at high (11%), moderate (64%), and low (25%) levels. Three percent (3%) of the women stopped consuming alcohol at pregnancy recognition, with 46% of the women continuing to drink, with average drinking levels mostly at low (93%) and moderate (6%) levels. Approximately 13% of the women reported at least one binge drinking episode prior to recognizing they were pregnant; none reported an episode after pregnancy recognition. The characteristics of this cohort (86.8% reporting as white Caucasian, with 75.8% reporting a household income of $80,000 or more and over 90% reporting some university or college education) indicate alcohol consumption during pregnancy is a population-wide concern.

INCIDENCE AND PREVALENCE OF FASD IN ALBERTA

Incidence: A study by Alberta's Institute of Health Economics (Thanh et al., 2014) found an incidence rate (percent of new cases per 1,000 births) of between 1.4 and 4.4% depending on the year of study (between 739 and 1,884 babies born annually with FASD in Alberta).[4] The authors of this study suggested that the incidence of FASD found in their study may be underestimated due to the relatively short period of follow-up (10 years). They concluded that if follow-up had been longer, incidence of FASD in Alberta would be at least 4.4% per 1000 births. This study also found that 60% of people diagnosed with FASD were younger than 20 years of age (9% were 20-29 years, 4% were 30-39 years, 4% were 40-49 years, and 5% were 50 years and older). This suggests that incidence may be higher than current estimates and/or that life expectancy of people with FASD may be lower. This study also found that more males than females are diagnosed with FASD, a finding also reported in a profile of young Albertans with FASD, which found a higher proportion of males diagnosed with FASD (58%) than females (42%) (PolicyWise for Children & Families, 2017).

Prevalence: Thanh et al. (2014) estimated a prevalence rate of 1.2% of the Alberta population. Based on 2016 census data, this prevalence rate suggests that 48,800 people with FASD were living in Alberta in 2016 (Statistics Canada, 2017). The Profile of Young Albertans with Fetal Alcohol Spectrum Disorder (PolicyWise for Children & Families, 2017) found that young people with FASD are disproportionately overrepresented in the lowest socio-economic neighbourhoods and underrepresented in the highest socio-economic neighbourhoods.

4 CanFASD cites this source in its Common FASD Messaging document: **https://canfasd.ca/wp-content/uploads/sites/35/2017/09/CanFASD-Common-Messages.pdf**

COST OF FASD IN ALBERTA

A 2015 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. A study by Jonsson (2017) translated the national cost identified in this study to Alberta by calculating the national cost per capita and applying this to the population of Alberta in 2015. This translation to the Alberta context found the total annual cost of FASD in Alberta to be $1.14 billion, with $459 million spent on criminal justice (including police, courts, corrections, and cost of victims), $235 million 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 Fetal Alcohol Spectrum Disorder (PolicyWise for Children & Families, 2017) examined 3,025 young Albertans from birth to 25 years diagnosed with FASD over a six-year study period (2005-2011). The profile found that 78% of those diagnosed, with FASD were high government service users, compared to 11% of those without an FASD diagnosis (PolicyWise for Children & Families, 2017). At some point during the study period, 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. At some point during the study period, 37% of young Albertans diagnosed with FASD (ages 0-17) received Family Support for Children with Disabilities (FSCD) services, 17-30% (ages 18-25) received Persons with Developmental Disabilities (PDD) services and 42% received Assured Income for the Severely Handicapped (AISH) services.

> A 2015 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.

KEY FINDINGS:

REFLECTIONS ON ACHIEVEMENTS AND CHALLENGES

To examine how the implementation of Alberta's FASD 10-Year Strategic Plan 2007-2017 impacted the evolution of Alberta's response to FASD, 30 key informants were interviewed exploring their perspectives on key innovations, accomplishments and challenges (Wirzba & Abells, 2017a). Five overarching achievements and innovations were identified.

THE FASD 10-YEAR STRATEGY

Sustained government commitment and predictable funding over the 10-year life of the Strategy was identified by key informants as a major accomplishment. The Strategy provided the infrastructure and leadership for a systematic, unified, inclusive and flexible response to FASD across the province resulting in increased recognition and awareness of FASD as a unique disability requiring action among government officials, professionals and the public. Due to the Strategy and other high profile undertakings, Alberta has been recognized as a leader in FASD in Canada and internationally: Alberta was a founding province of the Canada Northwest FASD Partnership; Alberta's Institute of Health Economics hosted two high profile international conferences that led to Consensus Statements on FASD (Institute of Health Economics, 2009) and Legal Issues of FASD (Institute of Health Economics, 2013); and Alberta's FASD experts made significant contributions to Canada's Low-Risk Drinking Guidelines (Canadian Centre on Substance Use and Addiction, 2017) and to the FASD Canadian Guidelines for Diagnosis (Cook et al., 2016).

Challenges: Inadequate funding was identified by key informants as the primary challenge. While the number of Albertans served by the funding has increased annually, funding has not increased proportionally. Increased awareness about FASD and access to assessment and diagnosis services have resulted in a greater demand for FASD prevention and support services and longer waitlists. Notwithstanding the successes of the Strategy, informants commented that women who consume alcohol during pregnancy are often stigmatized and those with FASD often face discrimination. Finding the right balance between helping people with FASD, their families and caregivers, and stigmatizing them is a perpetual challenge.

FASD-CMC GOVERNANCE STRUCTURE

The cross-ministry leadership of the FASD-CMC was identified by key informants as a key innovation of the Strategy. The FASD-CMC currently represents eight Alberta Government ministries and two provincial agencies, as well as federal government departments and agencies and external FASD experts. FASD-CMC representatives were recognized as champions who engage politicians, policy-makers, researchers, evaluators, clinicians, program developers and local community members to advance Alberta's FASD response. Based on the Year 5 Evaluation recommendations (Alberta Centre for Child, Family & Community Research, 2013), the FASD-CMC adopted an outcome-based management planning approach, which included clarifying outcomes, developing data collection models and preparing annual strategic and operational plans that identify priorities and expected outputs needed to achieve outcomes.

Challenges: Key informants suggested that changing government priorities have made it difficult to keep FASD a priority. With each ministry reorganization, new staff filled key positions on the FASD-CMC, and the commitment of some ministries has appeared to wane. The commitment of FASD-CMC partnering ministries must be sustained for the FASD initiative to continue. Key informants also suggested that there is still inadequate support for FASD within key health sectors, including addiction and mental health and primary care.

> The commitment of FASD-CMC partnering ministries must be sustained for the FASD initiative to continue.

THE FASD LEARNING ORGANIZATION MODEL

Based on recommendations from the Year 5 Evaluation (Alberta Centre for Child, Family & Community Research, 2013), the FASD-CMC defined sustainability as the ability to learn and adapt to changing circumstances in order to meet their goals. They then spearheaded the development of the FASD Advisory Councils and adopted a Learning Organization model. Many informants commented on the importance of these developments. The Advisory Councils offer a venue to improve communications, share information, set priorities, identify gaps, and support collaboration among the FASD-CMC, Alberta FASD Service Networks and FASD experts. The FASD Learning Organization has become central to knowledge management and mobilization and for the identification and adoption of evidence-based practices. The Learning Organization enables the FASD-CMC

to be more deliberate and purposeful in their efforts to inform changes in policies and has made stakeholder engagement a priority. This creates opportunities for individuals with FASD, their family members and caregivers, frontline workers, researchers and policy-makers to inform FASD-CMC decisions.

Challenges: Advisory Councils, which are central to the FASD Learning organization and its ability to mobilize knowledge and identify evidence-based leading practices, require administrative support. Members of the Councils are volunteers who are already deeply engaged in the FASD sector. High turnover in leadership and membership reflects the strain of the added responsibilities of being a Council member.

THE FASD SERVICE NETWORK MODEL

A cornerstone of the Strategy is the Alberta FASD Service Network Program and its 12 regional Networks. Under the direction of the FASD-CMC, the Networks have successfully developed, implemented and sustained an FASD service delivery model designed to meet the needs of their regions. Networks have effectively expanded and adapted services to meet community needs through regional collaboration and cooperation, and have improved access to services in rural and Indigenous communities. Key informants noted that the Networks have been working to continually improve their governance and operational structures and they play a vital role in knowledge mobilization at the regional and local levels. Networks have also played a key role in training non-FASD service providers to adopt FASD-informed practices and strategies in their organizations.

Challenges: While Networks have expanded their services and introduced new ones, many informants expressed concern that the Networks were rapidly reaching the point where they do not have sufficient resources to meet the demand for services. Core funding, while stable, has not increased, leaving Networks chronically underfunded. Scaling up their organizations to meet demand and implement emerging and promising practices remains a central challenge.

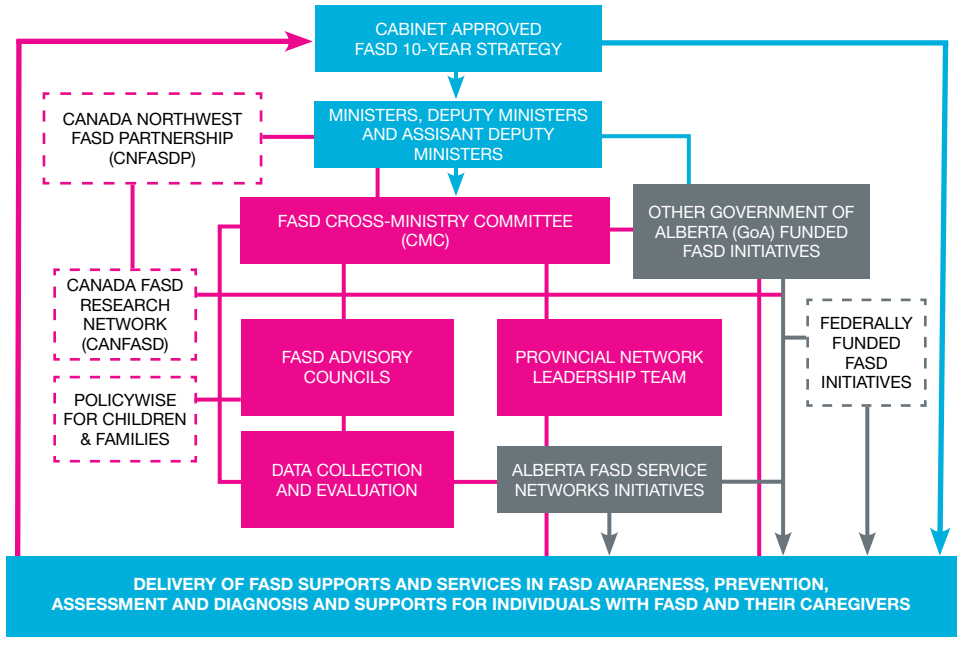
> The Networks have successfully developed, implemented and sustained an FASD service delivery model designed to meet the needs of their regions.

Figure 1 describes the FASD model developed through the implementation of **Alberta's FASD 10-Year Strategic Plan** from 2007 to 2017.

Dark grey boxes identify FASD service delivery. Regional leadership, as well as collaboration and cooperation with local service providers, is provided by the **FASD Service Networks**. Combined with other provincially and federally funded FASD-initiatives, Alberta's FASD model is effectively expanding and adapting services in urban, rural and Indigenous communities with practices that are both FASD-informed and provide a **culturally-informed response**.

