Public Health Agency of Canada
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Summary Report

National Thematic Workshop on FASD

Canada

Hosted by: the Canadian Centre on Substance Abuse Ottawa, March 29 and 30, 2005

The opinions expressed in this paper are those of the authors and do not necessarily represent those of their affiliations or the Public Health Agency of Canada.

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1 Introduction

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1.1 Context, Purpose and Agenda

This report provides a summary of the presentations and group discussion heard during the National Thematic Workshop on Fetal Alcohol Spectrum Disorder (FASD) held in Ottawa on March 29 and 30, 2005. The Canadian Centre on Substance Abuse (CCSA) hosted this workshop in partnership with the Public Health Agency of Canada (PHAC). The idea for a national workshop on FASD emerged as a result of several converging events and issues. Within the wider addictions context, the renewal in May 2003 of Canada's Drug Strategy (CDS) provided a much-needed opportunity to develop a comprehensive and coordinated national approach to reducing the harm associated with alcohol and other drugs. As part of this exercise, the CCSA and the Healthy Environments and Consumer Safety Branch of Health Canada were leading a broad consultation on a proposed National Framework for Action on Substance Use and Abuse (NFSUA). The NFSUA would link with other similar efforts, including the National Framework for Action on FASD. As part of the development of the NFSUA, CCSA and PHAC were coordinating and/or leading a series of thematic workshops to add to the collective understanding of key substance abuse issues and to identify key priorities for action among these. In November 2004, the CCSA hosted a national thematic workshop on alcohol policy. At that event, it became evident that, notwithstanding the unique interests of both FASD and alcohol interest groups, several areas of common interest were under-explored. It was felt that the emerging NFSUA would greatly benefit from an FASD-specific workshop aimed at identifying key linkage areas between the two respective Frameworks. A national workshop would aim to address both of these areas.

The objectives of this workshop were (1) to identify and prioritize issues of national significance in FASD as they relate to the development of the alcohol portion of the NFSUA, and 2) to identify areas for linking the National Framework on FASD with the NFSUA. An unstated, but implied outcome of the meeting was the opportunity to build and strengthen national partnerships within the FASD community.

The Workshop Agenda offered a mix of formal presentations and structured small group discussion, leading to large group reaction and summary. The Agenda is found in Appendix 1.

1.2 In Attendance

Of the 52 participants who were invited to attend the workshop, 36 were able to participate. Participants included those with longstanding involvement in FASD, such as individuals living in families with children who have FASD, front-line workers dealing with clients who have FASD, national non-governmental organizations (NGOs), regulatory bodies, practitioners, researchers, academics, and federal and provincial government representatives. In addition, invitations were extended to newer partners who are committed to supporting efforts to address FASD, such as the alcohol beverage industry. The list of participants is found in Appendix 2. Paula Stanghetta, CCSA Associate, provided design, facilitation and note-taking services.

1.3 About This Report

The purpose of this report is to capture the essence of the small group discussion and summarize the key points from the event. It is not intended to be a comment or editorial on the outputs of this consultation. Every effort has been made to stay as close as possible to the participants' own words.

The intent is to circulate the report widely across Canada. It will be sent to those who were unable to attend, and to partners and stakeholders in the FASD network. Readers will be encouraged to share their thoughts about the report, about the event and about what needs to happen to keep the momentum alive.

The authors regret any omissions of significance or distortions that may inadvertently have occurred.

2 Setting the Stage for Discussion

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2.1 Opening Remarks

The workshop began with opening remarks from Michel Perron, Chief Executive Officer of the CCSA, who thanked participants for taking the time to participate in the event and who brought a diverse and rich set of experiences to the group.

As Canada's national addictions agency, CCSA has had a long tradition of addressing substance use and abuse issues by working collaboratively with governments, researchers, enforcement agencies, treatment professionals and the private sector. Since the mid-1990s, it has been involved in the FASD issue by providing information, reference and consultation services through its toll-free service. It has contributed to the development of several key documents on FASD and has more recently conducted a scan of FASD training events across Canada. CCSA is committed to ensuring that FASD is fully integrated into both the public health and addictions landscape and will do that through its three global activities of transferring knowledge, developing policy and building partnerships. Mr. Perron provided an overview of the CCSA and highlighted its commitment to FASD as an issue of national public health significance.

Mary Johnston, Manager of the FASD Team, PHAC, addressed the group with opening remarks that described current work and emerging developments in the newly named "Health Portfolio" that relate to FASD. The Health Portfolio includes the PHAC, the First Nations and Inuit Health Branch (FNIHB), the Canadian Institutes of Health Research (CIHR), the CCSA, the Health Products and Food Branch, and the Healthy Environments and Consumer Safety Branch. Together, these organizations are responsible for the Pan-Canadian FASD Initiative whose mission is to promote and protect the health of Canadians through leadership, partnership, innovation and action in public health.

In addition to the organizations mentioned above, Ms. Johnston acknowledged the wider network of partners that contribute to the FASD initiative, including:

- Human Resources and Skills Development Canada
- Social Development Canada
- Justice Canada
- Indian and Northern Affairs Canada
- Public Safety and Emergency Preparedness Canada

Together, these partners are demonstrating a tremendous commitment to ensure that FASD remains high on the government and public policy agenda.

2.2 The National Framework for Action on Substance Use and Abuse

Colleen Ryan, Manager, Canada's Drug Strategy (CDS) Evaluation, Risk Management and Reporting (Canada's Drug Strategy Secretariat - Drug Strategy and Controlled Substances Program - Health Canada) provided an overview of the development to date on the NFSUA. She outlined the consultation process and additional activities that are helping to shape the NFSUA. The purpose of the NFSUA is to provide a visible pan-Canadian structure within which to:

- articulate principles and goals
- set direction and priorities, and coordinate action
- define roles, responsibilities and accountabilities of all partners
- share information about best practices and facilitate evidence-based decision making

At the present time, the NFSUA is in the conceptual stages. Several activities have already occurred that will provide input to it, including the:

- Canadian Addiction Survey
- Canadian Cost Survey
- Northern Addiction Survey
- Canadian Community Health Survey
- CCSA – Substance Abuse in Canada: Current Challenges and Choices
- Workforce Development Survey

An extensive process is well underway and includes preliminary consultations, videoconferences, consultations focusing on corrections issues and thematic workshops (of which this is one). Yet to occur is the Biennial Forum scheduled for June 2005 and the National Addictions Conference planned for November 2005.

Some of the preliminary findings that the process has revealed include:

- the need for integration/linkages (of strategies, approaches, information) at various levels and around different issues
- the need to identify and bridge research gaps and facilitate knowledge transfer
- the need to make alcohol use and its relation to FASD a priority

- the need for addictions to be fully integrated and highlighted as part of the health care system – at policy, programming and service delivery levels

Clearly, much still needs to be done and while there are challenges, there is tremendous momentum and a solid idea of next steps.

2.3 Fetal Alcohol Spectrum Disorder (FASD): A Framework for Action

Mary Johnston reviewed the National Framework on FASD in her presentation. She acknowledged that the document was familiar to most in the room and that many had participated in the creation of the Framework. PHAC is committed to ensuring that the Framework continues to evolve and will be looking at ways to build action plans out of the Framework. The Framework identifies five broad goals:

1. Increase public and professional awareness and understanding of FASD and the impact of alcohol use during pregnancy.
2. Develop and increase capacity in communities.
3. Create effective national screening, diagnostic and data-reporting tools and approaches.
4. Expand the knowledge base and facilitate information exchange.
5. Increase commitment and support for action on FASD.

