HOUSE OF COMMONS
CANADA

EVEN ONE IS TOO MANY: A CALL FOR A COMPREHENSIVE ACTION PLAN FOR FETAL ALCOHOL SPECTRUM DISORDER

Report of the Standing Committee on Health

Rob Merrifield, M.P.
Chair

September 2006

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THE STANDING COMMITTEE ON HEALTH

has the honour to present its

SECOND REPORT

In accordance with its mandate under Standing Order 108(2), your committee has examined federal initiatives with respect to Fetal Alcohol Spectrum Disorder, and presents its findings and recommendations.

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EVEN ONE IS TOO MANY: A CALL FOR A COMPREHENSIVE ACTION PLAN FOR FETAL ALCOHOL SPECTRUM DISORDER

BACKGROUND

Fetal Alcohol Spectrum Disorder (FASD) describes a range of disabilities that may affect people whose mothers consumed alcohol while they were pregnant.[1] Prenatal exposure to alcohol is considered to be the leading cause of developmental and cognitive disabilities among Canadian children.

At present, it is difficult to determine an accurate prevalence rate for FASD in Canada. However, estimates suggest that as many as 9 births per 1,000 will suffer from FASD. With respect to costs, it is estimated that fetal alcohol disabilities create about $1.5 million additional direct costs over the course of an affected individual's lifetime. This cost estimate does not include lost potential of the individual or the family or caregivers.

During the spring 2005 session of the 38th Parliament, the Health Committee studied a Private Member's Bill that would require warning labels to be placed on alcoholic beverage containers. One of the three proposed warnings about adverse effects of alcohol consumption identified the harmful effects on a developing embryo/fetus.

At that time, the Health Committee adopted a motion requesting the presentation of a comprehensive federal action plan with regard to FASD. Since then, the Committee has held public meetings that involved members of the Health Portfolio involved in FASD activities, namely Health Canada, the Public Health Agency of Canada, and the Canadian Institutes of Health Research. It has received documents titled *The Health Portfolio's Approach to Fetal Alcohol Spectrum Disorder* and *Vision to Address Fetal Alcohol Spectrum Disorder*. There is little evidence of any progress beyond the 2003 *National Framework on FASD*. Despite the repeated efforts to see a comprehensive action plan for FASD, Committee members remain dissatisfied. Clearly, FASD is not a priority for the Health Portfolio.

[1] Fetal Alcohol Spectrum Disorder (FASD) was previously referred to as Fœtal Alcohol Syndrome and Fœtal Alcohol Effect (FAS/FAE).

FASD LEADERSHIP, COORDINATION AND IMPLEMENTATION

What the Health Committee Knows

Over the last decade, Health Canada has provided the primary support for initiatives related specifically to FASD. Since 2004, the Public Health Agency of Canada has continued work on the national direction previously taken by Health Canada's Population and Public Health Branch. Community programming on FASD with the federal client group of First Nations and Inuit remains within the First Nations and Inuit Health Branch of Health Canada. While overall alcohol-related activities including the development of a national alcohol strategy under Canada's Drug Strategy (national and federal perspectives) stayed within the Healthy Environment and Consumer Safety Branch of Health Canada, the FASD focus was transferred to the Public Health Agency of Canada.[2] The Canadian Institutes of Health Research can fund research relevant to FASD through open competitions and through specific institutes.

Of the Health Portfolio group, only the Public Health Agency and Health Canada have dedicated resources for application to specific national and federal initiatives with respect to FASD. Specific money for FASD initiatives in the current fiscal year includes $3.3 million for the Public Health Agency and $16.7 million for First Nations and Inuit Health Branch within Health Canada.

Other Health Portfolio participants could play a role however. The Healthy Environment and Consumer Safety Branch of Health Canada indicated that it does not allocate funding to FASD but does support work on an alcohol strategy. Canadian Institutes of Health Research provided information indicating that, through its standard open competition, it is funding five individual projects related to FASD for a total of $710,000 for the current fiscal year.

With these financial resources, Health Canada and the Public Health Agency provide diverse supports for FASD activities. For example, the Public Health Agency through pan-Canadian initiatives with a multi-jurisdictional focus provides coordinating functions that complement FASD endeavours within the jurisdiction of provinces and territories. Health Canada has a direct role with eligible First Nations and Inuit clients.

