Enhancing Fetal Alcohol Syndrome (FAS)-related Interventions at the Prenatal and Early Childhood Stages in Canada

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Prepared by

Margaret Leslie
Breaking the Cycle

Gary Roberts
Canadian Centre on Substance Abuse

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Copies of this publication may be obtained from:

Canadian Centre on Substance Abuse
75 Albert Street, Suite 300
Ottawa, ON Canada K1P 5E7
Phone: (613) 235-4048; Fax: (613) 235-8101
Email: pubs@ccsa.ca
http://www.ccsa.ca

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Introduction

Health Canada's Community Based Programs addressing prenatal and early childhood issues, including Community Action Program for Children (CAPC), Canada Prenatal Nutrition Program (CPNP), and Aboriginal Head Start (AHS) projects across the country, hold great potential in reducing the harms associated with substance use during pregnancy because of their concern for the overall health of pregnant women, families and young children. Whether an individual child will have FAS or related effects[1] appears to depend on a number of factors in addition to alcohol exposure, including prenatal health, nutrition, and other drug use, lifestyle and socio-economic factors. Therefore, substance use and pregnancy issues are best addressed in the context of the overall health of a family and a comprehensive, integrated response by communities, as represented by the CAPC, CPNP and AHS projects.

The Community Action Program for Children (CAPC) and the Canada Prenatal Nutrition Program (CPNP) support a range of community-based programs and services for pregnant women and children and their families living in conditions of risk. Funded projects reflect the priorities of both federal and provincial governments but they all have one thing in common — they attempt to eliminate or minimize the conditions of risk for pregnant women and young children and their families. There are almost a thousand CAPC, CPNP and AHS projects across the country, representing a significant effort to support pregnant women, young children at risk, and their families.

When Health Canada surveyed CAPC and CPNP projects in 1997, 60% of projects indicated that FAS was a priority for them in their work with families. An Aboriginal Head Start survey also identified the issue as a priority. Because of the importance of the issue for Health Canada's community-based projects, FAS became one of the areas funded through the National Projects Fund.

The reasons for integrating FAS-related activities with CAPC/CPNP projects are as follows:

- There are almost 700 CAPC/CPNP projects across Canada that represent a significant support to pregnant women and young children at risk;
- CAPC/CPNP projects are well positioned to deliver FAS-related prevention messages, and to provide support to women at risk;
- CAPC/CPNP projects are well positioned to identify and support children, and their families, who may be affected by alcohol and other substance use;

[1] Many terms are used to describe effects associated with prenatal exposure to alcohol; the most common are Fetal Alcohol Syndrome (FAS), Alcohol-Related Birth Defect (ARBD), Fetal Alcohol Effects (FAE), partial FAS (pFAS) and Alcohol-Related Neurodevelopmental Disorder (ARND). The use of other substances during pregnancy can result in other effects on the child. For ease of discussion, the terms "FAS and related effects" and "FAS-related activity" and FAS/FAE are used to encompass this spectrum. A glossary of related definitions and terms is provided in Appendix 3.

- Sharing information on lessons learned and experiences in working with families will ensure that the problem of substance use during pregnancy is effectively addressed by communities and by society as a whole.

Since the onset of CAPC, CPNP and AHS, there has been much attention given to FAS. To date, however, FAS activities in community-based projects have not been accounted for or systematically shared among all projects. The purpose of this project was to search among programs for FAS-related activity in the prenatal and early childhood stages. This report will examine the gaps and identify good practices that will be shared with Health Canada projects to facilitate learning and development.

Breaking the Cycle, a CAPC project located in downtown Toronto, in partnership with the Canadian Centre on Substance Abuse has undertaken this project (see Appendix 5, for a description of these organizations). The partners have approached their work in a manner that will contribute to enhanced communication and synergy at the national as well as provincial and territorial levels. The project was assisted by an advisory committee, comprised of individuals from across Canada having experience in working with FAS.

During this same period, the Canadian Centre on Substance Abuse was contracted to conduct a project entitled *Best Practice and a Situational Analysis Regarding Fetal Alcohol Syndrome/Fetal Alcohol Effects and the Effects of Other Substance Use During Pregnancy*. The CCSA attempted to maximize synergy between the two projects by sharing: common terminology, a literature review required by the two projects and, a working Web site reporting progress by the two projects.

Methodology

This research project undertook the following activities:

1. Develop a national advisory committee.
2. Survey CAPC/CPNP/AHS projects regarding FAS activities, and compile into a database of FAS-related resources, knowledge and training.
3. Interview key informants across the country who have a broad knowledge of FAS policy and activities in their jurisdiction.
4. Identify good practices and gaps in services experienced by the projects.
5. Conduct in-depth examinations of projects that demonstrate elements of good practice.
6. Perform a literature review on FAS best practices.
7. Compile the findings in a monograph, which can be a source for other information products.
8. Disseminate these findings through training.

The methods employed for each of these activities are described below.

Advisory Committee

The committee membership was based on recommendations from Health Canada. Advisory Committee members are listed in Appendix 4. The committee's role was to provide advice on:

- Research objectives and survey design;
- Exemplary CAPC/CPNP/AHS projects addressing FAS/ARBD across Canada;
- Gaps that exist in prenatal and early childhood FAS/ARBD services across Canada;
- The final draft of the project monograph.

Members were also asked to support the project by:

- Helping to disseminate project materials and information;
- Giving visibility to the project;
- Participating in the project evaluation.

Mailed program surveys

Initial screening

A one-page survey (see Appendix 6C) was sent to all CAPC, CPNP and AHS projects in the spring of 1999. Project coordinators were asked whether they were doing anything to address substance use during pregnancy, the importance of the issue for their project, and the awareness level of service providers in their community. Six hundred and four (604) surveys were mailed, and there were 469 replies (77%). Of those, 403 projects (67%) responded that their project was doing something pertaining to this issue.

Full survey

In the late spring of 1999, a full seven-page survey (see Appendix 6D) was mailed to:

- Those who indicated in the first survey that they were doing anything to address substance use during pregnancy (403);
- Programs identified by Health Canada as engaging in some FAS activity (150);
- Pregnancy Outreach Programs in B.C. (19);
- Programs funded by Health Canada's First Nations and Inuit Health Branch (formerly Medical Services Branch (253)).

Eight hundred and twenty-five (825) surveys were mailed and 322 were returned, representing a 40% response rate. Some projects received funds from more than one of the Health Canada funding programs (i.e., CAPC, CPNP or AHS), so that a returned survey could represent more than one of the funding programs. The response overlaps are shown in the following table.

	CPNP	FNIHB	AHS
CAPC	28	10	2
CPNP		38	1

Percentage of responses from each region

Region	No. of surveys returned	Percentage of total responses
Atlantic (Newfoundland, PEI, Nova Scotia, New Brunswick)	27	8%
Québec	87	27%
Ontario	60	19%
Prairie (Manitoba, Saskatchewan)	49	15%
Alberta / Northwest Territories	31	10%
BC/Yukon	68	21%
Total	322	100%

There is considerable variability in numbers of projects funded across regions. For instance, there are a large number of projects funded in Québec, and far fewer in Atlantic Canada. Forty-six percent of returns were from western and northern Canada (Manitoba to BC, Yukon and NWT). Twenty-seven percent of the survey responses were from Quebec. Only eight percent of responses were from Atlantic Canada. Given the low overall representation from Atlantic Canada, caution must be exercised in interpreting results from that region.

Response rate by program

CPNP and CAPC projects together account for 83% of the responses. Of the 392 CAPC projects, 159 responded (41%); and of the 238 CPNP projects, 173 responded (73%).

Program	No. of surveys returned	Response rate within program
CAPC	159	41%
CPNP	173	73%
FNIHB	47	19%
AHS	20	5%

Of the 253 projects that are funded by FNIHB , only 47 responded (19%), and only 20 Aboriginal Head Start projects from across the country responded. In fact, there were so

few responses from FNIHB and AHS projects that no definitive statements about activities funded within those two programs can be made.

Key informant interviews concerning broad, jurisdictional issues

Ten key informant interviews were conducted between October and December of 1999. These interviews were meant to enrich the data that had been collected by mailed survey. Key informants were asked to comment from a broad, jurisdictional perspective on FAS-related activities and issues among CAPC, CPNP and AHS projects in their region. They were asked questions about:

- The extent and nature of FAS-related activity among projects;
- Project-level challenges, as well as challenges or gaps at the broader, systems level;
- What appears to be working both at the project level and at the broader systems level;
- Whether there is a need for more FAS-related training for staff;
- Identification of projects that reflect good practices.

It was concluded that regional Health Canada program staff were likely to have the best understanding of the broad issues in their jurisdiction so eight of the ten key informants were from Health Canada. The list of key informants is provided in Appendix 4.

Prior to the interview, each site was faxed or emailed a confirmation letter and an interview guide that included a copy of the opened-ended interview questions (see Appendix 6A). The questions were not pre-tested; however, the guide format and style of the questions were similar to those used in a concurrent project conducting an FAS-related situational analysis. The first informant interviewed was asked for feedback on the clarity of the questions and interview process. The questions were considered to be clear. A few minor adjustments were recommended and were introduced to the interview process.

In preparing for and answering the questions, the interviewees were asked to speak from the perspective of all three federally funded programs (CPNP, CAPC and AHS). They were also encouraged to speak with colleagues and others who may have relevant input to the questions. An additional 15 Health Canada staff persons were canvassed for their ideas and opinions by key informants. This additional input was incorporated into the interviews.

All interviews were conducted by telephone. Nine were in English and were conducted by a consultant living in Victoria. The tenth was in French and was carried out by a consultant living in Montreal. Interview times varied, ranging from forty minutes to two and a half hours.

Identification of good practices and gaps in services

The mailed surveys and key informant interviews were, among other aims, designed to gather information about good practices that have led to positive results in the opinion of respondents. They also gathered information about gaps in services and challenges to

providing effective services. A number of themes emerged over the course of the interviews, which are discussed throughout the report, and are summarized in the Conclusions section.