Encouraging progress has been made since the Framework was released in 2003 and the guideposts it offers continue to support ongoing collaboration and coordination across the country.

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3.1 Initial Group Discussion

The opening presentations were intended to stimulate discussion. Participants were then divided into small groups to respond to a series of questions.

The first question participants were asked to discuss was: ***How should the National Framework for Action on Substance Use and Abuse and the Fetal Alcohol Spectrum Disorder (FASD): A Framework for Action be linked?***

Most participants agreed that the two Frameworks should be linked and gave supporting reasons for their viewpoints. One of the realities that made this exercise somewhat frustrating for participants was not having a draft NFSUA to refer to since it is currently in development. Nevertheless, participants embraced the task enthusiastically.

Participants felt strongly that *integration* of the two Frameworks was critical. They suggested that it should be approached horizontally rather than vertically – that is, integrating and weaving FASD into every element of the NFSUA. This would be better than addressing FASD as a component on its own within the NFSUA. Part of the reasoning for this position is that FASD is a multifaceted disorder, impacting various sectors of society and requiring shared responsibility of many stakeholders to address it adequately. **In fact, participants referred to FASD as a public health issue and not simply one of addiction.**

Given that the Framework for Action on FASD has already been developed and disseminated, participants suggested that its goals be reaffirmed and used as a building block to identify potential areas for action and integration into the NFSUA.

There was much discussion about the potential to lose FASD under an "addictions" umbrella. **The concern here is that participants feel FASD is not solely an addictions issue.** In fact, one does not necessarily need to be addicted to alcohol to have a child who is born with FASD. Participants stated that there still is a lack of understanding of FASD, even though the disorder was named over 30 years ago and public and professional awareness has occurred at various levels. Because of these reasons, participants felt that embedding FASD within an addictions umbrella may be too broad a designation and possibly cause FASD to disappear or lose potency as a real public health issue.

Several comments were made about the need to have a national coordinating body, although how this related to integration with the NFSUA was not clearly articulated. It was expressed, however, that a coordinating body would ensure better alignment of support services and the allocation of funding for client services, which is desperately needed.

Participants indicated that questions about FASD need to be incorporated into current national data collection efforts. Existing surveys, consultations and discussions that focus on substance use, abuse and addictions should also solicit feedback on a range of topic

areas related to FASD. This would help contribute to our understanding of the national picture of FASD.

Although encouraging progress has been made within the FASD field in terms of diagnosis, particularly with the release of the Diagnostic Guidelines, much needs to be done around supporting individuals post-diagnosis. Participants suggested that those writing the NFSUA consider that communities, individuals and families need support post-diagnosis.

Horizontal integration (as described earlier) of the two Frameworks would also facilitate the opportunity to address FASD holistically – something that is not currently happening consistently in Canada. This would include programs and policies that are focused on breaking the cycle of alcohol abuse, treatment for individuals with FASD and increased supports for women who are alcohol dependent. As the NFSUA is developed, participants suggested that the treatment needs of individuals with FASD be considered.

There was encouragement from the group to identify existing resources that could be used to address FASD on a larger scale (i.e. nationally), and that wherever possible the NFSUA promote the use of resources that have already been developed.

A final comment on integration of the two Frameworks referred to the need to link prevention, intervention and support, and to do so at all levels of government.

The second question was: ***"Which FASD themes would best link to the NFSUA?"***

Participants identified three particular FASD themes that might link best to the NFSUA: diagnosis, prevention and education. With respect to diagnosis, participants recognized that while the Guidelines are "national," there must be a regional flavour or approach when it comes to implementation. There is great diversity across Canada around diagnosis; this must be recognized and worked through if real progress is to be made. Participants indicated that when it comes to prevention and education, a national overall approach is required. Champions are needed to bring all of these areas together for success, and they must be visible and active at both the national and provincial/territorial levels.

The third question was: ***"What would be the benefits of a coordinated effort (around FASD and substance use and abuse)?"***

Participants strongly agreed that there must be coordination between the initiatives in FASD and those in substance use and abuse. Participants were surprised when they learned that FASD was not addressed more prominently during the previous alcohol consultations. There was a sense that this was a significant, yet not totally unexpected, example of how FASD is still seen as an issue that is separate from addictions discussions. There is a responsibility for those within each area to reinforce the connection between FASD and the broader addictions field.

Participants noted that there is still a pressing need for terminology, definitions and vocabulary to be much clearer. This might simplify coordination efforts.

The final question asked whether there is a risk of confusion, duplication of effort and competing priorities, and, if so, how they should be addressed. Although participants thought that there may be a risk of duplication, most agreed that it could be addressed by ensuring that terminology was clear and consistent, by committing appropriate funding and related resources, by seeing FASD as a national public health issue, and by being sensitive to how FASD is integrated into a broader framework. Some of the groups did not respond completely to this question: it may have been a matter of time available to complete the task or a misunderstanding of the task.

3.2 Summary Insights

Participants finished the morning session by sharing insights from the linkages discussion, some of which repeated comments from the initial discussion and others that were broader. Participants reinforced the fact that the FASD Framework is already developed and familiar to those who are working within the FASD area. It contains specific goals and ideas around action to support the goals. The NFSUA is still in the formative stages; thus, this is the best time to look at opportunities to link the two. One of the ways to achieve better linkages is to include FASD as part of the Canadian Addictions Survey. Almost every aspect of the addictions field (practices, training, treatment) presents an opportunity to link into the FASD field and vice versa. Participants acknowledged that communication within the FASD community needs strengthening. All constituents need to identify ways to share their experiences, lessons learned and successes with each other. This is not currently happening, and it is believed it can lead to "silos of silence." Overall, both fields need to be more forthcoming in recognizing the tremendous impact of FASD on our society, our economy, and on those individuals affected by it.

4 A National Tour of FASD

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4.2 Public Health Agency of Canada/First Nations and Inuit Health Branch – Ms. Mary Johnston 14

4.3 Motherisk – Ms. Susan Santiago 15

4.4 Fetal Alcohol Syndrome Society of the Yukon (FASSY) – Ms. Judy Pakozdy 15

4.5 British Columbia – Ms. Nancy Poole 15

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To highlight some of the accomplishments across the country around FASD, several brief presentations were given by individuals who are involved with FASD.

4.1 Diagnostic Guidelines – Dr. Nicole LeBlanc

Dr. Nicole LeBlanc (member of the Sub-Committee of the NAC on FASD that developed the Guidelines) described the development of the **Diagnostic Guidelines**. Given the recent release of the Guidelines, not all participants had received copies. As a member of the group responsible for developing the Guidelines, Dr. LeBlanc noted that the process involved extensive national consultation. She indicated that the Guidelines are not prescriptive, but are intended to facilitate diagnosis and fill a much-needed gap in this respect. Tasks yet to be undertaken include the dissemination of the Guidelines, establishment of a national data collection system using information from the Guidelines, and training for individuals in the use of the Guidelines. Dr. LeBlanc stressed that diagnosis is very complex and while the Guidelines are a welcome tool, their use will require substantial collaboration among all stakeholders to maximize their usefulness.

