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GOVERNMENT RESPONSE TO THE SECOND REPORT OF THE STANDING COMMITTEE ON HEALTH

Even One is Too Many: A Call for a Comprehensive Action Plan On Fetal Alcohol Spectrum Disorder

Mr. Rob Merrifield, M.P. Chair, Standing Committee on Health

Room 304, Justice Building House of Commons Ottawa, ON K1A 0A6

Dear Mr. Merrifield:

I am pleased to respond, on behalf of the Government of Canada, to the recommendations of the Second Report of the Standing Committee on Health, "*Even One is too Many: A call for a comprehensive action plan for Fetal Alcohol Spectrum Disorder*". I would like to take this opportunity to thank you and the Committee members for the important work that you have undertaken to prevent and mitigate the impacts of FASD and improve the overall health, social and economic outcomes of those affected by alcohol-related disabilities.

Through your commitment to these issues and by working closely with the Government, you have contributed in an important way to improving the health of Canadians. The Government of Canada appreciates the insights and interest that you have shown.

The Government will carefully consider the recommendations included in the Report and make every attempt to take them into consideration in the current work to address FASD. The Government will continue to work towards fulfilling the federal role within the vision and goals outlined in *FASD: A Framework for Action*.

Yours sincerely,

INTRODUCTION

The Government of Canada (GoC) is pleased to present the following response to the Standing Committee on Health's report entitled, *Even One is Too Many: A Call for a Comprehensive Action Plan On Fetal Alcohol Spectrum Disorder*, which was tabled in the House of Commons on September 18, 2006. The Standing Committee on Health (HESA) should be commended for having conducted such a thorough analysis of the issue of Fetal Alcohol Spectrum Disorder (FASD).

The GoC takes a holistic, integrated approach to FASD, recognizing that FASD is not just a health issue but has long term societal and economic implications. Federal departments work in an integrated manner on prevention and awareness approaches, as well as on advancing joint work around FASD-related data collection and reporting. Federal FASD work is undertaken in partnership with Provinces and Territories (P/Ts), Aboriginal organizations, communities and stakeholders. Importantly, federal work is also addressing the specific needs of First Nations and Inuit (FN/I) communities. The goal of all partners, in all jurisdictions, is to prevent future alcohol affected births, and to improve outcomes for individuals already affected by FASD, together with their families, caregivers and their communities across Canada.

A COMPREHENSIVE NATIONAL AND FEDERAL ACTION PLAN TO ADDRESS FASD

The main thrust of the recommendations put forward in the HESA's report can broadly be summarized as a call to the GoC, and the Health Portfolio specifically, to develop a comprehensive FASD action plan with clear goals, objectives, and timelines.

The GoC recognizes that a comprehensive pan-Canadian action plan, developed in collaboration with P/Ts and stakeholders, is key to addressing FASD. Although P/Ts are responsible for service delivery, they have called on the GoC to assume leadership on FASD. In 2003, the GoC led national consultations to develop *FASD: A Framework for Action* (Framework). This comprehensive work plan stands as a vision for how jurisdictions can work together to improve the lives of those impacted by FASD, and prevent alcohol-affected births.

FASD: A Framework for Action – Overview

This *Framework*, released in 2003 by the GoC, guides activities which build or maintain the system of supports/services needed by those affected by this life long disability, and promotes the public professional awareness necessary for prevention. The *Framework* provides common ground for stakeholders to develop specific, measurable actions.

A companion federal document, *It Takes a Community*, was launched following discussions in 2000 with FASD experts, P/Ts, National Aboriginal Organizations and

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FN/I community representatives about the impact of FASD and FN/I needs in relation to the disability. Over the ensuing six years, these partner discussions have continued, ensuring that *It Takes a Community* remains relevant and guides all aspects of federal FN/I FASD programming.

To date, the *Framework* has guided multi-jurisdictional and stakeholder efforts to address the prevention of FASD and improve outcomes for those affected. In affirming the federal role to develop and strengthen coordinating functions, the GoC provides consistent access to tools, resources and expertise across the country.

The *Framework* articulates a common two-pronged vision for prevention of alcohol affected births, and improvement of outcomes for those affected by FASD. The consultations which led to the *Framework* document established five overarching goals, each with a distinct focus. The goals are in keeping with the thrust of the HESA's recommendations. These are:

- increase public and professional awareness and understanding of FASD and the impact of alcohol use during pregnancy;
- develop and increase capacity;
- create effective pan-Canadian screening, diagnostic and data collection and reporting tools and approaches;
- expand the knowledge base and facilitate information exchange; and,
- increase commitment and support for action on FASD.
- $A. \$ Increasing Public and Professional Awareness and Understanding of FASD

The GoC agrees with the views of the HESA, that since all women are at risk, there need to be clear, consistent messages from their health care providers, and from their family and friends: there is no safe threshold for drinking alcohol when planning or during pregnancy. The GoC also agrees that all frontline professionals need an awareness and understanding of the issue so that they can prevent and mitigate the effects of prenatal alcohol consumption.

