HEALTH CANADA FAS/FAE INITIATIVE

INFORMATION AND FEEDBACK SESSIONS

NATIONAL SYNTHESIS REPORT

JUNE, 2000

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INTRODUCTION

In the 1999 Budget, the Government of Canada increased funding to expand the Canada Prenatal Nutrition Program including the enhancement of current prevention efforts that address Fetal Alcohol Syndrome and Fetal Alcohol Effects (FAS/FAE). Health Canada's FAS/FAE Initiative received $11 million over three years to be used in the areas of public awareness and education, surveillance, early identification and diagnosis, FAS/FAE training and a Strategic Project Fund.

The FAS/FAE component is a joint initiative involving partnership among different branches of Health Canada including: Health Promotion and Programs Branch (HPPB), Health Protection Branch (HPB) and Medical Services Branch (MSB).

Through the Strategic Project Fund, grants will be administered for programs that focus on strengthening community capacity through prevention, early identification, and integration of services and research. Funding will be for short-term projects only and all projects funded must have national applicability. The Strategic Project Fund will be administered nationally by the Population Health Fund.

Consultations with the provinces, territories, non-governmental organizations, community groups and Aboriginal organizations have taken place across the country. These consultations provided the opportunity for participants to hear about Health Canada's FAS/FAE Initiative, to identify what initiatives are taking place already in the provinces and territories, and to increase collaboration with all groups. The individual consultation feedback summaries were combined in the attached report to form a national profile of FAS/FAE gaps and priorities across Canada. This national synthesis report will contribute to the development of a collaborative National Action Plan on FAS/FAE that builds on current activities.

Specifically, consultations were held at:

- Winnipeg, Manitoba — January 26, 2000
- Halifax, Nova Scotia (Atlantic Region) — February 9, 2000
- Edmonton, Alberta — March 13, 2000
- Montreal, Quebec — March 16, 2000
- Saskatoon, Saskatchewan — March 21, 2000
- Toronto, Ontario — March 24, 2000
- Vancouver, British Columbia — March 28, 2000
- Whitehorse, Yukon — April 25, 2000

Close to 500 people participated in these consultations, representing a cross section of all levels of government, First Nations, Metis and other Aboriginal groups, Elders, families (birth, adoptive and foster) and community organizations (both rural and urban).

The participants represented a wide variety of backgrounds including the fields of: prenatal health promotion, addictions, medicine, justice, education, childcare, health, employment, residential services, counselling and treatment, support groups, and a variety of community organizations. They gathered to hear about the national FAS/FAE Initiative and to address five specific questions as identified in the Health Canada FAS/FAE consultation workbook (see page 57).

The consultations varied from one-half day to two days during which time the participants were briefed on the FAS/FAE Initiative and time was provided for questions. This was followed by small group discussions to address the five questions in the consultation workbook. Participants divided into small groups with discussion focussing on one of the following topics: training, family, medical, prevention and awareness, children birth-6, children 6-18, Aboriginal issues, women's issues, adult services, or education. The number of group discussions varied at each consultation based on the number of participants and their areas of specific interest.

One person in each group facilitated the discussion while another was designated to record the main points. At the end of the afternoon, a representative from each group presented briefly on the main emerging issues and top priorities related to their topic of discussion followed by the possible role of Health Canada in addressing these needs and gaps. Many participants also answered the questions in the consultation workbook from the perspective of their organization, community or as an individual. A summary of these recommendations, from both group discussions and individual responses, is reflected in the attached report.

The Atlantic Region FAS Forum involved a second day of strategic planning to build on the small group consultation discussions. Additional recommendations and issues arising from the strategic planning discussions were also incorporated in this report.

Two provinces, Alberta and British Columbia, chose a slightly different format. The Alberta consultation involved representatives from the Alberta Partnership on FAS and constituted a general discussion of priorities, recommendations and suggestions for the role of Health Canada and the Federal Government. The Alberta Partnership on FAS representatives anticipated that the specific questions in the consultation workbook would be addressed more fully by their 2000-2001 strategic plan. Workbook responses were provided from a subsequent meeting of the coordinators for the Regional FAS Coordinating Committees.

The British Columbia consultation involved representatives from the Provincial FAS Consultation Group, whose members represent various government ministries, agencies, community groups and families. Their small group discussions were based on a February 2000 survey in which members ranked various areas of activity and chose their top priorities for project development. (The areas of activity were identified earlier at a March 1998 discussion on emerging issues and trends in the province.)

Participant comments and recommendations were often presented in the larger context of what the federal government or what a variety of departments could or should do to address FAS/FAE rather than strictly what Health Canada could do. Some recommendations fall under the jurisdiction of provincial, territorial or municipal governments.

Comments from participants from each of the consultations were condensed into the national synthesis report. For a complete summary of the feedback, please refer to the individual consultation reports.

The attached report is divided into six sections:

A. Needs/Issues/Gaps to address for each specific topic
B. Top Priorities in each area
C. Role of Health Canada in addressing the needs and priorities
D. Other areas that should be involved in addressing FAS/FAE
   (i.e. other government departments, organizations and groups)
E. Examples of successful partnerships
F. Consultation workbook questions

GENERAL FINDINGS

The western provinces and, to a lesser extent, Yukon, have made the most progress regarding awareness, education, training and development of resources. Movement around prevention and awareness education and training has taken place in Ontario, but there are few on-the-ground resources. There was a sense of frustration expressed by some working in the field regarding the lack of political will and acceptance of the seriousness of the issue. Quebec is gaining momentum in its recognition of FAS/FAE, research needs to be done on the cultural connections to alcohol. The Atlantic Region has made recent progress and used their consultation as a platform to build on connections and start the development of a network.

Partnerships and collaboration have already taken place in the western provinces, the largest being the Prairie Northern FAS Initiative. Membership initially included Alberta, Saskatchewan and Manitoba who came together to share best practices, expertise and resource materials, and develop joint strategies to address FAS/FAE. Yukon, Northwest Territories and Nunavut joined the initiative in fall 1999. British Columbia has already developed a number of resources and established networks within the province such as the Provincial FAS Consultation Group.

Leadership & political will across departments

Participants identified a need for clear leadership on the issue of FAS/FAE and coordination and sharing of information and resources at the national level. It needs to be identified what role the provinces are currently playing, what role the federal government will play, whether the federal government can do its initiative in partnership with the provinces, territories and Aboriginal governments, and how they can work together to do the most to address FAS/FAE in Canada. The bottom line is not to reinvent the wheel in this process and to use existing networks as much as possible.

Many commented on the need to cultivate political will in all provinces and territories to provide the focus and necessary funding to effectively address FAS/FAE. Coordinators, who are accountable to move FAS/FAE issues ahead, are needed to take the lead in each province and territory. It will be essential to link these people at the community, regional and national level. It was also suggested that there be a direct service agency developed for affected individuals.

Participants noted that FAS/FAE is an issue that crosses several jurisdictions —health/medical, education, justice, social services, housing, employment—requiring inter-departmental cooperation as well as cooperation between all levels of government. Barriers between government departments must be eliminated. All disciplines will need to work together in a team-management approach. It was noted that one of the first steps should be education as there are different levels of awareness among government departments.

Sharing materials and experience

Because much of the groundwork is already laid out in the western provinces, with resulting priorities and gaps already identified, it was noted that funding is the critical missing element. While the eastern provinces are the least developed in terms of addressing the issue, and, some might argue, the greatest in need as a result, there is concern in the west that monies may be allocated to regions that have not yet established the basics such as provincial and regional networks.

Many participants commented on the fact that many of the needed resources have already been prepared in one province or region and could be used elsewhere. It was suggested that resources and energies be pooled at the national level in the same manner as the Prairie Northern FAS Initiative and that others could learn from the prairie province's experiences regarding what approaches did and did not work.

Communications and information strategies

There was also concern from the west regarding competing messages, e.g. if the Prairie Northern Initiative's already completed communications strategy were to be overlapped by a pending national campaign. Even with a similar message, there would need to be a consistent style and content to avoid confusing the public. It was suggested that the prairie message be tested for possible use as a national campaign.

Many participants noted there are already mixed messages in society regarding the question of a safe amount of alcohol use during pregnancy. They suggested a broad-based national campaign targeted at all members of society with a positive and clear consistent message regarding no alcohol in pregnancy and if planning a pregnancy. It was recommended that social marketers be used to develop a universal slogan as effective as the 'Don't Drink and Drive' campaign. Furthermore, youth should be involved in preparing a message for that population. It was also noted that plain language materials and resources are needed that are sensitive to both language and culture. Many commented on the need to develop a national directory of services and a central registry to track information and research.

Canadian research & statistics

There was also a call for Canadian research in a number of areas including best practices across all disciplines. Suggestions included evidence-based research on incidence, effective intervention, messaging, survey of the priority population, management and treatment of offenders affected by FAS/FAE, and effective strategies for optimum functioning of affected adults in society among others.

It was noted that the research needs to be coordinated and consistent to be effective, e.g. if each jurisdiction conducts different sets of prevalence studies in different populations, it would not help to form a national picture.

One of the difficulties in building a case addressing FAS/FAE is the lack of statistics on prevalence. However, it was suggested that governments do not want to know the full extent of the problem for fear that the resulting demand for services and resources would be overwhelming.

Diagnosis & demand for services

Across the country, but particularly in the west where more awareness education has taken place, there is a strong concern that increased awareness is leading to a tremendous increase in demand for diagnosis/assessment that far outpaces the parallel development of the necessary supports and services.

Lack of diagnosis or diagnosticians was voiced across the country as well as the need for a consistent standard assessment process for diagnosis. Long waiting lists, for those areas with diagnostic clinics, were also cited. Many commented on the paradox that the need for early identification and intervention for the most hopeful outcomes for affected children is recognized and accepted, yet families and individuals are not able to access diagnosis or must wait months or years while the critical early years pass by.

It was suggested that there be a single point of entry for FAS/FAE with each health authority that provides access to a complete range of services. Participants noted frustration with fragmented services and the need for a holistic approach and individualized care plans.
Many commented on the need to clarify and use consistent terminology, i.e. FAS, FAE, partial FAS, ARBD, ARND. With even doctors using different terms, it is confusing for professionals and especially for families. It was also suggested that while there are concerns about a lack of diagnosis, informal diagnoses and misdiagnoses, there was also the concern of indiscriminate over-labelling.

Youth and adults affected by FAS/FAE often remain undiagnosed or misdiagnosed, many times because they have been adopted or in foster care and the maternal history is inaccessible or unavailable. Many participants, particularly parents, commented on the need to screen all children who come under care and to open the information files to prospective adoptive or foster parents.

It was also noted that in our prevention efforts, we might have presented the picture of those living with FAS/FAE as hopeless. This affects willingness to seek a diagnosis as well as the willingness to foster or adopt an affected child or attempt different teaching or parenting approaches among other things.

Addictions, treatment & root causes

Another barrier to diagnosis identified by participants is the shame, guilt and denial of birth mothers and families that often follows disclosure of drinking during pregnancy. To deal with this, families require sensitive support before, during and after diagnosis. There is also a need to remove the obstacles that keep addicted women from accessing treatment, e.g. a woman should not have to choose between going into an addictions program or being with her children. Family-centred treatment combined with transitional support upon return to the community, and peer support or mentoring programs are needed to stop the cycle of women losing their babies and then replacing them.

Across the country it was noted, however, that FAS/FAE is not just a mother who drinks. Governments and communities need to acknowledge how racism, poverty, sexual abuse and family violence are linked to addictions. We need to recognize that FAS/FAE is more than a women's issue or an Aboriginal issue—it is a societal issue.

We are now seeing intergenerational FAS/FAE in which affected parents are having affected children. In some northern communities, the problem can go back three generations. Parents with FAS/FAE are trying to parent and, in some cases, parenting children affected by FAS/FAE.

Family services & respite supports

The need for support services and qualified/quality respite for all families (birth, adoptive, foster) was identified. Without adequate supports, the multiple roles of parent, advocate and supporter of others can cause families to collapse under the strain. It was also noted that parents are not considered 'professional' yet they are the experts on their children since their commitment is 24 hours a day, 7 days a week. Parents asked for recognition and validation of their role and to be included in decision-making involving their children. Training in parenting skills and effective approaches are needed, as participants noted that mainstream parenting methods do not work with affected children.

Training across disciplines & professional development

Because FAS/FAE crosses many disciplines, there is a need for training in best practices, including train-the-trainer, across the board for teachers, teaching assistants, correctional officers, judges, lawyers, caregivers, families, respite workers, addictions workers, child care workers, etc. It was also suggested that professionals undergo sensitivity training to understand and develop non-judgmental approaches.

It was suggested in almost every consultation that FAS/FAE training should be included in the core curriculum of applicable faculties at the postsecondary level, e.g. Law, Social Work, Education, Nursing, Medicine, etc. It was suggested that ongoing accredited professional development should continue once practicing in their field and that it be a mandatory requirement of the respective professional associations.

Teaching strategies, classrooms & Ritalin

Specific school needs cited included the need for practical ready-to-use information for the classroom for all teachers, increased funding for teacher's assistants, classrooms geared to the special needs and abilities of children affected by FAS/FAE and effective strategies for teachers on how to teach affected children. It was suggested that we might need a separate education system with a different environment and different approach, as described by Susan Doctor. It was also suggested that FAS/FAE education should be part of the core curriculum in health and family life/family living programs in schools.

There was great concern across all communities regarding the use, misuse and overuse of the drug Ritalin as a method to control behaviours, particularly for classroom control. Alternative approaches and treatments need to be identified.