Pink boxes identify the **FASD Learning Organization**. Provincial leadership is provided by the Government of Alberta (top blue boxes) and the **FASD Cross-Ministry Committee**.

FIGURE 1: ALBERTA'S FASD MODEL

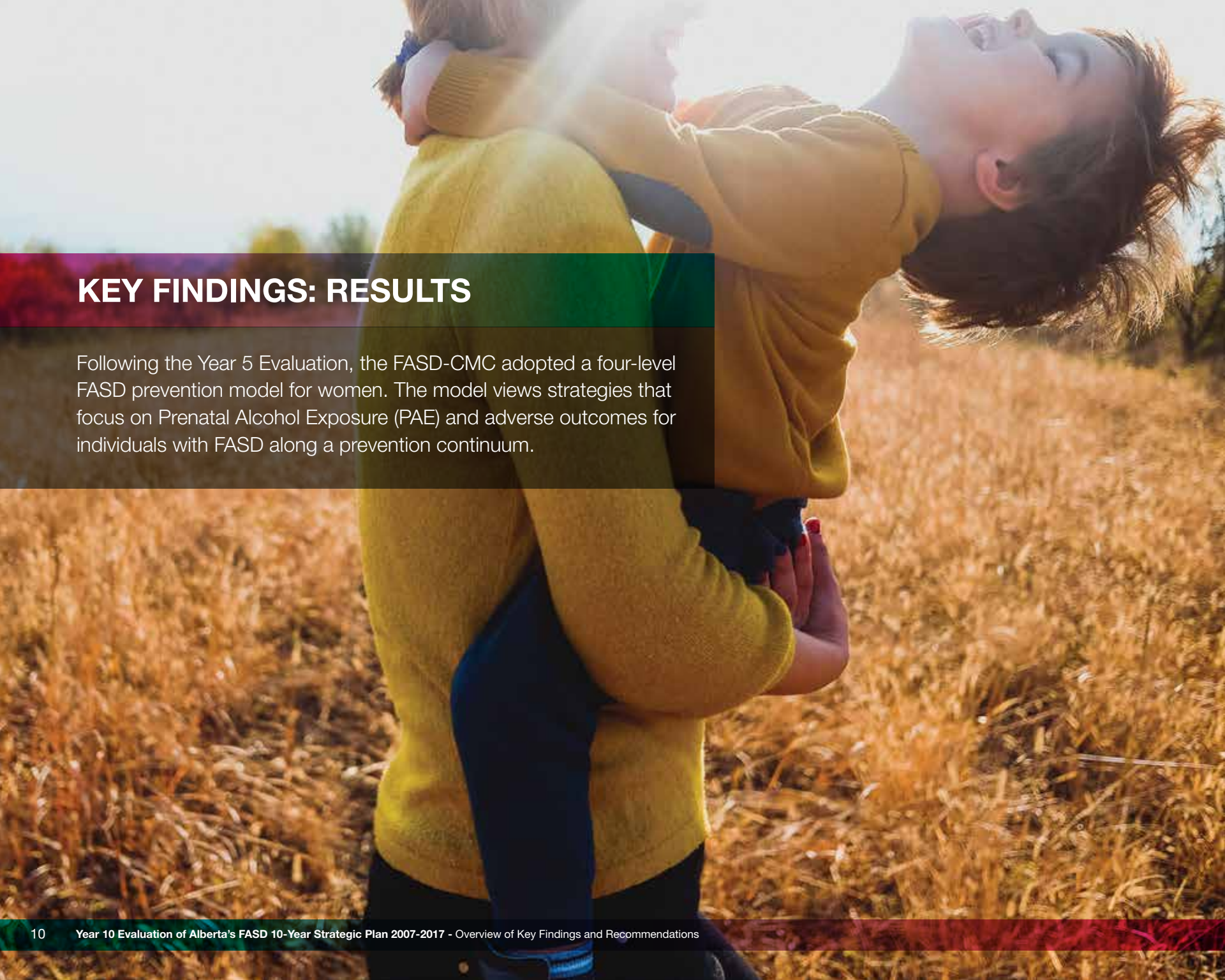


**Color categories are not relative to investment.*

A CULTURALLY-INFORMED RESPONSE TO FASD

The 2016-17 Strategic and Operational Plan (Government of Alberta, 2016a) added a section identifying key direction-setting documents that are to inform both policy and practice of FASD-CMC funded activities. These included the *Calls to Action* from the Truth and Reconciliation Commission's Final Report (2015), the *United Nations Declaration on the Rights of Indigenous Peoples,* and *Gender Based Analysis Plus* (GBA+), an analytical tool used to examine intersecting identity factors of gender, culture, disability, age, education, language, geography and income. Informants identified cultural awareness training combined with efforts to build relationships with Indigenous Peoples by working closely with Indigenous families and communities as a leading practice.

Challenges: Addressing intergenerational trauma, poverty and other disparities, including the stigma associated with FASD, will take time, resources, and commitment.



KEY FINDINGS: RESULTS

Following the Year 5 Evaluation, the FASD-CMC adopted a four-level FASD prevention model for women. The model views strategies that focus on Prenatal Alcohol Exposure (PAE) and adverse outcomes for individuals with FASD along a prevention continuum.

PILLAR #1: Public Awareness and Understanding (LEVEL 1 PREVENTION)

GOAL #1: Albertans are aware and understand that alcohol use during pregnancy can lead to FASD, FASD can be prevented and FASD prevention is a shared responsibility.

10-YEAR TARGET: 95% awareness and understanding of FASD among the general Alberta population

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

Achievements: The Alberta Gaming and Liquor Commission (AGLC) has been involved with Alberta's response to FASD since the Strategy was implemented in 2008 and has taken a leadership role in promoting FASD awareness. AGLC consults with FASD-CMC members and Network representatives when developing its FASD awareness resources, and partners with them to disseminate the resources. One of its priorities is to promote Canada's Low-Risk Drinking Guidelines. Evaluation of AGLC's 2015 social media campaign, using Facebook, website, video and online ads (from September 7 to 16), found that 94,000 people who saw the Facebook post and video, either liked, shared, clicked or commented on it; nearly 350,000 people viewed the video to the end (an overall completion rate of 79%); and online ads had over 970,000 impressions, with 11,841 clicks that led viewers to the website (Alberta Gaming and Liquor Commission, 2015).

Following the Year 5 Evaluation, the FASD-CMC acknowledged the key role Networks play in promoting awareness of FASD in their communities, and revised their Network Operating Grant Policies so that Networks can use a portion of their funding to support these activities. Annual year-end reports from the Networks demonstrate their active engagement in awareness campaigns in their regions.

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.

Awareness: Two Alberta-wide population surveys were conducted: the first in 2011 during the Year 5 Evaluation (N=1,205) and then again in 2017 for the Year 10 Evaluation (N=1,124). Responses to two questions indicated an increased awareness of FASD among Albertans:

- *Have you heard of FASD?* 89.7% of Year 10 respondents were aware of FASD compared to 85.7% in Year 5, a significant increase, although below the 95% target.

Have you heard of FASD? 89.7% of Year 10 respondents were aware of FASD compared to 85.7% in Year 5.

- *Do you know anyone who you think might have FASD?* 47.5% of Year 10 respondents say they may know someone with FASD compared with 35.2% in Year 5. This suggests that as awareness of FASD increases, respondents believe they know people with FASD.

There was an increase in awareness of FASD among respondents who were Canadian-born, female, Caucasian or less than 45 years old. Of the 10.3% who had not heard about FASD, these respondents were more likely to be 45 years old or older, male, non-Caucasian, childless and born outside of Canada (Jagodzinski, 2017).

Understanding: In the 2014-15 Strategic and Operational Plan, the goal for public awareness was expanded to include understanding. In the Year 10 survey, four statements tested key facts about FASD. 99.2% of all respondents answered 'True' to the statement '*Alcohol use during pregnancy can lead to life-long disabilities in a child*.' Even amongst those not aware of FASD, 100% of these respondents answered this statement correctly. However, only 72.3% of all respondents answered all four statements correctly,[5] indicating that 27.7% did not have full knowledge of key facts about FASD. Analyzed by region (Edmonton, Calgary and rest of Alberta), those living outside of Edmonton and Calgary had the greatest understanding of FASD, with 79.3% responding correctly to all four statements, while 70.3% in Edmonton and 67.3% in Calgary answered all four questions correctly.

Two questions were based on Canada's Low-Risk Alcohol Drinking Guidelines, which recommends: *If you are pregnant, planning to become pregnant, or before breastfeeding, the safest choice is to drink no alcohol at all.* While most respondents correctly identified the statement about not drinking alcohol during pregnancy, even among respondents who were aware of FASD, 32.8% did not correctly answer that women should avoid alcohol when planning to become pregnant.

5 The other three statements were: *There is a safe amount of alcohol to consume while pregnant* (Correct answer: False); *The last three months of a pregnancy is the safest time to consume alcohol while pregnant* (Correct answer: False); *Most of the effects of alcohol use during pregnancy usually disappear as the child grows older* (Correct answer: False).

Again, more respondents living in the rest of Alberta (69.5%) responded correctly to both statements, while 58.8% in Edmonton and 65.5% in Calgary responded correctly. This difference between regions becomes even larger when younger versus older respondents are compared: 78.2% of respondents less than 45 years old in the rest of Alberta answered both questions correctly, compared to 56.3% in Edmonton and 66.1% in Calgary (Jagodzinski, 2017).

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.

Shared responsibility: 93.2% of all respondents indicated that women should be supported by others not to drink while pregnant. When asked who is responsible for providing this support, most indicated it was the woman herself (96.4%), followed by the woman's spouse (91.4%), family (91%) and friends (87.7%). Only 72% thought the community has a responsibility and 61% thought the government has a responsibility.

Challenges: Despite increased awareness of FASD, some key informants suggested that public awareness campaigns alone are not sufficient to change behaviour and reduce the incidence of FASD (as demonstrated by the University of Calgary longitudinal study (McDonald et al., 2014) where only 3% of study participants stopped consuming alcohol at pregnancy recognition). Permissive messages are still given by some professionals about alcohol use and pregnancy, and several respondents commented that more focus is needed on alcohol consumption among youth and affluent families.

> 93.2% of all respondents indicated that women should be supported by others not to drink while pregnant.

PILLAR #2: Prevention (LEVEL 2 PREVENTION)

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

Alberta's 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 (Safe Discussions) strategy and initiatives are developed, delivered and evaluated using a collaborative and cooperative approach.

The FASD Prevention Conversation - A Shared Responsibility: Following the Year 5 Evaluation, the FASD-CMC identified the need to develop and implement a Level 2 Prevention program in Alberta. The Prevention Conversation is an innovative approach that focuses on the unique role healthcare professionals and social service providers can play in engaging women of childbearing age in supportive and non-judgemental conversations about alcohol use and pregnancy. The FASD Awareness, Prevention & Communications Council worked with stakeholders in Alberta and representatives from the Public Health Agency of Canada and the Centre of Excellence for Women's Health in British Columbia to guide the development of the project and materials, based on a literature review. The design of the program is consistent with the Public Health Agency of Canada's four-level FASD Prevention model (Poole, 2008) and with FASD prevention messaging developed by Canada FASD Research Network (CanFASD) (Pei, Atkinson et al., 2015). Eleven Prevention Conversation facilitators were hired by the FASD Service Networks to train and prepare service providers in Prevention Level 2 (Safe Discussions).[6] The facilitators also engage with and train the community on FASD to have safe discussions about alcohol and pregnancy. Additional Level 2 Prevention resources for youth and an online training curriculum are currently in development.

