Year 5 Evaluation of the Government of Alberta’s FASD 10-Year Strategic Plan

OVERVIEW OF KEY FINDINGS AND RECOMMENDATIONS
Drinking alcohol during pregnancy can cause irreversible brain damage to an unborn child. People living with the disorder may require support throughout their lives to cope with a variety of neurobehavioural impairments. Individuals with FASD are also at risk for secondary disabilities, including mental health problems, behavioural issues and substance abuse, leading to disruptions in school, legal issues, and involvement with the justice system. Children with FASD are found to have a lower quality of life than children without FASD in several domains, including physical, emotional, school, social, and cognitive functioning. FASD also significantly impacts families and caregivers, affecting their community and social life, their relationships, and daily functioning, such as their finances (Denys & Rasmussen, 2012).

FASD is an umbrella term that covers several alcohol-related medical diagnoses. It is often referred to as the “Invisible Disability,” as the difficulties may not be linked to prenatal alcohol exposure, leading to late diagnosis and access to appropriate interventions, which increases the risk for secondary disabilities including mental health disorders or addictions (Streissguth, et al., 2012).

FASD is a lifelong condition resulting from organic brain damage and has no cure. Many children with FASD are not raised by a birth parent and experience multiple placements and different caregivers with varied levels of understanding of the lifelong disability of FASD. It has a devastating impact on individuals and communities across the province, with an estimated prevalence of one in 100 live births (Stade, et al., 2009), affecting approximately 36,000 Albertans (Government of Alberta, 2012). In Alberta, the direct medical cost for FASD is estimated at between $140 million each year, using a low incidence rate of three FASD cases per 1,000 births, and $410 million, using a higher rate of nine FASD cases per 1,000 live births (Thanh and Jonsson, 2009).
A BRIEF HISTORY OF ALBERTA’S RESPONSE TO FASD

Knowing that FASD is preventable underscores that it is a complex, multidimensional social and public health issue, and not a disease that can be cured. Fetal Alcohol Syndrome (FAS) began to be recognized and addressed in Alberta in the early 1990s when the government established a workforce development initiative to support the training of social workers and support agencies to raise awareness of FAS. A cross-sectoral partnership on FAS between the government and community stakeholders was established in 1998, which led to the creation of regional FAS coordinating committees and the recruitment of “champions” from key government departments and organizations to disseminate information about FAS.

In 2003, the cross-sectoral partnership on FAS was transformed into a government-led Cross Ministry Committee on FASD (the CMC), a decision-making body responsible for developing and implementing a FASD 10-Year Strategic Plan (2007-2017), which was approved by the Government of Alberta’s Standing Policy Committee on Health and Community Living in 2006. Funding for this initiative was to be

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used by the CMC to support the planning and delivery of provincial government programs and services, with funding redistributed to each of the partnering ministries.

Based on the original funding received, the CMC made the strategic decision to transform seven of the regional FAS coordinating committees into regional FASD Service Networks (the Networks), enabling communities to make the most efficient use of the funding received. As funding increased, the number of Networks was increased to 12 in 2009. Each Network is designed as a community-based and community-led partnership that reflects local priorities and needs while at the same time demonstrating alignment with the government’s FASD 10-Year Strategic Plan.

**ALBERTA’S FASD 10-YEAR STRATEGIC PLAN**

This plan focuses on three areas of service (Awareness and Prevention, Assessment and Diagnosis, Supports for Individuals and Caregivers) and four areas of activity (Research and Evaluation, Strategic Planning, Training and Education, Stakeholder Engagement). It identifies seven specific outcomes and strategies to implement each service and activity area. The plan also calls for ongoing monitoring to ensure targets are being met and desired outcomes are being realized. Evaluations were set for Years 5, 7, and 10 of the FASD 10-Year Strategic Plan (2007-2017). See the diagram of the organizational structure on page 5.

**YEAR 5 EVALUATION OF THE FASD PLAN**

The Alberta Centre for Child, Family and Community Research (The Centre), a not-for-profit charitable corporation, was established in 2003 as a partnership between Alberta’s universities, the community and the Government of Alberta. The Centre was established to support and disseminate research knowledge and evidence on policy issues related to improving the well-being and health of children.