Examination of projects incorporating good practices

A second set of interviews was conducted with persons associated with projects reflecting the elements of good practice identified earlier in the project. Members of the advisory committee, together with Health Canada regional representatives, were invited to nominate CAPC/CPNP/AHS projects that they felt demonstrated one or more of the good practice elements that were identified through the mailed survey and key informant interviews. Approximately ten projects were nominated, and six were selected for closer examination to determine how they incorporate these practices into their projects.

The following projects were selected for closer examination:

- Healthy Generations Family Support Program (Sioux Lookout, Ontario);
- Interagency FAS Program (Winnipeg, Manitoba);
- Food for Thought (Saskatoon, Saskatchewan);
- Children's Centre (Fort McMurray, Alberta);
- Northern Family Health Society (Prince George, B.C.);
- Fetal Alcohol Syndrome Society – Yukon (Whitehorse, Yukon).

Literature review

The other FAS-related project conducted concurrently by CCSA involved an extensive literature review of prevention, identification and intervention practices and programs. That literature review was consulted for use in this project, particularly with respect to identifying good practices.

Develop monograph

This monograph incorporates findings from the surveys and interviews to present a picture of FAS-related activities in CAPC, CPNP, and AHS projects across Canada. The analysis of the data collected is summarized into a series of good practice statements, key learnings and case stories that can be used to develop FAS services, products and training. Key learnings about good practices are included in Appendix 2.

Develop and deliver training

Key findings from this project were presented at meetings, conferences and training events across Canada over the past year. The key findings from this project are also being compiled into an 'FAS Toolkit' that will be available online on the Internet. The information will be offered to all CAPC/CPNP/AHS projects as a pilot test. A crucial

evaluation component will be incorporated into the initiative. This will be reported upon separately at the conclusion of the knowledge transfer project.

Information gathered from participants about their training needs and about resources that have proved useful to the projects is summarized in Appendix 1.

Limitations

In any survey, there is always the problem of unknown bias in the response set. Little is known about the projects that didn't respond, or what might be different about the ones that did respond. There is a tendency to assume that those that respond have greater interest or 'more to say' about the issues under investigation, but this is not a certainty. However, caution should be exercised when reviewing the results, in that data may be missing from those projects that are less involved with prenatal substance abuse. Some of the reasons that people don't respond to mailed surveys are that they are over-worked and haven't the time to respond, or possibly have been over-surveyed.

With respect to the key informants survey, at least one of the key informants was new to the position and therefore was limited in experience with the issues.

Although key informants were able to speak about FNIHB and AHS activity, low response rates to the mailed survey from FNIHB and AHS projects means that less can be said of this activity.

Broad context for activities

FAS activity in Canada

A picture of FAS activity in Canada can be drawn from the project, *Best Practice and a Situational Analysis Regarding FAS/FAE and the Effects of Other Substance Abuse During Pregnancy*, which has been conducted concurrently by the Canadian Centre on Substance Abuse on behalf of Health Canada. This is summarized below.

Gaps

Fully routine and sustained activity across the range of activity areas (i.e., prevention, identification and intervention) and life stages is not occurring anywhere in Canada. Access to information, services and continuity of care are significant and ongoing issues, particularly for many remote and rural communities.

Public awareness of the personal and societal impact of alcohol and other substance use during pregnancy is relatively weak and current public awareness efforts tend to be sporadic and poorly resourced. School-based education on the nature and impact of FAS and related issues is not widespread.

Screening of women with substance use problems is generally not routine in social and health settings across this country. Primary care professionals, particularly physicians, are also in a strong position to screen by routinely asking questions about substance use of all their patients, but there is a sense on the part of informants that not enough physicians are incorporating this into their practice.

It appears that the substance abuse treatment field does not adequately address the needs of women who are pregnant and using substances. More attention needs to be given to appropriate withdrawal management services, harm-reduction oriented outreach or pre-treatment programming, priority placement for pregnant women in treatment, and ancillary services (such as childcare and transportation) for women accessing treatment. Critical to this service development is a welcoming, respectful approach, so that women do not avoid contact with alcohol and drug services out of fear of judgment, discrimination, or lack of control over their care.

Assessment and diagnostic services for Fetal Alcohol Syndrome are not routinely available across the country. This is particularly the case in more remote rural and northern locations. Early identification of FAS may significantly reduce the risk of secondary disabilities. However, there are not, as yet, the fully validated, commonly accepted and well-communicated screening and assessment tools that will lead to earlier intervention.

Specialized intervention services for those affected by prenatal alcohol and other substance use are infrequently available. There is a general lack of recognition of the special needs of clients with FAS who receive correctional and mental health services or substance abuse treatment. Services offered by these systems require modifications in order to be effective for this population.

Generally, there is a need for more FAS-related training and professional development. Many professionals do not fully understand the special needs of persons with FAS or related conditions. Some well-meaning professionals still hesitate to address FAS as a specific condition for fear of labelling and stigmatizing affected persons. An understanding of the different brain functioning of affected persons and the impact of secondary disabilities is critical. Skills to advocate for clients and to advance FAS services generally are also crucially important for professionals.

Readiness to address the issue

One way to view FAS-related activity across the country is in terms of apparent "readiness to act". The clearest distinction to be made in the level of readiness to be found across the country is that which occurs between the eastern provinces and the western provinces and territories. To date, western jurisdictions have demonstrated a much greater readiness to address this issue at both the broad and local levels than have the eastern provinces.

While there are notable exceptions, virtually all aspects of FAS-related activity are more likely to be better established in the west when compared with the eastern provinces. At the provincial/territorial government level, there is a greater likelihood of enabling policy, resources, and focusing and coordinating activity. Communities are more likely to be cooperating through multi-agency coalitions, while individual agencies are more likely to consider attention to FAS as a routine part of their services. Training on the issue is more institutionalized and available in the western jurisdictions and is more likely to deal with advanced issues. Emerging issues, such as those associated with FAS adults, have been typically identified first in the West. Most of the considerable array of resources now available has been developed in western Canada.

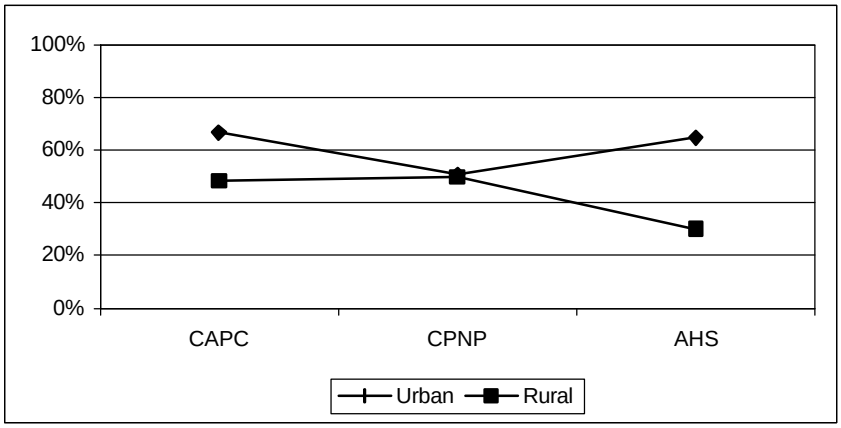
Just as readiness to address FAS varies with the region, so does it vary across disciplines. Health professionals have led the way in many jurisdictions. Social service professionals are now joining them. To a much lesser extent education, judicial/corrections and employment professionals are becoming aware of FAS as it relates to their teaching and their practice. Clearly missing are professionals in the recreational and leisure fields understanding FAS and increasing access to appropriately designed recreational programs. Such programs do not appear to exist in this country. In general, there is a long way to go before most professionals in most fields will be able to recognize, understand and practice interventions that are effective.

A third major way of distinguishing activity levels is with respect to life stage. Understanding of FAS and how to intervene effectively has grown along side those individuals who were first diagnosed. Consequently, there is greater experience and more services for affected children in their early and mid-childhood. The implications of FAS in adolescence and adulthood are now being experienced, but services are very limited. There is, at this time, little knowledge and virtually no specific services for individuals with FAS in their middle and old age.

Populations Served

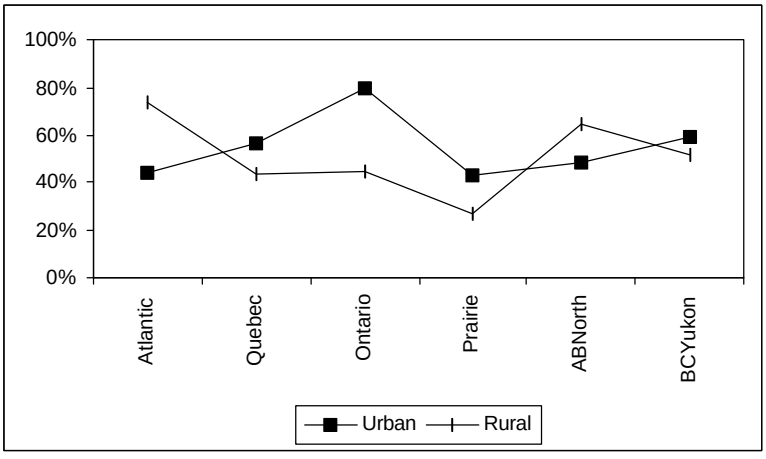
Responses from the survey of the projects indicate that they tend to serve a wide variety of clients. Projects from all three programs serve both urban and rural populations. CAPC and AHS projects serve more urban clients than rural, and CPNP projects were evenly split in serving urban and rural populations.

Percentage of Programs Serving Rural and Urban Populations



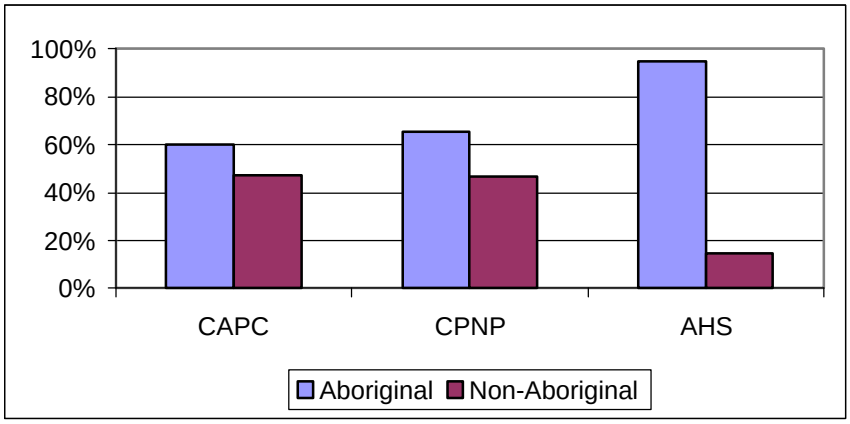
Projects in Alberta-NWT and Atlantic regions serve more rural than urban populations. Ontario region has twice as many projects reporting that they serve urban populations than rural ones. BC-Yukon, Prairie and Quebec region projects have approximately equal proportions of rural and urban projects.