Prevention Conversation year-end reports (Wirzba, 2016a; Wirzba, 2017b) indicated that from July 2015 to March 2017, facilitators participated in a broad range of training and community events that included Network-funded partners meetings and meetings with professional networks. In total, 14,282 participants attended 755 Prevention Conversation training events. In 2015-16, 43% of the training and community events were held in urban areas and 57% were held in rural and remote areas. In 2016-17, 58% of the training and community events were held in urban areas and 42% were in rural and remote areas. Since January 2015, 7,799 professionals and 1,579 post-secondary students in health, education, addiction and mental health, child protection and children's services and justice (police courts and corrections) received Prevention Level 2 (Safe Discussions) training.

6 The Métis Settlements FASD Network contracts facilitators from two other Networks to implement the Prevention Conversation in the eight Métis Settlements.

> 85% of respondents indicated they felt confident in their ability to effectively discuss alcohol use in pregnancy with women of childbearing age and their partners

Year-end reports indicated that this project has had broad community impact. The Prevention Conversation has contributed to increasing community awareness about FASD, raised the profile of the FASD Service Networks and strengthened community partnerships (Wirzba, 2016a; Wirzba, 2017a).

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.

Between July 2016 and March 2017, 957 surveys were completed by professionals (Wirzba, 2017a). Over 90% agreed that their knowledge about FASD and FASD strategies had increased as a result of the training; their knowledge about FASD resources and services in their community had increased; the training received was relevant to their work; and they intended to incorporate the FASD Prevention Conversation into their practice. 85% of respondents indicated they felt confident in their ability to effectively discuss alcohol use in pregnancy with women of childbearing age and their partners; 82% indicated they felt confident in their ability to intervene appropriately with women of childbearing age and their partners who require supports and services; and 85% agreed their knowledge about resources and services available to help women prevent alcohol-exposed pregnancies had increased as a result of the training.

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.

500 surveys were completed by members of the public who participated in Prevention Conversation community events (Wirzba H, 2017b). Based on these results, over 90% agreed that they had a better understanding of FASD; their knowledge about the risks associated with alcohol use during pregnancy had increased; they understood the importance of abstaining from alcohol during current and future pregnancies; and they intended to talk to and support their friends who were or intended to become pregnant to abstain from alcohol. 89% agreed their knowledge about how to access resources and supports to prevent alcohol-exposed pregnancies had increased. 84% agreed their knowledge about resources available for someone living with FASD and for their caregivers had increased. The Prevention Conversation, which relies on face-to-face training and education, may contribute to the reasons why respondents in smaller urban, rural and remote regions have a higher level of awareness and understanding of FASD than those surveyed in Edmonton and Calgary.

Challenges: In the 2016-17 year-end report (Wirzba, 2017b), all Networks reported that they still found it difficult to engage with medical professionals, especially physicians. They found that investing in high-quality information packages was proving helpful to initiate the process. Access to remote areas remains a challenge due to cost, weather and road conditions. Networks are looking forward to the availability of new resources for youth and Indigenous youth, which will find new audiences and be of interest as refresher courses for Network-funded partners they have already trained.

PILLAR #2: Prevention (LEVEL 3 AND LEVEL 4 PREVENTION)

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.

The Parent-Child Assistance Program (PCAP), developed by Dr. Therese Grant at the University of Washington, was chosen by the Alberta Government to offer specialized and holistic support to pregnant and post-partum women who use alcohol or drugs and face other health/social challenges. The primary goal of PCAP is to prevent future births of alcohol- and drug-exposed children. PCAP practices harm reduction and stages of change theory.[7] Abstinence is not necessarily a goal. Mentors build relationships with women admitted to the program and provide support using a multitude of strategies over a period of three years. The focus is on building community connections to support safe drinking and/or access resources if women are seeking treatment or if they relapse. The purpose of the Alberta PCAP Council is to assist programs to adhere to the Washington model to promote program fidelity and quality assurance (Alberta PCAP Council, 2009).

PCAP represents a major investment in FASD prevention in Alberta over the last 10 years. Seven evaluation projects were undertaken in collaboration with the PCAP Council. These include: documentation of the history of PCAP in Alberta; interviews with key PCAP informants regarding achievements, innovations and challenges; a fidelity assessment that examined how closely Alberta PCAP sites align with the Washington model and how PCAP sites are adapting the model to the Alberta context; analysis of data collected through the Penelope Case Management system; and an evaluation of PCAP training and supports.

The Alberta PCAP Council website lists 28 PCAP sites as of March 2017. The first three PCAP sites, two in Edmonton and one in Lethbridge, were established in 1999 as pilot projects. Two additional pilot projects opened in Calgary in 2000 and in Cold Lake in 2001. Seven federally funded PCAP sites on First Nations Reserves opened in 2005-06. In 2014-15, Alberta Health funded six FASD Networks to establish additional PCAP sites in First Nations communities. Each of Alberta's 12 FASD Service Networks funds at least one PCAP site.

7 PCAP intervention strategies are based on **harm reduction principles**, which posit that alcohol and drug addiction, and their associated risks, can be placed along a continuum with the goal of helping clients move from excess to moderation or to abstinence, thereby reducing the harmful consequences associated with substance use. **The Stages of Change** theory recognizes that women enrolled in PCAP will be at different stages of readiness for change at different times (from the PCAP Manual, University of Washington, **http://depts.washington.edu/pcapuw/inhouse/PCAP_Manual.pdf).**

PCAP represents a major investment in FASD prevention in Alberta over the last 10 years.

Achievements: 19 key informants from 15 PCAP sites (Wirzba, Fridman & Abells, 2017b) identified important achievements made by their clients, including that many had achieved alcohol-free pregnancies while in PCAP and after leaving the program. Their clients had improved their parenting skills, their abilities to advocate for themselves, to problem solve, and among clients who had lost custody of their children, some were able to regain custody. Current and past PCAP clients have also referred friends and family to the program.

Fidelity to the PCAP model: Key Informants identified that their programs had increased fidelity to the Washington PCAP model. They commented that to be successful, PCAP sites need to be aware of and adapt to the cultural, geographical, structural and social factors at play in their catchment area. At the same time, PCAP research has identified over 35 core characteristics that are essential for PCAP clients to achieve successful outcomes (Wirzba, Fridman & Abells, 2017b). A delicate balance is required between fidelity to the Washington model and adapting the program to the contexts within which PCAP services are delivered in Alberta.

PCAP Training: The Alberta PCAP Council is responsible for providing standardized training for PCAP mentors and supervisors. Seventeen PCAP sites participating in the fidelity assessment demonstrated a high degree of fidelity in 13 core characteristics (with over 80% fully meeting these characteristics); a good degree of fidelity in 18 characteristics (with 50 to 79% of sites fully meeting these characteristics) and a lower degree of fidelity in only six of the core characteristics (where less than 50% of the participating sites met these characteristics). Characteristics with a lower degree of fidelity included case manager professional qualifications and life experience and the frequency of meetings and supervision, which reflect the challenges of recruiting qualified personnel in rural and isolated locations and the large geographic regions these sites serve (Wirzba, Abells & Bonot, 2017). While maintaining fidelity to the model, participants reported adapting their model by adding new programming components, such as peer support and social gatherings and remaining engaged with program alumni.

Lucy* has experienced sexual, physical and emotional abuse from an early age. She has overcome significant obstacles, but is still afraid of relapse, rejection and of the lingering thought that she is not good enough. In moments of anxiety, Lucy relies on her relationships through PCAP to find hope and strength.

**Name has been changed to protect privacy.*

Cultural sensitivity: PCAP is informing leading practices in cultural sensitivity through its training of PCAP staff and engagement with Indigenous communities, by reconnecting their clients to family and culture, and hiring within Indigenous communities. Informants noted that PCAP values and practices were influencing other FASD-informed programming models, which are beginning to adopt mentoring, harm reduction, long-term commitment to their clients, a client-focused strength-based approach, a women/mother focus, flexibility based on needs and circumstance, an emphasis on training and support and reflective supervision for staff.

Economic evaluation of PCAP: 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 (Thanh et al., 2015b). Using an earlier study where the same authors estimated the incremental lifetime cost per case of FASD of $800,000, and a study population of 366 women in PCAP (from 2008 to 2011) at a cost per PCAP participants over the three-year period of $21,000 to $25,000, this study found that approximately 31 (range 20 to 43) cases of FASD were prevented within this study population resulting in a net monetary benefit for Alberta of $22 million (range $13 million to $30 million). This study concluded that PCAP is cost-effective and produces a significant net monetary benefit for Alberta. It stated that programs placing a high priority not only on reducing alcohol use during pregnancy but also on the use of effective contraceptive measures are successful in preventing future cases of FASD.

PCAP challenges: Travel and transportation, due to large rural catchment areas and poor access, contribute to higher costs when working in rural and remote areas. PCAP clients have complex needs and require highly trained staff to achieve desired outcomes. Rigorous data collection standards to track client outcomes also require both trained staff and a commitment to high administrative workloads. Addressing intergenerational trauma, poverty and other disparities within Indigenous communities, including the stigma associated with FASD, will take time, resources and commitment. There are still concerns within some organizations and communities about PCAP's harm reduction model, where they prefer a strong emphasis on abstinence.

Other Level 3 and Level 4 FASD Prevention programs: Three FASD Service Networks fund non-PCAP, less intensive programs for women at high risk for alcohol-exposed pregnancies, and report client data in the ORS database. For example, Lakeland Centre for FASD operates the *2nd Floor Women's Recovery Centre* in Cold Lake, Alberta, a nine-bed residential substance use treatment program exclusively for women. Priority is given to women who are challenged with addictions, are pregnant or at-risk of pregnancy. Every woman has an individual treatment plan and an aftercare plan that can sustain her throughout the early years her child's life. In 2016-17, 36 women received services. Data from 2012 to 2016 (McFarlane, 2016; Dewan & McFarlane, 2016) indicated that a total of 122 women have been served to date (11 of whom

returned for treatment for a second time), each staying in the program for an average of 43 days. Of the women served, 25% had a diagnosis of FASD and 50% were referred for an FASD assessment while in the program. Following their exit from the program, 25% of the women remained substance-free for three months. Of all clients, 55.2% were unhoused at intake, which was reduced to 25% of clients who remained unhoused at exit.

A social return on investment study for the *2nd floor Women's Recovery Centre* found that for every $1 invested, $5.74 of social value was created by realizing a reduction in the cost of homelessness, life-long care of a child born with FASD, justice system involvement, undiagnosed and untreated chronic disease and pregnancy and birth complications (Lakeland Centre for FASD, 2017).

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

ORS data: All 12 Networks and 25 Network-funded partners use ORS to track client data. According to the GOA FASD ORS data, the number of women accessing Level 3 and Level 4 Prevention services increased from 446 clients in 2012-13 to 785 in 2016-17. Based on 2016-17 ORS data, 553 clients received or were waiting for PCAP services and 232 clients received or were waiting for non-PCAP Level 3 and Level 4 services.