The Centre developed, coordinated, and managed the Strategic Plan evaluation in Year 5 of its implementation (2011/12). The evaluation was designed to measure progress toward a comprehensive and coordinated provincial response to FASD across the lifespan.
Multiple distinct projects with different methodologies and expertise were initiated to fulfil the scope of the evaluation. The Centre recruited individuals with the specialization necessary to complete each project (see Appendix A for a list of the Year 5 Evaluation Research Reports). Stakeholders and experts were consulted to focus and contextualize the inquiry and were kept informed and engaged throughout the evaluation process.

The evaluation provides baseline measures against the outcomes and targets set forth in the Plan and provides a foundation for subsequent evaluations. Recommendations based on the results address key policies and practices to support individuals affected by FASD, and the continuous improvement of the Alberta FASD Network model that has evolved over the past five years.

Following is a brief summary of findings from these reports. For the purpose of this overview, evaluation questions under each outcome are listed together, followed by key findings arising from the questions.
10 Year Target: 95% of Albertans understand that drinking alcohol during pregnancy can lead to FASD and lifelong disabilities.

Evaluation Question: Has there been an increase in understanding among Albertans that alcohol use during pregnancy can lead to FASD, that FASD can be prevented, and that FASD prevention is a shared responsibility?

Methodology: There was no existing data available to measure whether or not there has been an increase in understanding. A telephone survey of 1,203 adults was conducted in Alberta. Demographic characteristics of respondents were similar to the general Alberta population. Limitations: The survey did not include youth under 18, people without a telephone landline, or non-English speaking Albertans. The survey did not focus on reaching women who may be at-risk of drinking alcohol while trying to get pregnant and during pregnancy.

Key Findings: This survey found that 85.7% of respondents were aware of FASD. Of these, more than 96% know that alcohol use during pregnancy causes FASD, that FASD can be prevented, and that the best way to prevent FASD is by not using alcohol while trying to get pregnant and during pregnancy. Of Albertans who had heard of FASD, 40.1% knew someone with FASD, and 39.1% knew of someone who cares for an individual with FASD. 14.3% of respondents had not heard of FASD. These last respondents were more likely to be male (62.8%), between the ages of 18 and 44 years, non-Caucasian, and born outside of Canada. Almost all participants responded that they believed a woman should be supported by others not to drink while pregnant. The woman’s family and partner/spouse were identified most often as those who should provide support. More than 60% identified healthcare providers, government, and community as having roles in supporting pregnant women not to drink.
Evaluation Question: Is there evidence that alcohol use during pregnancy has been reduced or eliminated among at-risk women and overall among women in Alberta?

Methodology: There is no direct data measuring whether or not alcohol use during pregnancy has been reduced or eliminated. Researchers conducted an evaluation of the Parent-Child Assistance Program (PCAP) to use as a proxy. PCAP is a three-year home visitation intervention program, implemented across Alberta, for women who have a history of alcohol and drug abuse and are at risk of giving birth to a child with FASD. The program uses a mentorship model, where PCAP mentors work with clients to access needed services, to complete substance abuse treatment, and to choose effective family planning strategies. 

Data collection: Client file review (Addiction Severity Index (ASI) Intake/Exit Interviews and Biannual Client Progress Interviews from 2004 to 2011 inclusive). 

Limitations: Missing ASI exit and biannual progress interviews.

Key Findings: The number of Network funded PCAP service providers has increased from four (2008) to 18 (2011). The total number of clients served has increased from 15 in calendar year 2008 to 254 in fiscal year 2010/11. Of clients who responded to the interview question of ethnicity (N=95), 58.9% identified as Aboriginal, 20% as Caucasian, and 21.1% as Other. Trends for clients remaining clean and sober over 24 months (N=57) showed a significant increase over time. Over a period of six to 24 months, client employment trends dramatically increased (N=47) and clients receiving welfare dramatically decreased (N=60). Overall use of birth control methods dramatically increased from intake to 24 months (N=45). Of the 69 births reported over a 24-month period, 49 births (71%) occurred during the first six months of PCAP services. Only eight births (16%) may have potentially been exposed to alcohol over later periods (data limitations must be noted).

Diane’s Story
Diane is 29 years old and has two children diagnosed with FASD. Her mother helps her look after the kids. She has never accessed any adult support services, but her problems are piling up. She has a new boyfriend and is running with a rough crowd. Her probation officer called the FASD Network looking for help.

The Network organized an assessment with its clinic team in under 10 days. They called an agency to find a mentor to support Diane during the assessment process. The mentor is now helping Diane access the supports and services recommended by the clinic team. She is receiving addictions counselling, has been referred to a family doctor, and is using birth control for the first time since her youngest child was born.
10 Year Target: Multidisciplinary teams complete 900 assessments annually.