Projects Serving Urban and Rural Populations, by Region



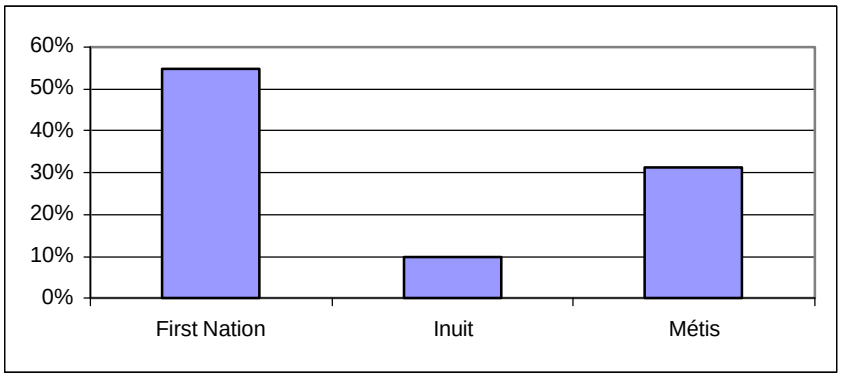
All three programs are serving both Aboriginal and non-Aboriginal populations. AHS serves predominantly Aboriginal clients, but a small proportion of projects are serving non-Aboriginal populations as well.

Projects Serving Aboriginal and Non-Aboriginal Populations, by Program



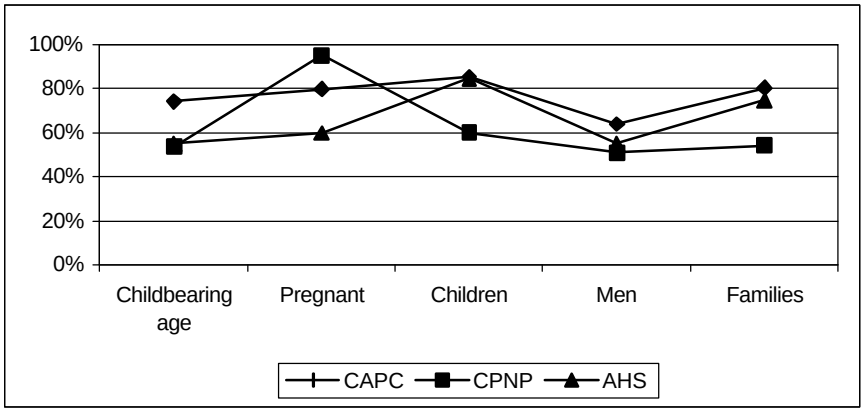
Of the 322 projects responding to the survey, more than 50% indicated that they are serving First Nations clients, 10% are serving Inuit clients, and approximately 30% are serving Métis clients.

Projects Serving Various Aboriginal Populations



The holistic approach to their respective mandates is reflected in how CAPC, CPNP and AHS programs perceive their client group. The CAPC projects indicated that they are serving a broad range of clients, including women of childbearing age, men and families, in addition to pregnant women and children. The CPNP projects are, not surprisingly, predominantly serving pregnant women. However, more than 50% of the CPNP projects responded that they are also serving children, women of childbearing age, men and families. The AHS projects that responded to the survey are predominantly serving children and families. However, again, more than 50% of AHS respondents are also serving women of childbearing age, pregnant women and men.

Client Group as Perceived by Projects, by Program



Successes at the broader, systems level

Key informants were asked to identify successes at the broader, systems level within their region. A number of themes emerged from the interviews, including: multiple funders, provincial and territorial support for FAS, federal collaboration, community development approach, partnerships and collaboration, and development of FAS resources. These are described below.

Multiple funders

Multiple sources of funding help to ensure a broad base of support for and awareness of FAS initiatives. This includes building strong associations with different levels of government, and with different community groups. Having multiple funding sources seems to be positively correlated with number of FAS-related initiatives and activities.

> *"I would like to really commend the Alberta Partnership on FAS. It is a multi-level collaborative initiative to look at FAS. Health Canada sits on it and has been on it from the beginning…I think that this has great potential because again this issue has got to be tackled from many levels, from community, regional, provincial and federal."*

Provincial and Territorial support for FAS

A number of provincial/territorial governments fund FAS activities and many also have developed a coordinating committee. In those that have an FAS coordinating committee that partners with projects and helps to link them to resources (i.e., FAS provincial coordinators, awareness campaigns, conferences, workshops, videos), there tends to be a much higher level of awareness about FAS. Where provinces or territories also fund FAS activities, more is happening. Several informants emphasized the importance of a good working relationship with their respective provincial partners.

> *"… at the risk of repeating myself, we have a good history of working with the provincial governments."*

"We kind of did an open invitation to anyone who had an interest in the topic and the topic was on harm reduction. We had quite a good response from provincial agencies and other community organizations in addition to all of our own projects and the on-reserve."

Provincial/territorial support for FAS is more prevalent in the western regions, with examples of collaborative initiatives in Alberta, Saskatchewan and Manitoba. No provincial government east of Manitoba allocates resources towards FAS activities, although the Government of Newfoundland and Labrador has announced plans to invest some of its federal Child Tax Benefit into the development of a Social Strategic Plan and some of that funding has been dedicated to raising awareness of FAS.

The provinces of Alberta, Saskatchewan and Manitoba and Yukon are working together under the Prairie Northern FAS Initiative. Each province has agreed to take a turn at hosting a conference and to lead particular FAS-related initiatives.

Manitoba has a Coalition on Alcohol and Pregnancy that has been in place for six or seven years. The Coalition has helped to support the development of the FAS Parents Association. Community awareness of the issue is further promoted by a local freelance reporter in Winnipeg who has taken on FAS as an issue. This reporter is now writing a book, which will tell the real life stories of FAS from various perspectives (children, birth parents, adopted families, etc.). The issue of FAS and prenatal substance use achieved national attention when Manitoba took a controversial and much-publicized case to the Supreme Court, which examined issues regarding a woman's use of alcohol and other substances during pregnancy.

Federal collaboration

In some regions, there have been FAS linkages with other federal departments, particularly Crime Prevention and Justice Canada. These linkages are seen to be important and beneficial, as they more accurately reflect the complexity of the issues of FAS.

Community development approach

One key informant noted the importance of using a grassroots, bottom-up approach to the development of FAS initiatives, involving a broad cross-section of community representatives. An example of such an approach is to hire women from the community to reflect the multicultural component of the community served.

The Northwest Territories initiatives include grants that support social marketing activities. A number of TV ads were produced that talked about community development and fostering the health of children. One of the ads had a 1-800 number and calls came in from across Canada.

As mentioned above, the Government of Newfoundland and Labrador has reinvested some of its National Child Tax Benefits into a Social Strategic Plan. Some of that funding has been dedicated to FAS awareness and community development work.

Partnerships and collaboration

Because of the complexity of the problem of FAS, the issue must be tackled from many levels: community, regional, provincial and federal. Given the complexity of needs from a population health perspective, the multiple needs of women who are using substances prenatally, and the limited timeframe of pregnancy in which to address these issues, an intersectoral partnership approach is required. Many informants spoke of the importance of the commitment and passion of even one person who can spearhead the FAS agenda in a community or in a region as a critical catalyst for development of initiatives.

A number of informants stressed the importance of working in partnership, supporting what is already in place, and linking the various regions to facilitate sharing of knowledge and experience, especially the sharing of parents' knowledge with others. Several informants spoke of the importance of pooling expertise but at the same time were mindful that many child and family issues fall under provincial or territorial jurisdictions.

> *"We need to determine at what level we are going to partner. So do we say, 'Okay that is where the province is and then CAPC fill in the gaps?' I think that the prevention aspect is a good example of what can happen if people partner. I think that we need to do a lot more in areas of interventions, proper assessing and treatment support and ongoing support beyond this. We would need to work with others in the province and other groups who have expertise in this area… And build on the ones that Saskatchewan, Manitoba and Alberta are doing in the tri-prairie group (now includes the Yukon under the Prairie Northern FAS Initiative)."*

As has been noted above, examples of FAS collaboration between federal departments primarily exist between Health Canada and Justice Canada. The Northwest Territories has collaborated with Justice Canada in the development of Pan Arctic FAS ads, as well as in the allocation of Crime Prevention funds.

In Alberta, there are strong associations and links at the program level. The Alberta Partnership includes key players from justice, education, health, children's services, people with disabilities and other community people. Having these key players around the table makes a difference in the community's ability to address FAS in a systematic way. Common concerns that are being examined at the community level through the partnership include how to address funding for children in the school system, how to support parents with FAS, and determining whether interventions in the Alberta justice system are appropriate.

Development of FAS resources

The majority of the key informants felt that information for staff to learn about FAS has been and is abundant in Canada and that, in many cases, this information has been developed within projects themselves. They also noted some of the additional benefits of developing a resource: people coming together to develop a video, a brochure or a Web site strengthens ownership and pride that seems to stay on in the community. In developing these resources, the ability to link with others, to partner and to share was also

seen as important. Although the effects of this kind of collaboration to develop a resource cannot be measured, these things help to sustain activities in communities.

Challenges or gaps at the broader, systems level

Key informants were asked to describe the challenges or gaps that they perceive at the broader, systems level. Their comments can be summarized into a number of themes: working upstream; research; public awareness and community support; coordination; community readiness; geographic isolation; knowledge and skills of practitioners; screening; diagnosis; post-diagnostic supports; support for parents; treatment facilities; funding; resources; and intergenerational links. These are described in more detail below.

