



**Alberta
Fetal
Alcohol
Spectrum
Disorder
(FASD)
Cross-Ministry
Committee**

2011/2012 Annual Report

ALBERTA FETAL ALCOHOL SPECTRUM DISORDER CROSS-MINISTRY COMMITTEE (FASD-CMC)

2011/2012 ANNUAL REPORT



Fetal Alcohol Spectrum Disorder (FASD) describes a cluster of birth defects caused by prenatal exposure to alcohol. It is a life-long condition causing health issues, speech and language problems, learning difficulties and behavioural problems, with varying levels of severity.

The Alberta FASD Cross-Ministry Committee (FASD-CMC) is a coordinating body that facilitates collaboration between ministries, government agencies, and

stakeholders, within the framework of Alberta's FASD 10-Year Strategic Plan. This report provides a summary of work funded by the FASD-CMC and partner ministries during the 2011/12 fiscal year toward improving the lives of children, youth, adults, and families affected by FASD.

Understanding the experiences of those who are impacted by FASD is critical. While statistics and data tell an important part of the story, integrating facts with the experiences of people living with FASD illuminates the significance of this work and how the Alberta FASD 10-Year Strategy is making a valuable difference in the lives of Albertans. One example of programs making a difference is the Parent-Child Assistance Program (PCAP), a mentoring program for women who are at high risk of giving birth to a child with FASD.



In 2012, a quilting project was undertaken to explore the experiences of 46 PCAP mentors working on the front lines of FASD prevention programs across Alberta. Each participant created a square that depicted the experience of working in PCAP; each individual square was then crafted into an interpretive quilt by a master quilter and psychologist. The final result is a visual collection of stories and experiences that capture what it is like to live with, and work with, FASD.



Creating the quilt was a moving experience for all involved, capturing the challenge, passion and vision of hope that goes into FASD prevention services. The quilt serves as a compelling metaphor for all of the work under the FASD-CMC umbrella – work that brings together many individual parts into a coordinated whole that responds to the needs of children, youth, adults and families affected by FASD. The results of this quilting project have been chosen as the theme for the 2011/12 FASD-CMC Annual Report, to help tell the story of FASD's impact and what Alberta is doing to help.

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1. EXECUTIVE SUMMARY



Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term used to describe a cluster of birth defects caused by prenatal exposure to alcohol. It is a disability that affects the individual from birth throughout adulthood, and can impact the individual in all aspects of his or her daily living, with varying degrees of severity.

For more than a decade, the Alberta government has recognized the significant impacts of FASD on individuals and their families, on communities, and on society. The Alberta Fetal Alcohol Spectrum Disorder Cross-Ministry Committee (FASD-CMC) was formed in 2002 to facilitate collaboration between ministries, government agencies, and stakeholders, within the framework of Alberta's FASD 10-Year Strategic Plan. A total of \$16.5 million was allocated under the Strategic Plan for FASD programs and services in 2011/12.

This report provides a synopsis of the key activities and results from programs and initiatives funded by the FASD-CMC and partner ministries during the 2011/12 fiscal year. Programs and initiatives fit into one of two categories: (1) the Provincial FASD Service Network Program; or (2) Provincial and Ministry-specific Initiatives.

Provincial FASD Service Network Program

The Provincial FASD Service Network Program is made up of 12 Networks across the province, each providing a single point of entry for individuals and caregivers seeking assistance. The Networks are responsible for developing or expanding FASD services in three areas:

Awareness and Prevention – In partnership with FASD-CMC, the Networks conducted a number of activities to raise awareness about FASD and the services provided by the Networks. In 2011/12, 2,340 individuals received Network services (25% more adults and 23% more youth than in 2010/11). Additionally, more than 360 women received prevention services through the Parent-Child Assistance Program (PCAP), a 48% increase from the previous year.

Assessment and Diagnosis – The 15 FASD assessment and diagnostic clinics that receive funding from the Networks provided services to 659 Albertans, 17% more in 2011/12 compared to the previous year.

Supports for Individuals and Caregivers – Network funding was provided to approximately 45 community-based organizations to provide a wide range of support services to individuals affected by FASD and their caregivers. Almost 1,800 individuals received support services in 2011/12, a 27% increase from 2010/11.



Provincial and Ministry-specific Initiatives

A number of FASD initiatives were carried out throughout the province in 2011/12 with a cross-ministry scope, in five key service areas. Highlights include:

Awareness and Prevention – The Parent-Child Assistance Program (PCAP) Council collaborated with the 24 PCAP programs throughout the province, including seven in First Nations communities, to provide PCAP mentors with quality training to strengthen services to women at risk of having a child with FASD. An Alberta PCAP Facilitator's Guide and Participant Manual are in development.

Assessment and Diagnosis – The Adult Assessment and Diagnostic Clinic Project was well underway in 2011/12 and included three-year funding for 10 of the 12 Networks for adult assessment and diagnosis services. Examples of programs include one at Glenrose Rehabilitation Hospital, and one located at Bowden Institution, a federal corrections facility.

Supports for Individuals and Caregivers – Achievements include:

- Recommendations from the FASD Community of Practice Initiative, which concluded in 2011, are now being implemented. The Initiative focused on improving outcomes and placement stability for children with FASD in child welfare care.
- Seven programs provided supports to adults with FASD who were involved with the criminal justice system.
- Employment supports programs in three regions of the province assisted numerous individuals with FASD with pre-employment awareness workshops, employability assessments, pre-employment training, and job supports.
- The Wellness, Resiliency and Partnerships Project (WRaP) supported 161 students with FASD in 19 schools across Alberta.

Research and Evaluation – The Corrections and Connections to Community (3C) Research Project, which concluded in 2012, worked with 49 men with FASD during their incarceration and after their release into the community. The project demonstrated positive outcomes in working with these men through transition to the community, but longer term support is needed.

Training and Education – Many training and education activities were undertaken in 2011/12, including training of more than 600 staff of the Justice and Solicitor General, and more than 1,500 training participants under the FASD Learning Series. Awareness materials were also distributed on Alberta campuses and through FASD-CMC partners to increase awareness of FASD.



2. INTRODUCTION



Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term used to describe a cluster of birth defects caused by prenatal exposure to alcohol. The effects of FASD can include health issues, speech and language problems, learning difficulties and behavioural issues, consequences that affect all aspects of the individual's life.

FASD is estimated to affect about 1% of Canadians, but the actual prevalence (the rate at which a condition occurs across a population, including all new and existing cases) is presently undetermined due to wide variations in the approach to FASD prevalence studies. Incidence refers to the number of new cases each year; currently estimated to be 9 per 1,000 births in Canada¹. Based on this incidence rate, it is estimated that more than 450 babies born in Alberta in 2011/12 are affected by FASD.

FASD is considered to be an 'invisible disability', as there are often no physical indicators of the disability. Consequently, individuals with FASD may be undiagnosed, misdiagnosed, or struggle with undiagnosed co-occurring issues such as mental health concerns. Research has shown that they are involved with child welfare agencies, mental health services, and the justice system in disproportionate numbers.

With individuals affected by FASD requiring services across many different sectors, the Alberta FASD Cross-Ministry Committee (FASD-CMC) was formed to facilitate collaboration across ministries, government agencies and stakeholders to support a collaborative approach to planning and delivering government FASD programs and services. The specific goals of the FASD-CMC are to:

- develop and promote a comprehensive and culturally sensitive cross-ministerial approach to FASD awareness, prevention, assessment, diagnosis and intervention over the lifespan;
- guide implementation and evaluation of the provincial FASD 10-Year Strategic Plan;
- ensure effective communication with senior officials from all partnering ministries;
- support strategic planning, research, evaluation and resource development; and
- support the sharing of expertise, best practices and resource materials.