Outside the Health Portfolio, other federal departments such as Justice Canada, Human Resources and Skills Development Canada, and Indian and Northern Affairs Canada have a role to play in the national focus on FASD. As well,

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[2] Health Canada provides leadership and national coordination for Canada's Drug Strategy, a federally coordinated and nationally collaborative initiative to reduce the harm associated with the use of narcotics and controlled substances and the abuse of alcohol and prescription drugs. It works with federal partners, provincial and territorial governments, addictions agencies, non-governmental organizations, professional associations, law enforcement agencies, the private sector and community groups.

federal departments and agencies can undertake activities for specific client populations directly under the jurisdiction of the Government of Canada. Thus, Health Canada gives direction to funding of FASD programs and services for First Nations and Inuit clients; Correctional Service Canada for FASD-affected offenders in federal institutions; National Defence for its Canadian Forces members; and the Royal Canadian Mounted Police for its officers.

What the Health Committee Wants

The Committee feels that the overall leadership on FASD properly resides in Health Canada. It is concerned about the apparent “disconnect” among the various partners in the Health Portfolio. In particular, it does not support the separation of FASD activities from the broader Health Canada involvement in the development of an alcohol strategy.

The Committee understands the substantial and separate focus on the delivery of community programs and services for First Nations and Inuit individuals who comprise the largest of the federal client groups. However, it needs assurances that this client group participates and that its concerns are included in the broader alcohol strategy.

The Committee is also distressed about the minimal amount of organized horizontal activity on FASD within the jurisdictional boundaries of the Government of Canada. It supports coordinated interaction among the multiple federal departments and agencies that have a role in preventing or minimizing the adverse impact of FASD on individuals and communities.

The Committee calls on Health Canada to provide a clear authoritative voice for FASD initiatives within the Health Portfolio. To this end, it wants the FASD component previously transferred to the Public Health Agency returned to the department. As well, it supports a leadership role for Health Canada on FASD initiatives within the Government of Canada. Clear authority to lead and coordinate a comprehensive FASD action plan will ensure strong and effective implementation.

Recommendation 1

The Committee recommends:

(a) that Health Canada be mandated to take the lead on a comprehensive FASD action plan within the larger alcohol strategy.

(b) that Health Canada lead and coordinate both the national and federal perspectives of the FASD action plan.

(c) that the FASD action plan be complementary to provincial and territorial initiatives.

(d) that Health Canada include the First Nations and Inuit Health Branch in its work on the FASD action plan.

COMPREHENSIVE NATIONAL AND FEDERAL ACTION PLAN

What the Health Committee Knows

Health Canada's 2003 document titled *FASD: A Framework for Action* sets out five goals that include activities to increase public and professional awareness; develop and increase capacity; create effective screening, diagnostic and data reporting tools; expand knowledge base and facilitate information exchange; and, increase commitment and support. The framework acknowledges that the federal government has a role with respect to national guidelines, evidence base, and increasing awareness while the provincial/territorial governments focus on building networks and providing programs, training and services. Additional Health Portfolio documents provided to the Committee outlining the approach and vision reiterate the same message.

Federal Health Portfolio partners are currently involved in multiple activities related to FASD. Health Canada's First Nations and Inuit Health Branch works directly with populations that are considered to be at high risk of FASD. It is responsible for providing community-based programming on reserves. These programs are geared to the particular needs of each community but are based on evidence that exists in other jurisdictions such as the Manitoba STOP FAS program. The programs also use experienced mothers in the community who have encountered problems, engaging them to provide mentoring to other women at risk. The Healthy Environment and Consumer Safety Branch is supporting the development of an alcohol strategy.

Although FASD is not a priority research area for the Canadian Institutes of Health Research, it does fund research relevant to FASD. Through open competition twice yearly, any researcher can submit an application for an operating grant related to FASD. Also, any of the relevant institutes can capture FASD-related research in a strategic research initiative in broader areas of interest. Currently, much of the focus is on disease pathology and treatment modalities.