Evaluation Question: Is there evidence of improved access to quality FASD assessment services provided by multidisciplinary teams?

Methodology: Interviews with 12 Alberta FASD clinics (directors and clinicians); document review.

Key Findings: There are currently 24 FASD clinics in Alberta, 17 of which are funded through the CMC’s FASD Service Network Program. The other clinics are private or funded by the government through Alberta Health Services. The number of Network funded clinics has increased from six (in 2008) to 17 (in 2011). The total number of annual FASD assessments conducted by these clinics has increased from 129 in calendar year 2008 to 401 in fiscal year 2010/11. The largest increase was for youth ages 7 to 18. Seven out of the 12 clinics interviewed see clients 5-years-old or younger, and eight out of the 12 clinics provide assessment services to adults. Assessment caseloads range from 12 to 180 clients per year, per clinic. All 12 clinics interviewed have team members from at least five different disciplines. Most consist of a clinic coordinator, pediatrician, occupational therapist, speech language pathologist, psychologist, neuropsychologist, and social worker. However, many professionals are employed only part-time, and clinic members reported feeling the need to complete tasks that are not under their area of specialty. Clinics have achieved an increasingly consistent standard of practice by following Canadian guidelines for general procedures and using the University of Washington’s 4-Digit Diagnostic Code.

Challenges to the assessment process include: waitlists, lack of sustainable funding, funding eligibility constraints, need for longitudinal assessments, lack of FASD awareness, lack of post-assessment support services, need for more coordination between agencies, and difficulty accessing research and best practices.

The Provincial Evaluation of Alberta’s FASD Service Networks suggests that the cost of assessment and diagnostic services can be up to $4,000 per client. A review of the Alberta FASD Inventory indicates that although government bodies fund a majority of assessment services, three out of 12 clinics charge an individual fee for services. Clinics utilize government funding on a per-needs basis, and with cases deemed as less critical, clients are expected to cover their own costs.
Supports for Individuals and Caregivers

OUTCOME #3: Individuals affected by FASD and their caregivers have coordinated access to support services to meet their needs.

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

Evaluation Questions: How has service coordination been facilitated to meet the support needs of individuals diagnosed with FASD? What proportion of individuals diagnosed with FASD in Alberta is receiving services to help manage their disability? Do caregivers believe they have coordinated access to support services that meet their needs?

Methodology: Literature review on frameworks supporting service coordination; review of FASD-specific data from research studies focused on intervention recommendations after clinical diagnosis and current service utilization; document review.

Key Findings: The literature identifies three levels of service integration and coordination: at the system/sector-based level, the agency-based level, and the client/family-based level. All three of these approaches are evident in the Alberta FASD Service Network model, with the CMC providing macro-level system coordination through communications and removal of policy barriers, the Networks developing local partnerships for clients and caregivers, and key caseworkers/mentors providing coordination and navigation directly to clients and caregivers.

ANNE’S STORY
Anne is a 74-year-old caregiver who still looks out for her five adult “foster” children who are FASD affected. She worries, “Who is going to help them when I am gone?” She helps them buy groceries and manages their money to make sure ends meet. She also helps them with their parenting and relationship problems. A friend suggested she contact the FASD Network. The Network is providing her with information, and is connecting her with other caregivers in her community.
Assessment and diagnostic clinics in Alberta do not currently collect data linking diagnosis to service access.

The clinics use a consistent multidisciplinary approach to assessment. The Rajani FASD Clinic Team located in the Lakeland Network provides training for clinics within Alberta and across Canada. The Provincial Evaluation of Alberta’s FASD Service Networks indicated that every Network has created successful collaborations in their communities, with examples cited in annual reports. Service delivery improvements through collaborations were identified, such as waitlist minimization, navigation, and follow-up planning. Quantitative evaluation is not available to support these findings. High rates of referral, especially to mental health related services, healthcare, income supports, and housing were identified in the data.

The literature also identifies other important frameworks needed to direct how services are delivered that stress the need for a continuum of supports and services. These include the World Health Organization’s International Classification of Function (ICF), and the Life Needs Model, which fits with ICF goals of community participation and quality of life. Alberta-based research in other areas of disability has identified important themes and areas of need that can be applied to the FASD population, including: standardization of services; a holistic integrated lifespan approach to care (wraparound services) based on ICF principles, and key caseworkers (such as mentors) to assist families with coordinating care.

