FETAL ALCOHOL SPECTRUM DISORDER (FASD)

Cross-Ministry Approach on FASD: Making a Difference for Individuals with FASD and their Caregivers

Denise Milne, Shelley Birchard and Janice Penner

First International Prevention Conference on the Prevention of FASD

Alberta Government

Overview

- Introduction
- Background of FASD Initiative
- FASD 10-Year Strategic Plan
- Year 5 Evaluation Results
- Summary

Introduction

- Profound person and societal cost
- In Alberta, the direct medical cost for FASD is estimated at between $140 and $410 million
- Lifetime cost per person with FASD $1.8 million, not including loss of productivity and caregiver burden:
  - Health: 30%
  - Education: 24%
  - Social services: 19%
  - Corrections: 14%
  - Other: 13%

Background of FASD Initiatives

- History of FASD Cross-Ministry Committee
  - 1990s – Raising awareness
  - 1998 – Established cross-sectoral FAS Partnership, creating regional FAS coordinating committees working with GOA champions.
  - 2003 – CMC established to develop a GOA-led 10-Year FASD strategy with funding to support GOA delivered programs and services.
  - 2006/07 – Only half of Cabinet-approved funding received.
  - 2007/08 – CMC makes strategic decision to transform 7 FAS coordinating committees into regional FASD Service Networks

Background of FASD Initiatives

- FASD Cross-Ministry Partners:
  - Human Services (co-chair)
  - Alberta Health (co-chair)
  - Aboriginal Relations
  - Education
  - Enterprise and Advanced Education
  - Justice and Solicitor General
  - Alberta Gaming and Liquor Commission

Ad-hoc Membership:

- Alberta Health Services,
- First Nations and Inuit Health,
- Public Health Agency of Canada
- FASD Expert Consultants (Dr. Sterling Clarren, Dr. Egon Jonsson, Dr. Gail Andrew, Mary Berube)

FASD 10-Year Strategic Plan

Vision

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

Mission

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

FASD 10-Year Strategic Plan

- Guiding Principles:
  - Reflect that needs exist across the lifespan
  - Recognize that services are needed across the continuum
  - Develop a cross-government approach
  - Align planning efforts with other government initiatives
  - Include a diverse range of perspectives.
  - Recognize that collaboration with stakeholders is critical

FASD 10-Year Strategic Plan

Strategic Pillars

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

FASD Service Networks

- Community-based
- Community-led
- Reflect local priorities
- Client focused
- Result based

FASD Service Networks

- Assessment and Diagnosis:
  - Local access
  - Increasing capacity
- Supports:
  - Community based
  - for individual with FASD and their caregivers
- Prevention:
  - community awareness and education
  - supports for women most at-risk through Parent-Child Assistance Program (PCAP) model

FASD Service Networks

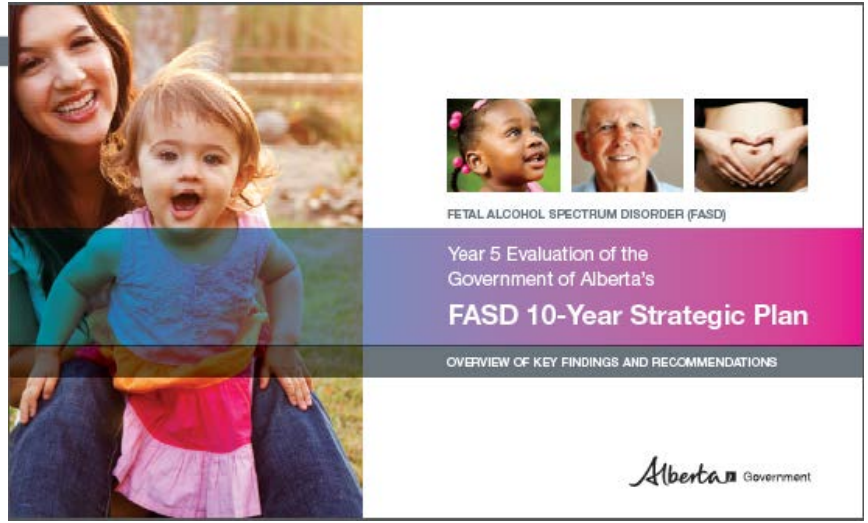
Network Boundary

- Mackenzie Regional FASD Network
- Northwest Alberta FASD Network
- Northeast Alberta FASD Network
- Northwest Central Alberta FASD Network
- Lakeland Fetal Alcohol Spectrum Disorder Society
- Edmonton Fetal Alcohol Network
- Prairie Central FASD Network
- Central Alberta FASD Network
- Calgary Fetal Alcohol Network
- Southeast Alberta FASD Network
- South Alberta FASD Network
- **Métis Settlements FASD Network**