The Public Health Agency of Canada has continued Health Canada's work of building a FASD knowledge base, promoting awareness of the newly developed diagnostic guidelines, learning from effective public and professional campaigns and assisting communities to build capacity.

What the Health Committee Wants

The Committee sees many things that the Government of Canada can do in developing a comprehensive approach to FASD. It supports an increased role in prevention through measures to raise public and professional awareness.

The Committee wants the public to understand clearly that there is no known safe threshold of alcohol that can be consumed during a pregnancy without the possibility of harm to a developing fetus. It desires an emphasis on messages focused on preconception as well as after conception, on abstinence from alcohol if thinking about pregnancy or if possibly pregnant.

The Committee sees collaboration by professionals and other "front-line workers" as an important element of any FASD action plan. It supports efforts to increase awareness of the characteristics and needs of those with FASD among various service providers who are in contact with such individuals. This includes social workers, the RCMP, police, correctional personnel, lawyers, judges and people operating homeless shelters.

Furthermore, the Government of Canada can promote the provision of supportive housing, remedial financial support, special training and other programs for affected individuals with FASD, and their families.

The Committee also urges those departments and agencies within the Government of Canada who have a direct role with and responsibilities for specific populations to develop a clear FASD component where relevant.

In developing any comprehensive action plan, the Committee understands that many different activities play a role in preventing FASD and in responding to the needs of those already affected by FASD. However, it wants to know that all the components essential for an effective plan can be united in a way that achieves specific objectives. It feels that it is important that Parliament and the public have access to regular and complete reporting about goals and achievements. It is particularly interested in specific measurable goals for reducing FASD incidence in the Canadian population with clear timelines for implementation.

Recommendation 2

The Committee recommends:

(a) that Health Canada take the primary responsibility for developing, coordinating, implementing and evaluating a comprehensive action plan for FASD.

(b) that the action plan identify specific goals and include concise timelines for implementation.

(c) that the action plan include coordinated and culturally appropriate public and professional awareness campaigns.

(d) that Health Canada submit the action plan to Parliament to be referred to the Health Committee by October 2006.

(e) that Health Canada report annually on the status of all FASD activities (both federal and national) to Parliament starting in 2007.

DATA COLLECTION AND RESEARCH

What the Health Committee Knows

Canada currently has no national picture of FASD across the country. Even within specific federal client populations at high risk of FASD such as First Nations, Inuit and federal offenders, there is no accurate tracking. The diagnostic guidelines for FASD issued by the Canadian Medical Association in 2005 can provide a key to the determination of prevalence and the establishment of effective interventions to prevent and to treat FASD.[3] They can serve as a standard for developing surveillance systems "over time" to obtain base-line data in order to track the rate of FASD in the Canadian population. Furthermore, surveillance can facilitate the recognition and evaluation of effective measures tailored specifically for different communities.

Health Canada and the Public Health Agency of Canada have the authority to collect data on disease prevalence. Specifically the Health Promotion and Chronic Disease Prevention Branch of the Public Health Agency of Canada currently coordinates the surveillance of chronic diseases and their risk factors for early disease detection. This permits the creation and evaluation of programs addressing common risk factors and specialized issues focusing on special populations. In fact, the Public Health Agency of Canada currently operates a number of surveillance databases, some of which may be amenable to including FASD. Within Health Canada's First Nations and Inuit Health Branch, it is difficult to determine whether there is any surveillance activity related to the multiple programs on FASD. Of the other population groups for whom the Government of Canada has responsibility for health care, federal offenders are not yet part of a specific FASD surveillance scheme.

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3 Albert Chudley et al., "Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis," *Canadian Medical Association Journal*, 172 (supplement), 1 March 2005, http://www.cmaj.ca/cgi/reprint/172/5_suppl/S1.

What the Health Committee Wants

The Committee is disappointed in the lack of statistics with respect to the incidence and prevalence of FASD. It is particularly concerned that, without this information, there is little ability to measure the effectiveness of a national initiative. It is frustrated that more time is needed to develop such a database and that, even when established, it will be for base-line data.

The Committee also emphasizes that the collection of data is to be appropriate to its future use. Data that provides some clear value in understanding where current and future investments can make a difference to FASD-related outcomes is important.