Assessment and diagnostic clinics in Alberta do not currently collect data linking diagnosis to service access. However, a research team at the Glenrose Rehabilitation Hospital reviewed 306 files with a confirmed history of prenatal exposure to alcohol to determine the recommendations given at the time of assessment (Baugh et al., 2012). Educational recommendations were predominant in all age groups. Younger children under age 5 were given recommendations for family supports, reassessment, and developmental therapy, while there was evidence of increasing need for mental health services in both the 6 to 12 and 13 to 17 age groups. A longitudinal follow up of 50 of those families was conducted to determine what recommended services were accessed. Families most often accessed the following services after recommendations: IPP/modified school program (100%), developmental

Peter’s Story
Peter’s mother drank during her pregnancy with him. He is now 23 years old, homeless, and living in rural Alberta. He has lost his ID. He is living in a tent, keeping warm by a fire and drinking with friends. It is several days before Peter meets with his mentor, who notices that his boots have melted and his feet are burned, and takes him to hospital. Peter is happy to have a mentor who helps him get replacement ID and set up a bank account so he can rent a place to live. The mentor also helps him get to his doctor appointments on time.
supports (95%), medication/psychiatry (81%), child counselling (67%), and support for the parent (67%). Parent advocacy/education (50%) and behavioural intervention for the child (14%) were the least accessed recommendations. Many caregivers had received education/advocacy prior to the assessment process. Behavioural interventions specific to children with FASD needs further research.

A pilot project at the Glenrose assessed 10 adults who had received a diagnosis of FASD five or more years prior by the Glenrose pediatric team (Brodeur et al., 2012). The increasing needs of this population were evident, with more impairment in all areas of functioning. The need for supports was across all systems and included areas such as mental health, addictions, employment, safe housing, income supports, legal issues, and general health care, especially reproductive health. The need to provide the adult with a mentor or support person prior to the clinic, throughout the assessment process, and in accessing the recommendations after the clinic was identified as critical. Many of the adults had aging caregivers or had become disconnected from any supports due to lifestyle patterns.

There is limited data on the caregiver perspective. However, parent/caregiver satisfaction surveys conducted by the Networks were done mainly around the assessment and evaluation phase of the FASD service provision. Of those surveyed, 85% indicated that after assessment and diagnosis they were completely or somewhat in agreement with the statements “people told me where to get help for my child/dependent” and “people made sure I got help for my child/dependent.” Of clients who accessed supports from the Parent Child Assistance Program (PCAP), 87% either completely or somewhat agreed that the PCAP program mentors “helped me to use programs and services available in the community that I hadn’t used before.”
Training and Education

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.

**Evaluation Questions:** Is there evidence that service providers, families, and caregivers have improved knowledge of and access to training and educational resources that are based on research and leading practices?

**Methodology:** There was no existing data available to measure whether or not knowledge of and access to training and educational resources has improved. A documents review and stakeholder interviews were used to compile data. **Limitations:** Reports on training do not use a standardized format and do not consistently report on participating stakeholder groups.

**Key Findings:** The FASD Learning Series was introduced in 2007. 90% of individuals accessing the sessions did so remotely via videoconference or webcasting (offered in 2011/12). The number of sessions offered fluctuated widely, from 682 in 2008/09 to 178 in 2009/10 and back up to 610 in 2010/11. Between 84% and 93% of those accessing these sessions were service providers. Between 5% and 15% were parents/caregivers. When the 2010/11 content was put up on the CMC website and made available for unrestricted use, 24,355 hits (from 09/10 to 03/11) occurred. Videos accessed were mainly in the individuals or family members/caregivers category. Annual attendance at the FASD Conference (from 2008 to 2011) ranged between 550 and 600. Other learning opportunities include an FASD Community of Practice showcase, a speakers series, PCAP training, and demonstration projects with First Nation (Siksika), Métis Nation, and in several Child and Family Services Authority (CFSA) regions.

The Networks are not funded to provide training and educational resources, and so do not report on these. Eight of the 12 Networks provide some information on their websites about resources and learning opportunities available in their regions, but information is inconsistent across sites. These websites are not yet being used to their full potential. Focus group results with Network Leadership Team representatives indicate they believe they are aware of and up to date with current research and best practices, that this informs their planning, that their Networks encourage the use of best practice guidelines, and that their funded service providers follow these guidelines.
Strategic Planning

OUTCOME #5: The planning and delivery of provincial government programs and services associated with FASD is accomplished through a collaborative approach.