The Health Portfolio's commitment to preventing and managing the health impacts of FASD is evident through ongoing activities, including development of publications, Web sites, tools and resources and shared awareness efforts spanning multiple jurisdictions. The Health Portfolio works to provide concrete answers to the questions of pregnant women. In support of this, the Portfolio was accorded \$3M for fiscal year 2006/7 to mount the *Healthy Pregnancy* public awareness campaign, including a FN/I-specific component. The associated Web site provides women with reliable information and easy steps to follow towards a healthy pregnancy.

B. Increasing Capacity

The GoC's efforts to increase capacity include consolidating the resources,

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skills and knowledge that already exist at all levels around the use of alcohol during pregnancy — in families, communities, regions, governments, private industry and non-governmental organizations.

Gaps are filled through training, sharing best practices, knowledge and need-generated resources. This again is undertaken in partnership with P/Ts and stakeholders. The Health Portfolio's *FASD National Strategic Projects Fund* encourages collaborating organizations to focus on increasing capacity by developing practical tools. Examples include: a best practice guideline for parenting those with FASD; a national database for access to FASD resources available in Canada; and, development of a train-the-trainer module for FASD knowledge and intervention skills in both official languages.

C. Creating Tools

Tangible results have been achieved by developing resources for use at the community level. The most ambitious undertaking was the development and ongoing dissemination of *Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis* for the diagnosis of Fetal Alcohol Syndrome and related disabilities. These diagnostic guidelines, published in 2005 as a special supplement to the *Canadian Medical Association Journal*. This followed national practitioner consultations and extensive expert peer review. The Health Portfolio continues to collaborate with partners such as, the Canadian Association of Paediatric Health Centres, to widen dissemination to allied professionals, to develop implementation training, and identification and screening tools.

D. Expanding Knowledge

The GoC is committed to increasing FASD-related knowledge and understanding, including: the life conditions influencing the health and well-being of those with FASD; supporting those affected; the root causes of alcohol use during pregnancy; how best to effectively support women to reduce or stop drinking; and, the permanent impacts of prenatal exposure to alcohol on children. Partners in theseknowledge development and exchange activities include the CIHR, the Centres of Excellence for Children's Well-Being and the Centres of Excellence for Women's Health.

E. Supporting Action

The GoC is committed to supporting the full range of FASD stakeholders, and to assist those touched by this disability. This includes coordinating efforts among partners across Canada to shape a comprehensive system of complementary services.

Recognizing Differences in Culture and Diversity

The GoC recognizes that an action plan must include coordinated, culturally appropriate programming and services that speak to the various groups in Canadian

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society. As part of the federal role under the *Framework*, the GoC established the *pan-Canadian FASD Initiative* within the Health Portfolio, composed of two parallel but integrated initiatives under the Public Health Agency of Canada (PHAC) and Health Canada's First Nations and Inuit Health Branch (FNIHB). This two-pronged initiative promotes new approaches to prevention, care and treatment of FASD between the federal Health Portfolio, P/Ts, community-based programs, national and local parents/caregivers, front-line and professional organizations.

The FN/I-specific program supports community based activities aimed at reducing the number of FN/I children born with FASD and improving the quality of life for those affected. It is focussed on five key areas:

- building FASD awareness in FN/I communities;
- targeted interventions for women at risk of having a child with FASD;
- collaboration with communities to address the broader determinants of health;
- education and training for front-line workers and health professionals; and,
- early diagnosis and early intervention for pre-school aged children.

Associated programming is based on FN/I regional priorities, and specific activities are set to occur over a three to five year period.

FEDERAL LEADERSHIP, COLLABORATION AND IMPLEMENTATION

The HESA's recommendations concerning leadership, coordination, and implementation addressed: the FASD lead for federal activities; concern that any action plan be complementary to P/T initiatives; and, that federal activities in direct support of FN/I communities be woven into an action plan. The GoC agrees that strong federal leadership around FASD is important and that accountability and governance structures are essential for program effectiveness and concrete improvements in outcomes.

FASD is an alcohol and addiction issue, with ramifications in areas including woman's health, disability, family violence, mental health, employment, child welfare, education and criminal justice systems. The GoC takes a multi-disciplinary approach to the federal role related to FASD. The Minister of Health is charged with overall coordination and as such he takes an integrated approach to both federal and Health Portfolio work, allowing the Minister to call upon FASD expertise from many federal sectors. This positions the GoC to address many of the underlying factors which influence health, development, and the prevention of chronic disease and disability. At this time, naming a single operational lead department or agency within the Health Portfolio is premature until further work on the alignment of activities across the Portfolio is completed.