- **Waitlists:** The number of clients on waitlists is captured quarterly. In 2016-2017, clients on waitlists at intake for PCAP or non-PCAP services ranged from 2-6% of total clients.

> Many clients achieved alcohol-free pregnancies while in PCAP and after leaving the program.

- **Demographics:** Of women receiving PCAP services, 42% were younger than 25 years and 58% were older than 25 years; 33% lived in urban areas, 30% in rural and remote areas, 28% on Reserve and 9% on Métis Settlements. Of women receiving non-PCAP services, 22% were younger than 25 years and 78% were older than 25 years; 9% lived in urban areas, 80% in rural and remote areas, 7% on Reserve and 4% on Métis Settlements.

- **Indigenous population served:** 76% of women receiving PCAP services identified as Indigenous; 72% of women receiving non-PCAP services identified as Indigenous.

These results indicate that Level 3 and Level 4 FASD Prevention programs are successfully reaching Indigenous women and women living in rural and remote areas of Alberta, which speaks to the success of the FASD Service Network model that provides access to services for women living in every region of Alberta.

The Penelope Case Management System (Penelope) tracked data for 548 unique clients from April 2014 to March 2017. Of these clients, 52% were between 15 and 24 years of age and 48% were between 25 to 39 years old. Penelope does not track the number of women on waitlists, and the Penelope report did not provide any information on client ethnic origin or the location where the PCAP service is provided.

System Outcome 2.5: Data is collected consistently using both ORS and Penelope Integrated Case Management software.

All FASD Networks enter client data in ORS[8], and all but two Networks enter client data in Penelope. These two Networks are currently being trained. Seven federally-funded PCAP sites do not enter data into Penelope. There is some overlap of clients tracked through Penelope and ORS.

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

PCAP Mentors focus on each client's priorities for health and well-being and help her obtain support for her priorities. PCAP mentors address substance use with their clients and share resources on treatment options.

FASD Diagnosis and comorbidity: ORS data for 2016-17 revealed that 16% of women receiving PCAP services have a confirmed FASD diagnosis at intake. Women receiving PCAP services reported numerous comorbidities (secondary diagnoses), such as depression (48% of all women), anxiety (43%), learning disabilities (25%), physical health conditions (22%), cognitive impairment (21%), post-traumatic stress disorder (20%) and attention deficit hyperactivity disorder (ADHD) (17%). Penelope data reveals that many women in PCAP have a family history indicating potential childhood trauma: 58% were in the foster care system; 55% reported having Child Intervention services involved in their lives as a child; 69% reported they had run away from home at least once as a child; and 48% reported that their mother consumed alcohol while they were pregnant.

8 The Métis Settlements FASD Network subcontracts other Networks to deliver PCAP services in Métis Settlements communities and is not responsible for data entry.

Data on alcohol and drug use: Penelope data (N=548 unique clients from 2014-2017), indicated that 19% of clients identified alcohol consumption, 20% identified alcohol and drug use and 53% identified use of various drug substances (cocaine, cannabis, amphetamines, poly drugs, and others) as their major problem at intake. The percentage of women in PCAP who engaged in alcohol/drug treatment was 35% at 6 months in the program, 31% at 18 months and 27% at 30 months. Outpatient treatment had the highest participation rate. Of women in PCAP, 52% reported abstinence from alcohol for at least one month at 6 months in the program, 47% at 18 months and 35% at 30 months. The percentage of women who were abstinent from drugs for at least one month was 54% at 6 months, 56% at 18 months and 48% at 30 months.

Decrease in alcohol consumption during pregnancy: Penelope data reported that of the pregnant women in PCAP, 28% never consumed alcohol during the first trimester of pregnancy, which increased to 77% during the second and third trimesters, exceeding the target of 75%.

Effective family planning: To effectively prevent alcohol-exposed pregnancies, a woman must not be using alcohol when pregnant or planning to become pregnant, or if not pregnant, must be using an effective method of contraception consistently. Penelope reported that 77% of pregnant women in PCAP were not using a regular method of contraception around the time of conception and 88% of the pregnancies were unplanned. At the end of 6 months in PCAP, 39% of non-pregnant women were using a method of contraception regularly, 57% at 18 months and 54% at 30 months. An analysis of the ORS data for 2016-17 suggests similar results, suggesting that 52 to 59% of all PCAP clients receiving services were effectively preventing FASD during this period.

Preventing adverse outcomes: An analysis of data available from Penelope (N=548 unique clients from 2014-2017), revealed the extent to which PCAP clients experienced improved well-being by accessing permanent/stable housing, finding employment and receiving income supports:

- At intake, 56% of PCAP clients reported being in permanent/stable housing, which increased to 59% at 30 months.
- At intake, only 12% of clients reported earning income from employment, which increased to 22% reporting being employed at some point in the previous 6 months at 30 months in PCAP. Clients who reported their main source of income from regular or causal employment increased from 4% at 6 months to 10% at 30 months.

"With the help of PCAP, I've been sober for over a year now. I am proud, my kids are happy and I am in school. And I am feeling happy. It's still hard. I'm taking it one day at a time, but without PCAP, where would my family be right now? I now have the belief that I can do this. I can stop drinking. I also had a baby boy on December 25, 2016, who won't have FASD." – PCAP participant

- Clients who reported their main source of income from income support decreased from 53% at 6 months to 46% at 30 months. Clients receiving PDD/AISH increased from 13% at 6 months to 20% at 30 months.

Service closure:[9] An analysis of the ORS data revealed that of the 106 PCAP service closures in 2016-17, presenting issues were fully or partially addressed for 6% of clients receiving PCAP services. Other reasons included discharged (25%), location unknown (14%), moved (13%), moved and referred to another service (9%), declined further services (9%) and other (25%).

Comparison of ORS results between clients receiving PCAP services and those receiving non-PCAP Level 3 and Level 4 Prevention services: An analysis of the 2016-17 ORS data from 533 PCAP clients and 232 non-PCAP clients revealed that PCAP serves a higher number of clients with a confirmed FASD diagnosis at intake (16%) compared to non-PCAP clients (8%); PCAP clients had higher rates of comorbidity than non-PCAP clients; 39% of PCAP clients used effective family planning consistently compared to 28% of non-PCAP clients; 33% of PCAP clients eliminated alcohol use compare to 16% of non-PCAP clients; and 33% eliminated drug use compared to 15% of non-PCAP clients.

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 with prenatal exposure to alcohol born to women who completed PCAP is not tracked by Penelope or ORS. However, because PCAP sites remain engaged with alumni who choose to remain in contact with the program, key informants indicated that some women who completed the program had subsequent births with no prenatal exposure to alcohol (Wirzba, Fridman & Abells, 2017b).

Client Outcome 2.8: Children of PCAP clients experience improvement in their well-being.

The Penelope data indicated that 97% of pregnant women in PCAP had live births. Of these babies, 61% had a normal discharge from hospital, 21% spent up to two weeks in the hospital following delivery and 18% of the babies spent more than two weeks in hospital.

Penelope data indicates that after the child's birth, 74% of women in PCAP had legal custody of their child, 17% of children were in the custody of Child Intervention services, 2% were in the custody of the child's father or other relative and 2% were in the custody of a legal guardian. The data indicates there is a decrease in the percentage of women in PCAP who retain custody of their child throughout the program,

9 In ORS, a service is closed when a client no longer accesses a particular service type. The client's file remains open, as the client may access more than one service type.

> The Penelope data indicated that 52% of all women in PCAP had an open case with Child Intervention services in the three years prior to becoming a PCAP client.

from 68% at 6 months to 58% at 30 months, while custody by the child's father or other relative or adoptive family increases.

The Penelope data indicated that 52% of all women in PCAP had an open case with Child Intervention services in the three years prior to becoming a PCAP client. There was a decrease in the number of women who had an open case from 53% of women at 6 months to 35% at 30 months.

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

PCAP sites funded through the FASD Service Networks completed satisfaction surveys as part of the Year 7 Evaluation (Government of Alberta, 2014). Responses to this survey indicated a high degree of satisfaction with the Program. PCAP Council is currently testing a client satisfaction survey specific to the Alberta PCAP model. A survey of clients was not conducted as part of the Year 10 Evaluation.

PILLAR #3: Assessment and Diagnosis

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 in Alberta.

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.

Achievements: In December 2016, Alberta had 24 clinics providing FASD assessment and diagnostic services to children, youth and adults (Burns, 2017). Twelve of the clinics provided services to both children and adults, eight clinics served children, and four clinics served adults. Seven of the 24 clinics were operated by not-for-profit organizations, seven by Alberta Health Services, four by FASD Service Networks, one was a partnership between a Network and a municipality, one was a partnership between a Network and Alberta Health Services, one was operated by a First Nations Health Organization and two clinics were private and operated as fee-for-service.

While clinics operate under different funding models, there are commonalities. All FASD clinics in Alberta follow the Canadian FASD Guideline for Diagnosis (Cook et al., 2016) and processes that involve four stages: (1) screening, referral and support; (2) completion of a social and medical history, a prenatal and maternal alcohol history and a physical exam; (3) neurodevelopmental assessment; and (4) management and follow-up (Burns, 2017). While there is no single oversight body that prescribes how clinics do their work in Alberta, all clinics have access to support from the FASD Assessment & Diagnosis Council and from Rajani Clinic Training Services, which provides ongoing training and mentorship, including training on the Canadian Guidelines and a best practice guide (Green, 2015). Clinics have formed a community of practice, where they support each other's information needs and provide mentorship.

The Government of Alberta's FASD Online Reporting System (ORS) collects data on Network clients referred for an FASD assessment. It includes all clients who completed an intake process, including those on a waitlist. The number of clients tracked by ORS has increased consistently from 419 clients in 2012-13 to 1,050 in 2016-17 clients who completed the intake process,

of which 622 clients received a diagnostic outcome in 2016-17 (assessments completed by clinics not funded by the FASD Service Networks are not included in this number).

Challenges: An FASD diagnosis requires a confirmed history of prenatal alcohol exposure, which can be difficult to obtain. There are a limited number of clinicians trained in FASD to staff multidisciplinary teams. A survey of 23 clinics in Alberta in December of 2016 (Burns, 2017) revealed that 15 clinics have "general referral waitlists" of potential clients requesting assessment information as well as clients with active files. While waitlist definitions have common themes, each clinic has its own unique definition and clinic processes for service delivery management. These waitlists are considered a starting point, where clinics begin the process of triage, screening and prioritizing clinic dates. In total, there were 544 children and youth and 589 adults on these waitlists[10]. Eight clinics do not have waitlists, including those that are fee-for-service, new clinics just starting up, those that do court-ordered assessment that cannot be waitlisted and one that does not accept referrals beyond what the clinic is contracted to provide. Lack of agreement on a waitlist definition and lack of reliable data make it difficult to find solutions to waitlist challenges.

> In December 2016, Alberta had 24 clinics providing FASD assessment and diagnostic services to children, youth and adults.

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

Researchers in Alberta examined intervention recommendations for children (aged 1-17 years) with FASD and those with prenatal alcohol exposure (PAE), and then subsequent access to services following clinical assessment (Pei et al., 2017). They found that children with FASD received more recommendations overall and more recommendations for education, anticipatory guidance, family support and safety interventions than undiagnosed children with PAE. Undiagnosed children received more mental health and reassessment recommendations. Older children received fewer family support and developmental therapy recommendations, but more mental health recommendations than younger age groups. Many families accessed modified school programming, developmental therapy, psychiatry, child counseling and parent support as recommended. The research highlighted areas of high/low service access, which provides insight into accessibility and perceived importance of interventions.