Working upstream

Many key informants emphasized the importance of ensuring that the issue of FAS is addressed in the context of the broader determinants of health, and expressed concerns about adopting a focus that was too limited. Understanding the broader social and systemic root causes of alcohol and drug use are fundamental to the development of effective FAS prevention, identification and intervention initiatives.

When asked what she thought of the definition for prevention used in this research report, one informant said she did not think that it reflected upstream work. A few noted that a population health approach brings additional challenges.

> *"What we need to do is ensure that we are looking at the broader determinants of health in this issue. The broader social and systemic causes of alcoholism, poverty, violence against women, cultural breakdown, under-employment, lack of housing, all of those broad issues that are fundamental to preventing FAS. That is a really scary issue for broad system and levels of government to look at. That is an area that I am worried about, and I think that there is a gap."*

The mandate of these projects is high-risk families, which limits how far upstream they can legitimately go. Two informants added that moving upstream creates accountability challenges for these programs, particularly in the short term and under the current funding policy.

> *"Things like funding programs like Girl Guides, girls' sports or recreation activities, or something along that line might be a very good way of dealing with it in the long run but it doesn't really focus on any specific FAS or health issue at this point."*

Research

There is a need for research to determine the prevalence of FAS and related effects in children and adults in Canada. This research needs to be linked to strategies to reduce harm and to identify best practice approaches.

"You probably have heard a lot about harm reduction approach. Is it feasible…? I think that there needs to be a lot more…research in this field…to give us a sense of how big this problem really is."

There are no prevalence or incidence rates for FAS in Canada. Without baseline data, we will be unable to determine whether project strategies are reducing the incidence of FAS.

"We seem to be able to track all kind of other illnesses and if we are going to do very specialized programming in this area then we need to be able to determine whether the rates are going down or if they are going up."

Public awareness and community support

There appears to be greater public awareness and community support in the west than there is in the east, with the Manitoba-Ontario border acting as the clear dividing line. This difference is attributed to political leadership, the degree of collaboration and cooperation among the different levels of government, and the degree to which communities have been supported to take ownership of FAS-related issues. Community support includes the availability of community awareness campaigns, platform for public dialogue, local leadership, FAS education (for professionals as well as lay workers, parent support groups, schools, and workplaces) and access to culturally sensitive materials in French and English.

Coordination

Many of the coordination challenges in the broad system are related to differences in philosophy, the lack of a common perspective, and the challenge of working in partnerships, at both the community and government levels. Respondents also noted the lack of collaboration across systems and sectors. The existence of such collaborations would result, for example, in seamless initiatives that support individuals across life stages, as well as services that integrate adult treatment with children's services. The need to connect people who are working on FAS-related issues in the different departments of the federal government and between sectors was also noted*:*

"When it comes to the broader system, it isn't just a health or education issue. What we would like… is to promote awareness among all sectors and that is something where an… awareness campaign might be of some help."

In some regions, there is very little FAS collaboration of any sort.

"There is no networking, or not a whole lot... Many are doing FAS work on their own without any real network, coordination or collaboration."

Another stated,

"There is really no linkage or partnership happening. There is no activity between the governments, or really between the governments and the communities."

There were only a few examples of coordination of FAS activity across federal departments and most were in the area of crime prevention. In one region, Human Resources Development Canada have asked Health Canada staff to help with professional development, but neither group has committed to work together as yet. All informants were pleased with the federal commitment to FAS. However, one of them spoke about the importance of ensuring that there is strong collaboration throughout the system.

> *"I am talking about community groups collaborating, and at federal, regional and national level…(and) we need to ensure that (there is) respect for, and collaboration with, our provincial counterparts."*

One informant cautioned that more work needs to be done, for example, in connecting with the perinatal surveillance program. Some regional offices are examining their relationships with other sections of Health Canada, particularly First Nations and Inuit Health Branch. Issues between on- and off-reserve FAS-related activities were noted.

> *"We are not really touching (on-reserve) because we are off-reserve. But for a (provincial) profile, I think that it is important to raise that point."*

Provincial/territorial commitment to FAS-related issues varies widely and presents a challenge to coordination. Working relationships between federal and provincial governments sometimes present further challenges.

> *"The difficulty is there have been issues about the implementation of Health Canada programs in the province in that there has never been a true acceptance and a good environment for partnerships because there still is a bit of a power struggle".*

At the project level, organizational interest in FAS, and the capacity to work with other groups appears to vary greatly among projects. The individual capacity of projects, their expertise, individual training, as well as who their community partners are, all really influence what type of activity they can have. In some regions, there are no community organizations ready to develop an FAS project proposal. Projects do not emerge because there is too little information and it is not known if, and to what extent, the problem exists there. Some service organizations maintain that they do not have any mothers at risk or children affected by FAS among their participants.

Community readiness

Community readiness to address FAS varies. If a community is not ready to deal with it, the issue can be forced underground. A case in point is when a community believes that it has dealt with the problem simply by declaring itself to be a dry community. There is a need for openness to all perspectives and to all groups at this stage to see what might work.

> *"The general attitude seems to be one of denial 'There is no FAS in my community'. For now, we have to take a very wide-open approach and simply publicize the issue, and then prejudices will fall. We need the widest campaign possible – to talk about FAS in medical schools, among nurses and school*

teachers, to reach the very young, professionals and young families. People have to hear about this as a reality and not a myth."

Geographic isolation

The geographical isolation of many communities, especially in the north, presents another challenge. There are limited human resources available when staffing those remote projects, which are often prioritized as high-needs communities. Project staff and key informants talked about the challenge that lack of transportation and limited accessibility present with respect to doing prevention activities, particularly in remote regions in the north and in rural areas.

Inconsistency in knowledge and skills among practitioners

Even when awareness about FAS and related issues is high, there still seems to be a fair degree of inconsistency in knowledge and skills. Health professionals, in particular, were singled out as being in need of further education to help them more effectively address FAS. Concern was expressed that some physicians are using outdated information and are giving confusing and inconsistent messages.

One particular worry is that some physicians advise their pregnant patients that having a drink of wine a day won't harm their fetus, which conflicts with the CPNP and CAPC message that there is no safe level of alcohol use during pregnancy. Inconsistent messages are a source of stress and confusion for pregnant women. One informant thought that it would be very difficult to convince doctors and the public in her province to agree with zero tolerance for alcohol consumption during pregnancy.

"They (referring to physicians) never think about alcohol…they just say oh 'you are a poor mother', or 'your parenting skills are bad', or 'your child has ADD'. So there is misdiagnosis and mistreatment because… the professionals are unaware of FAS and all the impacts."

Many health professionals and lay workers are uncomfortable asking questions or speaking about alcohol and drug use during pregnancy. Several informants felt that education and training could help professionals develop skills, particularly in how to speak to women, in a culturally sensitive manner, about use of alcohol during pregnancy.

Screening

Some respondents felt that there was a gap in knowledge and experience, as well as in methodology, with respect to screening for FAS. Projects need to know what tools or procedures to use, and what to do with the results. It was reported that the Government of the Northwest Territories has distributed a compilation of different screening tools; however, because these tools are not culturally sensitive, their use within the Aboriginal community has been controversial. Screening in the Northwest Territories is, therefore, more dependent on observation and interaction than on a prescribed tool or systematized approach. While the importance of observational assessment cannot be discounted in the process of identification of children at risk for FAS, the use of culturally sensitive and

validated screening instruments may provide confirmation of observations as well as consistency in screening and identification across projects and regions.

Diagnosis

Even when children are suspected of being affected by FAS, getting a diagnosis is a major challenge. There was agreement that a physician should be the one to determine whether a child has FAS. But many informants seemed frustrated by the scarcity of physicians who are willing and/or able to make the diagnosis. Families often must travel to larger centres (sometimes out of the province) to have their child assessed for diagnosis. In provinces where assessments are done, there are delays of up to six months because of limited resources.

Post-diagnostic supports

Many respondents expressed frustration about follow up, reporting that there is a lack of support once diagnosis has occurred, and diagnosis does not necessarily entitle a family to support. The school system was singled out for particular criticism with respect to post-diagnostic support. In most regions, FAS is not recognized as a distinct disability by either government or the school system, making it difficult for affected children to receive appropriate school-based support. Several informants spoke about the needs of school-aged children, highlighting a number of gaps, particularly the need to see FAS as a disability.

> *"FAS isn't recognized as a distinct disability either by government or the school system. I was told by somebody that if you have a slip from a doctor that says your child has ADHD or ADD you are entitled to special assistance from the school system whether it is a teacher assistant or withdrawal from the classroom for a certain time. But if you came in with a letter saying that your child has FAS they can't do anything special for you."*

There is also a concern about children being labelled, especially when there is inadequate follow-up or broad-based community planning.

Special services or therapy for children and families (e.g., occupational and behavioural therapy) is limited or lacking in many regions.

> *"Even if there is occupational therapy it is more of the sensory integration approach… as opposed to a real clinical perspective. So that (it is) not only the availability of services, but the type of services that are delivered."*

If there are specialized services in the community, their design is rarely based on a broader, long-term approach.

Support for parents

Several people spoke about the huge gap in support for the parents and families who are dealing with FAS. These parents feel alone; they are constantly fighting the system, and find themselves educating every new provider (including health professionals) about their

child. Every time the child enters a new grade, another teacher has to be informed and educated about FAS and the particular needs of the child.

> *"As somebody pointed out, there is even a general lack of public awareness. They just think that you have got a bad kid… he doesn't know how to behave or you are a bad parent."*

Improper labelling of children when they are having problems is also a concern.

> *"So many of the children have not been diagnosed that we don't want to create an atmosphere where teachers and staff are going back and labelling these kids when they have not been diagnosed."*

Specialized treatment centres

Lack of woman-focused treatment programs and residential treatment programs for women who are pregnant is a tremendous barrier to supporting women in the projects who use substances prenatally. Where these programs exist, there is generally limited, or no, childcare available, which presents another barrier to accessibility.

