

**INFORMATION AND FEEDBACK SESSIONS
HEALTH CANADA FAS/FAE INITIATIVE
ANNOUNCED IN THE FEBRUARY 1999 BUDGET**

WORKBOOK

WHAT’S INSIDE

Objectives 3

Background 4

Expected Outcomes of the Health Canada Strategic Framework on FAS/FAE 5

Implications and Consideration 6

Purpose of the Information and Feedback Session 7

Program Elements of the FAS/FAE Initiative 8

Guiding Principles 10

Goals and Objectives 12

Key Activities 13

Questionnaire 15

**HEALTH CANADA FAS/FAE INITIATIVE Information and Feedback Session
Workbook**

OBJECTIVES

- 1) Firstly, to share with you and give everybody here an update on what Health Canada is doing to address FAS/FAE.
- 2) Secondly, to hear from you and get an update on your work plan, priorities, needs and gaps regarding FAS/FAE.
- 3) Thirdly, to increase collaboration with provinces, territories, national organizations and Aboriginal organizations, both on and off reserve.
- 4) Lastly, the information gathered here today will be one mechanism that will assist us in creating a national profile of FAS/FAE gaps and priorities across Canada and will contribute to the development of a collaborative National Action Plan on FAS/FAE.

HEALTH CANADA FAS/FAE INITIATIVE Information and Feedback Session Workbook

BACKGROUND

In the 1999 Budget, the Government of Canada increased funding to expand the reach and number of community-based projects under the Canada Prenatal Nutrition Program. In addition, as part of this initiative:

- i current prevention efforts that address Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE), will be enhanced.

FAS/FAE is a wholly preventable lifelong condition and a leading cause of preventable birth defects in children. The rate of FAS is estimated at one to three per 1,000 live births, indicating that each year more than 350 children are born with FAS. Initial studies suggest that the rates of FAS in some Aboriginal communities may be significantly higher. FAS is a national health concern for individuals and society, constituting a life-long disability requiring ongoing support.

Funding of \$11 million over three years was allocated to enhance activities related to FAS and FAE. These new investments will support prevention, public education, capacity building, coordination of FAS/FAE activities, develop practical tools for CPNP and related community-based programs and establish a strategic project fund administered by the Population Health Fund.

The FAS/FAE component is a joint initiative through a partnership between Health Promotion and Programs Branch, Health Protection Branch and Medical Services Branch, with a management and accountability framework that outlines roles and responsibilities of the three Branches. This approach provides flexibility to meet emerging needs, capitalize on opportunities and support cooperative ventures. This presentation will describe the activities taking place within the Health Promotion and Programs Branch.

The FAS/FAE Component has introduced six areas of focus in the overall framework:

1. Public awareness, education and prevention
2. Coordination and collaboration
3. FAS training and community capacity building
4. Early identification and diagnosis
5. Integration of services; and a
6. Strategic project fund to support further development and capacity building.

HEALTH CANADA FAS/FAE INITIATIVE Information and Feedback Session Workbook

EXPECTED OUTCOME OF THE HEALTH CANADA STRATEGIC FRAMEWORK ON FAS/FAE

Through this initiative, it is anticipated that communities and society-at-large will have an increased awareness and recognize the importance of addressing FAS/FAE, research will be initiated in key areas, surveillance and monitoring will be enhanced, and resources/practical tools to community-based programs will be provided.

The FAS/FAE Component will focus on a coordinated approach to addressing the issue. With your help, it will build on the recent valuable and significant accomplishments in this area, including work undertaken by provinces/territories, First Nations, Inuit and other Aboriginal organizations, national, local, parent and community groups.

One of the key elements of the FAS/FAE initiative will be to enhance coordination and collaboration across the country and to share the expertise and resources developed.

IMPLICATIONS AND CONSIDERATIONS

FAS/FAE has been a priority in a number of provinces, territories and First Nations, Inuit and other Aboriginal communities and significant resources have been allocated in the development of overall program frameworks, strengthening community capacity, development of resources and providing training and education opportunities. Acknowledgement of the level of expertise and available resources are key elements in the development of a collaborative national action plan.