Steve* is 27 years old and was suspected of having FASD. With the help of one of the FASD Networks, he received an assessment and an FASD diagnosis. Steve and his parents are now learning about FASD and the support services available to him. With his disability diagnosed, he was also granted access to his young child, who he hasn't seen in over a year.

**Name has been changed to protect privacy.*

10 These waitlist numbers reflect "real-time data," and provide a picture of the waitlist on the day the clinic was interviewed in 2016.

ORS data: In 2016-17, all 12 Networks and 16 Network-funded partners posted data related to assessment and diagnosis services on ORS. ORS tracked information for 1,050 unique clients accessing assessment and diagnosis services:

- **Demographics:** Based on the ORS data and the client's age at April 1, 2016 (of the 2016-17 fiscal year), 49% were ages 0-17; 16% were young adults ages 18 to 24; and 35% were adults 25 years and older, which was similar to the distribution of age groups in 2015-16. The number of males (54%) was slightly higher than the number of females (46%) in 2015-16, but in 2016-17, the number of males (51%) and females (49%) was almost even. Of all clients, 31% lived in urban areas, 45% in rural and remote areas of the province, 19% on Reserve and 5% on Métis Settlements, which indicates there is access to clinical assessment in every region in Alberta.
- **Indigenous population:** In 2016-17, 70% of all clients identified as Indigenous.
- **Waitlists:** The number of clients on waitlists is captured quarterly. Of clients with an intake for assessment and diagnosis, 25 to 31% were on a waitlist at any point in 2016-17.
- **Diagnostic outcomes:** 622 unique clients received a diagnostic outcome in 2016-17. Of these, 346 received a diagnosis of FASD; 92 received another diagnosis and the remaining 184 were either deferred or determined at risk for neurodevelopmental disorder and FASD associated with prenatal alcohol exposure.
- **Comorbidity (secondary diagnoses):** Of the 622 clients who completed the assessment process in 2016-17, most received other diagnoses: ADHD (36% of all clients), cognitive impairment (34%), physical health issues (34%), learning disability (30%), anxiety (22%), communication disorders (22%), depression (18%), sensory issues (13%), post-traumatic stress disorder (9%) and attachment disorders (4%).

- **Services closure:** Of the 601 service closures for assessment and diagnosis in 2016-17, 62% were for completion of assessment and diagnosis services. Other reasons for file closure included discharged (16%), location unknown (6%), declined further service (5%), moved (3%), other (8%).

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.

Post-clinic surveys of clients completing Network-funded assessments were conducted for the Year 7 Evaluation of Alberta's FASD 10-Year Strategic Plan. These surveys 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. This survey was not conducted again as part of the Year 10 Evaluation.

> Older children received fewer family support and developmental therapy recommendations but more mental health recommendations than younger age groups.

PILLAR #4: Supports for Individuals and Caregivers

GOAL #4: 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;[11] and 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.

Achievements: Key informants identified that recognition of FASD as a life-long disability is now central to service provision. Beyond partnerships and collaborations, Networks now have the capacity to advocate for FASD-informed services, helping other service providers adopt FASD-informed practices. Several respondents commented on important province-wide FASD initiatives that have developed over the past 10 years with the support and guidance of the FASD 10-Year Strategy (Wirzba & Abells, 2017a).

Challenges: Key informants identified several areas where more supports are needed, such as youth transitioning to adulthood, especially for those transitioning out of government care. Alberta Children's Services was identified as a key relationship that needs to be strengthened. Access to more FASD-informed mental health and addiction services is needed. There is a growing realization that seniors with FASD are not well served. New research and pilot housing projects point to the need for more investments in housing (Wirzba & Abells, 2017a).

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

Emerging practice: As access to assessment for FASD has increased, many more individuals have received a diagnosis. However, funding to provide FASD support services has not increased proportionally, leading to waitlists for FASD services. Networks have found that FASD support services need to be customized based on the unique needs of the individual, their age, their natural support network, their receptiveness to receiving services and the availability of services they need. Many informants commented that an Individualized Service Plan is not always required (Wirzba & Abells, 2017a). As part of the Year 10 Evaluation, a case study examined emerging trends in providing improved access to support services for individuals with FASD. Seven Networks have responded by adapting their intake processes to more effectively and efficiently provide access to the supports needed and requested by individuals with FASD and their caregivers. A new tiered approach to service provision has emerged that better responds to the wide spectrum of service needs. These seven Networks were interviewed for this case study (Wirzba & Abells, 2017b).

> A new tiered approach to service provision has emerged that better responds to the wide spectrum of service needs.

11 Data on the percentage of individuals with integrated care plans is not collected.

Each Network was found to be developing a similar three-tiered model that triages services into three types: (1) rapid response, for requests for information from caregivers or service providers; (2) light-touch response, for short-term interventions that connect clients to services in the community; and (3) longer-term response, guided by diagnostic recommendations made by FASD clinics and based on Individualized Service Plans. To implement their model, each Network reorganized their existing resources to create a navigator position and developed intake, screening and tracking processes for light-touch supports to help navigators identify and prioritize needs of referred individuals, provide immediate time-limited crisis support if required and to keep in touch with those on waitlists for more intensive specialized FASD services. Each Network reported that the navigator needed to be knowledgeable about FASD and FASD-informed services offered in their communities and aware of community resources that individuals with FASD or their caregiver(s) may benefit from, so they can quickly and more efficiently respond to immediate needs. The study found that each of the seven Networks has been successful in developing and implementing a tiered approach to support services that is consistent with current knowledge of FASD best practices and reflects the principles of the Service Network program.

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

Many caregivers struggle to cope with the economic impact, emotional stress and fatigue that come with raising children with complex mental and physical health needs. A survey of caregivers receiving Network-funded supports in the Year 7 Evaluation found that only 47% reported their access to respite services had increased since accessing support services. Networks reported that families have difficulty finding trained respite care (Government of Alberta, 2014). See caregiver data under System Outcome 4.3 on the following page.

System Outcome 4.3: Data is collected consistently.

ORS data for individuals with FASD: In 2016-17, all 12 Networks and 45 Network-funded partners posted data related to support services on ORS. ORS tracked information for 2,276 individuals receiving or waiting for services.

- **Demographics:** Based on the client's age at April 1, 2016 (of the 2016-17 fiscal year), 62% were under 25 years of age and 38% of the individuals served were 25 years or older. 51% of clients identified as male and 49% identified as female. 46% lived in urban areas, 39% in rural and remote areas, 11% on First Nations Reserves and 3% on Métis Settlements.
- **Indigenous population served:** 60% of all individuals identified as Indigenous, with 11% of all clients living on First Nations Reserves and 3% on Métis Settlements.
- **Confirmed FASD Diagnosis:** At intake, 37% had a confirmed FASD diagnosis and another 3% had confirmed prenatal alcohol exposure.
- **Comorbidity:** In 2016-17, the most frequent secondary diagnoses/comorbidity known at intake were ADHD (26%), learning disabilities (24%), anxiety (22%), cognitive impairment (22%) physical health conditions (19%), depression (19%) and communication disorders (12%).
- **Supports received:** In 2016-17, 53% of all clients accessed one-on-one mentoring, 50% received outreach services[12] and 14% participated in a support group (clients can access multiple services and can be counted more than once).
- **Waitlists:** The number of clients on waitlists is captured quarterly. In 2016-2017, clients on waitlists at intake for services ranged from 7-11% of the total number of clients.
- **Service closures:** Of the 904 services that were closed in 2016-17, presenting issues were fully or partially addressed for 34%. Other reasons for service closure included discharged (19%), moved or moved and referred to another service (16%), location of individual unknown (13%), declined further services (11%), death (1%) and other (6%).

ORS Data for Caregivers: In 2016-17, 10 Networks and 23 Network-funded partners posted data on ORS for 543 adult caregivers receiving or waiting for support services.

- **Demographics:** 98% were 25 years and older and of these, 11% were 65 years and older. 76% were female and 34% identified as Indigenous. 51% lived in rural and remote areas, 19% lived on Reserve or on Métis Settlements and 30% lived in urban areas.
- **Caregiver type:** 40% were an adoptive parent, 26% were a biological parent, 11% were a legal guardian, 10% were a foster parent, 19% were a kinship caregiver and 4% were a spouse.
- **Caregivers with FASD:** 11% had a confirmed FASD diagnosis and another 3% had confirmed prenatal alcohol exposure at intake.

12 Outreach is a frontline intervention aimed at engaging individuals who may not be in direct contact with services by providing them with information about services available and assisting them to access supports.

- **Comorbidity:** ORS identified very few secondary diagnoses/comorbidities for caregivers. Service providers may not track this type of information for caregivers.
- **Supports received:** 45% of caregivers accessed one-on-one mentoring, 59% participated in a support group, 59% received outreach services and 10% accessed respite services (caregivers can access multiple services and can be counted more than once).
- **Waitlists:** The number of clients on waitlists is captured quarterly; 1 to 4% of caregivers with an intake for support services were on a waitlist in 2016-17.
- **Service closure:** Of the 109 services that were closed in 2016-17, presenting issues were fully or partially met for 39% of caregivers receiving support services. Other reasons for service closure included discharged (21%), moved or referred to another service (11%), individual declining further services (10%) and other (19%).

Client Outcome 4.4: Individuals diagnosed or suspected of FASD experience improvement in their well-being.

FASD and the school system: The Wellness Resiliency and Partnership (WRaP) project provided coach supports for Alberta school children and youth with FASD. The grant was funded by Alberta Education for eight years and provided students with a coach, who used a strength-based wraparound model to support school engagement, increase academic success, and enhance social, emotional and physical well-being (Alberta Education, 2016). The 2015-16 evaluation report indicated that 15 coaches served 254 students in 39 schools (Tremblay, 2016). Focus groups with coaches revealed strong relationships were developed with the students they coached and they had developed several successful strategies for connecting with students. Coaches also connected with parents/caregivers, school staff, other WRaP coaches and formed relationships with service providers to expand the circle of support around their students. The 2015-16 WRaP annual report reported that of the 152 students for whom course completion data was available, a 90% course completion rate was achieved and 82% did not receive a suspension during 2015-16 school year. The grant that initiated the WRaP project concluded at the end of the 2017 school year and participant school authorities are exploring ways to use the learnings from this project to address their local needs.

Since receiving FASD training, the Barrhead RCMP Detachment has enhanced the way they interact with individuals they suspect may have FASD. A more personable approach has been introduced, additional time is spent helping individuals to process information and plain language is used to help them better understand what is expected of them.