It was noted that society does not seem to place a high priority on addressing FAS/FAE and many, including professionals working with affected individuals, do not recognize it as a disability. It is particularly difficult with FAE as it is a hidden disorder. Affected children and adolescents with 'normal' IQ levels are not provided with the needed services as a result, in spite of the behavioural issues. Instead, they are labelled as 'bad' kids.

Adolescents & young adults

Even in some regions where there are services and programs for young children, it was noted that there is little to offer adolescents or adults and there is a vacuum of materials for working with adults, as if an affected person outgrows FAS/FAE. There is a need to recognize FAS/FAE as a lifelong disability requiring a continuum of services that adapts to the changing needs as the person ages. For example, school transitions, employment, assisted housing and assisted living.

Perhaps the biggest challenges with adolescents and young adults is keeping them in school, finding employment, keeping families together, keeping them out of jail and finding support living accommodations. It was noted there is a conflict between what adolescents are taught in school, i.e. to become independent individuals contributing to society, vs. the reality that many of them may never be able to live independently. Nonetheless, it was acknowledged that children and young adults affected by FAS/FAE could function with strong supports.

It was noted that adolescents and young adults who are being expected to live independently without supports often end up in correctional facilities where they are supervised 24 hours a day. However, safe placement for individuals affected by FAS/FAE is not the purpose of custody or jails. It was also acknowledged that affected adults cannot necessarily be forced to accept the services they need.

Justice & corrections

Considering the large numbers of incarcerated individuals either diagnosed or suspected to be FAS/FAE, participants noted we might need to rethink the legal system and look at other ways of protecting society and the offenders themselves. It was suggested that every offender, juvenile or adult, be screened for FAS/FAE and that this should be taken into account when sentencing. Alternative justice methods need to be considered, i.e. life skills/community service vs. incarceration. We need to set up the means for affected individuals in the justice system to return to their communities with the proper support system in place to avoid repeat offences.

It was also noted that FAS behaviours require different treatment and programs in correctional facilities and that the Aboriginal community requires the resources to design programs appropriate to their needs. One participant noted the irony that the bright lights and noise of penal institutions are exactly the wrong kind of environment for the sensitive eyes and ears of an affected individual.

Rural, remote and northern issues

Rural, remote and northern areas face specific issues, e.g. difficulty in forming partnerships, accessing or providing services, the expense of travel to see urban clinics and specialists, privacy and confidentiality issues in small communities, isolation, etc. Some communities, particularly in northern areas of the provinces and the Northwest Territories and Nunavut, have fly-in access only.

There was strong direction from Yukon that the territories should be aligned as a northern partnership rather than the current Health Canada linkages, i.e. Yukon in the British Columbia region, Northwest Territories in the Alberta region and Nunavut in the Ontario region. It was pointed out that Yukon, for example, looks to programs in Alaska rather than southern British Columbia for models to follow. It was also noted that northern areas often feel ignored for feedback or participation in provincial/federal consultations.

Recognizing cultural differences & First Nations models

Many participants commented on the need to recognize cultural differences and to incorporate traditional First Nations values, including both language and cultural sensitivity. Aboriginal people should be trained to work with Aboriginal people and any non-Aboriginal service providers should receive training for cultural competency. Treatment should be based on a First Nations model, rather than the medical model, that supports traditional family based approaches to prevention and intervention. It was also noted that Elders have a vital role to play in addressing FAS/FAE within Aboriginal communities.

Participants suggested that more Aboriginal input is needed, rather than a few voices at a consultation or one Aboriginal person on a large committee. There was also a call to break down the jurisdictional barriers between the provinces and the federal governments for on and off reserve support services. There was concern that many professionals automatically ‘write off’ Aboriginal children as FAS/FAE.

Community capacity building

Participants commented on the need to recognize and fund community-based programs, and to identify a 'point-person' in the community committed to FAS/FAE initiatives. It was noted that professionals in many organizations already have too many competing priorities, wear too many hats and are generally overworked. There is also a need for trained members of the community to remain in the community as advocates and educators. It was again noted that community programs are often undercut as soon as they start, or are under-funded and cannot function effectively. Participants expressed the need for long term funding with built-in flexibility and an end to project based funding.

Federal commitment to FAS & project based funding

There were many questions across the country regarding the federal government's commitment to address FAS/FAE. The $11 million over 3 years was deemed as grossly insufficient, particularly since it would be split between different branches within Health Canada and then spread across the country. The cap of $150,000 over 3 years on projects funded by the Strategic Project Fund was also criticized as grossly inadequate. The comment was made that funding dollars need to be substantial enough for future commitments so that people are willing to "jump on the wagon for the long ride."

Across the country, there is great concern about project based funding (e.g. Strategic Project Fund) as there are already many worthwhile projects that are in jeopardy due to lack of sustainable funding. Too often, community groups spend the majority of their project time searching for partner funding or sustainable funding rather than concentrating on the purpose of their project. Many effective programs die due to project based rather than sustainable funding.

New approaches to raise and distribute funds

In almost every consultation, it was suggested that a tax be levied on alcohol or that a portion of revenue be collected from the sale of alcohol. These funds would provide sustained funding for programs and services for individuals affected by FAS/FAE. Another suggestion was the creation of a foundation to raise and distribute money for programs and resources.

Participants noted that it is much harder to find funding for intervention in the lives of those already living with FAS/FAE, as opposed to prevention and awareness efforts. The suggestion was made that there be some kind of ratio of funding towards prevention and towards supporting families and individuals already living with FAS/FAE.

There was also the suggestion that it would be more effective to apply the entire Strategic Project Fund against one specific area, e.g. training, prevention and awareness, research, diagnosis, or any other area, rather than divvying the money into small time-limited projects, which often ends up pleasing no one.

Fear of raising false expectations

Finally, there was a concern that the consultations would raise false expectations for participants. Because there are so many needs for services, resources and programs for affected individuals, many participants were concerned that communities would think they would get these services as a result. Participants expressed frustration with too much talk and not enough action on the ground.

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A. NEEDS/GAPS/ISSUES TO ADDRESS:

MEDICAL

- diagnostic and referral clinics needed within all provinces
- long waiting lists at existing diagnostic clinics – there is a huge demand for diagnostic clinics and/or physicians that far exceeds what is available
- expensive for rural/northern families or individuals to access urban clinics – the Telediagnostic Link in Manitoba is a possible model in terms of diagnosis that offers the opportunity to bring the expertise to remote sites
- need to develop a consistent standard assessment process to diagnose individuals and ensure all doctors are using the same diagnostic tool
- general physicians need to be cognizant of FAS/FAE, ARBD, ARND and be cautious of misdiagnosis or indiscriminate overlabelling
- important to clarify consistent terminology, i.e. FAS, FAE, ARND, ARBD, etc. – even doctors doing the diagnosis are using different terms – confusing for professionals and really confusing for parents – also makes it more difficult for doctors to make a definitive diagnosis
- hear a lot about the need to diagnose but it's very complex – there is a blood test for Mono but no such thing for FAS/FAE
- diagnosis alone inadequate – it is only one piece of the puzzle – need holistic approach
- interventions and strategies need to be geared to specific child and family
- need a continuum of services and single point of entry – each health authority should have a single point entry for FAS/FAE with access to a whole range of services
- diagnostic and prevention networks are essential for the sharing of information, resources and expertise that already exist in the regions
- to prevent secondary disabilities, every child who is FAS/FAE needs a diagnosis as early as possible, but it is essential for the child to also have a detailed care plan and the family needs to have support – this means a key primary team to make the diagnosis and a secondary team within each community to provide and coordinate the necessary services
- need a support mechanism for doctors regarding diagnosis and intervention so they know where to send people for further support
- need to establish support systems for those affected by FAS/FAE like there are for other health disabilities
- there is an increase in young adults/adults coming forward wanting diagnosis
- lots of kids are assessed in school informally and teachers are trying to catch up on strategies
- it is important to get a formal diagnosis – lots of ways of getting an informal diagnosis – a child gets a label then in a formal diagnosis turns out it isn't FAS and the family is irate
- it's imperative that adolescents and adults receive diagnosis from fully-trained diagnosticians, and that in the case of adoption, records be opened with expedience so that a diagnosis can be made
- need education and training of health professionals (physicians and others)
- need mandatory diagnostic training in medical schools and ongoing professional development once practicing
- for those already practicing in the medical profession, need to offer them a FAS/FAE training program around diagnosis and other medical services for which they can earn professional development credits

(Medical – needs to address cont'd)

- get the doctors who have the expertise with diagnosis to give clinics for family practitioners and pediatricians so they can begin to diagnose – these training sessions should be accredited CME courses that the doctors can use to fulfill their training requirements
- ensure a copy of FAS Tutor Medical Training Software is on site at all medical clinics and at resource libraries in all appropriate government departments – it could be distributed through medical societies
- each province's medical society should make resolutions around FAS/FAE screening during their annual general meetings
- create awareness for doctors via regional medical committees and through clinical practice guidelines – need a doctor to lead/champion the cause
- professionals and caregivers should be familiar with and administer FASCET screening tool
- concern regarding the degree of specialization of professionals – need to see enough children that allow them to specialize and maintain their skills
- there is still a lot of work to be done to convince pediatricians and mental health workers that there is such a diagnosis
- need research aimed at defining a common cognitive profile for assistance in diagnosis and research of cognitive remedial strategies
- there is surprisingly little research that has been done – the rigour has not been met yet
- need helpful research on existing interventions and their effectiveness
- need Canadian experts and research
- need accessible information on where or how to get diagnosis
- need someone to take the lead in data collection of the diagnosis
- sense that there is a fear by professionals and governments that if the numbers were really known, the need will be overwhelming
- diagnosis essential to identify a benchmark for if and when services become available
- concern is getting the parents or individual to the place where they are ready for diagnosis – need family support before, during and after the diagnosis
- we may have oversold the tragedy of FAS – have told people (the world) that it is a hopeless condition – in our efforts to provide prevention, have had little opportunity to show our successes
- early diagnosis can bring hope through early intervention before age 6 – the 'Gift of the Diagnosis' – the earlier the diagnosis, the more hopeful the outcome
- context around giving the diagnosis should be 'how can I help this child to have a better life'
- can be even more complicated providing a diagnosis for a young adult or adult – what supports are there – diagnosis can be helpful when the youth/adult is in trouble with the law
- who tells the mother in a small community – repercussions for that family – the smaller the community, the bigger the denial – it's like pointing a finger at your sister
- once diagnosed, everyone needs to be on board especially parents – not enough collaboration between those involved
- special training needed to be able to work sensitively with families
- services and supports need to be available immediately upon diagnosis for ALL ages
- different medical groups think some other group is looking after the issue
- need long term planning and programming

(Medical – needs to address cont'd)

- mental health issues around FAS/FAE
    - FAS/FAE is one of the leading causes of mental illness
    - victims can be suicidal
    - burnout of caregivers is extremely high
    - implementation of programs dealing with the issue need action not more talk
    - whole families need supports not just individuals
    - local support groups need to be supported by all professional departments
    - caregivers need full disclosure
    - educational programs need to be supported
    - team approach needed to develop plan of action for each individual (with weekly follow-up)
- can't look at FAS/FAE in isolation from other social and economic determinants of health such as poverty, lack of employment, lack of financial stability

PREVENTION & AWARENESS – NEEDS TO ADDRESS

- need a stronger statement from the professional organizations on alcohol use during pregnancy. The Obstetricians and Gynecologists of Canada did not sign the 1996 Joint Statement which states the prudent choice for women is to abstain from alcohol.
- prevalence of FAS/FAE is unknown – FAE is invisible, a hidden disorder
- need to obtain statistics from all populations and inform public of size and scope of this disorder and its expensive impact on education, criminal justice, mental health, etc. – need an awareness campaign on the cost benefits of addressing FAS/FAE – make case that shows money can be saved in the long run because FAS/FAE is 100% preventable
- stigma attached – FAS/FAE should not be a label – it is a medical diagnosis
- rich people are ADD while poor people are FAS/FAE
- society's concept of alcohol consumption – alcohol use is part of a much bigger issue (smoking & alcohol, sex & alcohol, teens, binge drinking, etc.)
- general public needs to be aware that researchers have not been able to find a safe threshold of alcohol in pregnancy and that FAS is a health issue not a moral issue – posters, TV ads and labels will not prevent the women in the grip of alcoholism from drinking, but may dramatically reduce learning disabilities and attention deficit disorders in women who otherwise would have believed that 'moderate' drinking could not hurt their child
- many women don't realize they're pregnant – damage may already be done – education needed far before pregnancy is an issue – need to educate interviewers (doctors/obstetricians/public health nurses)
- society in general does not believe FAS/FAE is a high priority – need more public education
- message is not getting across, like MADD (Mothers Against Drunk Driving)
- should apply portions of revenue from sales of liquor stores to prevention and intervention
- should be more responsibility/commitment from the breweries for media and public education
- push for a "no alcohol when expecting" type messages on liquor cartons, bottles, etc. (much like Tobacco Strategy) – type of warning label
- develop mass media campaign designed by social marketers similar to MADD's (Don't Drink and Drive) campaign, Participaction, etc.
- all members of society should be target group – need to target men as well as women to increase general knowledge and support – prevalent in all areas not just low income – societal issue
- need to emphasize everyone has a part to play in supporting the choice not to drink
- need to bring it to a discussion point – no longer a taboo subject – need de-sensitization of FAS/FAE
- use positive messaging – research saying that really negative messaging is not effective – should include healthy lifestyle choices, not just what *not* to do
- use catchy phrases/name – a universal simple slogan as effective as 'Don't Drink & Drive'
- use personal stories and testimonials
- need a clear consistent message regarding no alcohol in pregnancy and if planning a pregnancy – inconsistent messages coming from physicians and communities that there is a safe drinking level in pregnancy
- need more public awareness of the *lifelong* effects and adults' issues
- need culturally sensitive materials and approaches
- need plain language resources