Recommendation 3

The Committee recommends:

(a) that Health Canada as part of the comprehensive action plan for FASD ensure that data is collected and made publicly available, whether in an existing database, or in another specifically designed for FASD.

(b) that Health Canada ensure that the federal departments and agencies responsible for specific client groups immediately begin to collect and make publicly available data on the incidence and prevalence of FASD within their respective populations.

VALUE FOR MONEY EVALUATION

What the Health Committee Knows

Health Canada through its programs for First Nations and Inuit communities employs diverse approaches relevant both to the culture and the life situation of the at-risk populations. The youthfulness of the population and the geographic dispersion create particular issues. Culturally appropriate messages and interventions generally need to focus on overall health and well-being. Because of the fragmentation of programs and services with essential elements such as housing and education falling to the federal Department of Indian and Northern Affairs, while the larger mental health and disability needs of adults are dealt with by provincial or territorial bodies, addressing this population is difficult.

The Public Health Agency of Canada is a new organization that has inherited initiatives formerly based within a branch of Health Canada. Many of the FASD-related activities fall under previously established health promotion programs aimed at pregnant women and children who are considered by their communities to be at high risk for adverse health outcomes. Even recent initiatives such as the diagnostic guidelines for FASD originated prior to the inception of the Agency.

For its part, the Canadian Institutes of Health Research does not have dedicated funding for FASD. Research has not focused on the needs of adoptive parents or other adults in custodial positions who face enormous financial, legal, emotional and other responsibilities or the needs of adults living with FASD with respect to residential and living support.

As noted earlier, in the current fiscal year, the Health Portfolio funding for FASD includes $3.3 million for the Public Health Agency, $16.7 million for First Nations and Inuit Health Branch within Health Canada, and $710,000 for the Canadian Institutes of Health Research.

When the Government of Canada undertakes initiatives, it is expected to have a strong base of evidence supporting the decision to take action. It is also understood that it will carry out ongoing assessments of resulting actions. For FASD, this means having reliable information and knowledge that identifies how ongoing interventions, practices and programs affect health outcomes. Among other things, this requires ongoing monitoring and review of existing programs to provide clear and transparent assessment of subsequent outcomes.

What the Health Committee Wants

The Committee understands that there is a well-intentioned desire to have policies and programs to prevent FASD and to improve life for FASD children and their caregivers. However, it is also conscious that simply developing programs can often be an inadequate response. Demonstrating their effectiveness is a critical element to protect and enhance outcomes.

The Committee strongly believes that effective and targeted awareness campaigns can bring about change. As well, elements like a national clearing house on best practices related to FASD prevention could be a useful knowledge source. But most importantly, the Committee calls for initiatives identified as part of a FASD action plan to be carefully assessed with respect to value for money. It wants the Canadian public to know how federal funding is being used and what outcomes it is producing. It seeks concrete accomplishments that prevent FASD and improve the lives of those already affected.

Recommendation 4

The Committee recommends:

(a) that Health Canada work with its partners to establish clear and concrete measures of effectiveness for initiatives undertaken as part of the FASD action plan.

(b) that Health Canada regularly evaluate the FASD action plan to assess whether it is achieving the expected outcomes within the existing funding structure.

(c) that Health Canada include an analysis of funding currently allocated specifically to FASD to assess how the resources address any stated goals of the action plan.

(d) that the analysis of funding be included in the annual report on the status of all FASD activities provided to Parliament.

LIST OF RECOMMENDATIONS

Recommendation 1

The Committee recommends:

(a) that Health Canada be mandated to take the lead on a comprehensive FASD action plan within the larger alcohol strategy.

(b) that Health Canada lead and coordinate both the national and federal perspectives of the FASD action plan.

(c) that the FASD action plan be complementary to provincial and territorial initiatives.

(d) that Health Canada include the First Nations and Inuit Health Branch in its work on the FASD action plan.

Recommendation 2

The Committee recommends:

(a) that Health Canada take the primary responsibility for developing, coordinating, implementing and evaluating a comprehensive action plan for FASD.

(b) that the action plan identify specific goals and include concise timelines for implementation.

(c) that the action plan include coordinated and culturally appropriate public and professional awareness campaigns.

