

FASD **10**-YEAR
STRATEGIC PLAN
2008



Alberta FASD Cross-Ministry Committee:

Alberta Children and Youth Services - co-chair/administrative lead

Alberta Health and Wellness - co-chair

- Alberta Health Services/AADAC
- Alberta Health Services/Alberta Mental Health Board

Alberta Aboriginal Relations

Alberta Advanced Education and Technology

Alberta Seniors and Community Supports

Alberta Education

Alberta Employment and Immigration

Alberta Justice and Attorney General

Alberta Solicitor General and Public Security

- Alberta Gaming and Liquor Commission

Health Canada

- Public Health Agency of Canada
- First Nations and Inuit Health Branch

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Message from the Minister

Over 23,000 Albertans have Fetal Alcohol Spectrum Disorder (FASD). The social and economic impacts of the disorder directly or indirectly touch every Albertan.

FASD has a devastating and life-long impact on individuals and communities across our province. Drinking alcohol during pregnancy can cause irreversible brain damage to an unborn child and those with the disorder often need support throughout their life coping with challenges associated with health and mental health problems, addictions issues, learning difficulties, and involvement in the justice system.

The Alberta government is committed to preventing and supporting those affected by FASD. Our recognition that multiple stakeholders need to be involved in order to develop and implement solutions to this problem has led nine provincial ministries and other agencies to join together to develop this FASD 10-Year Strategic Plan.

Work implementing the plan is already taking place and we are beginning to see the results:

- Targeted prevention programs, assessment and diagnosis services, and support for those affected by the disorder are more coordinated due to 12 FASD Service Networks in Alberta.
- A videoconference series and annual conference has educated caregivers and community members on ways to support those affected by FASD.
- Research projects to identify and pilot best practices in working with individuals with the disorder and their caregivers are underway.

We have made great strides over the last several years in the effort to address FASD. But the work has really just begun. Governments, community organizations, educators, health professionals, and families must continue to work together on strategies to promote healthy lifestyles during pregnancy and give hope to those affected by FASD and their caregivers.

This 10-Year Strategic Plan is a sign of hope and a call to action. It sets the stage for further action in the years to come by outlining

collaborative strategies for awareness and prevention, assessment and diagnosis, research and planning, and supports so people with the disorder and their families have access to the services they need to reach their full potential.

I would like to recognize and thank everyone involved in the development of this plan for demonstrating outstanding dedication and cooperation in addressing and supporting those affected by FASD and their caregivers. It is my hope that this plan is shared in communities across the province and is the foundation for making a positive difference in the lives of those with FASD and their caregivers.

By working together, our province will continue being a world leader supporting people and families affected by FASD.



Honourable Janis Tarchuk
Minister of Children and Youth Services

Executive Summary

FASD is increasingly recognized as a significant social and health issue facing Albertans. Basic scientific knowledge and other building blocks for a highly effective FASD support system are in the early stages. In many cases, the programs and services designed to prevent FASD, and to support those who are affected by FASD, are in the early stages of development or are limited in scope.

In response, the Government of Alberta established the Fetal Alcohol Spectrum Disorder Cross-Ministry Committee (FASD-CMC) to provide a coordinated approach for a unique made-in-Alberta framework for addressing FASD. The result is the FASD 10-Year Strategic Plan.

The FASD 10-Year Strategic Plan provides an overview of the scope and impact of FASD on individuals and families in Alberta. It identifies a vision, mission statement, guiding principles and a broad framework for the coordination, planning and delivery of FASD services across Alberta in the areas of:

- Awareness and Prevention
- Assessment and Diagnosis
- Supports for Individuals and Caregivers
- Research and Evaluation
- Strategic Planning
- Training and Education
- Stakeholder Engagement

The document provides a definition for each area, and identifies target groups, desired outcomes, and gaps in services and supports. In addition, the future strategies associated with each area are highlighted and strategy leads are identified for implementing the FASD 10-Year Strategic Plan.



Fetal Alcohol Spectrum Disorder

Fetal Alcohol Spectrum Disorder (FASD) is a term used to describe a range of disabilities that may affect individuals whose mothers drank alcohol while they were pregnant.

The umbrella term covers several alcohol-related medical diagnoses, which include Fetal Alcohol Syndrome (FAS), partial Fetal Alcohol Syndrome (pFAS), alcohol-related neurodevelopmental disorder (ARND) and alcohol-related birth defects (ARBD).

FASD is a lifelong condition that has no cure.

The only way someone can get FASD is if their mother drank alcohol when she was pregnant. Alcohol can cause brain damage in the developing baby, and when it does, the damage is irreversible.

In Canada, prenatal exposure to alcohol is a leading cause of preventable brain damage and birth defects, and one of the top three reasons for developmental delays in children.

It is estimated that nine in every 1,000 babies born in this country are affected with some form of FASD. This equates to more than 3,000 babies each year.

An estimated 23,000 Albertans are living with FASD. Each year, more than 360 Alberta babies are born with FASD.

The impact of FASD on individuals and families is significant, and the effects on many sectors of society, including the criminal justice, child protection, education, health and social systems, is costly.