Health Portfolio Coordination occurs through a Portfolio FASD Working Group, which facilitates the cooperation and collaboration of Portfolio partners including FNIHB, Healthy Environments and Consumer Safety Branch (HECSB), the Women's Health Bureau, Canadian Institutes of Health Research (CIHR), Health Products and Food Branch (HPFB), and several entities within PHAC. For example, this group has collaborated on the development of a *National Framework for Action to Reduce the Harms Associated with*

Alcohol, and Other Drugs and Substances and the National Alcohol Strategy, as well as FASD: A Framework for Action.

With respect to FN/I children, the Health Portfolio has led work to build an effective system for FN/I children and their families with strong linkages and partnerships. Key partners work together to address sectoral and jurisdictional barriers to implement a well coordinated system of services. For pregnant women and families with infants and young children who live on reserve and in lnuit communities this includes the FASD and Canada Prenatal Nutrition Programs as well as the National Native Alcohol and Drug Abuse Program. Recent investments in community-based programming for Maternal Child Health and Aboriginal Head Start On Reserve, further align programming and services on-reserve with what is available for other provincial residents. The strong leadership demonstrated by FN/I organizations, communities and other PT coalitions have created an opportunity to build on the momentum that exists among the breadth of FASD partners.

The National FASD Advisory Committee was a major past contributor to national and international level collaboration, providing strategic advice and expertise on the implementation of the federal *FASD Initiative*. This Advisory Committee, which formally reported to the Minister of Health, sunsetted following completion of activities requiring member expertise. Advisory Committee members played a major role in the establishment of the FASD diagnostic guidelines.

Federal Coordination has been underway since 1999. PHAC chairs an Interdepartmental FASD Working Group of officials that has served to identify federal priorities and opportunities for joint funding and collaborative action through multi-sector stakeholder partnerships. Joint activities have been funded through the Health Portfolio's *FASD Initiative*, the National Centre for Crime Prevention, the National Homelessness Initiative, Justice Canada and Canada's renewed Drug Strategy.

As FASD-affected children grow into adolescence and adulthood, the limitations of their disability and the challenges of interacting in an increasingly complex society often result in the secondary effects cited during the HESA hearings. Reducing the impact of secondary effects is as important as FASD prevention, in reducing costs to the health care and criminal justice systems and improving community safety. As such, prevention of the secondary effects is within the mandate of several federal departments and agencies beyond Health. For example:

- The **Department of Justice** (DoJ) has funded innovative community-based justice programs, among other projects, that while providing a fair and effective response to wrongdoing, respect the rights and needs of individuals with FASD.
- Public Safety and Emergency Preparedness Canada (PSEPC) through three of its Agencies, Correctional Services Canada, the Royal Canadian Mounted Police and National Parole Board, has front line projects related to FASD-affected offenders and victims.
- Human Resources and Social Development Canada (HRSDC) has funded some 10 projects to address gaps under its mandate, as well as three FASD-specific employment initiatives, to help address specific disability issues.

 Frontline workers in Departments such as, Indian and Northern Affairs Canada (INAC), DoJ, HRSDC, frequently uses resources at their disposal to address the needs of FASD affected clientele.

Coordination with P/Ts is focused around key P/T FASD coalitions, namely the Canada Northwest FASD Partnership, the Atlantic Inter-governmental FASD Partnership and the Fetal Alcohol Inter-governmental Action Network of Ontario. These coalitions focus their work on intervention and services and have provided significant regional leadership concerning FASD. The Pan-Canadian Public Health Network (PHN), established in 2005, maybe an excellent F/P/T venue, for discussion of FASD from a public health and health promotion perspective. The PHN is a forum for multilateral intergovernmental collaboration on public health issues. Leadership is provided by a Council, consisting of representatives of each P/T and the GoC, co-chaired by a rotating P/T member, and the Chief Public Health Officer of Canada.

Collaboration with External Stakeholders is highly valued by the GoC. For example, core federal partners, are the Canadian Association of Paediatric Health Centres, Canadian Paediatric Society, and the Society of Obstetricans and Gynaecologists. Further, the Canadian Centre on Substance Abuse maintains an FASD Information and Consultation Service for Canadian practitioners addressing FASD.

DATA COLLECTION, REPORTING AND RESEARCH

The GoC recognizes that FASD-related health research is vital. Since its inception in 2000, the CIHR has consistently supported research into FASD, primarily through its Institute of Human Development, Child and Youth Health, Institute of Aboriginal Peoples' Health, and Institute of Neurosciences, Mental Health and Addiction. CIHR has invested approximately \$3.7M — through various grants and awards programs — into research that will help in the prevention, treatment and diagnosis of FASD, as well as expand the knowledge base about the biological mechanisms underlying FASD, the impact of FASD on neurological systems of affected children, and the long-term health effects. CIHR-funded researchers are making significant advances that are leading to early diagnosis of FASD and treatment for affected children.