At the same time, there are some provinces/territories and communities where their has not been the same level of activity (Ontario, Quebec and some Atlantic provinces). This will need to be recognized in the overall development of the coordinated approach.

HEALTH CANADA FAS/FAE INITIATIVE Information and Feedback Session Workbook

INFORMATION AND FEEDBACK/DEVELOPMENT PROCESS:

The work in the first year will focus on consultation with stakeholders (provinces/territories, other federal departments, professional associations and non-governmental organizations) and with First Nations, Inuit and other Aboriginal organizations with respect to identification of needs and priorities for action; development of a coordinated approach and an evaluation framework and incremental program development. The second year will focus on the full implementation of the coordinated approach.

Along with the objectives that I mentioned earlier, it is anticipated that the information and feedback process will also:

- i develop an ongoing mechanism for information sharing,
- i develop linkages with professional groups and regulatory bodies, and other organization to ensure up-to-date information is shared,
- i identify areas for possible F/P/T collaboration on issues relating to FAS/FAE

Out of these information and feedback sessions we can develop a detailed synthesis report of the information shared today and also provide you with information that was shared at other meetings.

HEALTH CANADA FAS/FAE INITIATIVE Information and Feedback Session Workbook

PROGRAM ELEMENTS OF THE FAS/FAE COMPONENT:

A) Public Awareness/Education/Prevention:

A proposed multi-year campaign will endeavour to focus on FAS/FAE within a context that recognizes the entire spectrum of health-related issues - a “wellness” campaign.

This initiative will focus on practical tools to increase public awareness and education, with emphasis on reducing alcohol use during pregnancy. The prevention activities will use a holistic approach and will develop culturally appropriate resources and promotional materials.

B) Coordination:

As I mentioned, one of the key elements of the initiative will be to enhance coordination and collaboration across the country and to share the expertise and resources developed. The Health Canada FAS Management Committee provides leadership and coordination through consultation and other processes and strategic direction for FAS/FAE initiatives within the department. The Committee is a joint initiative, through a partnership among Health Promotion and Programs Branch, Health Protection Branch, Medical Services Branch and Policy and Consultation Branch and Regional Offices (Health Promotion and Programs Branch and Medical Services Branch).

C) FAS Training/Capacity Development

Identify and develop optimal approaches to best support staff workers in community-based programs (Canada Prenatal Nutrition Program, Community Action Program for

**HEALTH CANADA FAS/FAE INITIATIVE Information and Feedback Session
Workbook**

Children, Aboriginal Head Start, Brighter Futures and the National Native Alcohol and Drug Abuse Program) to work with FAS/FAE children and parents on a daily and ongoing basis.

D) Early identification/diagnosis:

Support for the development of innovative, cost-effective approaches (e.g. telemedicine and diagnostic centres) for the accurate early identification /diagnosis of FAS/FAE at the earliest possible stage of development.

E) Integration of services:

This program component is part of an overall prenatal health program and will be strongly linked with other community-based initiatives and national programs. Support for pilot projects using a comprehensive approach for prevention, identification and management (i.e., clinical practice guidelines, support for individuals and families) of FAS/FAE in diverse communities and model programs using multi-disciplinary and multi-sectoral approaches for care providers and communities to help these children and their families.

F) Strategic Project Fund:

This will be administered through grants and contributions and would focus on strengthening community capacity. The program elements of prevention, early identification, integration of services and research would be supported using this mechanism.

Guiding Principles for the FAS/FAE Initiative

Health Canada endeavours to work in collaboration within a population health/health promotion context with partners and stakeholders to:

- i Develop strategies to address and reduce inequities in the broad determinants of health that underlie or influence substance use during pregnancy and FAS/FAE.
- i Promote accountability by monitoring and evaluating the implementation of the FAS/FAE strategic framework.

It is however, the combination of these important guiding principles outlined below, that will provide the necessary components for sustainability of the FAS/FAE component in the future.

Integrated Approach: An integrated approach to children, youth, women and families is emphasized, reflecting a holistic understanding of mental, physical, emotional, spiritual and psychosocial aspects of development and the environments that influence healthy outcomes.