Children and adults with FASD may have difficulty learning and controlling their behaviour, thinking things through/reasoning, learning from experience, understanding the consequences of their actions, remembering things and getting along with others. Individuals affected by FASD may have life-long special needs that require costly and extensive supports and services to avoid outcomes such

as unemployment, involvement in the criminal justice system, mental health problems, failure at school and family breakdown.



The FASD Stakeholder Population

The Government of Alberta provides support and services to a wide range of stakeholders who are impacted by FASD. The following describes the target groups that are considered within the scope of the FASD 10-Year Strategic Plan.

Children and Youth Diagnosed with FASD

Children and youth with a formal FASD diagnosis based on one of the four diagnostic categories of full FAS, partial FAS, Alcohol Related Neurodevelopmental Disorder or Alcohol-Related Birth Defects (Health Canada diagnostic categories).

Adults Diagnosed with FASD

Adults with a formal FASD diagnosis based on one of the four diagnostic categories of full FAS, partial FAS, Alcohol Related Neurodevelopmental Disorder or Alcohol-Related Birth Defects (Health Canada diagnostic categories).

Children and Youth with Suspected FASD

Children and youth who do not have a formal FASD diagnosis, but have symptoms/indicators that have been identified by a medical doctor and multi-disciplinary diagnostic team.

Adults with Suspected FASD

Adults who do not have a formal FASD diagnosis, but have symptoms/indicators that have been identified by a medical doctor and multi-disciplinary diagnostic team.

Families and Caregivers

Families and individuals who provide an informal support network for people with FASD such as family members, volunteers or friends.

At-Risk Population

A sub-group of individuals within a community who participate in high-risk activities that are known to contribute to increased incidence of FASD, or who have other circumstances or factors that place them at higher risk.

Alberta Communities

Individuals and groups (both geographic and socio-cultural) who may not generally be considered at-risk, but would benefit from prevention and awareness-based services and activities. Includes all segments of the general population, as well as community-based organizations.

A Made-in-Alberta Approach

Addressing FASD is an important issue for the Government of Alberta. A multi-level approach to dealing with the issue provides supports and services to the FASD client population through a variety of ways.

A unique made-in-Alberta framework focuses on developing and delivering community-based solutions that are supported by government policy and funding. Community-based solutions help to ensure the unique needs of individual communities are met. Government supports these solutions by outlining shared goals and providing sustainable funding and other supports that motivate cross-sectoral collaboration.

FASD-CMC

As issues related to FASD are cross-ministerial, cross-jurisdictional and involve other levels of government, the **Alberta FASD Cross-Ministry Committee (FASD-CMC)** was formed in 2002 and includes representation from nine provincial government ministries.

The committee provides a collaborative approach to planning and delivery of government FASD programs and services, while ensuring consistency and synergy in government goals and priorities for FASD.

The participating ministries include:

- Alberta Aboriginal Relations
- Alberta Advanced Education and Technology
- Alberta Children and Youth Services (co-chair)
- Alberta Seniors and Community Supports
- Alberta Education
- Alberta Health and Wellness (co-chair)
 - Alberta Health Services/AADAC
 - Alberta Health Services/
Alberta Mental Health Board
- Alberta Employment and Immigration
- Alberta Justice and Attorney General
- Alberta Solicitor General and Public Security
 - Alberta Gaming and Liquor Commission

Alberta's approach is also coordinated through its partnership with the Canada Northwest Fetal Alcohol Spectrum Disorder Partnership (CNFASDP), which uses a cross-jurisdictional approach and a common message - **if you are pregnant, no alcohol is best** - to promote prevention and provide support to individuals already affected by FASD. The partnership also shares expertise, leading practices, materials and, where possible, effective and efficient use of resources.



If you are pregnant, no alcohol is best.

Other provincial initiatives that support this initiative include Alberta's Safe Communities Secretariat and the Children's Mental Health Plan for Alberta.

FASD Service Providers

Organizations with a service delivery mandate that are supported by Government of Alberta ministries, including:

- Local school jurisdictions
- Family and Community Support Services (FCSS)
- Agencies with a direct contractual relationship with one or more ministries for the provision of FASD-related supports and services

Government of Canada

Health Canada and its agencies, Public Health Agency of Canada and First Nations and Inuit Health Branch have a role in providing FASD-related services and sit at the Alberta FASD-CMC table.



Provincial FASD 10-Year Strategic Plan: 2007 – 2017

Introduction

This Fetal Alcohol Spectrum Disorder (FASD) Strategic Plan has been developed by the Fetal Alcohol Spectrum Disorder Cross-Ministry Committee (FASD-CMC) in response to the committee's mandate to "develop a strategic plan in order to advise and make recommendations to government and community in order to achieve desired outcomes". The following initiatives were completed as part of the strategic planning process.

1. Developed an inventory of current FASD programs and services in Alberta.
2. Developed a set of principles to guide the strategic planning process.

3. Developed an FASD service framework that identifies primary stakeholders, FASD service categories and activities, and future-oriented outcome statements that reflect a shared vision of FASD supports and services by 2017.
4. Performed a gap analysis in order to identify major areas for development over the next 10 years in relation to the identified outcomes.
5. Developed broad strategies for each of the outcomes identified.

This strategic plan is designed as a direction-setting document to provide a broad framework for the coordination, planning and delivery of relevant FASD services across Alberta. Development of the plan has engaged community partners and federal government agencies responsible for FASD initiatives.