¹ Public Health Agency of Canada (2007). *Alcohol Use and Pregnancy: An Important Canadian Public Health and Social Issue*. Available at: http://www.phac-aspc.gc.ca/publicat/fasd-ru-ectaf-pr-06/pdf/fasd-ru-ectaf-pr-06_e.pdf



FASD 10-Year Strategic Plan

The Alberta FASD 10-Year Strategic Plan (Strategic Plan) was signed by the 10 partner ministries in 2008. It is a unique made-in-Alberta framework that sets the direction for coordination, planning and delivery of FASD services throughout the province.

Initiatives under the Strategic Plan align with a number of other Alberta cross-ministry projects, including:

- A Plan for Alberta: Ending Homelessness in 10 Years
- Creating Connections: Alberta's Addiction and Mental Health Strategy and Action Plan
- The Alberta Crime Prevention Framework (including Safe Communities)
- Healthy Kids Alberta
- Maternal-Infant Health Strategy
- Early Childhood Education Strategy
- Addiction and Mental Health Strategy

On an annual basis, \$16.5 million has been allocated under the Strategic Plan to FASD services in the following areas:

1. **Provincial FASD Service Network Program**, to build and enhance community capacity to address FASD by providing specialized services across the province.
2. **Provincial Initiatives**, province-wide FASD activities with an integrated and coordinated cross-ministry scope.
3. **Ministry-specific Initiatives**, undertaken by individual ministries using their allocated portion of the FASD funding in alignment with the Strategic Plan and ministry priorities.





The Year 5 Evaluation of the Strategic Plan was conducted in 2011/12. Nine main outcomes were identified in the Strategic Plan; the findings are the subject of an Evaluation Report, which will be posted on the FASD-CMC website at <http://www.fasd-cmc.alberta.ca/>.

Briefly, the nine outcome themes and findings were as follows:

- **Outcome 1a: Albertans understand that alcohol during pregnancy can lead to FASD, that FASD can be prevented, and that FASD prevention is a shared responsibility.** Survey results indicated that 86% of Albertans are aware of FASD.

- **Outcome 1b: Alcohol use during pregnancy is eliminated.** PCAP focuses on women at risk of giving birth to a child with FASD. Through supportive relationships with mentors, women report increased sobriety and employment, decreased reliance on welfare, and reduced substance abuse. Women are also addressing their reproductive health with increased use of birth control.

- **Outcome 2: Adults, children and youth suspected as being affected by FASD have access to timely and affordable diagnostic and assessment services.** There are now more diagnostic clinics, more services for adults, and more assessments completed annually.

- **Outcome 3: Individuals affected by FASD and their caregivers have coordinated access to support services to meet their needs.** Presently, there is no provincial data linking diagnosis to service access, but responses from FASD Service Networks indicate strong community collaboration to facilitate service coordination.

- **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.** Training opportunities, educational resources and special events like the annual FASD conferences and the FASD Learning Series are well attended and highly rated. Webcasting and videoconferencing have increased accessibility, particularly in rural areas.



- **Outcome 5: The planning and delivery of provincial government programs and services associated with FASD is accomplished through a collaborative approach.** Alberta is a leader in maintaining a formal, coordinated FASD strategy (one of only three Canadian provinces to do so) and making a commitment to evaluating its efforts to address the issue of FASD. The evaluation plan includes mechanisms to measure collaboration between the 12 Service Network coordinators and agencies, the impact of the FASD-CMC investments, and the governance, structure, accountability, funding and sustainability of the FASD-CMC and the 12 Service Networks.

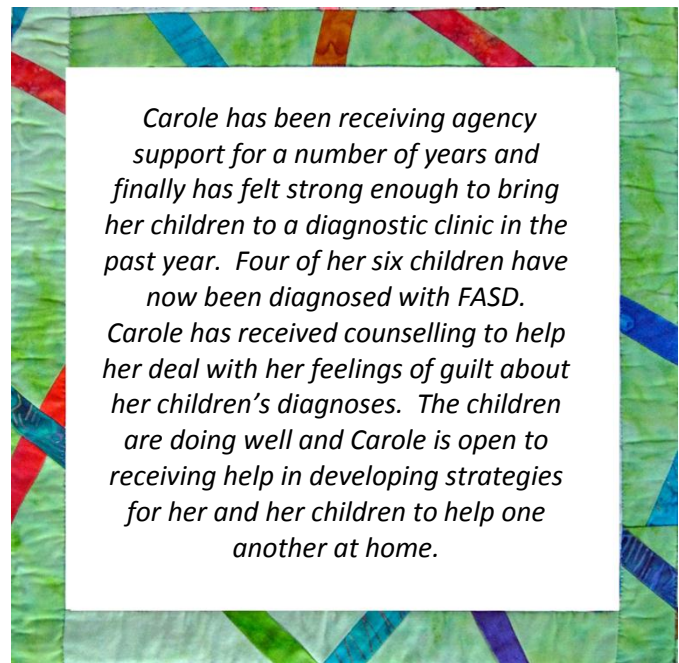
▪ **Outcome 6: Basic and applied research findings, including those from monitoring and evaluation systems, are used to inform FASD strategic planning, FASD prevention activities, and FASD-related programming.** The FASD-CMC has formed strong working relationships with many researchers with expertise in FASD. Research findings are used to guide strategic planning and funding allocation decisions, and shared through training, conferences and webinars to ensure wide dissemination and utilization.



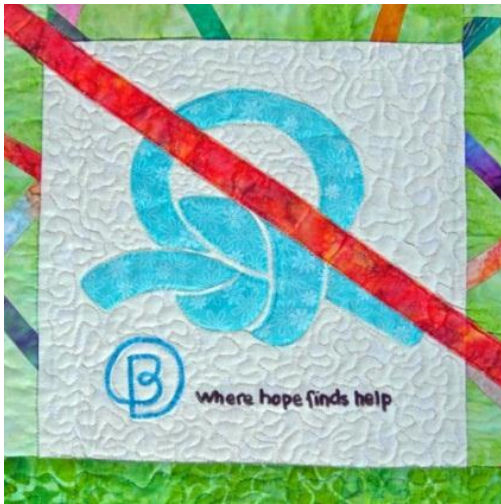
▪ **Outcome 7: Mechanisms are in place to facilitate and encourage stakeholder engagement in the FASD-CMC strategic planning process, as well as to provide stakeholder opportunities for networking and information sharing.** The FASD-CMC regularly invites key stakeholders to participate in the strategic planning process, and information is shared with stakeholders through meetings, presentations and conferences.

▪ **Outcomes 8 and 9: Secondary disabilities associated with FASD and their impact on Albertans is reduced. The cost of FASD to Albertans is reduced.** A limited study was possible, using an exploratory cost benefit analysis to assess the impact of the Service Networks on some secondary disabilities. While the findings indicated a reduction in school disruption (for children) and a reduction in unemployment, mental health problems, and homelessness (for adults), more research is required to demonstrate the long-term outcomes of FASD services in a more comprehensive way. The total monetary benefits for the reductions in secondary disabilities captured in this exploratory study were estimated to be between \$8.87 and \$17.73 million per year.

The remainder of this report highlights activities and results from programs that received FASD-CMC and partner ministry funding during the 2011/12 fiscal year.



3. PROVINCIAL FASD SERVICE NETWORK PROGRAM



The Provincial FASD Service Network Program, established in 2007, currently has 12 Networks across the province, enhancing FASD support and service delivery by providing a single point of entry for services. The Networks are community-based partnerships of agencies and organizations working with individuals affected by FASD and their caregivers. Their aim is to provide and/or enhance a continuum of coordinated services in three service categories as defined by the strategic directions of the FASD-CMC:

- Awareness and Prevention
- Assessment and Diagnostic Services
- Supports for Individuals and Caregivers

Due to the complex nature of FASD, individuals, families and caregivers often require a spectrum of programs and services. The Networks were established to help coordinate access to FASD services and supports throughout the lifespan, to enhance existing FASD services, and create new ones where none exist.

An evaluation of the FASD Service Network Program was completed in March 2012. Results indicate generally positive service delivery outcomes, with clients reporting an extremely high degree of satisfaction with available services.

In 2011/12, \$8.7 million was allocated to the FASD Service Network Program.