Evaluation Questions: How does the network model compare with other models? Do other models exist for comparison? Have these other models been evaluated? Develop an evaluation framework to determine how the 12 FASD Service Networks collaborate with community agencies to plan and deliver programs and services. What is the history of the CMC? How was it established? How has it evolved? What collaborations enable it and support its existence? What are the ripple effects of the CMC investments? Examine the CMC and 12 Service Network Model in terms of governance, structure, accountability, funding, sustainability, and recommendations.

Key findings: A scan of Canadian government websites found that there is great variability across Canada with respect to the nature and extent of FASD activity. Only three provinces were found to have a FASD strategic plan in place as of spring 2012: Alberta, British Columbia, and Manitoba. Evaluations of FASD services have been at the program and service level. Evaluations of governance models were not found.

The proposed evaluation framework to examine collaboration within Alberta’s FASD Service Network Program provides a tool to support consistent and continuous ways to measure collaboration within and between the CMC, the 12 Networks and other community services and agencies. A logic model and four different data sources are proposed, including a survey, focus groups, observation, and document review.

Key moments in the history of the development of Alberta’s Service Network Program have been described on page 2 of this report.

While there are examples of how the Service Network Program has extended its collaborative efforts outwards, generating partnerships and shared efforts with programs beyond those funded by the CMC, there are no direct measures of the ripple effects of this investment.

A focus group meeting with members of the CMC (conducted as part of the evaluation for Outcome #6) noted that the shift in role from
decision-making body to a more coordinating body for the Networks has resulted in a change in reporting mechanisms with senior management and a corresponding decrease in communication with senior government decision-makers, diminishing the ability of the CMC to raise awareness of FASD internally as a government priority. Locally, Networks are not uniformly structured. Nine of the 12 Networks are not legal entities and operate under the guidance of a Network Leadership Team, redistributing CMC funding to service providers. Two of the Networks are incorporated under the Societies Act and are led by a Board of Directors, providing services directly to the community rather than redistributing funds to service providers. The Métis Settlements Executive Council provides leadership for the Métis Settlements FASD Network.

The FASD Service Network Program has been successful in developing the tools needed to manage network operations and accountability at both the provincial and local scales. The Provincial Evaluation of Alberta’s FASD Service Networks analyzed the level of development of each Network with respect to network governance, planning, funding decisions, financial management, contract management, and performance reporting. Three of the networks received an overall rating of Excellent, five received a rating of Very Good and three Networks are in Development. This evaluation process identified leading practices and has created the tools needed to support continuous improvement in each of these six areas of operation.

The FASD 10-Year Strategic Plan called for the CMC to receive annual funding beginning with $8 million in 2007/08, levelling off at $42.250 million per year by 2013/14. However, the CMC received $4.225 million at start-up (2006/07) with increases to $16.5 million in 2008/09, where it has levelled off. A well-developed funding model is in place to support annual disbursement of funds to the Networks, but it does not address their need for stability, which would require a three-year funding cycle (rather than annual applications). Networks also receive project-specific funding from multiple government ministries, which necessitates separate proposals, each with different project management, accounting and reporting requirements. Focus group participants identified that the lack of coordinated accounting and reporting requirements results in an onerous administrative load for the Networks.

In addition to operations and accountability, management tools are needed to support network participation and maintenance, which include collaboration, research and evaluation, and knowledge mobilization (training and education). The CMC and Network budgeting processes do not separately recognize costs associated with these activities. The funding model does not support Network participation as partners in research and evaluation, nor does it support the training and education needs of their service providers and families/caregivers. Although the CMC established sub-committees to address communications and data collection, the work of these committees is not well defined nor was it evaluated as part of the Year 5 Evaluation Project.

In terms of sustainability of this FASD initiative, evidence from the Provincial Evaluation of Alberta’s FASD Service Networks and other Year 5 Evaluation reports suggest FASD project partners do not have a shared understanding of what success means for the FASD population, or how it should be measured. The reports identified that outcomes for the FASD 10-Year Strategic Plan were often poorly defined and some measures were considered to be unrealistic for the FASD population.

As stakeholder engagement is a key characteristic of network governance, findings from evaluation questions related to Outcome #7 are presented in the following section.
Stakeholder Engagement

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.

Evaluation Questions: What mechanisms has the CMC implemented to engage stakeholders in strategic planning activities? What opportunities have been available for stakeholders to engage in networking and information sharing?

Methodology: Document review; interviews with stakeholders.