(Prevention & Awareness – needs to address cont'd)

- need French language materials or French language versions of existing English materials especially in prevention and education/awareness (e.g. videos, handbooks, posters)
- use various media sources – e.g. newspaper, radio, TV, liquor stores
- use visual message in public places – e.g. bars, bathrooms, malls
- use nationwide 1-800 lifelines for parents, children, professionals
- advertise FAS/FAE issues in home pregnancy tests
- use medical society and other professional societies, doctor's offices
- implement FAS/FAE education/awareness in prenatal classes to get more young women aware – public health could put it in their prenatal classes
- identify a National FAS Day during addiction week
- network with all determinants of health and other issues such as nutrition, smoking, etc. to come to a multi-message such as a pregnancy message for healthy babies
- should expand awareness of FAS to all drugs (prescription and illegal) beyond alcohol
- need to determine effectiveness of advertising
- need different strategies for different populations
- need to present information on FAS at an earlier age in a meaningful way
- need to promote awareness among teenagers through:
    - peer education
    - a catchy, simple, visual message
    - reality of raising a child
    - use of 'Baby Think It Over' or 'crack baby' in the schools
    - Boys and Girls Clubs, YMCA
    - adding drugs to the message
    - a focus group with youth to find out how to get the message out
    - creating an FAS/FAE game or add FAS/FAE cards to other games such as Trivial Pursuit
    - putting posters in malls, health fairs, hairdressers, bulletin boards in churches, fridge magnets, advertising in teen magazines or soliciting feature articles on FAS/FAE, advertising on TV programs such as Spilled Milk and Jonovision and channels such as Much Music and YTV
    - having a celebrity talk to youth
    - developing a play that would go from school to school to educate youth
    - encouraging TADD or SADD may take this on as part of their work
- need to set up a committee, regional or provincial, and make sure youth are represented – get on the agenda of youth conference – search out groups who might assist – involve youth in developing resources and educational pieces
- increase knowledge level of society through public awareness campaigns and role model programs – increase knowledge of health professionals through professional development and within post-secondary curriculums
- business community needs to have a better understanding of FAS/FAE

(Prevention & Awareness – needs to address cont'd)

- may need to put less focus on public awareness until there are appropriate support services to families and individuals – education and awareness not helpful if supports are not available in the community to respond to initiatives
- prevention should involve more than woman/mom – include boyfriend, family, etc.
- need best practices on prevention/awareness – models provided and shared among communities – 'How to do prevention in our community'
- need a widespread commitment to rural and remote communities to do public education in their communities using their own community representatives
- need to fund local NGO-FAS groups who teach professionals and run community awareness programs
- need to work towards a practical community-based model of intervention and prevention
- staff cutbacks in the health system and education have greatly affected their role with regards to FAS/FAE prevention
- there is a role in the diagnostic and assessment process for birth moms and people affected by FAS/FAE to help communities understand

CHILDREN BIRTH TO 6 – NEEDS TO ADDRESS

- children falling through cracks because they're not fitting into the medical criteria for diagnosis
- children labelled as ADDH and learning disabled without considering FAS/FAE
- no access to diagnosis or programs or long waiting lists
- even without formal diagnosis, can provide intervention because strategies that work for FAS affected children don't harm non-affected children
- how to approach a parent to discuss or suggest that his or her child has FAS/FAE – a very emotional, personal and serious issue – FAS can be one result of a number of difficult or problematic social and health issues that an individual is facing which also have to be dealt with
- perinatal screening – question drinking and drug pattern before, during and after pregnancy
- one obstacle to screening is the minimization of consumption by women (denial)
- need sensitivity to issues about shame, grief, etc. – safety following disclosure of drinking
- every child taken into care must be adequately screened and maternal drinking carefully noted, even in those children who seem physically and mentally normal – learning behaviour problems often do not become obvious until children go to school
- should be permanency planning for children as soon as they are identified to provide stability in early years – most FAS/FAE kids are bounced from foster home to foster home
- need family (birth, adoptive, foster) support prior to and following identification/diagnosis
- multi-disciplinary team-based management approach – need a global approach which takes into account all the child's deficit areas
- information needs to be proactive/constructive (NOT victim blaming) and accompanied by a menu of solutions or avenues for action
- need to individualize care plans for FAS/FAE children as each child is affected differently
- need accessible and available services – networking and coordination of services province-wide, i.e. awareness of new programs, opportunities to refer clients
- need service coordination and cross communication – preschool to school environments
- children are placed in early childhood programs with no supports put in place
- need different training for early childhood educators and early intervention specialists – i.e. other than behaviour modification – need to have different tools available to work with children
- effect of child with FAS/FAE on other children within a family and in the school system
- overuse and misuse of Ritalin with no other supports – need to identify other alternatives to deal with FAS/FAE
- targeted FAS/FAE programs need to be normalized into general/universal programs with services for all children – universality of programs would lead to de-stigmatization
- need to expand Aboriginal Head Start programs and invest dollars into existing programs that are working with high-risk children and their families
- lack of respite services – funding not available for FAE children who do not have an intellectual disability ('normal' IQ)

CHILDREN 6 TO 18 – NEEDS TO ADDRESS

- choices seem to end at age 6 as if FAS/FAE issues end at 6 years old
- transition funding needed – don't cut it off at 18 – provide services to young adults who are leaving school and entering adult services – bridge the gap
- need advocates for young adults
- strong need for support for adolescents/young adults affected by FAS/FAE – very few can make it on their own
- need understandable educational materials for youth/adults about FAS/FAE to break the cycle
- employment issues – need supports and services for those approaching adulthood including lifeskills training and pre-employment skills – intensive intervention required
- need assisted independent living and long term support
- unable to finish school without extra care
- lack of flexibility and awareness/knowledge in educational system
- need to modify teaching to enhance the gifts and skills of children/youth with FAS/FAE
- need school/community-based support so children and young people can participate fully in activities that exclude them without such support and intervention
- needs – drop-in facility; structured, funded supports outside school time; and acknowledgement that what is needed is 24 hour/7 days a week lifelong commitment and real dollars
- should be recognized that FAS/FAE children/young adults can function with strong supports
- need to stop the cycle – undiagnosed children affected by FAS children having affected children – young women with FAS/FAE are at high risk of becoming pregnant before age 16, and giving birth to several damaged children before the age of 21
- diagnosis for age 16 and older is almost non-existent – high percentage are adopted therefore there is no background/history – lack maternal drinking history – doctors reluctant to confirm diagnosis without it
- community and individual resistance to possibility of FAS/FAE
- concern – teen pregnancy rates and binge drinking in teens
- should be concrete and factual material to children and youth of the damages caused by drug and alcohol consumption
- need youth health centres attached to or associated with the schools to promote awareness of FAS/FAE among teenagers
- should have youth teaching youth – peer education – could pay youth to be leaders or provide other perks (e.g. entertainment)

FAMILY – NEEDS TO ADDRESS

- loss of hope for parents when they hear brain damage in diagnosis/assessment process
- some research indicates that more than half of children with FAS/FAE will be raised by families other than their birth parents – all families raising these children are in serious need of support, from early childhood to adulthood as FAS/FAE is lifelong – the tragedy of FAS/FAE has broken the hearts and bank accounts of adoptive parents across this country, who have poured their retirement savings into psychologists, special schools, tutors, and in many cases, lawyers
- without adequate supports, families collapse under the strain of raising FAS affected children and the affected individuals themselves are left to flounder and end up with considerable difficulties – respite services are desperately needed for *all* families caring for FAS affected children – spouses of individuals with FAS also need support
- need adequate funding for quality respite with qualified respite workers
- adoptive parents must be informed about the possibility of FAS/FAE, and resources must be in place to assist them, if learning disabilities and behaviour indicate the need for diagnosis and family support down the road – red tape must be eliminated in obtaining birth family information if required for FAS/FAE diagnosis
- need to change the attitude towards professional caregivers as caring, confident, professional *parents*
- parents not considered 'professional' yet they are the experts – hard to get recognition of parents as experts in this field where medicine and public health are gate-keepers – adoptive and foster parents are good advocates
- concern that families and children at-risk or already affected are being identified at a rate far outpacing the parallel process of systems' overhaul/integration – the service system as such cannot respond in a timely, effective or user-friendly/responsive manner, thereby further burdening individual families
- need well trained coordinator to advocate between families and government
- need open lines of communication between parents/caregivers and professionals (parents really are the frontline workers)
- exhausting for parent to have multiple roles – parent, advocate, supporter of others
- needs support groups for caregivers of individuals with FAS/FAE and support for the guilt and hurt when parents realize drinking has affected their child
- challenges of parent/family support groups – parents are in crisis and burdened by overextension and the volume of need – experiencing burnout
- support groups are very difficult to maintain in smaller communities
- families are not referred until in crisis
- parents/caregivers need circle of support including family resource programs, family support workers and respite workers
- parenting techniques are different for children affected by FAS/FAE – parenting skills needed, especially for parents who have FAS – need to develop parenting programs
- family support services needed:
    - birth to 6 – diagnosis, respite, child development, daycare, therapy
    - ages 6-12 – school, respite, recreation, family support, therapy
    - ages 12-18 – transitional services, school; adulthood - housing, employment
- need universal programs not targeted ones
- parents/siblings/caregivers all need counselling to understand

(Family – needs to address cont'd)

- employment issues for parents – when parents cannot find qualified child care for their children affected by FAS/FAE (day care environment has too high activity), many parents quit their jobs and end up on social assistance (or go from two incomes to one income)
- parents in poverty can't advocate for themselves
- individuals affected by FAS/FAE have varying levels of cognitive and intellectual ability – system unable to accommodate the differences – lifelong continuum of supports needed with adjustments to changing issues made along the way
- lots of unidentified children/adults in the system – families reluctant to disclose drinking – biological parents fear losing their children if they admit to drinking during their pregnancy – need support group around diagnosis
- need personal, family and community healing programs
- barrier – children have to go into care for mom to receive treatment – need supported access to complete family healing programs and family rehabilitation facilities for pregnant substance abusers and their families (inpatient and outpatient)
- sometimes have to return to very negative non-supportive communities – need family treatment with transition support back into community
- schools, daycares and justice system are often the driving force for dollars – important that families be respected and approached in decision making and planning
- need models for family support programs and building healthy communities
- need to develop best practices for families and children from birth to adulthood
- parents/caregivers need to know what various organizations can offer (resource manual) – also need access to a resource library
- foster/adoptive/biological parents need training, advocacy and empowerment
- there is a stigma in communities around accessing services because it might imply there's something wrong with their child
- issue of reintegration of affected children with birth families

ADULT SERVICES – NEEDS TO ADDRESS

- housing – existing resources do not reflect the spectrum of residential support needs for adults with FAS/FAE
- need research into service needs for adults with FAS/FAE
- can't 'force' adults with FAS/FAE to accept the services they need
- informal diagnoses happens all the time in projects for adults – need to structure support strategies with that in mind
- there is a lack of diagnosis and misdiagnosis of adults
- need to identify the best way to approach the subject of diagnosis with an adult – how to talk to them about it or get them to pursue a diagnosis – may not be at all receptive – is a sensitive issue and could impact on their relationship with service provider, with family members, etc.
- more adults are realizing they may have some degree of FAE – the resources to explore this are too minimal
- if an individual does not receive a diagnosis of FAS/FAE then what assistance, treatment or intervention is available? – services that are available are inconsistent and often not FAS/FAE specific – some question the point of getting a diagnosis if there is no help available
- drug and alcohol rehabilitation – Ann Streissguth's Secondary Disabilities study indicates that between the ages of 21 and 51, close to 50% of people with FAS/FAE will have alcohol or drug problems – many are veterans of several rehab programs and their repeated crimes are often caused by their need to feed a drug habit – current 12-step programs rarely work for people with FAS/FAE as they have little insight and cannot understand abstractions such as 'a higher power' – research needs to be done in finding a more effective approach to helping the addicted person with FAS/FAE, who often "self-medicates" in order to feel normal
- job training - Ann Streissguth's study indicates that most individuals with FAS/FAE will not be able to hold regular employment – it might be possible for many of these people to work part-time (a three-hour day, for example) in a highly-structured, well-supervised hands-on job, with an employer who understands their disabilities
- homelessness/under-housing – a significant number of the hardcore homeless struggle with undiagnosed FAS/FAE – homelessness is the end result of lack of education, trouble with the law, addiction, and unemployment – fresh thinking in creating *permanent* housing is required and some interesting ideas have been documented in the Golden Report – the federal government must get back into the business of assisting with the development of low-cost housing
- disability support – different criteria needs to be used to judge whether an individual requires disability support – individuals with FAE may have seemingly normal IQs but be incapable of holding jobs or managing money – they deserve disability benefits and most also require a trustee to ensure that bills are paid and money is used wisely
- need for a safe environment to try and learn
- need steering committee to provide focus, sharing and proposals for adult services
- lack of appropriate funding models for services
- dealing with pregnant moms who are themselves FAS
- need more tolerance for our fellow human beings through a better understanding of them