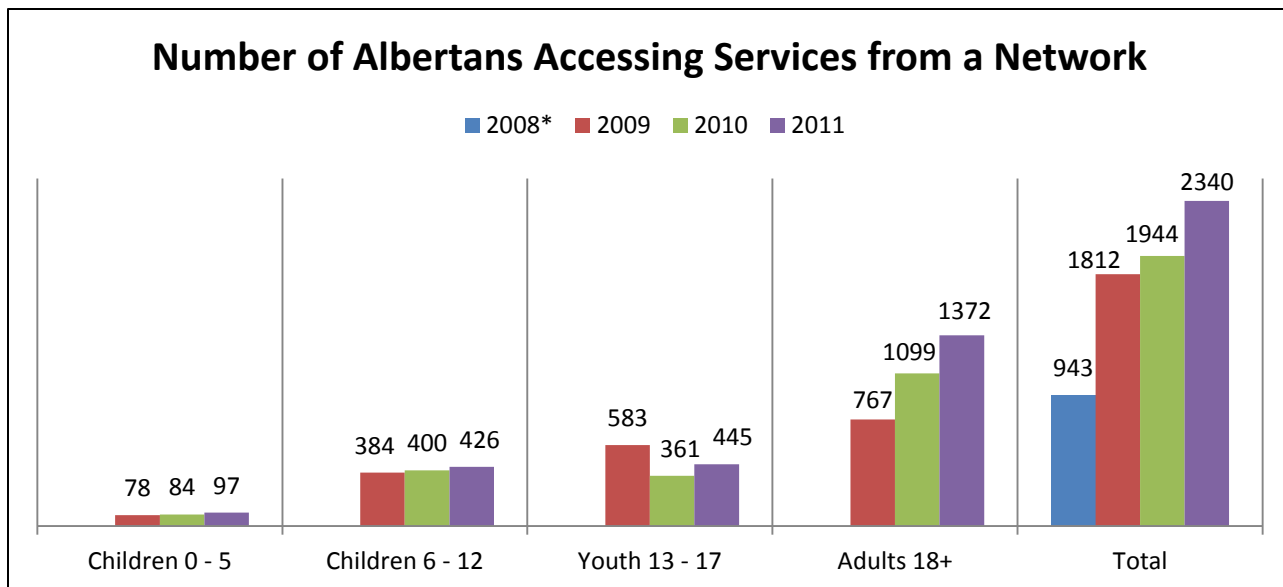
3.1 ALBERTANS SERVED BY FASD SERVICE NETWORK PROGRAM

In the 2011/12 fiscal year, 2,340 unique individuals received services from the FASD Service Network Program². This is a 20% increase over the number of Albertans served in 2010/11. The most significant increase was noted in the number of adults served by the Networks, with an increase of 25% over last year, followed closely by a 23% increase in the number of youth accessing Network services. These increases demonstrate that the Networks are continuing to reach members of the community who need FASD-related supports.



² The results reported in this section are limited to the FASD Service Network Program. In addition to these services, Albertans have access to programs and services outside of the FASD Service Network Program.

The following table compares the number of Albertans accessing Network services since the inception of the program in 2007.

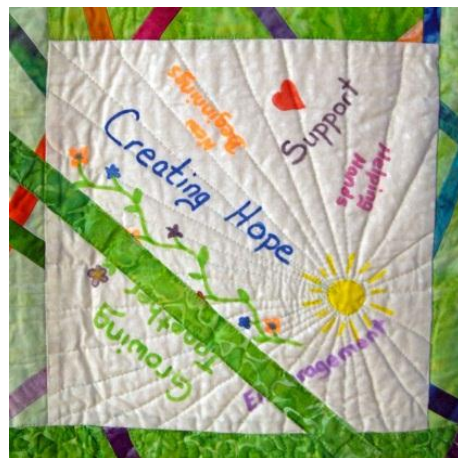


*Age breakdown data not available for 2008.

3.2 AWARENESS AND PREVENTION

The aim of FASD prevention is to provide support, information and referrals to education and inform about (1) the dangers of drinking alcohol while pregnant; (2) planned healthy pregnancy; and (3) the effects of FASD. Information sharing and education is targeted at both the general population as well as at-risk populations.

All Networks provide targeted and indicated prevention programming focused on directly supporting at-risk populations through the **Parent-Child Assistance Program (PCAP)**. PCAP works directly with women who are at high risk of having a child affected by FASD. Each client is paired with a mentor who works closely and intensively with her in a supportive, caring relationship over a three-year period. The intent of the program is to assist women to set goals, acquire basic life skills, and connect with service providers to prevent substance use during pregnancy and the occurrence of FASD.



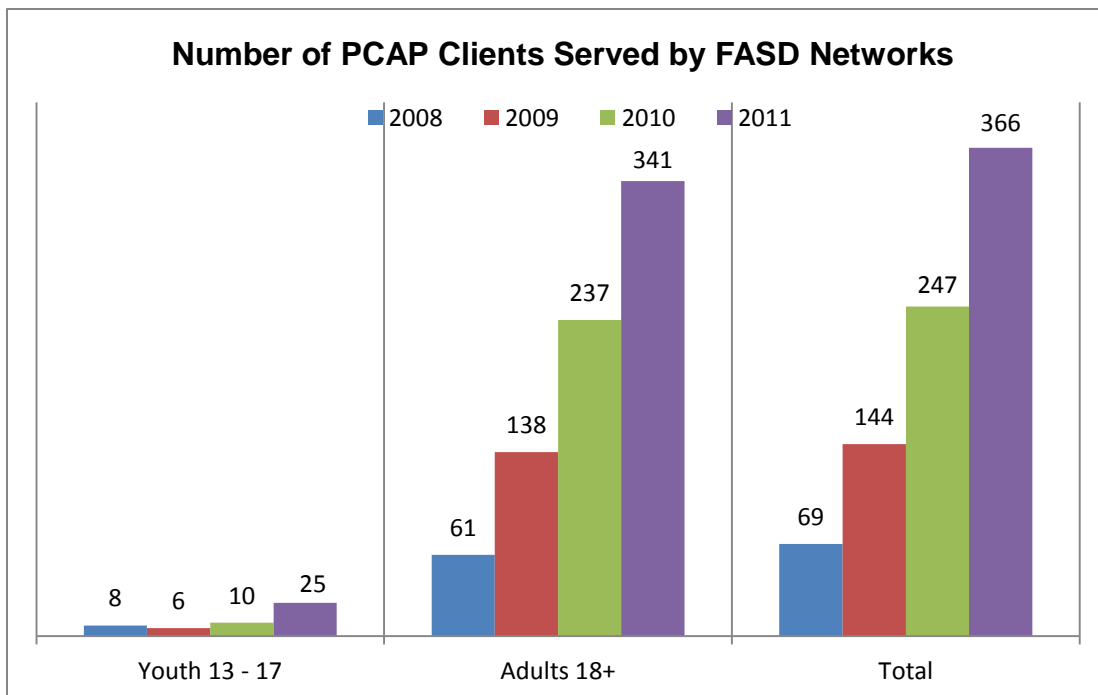


Although numerous PCAP programs are now available throughout the province (including on-reserve), this report is focused on those PCAP programs that receive funding from the FASD Service Networks. Within these programs, 366 women were enrolled and supported by 22 PCAP mentors.

Supplemental information about outcomes of the PCAP program for participants was available from five Networks (Edmonton, Northeast, Northwest, Prairie Central, and Southeast). PCAP programs in these areas found the following outcomes:

- Alcohol and drug use during pregnancy decreased or was eliminated for many women.
- Women were making gains in achieving permanent housing, securing employment, and participating in addictions treatment.
- Many women were successful in having their children returned to their care.

The following graph illustrates the growth of the Network-funded PCAP programs between 2008 and 2011. In 2011/12, the number of clients receiving PCAP services through the Networks increased by 48% compared to the previous year.