Key Findings: The CMC engages stakeholders in strategic planning at the provincial scale, while the Networks engage their stakeholders in needs assessment and business planning at the local scale. The CMC develops an annual Strategic and Operational Plan in consultation with its stakeholders. Since 2007, the CMC’s Operational Program Review Subcommittee reviews its Program Operating Grant Policies in consultation with stakeholders. These policies provide guidance and structure to the development of annual Network business plans, which are reviewed by the subcommittee as part of its grant application process.

The Provincial Evaluation of Alberta’s FASD Service Networks found that 10 of the 12 Networks have conducted formal needs assessments with their stakeholders since 2007. Four of the Networks reported conducting their business planning in a collaborative manner that included stakeholders and broader community members. Mechanisms to engage stakeholders in strategic planning activities include meetings, and gathering input from partners and researchers.
Research and Evaluation

**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.

**Evaluation Questions:** Have research, leading practice, and monitoring and evaluation informed FASD strategic planning, prevention activities, and programming? Have the efforts of the FASD-CMC resulted in increased availability to FASD-related data locally and provincially? Establish an inventory of Alberta-based FASD research and researchers covering all four pillars of basic, clinical, population, and health services to provide a baseline measurement for research capacity in Alberta. Are there indications that evidence is changing/influencing FASD policies and practice?

**Methodology:** There are no direct measures for this outcome. A document review, focus groups with the CMC, the Networks, and PCAP members, and interviews with FASD assessment and diagnostic clinic managers were used to compile the data.

**Key Findings:** Participants reported that the CMC has formed strong working relationships with researchers who have expertise in FASD and that it uses results from research evaluation studies (with an emphasis on Alberta studies) to inform strategic planning. The Networks use information from local needs and gap assessments, and results from local research and evaluations to inform their strategic planning and funding allocation decisions. However, sharing of research and best practice amongst Networks occurs infrequently and often informally. Information about research and evaluation is primarily received through watching the *Learning Series* videos posted on the CMC website.

Regular monitoring and evaluation is used to inform the PCAP program. PCAP members noted that while there have been increased training and information sharing opportunities, the research and best practice available for PCAP mentors are often theoretical, and not practical enough for mentors to apply to their practice. Clinic members noted that a strong multi-disciplinary structure has developed, with a corresponding increase in services across FASD clinics, where there are more patients seen, and importantly more adults seen. While clinic members recognize the importance of utilizing and informing research, they noted that their busy schedule limits the extent to which they are able to do this. Online professional development was reported as an effective dissemination activity, as was the online database, although it is currently available only for PCAP. Videoconferencing was identified as an effective medium for collaboration, and helpful in overcoming geographic barriers.
The inventory of Alberta-based FASD research indicates growth in research accomplishments, most of which have occurred in the clinical pillar, followed by the health, population, and basic pillars. A large portion of the clinical research is community-based fieldwork, which connects research to community-based programs and services. Health research has evaluated early intervention and support services tailored for individuals and families affected by FASD. Population research has grown to provide reliable data on FASD cost, prevalence, and prevention in Alberta, informing strategic planning. Basic research in the past five years has seen an increase in brain imaging research, which is important for developing an increased understanding about FASD.

Videoconferencing was identified as an effective medium for collaboration, and helpful in overcoming geographic barriers.
In addition to the seven outcomes identified in the FASD 10-Year Strategic Plan, the Year 5 Evaluation added two more outcomes related to assessing the social return on investment (SROI) of Alberta’s FASD Service Network Program by estimating the potential impact of the Networks on secondary disabilities associated with FASD. These include: crime, homelessness, mental health problems, and school disruption (for children) or unemployment (for adults).

It is important to note that this is not an assessment of value for money of the program, as the analysis does not consider all economic benefits associated with the Networks, such as the direct benefit to those experiencing FASD, their caregivers, any preventative benefits, or benefits from ameliorating secondary disabilities associated with FASD. The required data for a thorough and valid assessment of economic benefit is currently unavailable.

**Evaluation Questions:** Is there evidence of a reduction in secondary disabilities associated with FASD and their impact on Albertans? Has the cost of FASD to Albertans been reduced?

**Methodology:** An exploratory cost benefit analysis approach was used, where outcomes were monetized to compare the difference between benefits and costs using available information and data at the time of this analysis. **Limitations:** Limited data was available. No data was available to inform the effectiveness of the Networks on secondary disabilities. The estimates of the effectiveness used in this analysis varied from 40% to 80%; however the actual effectiveness rate of the Networks is not known.