ABORIGINAL ISSUES – NEEDS TO ADDRESS

- there is a lack of cultural activities/addressing cultural differences – First Nations' ways are not valued or used in interventions – mainstream society uses their interventions and values rather than building on First Nations values
- FAS is probably an end result of residential schools
- issues – community sadness and despair, residential school syndrome, family violence, powerlessness of women and children, family issues and breakdown
- historical influences in Aboriginal communities with residential schools and removal from communities of people with disabilities; no services on reserves and losing eligibility for funding if leave the reserve
- 2-3 generations affected in some communities – affected moms having kids
- not just a problem in the Aboriginal community or northern communities
- tendency to see white people as ADHD and Aboriginal as FAS/FAE
- reason FAS diagnoses are so high for Aboriginals is because of the cultural facial features
- teachers diagnose Aboriginal kids and write them off
- function of racism – one characteristic paints all of the group
- because of colonization and oppression, diagnosis cannot happen until the family and community are ready for it
- must do something – regardless of the issues of colonization and racism
- diagnosis is irrelevant without access to services and recognition of the benefits of diagnosis
- need jurisdictional barriers broken down for on and off reserve support services – e.g. organizations in Thompson, MB provide services for Aboriginal peoples living in the area, but those on the reserve are not eligible because they are federal rather than provincial responsibility
- access to special need education dollars is not the same for on and off reserve
- it is very important to work with the Aboriginal population both on and off reserve
- need Aboriginal advocates
- Elders are badly needed to speak about this issue
- should be language/cultural sensitivity
- need to define Aboriginal peoples, i.e. Metis, First Nation, Inuit, status, non-status
- for the Aboriginal people, need to bring together people from other parts of the community and find out what works for them – could be done in the form of a National Aboriginal Conference
- one of the barriers for First Nations is to be out of their environment – need to feel safe to openly talk about issues and heal in safety
- at First Nations level there is no coordinated effort between the service programs – disjointed services with no continuity – need long term initiatives
- not all reserves can find the money to send representatives for training – core funding would allow one person to be trained who can then train and educate people within the community
- all training needs to capture cultural competency for non-Aboriginal service providers
- Aboriginal people should be trained to work with Aboriginal people – implementing cultural strength based curricula – train professional and para-professional Aboriginals
- having First Nations staff does not always help – often they are required to embrace non-First Nations approaches in order to be hired or to fit in

(Aboriginal Issues – needs to address cont'd)

- funders must understand the critical need to be holistic – end up having to make Aboriginal programs fit funding requirements, but not meeting the community's needs – funders need to respect Aboriginal philosophies
- cultural issues are different – assessment tools don't take into account cultural and philosophic differences – cultural sensitivity is necessary
- Aboriginal perspectives, values and medicine wheel need to be taught to all to enable better understanding
- treatment is based on a medical model not a First Nations model – need to investigate appropriate models of intervention and treatment for individual communities
- more prevention initiatives must be done in First Nations
- issue – continuity for Head Start kids when they enter the school system
- need flexible models of application, i.e. for natives/non-natives
- need to break down barrier between mandated services and families – respect the abilities of the families and grassroots services
- should let Aboriginal communities design, develop and deliver their own programs
- one-on-one counselling is needed for the person who drank and for those who do not realize they are affected
- issue – transient moms/parents
- concern in First Nations Communities about the lack of recognition of the underlying issues that contribute to the high affliction rate in FN communities, both on and off reserve, and the fact that FN governments are not provided with anything more than minimal resources to begin addressing these issues
- existing resources tend to flow through a 'medical model' of service delivery that is diametrically opposed to FN values and beliefs – the greatest concern is that this model is based on a medical diagnosis, followed by medical treatment that generally forces drug therapy (primarily Ritalin) on the child – First Nations Elders support traditional family based approaches to prevention and intervention rather than the currently funded medical model
- in spite of the high affliction rate of First Nations children, funding criteria is established by non-First Nations organizations that control the resources specifically designated for FAS/FAE
- First Nations governments are searching for recognition and support for a FN traditionally-based approach to prevention and intervention that is based on FN values and beliefs, as well as the need to break the multi-generational cycle of abuse that is currently responsible for the high affliction rate in FN communities – this is the way to build healthy First Nations and must be part of a healing process that will allow FN to recover from the oppressive historic and contemporary policies that continue to disempower First Nations, resulting in the hopelessness and frustration that ultimately leads to successive generations of FN children who are afflicted by FAS/FAE and unable to succeed in education or in life
- other organizations have a tendency to 'invite' First Nations governments to participate in 'consultations' – however, even where First Nations clientele make up 50-90% of the service delivery, the other organizations tend to maintain control of the resources, once the consultations have been completed – generally, this practice is not effective in address in the impact on FN children, families and communities

WOMEN'S ISSUES – NEEDS TO ADDRESS

- moms are still losing their babies and replacing them – need more intervention and help for women with alcohol problems
- status of women in society – poverty, lack of power, access to resources, discrimination
- lack of protective services for pregnant women abusing substances
- need to involve women's partners
- issues of denial / guilt / low self-esteem / shame (depression)
- due to stigma attached, women are less likely to seek help
- single parenthood
- prostitution
- lack of respect and knowledge of cultural issues facing women
- lack of identity (loneliness, need to love someone)
- teen pregnancies – peer pressure and apathy
- poor support networks (partners, families)
- geographic isolation
- need to focus on the overall well being of women by increasing their self-esteem so they may become open to dealing with the FAS issue – improve access to counselling, programs, safe houses (crisis centres), women's health centers
- onus still on women regarding pregnancy and alcohol
- issues around women with addictions:
    - need to know what supports are in place for the woman and what stage of recovery she is at and if she is ready for this information
    - need to provide information/training around addictions issues for support people working with families affected by FAS/FAE (i.e. range of responses when asked from total denial to need to know everything now)
    - need to have resource person available for individual support for women who disclose
    - in recovery programs – put up posters, make pamphlets & fact sheets available, reference sources with detailed information – all staff need to be well informed to pass this information along
- need to remove obstacles that sometimes prohibit women from getting good treatment – systemic barriers to women getting treatment, i.e. care for their children/loss of children, loss of home
- shouldn't force a woman into a treatment program when she's pregnant or make her choose between going into an addictions program voluntarily or being with her children – need family treatment centres where moms can have their children with them
- need one-on-one support for mothers who are affected and raising children with FAS/FAE – need to understand how parenting skills are being affected by FAS/FAE
- some moms 'appear' FAS/FAE but aren't diagnosed therefore receive no assistance or support
- need grassroots movement to grow – need more mentoring and peer support models
- more education needed on addictions and how to make change in our lives – positive rather than judgmental – need to support women in healthier lifestyles
- need group homes for FAS/FAE affected moms where they can have support – life-long support to raise a family
- need to listen to the women and the people who are working with them

(Women's Issues – needs to address cont'd)

- nonjudgmental approach – understanding and acceptance of substance abusing-pregnant women important
- issue of how relationships affect success or no success
- need a mechanism for providing a voice for women who continue to drink alcohol in their pregnancies
- FAS/FAE is not an issue of just a mother who drinks – there are issues of why alcohol is being used to ease pain of abuse or poverty – need to acknowledge how racism, poverty, sexual abuse, family violence are linked to women's addictions
- priority should be on reduction of shame or blame factors
- language – non-labelling is important – less threatening and less judgmental language
- targeting of services to specific populations runs the risk of fragmentation

TRAINING – NEEDS TO ADDRESS

- need to train community level workers to provide support and education for families (birth, adoptive, foster) to enable best parenting
- training needed for virtually every professional an affected individual will encounter during his or her difficult lifetime, e.g. doctors, social workers, teachers, psychologists, day care workers, psychiatrists, lawyers, judges, addictions workers, youth workers, corrections staff, etc.
- need to train the trainers in all professions
- sensitivity training – train professionals to understand and not label – need to learn attitudes of care, compassion, concern – non-judgmental attitudes
- courses in FAS need to be on university curricula in various faculties including law, medicine, nursing, education, social work, etc. and be mandated by professional associations
- need to get FAS message out and into professionals' *own* training programs
- need to train people who work in addictions about FAS/FAE and how to deal with issues around disclosure, coping with the knowledge that you may have harmed your baby
- need parenting skills training for families and caregivers
- need respite training and need to find the right people to do respite
- need more training for working with adults – vacuum of materials in this area
- training for child welfare system needed in dealing with foster and adoptive parents
- need training for young mothers or teens on how to live a healthy lifestyle
- training for professionals outside urban centres (rural, remote, northern areas)
- need to train appropriate people from their own communities
- training would help FAS be seen as a health problem as opposed to a social problem

EDUCATION – NEEDS TO ADDRESS

- lack of financial support in the educational system – insufficient and untrained educational assistants in the classroom results in enormous burnout
- no resources available in some regions – kids in back of classroom in corner with headphones on
- need funding for teachers who specialize in FAS/FAE
- children need to be diagnosed prior to school to enable early support in school
- big gaps in supports within education – not consistent between school divisions
- lack of planning in the educational system for what an FAS/FAE child *can* do
- FAS/FAE should be a mandatory course for students in the faculty of Education
- need mandatory inservicing for teachers
- outdated materials for schools
- need practical useful resources, ready to use information for the classroom available for all teachers
- need to know what works and what doesn't for effective strategies for teaching students with FAS/FAE and effective training for teachers
- need development of classroom curriculum specifically for individuals with FAS/FAE – although there are guides for teachers about strategies for behaviour or learning, there are no specific curriculum materials for them to use
- lots of tools are being used that don't include FAS – seems barbaric and unfair – behaviours are different and treatment needs to be different
- FAS/FAE should be part of core curriculum in health and family life/family living programs
- there is no funding under the behavioural disorder category in the Ministry of Education – it is not recognized as a disability but the behaviour can be – IQ discrimination
- need someone within education departments to coordinate a network on information services and supports – ongoing contact for teachers with FAS/FAE resource people
- every student teacher should have to do a placement in a special needs classroom
- administrators and people at the school board level need in-servicing on FAS
- need community liaison person between school and home
- teachers need to be made aware of each affected child's problems and needs – individualized programming and specialized classrooms
- confidentiality issues sometimes prevents sharing of information
- need more sharing between teachers regarding new methods/ideas
- need more support for parents within the school setting
- need team approach to managing child's needs with every member being an equal partner including parents and child – shift from "you can't" to "we can"
- need to develop a working group within the Departments of Education to develop and implement programs and encourage input from other departments
- need to teach the teachers / teach differently – children with FAS/FAE learn differently and must be taught differently – as school subjects become more and more abstract in higher grades, learning becomes increasingly difficult – Ann Streissguth's Secondary Disabilities study indicates that the majority of these children will experience school drop-out, drug experimentation, and juvenile delinquency – creating classrooms geared to their special needs and abilities could dramatically reduce these secondary disabilities

(Education – needs to address cont'd)

- shouldn't have to wait for the students to become so frustrated and start acting out – shouldn't be lumped in with level funding
- education not a single system – connects everything else in the community
- prevention programs for at-risk women of all ages should be part of sex education in schools
- cutbacks in education mean some children are not in school (lack of special education) – zero tolerance will mean expulsions
- maybe need separate education system as suggested by Susan Doctor, i.e. not focussed on Grade 1,2,3,etc. – kids get disappointed when they don't move ahead – need different environment and approach – need to enter their world

JUSTICE – NEEDS TO ADDRESS

- great number of incarcerated individuals with FAS/FAE – justice issues with young offenders have become very high profile – publicity regarding high profile cases involving FAS
- need to re-think the legal system – it's possible that as much as $5 billion is spend on individuals with FAS/FAE, who do not understand why they have committed their crimes, do not learn from experience, and will repeat as soon as they are released – we need to look at other ways of protecting society and the offenders themselves
- the traditional path does not always work with these individuals – since it's known that persons affected by FAS/FAE do not understand consequences or feel remorse, perhaps an alternative to incarceration is needed
- every offender, juvenile or adult, should be screened for FAS/FAE and this should be taken into account in sentencing – need more awareness in the judicial system and more constructive sentencing – lack of alternative justice methods, i.e. life skills/community services vs. incarceration – restorative justice measures are not set up appropriately for FAS individuals
- need supervised living for adults before and after being in prison
- system needs to find positive talents in the inmates and build on them
- there are not enough programs specific for individual needs
- perhaps many with FAS have been victimized by the justice system because they are less apt to defend themselves – they are most likely to tell someone what they want to hear, making their statement inaccurate to the police – the justice system appears to use FAS/FAE people as scapegoats meaning if an individual with FAS admits to the crime, officers are less likely to go after anyone else
- there are not enough people advocating on behalf of those involved in the justice system
- need more education for lawyers, probation officers, and correctional staff, etc.
- need to appropriately train judges and counsel on FAS/FAE – even training defence counsel on FAS/FAE would be beneficial in order to ensure that their clients are represented to the best of their ability
- intervention should begin with the courts not correctional officers
- questions to address – is FAS a defence for the accused? Who is liable if a person with FAS/FAE does not do their community service or repeats crimes? What do we do with the information of diagnosis once it is received – where is it pertinent to share?
- multi-systems approach needs to be implemented, similar to those developed for addressing gangs
- should hire dedicated FAS facilitators in corrections to coordinate staff training and deal with justice issues
- need a focused, ongoing discussion surrounding needs and systemic responses to FAS adults in conflict, involving community agencies, family services, justice, mental health, advocates
- need interagency dialogue and cooperation – court, police, schools, social services – deal with same families, but seldom collaborate
- need a diversion program for FAS/FAE individuals in conflict with the law so they are not incarcerated
- need to develop programs for treatment in and out of custody
- FAS behaviours need different treatment/programs in corrections
- Aboriginal community requires resources to design programs appropriate to their needs (restorative justice, ADR, diversion programs, etc.)