Government is committed to working with all communities, including Aboriginal people and cultural communities, in the implementation of the plan and development of future FASD programming.

Vision

That Alberta has a comprehensive and coordinated provincial response to Fetal Alcohol Spectrum Disorder across the lifespan and a continuum of services that is respectful of individual, family, culture and community diversity.

Mission

The Government of Alberta will provide leadership and work collaboratively with partners to provide FASD services in Alberta.

*An estimated 23,000 Albertans are living with FASD.
Each year, more than 360 Alberta babies are born with FASD.*

Guiding Principles

The following principles continue to guide the planning process:

Reflect that needs exist across the lifespan:

Government focus on FASD is from pre-conception to death, as FASD is a condition that affects a person throughout their life.

Develop a cross-government approach:

Government interest in FASD is cross-ministerial, cross-jurisdictional and involves other levels of government.

Recognize that services are needed across the continuum:

Major strategic initiatives associated with FASD include prevention of FASD, diagnosis and support of affected individuals/families.

Align planning efforts with other government initiatives:

Goals associated with FASD in government business plans are complementary and synergistic.

Include a wide range of perspectives:

Input from both Aboriginal and cultural communities continues to be an important and fundamental component of planning for services related to FASD.

Recognize that collaboration with stakeholders is critical: Networking amongst stakeholders in FASD is important and is facilitated.

Understand and utilize appropriate terminology:

The term FASD is utilized as the appropriate descriptor of brain injuries associated with prenatal exposure to alcohol.





Canadian Northwest FASD Partnership

The Canadian Northwest FASD Partnership is an alliance of seven jurisdictions: Alberta, British Columbia, Manitoba, Northwest Territories, Nunavut, Saskatchewan and the Yukon, that work together to develop and promote an inter-jurisdictional approach to prevention, intervention, care and support of individuals who are affected by Fetal Alcohol Spectrum Disorder (FASD).

The goal is to bring together policy makers, front-line service providers, researchers, clinicians and other concerned individuals and communities to facilitate the development of shared and consistent: vision; messages for social marketing/public awareness; strategies

for prevention and building community capacity; training and education; collaboration with government leadership and evaluation/research. Results and analysis are shared with member provinces and territories.

The partnership has sponsored a number of symposiums and conferences and has initiated more than 350 FASD public awareness campaigns across the participating provinces and territories.

Alberta is one of the founding three provinces of the Partnership.

For more information, visit www.cnfasdpartnership.ca

Realizing the Outcomes: Strategic Directions for FASD Supports and Services in Alberta

FASD is increasingly recognized as a significant social and health issue facing Albertans. More work needs to be done to increase the knowledge of FASD and determine what types of supports and services will most impact people affected by FASD and their caregivers. Existing programs and services designed to prevent FASD, and to support those who are already affected, require further development and evaluation to determine their effectiveness.

Several types of activities have been identified to describe the range of services that are undertaken in Alberta relative to the prevention and treatment of FASD.

For each type of activity, the FASD 10-Year Strategic Plan:

- Defines the scope of activities included within the category;
- Identifies stakeholders (target groups) who should be the primary recipients of services and activities within the category;
- Identifies gaps in research, programming, system support and service delivery; and
- Identifies target outcomes to provide a broad framework for the coordination, planning and delivery of FASD services across Alberta. These statements are “forward looking”, and reflect a shared vision of FASD supports and services by 2017.

¹ Based on Child & Family Service Authority regional boundaries.

For each of the high-level outcome statements included in the FASD 10-Year Strategic Plan, an analysis was performed to identify:

- Programs/services that are currently operating and will contribute to achieving the outcome;
- Regions of the province¹ that programs/ services are operating in; and
- Target groups that programs/services serve.

The participating ministries identified key strategies to address these gaps that will be developed and implemented by 2017 in order to reach the measurable outcomes.



Many of the strategies are designed to build a foundation for success of future strategies and will not begin immediately. In other cases, the capability and capacity to develop and implement the strategy is in place, and work will begin immediately.

The strategic plan identifies a strategy lead/co-lead for each proposed strategy, as the ministry or ministries responsible for leading further development of each strategy. The strategy lead/co-leads will recruit partners from among participating ministries and others to participate in the strategy.

The lead(s) will play a project management role, coordinating action items with the other ministries and communicating progress to government. Strategy development may involve the use of sub-committees within the FASD-CMC, with the strategy lead or co-leads acting as committee chair/co-chairs.

The FASD-CMC has ultimate responsibility for implementing this strategic plan and all

partnering ministries will be actively involved in the development of all strategies.

The FASD 10-Year Strategic Plan is designed to provide services in the areas of:

- Awareness and Prevention
- Assessment and Diagnosis
- Supports for Individuals and Caregivers

Activities are also performed in the areas of:

- Research and Evaluation
- Strategic Planning
- Training and Education
- Stakeholder Engagement

Ongoing evaluation and monitoring of the strategic plan will ensure targets are being met and projected outcomes are being realized.

Details about the targets and desired outcomes can be found at www.fasd-cmc.alberta.ca



Significant progress has been made in a number of key areas of FASD prevention in Alberta. Co-operative efforts have helped to create new support and enhance service delivery across the province.