The HESA called on the GoC to begin collecting and publicly reporting data on the incidence and prevalence of FASD. The GoC agrees that incidence and prevalence data is essential to measure changes in health status, trends, and program/policy impact on indicators and outcomes, related to FASD. The availability of full national incidence and prevalence data is a long-term goal. As such, the GoC works with partners towards standardizing approaches to identifying, screening, diagnosing, data collecting and reporting.

FASD surveillance requires obtaining accurate data regarding, not only the diagnosis of FASD, but also, the exposure to alcohol in pregnancy. FASD surveillance also requires a system that collects data from sources other than hospitals where the identification screening and diagnosis of affected individuals is more likely to occur. These may include community health centres, physicians' offices and specialized diagnostic centres across the country. A surveillance system that is based primarily on hospital data or on data obtained

from specialized diagnostic centres would produce underestimated values of the true incidence of FASD. An FASD surveillance system also requires an extended ascertainment period as individuals affected by FASD may be identified and diagnosed with this disorder later in life, often even in adulthood.

Achievements in Data Collection and Research

FASD is difficult to diagnose, particularly in infancy. Therefore, the data collection focus among partners has been on monitoring fetal exposure to alcohol in utero, with Maternal Alcohol Consumption during Pregnancy as one of the 27 perinatal health indicators reported upon by the Canadian Perinatal Surveillance System. This indicator is based on various existing surveys such as, the National Longitudinal Survey of Children and Youth which includes Aboriginal children living off-reserve. The Maternity Experiences Survey, currently in the field and including FN/I in the sample, will provide data on maternal alcohol consumption before and during pregnancy.

Significant accomplishments have been achieved toward standardization, including the publication of the *FASD diagnostic guidelines*. To fully implement the guidelines, steps are being taken to develop and validate screening tools and adapt diagnostic tools for various culture groups and ages and to provide professional/allied professional training.

National surveillance of most congenital anomalies is already taking place as part of the Canadian Perinatal Surveillance System. Other activities pertaining to congenital anomalies surveillance and FASD include: national perinatal health and congenital anomalies reports; a survey of existing surveillance systems for congenital anomalies in Canada; and, the 2002 establishment of the Canadian Congenital Anomalies Surveillance Network which has examined the magnitude and challenges of FASD and FASD-related birth defects. Results and findings from these initiatives are accessible through reports such as Perinatal Health Indicators for Canada or Canadian Perinatal Health Report, also available on the PHAC Web site.

Data Collection and Research from Federal Client Groups

The HESA has also recommended that the GoC begin to collect incidence and prevalence data from client groups falling under federal responsibility, and that this data be made publicly available.

Among governments and National Aboriginal Organizations, there is agreement that distinction-based health data is necessary for each Aboriginal group (First Nations, Inuit and Métis), yet Aboriginal identifiers for primary and public health data do not exist. Canada's Aboriginal health-related information resides mainly with P/Ts and is subject to the legislation, regulations and policies of the jurisdictions concerned.

Work is underway by the Correctional Service of Canada to develop accurate estimates of offenders in federal institutions who may be affected by FASD. No such data currently exists. Development of a screening tool is underway to identify possible FASD-affected offenders so they can be referred for full assessment.

VALUE FOR MONEY EVALUATION

The HESA emphasized the importance of value for money evaluation to frame FASD activities. Specifically, the HESA recommended that the GoC work with partners to establish clear and concrete measures of effectiveness for initiatives undertaken as part of the FASD action plan, and to report regularly.

The GoC recognizes that demonstrating program effectiveness is essential to enhancing progress. As such, the Health Portfolio's *pan-Canadian FASD Initiative* is part of two major Results-based Management and Accountability Frameworks (RMAF), which have evaluation plans attached. An evaluation report through the Promotion of Population Health Framework is due March 2009.

Moreover, implementation of the 2005 Management, Resources and Results Structure Policy will lead to the development of a common, government-wide approach to the collection, management and reporting of financial and non-financial performance information by departments. This mechanism provides the basis for Parliamentary Reports on Plans and Priorities and Departmental Performance Reports. Through these existing reporting mechanisms, Parliament will have the means to review GoC programs as to their consistency with the goals of the FASD Framework and results achieved.

CONCLUSION

There is a shared recognition of the importance of preventing alcohol-related congenital disabilities, and supporting those affected by FASD, despite the challenges of working across jurisdictions, sectors and with an array of professionals. The GoC will continue work with all partners to ensure that opportunities are leveraged toward FASD prevention and management. It will strengthen partnerships with National Aboriginal Organizations, P/Ts, industry, and other FASD stakeholders. Health Canada will also continue to support FN/I communities to acquire the skills and develop the capacity to deliver health programs and services, including those related to FASD.