(d) that Health Canada submit the action plan to Parliament to be referred to the Health Committee by October 2006.

(e) that Health Canada report annually on the status of all FASD activities (both federal and national) to Parliament starting in 2007.

Recommendation 3

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(a) that Health Canada as part of the comprehensive action plan for FASD ensure that data is collected and made publicly available, whether in an existing database, or in another specifically designed for FASD.

(b) that Health Canada ensure that the federal departments and agencies responsible for specific client groups immediately begin to collect and make publicly available data on the incidence and prevalence of FASD within their respective populations.

Recommendation 4

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(a) that Health Canada work with its partners to establish clear and concrete measures of effectiveness for initiatives undertaken as part of the FASD action plan.

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(c) that Health Canada include an analysis of funding currently allocated specifically to FASD to assess how the resources address any stated goals of the action plan.

(d) that the analysis of funding be included in the annual report on the status of all FASD activities provided to Parliament.

APPENDIX A
LIST OF WITNESSES

Associations and Individuals	Date	Meeting
Canadian Institutes of Health Research	2006/05/30	5
Barbara Beckett, Assistant Director, Institute of Neurosciences, Mental Health and Addiction		
Department of Health		
Linda Dabros, Director, Office of Drug Strategy Secretariat and Strategic Policy		
Kathy Langlois, Director General, First Nations and Inuit Health Community Programs Directorate		
Public Health Agency of Canada		
David Butler-Jones, Chief Public Health Officer		
Kelly Stone, Director, Childhood and Adolescence Division, Centre for Health Promotion		

REQUEST FOR GOVERNMENT RESPONSE

Pursuant to Standing Order 109, the Committee requests that the government table a comprehensive response to this report.

A copy of the relevant Minutes of Proceedings *(Meeting Nos. 5, 7, 9, 11 and 12)* is tabled.

Respectfully submitted,

Rob Merrifield, M.P.
Chair

DISSENTING OPINION
in reply to *Even one is too many: A call for a comprehensive action plan for Fetal Alcohol Spectrum Disorder*

Tabled by the Bloc Québécois members
Christiane Gagnon — MP for Québec
Nicole Demers — MP for Laval

1. Fetal Alcohol Spectrum Disorder: a major issue

The Bloc Québécois is aware that alcohol consumption can have adverse effects and recognizes that Quebecers and Canadians need a greater awareness of the risks of inappropriate alcohol consumption.

Alcohol use by pregnant women is a problem for Quebec and Canada. It has been scientifically proven that drinking alcohol during pregnancy can cause congenital defects in the fetus. Fetal Alcohol Spectrum Disorder (FASD) has social and economic costs that put evident pressure on the healthcare systems in Quebec and the other provinces.

These facts are acknowledged by all the members of the Standing Committee on Health. The Bloc Québécois MPs, however, feel that leadership in this field should come from the governments that provide healthcare services to the people—the governments of Quebec and the provinces.

2. A question of jurisdiction

Under the Constitution (sections 92(7) and (16) of the *Constitution Act, 1867*), health and social services are areas of exclusive jurisdiction of Quebec and the other provinces. This is why the governments of Quebec, regardless of which party is in power, have all denounced federal intrusions into the healthcare field.

In this light, it is clear to the Bloc Québécois that solutions to Fetal Alcohol Spectrum Disorder must be implemented only by Quebec and the provinces. It is Quebec and the provinces that have the expertise, the resources and the structures that allow them to manage public health issues such as FASD.

Moreover, Quebec has its own mechanisms for increasing awareness of and preventing the effects of alcohol consumption, one of which is *Éduc'alcool*, an independent, not-for-profit organization established jointly in 1989 by the alcoholic beverage industry and parapublic institutions to "implement information, education and prevention programs designed to help young people and adults make enlightened, responsible decisions about drinking."

The Bloc Québécois believes that the impetus for an FASD strategy must come from Quebec and the provinces. As the Chair of the Romanow Commission concluded, more federal funding is needed for the healthcare systems in Quebec and the provinces. In this regard, the main problem is the under-financing resulting from the fiscal imbalance that prevails in Canada. This situation deprives Quebec and the provinces of the income necessary to carry out their health and social services responsibilities. With adequate federal funding, Quebec would be in a much better position to tackle FASD—something which the federal government could never hope to do.