Aboriginal Outreach in Central Alberta

With a goal to ensure FASD outreach services are inclusive of the local Aboriginal population, the Central Alberta FASD Service Network has formed an Aboriginal subcommittee as the first step in creating a hub of FASD supports and services designed for the specific needs of Aboriginal communities.

By working together with and engaging Aboriginal stakeholders to clarify their needs and opportunities for developing comprehensive FASD services, a culturally relevant support model is being developed to support Aboriginal people affected by FASD in central Alberta.

In addition, regional FASD agencies, service providers and network partners receive training to assist in understanding the specific cultural needs of the Aboriginal population.



1. Awareness and Prevention

Definition:

Awareness and prevention services are those that educate and inform about the risks of drinking alcohol while pregnant, the effects of FASD, as well as those services that increase overall awareness about healthy pregnancy. Consideration is required to ensure awareness and prevention services are culturally-appropriate for Aboriginal and other communities including:

Information – Information available to the general public about the risks of using substances during pregnancy and on support services available.

Universal Prevention – Strategies undertaken with a healthy population to maintain or enhance physical and emotional health. Universal prevention activities typically focus on behaviour change, systems or the environment. Services may include population health promotion, public awareness approaches, etc.

Targeted Prevention – Strategies targeting women of child-bearing age who use substances. Activities could include outreach, screening,

referral and brief intervention activities. The intent is to enhance protective factors to promote the health of the mother and prevent or minimize harm to the fetus.

Indicated Prevention – Strategies targeting women who have given birth to one or more children affected by FASD, and women who are known to be pregnant and consuming alcohol or other harmful substances. The aim of indicated prevention is to minimize the damage to the fetus, reduce the likelihood of further affected pregnancies, and increase the capacity of the mother and her partner to effectively care for her children affected by FASD. This involves intensive multi-component activities, including such strategies as substance abuse treatment, planned pregnancies and parenting programs.

Treatment – Services for women who have recently given birth to children affected by FASD to help them recover from the harmful effects of substance abuse and to stabilize and enhance their physical and mental health.

Awareness and Prevention continued

Target Groups:

- Alberta communities
- At-risk population

Outcome 1a:

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

There is no known safe level of alcohol for an unborn child and there is no safe time to drink alcohol during pregnancy.

Gaps:

Historically at the provincial level, there was no coordinated approach to awareness and prevention activities across ministries, including those related to the development and dissemination of leading practices. Similarly, there was a lack of clarity regarding the most appropriate role for some ministries, as well as industry and community organizations/groups, as it relates to the development and delivery of awareness and prevention activities.

Finally, there was a notable lack of mechanisms to evaluate effectiveness of awareness and prevention activities, making it difficult to assess the gap in awareness and prevention programming in a precise manner.

Strategies:

- 1.1 Promote a coordinated approach to FASD prevention activities.
- 1.2 Encourage regional bodies and communities to provide early intervention and harm reduction programming to high-risk populations, including services designed for Aboriginal communities.
- 1.3 Continue to inform Albertans across government regarding the complex nature of FASD and its cause.

Strategy Leads:

- 1.1 Alberta Children and Youth Services, Alberta Health and Wellness, Alberta Health Services/AADAC
- 1.2 Alberta Children and Youth Services, Alberta Health Services/AADAC
- 1.3 Alberta Health and Wellness, Alberta Health Services/AADAC

Outcome 1b:

Alcohol use during pregnancy is eliminated.

Gaps:

The ultimate goal of the FASD strategy is elimination of alcohol use during pregnancy. However, the root causes of alcohol use during pregnancy are highly complex. As a 10-year target, this outcome is extremely challenging and will require a high level of understanding and involvement by all stakeholders involved in FASD programming and service delivery. There is a need for programming designed to increase knowledge among ministries regarding the root causes of FASD and necessary awareness/prevention activities.

Historically, there were significant gaps in most regions of the province as it relates to one or more target groups. There was a need for funding to support appropriate programs and services targeted at pregnant women, as well as individuals in high (i.e., chronic consumers of alcohol) and moderate risk (i.e., occasional consumers of alcohol) categories.

Strategies:

- 1.4 Ensure that women of child-bearing age have access to and are educated about the causes and effects of FASD.
- 1.5 Coordinate FASD strategies with agencies that focus on reducing unplanned pregnancies.

Strategy Leads:

- 1.4 Alberta Children and Youth Services, Alberta Health and Wellness, Alberta Health Services/AADAC
- 1.5 Alberta Health and Wellness



Ongoing research will help to determine effective strategies for supporting women who are pregnant or may become pregnant to make changes and choose healthy lifestyle options.

2. Assessment and Diagnosis

Definition:

“Assessment and diagnostic services include medical, cognitive, behavioural, communication, adaptive and executive functioning information provided by a multi-disciplinary team trained in the current best practice model. Referrals to the team require the history of prenatal alcohol exposure and areas of suspected dysfunction.” – *Dr. Gail Andrew*

Assessment and diagnosis services may or may not lead to a confirmed diagnosis of full Fetal Alcohol Syndrome, partial Fetal Alcohol Syndrome, Alcohol Related Neurodevelopmental Disorder or Alcohol-Related Birth Defects.