3.3 ASSESSMENT AND DIAGNOSIS

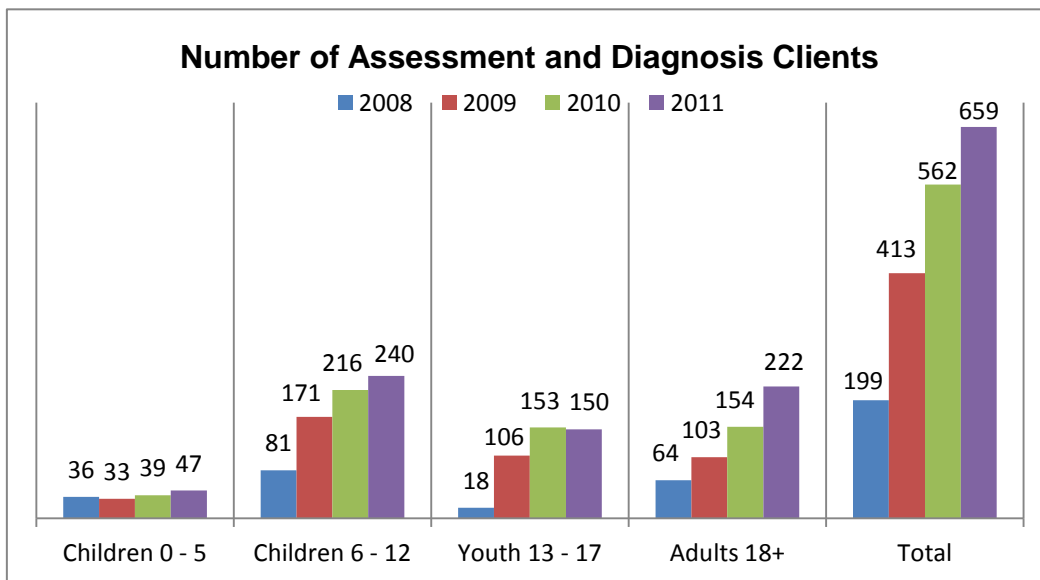


Assessment and diagnosis services include medical, cognitive and behavioural assessments by a multidisciplinary team comprised of physicians, psychologists or neurologists, and other developmental and/or behavioural specialists, depending on the age or the presentation of the client. This comprehensive process guides planning to meet the ongoing needs of the client.

Assessment and diagnosis services may or may not lead to a confirmed diagnosis under the FASD spectrum, which includes Fetal Alcohol Syndrome (FAS), partial FAS, and Alcohol-Related Neurodevelopmental Disorder (ARND). A confirmed diagnosis under the FASD umbrella indicates that there is sufficient evidence that the individual has experienced a level organic brain damage from prenatal alcohol exposure that meets the diagnostic criteria under the ***Fetal Alcohol Spectrum Disorder: Canadian Guidelines for Diagnosis***³, a thorough guide that standardizes current approaches to diagnosis in Canada. All clinics are required to follow these Guidelines, as well as the principles of the ***Prevention & Diagnosis of Fetal Alcohol Syndrome***⁴.



Of the 25 FASD assessment and diagnostic clinics in Alberta, 15 receive some level of funding from the FASD Service Networks. **In 2011/12, 659 Albertans accessed assessment and diagnosis services through Network-funded clinics, a 17% increase over the 2010/11 fiscal year.** The graph below illustrates the number of individuals who received assessment and diagnostic services between 2008 and 2011.

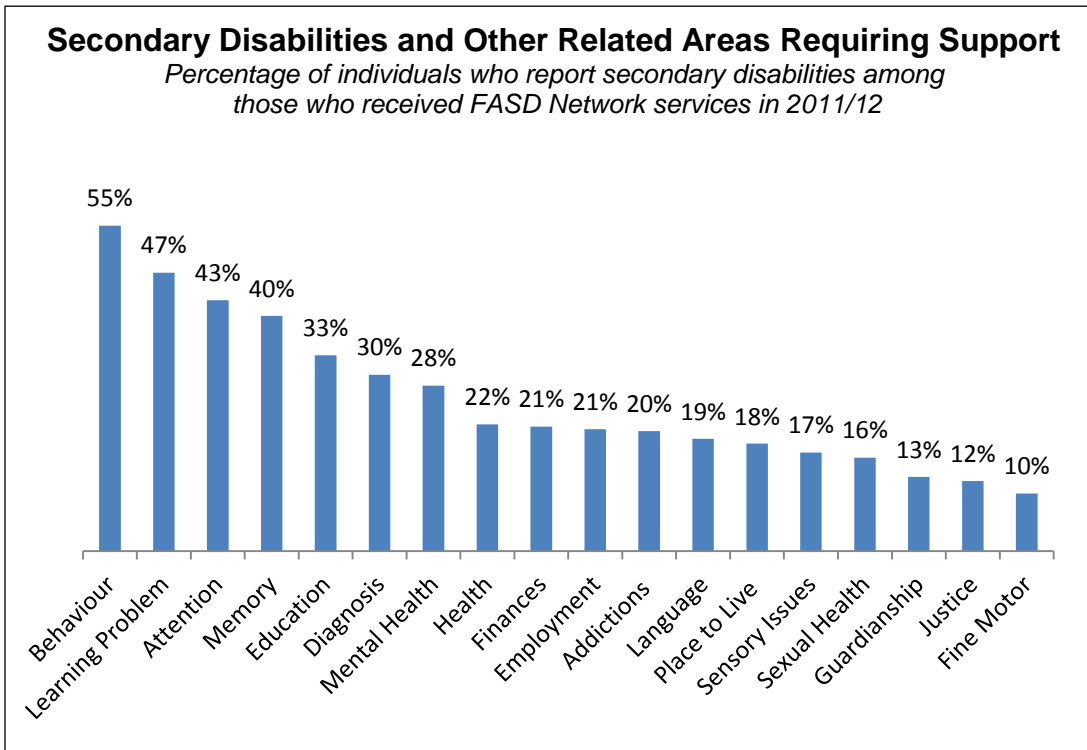


³ National Fetal Alcohol Spectrum Disorder: Canadian Guidelines for Diagnosis (Chudley et al., 2005)

⁴ Prevention & Diagnosis of Fetal Alcohol Syndrome (FAS) (Alberta Medical Association, 1999)

What does this mean for Albertans?

An FASD diagnosis is a fundamental step in accessing supports to address all areas of the individual's life that may be impacted by FASD. Secondary disabilities are common struggles for individuals with FASD, including mental health problems, addictions, school difficulties, inappropriate sexual behaviour, and involvement with the criminal justice system. Information about secondary disabilities is collected during the assessment and diagnosis process to ensure appropriate community resources are identified and accessed.



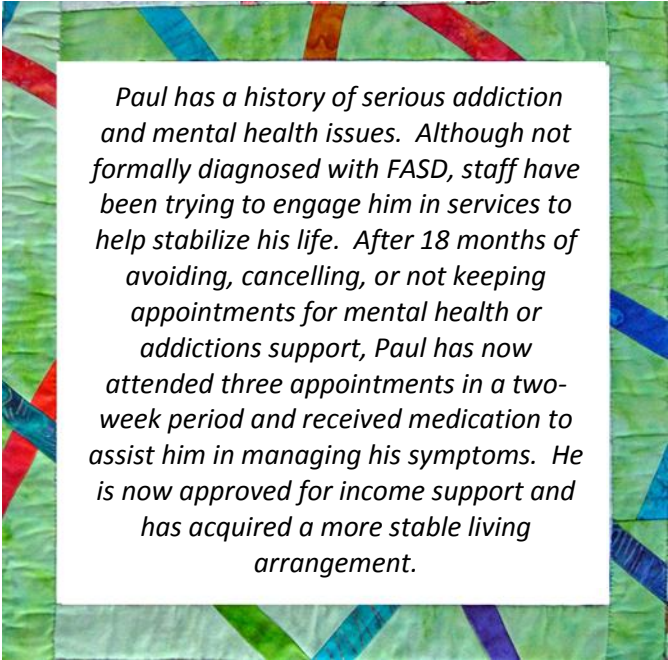
The above graph illustrates the percentage of the 2,340 individuals who accessed the Networks in 2011/12 and reported FASD-associated secondary disabilities or issues.