4.2 Public Health Agency of Canada/First Nations and Inuit Health Branch – Ms. Mary Johnston

Mary Johnston described the **Pan-Canadian FASD Initiative** that is part of the Health Portfolio, defined as PHAC, Health Canada branches such as First Nations and Inuit Health Branch, Healthy Environments and Consumer Safety Branch, Health Products and Food Branch and the Canadian Institutes of Health Research, Canadian Centre on Substance Abuse. With PHAC as lead, the Initiative is working with several federal partners, including:

- Human Resources and Skills Development Canada
- Social Development (Homelessness) Canada
- Justice Canada
- Indian and Northern Affairs Canada
- Public Safety and Emergency Preparedness Canada (Crime Prevention Centre, RCMP, National Parole Board, Corrections and Aboriginal Policing)

The Initiative has six main activities: Policy Development; Coordination and Collaboration; Identification, Screening, Diagnosis and Monitoring; Professional Awareness and Education; Public Awareness and Education; and Capacity Building. A parallel initiative is underway in FNIHB with the goal of reducing the incidence of FASD births and improving the quality of life for those affected by FASD.

4.3 Motherisk – Ms. Susan Santiago

Susan Santiago, FACE Research Network Coordinator, provided an overview of the **Motherisk Program** operating in Toronto and focused on the telephone-based support to callers across Canada. The program offers information and counselling about medications, chemical and other exposures, nausea and vomiting during pregnancy, alcohol and substance use in pregnancy, and HIV treatment in pregnancy. The service receives between 35,000 and 40,000 calls each year. In addition to the phone support, **Motherisk** provides pediatric FAS assessment and diagnosis and is a founding partner of **Breaking the Cycle** (community-based program that provides services and support for drug- and alcohol-involved mothers and their children with funding contribution from PHAC). Several research initiatives are in progress as well as an annual FACE Research Roundtable that Motherisk established in 2000 and continues to offer in partnership and sponsorship with The Brewers of Canada and the Canadian Mothercraft Society.

4.4 Fetal Alcohol Syndrome Society of the Yukon (FASSY) – Ms. Judy Pakozdy

Judy Pakozdy of the **Fetal Alcohol Syndrome Society of the Yukon (FASSY)** described how parents formed the organization almost 20 years ago to address FASD among adults. FASSY currently works with approximately 50 adults who are suspected of having FASD. The organization receives all of its funding from projects and proposals and has no core funding. FASSY is a thriving example of the passion and energy that committed individuals can harness to respond to a need when services and supports are limited or non-existent.

4.5 British Columbia – Ms. Nancy Poole

Nancy Poole, Research Consultant on Women and Substance Use, BC Women's Hospital and British Columbia Centre of Excellence for Women's Health, described five core areas where British Columbia is working to address prevention of FASD by working with women. The work is a combination of research, policy, programs and training. The approach in the province is characterized by collaboration and integration among many initiatives, looking for opportunities to link efforts wherever possible.

4.6 Key Messages – Afternoon Discussion

Although the presentations were only a very small sampling of the type of FASD work across the country, they gave a glimpse into the diverse efforts that are ongoing. Each participant brought a variety of experiences to share. Thus, the afternoon discussion was

designed to generate response from the large group around activities/interventions that Canada is "doing well" (and should continue doing), along with activities and interventions that we need to "stop doing." Participants suggested an additional category for discussion called "what we should start doing" and offered many suggestions.

In the doing-well category, participants identified several prevention-type accomplishments that included promoting general awareness of harms of alcohol use during pregnancy; well-designed primary prevention messages; the Best Start prevention campaign; and bilingual public awareness campaigns. Participants felt that we are doing well in supporting families at the beginning of the life cycle (0–6 years of age) and in prenatal programs. We are doing well in identifying and implementing best practices, and creating and evaluating models for service. When it comes to what we are doing well with respect to women, participants said that differentiating women's treatment services is starting to progress; that we are getting better at engaging pregnant women in care; that treatment is becoming more woman-centred; and that we are doing well at outreach to pregnant women. We are building bridges to Aboriginal communities. The Aboriginal HeadStart Program was mentioned as an example of good work with Aboriginal people. CCSA's clearinghouse function was identified as a resource that is meeting a need across Canada. The grassroots movement is strong and growing, as are the supports for families and peers and especially mentorship programs. The guiding partnerships that PHAC has fostered with the provinces and territories seem to be working well. Participants were quick to note that while there are many examples of what is working well, it does not mean that the activities are happening everywhere in Canada or that there is any systematic, coordinated effort to ensure the successes are being replicated for greater impact.

There were plenty of ideas about what we should stop doing around FASD. Most fell into a few broad categories: **funding, service delivery, coordination, and awareness/education**. On the **funding** issue, many comments were made about barriers to accessing funding, that funding is erratic, that funding mechanisms deter community collaboration, and that the current trend to fund demonstration projects only is limiting – especially when "successful" projects cannot extend beyond the demonstration phase. One individual noted that we should stop "unfunding" programs that are shown to have impact.

On the **service delivery** side, participants felt that we need to stop carrying on with "business as usual." This can happen in several ways: when we use IQ as a determinant for services; when we see FASD as an Aboriginal- or women's-only issue; when we continue to reinvent the wheel (by keeping mental health, addictions, violence against women and other similar areas as separate rather than related issues); when we put up barriers to treatment; when we see addiction as something that ends; when we use judgmental approaches; when we do not continue service after the age of 6; and when we fail to stop inappropriate interventions.

In terms of **coordination**, participants stated that we need to stop having communities develop their own resources and approaches. Perhaps it is time to take a closer look at what works, how it can be adapted for different areas, and then implement and evaluate to determine impact. This can happen only when the current disconnection that characterizes the field (from program delivery to national policy development) is reversed. This disconnect also occurs with respect to FASD curriculum that is being developed in many areas of Canada.

As far as **awareness/education** efforts are concerned, participants indicated that we must stop inconsistent messages around alcohol use in pregnancy. National, consistent and clear messaging around "how much alcohol is too much" would minimize the confusion around what is safe for women who are pregnant. Some participants thought that the use of posters is ineffective and should be stopped, along with duplication that is occurring around primary prevention messages.

The list of start-doing ideas includes some of the points mentioned in the previous two categories, demonstrating that while some parts of Canada have made progress in certain areas, much needs to be done. Key suggestions included:

- establish a national school curriculum
- develop core competencies for training service providers in all sectors and institute accreditation for trainers
- fund adult diagnosis and services
- implement a national public awareness campaign on FASD
- create a cost/benefit analysis to serve as a foundation for building a business case for FASD
- develop a "standardized" functional assessment
- start collecting reliable Canadian statistics on FASD

Participants stated that we need to start improving communciation with and between levels of govenment on FASD and encouraged all stakeholders to develop long-term plans and visions.

5 Identifying Priorities

The second day began with a review of the main themes of discussion from Day One and an overview of the task for the final day of the workshop – identifying national priorities for FASD within the NFSUA.