(Justice – needs to address cont'd)

- issue – the bright lights and noise of penal institutions are exactly the wrong kind of environment for the sensitive eyes and ears of the individual with FAS/FAE and do nothing to help him or her
- judge ordered assessments – programming as a result of justice orders – more requests from courts wanting a "diagnosis"
- need to set up ways for affected individuals in the justice system to go back to their community with the proper support system in place to avoid repeat offences
- new issue – educating incarcerated women about FAS
- issue – overcrowding of youth detention centres
- need to do FAS diagnosis in all provincial young offender facilities and foster care so we have a better idea of how many youth and children are FAS
- support and services for affected youth into adulthood needs to become accepted practice, instead of these youth being expected to live independently with no support – this situation leads to youth entering the criminal justice system and/or continuing to be in custody / jail where they are constantly supervised – not the purpose of custody or jails (i.e. safe placements)
- what some find successful is returning to traditional lifestyles – Justice system should consider this in programming – seems to be something that works
- concern regarding use of an FAS diagnosis as a way of obtaining child custody – either the father or the mother has been diagnosed with FAS and the spouse wants to present evidence in a court of law showing that the FAS parent is unable to provide proper care

COMMUNITY CAPACITY BUILDING – NEEDS TO ADDRESS

- unless the issue of FAS/FAE is directly addressed according to the needs of communities and a 'point person' is committed to work diligently, the problems around FAS will not go away
- collective effort from groups and community services needed to put necessary supports in place
- services need to be community specific
- need community based support – it is important for programs to be community based and work from a bottom-up approach rather than a top-down approach
- sustainability to keep programs going is a big issue
- community-based programs are effective – need to be funded on an ongoing basis and they need to be recognized as credible by the more traditional government-based organizations within the community
- there is a very large lack of respect by the older recognized organizations (Health Districts, Department of Social Services, school divisions, etc.) in recognizing smaller community organizations and giving up control on things they customarily had control over, especially to a First Nation or Metis organization
- it is important to take advantage of and build on the organizations and structures in place
- statistics are important to receive funding – need more information on how to collect stats
- need to have programs in place at community level for youth/adults with FAS/FAE
- need education in communities on how to better support persons with FAS
- community-based programs that work with prevention and education in the school system should continue to be supported, but need to address programs that focus on development of the family, on issues of poverty, on affordable housing co-op programs, on creating wrap-around services for individuals
- a lot of resource materials are in place but communities need funding to access these materials
- need educated community members who will stay in the community and be advocates for FAS/FAE education and support for families
- frontline service providers in communities need to be at the policy and decision-making table
- there are always many other initiatives being targeted within organizations making it very difficult to have another initiative like FAS/FAE targeted – overworked, wearing too many hats, lack of funds are all factors why it doesn't get addressed
- initiatives such as CAPC, CPNP, Aboriginal Head Start, which are delivering direct services, could easily implement FAS components as they are already working with high risk individuals and families – funding would be needed for training, resources, staff, etc.
- education, training and development of programs/resources needed in north and rural areas
- larger groups/communities could mentor smaller groups/communities to reduce isolation
- support systems in the north are scarce – northern communities require specific attention and funding to improve the lives of its citizens – with low employment and little support, problems such as FAS will continue to be an issue – on reserve funding is a must to address the underlying issues of poverty, violence and abuse
- federal/provincial/municipal/Aboriginal forums are necessary to develop the programs that will meet the needs of communities
- decision making must be at the community level – programs that develop leadership within the community should be one of the first steps
- federal, provincial and community-based programs need to be more aware of each other and cooperative in services offered

- community programs are undercut almost before they get started or they are underfunded so they cannot run effectively – there is too much red tape tied to funding – need long term permanent financing – enough with the project based funding
- governments need to recognize community-based organizations and know what they are doing – there is no need for another level of bureaucracy – provide the funding and let community groups get to work – it is hard to get the job done when they constantly have to stop and advocate, write grant proposals and adjust to meet project timelines
- Health Canada should provide a broad policy in which communities can fill in the blanks
- need a framework that builds on what is already in communities
- community development – need to include information about FAS/FAE as well as projects that increase the level of independence that men, women and children feel in their community – alcohol addiction and FAS are often a symptom of an individual's sense of loss, anger and/or grief – a healthy community approach would target support to increasing self-esteem thus reducing the reliance on alcohol and/or drug use

POLICY / COORDINATION / COLLABORATION – NEEDS TO ADDRESS

- question of whose mandate is it – a lead role needs to be assigned
- there should be increased federal/provincial/territorial/community partnerships showing clear leadership on FAS/FAE
- federal government needs to take a real leadership role and back it up with real dollars
- need to eliminate barriers between government departments, e.g. Education, Justice, Family Services, etc.
- collaboration – each agency runs differently – need to learn from each other – develop understanding of different mandates, ways to work, etc.
- barriers to effective partnerships:
    - not many models of good partnerships available
    - territoriality
    - partnerships need to be supported and nurtured through coordinators (Alaska & Alberta – both created model of regional coordination)
    - coordinators need continuing funding to sustain community development model
    - allocation of dollars creates competition and not collaboration
    - dialogue and relationship building takes a long, long time
- partnering with Health Canada:
    - inadequate/lack of partnering initiatives from Health Canada
    - Health Canada dictatorial
    - consultation process is top down (inadequate) and is ineffective
    - more effective partnering among frontline organizations than with Health Canada
    - pre-commitment of funds before consultation process
    - tendency by government departments to over-process issues and not take enough direct action or provide resources for frontline workers to take action
- current absence of collaborative community-wide strategic planning
- funding is essential for effective coordination
- should use existing networks as much as possible
- governments need to improve partnerships/relationships with communities and between different levels of government
- there is a lack of communication between people and organizations and system
- need to cultivate the political will in all provinces/regions to provide the focus and the funding necessary to really deal with FAS/FAE
- Prairie Ministers are fired up about FAS/FAE through the Prairie Northern initiative – could be influential with ministers in other regions
- need to share FAS/FAE materials and resources
- need a network of professional people and agencies or associations including teachers, doctors, psychologists, nurses, lawyers, front line workers, social workers, etc. to address FAS/FAE – all sectors need to be involved
- need dedicated core funding for coordination on a regional and also community level

- links need to be made and contacts established within the provinces – important to identify people who will take the lead in each province – need FAS Coordinators who are accountable for moving FAS issues ahead
- should have a national FAS/FAE committee in place with a representative from each province to sit on the committee
- need to establish a resource library and make it available on the Internet so it is accessible to those in isolated communities – need an FAS/FAE newsletter to create a collective rather than individuals working in isolation – also need a list of resource people
- resources need to be available throughout each province and information shared on where they are and how to access them through the transitions of life
- need to develop a national FAS/FAE directory of all services – central registry to track information
- there are very different levels of awareness of government people – need to create awareness in other departments – first step in involvement
- need to get high level government workers on board to ensure government commitment even if ministers change
- need better coordination and collaboration of the various services offered – development of a lifelong continuum of services
- should be a direct service agency developed for individuals with FAS/FAE
- need to get government services going to the people and their neighbourhoods in a proactive way rather than waiting for people to come to them with their problems (i.e. reactive services)
- grassroots groups are key
- federal government needs to work closely with provincial governments to avoid duplication, increase communication, pool funding and 'share' the credit instead of competing for it
- provinces definitely need to partner and align – the argument about 'who paid' (feds vs. province) doesn't wash at the community level – it divides and confuses the local population and causes duplication of efforts
- the issues are the same as they were 10 years ago – after all the years parents have coped with the issues and hammered at the "system," the federal government is finally beginning to wake up and listen – fear is that they will try to re-invent the wheel and waste what few resources have been allocated to FAS/FAE issues
- northern areas often feel ignored for feedback or participation in provincial/federal consultations

FUNDING & SUSTAINABILITY – NEEDS TO ADDRESS

- need more money, more staffing for existing agencies and organizations
- need flexibility in funding programs – formal and informal structures
- need sustainable funding for all programs – sustainability is a really hard row to hoe for community groups – what ends up happening within a three year time frame is that they devote their energies and efforts to finding multiple funding sources and developing proposals, each one varying in requirements, for the possibility of future funding – the energy that should be invested into delivering services into communities is divested into developing proposals
- concern – in the past, federal government has given out funding to non-profit groups to develop short term projects – these groups then have to look for sustained funding – frequently those who know best what's happening in the province might not have funded the project in the first place – need that sort of consultation with provinces to spend funding in the best possible way.
- question how serious federal government is in its commitment to address FAS nationally – $11 million over 3 years is a drop in a huge bucket
- Strategic Project Fund:
    - $150,000 over 3 years is not a lot to develop anything of subsistence – at best, would be something very basic – even with the expectation you'll find other funding partners, it's not a lot of money
    - different communities will be at different stages of readiness – some have ideas all ready and letters of intent organized looking for funding – it will be easier for them than have to start thinking of something when the Request for Proposals comes out – those who are not at that stage will need at least two months to prepare a full proposal
- how financially involved are the alcohol manufacturers going to be – would be a natural since they helped create the problem, they should be made to support these efforts – they have a responsibility if not an interest – need to be careful, however, as they have a tendency to try to control the message
- should look to other sources such as foundations for donations and approaches such as directing a portion of revenue from liquor sales towards programs and services for affected individuals
- there should be some kind of ratio towards prevention and what goes towards supporting families and individuals already living with FAS/FAE – it's a lot harder to get funding for projects for intervention in lives of people living with FAS/FAE
- policy coordination requires dollars – won't have a policy coordination role with short term project funding – provinces unlikely to be willing to partner on that basis
- Premiers have repeatedly said the way to affect policy is to transfer dollars
- financial support will be needed for people to participate in a national forum

B. <u>TOP PRIORITIES</u>:

MEDICAL

1) Accessible & universal diagnosis province-wide with appropriate partnerships and support services.
2) Accessible information on where and how to get diagnosis.
3) Evidence-based research in support of resources and funding.
4) Services and supports available immediately upon diagnosis for *all* ages.
5) Diagnostic training, education for doctors – writing 'probably ARBD' to help get intervention.
6) Standardized diagnostic toolkit for physicians/pediatricians.
7) Adolescents and adults must receive diagnosis from fully trained diagnosticians, and that in the case of adoption, records be opened with expedience so that a diagnosis can be made.
8) Standardized screening based on appropriate training and tools within a supportive and nonjudgmental environment.
9) Development of diagnostic teams (e.g. Dr. Sterling Clarren model) and referral teams.
10) Universal terminology, i.e. FAS or ARBD, etc.
11) Consider other models besides a medical model, e.g. look at a First Nations model.
12) Diagnostic centres with multi-supports (in major centres but accessible to smaller centres).
13) Universal approach/methodology.
14) Effectively deal with the fear of labels and handle diagnosis without labelling.
15) More Canadian research funding on all aspects of FAS/FAE, beginning with why women still drink during pregnancy even when they know it will hurt their baby; better diagnostic tools for identification, etc.
16) Holistic approach.
17) Support for mental well-being.

PREVENTION & AWARENESS – PRIORITIES

1) Community awareness team approach – collaboration and partnerships between educators, social workers, justice (probation, police), physicians, general public, youth, parents, nurses, nutritionists, addiction counsellors, child welfare, Elders, mental health workers, etc.
2) Funding for programs, information sessions, workshops and train the trainer sessions.
3) Media – newspaper, radio and TV ads, web sites, handouts at doctor's offices, posters in bars, schools, family life courses, home and school meetings, articles about the seriousness of the issue and success stories in popular magazines, focused coverage on International FAS Day
4) Positive messaging instead of negative – cultural and meaningful messages.
5) A clear, consistent nationwide prevention message directed at entire population.
6) Integrate information somehow into school curriculum, e.g. Grade 9 reproductive science.
7) Resources more appropriate for youth.
8) Research into the grey areas so standard information is presented by all, i.e. one piece of research says don't drink at all and another says you can have a few – allows people to rationalize drinking.
9) Determine what the priority population need or want – what would make a difference to them and how can we use this information to help inform the rest of the population.
10) Labelling – include message and what community resources or services are available and where to find them on liquor bags (e.g. could be a help line number).
11) Legislation – liquor bottles with messages about drinking while pregnant.
12) Increase population awareness about substance use *before* pregnancy – planning pregnancy, lifestyle choices.
13) More and better educational resources that are widely distributed.
14) Specific community awareness campaign about the fact that 50% of pregnancies are unplanned so this is when there is an increased degree of vulnerability – campaign should not be FAS specific but should also include AIDS, STDS, abuse, nutrition, etc.
15) Public awareness in all communities including rural, urban, First Nations and other Aboriginal communities.
16) 24-hour parent and professional information and support communications on FASlink listserve, web site and archives.
17) Awareness message to deliver to pregnant women, including alcoholic women.
18) Cultural sensitivity/awareness.
19) Consistent intervention/prevention.
20) Effective prevention strategies incorporating best practices in population health approaches
21) Need 1-800 lifelines promoted nationally.
22) Education of corporate world, e.g. so that businesses understand you don't hand out breath freshener samples with 12% alcohol in the movie theatres.
23) Address alcohol and pregnancy as a societal community issue that involves everyone and everyone's lifestyle choices.
24) Ensure that frontline workers know about the resources and that they make the appropriate referrals (no obstacles between sectors).
25) Given limited resources everyone works with, build on what's been done already and look at expanding rather than developing something that is different.