Network Highlights

- Networks have found that investing in assessment and diagnosis services often reduces or eliminates the need for other, more restrictive and more costly programming, such as incarceration or hospitalization.
- One Network initiated a mobile diagnostic clinic project to explore options for reducing costs and increasing access to FASD diagnosis in remote areas of the province.

- Networks have found that having a mental health therapist on the FASD diagnostic team has proven to be successful in identifying mental health issues for early intervention.
- Partnerships between Networks and Aboriginal communities have strengthened and grown in the 2011/12 year, leading to enhanced supports for diagnosis of individuals living on-Reserve and in Métis Settlements.



3.4 SUPPORTS FOR INDIVIDUALS AND CAREGIVERS



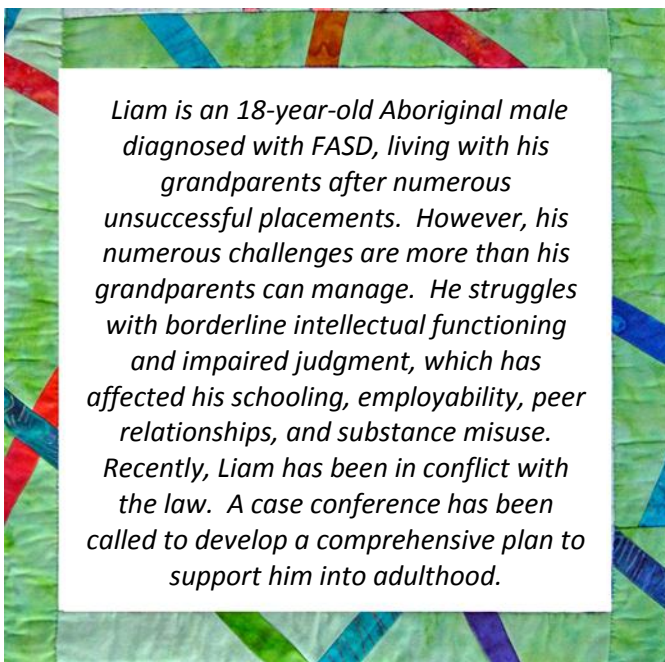
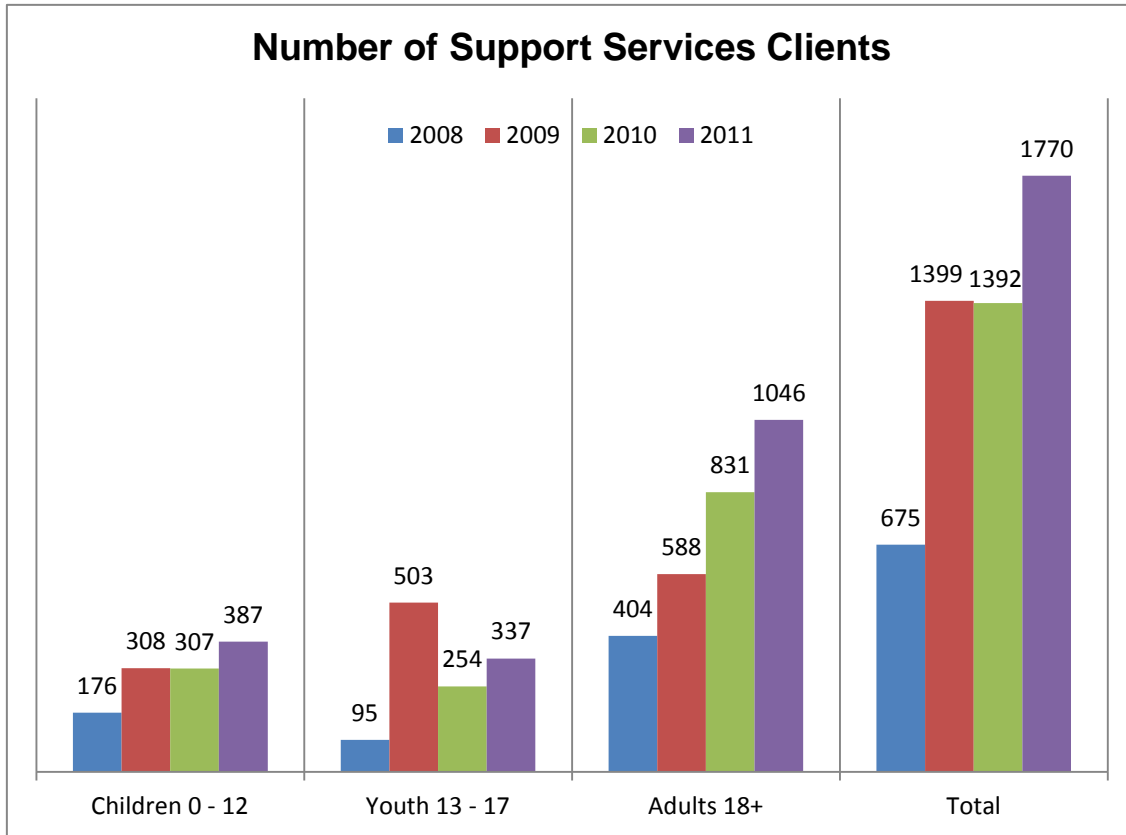
Support services promote the development and well-being of FASD-affected individuals, their families, and their caregivers, to keep them safe and protected and to promote healthy communities that are responsive to FASD across the lifespan.

Funding from the FASD Service Networks was provided to approximately 45 community-based organizations to provide a wide range of support services through a variety of different programs to individuals and their caregivers. Services ranged from supports to children and youth in schools to help them succeed in course completion and attendance, to supports for formerly homeless men

affected by FASD. Supports were provided in numerous ways, such as through services in group-settings, one-on-one mentoring programs, and respite services.

Many caregivers have shown a decrease in indicators of stress and burnout after being involved with programming. Further, the provision of support services has sparked the development of natural support networks among caregivers and family members in some communities.

Almost 1,800 individuals received support services in 2011/12, a 27% increase. The following graph illustrates the number of individuals who received support services from 2008 to 2011:



Network Highlights

- The mental health therapist in one Network leads a successful parent/caregiver support group, which has filled a gap in the community.
- Networks continue to expand their efforts to provide support services in rural areas.
- Creative approaches to raise awareness of FASD services and supports were employed by Networks, such as presentations at community events, outreach to community organizations, and even a ‘flash mob’ choreographed dance performance with 100 participants.

3.5 ACCOUNTABILITY AND QUALITY IMPROVEMENT

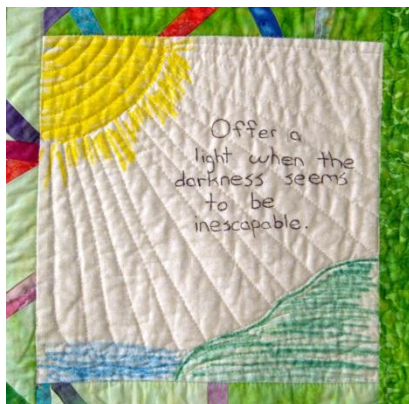


All 12 Networks continued to demonstrate strong commitment to being accountable and enhancing the quality of FASD services throughout the province. A number of key examples from 2011/12 are noted below:

- For many Networks, 2011/12 involved the development and/or renewal of governance frameworks to guide planning and ensure alignment with the objectives of the FASD-CMC.
- Strategic planning sessions were also held by many Networks to ensure all stakeholders share a common understanding of the Network's mission and goals and expectations for Network compliance.
- Networks participated in the Year 5 Evaluation of the FASD 10-Year Strategic Plan, despite demanding workloads and challenges in securing the required information.
- To further strengthen data collection and analysis, many Networks have developed new data collection templates, online reporting systems for FASD data, and Network surveys.
- One Network created a comprehensive community engagement blueprint to ensure efficient communication with external partners.
- Alberta Health provided a grant of \$50,000 per year on a three-year basis to evaluate the pilot mobile diagnostic clinic project.