For this activity, participants had been asked to identify national priorities for FASD within the NFSUA and to share their priorities with the larger group (in preparation for a group ranking task). Somewhere between the explanation of the task and the group reporting of the priorities, the understanding of the task changed for some of the participants and led to discomfort with the activity. As the groups reported their priorities, it began to look like an action plan for an integrated FASD initiative rather than priorities for linking FASD with the NFSUA. When queried, the groups stated that they felt that FASD already had a framework and that it was well thought out and developed through a consultative process. They wanted to see an *action plan* developed for the FASD Framework. They felt that while it was critical that the frameworks be linked, they wanted the FASD Framework to move toward an action plan and not wait for the NFSUA to be developed and finalized. The delegates who stated that they would like to be involved in developing the FASD Action Plan wanted some assurance that this would happen.

The issues and concerns were processed through large group discussion and the groups proceeded with a modified final task. However, the intent to identify priority areas remained; thus, participants identified four priorities for integration within the NFASUA:

1. Prevention
2. Policy
3. Intervention and Management
4. Community and Families

All participants ranked items (through multi-voting) within each priority area and the results are summarized below:

Priority: Prevention

1. Conduct research to learn which prevention measures actually affect behaviour, for whom, and where, and then link to education, policy and funding.
2. Develop a strategy to address the stigma of addictions so that FASD can rise to the level of a public health issue and be treated and funded accordingly.
3. Provide professional training/education for physicians, nurses, health professionals and social workers based on evidence (be sure to use consistent information and messaging, customize for targeted audiences, and include cross training).

3. **Give priority for treatment of pregnant women** (including children) with low barriers for access to treatment (expand treatment options, including after care).

3. **Screen, identify and engage pregnant women,** not only addicted women.

(N.B. The last three items received the same number of votes, hence the identical rank.)

Priority – Policy

1. **Prepare a business case for FASD**, including incidence/prevalence, cost analysis/cost benefit, and communication for comprehension among all stakeholders.
2. **Develop partnerships with all stakeholders** to create clear roles, responsibilities and clear action plans – federal/provincial/territorial mechanism for communication and work, knowledge transfer.
3. **Develop a fund and prioritize a research** agenda intended to fill gaps, which is practice-based.
4. **Designate FASD as a disability** across all sectors.

Priority – Intervention and Management

1. **Create lifespan accessibility and eligibility for services** based on all FASD diagnoses that are culturally- and language-sensitive.
2. **Develop and provide cross-jurisdictional professional training** for comprehensive case management.
3. **Find out what works and share** this with other jurisdictions.
4. **Provide adequate funding** to meet service needs.
5. **Change existing legislation** to support the needs of individuals with FASD.

Priority – Community and Families

1. **Develop core funding strategies** for community groups.
2. **Recognize the importance of family-based care** and provide seamless services for families and individuals through the lifespan.
3. **Empower communities to build capacity** with mentorship, support and training as needed.
4. **Facilitate national networking** among families and communities.
5. **Provide a range of promotional tools** to raise awareness in communities.

6 Recommendations for Integrating the Frameworks

The afternoon discussion was an extension of the morning discussion. Participants were invited to join one of four groups (prevention, policy, intervention and management, or community/families) to discuss in greater detail messages and recommendations to the CCSA, PHAC and Health Canada around integration of the two frameworks. Each of the groups offered some broad considerations for the three organizations to contemplate as the process moves forward.

For the **Community/Family** group, participants urged that a set of core values be developed, around which the NFSUA will be implemented, especially with respect to implementation of community services. Group members also commented that it is necessary to develop national standards for training on FASD. One of the areas where participants would like to see more emphasis is that of the important and unique role of fathers. This group also suggested that the term "FASD" be specifically mentioned in the mission, vision and values of the NFSUA.

The **Prevention** group thought that the goals and strategies from FASD: *A Framework for Action* set the baseline for action and should be integrated into all areas of the new emerging NFSUA. One of the suggestions for the new Framework was that it should identify ways to create a sustained focus on supporting mothers and promote cooperation between addiction/substance agencies and child protection agencies. Additional linkages that would be important include strategies that address polydrug use, tobacco and prescription drugs. A final word from the group related to leadership: their recommendation was that the NFSUA activities should be guided by multisectoral leadership, including Health Canada, service providers, researchers, provincial and territorial decision makers, experiential women (i.e. birth mothers), the CCSA and the alcohol industry. The entire process should be guided by values and principles similar to those developed and followed by individuals and organizations currently involved in FASD work.

The **Intervention and Management** group had six core messages. The first was simply a statement of recognition that individuals with FASD are present throughout the service system; they are clients who have complex needs that must be addressed and not ignored. Participants noted that treatment services must recognize the unique needs of individuals with this organic brain disability – it is permanent and irreversible and intervention strategies must accommodate this fact. In order for intervention and management strategies to be effective, prenatal alcohol exposure histories must be taken and that information must be valued throughout all points of contact with the client. When addressing addiction issues with people who have FASD, professionals must know that there is the possibility of change and improvement and the addiction must be addressed not separately, but within the context of the disability. The group also noted that the Framework must recognize that pregnant women who present for treatment must be provided priority service within an appropriate service delivery model. To sum up their comments, the **Intervention/Management** group reinforced that individuals with FASD who are using or abusing substances require lifelong treatment and a multidisciplinary case management approach. The NFSUA must recognize this and provide for it.

7 Closing Remarks

Michel Perron thanked participants for their presence and hard work, and most of all for their openness, respect and genuine interest. He indicated that the objective of getting everybody together for a meaningful exchange of ideas had been reached and that he felt the meeting was a success.

He invited participants to extend the dialogue that began with this workshop with other colleagues, organizations and the FASD network across Canada. He emphasized that champions are needed to make progress on the issue and that the people present were these champions. Mr. Perron ended by thanking the different individuals who had made the meeting a success.

Mary Johnston echoed Michel's comments and stated that PHAC will be working to take the messages from this workshop forward in its planning over the next few months. She acknowledged the dedication of individuals and organizations in the room, and those who were not able to attend, and extended the Agency's appreciation for everyone's commitment to FASD.

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Appendix 1: Agenda

Day One – March 29, 2005

8:15	**Continental Breakfast**
9:00	Welcome and Introductions Agenda and Process
9:30	Opening Presentations • Canadian Centre on Substance Abuse (CCSA) • Public Health Agency of Canada (PHAC)
10:00	The National Framework for Action on Substance Use and Abuse
10:15	Fetal Alcohol Spectrum Disorder (FASD): A Framework for Action
10:30	**Refreshments**
10:45	Small Discussion Groups
11:45	Insights from Discussion
12:00	**Lunch (provided)**
1:00	A National Tour of FASD
2:15	**Refreshments**
2:30	Small and Large Group Discussions (Linking FASD and the National Framework)
3:45	Group Reports
4:15	Summary of Day One
4:30	**Adjourn**

Day Two – March 30, 2005

7:45	**Continental Breakfast**
8:30	Debrief of Day One and Overview of Day Two
8:45	Small and Large Group Discussions (National FASD Priorities)
10:00	**Refreshments**
10:20	Group Reports
11:45	Insights from Discussion
12:00	**Lunch**
1:00	Action/Implementation Planning
2:00	Presentation of Action Plans
2:45	Next Steps
3:00	Wrap-Up and Closing Remarks
3:15	**Adjourn**