Target Groups:

- Children and youth with suspected FASD
- Adults with suspected FASD

Outcome 2:

Adults, children and youth suspected as being affected by **FASD** have access to timely and affordable **assessment diagnostic services**.

Gaps:

Available data shows that while all regions of the province have access to assessment and diagnostic services available for children, there are regional disparities. There is a significant range in availability of assessment and diagnostic services for youth and adults operating across the province. The large majority of assessment services across the province focus on young children. In addition, there needs to be improvements to consistency of diagnosis and development of a provincial standard.

Even in situations where assessment and diagnostic services are available, anecdotal evidence suggests that services must be enhanced to meet the demand.

Other priority areas requiring attention are the development of common screening/diagnostic standards across the province and targeted assessment/diagnostic funding.

Strategies:

- 2.1** Support screening and multi-disciplinary assessment and diagnostic teams so that sufficient, affordable and timely FASD diagnostic services are in place across the lifespan, with particular consideration given to rural and Aboriginal communities.
- 2.2** In consultation with relevant clinicians in Alberta, review, update and summarize provincial standards for FASD assessment and diagnosis.

Strategy Lead:

- 2.1** Alberta Health and Wellness
- 2.2** Alberta Health and Wellness, Alberta Children and Youth Services



3. Supports for Individuals and Caregivers

Definition:

The service category Supports for Individuals and Caregivers addresses the needs of individuals with FASD and their informal/unpaid support network. It does not include formal, paid caregivers. Programs and services in the community, aimed at enabling individuals affected by FASD to reach their potential, as well as supports and assistance to families and caregivers of individuals affected by FASD are included. Consideration is required to ensure supports for individuals and caregivers are inclusive of the needs of Aboriginal, cultural, and rural peoples.

Supports and services required for affected individuals and their families/caregivers include the following areas, but are not limited to the services listed:

Information – including supports and services that are available, how to support affected individuals and how to live with FASD.

Service Coordination/Case Management – including assistance in accessing supports and services, screening, assessing, service planning, monitoring and evaluation, and identification of gaps in resource development and advocacy.

Supports for Daily Living – including coaching, mentorship, training and support in activities of daily living, diversion programs and working with employees and social support networks.

Rehabilitation/Behavioural Services – including physical therapy, occupational therapy, speech therapy, mental health services and behavioural interventions.

Opportunities for Meaningful Activities – including school/education programs for children and adults, employment supports and day programs.

Social Supports – including supports and services based on the needs of the family/caregiver that prevent burnout or placement breakdown such as respite services, network support, in-home or out-of-home relief, etc.

In addition, affected individuals require improved access to:

Housing – including places to live that are affordable and provide structure and support for affected individuals.

Income Support – including support and services available through, but not limited to, Assured Income for the Severely Handicapped (AISH), Alberta Works.

Some of the supports and services listed above, as well as others such as health/medical services, mental health services and income support programs, are available to all Albertans, regardless of diagnosis. It is recognized however, that access to these services may be more difficult for affected individuals.

Target Groups:

- Children and youth diagnosed with FASD
- Adults diagnosed with FASD
- Children and youth with suspected FASD
- Adults with suspected FASD
- Families and caregivers

Outcome 3:

Individuals affected by **FASD** and their caregivers have **coordinated** access to **supports and services** that meet their needs.

Gaps:

Available data suggests a significant gap exists in most regions of the province regarding coordinated access to services based on assessed need. It is notable there is no single ministry with the mandate to provide programs and services for adults diagnosed with FASD or suspected

to be affected by FASD. Finally, there is also a need for enhanced coordination of support services for individuals in all target groups.

Significant gaps in service also exist in many regions for adults and for children suspected to be affected by FASD. This gap is prevalent across the lifespan, from childhood through adulthood, and is particularly significant for youth-in-transition to adulthood and for adults.

Current information suggests that programs and services are available to support families and caregivers at the provincial level and in all regions of the province. However, programming of supportive services for families and caregivers could be coordinated and there is limited engagement of families and caregivers in assessing their needs. Although data shows that programs and services are operating, the level of support available to families and caregivers with children affected with FASD is not sufficient to meet their needs.

Strategies:

- 3.1 Facilitate enhancement and integration of coordinated services for adults, children and youth affected by FASD as well as their caregivers.
- 3.2 Improve access to services for individuals affected by FASD, including vulnerable populations who are not receiving the support they need, with a particular focus on youth-in-transition to adulthood.

Strategy Leads:

- 3.1 Alberta Seniors and Community Supports, Alberta Children and Youth Services
- 3.2 Alberta Seniors and Community Supports



Innovative Housing Program Supports FASD Affected Men

The North East Alberta Fetal Alcohol Network in the Fort McMurray/Wood Buffalo region launched an innovative supportive housing project for men affected with FASD in the spring of 2008. The goal is to support three to four males from the community who are homeless or at risk of being homeless and affected by FASD. The initiative is the first of its kind in Alberta.

Located in Fort McMurray, the project offers a home for adult males with FASD to live independently with 24/7 support. Additional aid ensures the men receive wrap-around services from within the community by connecting them with the supports they need, assisting them in finding employment and developing life skills, and providing them with other resources, information and supports that are necessary for them to become healthy and socially successful citizens.