CHILDREN BIRTH TO 6 – PRIORITIES

1) Diagnose children early to give adequate care.
2) Coordination / case management – use multidisciplinary teams to share knowledge. Have coordination between possible services and continuity of services for the family.
3) Supports before and after diagnosis.
4) General awareness throughout the various systems, e.g. physicians, addictions services, etc., that are women/mother friendly
5) Services that fit the child.
6) Accessing diagnosis, waiting lists, specialized, consistent and coordinated services.
7) Service availability – geographic availability, wait lists, eligibility and long term funding stability.
8) Emphasized national childcare agenda.
9) Proactive rather than reactive approach.
10) Support services for everyone (birth to adult).
11) Diagnosing children with the objective of meeting the children's needs (ongoing throughout the early years).
12) Training of doctors and workers to favour screening and preparation of diagnosis.
13) Intervention plans.
14) Training of professionals, e.g. social workers (childhood), teachers, educators, nurses, etc., on ways to intervene to stimulate the development of children with FAS/FAE and avoid the appearance of secondary disabilities.
15) Lack of sufficient funds.
16) Increased access to professional diagnosis and consultation services – diagnosis should provide detailed description of child's strengths and weaknesses to help parents, teachers and community workers.
17) Need early identification screening tool in place – perhaps integrate into current early identification programs.

CHILDREN 6 TO 18 – PRIORITIES

1) Stigmatization of FAS/FAE label.
2) Diagnosis for youth and adults.
3) Documented best practices made available to parents and schools.
4) Improved transitions at both ends – up to 6 and past 18 needs – better continuum of services at all stages of life.
5) Different criteria to determine whether an individual with FAS/FAE is eligible for disability support.
6) Intervention programs for FAS adolescents having FAS children.
7) Gap in culturally appropriate services for youth and adolescents.
8) Housing and assisted living supports.
9) Affected individuals not welcomed into community programs due to behaviour issues and lack of qualified trained staff; creates potential of leading to justice issues later.
10) Education of children on the dangers of alcohol, sex, drugs (curriculum planning) so when they get into the childbearing years they can make appropriate decisions.

FAMILY – PRIORITIES

1) Work with professionals (educational psychologists), Aboriginals, Elders, parents and children to develop a parent education program – in plain language and culturally sensitive – that includes:
   - different approaches for parenting a child with FAS/FAE
   - parenting skills
   - coping skills
   - how children are different and process information differently – interventions used must be adapted to meet these different needs

   Need complementary education piece for professionals (teachers/social workers/clinicians) to assist in the identification and appropriate intervention process.
2) Supports for families designed from their perspective (i.e. child/individual/family centred as opposed to system-centred) as needs are identified.
3) Employment issues around lack of adequate and proper/qualified care for affected children therefore parents are forced onto social assistance.
4) Working towards identification without intervention services to flow them through.
5) Advocating and lobbying for parents.
6) Decreased stigma for families.
7) Support for families and individuals – knowing who to call for help (resource lists) – 'warm line needed – make existing parenting 'hot lines' aware of FAS.
8) Screen every child taken into care and note any maternal drinking.
9) Accessibility of birth family information and the need to inform foster and adoptive parents about the possibility of FAE.
10) Support for families to keep the children in one family.
11) Enhancement of parent-to-parent support networks including FAS parents of FAS children.
12) Improve respite services – broaden the mandate for respite funding.
13) Personal, family, and community healing programs not just singly focussed on addictions.
14) Support for families to keep from relapsing and to stay healthy.
15) Breaking the cycle.
16) Long term supports for parents and families to address their needs to best parent and advocate for kids – recognize their capacities and build supports where necessary.
17) Constant intervention and multidisciplinary support (spiritual, medical and social) for families.

ADULT SERVICES – PRIORITIES

1) Lack of diagnosis and misdiagnoses in adults.
2) Team approach for diagnosis and follow-up.
3) Lack of resources for support, treatment, prevention and after treatment support.
4) Secondary addictions and psychosocial problems.
5) Employment that is highly structured, well supervised and hands-on for adults with FAS/FAE.
6) Permanent, low-cost housing for adults with FAS/FAE (to address homelessness).
7) Lots more adults needing services including parents who have FAS and are raising children.
8) Residential support for adults with FAS/FAE.
9) Research about the residential support needs of adults with FAS and their families.

ABORIGINAL ISSUES – PRIORITIES

1) Real consultation with Aboriginal people rather than in a token way and more than just one voice on a huge board of non-Aboriginal people.
2) Funding – education, networking, treatment/prevention.
3) Holistic approach with culture/language sensitivity.
4) Aboriginal advocates.
5) Intergenerational FAS.
6) Community-based training and capacity building for frontline workers based on cultural competency and proficiency philosophy (values of communities – flexible education).
7) Clearly define Metis, First Nation and Inuit, non-status jurisdictions.
8) Holistic healing of family, community and individual – family centred approach vs. women centred approach.
9) Provision of diagnostic tools – importance of early diagnosis – ability to support.
10) Empowerment of children and youth to achieve healthy lifestyles.
11) Training of the frontline service providers.

WOMEN'S ISSUES – PRIORITIES

1) Lack of emotional wellness.
2) Lack of awareness/education.
3) Lack of a "well-oiled" support network (financial, professional, personal).
4) More intervention and help for women with alcohol problems and help for the woman's partner.
5) Giving a voice to the women who may or may not change.
6) Getting feedback from women regarding what worked and what did not.
7) Getting feedback from frontline people who work with women.
8) Reaching out to the community and making people feel safe.
9) Women's need for autonomy should be accepted and encouraged.
10) Acknowledgement of women's need to belong and to be connected.
11) Core issues need to be addressed, i.e. residential schools, abuse, relapsing, changing behaviours, co-dependency, etc.
12) Women must know we are there to help not to judge – need to look beyond the dysfunction.
13) Not enough dollars to do what needs to be done.
14) Form partnerships to enhance support.
15) Increased awareness within addiction services for both frontline workers and clients.
16) Better communication regarding opportunities to enhance existing projects/programs/supports that support childbearing women who use alcohol.
17) Treatment services with childcare.
18) Supports for women to make healthy choices.
19) Addressing the issue of the drinking mother: why and how can we meet those needs.
20) Needs identification of pregnant women who continue to drink even if they know they are pregnant.

TRAINING – PRIORITIES

1) Continued education and training or accredited professional development for:
   - medical – family doctors, pediatricians, child and adult psychologists, obstetricians, midwives, public health nurses, chiropractors, dentists, speech and occupational therapists, nurse practitioners
   - education – early childhood educators, elementary, primary, special education, mid-school, high school, college, teaching assistants, university level
   - community support – CAPC, Healthy Babies, Better Beginnings Better Futures, Aboriginal Head Start, parental support workers, FAS support groups, Child Welfare
   - mental health – psychologists, social workers, counsellors, adult support workers, outreach workers, youth workers
   - addictions – counsellors, street workers, residential / outpatient treatment
   - justice system – probation officers, lawyers, judges, police, corrections officers, group home workers, half-way homes, juvenile detention centres
2) FAS/FAE workshops for professionals in the community.
3) Inclusion of FAS/FAE research in professional association conferences.
4) Culturally appropriate education and training for communities.
5) Sensitivity training around disclosure issues, e.g. shame, guilt, grief.
6) Diagnostic training for health professionals.
7) Training of professionals around substance abuse and women.
8) Standardized training.
9) How to and best practices.

EDUCATION – PRIORITIES

1) Increase awareness of FAS/FAE in entire educational system – teachers, TA's, schools, divisions – modify and increase the flexibility for how the educational system works.
2) Mandatory inservicing for teachers.
3) Practical and useful information available to all teachers for use in the classroom.
4) Education of students, e.g. make FAS education part of curriculum in Junior High.
5) Set up networks and consultants for FAS within each provincial Education Department for information, services and support.
6) Development of a special curriculum and skills for teaching children with FAS/FAE.
7) Getting children into special education.
8) Creating classrooms geared to the special needs and abilities of children with FAS.
9) Overhaul of the educational system.

JUSTICE – PRIORITIES

1) Incarceration rate of individuals with FAS/FAE.
2) Identification and diagnosis of individuals within the corrections system.
3) Personnel within the Justice System need more training, e.g. medical personnel, correctional officers.
4) Corrections staff should be trained to find the positives in the inmates and try to understand rather than condemn them. The inmates are already incarcerated; while there, they should be treated as individuals and have their problems recognized and start from there.
5) More programs for individuals needs.
6) Elders in the prison systems for First Nations inmates.
7) Detection at the point of arrest – diagnostic screening province-wide for assessment and then develop applicable evidence-based programs.
8) Every offender, juvenile or adult, should be screened for FAS/FAE and this should be taken into account in sentencing.
9) Education and training – at all levels. Key people at key offices for dissemination of information so that workers in the justice system can access the information at their worksite.
10) Number of children in welfare system as a breeding ground for individuals who will end up in the justice system.
11) Aboriginals lose treaty/aboriginal rights when incarcerated (e.g. health insurance benefits).
12) Resources for disability-appropriate treatment in justice system.
13) Management and rehabilitation of FAS/FAE inmates.
14) More interagency collaboration in system, i.e. courts, schools, social services, police.
15) Money for 'aftercare' component for youth coming out of highly structured environments like treatment or custody (or spiral out of control again).
16) Adolescents need services and support (like sex offender treatment) outside of the Probation Order. Non-criminals should also be able to access services.
17) Court process takes too long – people with FAS need immediate consequences.

COMMUNITY CAPACITY BUILDING – PRIORITIES

1) FAS coordinators/leads in every province with the appropriate resources to develop coordinated responses.
2) Sustainability – okay to get programs up and running and build partnerships, but need to have them continue.
3) Funding for education / sustainability / partnerships.
4) Community driven prevention and early intervention.
5) Support for local initiatives.
6) Build capacity for community development – need education in this area.
7) Support from organizations that are more mature.
8) Funding mechanism to develop community capacity to support people with FAS/FAE that is individualized for families in the community.
9) Funding for community-based initiatives to enhance community-based organizations that already have the capacity to support families (e.g. already have Family Resource Centres in Atlantic Canada).

POLICY / COORDINATION / COLLABORATION – PRIORITIES

1) Great need to develop networking/partnership. Need to know there is an authority to regroup the efforts, i.e. a coalition with:
   - expertise on the subject
   - global vision
   - claims to “push the file”
2) Building early intervention partnerships with physicians and hospitals, school boards, social services, youth protection, economic development councils, justice etc.
3) National policy to recognize individuals diagnosed FAS/FAE as disabled.
4) Communication and integration of FAS on provincial and national levels.
5) Integration of FAS into larger systems (health, school, etc.) and into broader health issues in the community.
6) Coordination at all levels – federal, provincial, municipal.
7) Clearinghouse for information and intersectoral communication.
8) Single point of entry to all services and across all systems.
9) Address the root issues instead of reacting to results. C
10) Critical lack in sharing knowledge at national level – not being shared beyond the regions.
11) Integration of FAS/FAE into current provincial and federal information documents.
12) Move FAS/FAE higher up on priority list regarding Health Canada and provincial/territorial ministries of health.
13) Collaborative partnerships between federal, province, municipal governments and local groups and organizations to increase the capacity to respond to FAS/FAE.
14) Registry of help groups throughout each province – not just health groups but any group working in the area of FAS/FAE.
15) Need to know that there will be positive outcomes from these consultations and others across the country – need feedback/communication – “No more spinning our wheels/beating our heads against a brick wall.”
16) Provincial ‘centres of excellence’ to be research leaders in the field of FAS/FAE.

C. ROLE OF HEALTH CANADA:

PREVENTION & AWARENESS

- develop policies, programs and strategies that address awareness and prevention of FAS/FAE in a sustainable national framework
- expand or test the Prairie Northern FAS Initiative communications message in the eastern Canada and Atlantic provinces, i.e. save dollars by using the Prairie Northern and BC messages to create a national message
- appoint a national spokesperson around prevention and awareness, e.g. Aline Chretien – most big campaigns have a spokesperson
- develop a consistent national statement like 'the ideal is no alcohol' – implement this message in a national awareness campaign with appropriate media materials – mass media campaign should be designed by social marketers along the lines of the MADD (Mothers Against Drunk Driving) and Participaction campaigns
- come up with a catchy phrase like that used for 'don't drink & drive'
- develop a broad national public awareness campaign that is long term and have many different levels similar to the drinking and driving campaigns over the past 20 years
- develop a media campaign with strong impact, e.g. on Fox network, at 10 o'clock every night, they say, "It is 10 o'clock now, are your teenagers home?"
- develop a public awareness policy much like the tobacco strategy, i.e. push for 'no alcohol when expecting' messages on liquor cartons, bottles, etc.
- social marketing – include public services announcements, liquor ads, posters, billboards, pamphlets, TV, radio, media at different levels
- use a coordinated approach to develop education/awareness materials that are culturally sensitive, culturally relevant and in plain language
- message should be positive and targeted at everyone not just women (societal issue)
- promote FAS as a community issue not just a health issue
- make public statement that this is an epidemic – sometimes escalating with words helps get people's attention – using the right words important
- conduct awareness campaigns at the population level, individual level and professional level (training) – awareness for population and workers should be done simultaneously
- focus an awareness campaign for teenagers – involve youth in preparing the message and get info out in malls, teen magazines and TV programs, etc.
- inform public and professionals alike of the size and scope of this disorder – its expensive impact on education, criminal justice, mental health
- create public awareness of lifespan issues of FAS/FAE
- acknowledge and validate people with FAS/FAE – recognize that FAS is a permanent issue in Canada
- use TV shows (NFB, CBC) to talk about FAS – healthy attitudes towards people with disabilities, awareness of FAS
- provide more information on the effects of drugs as well as alcohol – broaden the FAS campaign to substance abuse prevention
- work with the Canadian Medical Association to issue a stronger statement on alcohol use during pregnancy and to include FAS into their training, medical schools, conferences, newsletters, etc.