Appendix 2: Invitation and Participant Lists

Invitees

1.	Dr. Christine Loock	2.	Dr. Nicole LeBlanc
3.	Sterling K. Clarren	4.	Mary Cox-Millar
5.	Della Maguire	6.	Mark Schindel
7.	Darren Joslin	8.	Margaret Leslie
9.	Susan Santiago	10.	Louise Morin
11.	Dr. Jo Nanson	12.	Ms. Donna De Filippis
13.	Kim Meawasige	14.	Ms. Darlene Oakes
15.	Howard Collins	16.	Bill Ross
17.	Mr. Helie for Jan Westcott	18.	Jan Lutke
19.	Dr. Sarah Nikkel for Judith Allanson	20.	Michelle Dubik
21.	Deborah Kacki	22.	Dr. Lindsay Crowshoe
23.	Ms. Elizabeth Dawson	24.	Mr. Miguel LeBlanc
25.	Ms. Lona Hegeman	26.	Ms. Wendy Burgoyne
27.	Ms. Judy Pakozdy	28.	The Hon. Judge Mary Ellen Turpel Ladond
29.	Mrs. Dawn Ridd	30.	Dawn Bruyere
31.	NAHO	32.	Anne Fuller
33.	Ms. Nancy Poole	34.	Ms. Barbara Smith
35.	Ms. Donna Wheway	36.	Ms. Donna Debolt
37.	Ms. Audrey McFarlane	38.	Carol Parder for Ms. Laura Heal
39.	Ms. Ruth Morin	40.	Ms. Bonnie Buxton
41.	Diane Fox	42.	Eugenie Dore
43.	Dr. Françoise Bouchard	44.	Karen Palmer

Invitees

45.	Colleen Ryan for Linda Dabros	46.	Robin Gearing
47.	Marie-Claude Paquette	48.	Dr. Lori Vital-Cox
49.	Patricia Blakely	50.	Lois Crossman
51.	Dr. Louise Nadeau	52.	Dr. James F. Brien
53.	Mary Johnston, PHAC	54.	Tammy Bambrick
55.	Isabelle Mélançon	56.	Diane Stefaniak

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Appendix 3: Workshop Background Paper

Key Findings on FASD and Alcohol Policy in Canada March 2005

Introduction

On March 29 and 30, 2005, the Canadian Centre on Substance Abuse (CCSA), in partnership with the Public Health Agency of Canada (PHAC), will host a National Thematic Workshop on Fetal Alcohol Spectrum Disorder (FASD). The objectives of the workshop are:

- to identify and to prioritize issues of national significance related to FASD
- to identify specific FASD work relevant to the development of the alcohol portion of the National Framework for Action on Substance Abuse
- to assemble and disseminate information that supports the ongoing consideration of important FASD issues

This paper is a summary of the status of key relevant FASD information regarding prevention, diagnosis, intervention/treatment and alcohol policy. Its intention is to stimulate and guide discussion over the course of the two-day workshop – it is not intended as a comprehensive literature review.

What Is FASD?

FASD is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioural and learning disabilities with lifelong implications. The term "FASD" is not intended for use as a clinical diagnosis (Chudley et al., 2005). The diagnoses under the FASD umbrella include fetal alcohol syndrome (FAS), partial-FAS, and alcohol-related neurodevelopmental disorder (ARND).

FASD is the leading cause of developmental and cognitive disabilities among Canadian children, (Health Canada, 1996; Canadian Pediatric Society, 2002) and has surpassed Down syndrome, spina bifida and cerebral palsy in estimated prevalence in the United States (Anon., 1983).

Effects of FASD

Human and animal studies have clearly demonstrated that alcohol is both a physical and a behavioural teratogen and that heavy prenatal alcohol exposure can lead to the distinct pattern of birth defects characteristic of fetal alcohol syndrome (Jones et al., 1973; Randall and Taylor, 1979; Randall and Riley, 1981). Neurobehavioural effects associated with pFAS

and ARND are just as debilitating as those characteristic of FAS (Mattson et al., 1997; Mattson and Riley, 1999). Thus, the consequences of FASD include irreversible, lifelong disabilities that affect physical, cognitive, social and behavioural development. A recent study concluded that the impact of FASD on the affected individual's health related to quality of life (HRQoL) is profound (Stade, 2003).

Individual, family and community impacts of FASD are dynamic. For example, research suggests that as children with FASD reach adolescence, their social and behavioural problems increase (Olson et al., 1997; Streissguth et al., 1991). Adolescents with FASD have been shown to have increased rates of mental illness, substance abuse and school failure, as well as early and repeated trouble with the law (Fast et al., 1999; Fast and Conry, 2004). Adults with FASD suffer from a range of psycho-social problems that increase the likelihood of confinement in detention, jail, prison, or a psychiatric or alcohol/drug inpatient setting (Streissguth et al., 2004).

Fortunately, appropriate intervention has been shown to mitigate the onset of secondary disabilities (i.e. those not attributed directly to the physical and neurobehavioural damage of FASD), including depression and conduct disorders, disrupted school experience, inappropriate sexual behaviour, alcohol and drug problems, dependent living, and problems with employment and the law (Streissguth et al., 1997). Expert researchers in the field (Streissguth et al., 1997; Streissguth, 1997; Streissguth and Kanter, 1997; Astley and Clarren, 1999) have called for early diagnosis and prompt intervention with families of alcohol-affected children to promote the development of these children and to minimize the occurrence of secondary disabilities.

FASD and its related secondary disabilities exert a significant impact on Canada's economy. Individuals affected by prenatal exposure to alcohol often require specialized education, mental health attention, care and facilities throughout their lifetime and tend to overutilize systems and services (Loney et al., 1998). In addition, the many secondary disabilities that arise impact their ability to live independently, function according to societal norms and remain gainfully employed. Thus, the economic cost of FASD is significant.

Economic Cost of FASD

Researchers in the United States have estimated that the lifetime direct health care costs for an individual with FAS are approximately $1.4 million (Lupton et al., 2004). Canadian research has estimated annual adjusted costs associated with FASD at the individual level to be $14,342 (Stade, 2003). These costs include those incurred by the health care system related to health service utilization and direct out-of-pocket expenses incurred by the biological, adoptive and foster parents. The additional lifetime costs (from age 0–65) for affected individuals were estimated at just under $850,000. This estimate does not include

indirect costs (including those related to the correctional or justice system) or opportunity costs (such as lost potential or productivity).