4. PROVINCIAL AND MINISTRY INITIATIVES



The partnering ministries of the FASD-CMC undertake critical initiatives that make a significant contribution to the continuum of services for individuals affected by FASD and their caregivers. Each partner ministry uses its allocated portion of the FASD funding in alignment with the FASD 10-Year Strategic Plan and ministry priorities.

Provincial initiatives include province-wide FASD activities with a cross-ministry scope. Ministry-specific initiatives are undertaken by individual ministries. In 2011/12, \$16.5 million was allocated to provincial and ministry initiatives. For ease of reporting, both types of initiatives are discussed in this section, and include those focused on:

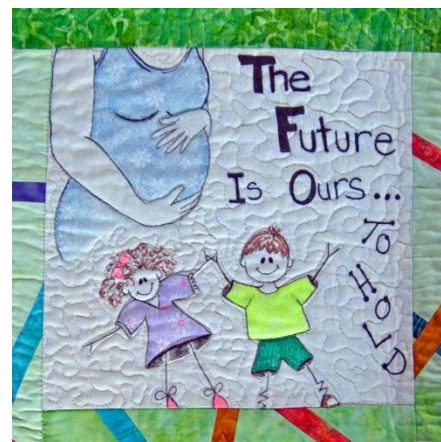
- Awareness and Prevention
- Assessment and Diagnosis
- Supports for Individuals and Caregivers
- Research and Evaluation
- Training and Education

4.1 AWARENESS AND PREVENTION

Parent-Child Assistance Program (PCAP) Council *Provincial Initiative*

The PCAP Council assists programs to operate throughout the province in adherence to the research-based, validated PCAP model to promote program fidelity and quality assurance. Membership consists of representatives from various stakeholder groups across the province, including one representative from FASD-CMC and one representative from an FASD Service Network.

The PCAP Council is committed to supporting Alberta PCAP programs to deliver quality mentoring services. The Council believes that quality PCAP training is foundational to being able to deliver services in the manner that has been validated by research and lead to positive client outcomes.





Historically, Dr. Therese Grant, who founded the PCAP program in Seattle, was brought in to provide training while other PCAP service providers from Alberta went to Seattle for training. However, to make training more cost effective and sustainable, a consultant was hired to develop PCAP training materials for the province. In development is the Alberta PCAP Facilitator's Guide and Participant Manual that will be used to deliver Alberta PCAP training in the future.

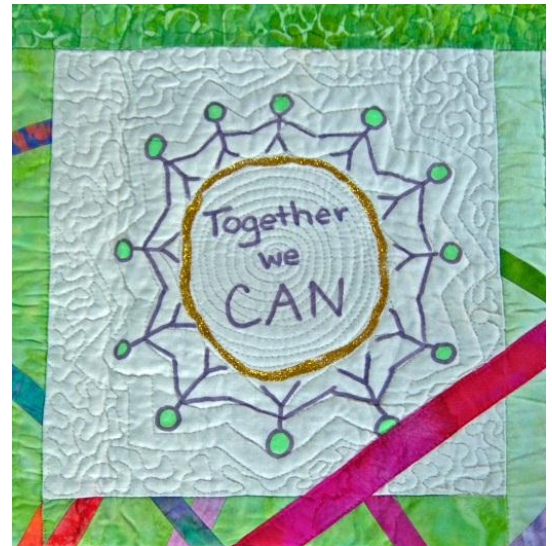
Nine PCAP facilitators completed the four-day "Train the Trainer" program in October 2012, and Dr. Grant and a colleague will observe and provide feedback to the trainers in 2013. The aim is to provide three-day PCAP training sessions annually (at a minimum) in each of the North, Central and South zones, as well as the two-day refresher course annually in each zone to reduce mandate drift.

4.2 ASSESSMENT AND DIAGNOSIS

Adult Assessment and Diagnostic Clinic Project

Lead Ministry: Alberta Health

Recognizing that assessment and diagnostic guidelines are not well established for adults suspected of having FASD, Alberta Health initiated the Adult Assessment and Diagnostic Clinic Project in 2011/12. Three-year funding for adult assessment and diagnosis was provided to 10 of the 12 Networks. Two examples of projects are the following: one focusing on adult assessment of FASD at Glenrose Rehabilitation Hospital, the second focusing on adult assessment at Bowden Institution, a federal corrections facility under Correctional Services of Canada.



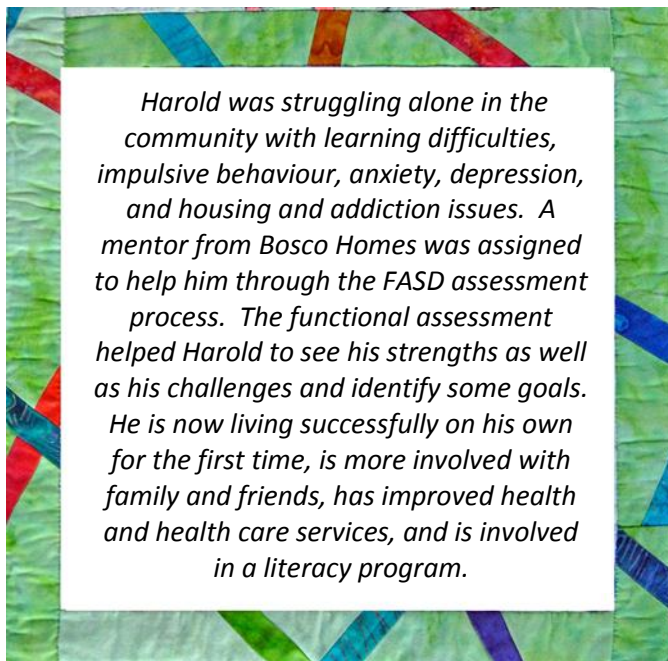
- **Glenrose Rehabilitation Hospital:** Strong partnerships (with the University of Alberta Hospital, Medical Genetics Clinic, and Edmonton Fetal Alcohol Network) and an assessment and diagnostic service delivery model, were established by November 2010. The family-centred, strengths-based service model remains flexible to adapt to the needs of adults and their families referred for FASD assessment. Six assessments were completed by November 2011, in addition to the 10 assessments completed in the pilot stage, and a further 17 assessments were completed from December 2011 to May 2012. The project has been extended to June 2013 due to delays in the start-up phase, with a total of 80 assessments targeted for completion by the conclusion of the project.

- **Bowden Institution:** The project team investigated existing models of adult assessment, identified community linkages, established an advisory committee, and developed a diagnostic service model. However, the process of developing the necessary partnerships was fraught with unexpected delays and challenges, which were mainly resolved by March 2012. Team members who have been identified at Bowden Institution include a physician, clinical coordinator, two mental health practitioners, and an occupational therapist.

Training sessions on enhancing the observational skills of parole, probation, police, correction services, and mental health staff at Bowden Institution were developed, with the first one delivered in March 2012. The intent of the training is to strengthen skills of staff at Bowden Institution in identifying observable FASD characteristics in an individual that might indicate that an assessment for FASD is appropriate.



Service Delivery and Evaluation: Due to the delays as well as complications in locating the birth mothers of participating individuals to confirm maternal use of substances during pregnancy, the first year goal of completing 10 adult assessments will not be met. The intended goal of 30 assessments to be completed in the second and third years of the project may also require review.



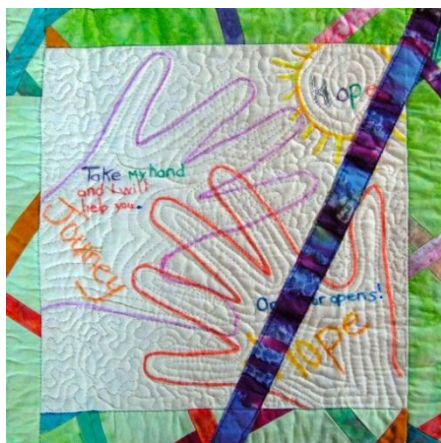
Evaluation of the Adult Assessment and Diagnostic Clinic: A comprehensive evaluation of the project is planned, which will incorporate formative⁵ and summative⁶ findings in order to guide the project's evolution.