Respect, Value and Recognition of Diversity: Respect, value as well as recognition of diversity across and within communities for all children, youth, women and families will be encouraged in order to achieve a non-judgmental and non-blaming approach. Activities will be developed and/or adapted, acknowledging the unique needs of different population groups, especially Aboriginal groups.

HEALTH CANADA FAS/FAE INITIATIVE Information and Feedback Session Workbook

Intersectoral Focus: Recognizing the broader determinants of health and using a population health approach, the focus will be on intersectoral collaboration, both at the governmental and community levels.

Evidence based approaches: Strong linkages between research and programs will be fostered, with information dissemination on best practices and evidenced-based approaches provided to support community-level programming.

Innovation and Creativity: Innovation and creativity will be encouraged, both in the management of the program and through the activities and initiatives supported by the program.

Partnership and Collaboration: An ongoing emphasis will be placed on working in partnership with other Divisions, Branches, federal departments, provincial and territorial governments, Aboriginal, First Nations and Inuit organizations, non-governmental organizations, professional associations and the private sector. Opportunities for collaboration, both within federal government and with other external partners, will be incorporated as a priority/initial step in the development of the program. This component is intended to build on experiences, create linkages and provide opportunities for further capacity development and promotion of best practices.

Focus on Accountability and Evaluation: An emphasis will be placed on efficiency, effectiveness and quality as key elements of the overall approach, on both the day-to-day operations, and the ongoing monitoring and evaluation of the activities and programming.

Building Community Capacity: Emphasis will be placed on fostering better linkages and integration of services, as well as developing capacity at the individual, family and community levels while recognizing the importance of prevention and early intervention. Priority will be given to identifying communities, their best practices, and strategies for reaching children, youth, women and families most at risk. Priority will also be given to building community capacity in order to strengthen and sustain programs, and foster integration and accountability.

**GOALS AND OBJECTIVES FOR
HEALTH CANADA'S STRATEGIC FRAMEWORK
ON FETAL ALCOHOL SYNDROME/FETAL ALCOHOL EFFECTS**

GOAL ONE: TO PREVENT FAS/FAE (PRIMARY PREVENTION)

Objectives:

- i** To reduce the use of alcohol and other substances during pregnancy;
- i** To promote and enhance mechanisms for identifying individuals, families and communities at risk of having a child with FAS/FAE;
- i** To promote and enhance mechanisms for supporting individuals, families and communities at risk of having a child with FAS or FAE;
- i** To increase public awareness of the effect of alcohol and other substance use during pregnancy.

**GOAL TWO: TO REDUCE THE SIGNIFICANT HEALTH EFFECTS OF FAS/FAE
(SECONDARY PREVENTION)**

Objectives:

- i** To increase awareness and provide support for persons and family members living with FAS/FAE (e.g., access to diagnosis, care and treatment, medical, educational, social and vocational services, as well as caregiver support).
- i** To develop mechanisms for monitoring the incidence, prevalence and impact of FAS/FAE and substance use during pregnancy across Canada and in different population groups.
- i** To increase the capacity of relevant systems (e.g., education, justice, corrections, health, social services, voluntary and non-profit sectors) and people within those systems for improved identification, intervention, treatment, and support.

HEALTH CANADA FAS/FAE INITIATIVE Information and Feedback Session Workbook

THE FOLLOWING OUTLINES THE PROPOSED PLAN OF KEY ACTIVITIES FOR THE FAS/FAE COMPONENT IN YEAR ONE:

Public Awareness

- i A telephone survey, of approximately 1200-1500 people, to measure Canadian's awareness levels, attitudes and knowledge levels related to drinking while pregnant was conducted. Plans are in underway to supplement the telephone survey with focus groups for at risk populations. Results from the market research initiative will guide the development and focus group testing of public education resources.
- i Over the next three years, a public education and awareness campaign will be developed and implemented based on quantitative and qualitative research with targeted audiences. Evaluation of the marketing campaign will be done in year three to identify adjustments needed.