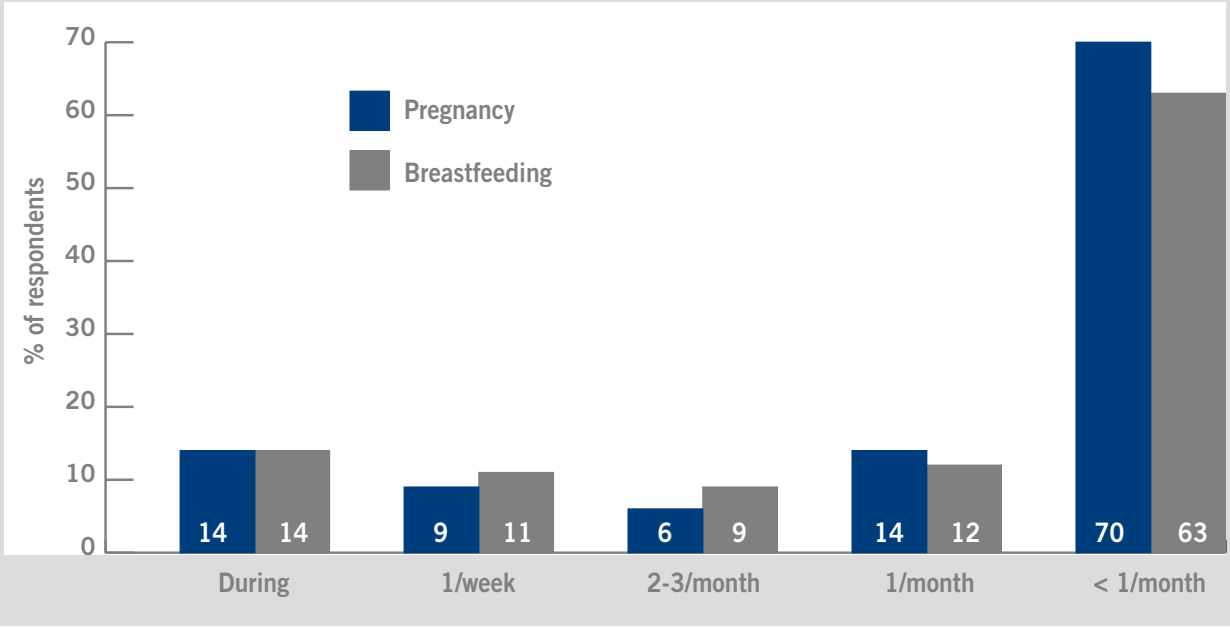
At an estimated cost of $14,342/individual/year, FASD is more than 10 times as expensive as childhood asthma, estimated at $1,400/patient/year (Ungar and Coyte, 2001).

Maternal Alcohol Use

In general, most outcome measures for alcohol use and abuse have increased in Canada in recent years, with exceptions being around alcohol consumption during pregnancy and drinking and driving.

Women were asked about alcohol consumption during pregnancy and during breastfeeding in the Canadian Community Health Survey (cycle 2.1) 2003. Figure 1 illustrates the data from women who had been pregnant in the last 5 years, but unfortunately these data do not report on the amount consumed during each of these drinking sessions.

Figure 1: Canadian Community Health Survey (cycle 2) Data From Women Who Had Been Pregnant in the Last 5 Years



Canada's National Longitudinal Surveys of Children and Youth, conducted in 1994-1995 and repeated again in 1998-1999, asked respondents to report on their alcohol consumption during pregnancy. The number of Canadian women who report drinking alcohol at some point during their pregnancy has decreased from 17% to 25% in a 1994-1995 survey (National Longitudinal Survey of Children and Youth (Statistics Canada, 1995) to 14.4% in 1998-1999 (Statistics Canada, 1999). In the same surveys, 7% to 9% of respondents reported drinking throughout their pregnancy in 1994-1995 and 4.9% reported the same in 1998-1999. Incidentally, in the later survey 3% reported binge drinking during pregnancy.

The most recent data from the Canadian Addiction Survey (CAS) released on March 23, 2005 suggest that the rate of past-year drinking (any amount of alcohol consumed) among females was 76.8%. Nearly 33% of females reported drinking at least once a week. The survey did not address drinking during pregnancy (Canadian Centre on Substance Abuse, 2005).

Adolescent drinking is also of concern since teenaged girls are of childbearing age. The Health Behaviours in School Aged Children Survey 2000/01 shows that 23% of Grade 10 girls reported that they had an alcoholic drink at least once a week. This rate increased steadily from 3% at Grade 6 to 11% at Grade 8 to 18% at Grade 9. Forty-two percent of Grade 10 girls said they had been drunk at least twice. While variable, the same study shows that the majority of students first tried alcohol between the ages of 12 and 14 and first got drunk between the ages of 13 and 15. The trends in these data seem to be going in the inverse direction to the tobacco use data for Canada.

Risk Factors

The severity of the effects of prenatal alcohol exposure depends on interactions between maternal and fetal physiology and genetics, timing and duration of fetal exposure, pattern of maternal drinking, and a number of maternal lifestyle factors, including higher maternal age, lower education level, cocaine use, smoking, custody changes, lower socio-economic status, and paternal drinking and drug use at the time of pregnancy (Sood et al., 2001), as well as reduced access to pre- and postnatal care and services, inadequate nutrition and a poor developmental environment (e.g. stress, abuse, neglect) (Bingol et al., 1987).

Defining the Scope of the Problem

Prevalence estimates of FASD vary widely (Roberts and Nanson, 2000). The prevalence of FAS in the United States has been estimated to be 0.5 to 2 cases per 1,000 live births and FASD as 9.1 cases per 1000 live births (Sampson et al., 1994).

In Canada, a few small studies have estimated prevalence of FASD in sub-populations. One study conducted in an isolated community in British Columbia reported FAS rates of 190 per 1,000 live births (Robinson et al., 1987), while another conducted in a First Nations community in Manitoba reported rates between 55 and101 per 1,000 (Square, 1997). Other surveys conducted in Yukon and northern British Columbia estimated the rate of FAS and related effects as 46 per 1,000 and 25 per 1,000 respectively (Asante and Nelms-Maztke, 1985). It is important to note, however, that these estimates are specific to these communities and cannot be extrapolated to apply to the Canadian population as a whole. The rate used as an estimate of national prevalence rate of FASD in Canada is 9.1 per 1,000 live births, based upon Sampson's data from Seattle (Sampson et al., 1994).

Addressing the Problem

Prevention in Canada

There are three levels of prevention – primary, secondary and tertiary. Primary prevention targets the entire population and includes public awareness campaigns, community education and alcohol control measures. Secondary prevention specifically targets at-risk populations and can include outreach, screening and referral for women who are pregnant, or of childbearing age, and using substances. Tertiary prevention targets those for whom FASD is already a concern, such as women who are at risk of having a child affected by prenatal substance use, or women who have already given birth to a child with FASD (Roberts and Nanson, 2000).

Primary Prevention

There are two key national resources on FASD. The first is the CCSA's FASD Information and Consultation Service, which provides links to support groups, prevention projects, resource centres and experts on FASD.

The second is the toll-free bilingual Motherisk Alcohol and Substance Use Helpline (1-877-FAS-INFO) that provides information and counselling to pregnant and breastfeeding women, their families and health care providers on the effects of alcohol use and other substances during pregnancy and lactation; referrals to services in the caller's home community; and referrals to FASD assessment at The Hospital for Sick Children in Toronto.

At the provincial/territorial and community levels, primary prevention ranges from large, multifaceted campaigns to very basic awareness efforts. The Canadian provinces and territories are at different stages of primary prevention programs, services and campaigns, and all recognize the importance of FASD prevention.

There is a growing body of research specific to primary prevention and the public awareness of the risks of drinking alcohol during pregnancy. An Environics survey of Ontario women of childbearing age in July 2004 determined that there are high levels of awareness that alcohol use in pregnancy leads to lifelong consequences. A national survey in 2000 showed similarly high levels of general awareness (Environics, 2000). Awareness breaks down around more specific issues, such as the amount that may be "safe" to drink in pregnancy and when to stop drinking (Best Start, 2004).

Other research has sought to establish a link between awareness activities and behaviour. Efforts that take a single approach, such as signs or warning labels, have shown mixed results and limited impact (Health Canada, 2000; Caprara et al., 2004), while multilevel campaigns that include media, workshops, public events and links to additional services are more effective (THCU, 1999). Cumulative exposure to health messages has also been found to have effect (Kaskutas and Graves, 1994).