The service delivery project is a cooperative effort of the Network and partner agency, the Centre of Hope.

4. Training and Education

Definition:

Training and education services consist of formal education, pre-service and in-service training programs, typically targeted at program/service providers (including health, medical and human services professionals) and/or community groups. It is particularly important that training and education services be culturally appropriate for Aboriginal and other populations.

Target Groups:

- FASD service providers
- Families and caregivers
- Educational institutions
- Government of Alberta employees

Outcome 4:

Service providers and families/caregivers have knowledge of and access to training and educational resources that are based on research and leading practices.

Gaps:

Gaps in training and education currently exist from several perspectives. First, no province-wide FASD training standards currently exist in Alberta. Second, there is limited research to inform content of FASD training and educational programs, no formalized linkage between FASD research and development of leading practices, and limited availability of FASD training opportunities and educational materials in both pre-service and in-service curricula. Although some material is available in most regions, educational opportunities, supportive mechanisms to facilitate family/caregiver access to educational programs, and materials for families and caregivers designed in a culturally sensitive manner are limited. Third, there is recognition that further workforce development and capacity building in the field of FASD across the lifespan is required.

Strategies:

- 4.1 Encourage integration of research and leading practice with post-secondary and in-service training.

- 4.2** Facilitate access to and knowledge of FASD educational and training resources for service providers and families/caregivers in both Aboriginal and cultural communities.

Strategy Leads:

- 4.1** Alberta Advanced Education and Technology,
Alberta Health Services/AADAC
- 4.2** Alberta Children and Youth Services,
Alberta Seniors and Community Supports,
Alberta Health Services/AADAC

Research in Education and Training

An environmental scan is being completed of all FASD-related education and training currently offered within Alberta, nationally and internationally. With a completed inventory, the FASD-CMC will be able to address cultural and diverse education and training issues, and develop recommendations for best practices in the delivery of education and training for FASD.



Telelearning Sessions Support Staff, Caregivers, Parents

Through a collaborative effort between Workforce Development, the Cross-Ministry Partnership, FASD Service Networks and Alberta Children and Youth Services, videoconferencing learning sessions support the front-line staff of FASD Service Networks and community agencies that work directly with clients with FASD, their parents and caregivers.

The goals of these videoconferencing sessions are to build capacity for awareness and identification of mental health concerns of children and youth, and to provide staff with information and resources to support children and families dealing with these concerns. The sessions support the FASD 10-Year Strategic Plan, specifically in the areas of awareness and prevention, assessment and diagnosis, and supports for individuals and caregivers.

Feature topics include:

- Understanding a diagnosis of FASD and the impact on the child and their caregiver;
- Compassion fatigue of staff working with children, youth and their families with FASD;
- Behaviour problems of children with FASD;
- Treatment approaches for children with FASD; and
- Secondary disabilities of children with FASD such as conduct disorder, Attention Deficit Hyperactivity Disorder (ADHD), depression, attachment disorder and/or other mental health concerns.

The first series for parents and caregivers in 2007 was made available in 40 communities and featured renowned author Diane Malbin, speaking on issues related to raising children with FASD across the lifespan.

5. Strategic Planning

Definition:

Strategic planning refers to the range of activities performed by government that are aimed at recommending priority areas for government policy and action.



Target Groups:

- Government of Alberta ministries

Outcome 5:

The planning and **delivery of provincial government programs** and services associated with FASD is accomplished through **a collaborative approach**.

Gaps:

While FASD has a high profile in the operational plans of some Alberta government ministries serving children and youth, there is a gap in the plans to address FASD for ministries serving adults, regional bodies, agencies and boards and commissions.

As the profile of FASD is raised across the Government of Alberta, there is a need to ensure continued discussion, planning coordination and communication of new initiatives. This translates into a need for a systematic way of sharing information about cross-ministry initiatives and frameworks across the ministries and with the regions.



Strategies:

- 5.1 Encourage government ministries to reflect FASD-related priorities in operational plans.
- 5.2 Maintain the profile of FASD-related priorities among applicable government and non-government agencies.
- 5.3 Align FASD strategic priorities with applicable cross-ministry policy frameworks.

Strategy Leads:

- 5.1 All participating ministries
- 5.2 All participating ministries
- 5.3 All participating ministries

Addressing the Complex Needs of Children with FASD

A cooperative research project between the University of Calgary Faculty of Social Work and Alberta Children and Youth Services is examining the impact of enhanced case-management practice standards on children in foster care who are diagnosed or suspected to have Fetal Alcohol Spectrum Disorder (FASD). The project will directly inform ministry policy and practice regarding children in care who are affected by FASD by exploring and understanding how each of the standards influences placement outcomes.

Data gathered will include information related to the placement stability and risk behaviour for the two years prior to implementation of the practice standards, 12 months after implementation and 18 months after implementation. Findings which promote placement stability may contribute to more positive outcomes for children and families who are affected by FASD.

The project involves two components:

- Focus group discussions with staff and foster parents at the beginning, mid-point and end of pilot implementation as well as case reviews to determine the level of compliance with practice standards.
- For the purpose of hypothesis testing, two comparison groups are being studied — a pilot group that will implement the practice standards and a comparison group that will not. Children in the study are matched based on age, gender, child welfare status, number of years in foster care and diagnostic classification (diagnosed or suspected).