Funding

Informants were concerned about the costs attached to dealing with the complex issues associated with FAS in community-based projects. Some spoke about the challenges of the ratio of the women to staff being so high, making it difficult to address individual and complex needs. The CPNP program, for example, is designed to operate on more of a drop-in, group-based model and CPNP projects do not, for the most part, have the resources to offer individual counselling. Some respondents said that CAPC projects are funded on an objective basis, and some projects are better able to address FAS-related activities. Projects (including Aboriginal Head Start) that are not funded to do FAS-specific activities are struggling, and are faced with many challenges as to what they should do to further address the needs of these high-risk women and children.

Limited resources

Some regions of the country have limited access to FAS materials.

> *"Whether (we are) talking about simple things like posters or pamphlets or things to hand out to the community, we just don't have it. For example, we held a province-wide CAPC and CPNP conference recently… and all of the materials for FAS we had to get from the western provinces… some of our northern projects are bilingual… There is a real dearth of francophone materials on FAS."*

Concerns were also expressed about the degree of judgment that is sometimes communicated in FAS resources. Of particular concern is the degree of blaming and shaming that is sometimes directed to women who drink during pregnancy and to some groups of people, particularly Aboriginal people.

Intergenerational link

It is not uncommon to discover that FAS is intergenerational. Two informants noted that some parents are themselves affected by FAS, but there is a lack of resources for adults with FAS.

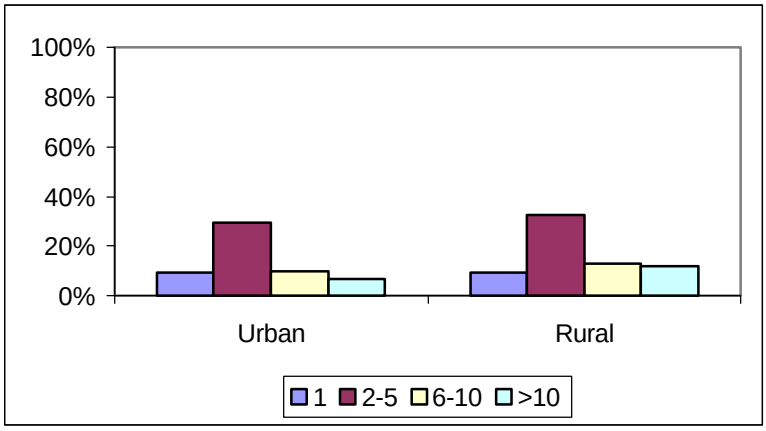
> *"…another gap is mothers who have FAS, parenting children with FAS."*

FAS-Related Activity in Projects

Collaboration among projects

Programs configure their service delivery arrangements in different ways. Sometimes a way to organize program delivery in rural areas is with multi-site configurations; however, some urban areas also use a multi-site configuration. In fact, there appears to be little difference between those serving urban and rural populations in terms of the prevalence of single versus multi-site service configurations. There are a few more projects in rural areas that use a multi-site configuration than those in urban areas. The norm is for projects to have two to five sites.

Projects Using Single Versus Multi-site Delivery Arrangements



Projects were asked whether they are part of a partnership or coalition that deals *only* with issues of substance use during pregnancy. Only 6% answered in the affirmative. They were also asked whether they are part of a partnership or coalition that deals with substance use during pregnancy *among other issues*. Seventy-five percent are doing so.

To gain more information about how projects collaborate with others, they were asked to indicate the frequency with which they engage in several collaborative activities. The results are provided in the table below.

Collaborative Activities Among Projects

How does your project work with others?	Often	Occasionally	Never
Refer clients to other agencies	102	193	11
Other agencies refer clients to the project	91	161	49
Hold joint client consultations	42	159	99
Exchange program information and services	135	133	31
Outside practitioners volunteer time to the project	81	110	108

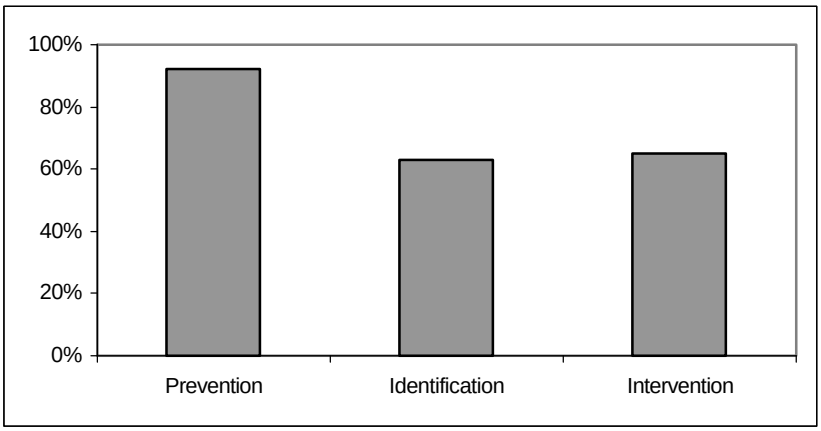
Two-thirds of the projects refer clients to other agencies occasionally (63%); one-third refers clients often (33%). Fifty-three percent of projects receive referrals from other agencies occasionally; thirty percent receive referrals often. More than half of respondents hold joint client consultations occasionally (53%); only fourteen percent do so often. Ninety percent of projects exchange program information and services either often (45%) or occasionally (44%). Approximately one-quarter of projects use outside practitioners as volunteers often (27%); one-third use them occasionally (37%); and one-third of projects never use outside practitioners (36%).

It appears that most projects engage in activities involving other programs and agencies fairly frequently. It would be useful to know why a large proportion never uses outside practitioners as volunteers. The breakdowns seem consistent between the rural and urban populations, and from program to program.

Allocation of effort to prevention, identification, or intervention

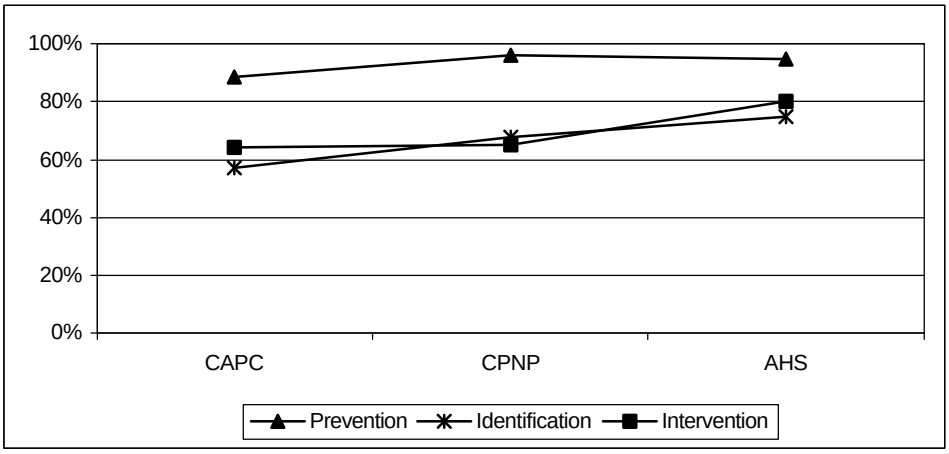
In the survey, projects were asked whether they do prevention, identification and intervention activities to address FAS. As indicated in the figure below, a high percentage of respondents reported doing prevention, identification and intervention activities. Clearly, however, the most prevalent activities are in prevention.

Projects Conducting Prevention, Identification or Intervention Activities



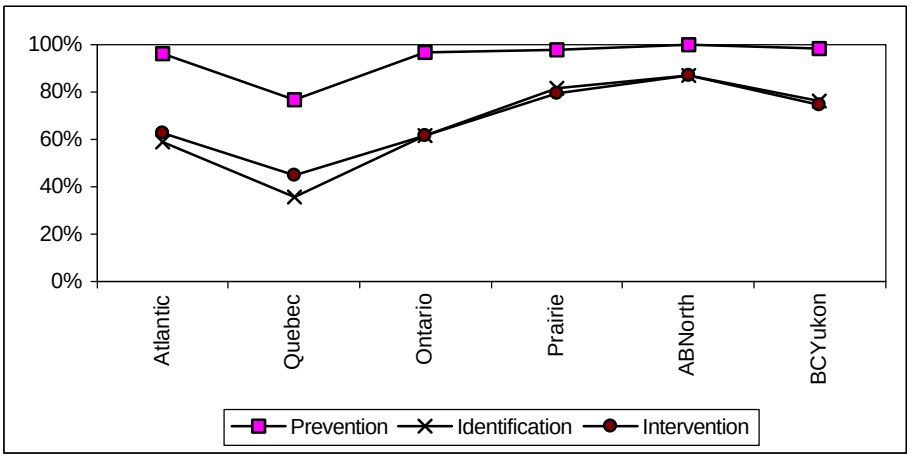
Interestingly, the proportions remain relatively consistent across funding programs, with prevention being the dominant activity area in each. It might have been anticipated that CPNP programs would be more involved in prevention activities because their program focus is pregnant women. Similarly, CAPC projects, with their focus on young children, might have been expected to be more involved in intervention activities. The fact that this is not the case again suggests that projects approach their programming in a broad, inclusive way.

Projects Involved With Each Activity, by Program



The relative proportions of respondents doing work in each of the three activity areas remain fairly consistent across the regions. The bulk of the activity across all regions lies in the area of prevention. The greatest amount of activity across all areas of prevention, identification and intervention occurs in the western regions.