Numerous resources have been developed to provide guidance on where to start, what works, guiding values, building partnerships, understanding the audience, defining the message, and evaluating the impact of a prevention campaign (Roberts and Nanson, 2000; BC FAS Resource Society, 2004). Organizations such as Ontario's Best Start have sought to define effective communication messaging about alcohol and pregnancy, based on the evaluation of its 2004 alcohol and pregnancy campaign in Ontario (Best Start: Evaluation 2004).

Most recently, the Alberta Centre for Child, Family, and Community Research funded a state of the evidence review on FASD prevention. The report should be available on its Web site in spring 2005 (http://www.research4children.com).

Secondary and Tertiary Prevention

Secondary and tertiary prevention efforts have been developed based upon the evaluation of community-based prenatal and early childhood projects (including Community Action Program for Children, Canadian Prenatal Nutrition Program, Aboriginal Head Start, Early Childhood Development Initiative) and women-centred research aimed at identifying non-coercive ways to reach and support pregnant women who use alcohol and other substances (Poole, 2000; Pepler et al., 2002).

Research and help guides have focused on the barriers to access, such as homelessness and the effects of early engagement of pregnant women using substances (Hicks, 1997); identification and support of children and families affected by prenatal alcohol exposure (Leslie and Roberts, 2004); barriers to treatment, such as the fear of apprehension, for substance-use mothers (Poole and Isaac, 2001); effects of homelessness on women's health (Kappel Ramji Consulting Group, 2002); and applied strategies to support pregnant women with substance use problems (Leslie and Reynolds, 2002; AADAC 2003).

Researchers have also considered the role of the physician in screening for alcohol use during pregnancy and have found varying attitudes and approaches to preconception counselling (Tough et al., 2005), as well as varying levels of awareness and ability to provide FAS diagnosis (Sarkar, 2003).

Many workshops, conferences, teleconferences and training manuals have been developed for physicians and front-line workers (e.g. CCSA FAS Tool Kit; Motherisk and Best Start physician training; Breaking the Cycle/CCSA Nurturing Change). Also, new ways to transfer knowledge (e.g. Web-based information) have been tested through projects such as the "Demonstration Project to Provide On-Line Training and Consultation on Evidence-Based Practices for Front-Line Practitioners in Health Canada's CAPC/CPNP Network" (2002).

What emerges from this cursory review is a patchwork of intermittent prevention activities throughout Canada. At one end of the spectrum are single-message prevention activities

and products; at the other end are a few coordinated multilevel campaigns. At best, prevention activities to date have aimed at promoting healthy choices in pregnancy to achieve healthy birth outcomes. At worst, prevention messaging has oversimplified the problem by suggesting that any woman can "just say no," "FASD is 100% preventable" or that "any amount of alcohol during pregnancy will cause FAS."

Growing evidence suggests, however, that FASD prevention requires integrated programs that deliver culturally sensitive perinatal services to high-risk women, neonatal screening, and prompt and sustained intervention for affected children and mothers. Furthermore, these programs should be based on an understanding of the determinants of health and factors that contribute to alcohol use in pregnancy and addiction. It would also be desirable to gather Canadian data on risk factors so that appropriately targeted programs and services can be developed.

The Diagnostic Process

Early diagnosis of FAS, pFAS and ARND is the crucial first step in the timely delivery of effective intervention. In fact, diagnosis before age 6 is recognized as a major factor in preventing the onset of secondary disabilities (Astley and Clarren, 1999). Also, diagnosis in early childhood may "serve as a clinical biomarker for unrecognized maternal mental health and addiction concerns and provide an opportunity to offer interventions, support and counseling for the birth mother." It may also prompt interventions for other affected siblings and help to prevent alcohol exposure during subsequent pregnancies (Loock et al., 2005). In effect then, early diagnosis identifies two patients (baby and mother) and possibly more (siblings and partners).

Diagnosis extends beyond physical examination, and the diagnostic procedure is complex and labour-intensive. A diagnosis is not a label, but rather a blueprint for intervention and prevention. As stated in the recently released Canadian Guidelines for diagnosis, "the diagnostic process consists of screening and referral, the physical examination and differential diagnosis, the neurobehavioural assessment and treatment, and follow-up" (Chudley et al., 2005). This is accomplished through the coordinated efforts of a multidisciplinary team of health and allied health experts.

Comprehensive, age-appropriate neurobehavioural assessment consists of standardized measures of intelligence, language, memory, attention, executive functioning, sensorimotor, visuospatial and social/emotional functioning. Time must also be spent with parents or guardians to discuss the results of the assessment and to share information regarding appropriate resources in their community, based on a report summarizing the test results, the diagnosis and specific recommendations for home and school. Ideally, the diagnostic process should also include pre- and post-assessment counselling and support to the mother and child (Chudley et al., 2005). As women learn more about the risks of prenatal

alcohol use in relation to their own children, they may become aware that they experience many symptoms consistent with FASD (Rouleau et al., 2003). Adult FASD assessment of these women may help to promote renewed hope among those who always knew "something was wrong" but were unable to identify the nature and cause of their disability.

Clearly, setting standards for diagnosis also leads to questions. For example:

- Who will deliver this basket of specialized diagnostic services and supports?
- How can capacity be built to ensure that services are accessed in urban as well as rural areas throughout Canada?
- If pre- and post-counselling and support are important parts of the diagnostic process, what service models are best and how are they to be funded?
- How does the process need to be adapted to address special populations and contexts (i.e. rurality, culture)?

Intervention

As discussed above, intervention is an important element of tertiary prevention. It is also an element of the diagnostic process that calls for treatment and follow-up. FASD management requires a seamless and comprehensive assessment–diagnosis–intervention–support continuum for both the mother and the child.

Interventions for persons affected by prenatal substance use seek to prevent and reduce harmful effects associated with the primary and secondary disabilities of FASD (Roberts and Nanson, 2000). Effective intervention aims at promoting the development of affected individuals throughout the stages of life, and supporting those caring for them. Those charged with their care will have to face a multiplicity of issues, including appropriate medical care, educational and vocational supports, social problems associated with the affected individual's impulsivity, poor judgment and decision-making skills, and interactions with the law and criminal justice system.

Much of what is known about effective interventions has been gained through the experiences of biological, adoptive and foster parents who are raising affected children, and community workers who have been meeting the challenge of FASD management one issue (or crisis) at a time. Recognizing that so many children and adolescents with FASD are living in foster care, case managers are learning that the best case scenario is diagnosis by age 6, stable placement in a family that is trained to help the child over each developmental hurdle and supported with respite, and that the child is placed in a school program that understands and supports the primary disabilities of FASD. But the task is far from easy. Appropriate service planning requires the development of case management standards, shared information and reconciling often competing mandates and demands of agencies charged with child safety, community safety and family preservation.

A topic of much discussion relates to FASD and intervention within the criminal justice system and the appropriateness of incarceration for FASD-affected individuals. Does the justice system have the capacity to ensure that these individuals are treated properly? And if not, what judicial or extra-judicial options exist (UBC, 2005)? Others within the criminal justice system have taken steps to incorporate First Nations practices and values into the mainstream legal system (Turpel-Lafond, 2004). This paper cannot begin to enumerate the many efforts of individuals and groups nationwide to grasp at least a piece of the problem and implement workable solutions, but much valuable work is being done.