Findings from the project will be used as evidence-based information to guide the FASD Community of Practice and to provide Alberta Children and Youth Services and child welfare services providers in other jurisdictions with the evidence to inform decision making, resource allocation and policy development in the areas of FASD.

6. Research and Evaluation

Definition:

Research refers to basic scientific and applied research leading to increased understanding of FASD, its epidemiology (i.e., incidence and prevalence), leading practices in the prevention and treatment of FASD, and development of standards to guide the delivery of FASD clinical services and/or FASD programming.



Target Groups:

- Government of Alberta ministries
- FASD service providers
- Post-secondary institutions
- Clinicians

Outcome 6:

Basic and applied research findings, including those from monitoring and evaluation systems, are used to inform FASD strategic planning, FASD prevention activities and FASD related programming.

Gaps:

Available data suggests that research infrastructure is being developed, particularly at the provincial level. There is recognition that individual agencies at the community level are likely conducting their own research as part of program planning, and therefore does not appear in the current analysis. The primary gap exists in the lack of a mechanism to support coordination of research at the provincial level. Historically, there was no mechanism to allow the government to participate in or influence regional and community-level research agendas across the province.

FASD is a lifelong condition that has no cure.

Existing mechanisms to facilitate and share research findings include the Clinical Practice Guidelines of the Alberta Medical Association, the Alberta Centre for Child, Family and Community Research, the University of Lethbridge FASD Research Project and the Canada Northwest FASD Partnership.

While these programs have dissemination of knowledge as a key role, many are in the early stages of development. Consequently, a gap exists in the sharing of research findings with regional service providers. Similarly, there was no process to bring in research findings from national and international sources and validate them for application in Alberta. The FASD-CMC is working with the Alberta Centre for Child, Family and Community Research and the Canada Northwest FASD Research Network to coordinate and share research.

There are no significant Alberta epidemiological studies to form the basis of plans or to measure success in prevention programs. Clearly, the epidemiology of FASD is an area for development not only in Alberta but internationally as well. The data and information that would come

from epidemiological studies would be useful in a variety of ways. There is an immediate need for the development of ways for counting cases because of a lack of standardization in diagnosis. Such studies will provide a means of benchmarking for prevention programs. Finally, small area variations are known to exist in the distribution of cases, so regional statistics are also needed for province-wide studies.

Currently, the knowledge-management activities needed to acquire, aggregate and synthesize research information from Alberta, national and international studies are not happening. These knowledge-management activities are needed to inform a wide range of planning and service providers' initiatives. As program evaluations are undertaken, a means of sharing results with interested parties would be valuable.

Strategies:

6.1 Support the development of research infrastructure and mechanisms with consideration given to appropriate methodologies for rural and Aboriginal communities.

- 6.2** Collaborate with stakeholders, including the Alberta Centre for Child, Family and Community Research, to support and facilitate sharing of research findings.
- 6.3** Promote basic and applied research that leads to increased knowledge of the epidemiology of FASD.
- 6.4** Support the development of an evaluation framework to determine the effectiveness of FASD programs and services in Alberta.

Strategy Leads:

- 6.1** Alberta Children and Youth Services, Alberta Gaming and Liquor Commission
- 6.2** Alberta Children and Youth Services
- 6.3** Alberta Health and Wellness, Alberta Gaming and Liquor Commission
- 6.4** All participating ministries



Research Pilot Project Targets Preconception Women

A research pilot project, launched in the fall of 2008 in Fort McMurray, will gather information on the knowledge and understanding of FASD among preconception women in order to shape the most appropriate and effective FASD awareness campaign for the community.

Local pharmacists will be recruited to provide input to the development of the survey tool and to ask clients to complete the questionnaire to determine their knowledge about FASD. A FASD fact sheet, which addresses myths and provides evidence-based realities associated with FASD, will then be provided to the women.

Information will also be gathered from the pharmacists to determine their level of comfort in discussing FASD with clients as well as the need for additional information and/or support.

The project's proposed five-phase approach includes a literature search, survey development/pretesting, data analysis, selection of messaging materials, and information gathering from pharmacists.

7. Stakeholder Engagement

Definition:

Stakeholder engagement refers to the sharing of information among the government, practitioners and the FASD client population to facilitate informed and balanced decisions regarding government priorities and actions. Engagement occurs among stakeholders at different levels of the system (e.g., between ministries and regional organizations) and stakeholders at the same level of the system (e.g., among regional organizations). Stakeholders will include provincial, federal and local governments, community organizations, research organizations and advocacy groups.

Target Groups:

All target groups

Outcome 2:

Mechanisms are in place to facilitate and **encourage stakeholder engagement** in the FASD Cross-Ministry Committee strategic planning process, as well as to provide stakeholder opportunities for networking and information sharing.

Gaps:

During initial planning stages there was no single province-wide “community” organization representing a broad range of stakeholders who could participate in the development of this strategic plan. There is a need for a process to define and engage groups who can provide meaningful input, on behalf of the defined stakeholders, to the Provincial FASD 10-Year Strategic Plan.