FASD and the criminal justice system: An evaluation of Alberta's FASD Justice Support Project for Youth, which organizes case conferences ordered by youth court judges under Section 19 of the *Youth Criminal Justice Act,* examined its effectiveness in preventing recidivism among justice involved youth (Cooper & Guyn, 2016). The evaluation found that reductions in offending (as represented by the number of criminal charges, particularly those involving violence) were strongly associated with reductions in criminogenic risk factors following the case conference. This led to significant improvement for a high percentage of the youth in areas of anti-social attitudes, personality/ behaviour, criminality, substance use and peer association. These improvements translated into a statistically significant decline in the score for "overall risk of offending" for 32% of youth with a Section 19 conference, for whom data was available. The report concluded that most justice involved youth are unable to navigate the health, education, social and justice systems to obtain the supports and services they needed to avoid conflict with the law, substance use, homelessness, exploitation by others and unplanned parenting. The report recommended that youth with FASD require skilled mentors to supervise and support their daily activities and serve as role models (Cooper & Guyn, 2016, p. 15).

There are several examples of regional partnerships between the Networks and Alberta's criminal justice system. Networks partner with police, courts and corrections to support clients involved in the justice system. Several Networks offer advocacy and mentoring supports to adults and young persons during and after their court cases and one Network is involved in restorative justice initiatives (Northwest Central FASD Network). In their 2016-17 Annual Report, Calgary Fetal Alcohol Network reported that of 270 clients involved with the justice system who received one-to-one case management supports, 85% did not experience new involvement. South Alberta FASD Network's Youth Justice Project served 56 youth in 2016-17. Of these, 34% were diagnosed with FASD, 79% were male, 79% identified as Indigenous and 57% were involved with Child Intervention services. Twenty-five youth were involved with the justice system. Of these, 20 did not experience re-involvement. Of the 31 youth

> Relationship building both between clients and their support worker, as well as between the employer and service provider, were identified as critical.

in the program who were at-risk of involvement and receiving preventative services, none became involved with the justice system (Wirzba, 2017b).

FASD and employment: This study by CanFASD (Green, 2016) included a literature review and interviews with nine Canadian organizations with employment programs for people with FASD, four of which were in Alberta. Researchers found that while there was a paucity of literature on the subject, all nine organizations had adopted a supported employment model and had similar approaches to supporting their clients. While a strength-based (person-centred) approach was considered most effective, it was also found to be very resource-intensive. Relationship building both between clients and their support worker, as well as between the employer and service provider, were identified as critical. Education, awareness and support were significant contributors to the overall success of the employment opportunity, as service providers needed to educate prospective employers about FASD and work collaboratively to support their clients.

FASD and housing: University of Calgary researchers explored the needs of adults with FASD within the episodically and chronically homeless population in Calgary and the impact of FASD on service utilization and housing outcomes (Badry et al., 2015). Interviews with 16 adults diagnosed or suspected of FASD found that 93% reported addiction issues, 50% reported having a physical disability, 68% reported involvement with the justice system, 63% reported mental health issues and 50% reported involvement with child welfare. The women reported being at heightened risk (engaged in sex trade work, exposed to sexual abuse and domestic violence) and reported severe experiences of trauma. Beyond housing, ongoing case management is necessary for this population. The need for continued support, care, advocacy, funds management, harm reduction and vigilance for vulnerability is required to support and promote stability for individuals with FASD.

Two evaluations of housing projects in Alberta were conducted in 2017. Hope Terrace is a permanent supportive housing program funded

Karl* is 19 years old and living with a foster parent. He is financially supported through AISH and also works at McDonald's. With support and guidance from his mentor, Karl asked his work supervisor for responsibilities that allow him to feel more confident and excel in his role. His mentor also helped him create a budget to manage his finances. Karl's rent and bills are now paid on time and he knows how much money he can spend each month.

**Name has been changed to protect privacy.*

Ethan* has been homeless off and on for long periods of time. With the help of the FASD Network, he was able to find stable and safe housing. Having somewhere to live has allowed Ethan and his support worker to focus on making plans for the future, consider educational opportunities and create a resume for employment.

**Name has been changed to protect privacy.*

by Homeward Trust and Edmonton Fetal Alcohol Network (EFAN) and operated by EFAN. It provides permanent housing and 24/7 support services in an apartment building with 15 units, for to up to 27 adults with FASD and concurrent disorders, who have experienced challenges maintaining housing. An evaluation of the first year of operation (Wirzba, 2017c) found that 29 individuals were housed between January 2016 and March 2017. Hope Terrace helped residents enhance their life and social skills and reduced their use of ancillary health, police and justice system services. Residents expressed a high level of satisfaction with the program. Mackenzie Network Supportive Housing provides supported, supervised and structured accommodations for adults with FASD, as well as daily programming focused on life skills, mental and physical health and addictions. An evaluation of the first year of operation (Wirzba, 2017d) found that since March 2016, the program has served eight residents, of which four were still housed at the end of March 2017. The program employs eight full-time frontline workers, several casual workers and one supervisor. Some residents have been able to maintain their housing and their satisfaction with the program is high. Those who left the program were found alternative housing and several were able to live with family again. Those exiting the program continued to receive services from Network life coaches, and they all chose to have the Network continue as their financial trustee.

Data from ORS on the frequency and severity rating of presenting issues over subsequent reporting periods from 2015 to 2017 was not available for inclusion in the Year 10 Evaluation.

Client Outcome 4.5: Caregivers of individuals affected by FASD experience improvement in their well-being.

Parents and caregivers were surveyed as part of the Year 7 Evaluation of Alberta's 10-Year Strategic Plan (Government of Alberta, 2014). Results from a survey of parents and caregivers whose child/dependent was receiving supports found that 96% reported they knew where to look for help, 90% said they learned about things they needed to change or do differently and 85% said they were better able to take care of themselves since they started receiving services for their child/dependent. A survey of parents and caregivers receiving support services for themselves found that 96% reported the support they received helped increase their understanding of FASD, 92% said the support 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. These surveys were not repeated for the Year 10 Evaluation.

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

Client surveys were conducted as part of the Year 7 Evaluation of Alberta's 10-Year Strategic Plan (Government of Alberta, 2014). Overall, over 90% of individuals and parents or caregivers were very satisfied with the services they received (exceeding the 10-year target of 80%); over 95% said they were treated with respect and dignity by service providers; and the majority (78-86%) said they were involved in planning the services they received. Client satisfaction surveys were not repeated for the Year 10 Evaluation. Some Networks conducted surveys with their clients, and reported the findings in their Annual Reports. For example, South Alberta FASD Network reported in their 2016-17 annual report that of the 94 clients who completed post-clinic surveys, 99% reported accessing new services and 95% reported improvement in well-being because of the program. Calgary Fetal Alcohol Network reported in their 2015-16 annual report that 91% of caregivers who accessed services increased their support network and 97% reported increasing their capacity to care for their child/dependent, an increase of 10% since 2014-15.

> Overall, over 90% of individuals and parents or caregivers were very satisfied with the services they received (exceeding the 10-year target of 80%); over 95% said they were treated with respect and dignity by service providers; and 78-86% (the majority) said they were involved in planning the services they received.

PILLAR #5: The FASD Learning Organization

GOAL #5: Stakeholders collaborate to develop and mobilize knowledge to continuously transform Alberta's FASD model to achieve outcomes and goals.

10-YEAR TARGETS: Not identified.

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.

Achievements: Key informants agreed that the FASD-CMC was very successful in supporting collaboration, cooperation and coordination among ministries. They noted that stakeholders had multiple opportunities every year to meet, share information, network with each other and access new information. The 10-Year Strategic Plan helped create a high degree of cohesion within the FASD sector, and the 12 Alberta FASD Service Networks were described as the "eyes and ears of the community." (Wirzba & Abells, 2017a).

Network governance and operations: As part of the Year 10 Evaluation, a review of Network governance and operations was conducted (Wirzba, Fridman & Abells, 2017a). The methodology was based on criteria used for the Year 5 Review to support comparison (KPMG, 2011). The Year 10 Review found that the way Networks deliver their services has not changed significantly since Year 5. Six Networks contract other service providers/organizations to provide frontline services; two Networks deliver all services directly and four Networks have a combined service delivery model, where they both provide services directly and contract other service providers/organizations to provide FASD-informed services. Network governance and operations models, however, have changed significantly since Year 5. When first established, most Networks were unincorporated entities led by a leadership team and their finances and staff were managed externally by other organizations. Since the Year 5 Review, the number of Networks registered as societies in Alberta has increased from four to nine in Year 10, and seven of the Networks now directly employ their network coordinator and manage their finances internally.

The Year 10 Review (Wirzba, Fridman & Abells, 2017a) confirmed that Networks are continually working to improve and achieve excellence in six core non-service delivery areas of governance, planning, funding decisions, financial management, human resources & contract management and performance reporting. Seven Networks received an overall score of *excellent*, two of which received a score of *excellent* +, signifying that they had achieved an *excellent* score in previous reviews and had demonstrated continuous improvement. Four Networks received an overall score of *very good*. None were given a score of *developmental*. The review also examined how well Networks aligned with the 2016-17 Operating Grant Policies. Five Networks demonstrated *excellent* alignment, three had *very good* alignment and three were rated as *developmental* in their alignment with these policies. Recommendations were made to support continuous improvement in these core non-service delivery areas of function.

Challenges: A broad survey of stakeholders was not conducted as part of the Year 10 Evaluation. However, key informants noted that stakeholder engagement was an ongoing process, and that developing partnerships is sometimes easier than maintaining them, especially in times of transition and economic restraint. Resourcing collaboration remains a challenge, as is funding to support face-to-face participation from rural and isolated communities and providing sufficient resources for the FASD Advisory Councils to fully capitalize on the highly-valued expertise offered by volunteer experts (Wirzba & Abells, 2017a).

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

Achievements: FASD training and education has been a priority for the FASD-CMC and a key direction of the FASD 10-Year Strategy. The Alberta FASD Supports & Services, Education & Training Council has guided the development, delivery and evaluation of FASD training in Alberta. A large inventory of training initiatives and support services speaks to the diversity of learning needs this training must meet (FASD Supports & Services, Education & Training Council, 2016).

Workforce development: Key informants indicated that it is critical that FASD-specific training be available for professional development, especially in social work, education and health (Wirzba & Abells, 2017a). Alberta Justice and Solicitor General, for example, has included training on FASD in its workforce training curriculum for correctional peace officers, correctional service workers, probation officers, sheriffs and community partners including police agencies. Forty-eight (48) training and education sessions were provided to 800 individuals across Correctional Services Division, the Sheriffs' Branch, and Community/RCMP members (Government of Alberta, 2017). As part of the FASD initiatives, a Workforce Development Framework for Alberta's mental health professionals, child and youth care workers, primary health/healthcare practitioners, educators, probation officers and correctional officers is currently underway. The framework is intended to provide a systematic approach to developing FASD education and training resources and to promote knowledge mobilization and best practice. The framework will be used to support the development of best practice guidelines, educational programming and tool kits and evaluation tools for each sector (CanFASD, 2017a).

Caregiver curriculum: In addition to workforce training, an updated Caregiver Curriculum on FASD was launched in June 2016 that provides an online venue for caregivers, including birth parents, foster parents, kinship caregivers, as well as for youth and child care workers, child welfare services and others trying to understand and cope with many of the life challenges faced by children and dependents with FASD. The Government of Alberta partnered with the Public Health Agency of Canada, the University of Manitoba and the Children's Aid Society of Ontario to develop this online curriculum that is available free of charge to all caregivers and the public (Caregiver Curriculum on FASD, 2016).