FASD Year 5 Evaluation

Purpose

- Measure progress against desired outcomes and targets for service and activity areas.
- Support continuous improvement.
- Inform subsequent evaluations.



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Year 5 Evaluation

- Findings in each of the Strategic Pillars and SROI
  - Awareness
  - Prevention
  - Assessment and Diagnosis
  - Supports for Individuals and Caregivers
  - Research and Evaluation
  - Strategic Planning
  - Stakeholder Engagement
  - Social Return on Investment

Year 5 Evaluation

Evaluation questions developed for each outcome to create context and focus

1a	Albertans understand FASD
1b	Alcohol use during pregnancy is eliminated
2	Access to diagnosis & assessment services
3	Access to coordinated services
4	Access to training and educational resources
5	Collaborative approach to programming
6	Research findings inform strategic planning, prevention and programming
7	Stakeholder engagement mechanisms are in place
8	Secondary disabilities are reduced
9	Cost of FASD is reduced

Year 5 Evaluation Recommendations

1. **Provide clients with assessment for intervention** and wraparound services supported by a mentor system.
2. **Define sustainability:** Develop a shared understanding of what sustainability means among FASD Network partners.
3. **Clarify outcomes** and articulate measurable outcomes for both FASD clients and the service delivery system.
4. **Develop a data collection model** to provide consistent, reliable data available to all stakeholders.

Year 5 Evaluation Recommendations

5. **Further develop CMC governance structure** to oversee participation in collaboration; research & evaluation and knowledge mobilization and to support continuous improvement and standardization.
6. **Improve CMC funding model** to provide Networks with stability and to recognize collaboration, research and evaluation and knowledge mobilization as core functions of network governance model that requires funding.
7. **Increase access to Network services by increasing funding** to meet service targets.

Questions?

Denise Milne, FASD-CMC Co-Chair (Alberta Human Services)
780.415.0523 or denise.milne@gov.ab.ca

Shelley Birchard, FASD-CMC Co-Chair (Alberta Health)
780.427.3117 or shelley.birchard@gov.ab.ca

Year 5 Findings: *Awareness*

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

- Target: 95% awareness among Albertans
- Survey of 1203 Albertans
  - 85.7% of respondents are aware of FASD.
  - 40% know someone with FASD or know a caregiver.
  - 14.3% had not heard of FASD (mostly male, non-Caucasian, born outside of Canada.
  - Almost all responded that women should be supported not to drink, and that it is a shared responsibility

***Conclusion:* Baseline established to measure change in awareness.**

Year 5 Findings: *Prevention*

Outcome #1b: Alcohol use during pregnancy is eliminated.

- Proxy: Evaluation of PCAP Model (3-yr home visitation program for at-risk women, providing wraparound services using mentorship model)
  - Increase in Network funded PCAP providers: 4 (2008) to 18 (2010/11).
  - Increase in clients: from 15 (2008) to 254 (2010/11)
- Clients: 59% Aboriginal; 20% Caucasian; 21% "Other"
- Trends for clients in the program over 6-24 months show evidence of dramatic improvements:
  - increases in employment;
  - decreases in welfare use
  - Increases in use of birth control, with fewer newborns with potential exposure to FASD

Conclusions: **Useful proxy. Good prevention model.**

Year 5 Findings: *Assessment and Diagnosis*

Outcome #2: Adults, children, and youth suspected as being affected by FASD have access to timely and affordable diagnostic and assessment services.