Comprehensive, lifelong intervention requires leadership and coordination of FASD initiatives at the community, regional, provincial/territorial and national levels. A number of provincial/territorial and federal priorities have been identified related to family supports, education, funding and research.

Current issues related to intervention include:

- What are appropriate ways to deliver culturally sensitive services and support (Masotti et al., 2003)?
- How can barriers to access be overcome for Aboriginal women and families?

Research

Canada has leading researchers in the field of FASD. Research focuses on mechanisms underlying neurobehavioural development, prevention in Aboriginal communities, biomarkers for screening pregnant women for alcohol use, effective interventions and antioxidant therapy to prevent disabilities associated with prenatal alcohol exposure.

Policy and Prevention

There is considerable debate concerning effective alcohol policy. Some researchers recommend policies that lower overall alcohol consumption, in the belief that information and education campaigns have little if any impact on drinking rates or damage from alcohol use (Giesbrecht, 2003). Others propose that policy should be aimed at reducing problem drinking (Grant and Litvak, 1997).

In Canada, a variety of regulatory measures have been implemented to decrease alcohol consumption, in general. These include increased taxation, government monopoly of retail sales, minimum purchase age and limiting hours of service. The measure shown to be most effective to date is increased pricing through taxation. Other policies have been adopted at the municipal and provincial levels, to varying effect (Roberts and Nanson, 2000).

Some provinces and territories require warnings about the dangers of alcohol consumption during pregnancy to be printed on liquor store bags and receipts. Sandy's Law has gained

recent press. It requires the placement of signs that warns about the effects of alcohol use during pregnancy in places where liquor is sold in Ontario.

At the federal level, Bill C-206 requiring the application of warning labels on alcoholic beverages is currently being debated in the House. The purpose of Bill C-206 is to require alcoholic beverages to bear a warning regarding the effects of alcohol on the ability to operate vehicles and machinery and on the health of consumers, and the possibility of birth defects when consumed during pregnancy. As with so many issues related to policy and prevention, there are strong opinions for and against the effectiveness and utility of warning labels (Babor et al., 2003).

Effective FASD-related policies will require partnership, cooperation and communication among provincial and territorial governments, the federal government and private stakeholders. The following guidelines for alcohol policy development have been recommended by Edwards et al. (1994).

- There is no one policy panacea. The effective policies will be a mix.
- Some policy measures are more effective than others. The basic, evidence-based policy mix includes taxation, control of physical access, drinking–driving countermeasures and treatment – particularly primary care. Educational strategies, restrictions on advertising and community action programs are additional measures with the potential for long-term pay-off.
- Political feasibility and public acceptance are important in selecting alcohol policies.
- Policy choices have national and international dimensions.
- Policy choices have to be determined not only by what is effective, but by what provide value for money.

A number of principles and criteria for effective policy were discussed at the Roundtable on Alcohol Policy, hosted by CCSA on November 18 and 19, 2004. Roundtable participants noted that effective policy:

- generates buy-in
- can adapt to different communities
- reflects community needs and is driven by community

The group recommended that a national Centre for Excellence on FASD be created and selected five policy areas for further discussion and exploration:

1. promoting the use of brief intervention
2. developing and promoting policies to reduce chronic disease
3. addressing drinking context and use of targeted intervention
4. structuring alcohol taxes in a discerning and purposeful manner
5. developing the culture of moderation vs. a culture of intoxication (i.e. a culture of healthy lifestyles) (CCSA, Draft Key Messages Report, 2005)

Policy and Treatment

Pregnant substance-using women have been profoundly impacted by alcohol and drug-related policies and sanctions (Roberts and Nanson, 2000). Aside from neglect and inadequate service delivery (e.g. services for pregnant women based on treatment models for men and failure to provide child care for women seeking treatment), pregnant substance-using women have faced coercive civil and criminal sanctions. In Canada, the case of Ms. G. highlighted the issue of mandatory treatment for pregnant substance-using women, while in the United States, prosecutors in various states are charging women who use alcohol and other drugs while pregnant with serious crimes, such as misdemeanor counts of endangering the welfare of a child and homicide.

In Canada, the court ruled against mandatory treatment of pregnant women. Still, there is a need for comprehensive treatments and services that respect the rights of women, while also preventing FASD. Examples such as the Sheway Program in Vancouver and Breaking the Cycle in Toronto illustrate that effective solutions require collaboration among those charged with child welfare and protection, health care provision for mother and child, women's addiction services, counselling, family planning, housing and other services (Pepler et al., 2002; Poole, 2003). The challenge is to continue to enhance these existing models, duplicate them and ensure that they are sustained through adequate funding and support.

Two National Frameworks for Action

In 2003, Health Canada introduced the **Framework for Action on FASD.** Developed through consultation with hundreds of organizations and individuals across Canada, the FASD Framework lays out a vision for the future, five broad goals, strategies and guiding principles.

The **Framework for Action on FASD** recognizes that individual and collaborative action is required in all sectors, at all levels – federal, provincial, territorial and community. The five broad goals calling for action are:

1. Increase public and professional awareness and understanding of FASD and the impact of alcohol use during pregnancy.
2. Develop and increase capacity.
3. Create effective national screening, diagnostic and data-reporting tools and approaches.
4. Expand the knowledge base and facilitate information exchange.
5. Increase commitment and support for action on FASD.

Meanwhile, Health Canada and CCSA are engaged in a broad consultation on a proposed **National Framework for Action on Substance Use and Abuse.** The initial goal is "to determine the level of commitment across Canada to developing such a Framework." A comprehensive process is underway to involve stakeholders in the development of the Framework. To date, several regional consultations have been held, along with thematic workshops. A biennial forum that will introduce a draft National Framework will follow, and finally a National Addictions Conference will occur in late 2005 to also inform the Framework. Likewise, a series of reports and studies will provide key information about:

- substance use in the Canadian population
- culturally appropriate surveys in each of Canada's territories that complement the Canadian Addictions Survey
- education and training needs of treatment professionals
- data on the health and economic well-being of Canadians

Summary and Questions to Consider

Given the impact of FASD on individuals, families, communities and the Canadian economy, the state of prevention and intervention efforts in Canada, the current debates over alcohol policy development and the persistent lack of funding for FASD-related efforts, it may be helpful to integrate FASD-related issues into a broader alcohol framework. Thus:

- How should the Framework for Action on FASD and the National Framework for Action on Substance Use and Abuse be linked?
- Which FASD-related themes would best link?
- How would integration of FASD into the National Framework for Action on Substance Use and Abuse be most effectively conducted?

- What would be the benefits of a coordinated effort?
- Who would be the necessary partners and how would the partnerships be developed?
- Where would funding come from?
- Would there be jurisdictional barriers (i.e. provincial/territorial vs. federal) that would have to be overcome?
- What would be the draft FASD strategy?
- What would be the draft action plan?
- What might be the consequences of proceeding with a National Framework on Substance Use and Abuse that does not include a FASD component?
- Is there a risk of confusion, duplication of effort, competing priorities?

It is expected that answers to these questions, as well as others, will determine the best use of efforts and resources to improve outcomes for FASD-affected individuals and families in the long run.

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