Projects Involved With Each Activity, by Region



Project activities

Prevention activities

Projects were asked to identify specific prevention activities when women come to the project and when the project reaches out to the community. Prevention activities were defined as,

> *Those activities directly or indirectly intended for pregnant women, women of childbearing age and their partners. These activities can occur from pre-conception to the birth of the child and may help in preventing alcohol and other drug use during pregnancy or in reducing the harm arising from prenatal substance use.*

Frequency of Prevention Activities, by Program

When women come to the agency	CAPC (159) %	CPNP (173) %	AHS (20) %
Building trusting relationships with women	84	92	75
Promoting prenatal health care	82	96	80
Promoting prenatal nutrition	79	97	60
Fostering prenatal attachment	64	79	50
Providing written information	69	85	60
Providing education on prenatal substance use	60	82	55
Identifying at-risk women	60	81	40
Identifying at-risk families	57	69	40
Providing information or referral for addiction treatment	67	71	55
Providing addiction counselling	22	27	10
Providing access to birth control	26	54	15
Referral to other community services	84	84	85
Case management	40	44	15
Advocacy for the client	63	63	55
Facilitating access to childcare	56	53	40
Transportation to appointments	50	58	30
Other	16	16	15

The survey responses indicate that the most prevalent activities are those that are more closely related to core responsibilities and mandates of the project (engagement, support and referral):

- Building trusting relationships with women in order to discuss substance use;
- Promoting prenatal health care and good prenatal nutrition. Prenatal substance use co-exists with many other prenatal risk factors, including poor prenatal health care, and poor nutrition. Improving these areas of care in the woman's pregnancy improves fetal outcome regardless of substance use;
- Fostering prenatal attachment. The level of a woman's attachment to her infant prenatally is positively correlated with her motivation to make changes about her substance use;
- Providing written information on prenatal substance use;
- Providing education to women and families on prenatal substance use, either through individual or group services;
- Providing referral for addictions treatment or to other community services.

The prevention activities engaged in less frequently by projects include those requiring more specialized services and resources:

- Addiction counselling;
- Service coordination;
- Case management;
- Access to birth control.

On average, groups are engaged in fewer prevention activities that are directed to the community than they are in activities directed to the women whom they see in their services. This is not unusual given issues of priorities, mandates, and resources.

Frequency of Community Outreach Activities, by Program

Reaching out to the community	CAPC (98) %	CPNP (107) %	AHS (6) %
Group education/awareness sessions	62	62	30
Training community workers to identify high risk men and women	25	20	15
Distributing materials/resources	69	79	65
Outreach/identifying at-risk clients	43	46	30
Advocacy for preventing substance use during pregnancy	42	44	40
Community development	45	41	40
Home visits	64	78	55
Establishing networks/coalitions to address prenatal substance use	32	29	20
Other	14	9	25

Nevertheless, there are many examples of prevention work directed to the community. The most prevalent activities are those that are less intensive and closer to the core project mandate:

- Group education/awareness sessions;
- Distribution of materials/resources;
- Home visiting to decrease isolation and provide education.

Less prevalent community prevention activities are those that are further from the core mandate and those that require specialized knowledge and training:

- Outreach/identifying at-risk clients or training other community workers on identification of high risk families;
- Advocacy for preventing substance use during pregnancy;
- Community development;
- Establishing networks/coalitions to address prenatal substance use.

Identification Activities

Projects were asked to indicate which activities they use to identify infants and children who have been affected by prenatal substance use. Identification was defined as

> *Those activities that identify the drug affected person—either as newborns, children, adolescents, or adults—through identification or diagnosis by a physician; and support screening by intermediaries (i.e. public health nurses, teachers, social workers and others) for referral and possibly case managing.*

The responses, by program, are given in the table below.

Frequency of Identification Activities, by Program

Identification activities	CAPC (159) %	CPNP (173) %	AHS (20) %
Building trusting relationships in order to discuss substance abuse with family members	70	68	80
Observations of children (physical, developmental, behavioural)	69	66	85
Screening/assessment of children	26	29	30
Referral to physicians for assessment/diagnosis	43	46	55
Case management	28	25	5
Home visits	45	55	55
Other	11	14	15

The most prevalent identification activities are those closest to the basic support role:

- Building trusting relationships in order to discuss substance abuse with family members;
- Observations of children in their programs;
- Home visits. Home visits not only provide significant support for families, but also offer an opportunity for providers to gain a broader understanding of the situations of families and children. This may facilitate relationship building, provide additional opportunities for observation, and, therefore, greater opportunities for identification of needs.
- Referral to appropriate community services. Projects report that if they have concerns, based on observations or on information from families, they make referrals to physicians or other professionals for assessment and/or diagnosis.

The less prevalent identification activities are those that are more clinical or that may feel more intrusive or counter to the support role they play:

- Screening and assessment. Some projects use developmental screening tools, but there is no common screening approach across all projects and across regions. Readiness and skills to assess FAS-affected children are noticeably different across the country, although capacity is better in western Canada.
- Case management activities relating to identification of children who have been affected by prenatal substance use.

Projects were asked which screening tools they use to identify affected children. The responses are given in the table below. It is clear that few projects are using the screening tools identified in the survey.

Frequency of Use of Screening Tools, by Program

Screening/assessment tools used	CAPC (159) %	CPNP (173) %	AHS (20) %
FASNET Assessment Tool	8	0.6	5
Battelle Developmental Inventory	1	0.6	0
Bayley Scales of Infant Development	1	2	0
DISC	6	2	20
Stanford Binet Intelligence Scale	2	0	0
Vineland Adaptive Behavioural Scales	1	0.6	0
Other	25	35	10

There may be several reasons why reported use of screening tools is so low:

- Many instruments are not normed culturally;
- There is a cost issue attached to purchasing screening/assessment tools, and to training or hiring credentialed staff to administer them;
- Formal screening does not fit with the overall approach of the project.

Intervention Activities

Projects were asked to indicate those activities that they use to assist infants, children and families who are affected by prenatal substance use. Intervention is defined as,

> *Those activities that are intended to prevent and reduce harms associated with primary and secondary disabilities of alcohol or other drug exposed persons. Includes measures directed to individuals with FAS as children, adolescents, adults and management of the FAS child, parenting, family support, school issues, vocational training, young offender and criminal justice issues.*

There was little variation from program to program. The responses are provided in the table below.

Frequency of Intervention Activities for Affected Children, by Program

Intervention activities directed to affected infants/children	CAPC (159) %	CPNP (173) %	AHS (20) %
Facilitating appropriate assessments, diagnosis and interventions	30	34	35
Providing a consistent and structured environment for children	35	25	70
Assisting other organizations to provide an appropriate environment for affected children	22	19	25
Regulating sensory stimulation in their environment	29	34	40
Providing early intervention services for children with developmental vulnerabilities	65	50	70
Strengthening the parent/child interaction	42	28	65
Assisting children to become school ready	11	9	35
Academic assistance	36	29	45
Home visits	47	49	50
Other	13	12	10

Projects reported that the most prevalent intervention activities for affected children were those that were consistent with their core mandates:

- Providing early intervention services for children with developmental vulnerabilities;
- Strengthening the parent-child interaction in families who are affected;
- Home visits.

Less prevalent intervention activities were again those that may be perceived to be less central to project mandates or involved greater specialization. These included:

- Facilitating assessment, diagnosis and interventions;
- Regulation of the environment;
- Assisting children to become school-ready, or providing academic assistance.

Projects were asked about intervention activities directed to families of affected children. Their responses are given in the table below.

Frequency of Intervention Activities for Families of Affected Children, by Program

Intervention activities directed to families of affected infants/children	CAPC (117) %	CPNP (113) %	AHS (16) %
Supporting and promoting positive parenting practices	74	65	80
Providing parents with general knowledge of child development and behaviour	42	34	50
Helping parents understand what can or cannot be changed with regard to behaviour, learning style and memory in their affected children	76	64	75
Helping parents develop specific skills in behaviour management	33	28	35
Providing counselling and emotion support to parents	52	48	55
Encouraging male participation in counselling	36	32	30
Linking parents to others who have coped in similar circumstances	36	24	35
Drop-in service for parents	35	21	30
Referral to treatment services for family members	53	57	65
Facilitating appropriate childcare services	35	30	35
Facilitating appointments and access to services	42	39	30
Facilitating respite care	25	20	15
Other	9	7	15

The activities with greatest prevalence were:

- Supporting and promoting positive parenting practices;
- Helping parents understand what can or cannot be changed with regard to behaviour, learning style and memory in their affected children;
- Providing counselling and emotional support to parents;
- Referral to treatment services for family members.

The other activities were all reported at about the same level. These are activities that tend to fall outside core activities, such as facilitating childcare services and appointments. Activities involving general parent coping and respite are done to a lesser extent than those that involve direct education of and interaction with parents.

Project-level challenges to conducting FAS-related activity

Gaps in service

In the survey, projects were asked to identify gaps in the community with respect to services addressing pregnancy and substance use, and FAS. This was an open-ended question. The responses have been grouped into several general categories or themes that are described below, in decreasing order of frequency of response.

1) Lack of treatment and counselling services for substance abuse, and lack of services for prenatal substance abuse. A number of people mentioned lack of treatment services that allow women to retain custody of their children and to care for their children while in treatment. There was frequent mention of the fact that there were no services within the community to which clients could be referred for help. (Mentioned by 85 respondents)
2) Lack of coordination of services and lack of inter-agency awareness. (Together, mentioned by nearly 30 respondents) Several respondents also mentioned lack of case management.
3) Lack of community-wide support and awareness of the issues around substance use during pregnancy, leading to judgmental approaches. A number mentioned lack of support for the issue by elders. (Mentioned by more than 20 respondents)
4) Lack of school education programs and lack of general education programs within the community. A number of respondents mentioned the importance of early outreach and education for young people. (Mentioned by more than 20 respondents)
5) Lack of follow-up support and care: post-pregnancy and post-treatment. This included several mentions of need for a support group. (Mentioned by more than 20 respondents)
6) Lack of support by health professions, and health professionals as poor role models. A number of these refer specifically to problems with doctors who do not recognize or identify the problem, and who do not advise against drinking while pregnant. There was also a mention by several people of poor role models within the helping professions, e.g., nurses who smoke. (Mentioned by more than 20 respondents)
7) Lack of good resources, including culturally sensitive and linguistically appropriate resources. (Mentioned by more than 15 respondents)
8) Lack of funding. This includes lack of long-term funding. Several respondents mentioned the problem of using a short-term approach to the problem and the challenges of working with year-to-year funding. (Mentioned by more than 15 respondents)

9) Lack of staff. Lack of qualified individuals to do diagnosis and assessment. Lack of transportation or availability of services within the local area. Lack of information about the issue. (Each mentioned by 10 or more respondents)

Additional gaps that were mentioned by a few respondents were lack of training for staff, lack of general services (housing, social), lack of services reaching out to new immigrants, and lack of early intervention programs.