**Key Findings:** Corresponding to effectiveness rates ranging from 40% to 80%, the Networks were estimated to reduce the following number of occurrences: school disruption among children, between 187 and 281 occurrences; adults being unemployed, between 144 and 289; crimes committed, between 297 and 593; mental health problems, between 456 and 930, and being homeless, between 74 and 148. The total gross monetary benefits of reducing these occurrences range from $8.87 to $17.73 million per year with annual program costs estimated at approximately $6.12 million.

What these results show is that the economic and social burden associated with secondary disabilities is significant and there is an economic opportunity to reduce the resource burden on already constrained social resources and programs. Programs that are effective at not only ameliorating secondary disabilities, but are also effective in prevention, are likely to be cost effective. However, until data measuring the effectiveness of these programs are collected and made available, the full economic value of these programs cannot be demonstrated.
Following are the conclusions drawn based on the key findings from the FASD Year 5 Evaluation.

CONCLUSIONS

Awareness and Prevention
OUTCOME #1A:
Baseline data has been collected to measure whether or not there has been an increase in understanding among Albertans that alcohol use during pregnancy can lead to FASD, FASD can be prevented, and FASD prevention is a shared responsibility. Going forward, the CMC is well positioned to measure a change in FASD awareness and understanding among Albertans.

Awareness and Prevention
OUTCOME #1B
The effectiveness of the PCAP program is a useful proxy to measure if alcohol use among women at-risk is reduced, and the program is a good example of the wraparound service model needed to support reduction of alcohol among woman at-risk of using alcohol while trying to get pregnant or during pregnancy.

Assessment and Diagnosis
OUTCOME #2
The FASD 10-Year Strategic Plan has successfully increased the number of clinics in Alberta, and assessments by multidisciplinary teams associated with the Networks have increased from 129 to 401 per year from 2008 to March 2011. In addition, all teams are following Canadian guidelines for standardized procedures and diagnosis.

Supports for Individuals and Caregivers
OUTCOME #3
The strategic plan has created a framework to address service coordination at three scales (system/CMC level, agency/Network level, and client/family level). The literature identifies the need to shift the purpose of assessment from diagnosis to intervention, and to apply an integrated lifespan approach to providing wraparound services where key caseworkers and mentors assist clients and caregivers with
accessing coordinated services. Clinics need to be funded to collect data linking diagnosis to service areas in order to determine if recommended service targets are being met.

**Training and Education**

**OUTCOME #4**

There is evidence that training and education resources are based on research and leading practices, and that they are being accessed by service providers and caregivers. However, Networks need funding to support targeted access to training and education for service providers and caregivers in their region, and need to evaluate the effectiveness of these resources using standardized methods for data collection.

**Strategic Planning**

**OUTCOME #5, AND**

**Stakeholder Engagement**

**OUTCOME #7**

A network governance model is being used to support Alberta’s FASD Service Network Program. The CMC and most of the Networks are actively engaging their stakeholders in their strategic planning processes. The CMC has established a subcommittee to oversee Network operations and funding and has successfully developed the management tools needed to oversee Network operations and accountability at both the provincial and local scales, based on best practices and continuous improvement. Subcommittees are needed to oversee collaboration, research and evaluation, and knowledge mobilization (training and education), with management tools developed to measure their effectiveness. The Networks identified that outcomes for the FASD 10-Year Strategic Plan were often poorly defined and some measures were considered to be unrealistic for the FASD population. To address issues of sustainability, FASD partners must develop a shared understanding of what success means for both the FASD population and the Networks, and how these outcomes should be measured to demonstrate the effectiveness and efficiency of this model of delivery.

**Research and Evaluation**

**OUTCOME #6**

There is evidence that research, leading practice, and monitoring and evaluation has informed FASD strategic planning, prevention activities, and programming, and an inventory of research has been developed. Networks, however, need funding to participate in research, as fieldwork and standardized data collection are essential if research is to inform and influence policies and practice.

**Social Return on Investment**

**OUTCOMES #8 AND #9**

The evidence suggests that programs, such as Alberta’s FASD Service Network Program, that are effective at both ameliorating secondary disabilities and in prevention are likely to be cost effective. However, all economic benefits associated with the Networks and data measuring the effectiveness of these programs must be collected and made available in order to demonstrate the full economic value of these programs. The required data for a thorough and valid assessment of economic benefit is currently unavailable.