- Target: 900 assessments by multidisciplinary teams
  - # of Network funded clinics increased from 6 (2008) to 17 (2010/11).
  - # of annual assessments increased from 129 (2008) to 401 (2010/11).
  - Cost/assessment ~$4,000
  - Largest increase in assessments was for youth ages 7 to18
  - Assessment caseloads range from 12 to 180 clients/year/clinic
  - Clinics follow Canadian guidelines for general procedures and use 4-Digit Diagnostic Code.

***Conclusion:* Access to assessment has increased.**

Year 5 Findings:
Supports for Individuals and Caregivers

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

- Target: 80% receiving access to coordinated services
  - Network governance model providing coordination at 3 levels: System=CMC; Agency=Networks; Service Providers=Clients and Families/Caregivers
- Glenrose research:
  - Families are accessing educational services; developmental supports; medication/psychiatry services; child counseling and support for parents
  - Parent advocacy/education and behavioural interventions for children are less accessed.
  - Adults with FASD demonstrate more impairment in all areas of function.

***Conclusion:* A continuum of supports and services is needed using a wraparound service/mentor model. Clinics need to be funded to collect data linking diagnosis to service area.**

Year 5 Findings: *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.

- Research informs educational videos
- 90% of individuals accessing the sessions did so remotely via videoconference or webcasting (offered in 2011/12)
- 610 sessions (2011/12) mostly accessed by service providers

- When content was put up on the CMC website:
  - 24,355 hits (from 09/10 to 03/11).
  - Videos accessed: mainly individuals or family/caregivers category
  - Networks are not funded to provide training and education.

Conclusion: **Networks need funding to support targeted access for their service providers and caregivers. Networks need to evaluate effectiveness of resources using standardized data collection.**

Year 5 Findings: *Strategic Planning*

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

- Network governance model is being used.
- Networks are not uniformly structured (9 not legal entities – led by a Network Leadership Team; 2 societies – led by a Board; 1 led by Métis Settlements Executive Council)
- CMC Operational Review subcommittee – has developed management tools needed to oversee Network operations, funding and accountability that support continuous improvement.
- 3 Networks rated Excellent; 5 rated Very Good; 3 are in Development.

Conclusions: **Funding stability is needed (3-year cycle). Outcomes need to be re-evaluated based on a shared understanding of success for FASD population and sustainability of the system needed to deliver supports and services. Outcomes must be measurable.**

Year 5 Findings: *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.

- CMC has good relations with research community and actively engage stakeholders in strategic planning.
- 10 of 12 Networks have conducted formal needs assessment with their stakeholders since 2007.
- 4 of 12 Networks conduct business planning in a collaborative manner that included stakeholders and broader community members.
- Mechanisms, management tools and funding are needed to support Network participation and maintenance (collaboration, research& evaluation, and knowledge mobilization (training & education).

Conclusion: **Establish CMC subcommittees to oversee stakeholder participation. Develop management tools to support evaluation and continuous improvement.**

Year 5 Findings : *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.

- Research informs FASD strategic planning (emphasis on Alberta studies)
- Sharing of research and best practice amongst Networks occurs informally.
- Regular monitoring and evaluation informs the PCAP program.
- Information about research and evaluation is primarily received through the *Learning Series* videos posted on the CMC website.
- A large portion of the clinical research is community-based fieldwork, which connects research to community-based programs and services.

***Conclusion*: Networks need funding to participate in community –based research, as fieldwork and standardized data collection are essential if research is to inform and influence policies and practice.**

Year 5 Findings:
Social Return on Investment (SROI)

Outcome #8: Secondary disabilities or adverse outcomes associated with FASD and their impact on Albertans is reduced. Outcome #9: The cost of FASD to Albertans is reduced.

- *Limitation*: No data is available to inform effectiveness rates of the Networks on secondary disabilities.
- Using estimated effectiveness rates ranging from 40 to 80%, suggest Networks reduce the number of occurrences of:
  - School disruption among children; adults being unemployed ; crimes committed mental health problems; being homeless.
- Total gross monetary benefits: $8.87 to $17.73 million/year with annual program costs estimated at approximately $12.6m.

***Conclusion:* Programs that are effective at both ameliorating secondary disabilities and in prevention, are likely to be cost effective. Data is needed to measure all economic benefit.**