(Prevention & Awareness – Role of Health Canada cont'd)

- facilitate development of youth health centres attached to or associated with the schools to promote awareness of FAS/FAE
- act as a leader in prevention and promotion – develop national clinical practice guidelines for health professionals

POLICY / COORDINATION / COLLABORATION – ROLE OF HEALTH CANADA

- make children and families a national agenda and stop backing away using lack of agreement with provinces as an excuse
- develop national childcare agenda/strategy (i.e. childcare being 'early child development and parenting centres' not just custodial care)
- take a stand on alcohol and pregnancy
- have one body/agency within Health Canada that takes on FAS
- set up an authority group or coalition to provide expertise on the subject, a global vision and mandate to 'push the file'
- Health Canada needs to acknowledge and play a role in affecting the determinants of health
- social policy – racism, poverty, abuse, violence – determine the underlying causes and what are we able to do – "women continue to medicate their problems"
- require other federal and provincial governments to address other root causes, i.e. poverty, literacy, high unemployment, housing, child care, etc.
- broaden scope and acknowledge and act on a holistic approach to health (poverty, housing, child care, etc.)
- develop national prevention policy/guidelines (including women and addictions with priority given to women who are pregnant and struggling with addiction)
- develop national standards on FAS/FAE and approaches that can be adapted to meet the needs of individual communities
- determine and communicate standards and policies
- ensure all professionals use consistent guidelines and standards
- conduct a 5-year review of the impact of the 1996 "Joint Statement" published by Health Canada
- from the start, include members and the target group in the planning, implementation and evaluation of all efforts (e.g. youth, members of specific cultural groups, etc.)
- ensure voices of families and persons with FAS are central to building of vision
- provide strong leadership across the country to ensure desired outcomes are generated – develop and implement a national FAS strategy with provincial participation – take a leadership role in coordinating the different levels of government around FAS/FAE
- partner with and motivate federal and provincial ministries to cooperate in the development and implementation of FAS/FAE services, e.g. Health, Justice, Education, etc.
- encourage, develop and facilitate partnerships with other levels of government and key stakeholders to develop consistent messages and resources
- help provinces put together something that is comprehensive and help them share with other provinces and territories, i.e. develop a nation-wide picture
- help with the political 'provincial will' agenda – prepare a business case on the cost benefits for addressing FAS/FAE – help make case that shows money can be saved in the long run because FAS is 100% preventable – leadership role by Health Canada would assist provinces in putting forward their agendas
- work closely with provincial governments to avoid duplication, increase communication, pool funding and 'share' the credit instead of competing for it
- set up framework agreements where communities can fill in the blanks (Federal Government, Provincial Government, communities and families) – facilitate leadership and provide funding in developing a framework

- facilitate coordination regionally (similar to Prairie Northern FAS Initiative) – create a broadly based coordinating body in each province and link regionally – should include provincial FAS/FAE coordinators, a regional coordinator, professionals, advocates, caregivers and persons affected by FAS/FAE – ensure regional networks have the appropriate resources to develop a coordinated response
- connect/link regional networks once they are set up across the country – coordinate information among partners from Federal and Provincial initiatives
- link organizations with similar mandates and clients
- identify national resources and development of resources – coordinate any production of and sharing of information and data across Canada to reduce duplication – provide policy coordination to avoid duplication of programs and policy development – coordinate services across departments
- encourage the use and adaptation of existing materials so they are not written from scratch, e.g. take Western Canadian materials, add national resources and translate
- support a Northern Region made up of Yukon, NWT and Nunavut for all funding and representation/regional offices (as opposed to Yukon being joined to BC, NWT with Alberta and Nunavut with Ontario)
- increase cooperation, collaboration and capacity building among federally funded projects, i.e. CPNP, CAPC, Aboriginal Head Start
- create a tracking system for children and individuals living with FAS/FAE
- develop best practices and models in all areas
- facilitate the development of and dissemination of best practices in all areas
- model centres of excellence
- organize provincial and national associations for FAS/FAE caregivers
- ensure there are enough competent resources to respond to increased awareness about FAS and that these resources are well known to workers at all levels in all professions
- lobby for stricter regulations on u-brews/micro-breweries, etc. regarding quantity and marketing of products with alcohol focussing on youth

COMMUNICATIONS / INFORMATION – ROLE OF HEALTH CANADA

- coordinate French materials
- stage annual FAS/FAE regional workshops/symposiums
- organize a 'world class' well funded 2-day conference for everyone, i.e. professionals, community members, students, teachers, etc.
- create a resource library that is also available on Internet
- act as a national registry / resource centre / clearinghouse for collection and dissemination of up-to-date (low cost and accessible) information, resources and expertise
- develop a national directory of services and programs (who to contact and where for what) – share information on what is already available - coordinate provincially and nationally
- produce 'catalogues' of information and resources (not just web site) – listing programs done elsewhere so don't have to reinvent it
- provide links to web sites
- facilitate networking through Internet/e-mail or other communications mediums
- create means to keep health and other professionals updated, e.g. develop a nationwide newsletter on different areas, i.e. prevention, intervention, issues in education, who is doing what, events, call for papers, new resources, publications, news, etc.
- assure the continued existence of the online support group and educational FAS web site / resource, FASlink – allows professionals and families to share experiences, resources, information internationally as well as within Canada
- make resources available on CD-ROM – universal design format for each discipline – make access to resources easy
- good web site (www.fas-saf.com) – promote it!
- develop a speakers bureau
- assist with collection and dissemination of research – develop easily accessible and consistent national and provincial research base – make research results available to everyone through web site, national library
- provide better information on the number of individuals affected – regionally, provincially and nationally
- find methods to gather and distribute information about best practices in FAS prevention and intervention

COMMUNITY CAPACITY BUILDING – ROLE OF HEALTH CANADA

- develop partnerships and programming at the community level
- increase human resources in remote northern communities – provide stability
- increase the level of funds for more programs in rural communities to offer services to children/adults affected by FAS/FAE
- support community capacity building

ADULT / YOUTH / FAMILIES – ROLE OF HEALTH CANADA

- develop a steering committee for adult services – interagency, intercommunity, interjurisdictional (Federal, Aboriginal, Provincial, Municipal)
- develop appropriate funding models focused on self-reliance, and inclusion for adults – need to include supported employment, residential support services and lifeskills training
- develop more support programs for adults affected by FAS/FAE
- fund employment programs for highly structured, well-supervised hands-on part-time jobs for adults with FAS/FAE with employers who understand their disabilities
- assist with the development of permanent, low-cost housing for adults with FAS/FAE
- increase access to supported living (don't pull out services after they become adults)
- help develop more people able to provide private home placements for people with FAS/FAE
- make materials available to more community-based workers to facilitate prevention programming for children / youth
- provide additional support for youth – extended programming
- facilitate programs for young women with FAS/FAE who are at risk of becoming pregnant before age 16, e.g. a version of 'Breaking the Cycle' (Ontario) programs for young teenagers
- fund initiatives for prevention programs for youth such as:
  - templates for ideas to work with youth and children (e.g. "Making Decisions" for Grade 6).
  - comic book for children / youth
  - use of the Internet, e.g. community development workbook developed in Minnesota – readable, fun, entertaining, and current.
  - videogame on substance abuse prevention or CD-Rom (i.e. social determinants of health).
- fund initiatives supporting parents and families such as:
  - database of families and their particular situations, for use by families so they can contact others with similar experiences and difficulties
  - financial and mentor support for family support groups, money for speakers and training
  - portable training that is community-based and can provide back-up and refresher courses afterward
- make children a priority – children should have first call on society's resources
- build a coordinated/integrated approach – provide continuum of care
- support respite programs and increase access to respite for all parents and caregivers of children with FAS/FAE
- provide financial support for adoptive parents of children FAS/FAE
- provide tax breaks for additional costs for children FAS/FAE such as education, etc.
- review income distribution as it relates to child poverty
- take a leadership role that supports families and early development – current programs target problems that emerge rather than focussing on prevention – research supports the economic and social benefits of family support and early childhood services

ABORIGINAL ISSUES – ROLE OF HEALTH CANADA

- organize a National Aboriginal Conference to bring together people from across the country and find out what works for them
- provide more funding for mental health, especially in First Nations communities
- remove jurisdictional barriers to services on reserves – take a leadership role on reserves
- break down the jurisdictions so that the work done is not segregated to on/off reserve
- fund community efforts, especially on reserve
- disseminate information to everyone including reserves
- recognize Elders' contributions and their roles in community support – recognize Elders as professionals (pay disparity)
- include Elders in role of FAS/FAE identification and treatment – appropriate cultural treatment
- assist by providing accurate research data respecting First Nations numbers on which to base level of resourcing needed at FN community level
- support a return to traditional ways, e.g. the training of a girl at puberty by the elders and aunties (balance with similar programs for boys and men)
- facilitate and support family healing circles as a culturally relevant form of support for families that includes social services, education, medical field to map out wrap-around treatment process for both mothers and for children/youth affected by FAS/FAE
- Federal Government *must* respect First Nations Treaty and Inherent Rights and must flow resources *directly* to the First Nations Government Organizations responsible for service delivery, on and off reserve
- First Nations approaches that are based on traditional values, beliefs and practices must be respected and funded rather than the current practice of funding according to 'medical model'

FUNDING – ROLE OF HEALTH CANADA

- provide funding that:
  - is sensitive to integrated approaches (not just health *or* education)
  - fosters a collaborative and partnership approach
  - recognizes cultural differences
  - allows communities to do the planning (needs have often been identified already)
  - supports community development
  - is long term and not project based
- provide funding for support, treatment, diagnosis, training, education/awareness, programs, etc. – funding based on *need* not per capita with serious emphasis on accountability and program management through strict evaluation – need dedicated sustained core funding for coordination on a regional and also community level
- provide funding for community-based initiatives to enhance community-based organizations which already have the capacity to support families
- provide long term stable funding for existing programs and development of new services including prevention, research, diagnosis, pilot projects, community initiatives, etc.
- use dollars to enhance existing projects rather than fragmenting and using funding to support new projects – support front line activities
- build on existing capacity of CAPC/CPNP network to focus some work on FAS/FAE – provide funding for staffing, purchase of resources and program development
- fund national program targeting FAS/FAE like Aboriginal Head Start
- provide a clear route of getting information out around funding
- provide implementation funding and service evaluation
- improve proposal process – proposals to Health Canada have been a barrier to grassroots organizations because of the terminology, wording, tight timelines (e.g. two-week turnaround)
- make funding/program 'criteria' more flexible so that families do not need a diagnosis to access services and so that services can be provided in a flexible way (e.g. hours needing to be used within specified time frames rather than to meet waxing/waning needs)
- continue to help fund and facilitate networking activities
- match provincial FAS dollars
- direct federal funds to existing provincial coordinators
- support a foundation for fundraising – have a national board that would drive where the money would go – use the limited dollars available in the Strategic Project Fund to raise more dollars – most effective use for this national funding – a 'FAS/FAE Foundation' established as a charitable organization on a national level could function to fundraise for services – services and research funded by the foundation would be prioritized by a board consisting of parents and service providers from across the country – foundation would be responsible for developing corporate partnerships and direct mail drives which would also be educational in nature
- ensure the distillers and brewers do not have financial control over organizations that disseminate information
- apply a one cent per drink or one cent per ounce tax on users of alcohol products to come up with some sort of sustainable fund that could be used to provide funding to ongoing community projects – this would provide a regenerative sustainable funding source instead of looking to provinces or municipalities who say they don't have it either – maybe the federal government is able to look at that kind of cross-Canada taxation system

- lobby for the use of tax dollars from liquor stores to be used towards prevention, education, services, treatment, diagnosis, support, management, support for individuals with FAS/FAE, etc.
- create legislation around labelling and signage (bottles, bars, washrooms, schools, supermarkets, work places, restaurants, etc.)