Professional Education and Training

- i **A national survey of health professionals' knowledge and behaviours** with respect to alcohol, pregnancy and FAS/FAE.
- i The data analysis of this survey will guide the development and implementation of appropriate education, training and other supports in year two and three and complement the Inter-Professional Faculty Training Plan on Substance Use already underway through Canada's Drug Strategy Division.
- i MSB and HPPB will also review, identify and develop **optimal approaches on how to best support staff workers that are assisting individuals and families affected by FAS/FAE** on a day to day basis in community-based programs (i.e. CPNP, CAPC, AHS, NNADAP). This will build on a project already underway to identify best practices in CPNP, CAPC and AHS projects and will complement an initiative to develop on-line training and consultation for community based programs in partnership with the Canadian Centre on Substance Abuse and Breaking the Cycle project, Toronto.

Strategic Project Fund

- i HPPB and MSB will design and implement a Strategic Project Fund that will be administered by the Population Health Fund.
- i The Strategic Project Fund will focus on evidence-based models/best practices and integrated sustainable approaches in prevention, education, early identification and diagnosis, integration of services, capacity development and research. There will be a particular focus on innovative and culturally appropriate initiatives.
- i In June 1999 the Minister announced funding, in partnership with the Crime Prevention Centre, of the FAS/E Support Network of British Columbia to develop a training manual on FAS/FAE. Phase one of this project will focus on strengthening working partnerships and more clearly define the needs for training on FAS/FAE in communities across Canada.

Surveillance

- i The Canadian Perinatal Surveillance System, under LCDC, is including questions on alcohol use and prevalence in a national survey on women's knowledge, perspectives, experiences and practices during pregnancy, birth and early parenthood.

QUESTIONS:

1. A) IS FAS/FAE A PRIORITY FOR YOUR ORGANIZATION?

i _____ VERY HIGH PRIORITY

i _____ SOMEWHAT A PRIORITY

i _____ NOT A PRIORITY AT ALL

B) WHAT ARE SOME OF THE NEW AND EMERGING ISSUES THAT HAVE ARISEN WITH RESPECT TO FAS/FAE IN YOUR PROVINCE WITHIN THE LAST TWO YEARS?

C) PLEASE LIST THE TOP 3-5 PRIORITIES WITHIN THOSE EMERGING ISSUES THAT HAVE BEEN IDENTIFIED FOR YOUR ORGANIZATION (E.G. PUBLIC AWARENESS, SUPPORT FOR MENTAL WELL-BEING, SUPPORT FOR COMMUNITY-CAPACITY BUILDING ETC).

2. NAME SOME OF THE KEY ACTIVITIES YOUR PROVINCE/TERRITORY AND/OR ORGANIZATION IS CURRENTLY ENGAGED IN OR PLANNING, SPECIFICALLY RELATED TO FAS/FAE.

(NOTE: IF YOU HAVE ALREADY ANSWERED THIS QUESTION IN A PREVIOUS HEALTH CANADA QUESTIONNAIRE, PLEASE PROCEED TO NEXT QUESTION)

i SHORT-TERM
(PRESENTLY AND WITHIN THE NEXT 12 MONTHS)

i LONG-TERM
(IN 12-36MONTHS)

3. A) WHAT ROLE CAN HEALTH CANADA AND/OR THE FEDERAL GOVERNMENT PLAY TO HELP BUILD ON THOSE ACTIVITIES REPORTED ABOVE? (E.G. POLICY, COORDINATION, PARTNERSHIP, SOCIAL MARKETING, DISSEMINATION, RESEARCH, FINANCIAL ETC)

**B) WHAT OTHER AREAS SHOULD BE INVOLVED?
(E.G. OTHER JURISDICTIONS, PROVINCES, SOCIAL
SERVICES, NGO'S, COMMUNITY ORGANIZATIONS
ETC)**

4. HOW IN THE PAST, WITHIN FAS/FAE OR OTHER ISSUES, HAS YOUR ORGANIZATION BEEN SUCCESSFUL IN FORMING PARTNERSHIPS BETWEEN SECTORS, FEDERAL/PROVINCIAL LEVELS AND/OR ORGANIZATIONS?

5. FURTHER QUESTIONS, SUGGESTIONS AND FEEDBACK ARE WELCOME. THANK YOU.