Funding

There are very few Health Canada funded projects that are funded specifically to address substance use issues during pregnancy. We asked whether project mandates deal specifically with issues of substance use during pregnancy (single issue), or whether they deal with prenatal substance use among other issues (multi-issue). The results are provided in the table below.

FAS Funding for Programs

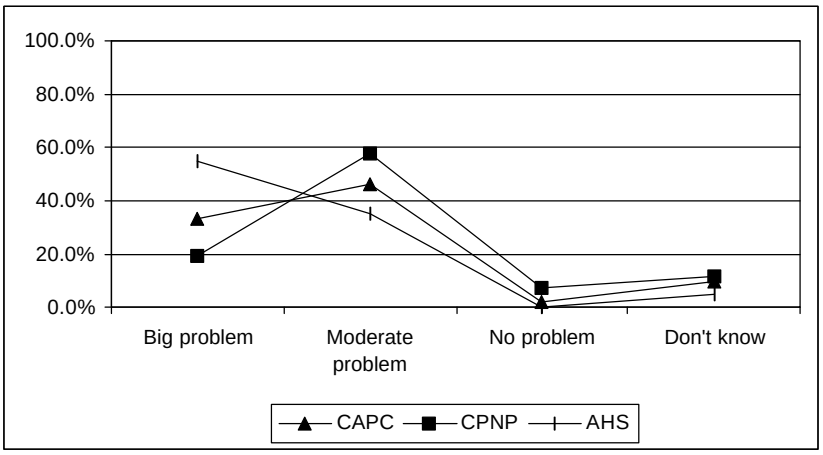
Program	Number reporting	Single Issue	Multi-Issue	Receiving FAS funding
CPNP	173	7	132	4%
CAPC	159	13	112	8%
AHS	20	2	16	10%

Relatively few projects receive specific funding for prenatal substance use issues. While FAS-related activity is occurring within an overall concern for mother and child health, the level of FAS activity undertaken by projects is, understandably, related to the amount of funding for FAS activities.

Public awareness and community support

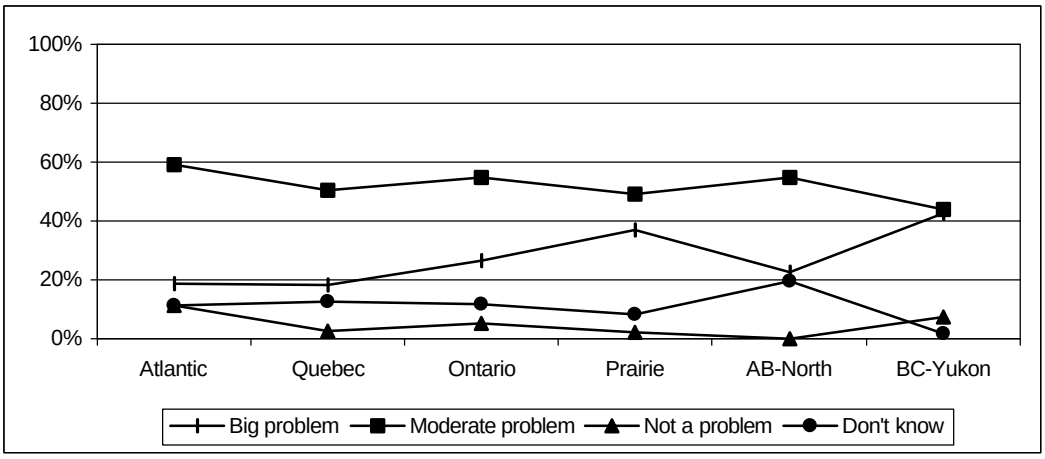
Agency and public awareness is in many ways fundamental to advancing any issue. In the survey, projects were asked to estimate how big a problem prenatal substance use is in their community. This question addresses the level of awareness of the issue across projects and communities, and the fact that it is variable.

Estimate of Severity of Problem, by Program



Most respondents considered substance use during pregnancy to be a moderate problem. More AHS projects considered it to be a big problem than a moderate problem.

Estimate of Severity of Problem, by Region



BC-Yukon and the Prairie regions had the highest percentage of projects responding that pregnancy and alcohol use was a big problem in their communities (43% and 37%, respectively). Most regions reported that they considered prenatal alcohol use to be a moderate problem in their communities. Eleven percent of projects in Atlantic Canada reported that substance use during pregnancy was not a problem. BC-Yukon was the second highest region reporting that it was not a problem (7.4%). It appears that readiness to recognize and address FAS varies quite widely within regions and within funded projects.

Good practices in addressing FAS

The lessons learned from the experiences of CAPC and CPNP projects, working with families and children affected by alcohol or other substance use, are of benefit to all Health Canada community-based projects that are working in this area, or intend to develop services to address these issues. The work of projects active in this area constitutes a rich resource for others and can serve to enhance community capacity to prevent, identify and intervene effectively in support of women at risk, affected children, and their families.

In both the project survey and the key informant interviews, respondents were asked to identify elements of good practice in FAS programming within CAPC and CPNP projects. The practices identified through these methods were generally supported by the findings of the concurrent Health Canada project *Best Practice and a Situational Analysis Regarding Fetal Alcohol Syndrome/Fetal Alcohol Effects and the Effects of Other Substance Use During Pregnancy,* and are discussed below.

Elements of good practice

Providing one-to-one support, counselling and teaching

The most important practice is to create a physical and emotional environment that is welcoming, and safe. This means that clients always know what to expect and there is a consistent message given out by the staff that reflects an overall philosophy of non-judgmental acceptance, caring, and belief in the capacity of women to improve their own health and that of their children. Incorporating culturally relevant pictures and objects helps to provide a familiar and welcoming setting. It helps if attendance is voluntary and clients can withdraw when they decide the time is right. Providing opportunities for one-on-one counselling is essential to the development of a relationship of trust with the clients, within which they can feel safe to discuss difficult and sensitive issues such as substance use. This may take considerable time and may evolve in unexpected ways. Being open and honest about the project mandate and goals is essential, including openness about relationships with other agencies, such as child protection services. The paramount guiding principle is to be respectful and non-judgmental.

If possible, allow the client to direct where the interaction takes place (at the centre or in the home). Ideally, programs using a combined centre-based and home-based approach have an opportunity to assess, observe and intervene in a variety of settings. It is particularly important to assess the home environment of affected children. This is not always possible, however, given the resources of the project, and the nature of the work to be done.

Many women who are in recovery must sever relationships with friends and family members who were part of their lifestyle when using. These losses often result in feelings of loneliness, sadness, and isolation. It is important to provide an opportunity for forming new relationships, to reduce the woman's isolation and to promote the development of a healthy, non-using, personal support system.

There must be adequate staffing resources to ensure that clients receive the attention they need, and that the staff is not overburdened. Caseloads must be reasonable. Financial and other resources are rarely adequate to meet all program needs, and one-to-one interactions are time-intensive and expensive. These activities can be justified, however, by their importance in the development of relationships that allow for the discussion of sensitive and difficult issues such as prenatal substance use. One-to-one interactions can accomplish things that group sessions cannot. Consider delegating some of the work to peer leaders or other staff, to allow time for one-to-one counselling at the end of group sessions. Build upon linkages with other agencies and initiatives that provide one-to-one services. Know what is available in the community and work to promote a consistent philosophy in working with the client.

Bringing an addictions worker into the project can work well, especially when the role of that worker is integrated into the overall project activities and their philosophical approach is compatible with that of the project. The addictions worker will need to build trust before doing education or intervention with clients. The good practice projects have embraced a harm reduction approach, and the addictions worker should accept and adopt the same philosophy in working with clients of the project. When doing addictions work, it is important to --- recognize that the issues underlying women's substance use may be different from those underlying substance use by men. There tends to be a lack of understanding about women's substance abuse and its complex dynamics.

Lack of childcare is identified as a primary barrier to service for women who struggle with substance use issues. Availability of on-site childcare is critical in order to acknowledge women's roles as mothers and to support women to access the supports that they require around addiction and parenting. Finding appropriate space for one-to-one meetings, as well as for childcare, is an additional burden on scarce resources, but is crucial. Transportation is also cited as a barrier to service for women whose financial resources are fixed and limited. If possible, support for transportation to and from sessions should be arranged.

In the context of a supporting, non-judgmental relationship, using a brief screening instrument to help women recognize when their alcohol or substance use is at high risk levels.

Only one project that was surveyed uses a screening instrument to help women recognize when their alcohol or other substance use is at high-risk levels. Questions from the TWEAK screening instrument are embedded in their general intake questionnaire that is administered to all clients during the first visit to the program. These questions are asked again, for tracking purposes, every time clients come in for the program. The first intake session takes approximately one hour, although it may take longer if a difficult or sensitive issue arises during the interview that requires more time to adequately explore or process.

> *"It happens all the time where you get to the question about miscarriage or that they've had a SIDS death, and that's as far as you go on that day."*

Before the interviews begin, women sign a consent for release of information, so that they are aware that the information they give may be shared with their doctor, the public health

nurse, and the labour and delivery personnel. Project staff explain that the interview is an opportunity to get to know them. Women are told that these questions are asked of everyone in the project. It is a structured interview, interspersed with questions designed to build trust and emphasize strengths. It begins with questions about relatively non-threatening issues, including demographics, health and obstetric history, nutritional status and dental practices. Then, there is a gentle transition to questions about use of caffeine, use of cigarettes, use of alcohol, and use of illicit drugs. It is important to assume that everyone is using something. Occasionally, there are people who report that they do not use anything during their pregnancy, but these are certainly the minority.