The FASD Learning Series has provided webcasts since 2008, and is often accessed by the Networks to support education and training in their regions. It is designed for individuals, caregivers, frontline workers and professionals to learn about FASD and how to support individuals with FASD. The webcasts cover a broad range of topics, such as housing and FASD, navigating the justice system, impact of FASD on women and dealing with employment and FASD. In 2014/2015, 1,500 people joined the webcasts. The 2015/16 Final Report (Government of Alberta, August 2016b) indicated that 93 webcasts were conducted since the beginning of Alberta's FASD 10-Year Strategic Plan. Across 10 sessions, 2,249 viewers logged on to view all or part of a webcast. Of those, 411 completed post-webcast surveys. Of these, 18% indicated they viewed the webcast as a group. Feedback was very positive: 93% thought the learning objectives of the webcast had been met, 86% indicated that their awareness of the topic had increased, 91% found the content relevant, 86% said they would apply what they had learned, 92% thought the webcast was a valuable experience and 96% thought that

webcasting helped them attend a session. Only 38% indicated they participated in the group discussion (live chat), which is an area that could be improved.

PCAP training: The Year 10 Evaluation of PCAP training in Alberta (Wirzba & Abells, 2017c) found that the PCAP Council has provided 22 training sessions and has trained 302 PCAP staff since 2013. Of the 102 mentors surveyed who participated in PCAP Core Training in Alberta between 2013 and 2016, over 90% indicated that the training had met their learning objectives and all trainees indicated the training provided them with information and skills they could apply in their work. Of 55 PCAP supervisors surveyed who had received training on how to administer and code the Addiction Severity Index (ASI) interview, 89% agreed that the training prepared them to work more effectively with their clients by improving their interview skills.

Training in assessment & diagnosis: Rajani Clinic Training Services provides ongoing training and mentorships to all of Alberta's clinics, including training on the Canadian Guidelines for FASD Diagnosis and a best practice guide for FASD Assessment and Diagnostic Clinics (Green, 2015). Over 300 viewers logged in to view the webinar on the Canadian FASD Diagnostic Guidelines.

Challenges: While some post-secondary institutions have included FASD in their curricula (in Social Work at the University of Calgary and in Pharmacy at the University of Alberta), disciplines such as education and health have not yet added FASD-specific training to their curricula.

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

Achievements: Key informants commented on the high value the Government of Alberta places on research, remembering that the government had invited researchers to the table when the Strategy was being developed (Wirzba & Abells, 2017a). As a result, a culture of evaluation and research was embedded in the Strategy and supported over the last 10 years. Researchers have had many opportunities to directly engage with the FASD-CMC and policy makers to inform decisions. Networks also played an important role, both by informing the development of research projects and by contributing data to research projects. Provincial and national research centres, including PolicyWise for Children & Families, the Institute of Health Economics, CanFASD and Alberta's universities continue to make important contributions to Alberta's response to FASD, both by supporting collaboration among researchers and by contributing important research.

Research: An analysis of Alberta-based FASD research undertaken in the four pillars of basic, clinical, population and health research (PolicyWise for Children & Families, 2016a), found that research and evaluation in Alberta has focused primarily on identifying and improving services and interventions that consider the functional needs of individuals with FASD and their families through the lifespan.

As a result, there is a breadth of research involving partnerships between institutions, FASD clinics and community-based programs (PolicyWise for Children & Families, 2016a).

Evaluation and data collection: Key informants indicated that evaluation has been central to the success of the FASD 10-Year Strategy, as most major FASD initiatives have included strong evaluation components. As one key informant stated, "FASD is one field in Alberta where we can be quite confident about program development and policy setting because we have been continually learning, evaluating, improving, building and sharing knowledge" (Wirzba & Abells, 2017a). There has also been an ongoing commitment and investment in FASD data collection. PCAP Council provides data collection training for the Penelope Case Management System, and the Government of Alberta has invested in the ongoing development of the FASD Online Reporting System (ORS). PolicyWise for Children & Families, with the guidance of FASD-CMC, has developed a Data Capture and Analysis Framework to support the broad capture of data from Government of Alberta administrative databases to create a centralized FASD data system solution (PolicyWise for Children & Families, 2016b).

A Best Practices Guide and Evaluation Tool Kit has been developed for Networks and service providers to assess their current service delivery models. It provides a framework and a set of outcomes and indicators that can be used to inform policy and practice improvements (Pei et al., 2015). The Guide will be tested in 2017-18.

Challenges: The analysis of Alberta-based FASD research found that current research conducted in Alberta between 2014 and 2016 is similar to what was undertaken in previous years. The authors concluded that while research has increased in the clinical pillar, research in basic, health and population pillars has plateaued. They advise for more research and evaluation in all four pillars (PolicyWise for Children & Families, 2016a).

The FASD Service Network Evaluation, conducted as part of the Year 7 Evaluation, developed a comprehensive set of evaluation tools and templates that align with FASD-CMC's Strategic and Operational Plan outcomes and key performance indicators (Wirzba, 2016b). While Networks were not required to continue using these tools, some Networks chose to do so. Recognizing a gap in the continuous use of standardized evaluation tools, a further report was commissioned by the FASD Evaluation and Research Council and the FASD Education and Training Council to develop and implement standardized evaluation tools (Wirzba, 2016c).

> Key informants indicated that evaluation has been central to the success of the FASD 10-Year Strategy

RECOMMENDATIONS

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

1. To reduce incidence of FASD in Alberta:

a. Expand the Parent-Child Assistance Program (PCAP) for women of child bearing age at risk of having alcohol-exposed pregnancies.

b. Explore innovative population-based prevention approaches.

PCAP successfully prevents future births of alcohol and drug exposed children. Each prevented case of FASD results in an estimated cost savings of $800,000 over the lifetime of an individual with FASD (Jonsson, 2017). PCAP, Alberta's largest investment in FASD prevention, is achieving results and providing a significant net monetary benefit for Alberta (Thanh et al., 2015b). In 2016-17, 76% of women participating in PCAP identified as Indigenous; 33% of the women lived in rural and remote areas, 28% lived on Reserve and 9% on Métis Settlements.

Women in PCAP demonstrated a decrease in alcohol use. Of these women, 52% reported alcohol abstinence for at least one month after six months in program and 28% of pregnant women reported alcohol abstinence during the first trimester, which increased to 77% reporting abstinence in the second and third trimesters. Women in PCAP also demonstrated increased use of effective family planning. 77% of pregnant women in PCAP were not using a regular method of contraception around the time of conception and 88% of the pregnancies were unplanned. At the end of the 3-year program, 60% of non-pregnant women reported using a method of contraception regularly (Wirzba, Fridman & Abells, 2017b). PCAP has shown to be successful and effective in reaching Indigenous communities. Moving forward, population-based approaches will continue to be explored and the model modified as needed to reach other groups such as newcomers[13] to Canada and women and families of child-bearing age across all socio-economic backgrounds.

13 An immigrant or refugee who has been in Canada for a short time, usually less than 5 years is considered a newcomer.

2. To prevent adverse outcomes for individuals with FASD, expand access to FASD-informed services.

Over $1 billion is spent annually in Alberta responding to adverse outcomes that result from FASD, of which 40% is spent on criminal justice, 21% on health care services, 17% on educational services, and 13% on social services (Jonsson, 2017). Over 60% of all individuals with FASD are under 20 years old (Thanh et al., 2014), and 78% of young Albertans diagnosed with FASD are high government services users (PolicyWise for Children & Families, 2017).

To prevent adverse outcomes for youth with FASD:

a. Build on the lessons learned from the Wellness Resiliency and Partnership (WRaP) program and continue to provide FASD-informed supports for students with FASD in Alberta schools.

b. Prevent initial contact with the criminal justice system by providing FASD-informed supports for young people at-risk or involved with the justice system.

c. Prepare young people with FASD transitioning to adulthood by providing them with reassessment and recommended supports.

To prevent adverse outcomes for adults with FASD:

d. Offer stable and supportive housing for individuals with FASD as it is key to reducing adverse outcomes for both individuals and communities.

e. Provide easy access to mental health and addiction services.

f. Provide supports to find and maintain meaningful employment.

g. Increase access to assessment to break the cycle of recidivism for adult offenders suspected of FASD.

h. Provide FASD-informed supports when individuals with FASD are released back into the community from the justice system.

3. Develop a broad FASD-informed workforce across sectors that can deliver the right information at the right time to prevent alcohol-exposed pregnancies and deliver FASD-informed services.

While 89.7% of Albertans responded that they were aware of FASD (Jagodzinski, 2017), only 3% of women participating in a University of Calgary longitudinal study reported they had stopped drinking at pregnancy recognition (McDonald et al., 2014). Investments in province-wide training initiatives, such as the Prevention Conversation and the FASD Learning Series, have proven effective in providing professional development training for workers in a broad cross-section of disciplines. The FASD Service Networks play a critical role identifying and delivering education and training in their regions. The PCAP Council is effectively training PCAP staff and clinicians have access to training and mentoring tailored to meet their needs. A Workforce Development Framework is in development. Continue investment in training an FASD-informed workforce to deliver the right information at the right time that is needed to change behaviour to prevent alcohol-exposed pregnancies, and to deliver FASD-informed services to the 48,800 individuals with FASD living in Alberta (based on a prevalence rate of 1.2% and 2016 Alberta census data). In collaboration with the regulatory bodies and professional associations (e.g., Alberta College of Social Workers, police associations and the Alberta Psychiatric Association), work continues to include FASD in post-secondary curricula and in ongoing professional development/ competencies for all health, education, justice and social services disciplines.

4. Increase capacity to address waitlists for FASD assessment and diagnosis and for FASD-informed services.

Increased awareness and understanding of FASD has resulted in greater demand for FASD prevention services and longer waitlists. According to 2016-17 data from the FASD Online Reporting

System (ORS), almost one-third (25-31%) of all clients receiving Network-funded services are on waitlists for assessment and diagnosis. In March of 2016, 1,133 clients (544 children and 589 adults) were on clinic waitlists – more than the target number of 900 assessments per year. Assessment and diagnosis should be the starting point for access to services, yet only 37% of Network clients have a confirmed diagnosis for FASD.

To address waitlists, additional resources are needed for assessment and diagnosis and for reassessment of youth transitioning to adulthood, with corresponding funding for Networks to meet the increase in demand for services. Seven Networks created navigator positions and a three-tiered triage model to better respond to the wide spectrum of requests for services (Wirzba & Abells, 2017b). Navigators are needed by Networks and clinics to effectively manage waitlists. Like the PCAP Council, the role of the FASD Assessment and Diagnosis Council should be expanded and funded to become an oversight body for Alberta clinics with a focus on addressing and managing waitlists.

5. Collaborate with Indigenous families and communities to enhance delivery of a culturally-informed response to FASD.

While FASD does not discriminate and affects all sectors of society, according to 2016-17 ORS data, 76% of PCAP clients, 70% of clients receiving FASD diagnostic services and 60% of individuals receiving FASD-informed services identified as Indigenous. *Calls to Action* from the Truth and Reconciliation Commission, the *United Nations Declaration on the Rights of Indigenous Peoples, OCAP®* (data collection standards determining how First Nations data should be collected, protected, used, or shared), and Gender Based Analysis Plus (GBA+)[14] are among the direction-setting documents that inform the policies, practices and funded activities of the FASD Cross-Ministry Committee (CMC). Combined with building relationships with Indigenous families and communities and hiring of Indigenous staff to provide FASD services, this culturally-informed approach is becoming a leading practice that is successfully delivering FASD prevention services in collaboration with Indigenous communities. This response is central to reducing the incidence of FASD among Indigenous Peoples and addressing the intergenerational trauma, poverty and other disparities, including the stigma associated with FASD.