Contribution to Public Policy and Development of Training Materials: An outcome goal of the project is to contribute to Alberta policy on adult FASD assessment and diagnosis. Additionally, the development of training, service delivery and evaluation materials is slated for Year 3 of the project.

⁵ Formative evaluation is defined as a means of validating and ensuring the goals of the project are being achieved and to improve the quality of the project by identification and subsequent remediation of problematic aspects (Weston, McAlpine & Bondonaro, 1995).

⁶ Summative evaluation is defined as providing information on the project's efficacy, that is, the ability to do what it was designed to do. The focus is on outcomes (Bhola, 1990).

4.3 SUPPORTS FOR INDIVIDUALS AND CAREGIVERS



FASD Community of Practice Initiative

*Lead Ministry: Alberta Human Services**

The FASD Community of Practice Initiative (FASD-CoP) was conducted between 2009 and 2011 in five regions across Alberta through a partnership between the Faculty of Social Work (University of Calgary), the ministry's Research and Innovation Branch, and an FASD consultant. The aim of the project was to improve outcomes and placement stability for over 100 children and youth in provincial government care with FASD.

The focus of the work was on the delivery of Promising Practices for intervention that enhanced the quality and care of the lives of children, youth and caregivers in responding to the specific casework needs associated with FASD. This project contributed to building a substantial base of knowledge about practice-based issues and resulted in several key outcomes:

- enhanced practice, including increased caseworker contact and engagement with the child or youth and foster homes;
- more training and education for foster parents;
- the provision of adequate respite to caregivers; and,
- increased placement stability for children and youth with FASD.



The FASD-CoP project demonstrated through research that the Promising Practices interventions were successful. Further, the importance of innovative practice with children and youth with FASD in care was clearly shown. Implementation of the project recommendations is underway and will continue through 2013/14. Future areas of focus include advanced FASD training for caseworkers and supervisors, establishment of a case consultation/review process, and the development of internal leadership to support the ongoing development of FASD policies and programs in child intervention.

Support Services for Adults

*Lead Ministry: Alberta Human Services**

Alberta Human Services has contracts with 16 community agencies to provide service coordination supports to adults diagnosed with FASD, or suspected of having FASD, in all 12 FASD Service Networks across the province. These organizations provide supports to adults living with FASD and their support networks, with the goal of assisting the individual to meet his or her full potential. Services may range from assistance to understand FASD and its impact on the individual, to accessing required assessments and diagnosis, to accessing community supports.

Approximately 250 adults received service in 2011/12, under a budget allocation of \$1.65 million.

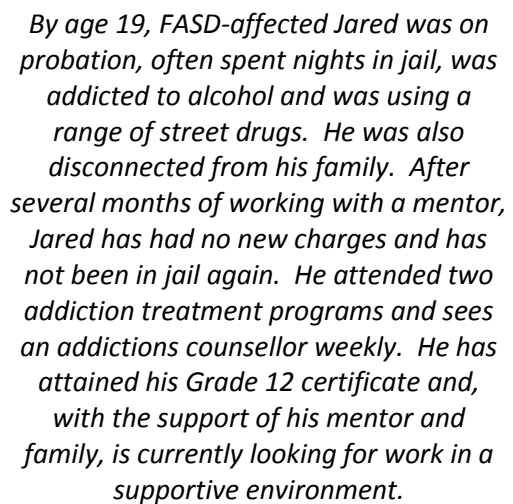
** formerly Alberta Seniors and Community Services*

Supports for Offenders Impacted by FASD

Lead Ministry: Justice and Solicitor General

Seven programs provided supports for offenders living with FASD:

- **FASD Justice Support Project for Youth:** Initially established in Edmonton and expanded to Calgary in 2010/11, this project provides case conferencing for young persons affected by FASD who are involved with the justice system. It addresses the need for further assistance and resources, especially around sentencing and release. In 2011/12, the project received 15 referrals.
- **Courage to Change:** This program uses interactive journaling to change criminal and substance-using behaviour. Content has been adapted for youth with FASD and the program has been implemented in young offender centres and youth attendance centres in 2011/12, with 495 participants in the past fiscal year. This year, group homes have been given samples of the Courage to Change program for review and possible future implementation.



By age 19, FASD-affected Jared was on probation, often spent nights in jail, was addicted to alcohol and was using a range of street drugs. He was also disconnected from his family. After several months of working with a mentor, Jared has had no new charges and has not been in jail again. He attended two addiction treatment programs and sees an addictions counsellor weekly. He has attained his Grade 12 certificate and, with the support of his mentor and family, is currently looking for work in a supportive environment.



- **Voices:** Focused on the unique needs of adolescent girls and young women, Voices encourages celebrating their “true selves” by providing a safe place, structure, and support to embrace their journeys of self-discovery. The program consists of four modules – Self, Connecting with Others, Healthy Living, and the Journey Ahead – and has been adapted for offenders with FASD. In 2011/12, 105 female youth from the Edmonton and Calgary Young Offender Centres participated in the program.

- **Aboriginal Female Mentor Program:** This program involves an Aboriginal mentor working with female offenders impacted by FASD to assist them with successful reintegration into the community and access to community resources, including treatment and income support. It is offered at Lethbridge and Fort Saskatchewan Correctional Centres.

- **Specialized FASD Mentoring Program:** This mentoring program provided under contract by Edmonton Catholic Social Services (CSS) assists FASD-affected young people in addressing homelessness and other challenges upon release from custody. Two mentors work with identified youth to facilitate reintegration into the community after being in custody at the Edmonton Young Offender Centre or CSS open custody group home, with 29 youth receiving mentoring in 2011/12.

- **Life Skills and Employability Programs:** Many life skills and employability programs for offenders with FASD are offered at Peace River Correctional Centre (PRCC), which target individual needs and offer opportunities for certification in First Aid and CPR, H2S Alive, Workplace Hazardous Materials Information System (WHIMIS), Fall Protection, and Ground Disturbance. In 2011/12, 104 participants received certification in these various safety programs. PRCC has also partnered with Alberta Works to have a Career and Employment Consultant provide group training sessions with offenders on budgeting, job search, resume preparation, interviewing, problem-solving and self-esteem.

- **Resource Materials:** Resource materials specific to individuals affected by FASD in a correctional setting continue to be distributed to offenders and staff in adult and youth correctional centres, attendance centres, probation offices, and Sheriff’s offices. The topics include parenting skills, employability, addictions, gang affiliation and life skills.





Employment Supports

Lead Ministry: Alberta Human Services

Human Services provided funding to initiatives supporting individuals affected by FASD in Northwest, Northeast, and Calgary Regions in 2011/12.

- **Northwest Region:** The Planned Success project supported two young women with FASD to develop skills and address barriers towards finding employment. An additional five individuals were referred to the project but for various reasons decided not to participate.
- **Northeast Region:** In 2011/12, 447 people attended a pre-employment awareness presentation, 84 individuals were referred for services, and 62 clients received support services to assist them with employment.
- **Calgary Region:** The Prospect Human Services Society employment placement service supports individuals with FASD through employability assessments, individualized service plans, pre-employment training and job supports to find meaningful engagement and employment in the community. Since 2009 until September 30, 2012, 25 clients have received services, with 12 employed full-time or part-time. Annual funding of \$110,000 has been available to support individuals with FASD through this program, with an additional \$80,000 provided by FASD-CMC to assist other clients with FASD who were referred for services.

Seventeen-year-old Brad, diagnosed with FASD and ADHD, has lived with his aunt since age 4. He was bullied as a child, tries to act tough, and will do anything to make friends or get attention. He is street-smart, witty, charming and has a good sense of humour. However, he can be aggressive, defiant and manipulative. Current concerns include substance abuse, selling drugs, theft, assault and destruction of public property, leading to his placement in a structured environment, but this program is not available once he reaches adulthood.