3. Focus federal government intervention on the target groups for which it is responsible

The federal government is responsible for providing healthcare services to specific target groups, such as First Nations people, Inuit, members of the Canadian Armed Forces and the RCMP, as well as inmates in federal penitentiaries. Although the data is not yet conclusive, FASD seems to be particularly prevalent in these groups.

However, it appears that the federal government has shown little initiative in dealing adequately with the problems of FASD among its own target groups. It has not yet managed to reduce the incidence of FASD significantly in the populations for which it is responsible. Rather than trying to extend its area of intervention, the federal government should concentrate on the fields that concern it and that are under its responsibility. Agencies in the health portfolio and the other federal partners must make it a priority to find concrete solutions to the problems caused by the high rate of FASD in client groups for which the federal government is responsible.

There is no point in the federal government's becoming involved in areas of jurisdiction that belong to Quebec and the provinces, as they already have the medical expertise required to manage FASD-related problems. The Bloc Québécois is of the view that the federal government should focus its actions on the client groups for which it is responsible. Furthermore, these are the client populations that are at particular risk of FASD. This is why Health Canada's leadership should be exercised only on the populations which have the greatest need of it.

MINUTES OF PROCEEDINGS

Thursday, June 22, 2006
(*Meeting No. 12*)

The Standing Committee on Health met *in camera* at 11:15 a.m. this day, in Room 237-C, Centre Block, the Chair, Rob Merrifield, presiding.

Members of the Committee present: Patricia Davidson, Nicole Demers, Ruby Dhalla, Rick Dykstra, Steven John Fletcher, Tina Keeper, Rob Merrifield and Penny Priddy.

Acting Members present: Laurie Hawn for Dave Batters, Jean-Yves Laforest for Christiane Gagnon and John Maloney for Hon. Ken Dryden.

In attendance: Library of Parliament: Nancy Miller Chenier, Analyst; Sonya Norris, Analyst; Odette Madore, Analyst.

Pursuant to Standing Order 108(2), the Committee resumed its study of a new strategy for the prevention of Fetal Alcohol Spectrum Disorder.

The Committee resumed consideration of a draft report.

It was agreed, — That the draft report be adopted.

It was agreed, — That the report be entitled: *Even One is too Many: A call for a comprehensive action plan for Fetal Alcohol Spectrum Disorder.*

It was agreed, — That the Chair, Clerk and analysts be authorized to make such grammatical and editorial changes as may be necessary without changing the substance of the report.

It was agreed, — That the Chair present the report to the House.

It was agreed, — That, pursuant to Standing Order 109, the Committee request that the Government table a comprehensive response to the report.

It was agreed, — That the Committee append to its report a dissenting opinion from Christiane Gagnon, M.P. and Nicole Demers, M.P. from the Bloc québécois, provided that it is no more than two pages in length and submitted electronically to the Clerk of the Committee in both official languages, no later than 5 p.m., on Friday, June 23, 2006.

The Committee proceeded to the consideration of matters related to Committee business.

It was agreed, — That, in the fall, the Committee undertake a study on Childhood Obesity with an emphasis on First Nations and Inuits, to be followed by a study on Prescription Drugs.

Pursuant to Standing Order 108(2) and the motion adopted by the Committee on Thursday, May 11, 2006, the Committee resumed its study of silicone gel-filled breast implants.

The Committee commenced consideration of a draft report.

At 12:07 p.m., the sitting was suspended.

At 12:13 p.m., the sitting resumed.

It was agreed, — That the draft report, as amended, be adopted.

It was agreed, — That the report be entitled: Silicone Gel-Filled Breast Implants: Areas of Concern.

It was agreed, — That the Chair, Clerk and analysts be authorized to make such grammatical and editorial changes as may be necessary without changing the substance of the report.

It was agreed, — That the Chair present the report to the House.

It was agreed, — That, pursuant to Standing Order 109, the Committee request that the Government table a comprehensive response to the report.

At 12:27 p.m., the Committee adjourned to the call of the Chair.

Carmen DePape
Clerk of the Committee