6. Sustain and increase investment in Alberta's FASD governance model.

Long-term commitment and investment by the provincial government, with support from the federal government, in the FASD 10-Year Strategy achieved results. Prevention and supports for individuals with FASD, their families and caregivers have proven effective in addressing FASD and reducing societal costs (Thanh et al., 2013 and 2015b), costs which now exceed $1 billion a year (Jonsson, 2017). Led by the FASD Cross-Ministry Committee, supported by the FASD Learning Organization and implemented

14 GBA+ is an analytical tool the government uses to advance gender equality. This tool is used to assess the effects of policies, programs, services, and legislation on diverse groups of women, gender non-conforming people, and men. GBA+ also promotes stronger policies and programs, raises awareness about differences among the genders, and identifies ways to reduce and prevent inequality.

in every corner of the province by the FASD Service Networks, this model has proven to effectively mobilize knowledge, passion and commitment through collaboration. While most Networks have evolved into efficient, well-managed organizations with deep roots in their communities (Wirzba & Abells, 2017a), funding received from the FASD-CMC has not increased proportionally to increasing demands for services. Without an increase in funding, Alberta is not in a position to address the targets going forward. A focus on increasing engagement with Alberta Children's Services, Primary Care Networks and Addiction and Mental Health is recommended.

7. **Update FASD strategic goals, outcomes and indicators, require the use of standardized evaluation and data collection tools and build capacity for cross-system data analytics to inform continuous improvement.**

With the FASD 10-Year Strategy successfully concluded, continue with this planning model, set new targets for the next 10 years and require system-wide evaluations of results achieved at least every five years. Review and refresh the outcome-based management and reporting system. Investments in data collection have supported reporting, not just of inputs, activities and outputs, but also of results, learning and adaptation. Penelope Case Management System (Penelope), FASD Online Reporting System (ORS) and the new FASD Data Integration project are producing powerful tools for data capture and analysis. Tracking FASD assessment recommendations and linking these to services received is recommended for inclusion as part of this suite of tools. Standard definitions for clinic and program waitlists are needed to accurately measure the number of clients and length of time they are waiting for services. Invest in the analysis of data collected to inform continuous improvement. Explore opportunities to imbed FASD-related questions in national population surveys.

8. **Mobilize knowledge regarding the design and implementation of Alberta's model to address FASD.**

Over the past 10 years, Alberta has developed a successful model for addressing FASD. Lessons learned from the development and implementation of Alberta's FASD model (a funded long-term strategy supported by cross-ministerial leadership with federal participation; directly linked to a network that provides regional and local leadership and services across the province; connected by a learning organization that mobilizes knowledge based on evaluation and research through every part of the model; and culturally-informed by Indigenous peoples to meet the needs of their communities) should be disseminated across government as an Alberta success story. Through a strong partnership with academia and service organizations, mobilize knowledge of FASD, its prevention and service provision through participating in and sponsoring ongoing research.

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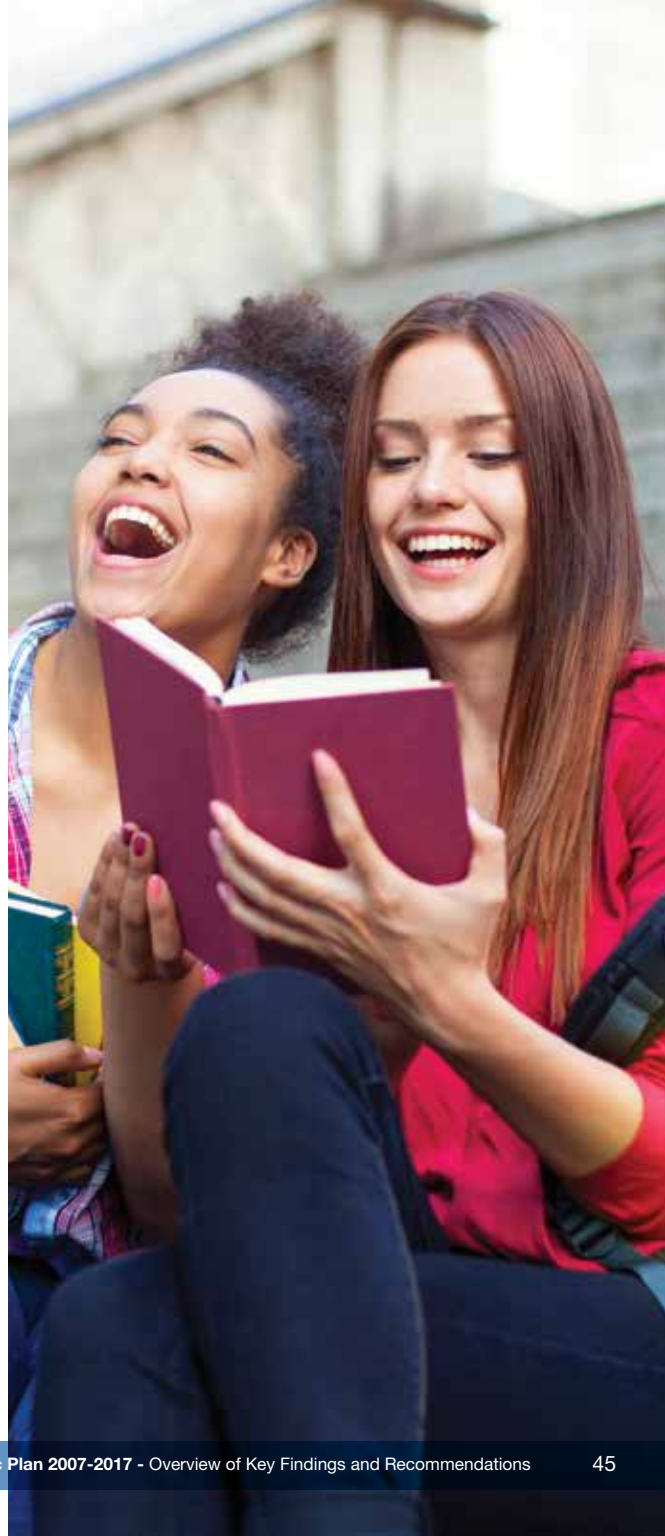

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Appendix A: List of Year 10 Evaluation Final Reports

The following list includes studies prepared by the Year 10 Evaluation team of Susan Abells, Hélène Wirzba and Daniel Fridman, which supported the development of this Overview Report:

Evaluation Framework

Abells S, & Wirzba H. (August 2017). *Year 10 Evaluation of the Government of Alberta's FASD 10-Year Strategic Plan: Year 10 Evaluation Framework.* Edmonton: PolicyWise for Children & Families.

Key Informant Interviews

Wirzba H, Abells S, & Preston, T. (March 2017). *Innovations, accomplishments and challenges: Reflections on the Government of Alberta's FASD 10-Year Strategic Plan (2007-2017).* Edmonton: PolicyWise for Children & Families.

Parent-Child Assistance Program (PCAP)

Wirzba H, & Abells S, (2017). *Year 10 Evaluation of the Government of Alberta's FASD 10-Year Strategic Plan: Evaluation of PCAP Prevention Strategies - Consolidated Report.* Edmonton, AB: PolicyWise for Children & Families.

Wirzba H, Fridman D, & Abells S. (2017). *Year 10 Evaluation of the Government of Alberta's FASD 10-Year Strategic Plan: History and Evolution of PCAP Programs in Alberta.* Edmonton, AB: PolicyWise for Children & Families.

Wirzba H, Abells S, & Bonot K. (September 2017). *Year 10 Evaluation of the Government of Alberta's FASD 10-Year Strategic Plan: PCAP Fidelity Assessment.* Edmonton: PolicyWise for Children & Family.

Wirzba H, & Abells S. (September 2017). *Year 10 Evaluation of the Government of Alberta's FASD 10-Year Strategic Plan: Evaluation of PCAP Council Training Sessions.* Edmonton: PolicyWise for Children & Families.

Support Services

Wirzba H, & Abells S. (October 2017). *Year 10 Evaluation of the Government of Alberta's FASD 10-Year Strategic Plan: Emerging trends in FASD support services - A case study.* Edmonton, AB: PolicyWise for Children & Families.

Summary of Data Reporting to Outcomes

Wirzba H, Fridman D, & Abells S. (November 2017). *Year 10 Evaluation of the Government of Alberta's FASD 10-Year Strategic Plan: Data Sources Reporting to FASD Strategic & Operational Plan Goals, Outcomes and Indicators*. Edmonton, AB: PolicyWise for Children & Families (accompanied by an Excel Spreadsheet of data sources)

Wirzba H, & Abells S. (2017). *Year 10 Evaluation of the Government of Alberta's FASD 10-Year Strategic Plan: ORS Data Analysis and Reporting*. Edmonton, AB: PolicyWise for Children & Families.

Network Governance and Operations

Wirzba H, Fridman D, & Abells S. (October 2017). *Year 10 Evaluation of the Government of Alberta's FASD 10-Year Strategic Plan: FASD Service Network Program Governance and Operations Review*. Edmonton, AB: PolicyWise for Children & Families

Network-specific Reports: Governance and Operations

Fridman D, Wirzba H, & Abells S. (September 2017). *Year 10 Evaluation of the Government of Alberta's FASD 10-Year Strategic Plan: Network-specific Findings from the FASD Service Network Program Governance and Operations Review - Central Alberta FASD Network*. Edmonton: PolicyWise for Children & Families.

Fridman D, Wirzba H, & Abells S. (September 2017). *Year 10 Evaluation of the Government of Alberta's FASD 10-Year Strategic Plan: Network-specific Findings from the FASD Service Network Program Governance and Operations Review - Calgary Fetal Alcohol Network*. Edmonton: PolicyWise for Children & Families.

Fridman D, Wirzba H, & Abells S. (September 2017). *Year 10 Evaluation of the Government of Alberta's FASD 10-Year Strategic Plan: Network-specific Findings from the FASD Service Network Program Governance and Operations Review - Edmonton and area Fetal Alcohol Network*. Edmonton: PolicyWise for Children & Families.

Fridman D, Wirzba H, & Abells S. (September 2017). *Year 10 Evaluation of the Government of Alberta's FASD 10-Year Strategic Plan: Network-specific Findings from the FASD Service Network Program Governance and Operations Review - Lakeland Centre for FASD: An Alberta FASD Network*. Edmonton: PolicyWise for Children & Families.

Fridman D, Wirzba H, & Abells S. (August 2017). *Year 10 Evaluation of the Government of Alberta's FASD 10-Year Strategic Plan: Network-specific Findings from the FASD Service Network Program Governance and Operations Review – Northwest Regional FASD Society-Mackenzie Network.* Edmonton: PolicyWise for Children & Families.

Fridman D, Wirzba H, & Abells S. (September 2017). *Year 10 Evaluation of the Government of Alberta's FASD 10-Year Strategic Plan: Network-specific Findings from the FASD Service Network Program Governance and Operations Review - Métis Settlements FASD Service Network*. Edmonton: PolicyWise for Children & Families.

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