Wellness, Resiliency and Partnerships (WRaP) Coaching Demonstration Project

Lead Ministry: Alberta Education

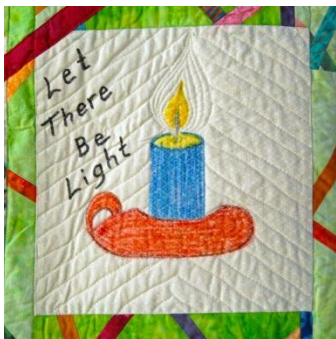
Since 2008, Edmonton Regional Educational Consulting Services has continued to support and expand the Wellness, Resiliency and Partnerships (WRaP) coaching project in Alberta supporting junior and senior high school students with FASD. Success Coaches work directly with individuals and student groups, as well as connect with caregivers and support services in the community.

In the 2011/12 school year, 161 students were supported by nine Success Coaches in 19 different Alberta schools. Overall, the WRaP Project has met its intended outcomes to increase school engagement, demonstrate academic success, and support physical, social and emotional well-being. Key project findings were:

- 87% of courses were successfully completed by WRaP Project participants.
- Among students in their second year of the WRaP Project, 97% of their courses were successfully completed.
- 75% of participating students did not experience any suspensions or expulsions.
- 13% of participating students experienced only one suspension or expulsion.
- 51% of participating students were involved in at least one extracurricular activity, in school or in the community.



4.4 RESEARCH AND EVALUATION



Corrections and Connections to Community (3C) Research Project Provincial Initiative

The Corrections and Connections to the Community (3C) project has provided specialized support to men with FASD being released from the Fort Saskatchewan Correctional Centre. The project was a collaboration between Alberta Health, Justice and Solicitor General and Alberta Human Services, in partnership with the Occupational Performance Analysis Unit (OPAU) of the Faculty of Rehabilitative Studies, University of Alberta. The final year of the pilot project was 2012. Bosco Homes provided a transitional support worker to 49 men in four cohorts to work with them while they were incarcerated and after their release into the community. Support services included life skills training, recreation programming, Elder and psychological services, and assessment and diagnosis. The 3C Project found that these services can run successfully within a provincial correctional institution, but long-term community support must be available, especially for men living in rural communities.

4.5 TRAINING AND EDUCATION

Frontline Staff Awareness and Educational Programs

Lead Ministry: Justice and Solicitor General (JSG)

Funding was provided by JSG to develop and deliver training materials for Correctional Service Workers, probation officers and Sheriffs on a variety of topics, including an overview of what the ministry is doing with respect to FASD in collaboration with the FASD-CMC; the criteria for a diagnosis of FASD; the cognitive deficits associated with FASD; the strategies to manage the behaviours of individuals with FASD in a custodial or community setting; and tools to work with clients with FASD who have addictions issues. Training was provided to 622 participants in 2011/12.



Institute for Health Economics

Consensus Development Conference on Legal Issues of FASD

The FASD-CMC is supporting the Institute for Health Economics (IHE) in planning the first consensus development conference on Legal Issues for FASD, a juried hearing over three days, scheduled for September 18 – 20, 2013 in Edmonton. Approximately 25 experts will deliver evidence to a 12-15 member jury, in front of an audience of approximately 300 people. Based on the evidence presented, the jury will synthesize the findings in a consensus statement, including recommendations for policy improvements. The jury will be

chaired by the Honourable Mr. Justice Ian Binnie, former Judge of the Supreme Court of Canada.

Institute for Health Economics

First International Conference on FASD Prevention

While not funded by FASD-CMC, the Committee is involved in supporting the Institute of Health Economics (IHE) in planning the First International Conference on Prevention of FASD in Edmonton, scheduled for September 23 – 25, 2013. This ground-breaking conference will bring together experts from across the country and around the world to share knowledge about best practices and strategies to prevent FASD.



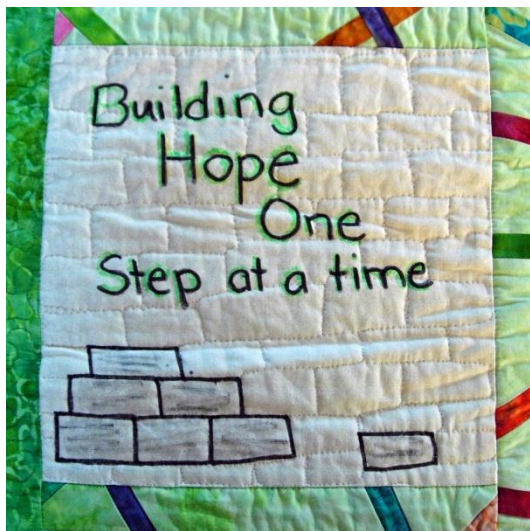
Training for Individuals in the Service Industry

Lead Agency: Alberta Gaming and Liquor Commission (AGLC)

AGLC supports projects to increase awareness of FASD in the food and drink industry and on Alberta campuses. In 2011/12, AGLC partnered with the Council of Alberta Universities Students (CAUS) and Alberta Graduate Council (AGC) to create and distribute FASD coasters and posters. In total, 188,000 coasters and 2,000 posters were produced and all but 1,500 coasters were distributed.

Approximately 160,000 coasters were sent to the 25 schools represented by CAUS and AGC. Additionally, 23,000 coasters were sent to various FASD-CMC partners, including each of the 12 FASD Service Networks (1,000 each), Justice and Solicitor General (3,000), Alberta Children's Services* (9,500), the Public Health Agency of Canada (6,000) and Alberta Seniors and Community Supports* (1,500).

* Now part of Alberta Human Services.



FASD Learning Series

Lead Ministry: Alberta Human Services

The FASD Learning Series was introduced in 2007 to increase community and individual capacity to support individuals with FASD and their caregivers across the lifespan. The videoconference educational sessions cover a broad range of topics that target both urban and rural audiences.

In 2011/12, the FASD Learning Series presented seven educational sessions, with an overall attendance of 1,531 participants (an average of 219 per session, an increase of over 100 more than the average session attendance the previous year). The majority of participants were service providers (61%). Almost 70% of viewers were from Alberta, and 31% stated that they or their organization was a member of an FASD Service Network. There was overwhelmingly positive feedback about the value of this learning experience – more than 90% of survey respondents indicated that learning goals were met, the content was relevant, and they could apply what they learned to their work.

Since 2008, all videoconference and webcast sessions have been archived on the FASD-CMC website – 57 in total by the end of 2012.

THE EMPTY SQUARE

The quilt created by the 46 Parent-Child Assistance Program (PCAP) mentors was named *Pick-Up Sticks*, based on the children's game of using skill and strategy to carefully collect sticks tossed into a tangled disarray. The game is an apt metaphor for the process engaged by PCAP mentors to patiently and lovingly seek out the interventions and services that will be most effective in engaging at-risk women to prevent FASD. Like each game, each woman involved with a PCAP mentor requires a different combination and sequence of "sticks" – interventions that fit her unique needs and circumstances.

At the centre of the quilt is a picture of a baby depicting the ultimate goal of prevention work: the birth of healthy children who are unaffected by prenatal substance exposure. The quilt is bordered in green to represent health and growth. Across the quilt are strands of bright fabric representing the sticks, linking the parts together in its unifying theme.

The quilt is comprised of 55 unique, colourful squares, each one telling one part of the story of individuals and families affected by FASD and the work of PCAP mentors to help prevent FASD. Each square was created individually by a PCAP mentor to capture her experience of this important work. All participants signed another square, stitched at the back of the quilt, to acknowledge each mentor's contribution.



But one square of the quilt, the 56th, is deliberately left empty to represent the untold stories of those living with FASD.

Indeed, we are only at the beginning of our journey to understand the impact of FASD on individuals, families and our communities.

There are many more stories that need to be told. Stories that we need to hear, document, learn from, and address. This important work is well underway, but there is much more work ahead of us.