Issues identified in the conclusions relating to assessment, service provision, outcomes, data collection and research, funding, and sustainability, are addressed in the recommendations.
These recommendations are made to address key policies and practices needed to support individuals affected by FASD in Alberta, and continuous improvement of the Alberta FASD Network model that has developed over the last five years as a direct result of the Government of Alberta’s FASD 10-Year Strategic Plan.

RECOMMENDATIONS

1. **Provide clients with assessment for intervention and wraparound services supported by a mentor system:** Provide clients with services based on assessment for intervention rather than diagnosis. Develop wraparound services, supported by a mentor system, that facilitate the provision of a continuum of supports and services through the lifespan of FASD clients based on principles of participation and quality of life with planned transitions.

2. **Define Sustainability:** Clearly define the scope of the FASD Service Network Program by developing a shared understanding among the CMC, Networks, and other stakeholders of what sustainability means within the context of FASD, both for the population directly affected by FASD and for the delivery system that provides them with supports and services.

3. **Clarify outcomes:** Examine current FASD 10-Year Strategic Plan outcomes in light of this shared understanding of sustainability. Articulate clear, measurable outcomes for individuals affected by FASD (client outcomes) and for the FASD delivery model (system outcomes) that demonstrate system effectiveness and efficiency.

4. **Develop a data collection model:** Identify indicators and develop data collection templates. Provide funding to the Networks to support consistent data collection that is available to all stakeholders working collaboratively to achieve outcomes. Fund the Networks to participate in research and evaluation projects in order to support continuous, reliable data collection.
5. **Further develop CMC governance structures:** Following the model of the CMC’s Operational Program Review subcommittee, develop the other CMC subcommittees to oversee stakeholder engagement and collaboration (participation in strategic planning), research and evaluation (participation in research and data collection), and knowledge mobilization (participation in training and education). Develop management tools for each domain to support continuous improvement and standardization based on research and best practices.

6. **Improve the CMC funding model:** Support Network stability by providing core operating funding on a three-year cycle based on achieving annual objectives described in Network business plans. Recognize that collaboration, knowledge mobilization (training and education), and research and evaluation are core functions of a network governance model that require funding at both the provincial and local scales. Associated costs should be clearly itemized and become an integral part of the CMC funding model.

7. **Increase access to the Alberta FASD Service Network Program services:** Increase funding in order to reach targets set for Prevention and Awareness, Assessment and Diagnosis, and Supports for Individuals and Caregivers, as described in the FASD 10-Year Strategic Plan.
The following Year 5 Evaluation reports were prepared and completed in 2012 for the Alberta Centre for Child, Family and Community Research and are available at fasd.alberta.ca:

**YEAR 5 EVALUATION RESEARCH REPORTS**

**OUTCOME 1A**  
Dr. Cecilia Bukutu, Tara Hanson, MACT, and Dr. Suzanne Tough

**OUTCOME 1B**  
Dr. William Pelech, Dr. Jacqueline Pei, Dr. Cheryl Poth, and the University of Alberta ACCERT Evaluation Team Members.*

**OUTCOME 2**  
Dr. Cheryl Poth, Dr. Jacqueline Pei and ACCERT

**OUTCOME 3**  
Dr. Gail Andrew, MDCM FRCP (C)

**OUTCOME 4**  
Michelle Anderson-Draper MSc, CE

**OUTCOME 5**  
Michelle Anderson-Draper, MSc, CE, Dr. Cheryl Poth, Dr. Jacqueline Pei and ACCERT, and Susan Abells

**OUTCOME 6**  
Dr. Cheryl Poth, Dr. Jacqueline Pei and ACCERT

**OUTCOME 7**  
Michelle Anderson-Draper MSc, CE

**OUTCOMES 8 AND 9**  
Institute of Health Economics: Dr. Thanh Nguyen, Dr. Jessica Moffatt, Dr. Anderson Chuck, Dr. Philip Jacobs, Dr. Egon Jonsson

**LIVED REALITIES – REALISTIC OUTCOMES**  
Teresa O’Riordan, Executive Director, Northwest Central Alberta FASD Service Network

* The University of Alberta’s Alberta Clinical and Community-based Evaluation Research Team (ACCERT) included the following student members: David St. Arnault, Jenelle Job, Ellis Chan, Wence Leung, Sukhpreet Tamana, Kendra McCallum, Laura Gould, Virginia Tze, Katy Wyper, and Erin Atkinson.
OTHER REFERENCES CITED


Provincial Evaluation Report of Alberta FASD Service Networks (March 30, 2012) was coordinated by KPMG LLP and prepared for the CMC.


For more information visit fasd.alberta.ca