The federal government has identified community capacity as a priority area for FASD. The provincial government is committed to engaging the federal government to enhance community capacity in Alberta. Development of the FASD Service Networks was therefore determined to be a priority.

Strategies:

- 7.1 Identify and link key FASD stakeholders in Alberta.
- 7.2 Collaborate with stakeholders to identify and update strategic directions for FASD supports and services in Alberta.

Strategy Lead:

- 7.1 Alberta Children and Youth Services, Alberta Solicitor General and Public Security/Alberta Gaming and Liquor Commission
- 7.2 Alberta Children and Youth Services, Alberta Solicitor General and Public Security/Alberta Gaming and Liquor Commission



A research project is exploring whether or not the leading practices outlined in the program guidelines for the FASD Service Networks are applicable to the entire province.



Developed and implemented FASD Service Networks Model

- In 2007, \$4 million was allocated to support the initial implementation of the 10-Year FASD Strategic Plan.
 - Seven FASD Service Networks were established across the province. These networks are comprised of community agencies and organizations that provide services either specific or related to FASD in their communities. The networks are tasked with developing or expanding services and encouraging collaborative approaches to fill existing gaps focusing on three areas of service delivery: assessment and diagnosis, targeted and indicated prevention and supports for individuals affected by FASD and their caregivers.
- In 2008, \$16.5 million was allocated to the continued implementation of the 10-Year Strategic Plan.
 - Five additional FASD Service Networks were established.

In Canada, prenatal exposure to alcohol is a leading cause of preventable brain damage and birth defects, and one of the top three reasons for developmental delay in children.

Summary

DEFINITION	OUTCOME	STRATEGIES
1. Awareness and Prevention	1a. Albertans understand that alcohol use during pregnancy can lead to FASD, that FASD can be prevented and that FASD prevention is a shared responsibility. 1b. Alcohol use during pregnancy is eliminated.	1.1 Promote a coordinated approach to FASD prevention activities. 1.2 Encourage regional bodies and communities to provide early intervention and harm reduction programming to high-risk populations, including services designed for Aboriginal communities. 1.3 Continue to inform Albertans across government regarding the complex nature of FASD and its cause. 1.4 Ensure that women of child-bearing age have access to and are educated about the causes and effects of FASD. 1.5 Coordinate FASD strategies with agencies that focus on reducing unplanned pregnancies.
2. Assessment and Diagnosis	2. Adults, children and youth suspected of being affected by FASD have access to timely and affordable assessment and diagnostic services.	2.1 Support screening and multi-disciplinary assessment and diagnostic teams so that sufficient, affordable and timely FASD diagnostic services are in place across the lifespan, with particular consideration given to rural and Aboriginal communities. 2.2 In consultation with relevant clinicians in Alberta, review, update and summarize provincial standards for FASD assessment and diagnosis.
3. Supports for Individuals and Caregivers	3. Individuals affected by FASD and their caregivers have coordinated access to supports and services to meet their needs.	3.1 Facilitate enhancement and integration of coordinated services for adults, children and youth affected by FASD as well as their caregivers. 3.2 Improve access to services for individuals affected by FASD, including vulnerable populations who are not receiving the support they need, with a particular focus on youth-in-transition to adulthood.

Details about the targets and desired outcomes for these strategies can be found at www.fasd-cmc.alberta.ca

Summary continued

DEFINITION	OUTCOME	STRATEGIES
4. Training and Education	4. Service providers and families/caregivers have knowledge of and access to training and educational resources that are based on research and leading practices.	<p>4.1 Encourage integration of research and leading practices with post-secondary and in-service training.</p> <p>4.2 Facilitate access to and knowledge of FASD educational and training resources for service providers and families/caregivers in both Aboriginal and cultural communities.</p>
5. Strategic Planning	5. The planning and delivery of provincial government programs and services associated with FASD is accomplished through a collaborative approach.	<p>5.1 Encourage government ministries to reflect FASD-related priorities in operational plans.</p> <p>5.2 Maintain the profile of FASD-related priorities among relevant government and non-government agencies.</p> <p>5.3 Align FASD strategic priorities with relevant cross-ministry policy frameworks.</p>
6. Research and Evaluation	6. Basic and applied research findings, including those from monitoring and evaluation systems, are used to inform FASD strategic planning, FASD prevention activities and FASD related programming.	<p>6.1 Support the development of research infrastructure and mechanisms with consideration given to appropriate methodologies for rural and Aboriginal communities.</p> <p>6.2 Collaborate with stakeholders, including the Alberta Centre for Child, Family and Community Research, to support and facilitate sharing of research findings.</p> <p>6.3 Support and promote basic and applied research that leads to increased knowledge of the epidemiology of FASD.</p> <p>6.4 Support the development of an evaluation framework to determine the effectiveness of FASD programs and services in Alberta.</p>
7. Stakeholder Engagement	7. Mechanisms are in place to facilitate and encourage stakeholder engagement in the FASD-CMC strategic planning process, as well as to provide stakeholder opportunities for networking and information sharing.	<p>7.1 Identify and link key FASD stakeholders in Alberta.</p> <p>7.2 Collaborate with stakeholders to identify and update strategic directions for FASD supports and services in Alberta.</p>



For more information visit:
www.fasd-cmc.alberta.ca