MEDICAL – ROLE OF HEALTH CANADA

- consult with jurisdictions to come up with a national strategy on prevalence studies – if each of the jurisdictions are doing different sets of prevalence studies it doesn't help us nationally – would be if got together to determine a strategy, i.e. where to do prevalence studies (e.g. Grade One's, correction facilities, etc.) – should try to be consistent across the provinces and across time so we can show what changes have occurred and what impacts have been
- develop and disseminate diagnostic criteria
- develop national standards on diagnosis and distribute nationally with the appropriate training materials and resources
- develop diagnostic clinics in all provinces – increase accredited training of doctors who are able to diagnose – the telediagnostic link in Manitoba is a possible model for satellite communities
- develop a diagnostic and prevention network to share information, resources and expertise that already exists in the region
- fund initiatives around greater access to diagnostic materials and develop a consensus around/on diagnosis and broad community based screening materials for teachers/daycare, etc.
- support development of assessment tools that can be used by *all* service providers along with the appropriate training around that tool
- facilitate telemedicine
- spearhead whole family treatment centres
- develop treatment facilities for women and their children
- create treatment facilities for addictions – outreach support
- highlight need for addictions treatment for high risk women (so they can keep their children)
- help with determining FAS as a medical condition (Medical National Standards Health Canada) so additional services are available for youth and adults, e.g. supportive, independent living and group homes with support
- look at alternative methods of treatment, e.g. herbal medication
- ensure national health surveys include questions on drinking/drug use during pregnancy

RESEARCH – ROLE OF HEALTH CANADA

- fund and facilitate regional research to develop good baseline data
- research what works for women
- reach a consensus regarding substance use (FAS/FAE info) so there is no conflicting information on safe use
- support research to provide evidence, i.e. incidence, effective intervention, messaging, etc.
- fund Canadian research on FAS/FAE
- survey the priority population – what do they say their needs are
- epidemiology, statistics, research – dissemination of current research
- facilitate research to find a more effective approach to help the addicted person with FAS/FAE, who often "self-medicates" in order to feel normal (current 12-step programs rarely work)
- support research into effective interventions, management and treatment of offenders with FAS/FAE, effective strategies for optimum functioning of adults with FAS/FAE in society and within the prison systems, etc.
- advocate for and support research into FAS/FAE statistics – research the genetic disposition, determine the population, determine the extent of the situation and what can be supportive
- facilitate research on the cost of FAS/FAE to society – make the economic rationale why it is best to become involved in prevention and early intervention
- conduct or facilitate research on efficacy (what has worked – qualitative vs. quantitative) rather than prevalence or surveillance – practice-based research
- advocate for research into alternative therapies including holistic medicine (as opposed to Ritalin)
- facilitate research that will enhance teaching in the classroom (difficulty of integrated classroom and use of Ritalin)

TRAINING – ROLE FOR HEALTH CANADA

- develop training tools for professionals (e.g. medical/health, educators, social workers, justice system workers, addictions counsellors), community organizations and families/caregivers and train the trainers in each sector
- training materials and approaches should be culturally appropriate, in plain language, practical, useful, and sensitive to issues around addictions and disclosure
- provide training sessions regionally/provincially on prevention and intervention
- facilitate development of a training package for medical schools, residency programs and ongoing professional development for practicing physicians and credits as well as allied health training programs, e.g. speech pathologists, occupational therapists, physiotherapists, early childhood educators, teachers, etc.
- fund awareness programs and training in hospitality industry
- develop standardized training for frontline workers (formal/informal) – anyone who is involved with children (even ministers, priests, etc.)
- bring key people together to see how best to provide training and materials

JUSTICE – ROLE FOR FEDERAL GOVERNMENT

- sponsor programs within justice system for FAS/FAE
- educate all members of justice system (lawyers, judges, police, corrections officers, etc.)
- provide legal aid for young offenders with FAS/FAE
- work with Justice to ensure that every offender, juvenile or adult, is screened for FAS/FAE and that the diagnosis is taken into account in sentencing
- coordinate case history (diagnosis or symptoms) as offender moves between federal and provincial justice systems and coordinate/partnership on staff training strategies in justice system

EDUCATION – ROLE FOR FEDERAL GOVERNMENT

- influence universities to include FAS/FAE in the curriculum of faculties such as education, nursing, medical school, law, social work, etc.
- transfer payments to provincial boards of education for special medical needs

D. OTHER GOVERNMENT DEPARTMENTS, ORGANIZATIONS AND GROUPS THAT SHOULD BE INVOLVED IN ADDRESSING FAS/FAE:

- Provinces / Territories / Municipalities / Aboriginal governments
- Provincial/Territorial and Federal departments of: Health, Social Services, Children and Family Services, Community Services, Education, Justice, Indian Affairs, Employment, Housing
- Provincial partnerships, groups and associations – e.g. Prairie Northern FAS Initiative, BC Provincial FAS Consultation Group, Alberta Partnership on FAS, Coalition on Alcohol and Pregnancy (Manitoba), Fetal Alcohol Syndrome Society Yukon (FASSY), Saskatchewan Institute for Prevention of Handicaps
- Provincial/territorial representatives, MPs and Senators
- First Nations, Métis, Inuit and other Aboriginal groups and organizations
- First Nations Governments at all levels – national, regional, tribal councils and band
- Band Chiefs and Elders
- Local communities & leaders – rural and urban
- Solicitor General, Attorney General
- Corrections Canada and Provincial/Territorial Justice/Corrections system
- Justice professionals and societies
- Community crime prevention projects; justice programs
- Community Police Boards
- Lawyers, prosecutors, judges, courts, probation officers, correction officers, police officers
- Professional associations – e.g. physicians, obstetricians, pediatricians, speech pathologists, nurses, midwives, social workers, psychologists, psychiatrists, guidance counsellors, dietitians, teachers, mental health, unions, police, probation, lawyers, judges, etc.
- Universities – Faculties of Medicine, Nursing, Education, Social Work, Law, Physical Therapy, Speech Pathology, etc.
- Student services and health services – universities, colleges, alternative schools, schools
- Academics – university and hospital centres of excellence
- Aboriginal Friendship Centres
- Military family resource centres
- Employment resource centres
- Youth groups and youth centres
- Family Resource Centres
- At-risk populations – e.g. people dealing with homelessness, low socio-economic status, domestic violence, drug-users, alcohol and binge drinkers
- Families and children/adults affected by FAS/FAE
- Birth, adoptive and foster families

(Other groups who should be involved cont'd)

- Foster parents associations, adoptive parent associations, associations of parents who have given up their children for adoption
- FAS support groups including adoptive, foster and birth family support groups
- People working with young children – e.g. school boards, childcare providers, pre-school age workers, daycare providers, early childhood programs
- NGOs for children and families, e.g. National Children's Alliance, National Children's Agenda, child and Family Canada
- Advocacy organizations – e.g. Associations for Community Living
- People working with women of childbearing age – e.g. preconception health educators and sexual health educators
- Women and women's groups/networks/associations
- Single parent programs
- FASlink – Internet listserv and web site
- Media – TV, radio, newspapers, broadcasting associations
- Bars, taverns, restaurants, liquor commissions, and other businesses related to alcohol
- Liquor industry (distillers & brewers)
- Addictions agencies and treatment services (e.g. detox, shelters)
- Drug dependency, mental health, homeless networks, shelters, food bank networks
- CAPC, Aboriginal Head Start, CPNP
- Medical community
- Canadian Health Network
- Hospitals
- Boys and Girls Clubs, Big Brothers/Big Sisters, recreation associations
- United Way
- Churches and church groups
- Elizabeth Fry, John Howard, Salvation Army
- Service organizations – e.g. Kinsmen
- Workplaces and business sector
- Training and employment sectors
- Health insurance sector
- Revenue security sector

E. EXAMPLES OF SUCCESSFUL PARTNERSHIPS:

WESTERN CANADA

- Prairie Northern FAS Initiative

BRITISH COLUMBIA

- Provincial FAS Consultation Group – members network and partner on efforts as well as share information
- Moving Forward: FAS Activities in B.C. booklet (October, 1999) provides a listing and profile of various groups across the province involved in FAS activities (funded by the BC Ministry for Children and Families) – helps groups looking to partner
- Society of Special Needs Adoptive Parents (SNAP) has partnerships with the Greater Vancouver Alcohol Society and the FAS Family Support Centre as well as the B.C. FAS Resource Society and the Queen Alexandra Centre in Victoria. SNAP has assisted individuals in other parts of Canada start up FAS support centres, e.g. a Fetal Alcohol Support and Information Centre in Windsor, Ontario, and an FAS support centre in Morris, Manitoba.

YUKON

- Options for Independence (OFI) – a supported, independent living housing project for adults with FAS/FAE - partnerships with other NGOs has been productive – cooperation with governments (Federal and Territorial) has been excellent – involvement in OFI board of a wide variety of volunteers has resulted in a variety of experiences and viewpoints
- FASSY (Fetal Alcohol Syndrome Society Yukon) is very involved in networking with people in all aspects of the community, giving workshops to First Nations Bands (when asked); Justice (court workers, lawyers, judges, staff at jail); teachers; child care workers; foster parents; social workers; and parents

ALBERTA

- Every region in Alberta has a FAS Committee made up of agencies in their city/area – these committees have partnered with many local agencies to provide good services to families living with FAS/FAE
- Youth Justice, United Way, Health Canada, Alberta Health, Children’s Services:
  - Secondments to coordinator positions
  - Matched funding
  - Shared office space
  - Administrative assistants
  - Non-profits willing to be fund administrators
  - Donations-in-kind

(Examples of successful partnerships cont'd)

SASKATCHEWAN

- Saskatchewan Institute on Prevention of Handicaps – have recognized the immense value of working in partnership with other organizations, at provincial and national level – as a non-profit organization have no barriers to providing support and resources to on/off reserve, etc.
- Provincial Coordinating FAS Committee and SK Regional Intersectoral Committees
- Battleford FAS/FAE Initiative – development of Battleford Tribal Council (BTC) Child Development Centre where many pre-school Head Start students have been assessed by Dr. Pat Blakley with follow-up feedback sessions in developing programs suitable for these children – partner with speech pathologist, educational psychologist, Head Start, BTC Indian Health, Social Services
- Pine Grove Correctional Centre for Women is in partnership with Prince Alberta Health District and NGO in the P.A. Baby S.A.F.E. Program (a support group for pregnant and nursing mothers who wish to abstain during pregnancy and lactation)
- Formal partnership between SK Association for Community Living, Community Living Division (Government of SK) and SK Association Rehabilitation Centres

MANITOBA

- Coalition on Alcohol and Pregnancy (CAP) – brings groups together to share information, resources and opportunities to partner
- Interagency FAS/FAE Program – partnership between Child and Family Services, Mount Carmel Clinic, Pregnancy Distress Family Support Services and New Directions
- Provincial Community Initiatives Grant Program – e.g. STOP FAS Program – province partners with the Aboriginal Health & Wellness Centre, Nor'West Community Health Co-op and the Oski-Keesekow Project in Norway House
- Thompson FAS/FAE multi-disciplinary support team
- Telelink project connecting family and multi-disciplinary team in Thompson with specialists at the Clinic for Alcohol and Drug Exposed Children (CADEC) in Winnipeg
- CADEC and Child Guidance Clinic

ONTARIO

- Algoma Health Unit – working with coalitions has enabled networking with local partners, e.g. Algoma Best Start looked at reproductive health issues for the district of Algoma – ARBD committee evolved from this
- Fetal Alcohol Support Network (formed in 1990) was the seed for the formation of FAS groups throughout Canada – FASlink was an evolutionary product and served to coordinate and communicate the first International FAS Day (September 9, 1999) involving eight nations – continues to be a catalyst to community awareness activities – FASlink's archives are huge and have identified urgent areas of research, such as the link with Tourettes Syndrome
- Healthy Babies/Healthy Children Program in Ontario has worked and does work in conjunction with CAPC programs – these coalitions bring partners around the table related to families from conception to age 6.
- CCSA (Canadian Centre on Substance Abuse) is proactive in this area and has formed partnerships for many research and publications projects – the CCSA has both initiated partnerships and formed partnerships through requests from other organization

QUEBEC

- In Kanahwake, the entire community (social services, hospital, etc.) works for the betterment of the children.
- Educ'alcool - developed a partnership with the Quebec Doctor's College to include our leaflet in the "pregnancy" diary. It is a joint leaflet. The New Brunswick Liquor Board has been authorized to use the content of our leaflet. The Canadian Centre on Substance Abuse (CCSA) has also included it on its Internet site.
- The Quebec Regie Regionale [developed] partnership working habits a long time ago. Institutions as well as organizations are represented. The "Maternity and Addictions" regional committee is the last one of a long successful series including: the regional committee on perinatality and childhood, the dialogue group on youth prevention, etc.

ATLANTIC REGION

- Reproductive Care Program – partnership between the Department of Health and Medical Society – multidisciplinary committee
- Family Resource Centres / CAPC / CPNP – depend on NGOs, provincial and federal departments, participants, volunteers and community-based organizations to enhance, expand and inform their work – very successful model in Atlantic Canada and beyond (FAS/FAE has not yet been the focus, but fits well within the mandate/context of this work)
- NFLD and Labrador government, MUN medical school and hospital health boards came together to develop a Provincial Genetics Program – under this umbrella, Dr. Rosales has been working with and seeing children/individuals with FAS/FAE

F. CONSULTATION WORKBOOK QUESTIONS

QUESTIONS FROM THE HEALTH CANADA CONSULTATION WORKBOOK

1. a) Is FAS/FAE a priority for your organization?

   b) What are some of the new and emerging issues that have arisen with respect to FAS/FAE in your province within the last two years?

   c) Please list the top 3-5 priorities within those emerging issues that have been identified for your organization (e.g. public awareness, support for mental well-being, support for community-capacity building, etc.)

2. Name some of the key activities your province/territory and/or organization is currently engaged in or planning, specifically related to FAS/FAE (short term and long term).

3. a) What role can Health Canada and/or the federal government play to help build on those activities reported above? (e.g. policy, coordination, partnership, social marketing, dissemination, research, financial, etc.)

   b) What other areas should be involved? (e.g. other jurisdictions, provinces, social services, NGOs, community organizations, etc.)

4. How, in the past, within FAS/FAE or other issues, has your organization been successful in forming partnerships between sectors, federal/provincial levels and/or organizations?

5. Further questions, suggestions and feedback are welcome. Thank you.