Most women agree to participate in the intake process. In fact,

> *"…the first thing that we find is that they're usually relieved. They're so relieved to have been finally able to talk about it, because there isn't one woman, including myself, that didn't do something at the beginning of her pregnancy that she regretted. And it is a relief to know that she has a forum to talk about it, where she feels safe, understood, non-judged, and where she can ask the questions that she wants to ask."*

This CAPC/CPNP project reports that it is not necessarily the *nature* of the questions that are asked, but *how* they are asked that makes a difference as to whether this process will be perceived as threatening or not. In this project, the interview is conducted using a solution-focused counselling approach at all times. Throughout the interview, there is an effort to notice and acknowledge women's strengths and capacities, and to build self-esteem. It is critical to not react or judge, but to normalize the behaviour that is being reported and to speak openly about it in a supportive context:

> *"I know during you're pregnancy you're going to have birthdays, you're going to be going to parties, you're going to be going to places where there's marijuana smoke, (where) there's alcohol, (where) there's cocaine…Probably your partner uses. What is that going to be like for you? What has it been like so far?"*

There was initially some resistance from staff to introducing a structured, formal interview procedure. Until the interview had been integrated with a motivational counselling approach, "it did feel like you were interrogating". The use of a motivational counselling approach, however, transforms the process from an interrogational, information-gathering exercise that is project-directed, to one that is supportive, positive, and designed to build an open and trusting working relationship between provider and client.

Incorporating a motivational counselling approach to help women recognize their substance use and to seek support.

Motivational interviewing is an approach designed to help clients build commitment and reach a decision to change. It draws on strategies from client-centred counselling, cognitive therapy, systems theory, and social psychology. It combines elements of

directive and non-directive counselling approaches, and can be integrated with a broad range of strategies and models.[2]

Some good practice projects use a motivational counselling approach to implement a stages of change model[3]; others have implemented a solution-focused brief therapy approach[4]. Whichever model is applied through motivational counselling, creating a sense of empowerment is central. There is recognition that, to a great degree, people know what works and does not work for them.

> *"It's a way of talking about solutions and having the client tell you through their lens what it is that they're doing that's making a difference in their life."*

There is a clear consensus, among successful projects, that emphasizing small steps and small changes, and celebrating those accomplishments is crucial. Acknowledging small gains and always emphasizing positive changes is essential to create in women a sense of positive self-esteem and empowerment, and a context of hope and possibility for change. Providing factual information and education in the context of a caring, non-judgmental trusting relationship can support women to make significant and difficult changes regarding their substance use..

Integrating an addiction counsellor or other staff member with addictions-related expertise into the program can be very helpful. One project had difficulty working with the local treatment centre because of their zero tolerance approach; however, they had great success when they began working with the counsellors at the Native Friendship Centre. They had a harm reduction approach that was entirely client-driven.

Accepting that women may not be able to quit but can only reduce harm

For the good practices projects that were interviewed, a harm reduction philosophy was the 'only thing that made sense'. As one person put it,

> *"If we're not using a harm reduction approach, who's going to come?"*

Harm reduction is a public health alternative to the moral/criminal and disease models of drug use and addiction. It recognizes abstinence as an ideal outcome but accepts alternatives that reduce harm. This includes encouraging reduction of substance use without requiring abstinence, and giving a 'less is better' message to clients. A harm reduction approach recognizes the complex needs of the client rather than focusing solely on the substance use issue.

It is essential to understand alcohol and drug use in the context of other risk factors in a pregnant woman's life. When staff understand, for example, that improving a woman's

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[2] Miller, William R. & Rollnick, Stephen (1991). *Motivational Interviewing: Preparing People to Change Addictive Behaviour*. New York: The Guilford Press.

[3] Prochaska, J.O., & DiClemente, C.C. (1982). Transtheoretical therapy: Toward a more integrative model of change. *Psychotherapy: Theory, Research, and Practice,* 19, 276-288.

[4] Berg, Insoo Kim & Reuss, Norman H. (1998). *Solutions Step by Step: A Substance Abuse Treatment Manual.* New York: W.W. Norton & Company.

nutritional status as well as her access to prenatal health care means that her baby is less likely to be affected by prenatal substance use, they are better able to recognize that they can have important impacts on the outcomes for mothers and babies in their programs. Understanding how important these small steps can be in contributing to positive outcomes can act as strong motivators for staff who may feel overwhelmed by the complex needs of a pregnant woman who is using substances.

A harm reduction approach takes into account woman-centred and family-centred approaches. It recognizes and respects the ability of the family, and assists the family to regain ability after trauma (such as residential school experiences). It recognizes the complex needs of the woman, and the various interventions that may promote better outcomes for herself and her fetus.

Successes may be undermined when the client interacts with professionals (e.g. medical professionals/hospital providers) and others (e.g. family members) who deliver negative and judgmental messages about their behaviour. It is important to advocate within the community for a common approach to the problem. Clients who are using can be resistant, overburdened and very difficult to work with, and their behaviour may alienate health professionals, family members, friends and others

In many communities, it can be difficult to find appropriate addictions treatment, particularly for pregnant women. Many treatment facilities require abstinence and will refuse treatment with a single "transgression". The best treatment option is a program utilizing woman- anf family-centred approaches to treatment, which, if available, can mean long waiting lists to contend with.

Women who use substances fear apprehension of their children. Indeed, substance use can present an impediment to appropriate parenting, and children of parents who use substances are at greater risk for developmental problems as well as for abuse and neglect. Providing clients with education and information about how children can be affected by their parents' substance use can be a strong motivator for change for some clients. Be clear with clients about your relationship with child welfare services, and outline your responsibilities should you be concerned about the child's safety or well-being. Be open about how you will involve clients and inform them about any discussions you might have with other agencies regarding your concerns. Advocating for the client is an important role for staff; however, this advocacy becomes much more complex when there is a child involved who may be at risk. In all good practice projects, the needs of the child are recognized as paramount in the work that is done with women and their children. Balancing the role of supporting and advocating for the woman with that of advocating for the child when necessary is the most challenging work to be done. The good practice projects have been able to process these difficult issues and concerns with women honestly, openly and directly, and in a manner that does not rupture the trusting relationship that has been developed.

Incorporating a peer support component as part of the model

Parent support groups are very important in the lives of parents of children with FAS. The challenges of parenting an FAS child can lead to isolation and frustration. Talking to other

parents allows an opportunity to exchange important information and to vent frustrations experienced with the system. It may be necessary to create different parent support groups within a community in order to meet specific needs; for example, a support group for birth parents, a group for foster parents, a group for older children of FAS parents (especially teenagers), and a group for parents who have FAS.

The creation of 'empowerment groups' or 'discovery and empowerment groups' allows women to talk about what's important to them. They may choose to talk about assertiveness and relationships rather than alcohol and drug use, i.e., the underlying factors for their use. AA meetings do not work for some people, and it can be important for women to have a venue of their own to discuss the unique factors of their lives that lead them to alcohol and drug use.

Use of peer leaders in projects can accomplish a number of things. It can allow staff to focus on things they do best, such as one-to-one counselling, while peer leaders work in other areas. It can be a tool for empowering clients to feel good about themselves and to pass along their own successes to others. Peers can work to raise community awareness, or to facilitate groups. Inclusion of peers can add essential credibility to workshops and community visits. Peer testimony at such events breaks down barriers and encourages sharing of experiences. Compensate peers for their efforts, if at all possible. It helps build self-esteem by formally recognizing the importance of their contribution. Peers can attend conferences with staff, talking about their experiences and meeting other peers.

Peer leaders do continue to require individual support and supervision. To justify the expense of developing peers, consider asking for a three-month time commitment.

One project has developed a student peer education group within local schools that has been successful. It operates over multiple years, reaches the entire student population, and compensates the peer leaders for their time.

There are challenges in using peer leaders and the boundaries must be clearly established. It can be difficult for staff to adjust from seeing someone as a client to seeing them as a peer. If someone has never had an opportunity to show leadership, there may be issues of misuse of power and control within the group.

Providing early identification of children affected by substance use during pregnancy

Early identification allows for more effective interventions for children who may be affected by prenatal substance use. Problems within the family can be reduced through early education and altering of the child's functional environment. Outreach to education and service providers will help with the integration of the child into the environment, and help to avoid labelling the child as 'just a bad kid'. It provides an opportunity for counselling, education, and modification of environmental factors that are difficult for the child.

Early identification initiatives should involve public education and community consultation. A community task force or committee on alcohol and pregnancy can be an effective tool for getting the message out. If building community capacity is incorporated

into the project's mandate, then it is easier to initiate programs that work with other agencies and services.

If possible, don't wait for a formal diagnosis before intervening with an affected child. The project can facilitate obtaining a diagnosis with the family, and support the family through the process from beginning to end. It can take a long time to obtain a formal diagnosis of FAS, and in the meantime little is happening to help the child.

The mandates of most projects do not allow identification and intervention with older children with FAS or adults with FAS. When the project becomes known in the community as having expertise with this issue, there will be appeals for information and help from extended family or friends of people with FAS. Consider offering a phone consultation service, with referral to other agencies (if they exist) for people who need to know what to do for older affected children or adults. Confidentiality, and often anonymity, is important for such a service.

Identification and diagnosis do not mean access to services. Because services continue to be tied to the child's Developmental Quotient (DQ) or IQ, children affected by alcohol may be excluded from some supports. To overcome this barrier, it is important to inform policy-makers and advocate with other agencies and services.

Advocating for the child and family with other agencies in the community

Providing case management and service coordination functions in addition to referral are important. A single staff person can be a most effective support in negotiating the myriad services and systems, and advocating on behalf of the family. However, this can be very time consuming and difficult work, involving everything from attending case meetings to accompanying families to appointments.

It means developing strong partnerships. Often great partners are found, but subsequently move on to other work or other locations. It is ongoing work to find partners and it can be frustrating. However, as one person put it,

> *"Any program that says 'I'm going to work by myself and just do this' is never going to work."*

It helps if there is coordination among agencies and governments. Staff can help those agencies evolve in their understanding and commitment. Education of service providers works best if the educator is at the same level as those being educated, e.g., geneticists talking to physicians; alcohol and drug experts to educate addictions workers. As one person put it,

> *"It helps to think of the agency in the same way as the family, using a stages of change approach. Look for small steps and improvements."*

If there aren't sufficient services within the community, try to create linkages with agencies outside of it. One project successfully negotiated an inter-provincial health service support for the community.

In the Yukon, where FAS awareness is relatively high because of media coverage, there are projects to provide support for adults with FAS. These include projects to provide residences for assisting adults living with FAS.

Providing a stable program environment for an affected child and supporting stability at home

The best way to accomplish this is to build relationships with providers in other systems that have contact with FAS-affected children and their families. The project may need to provide direct consultation with other systems and providers in the community, e.g., childcare centres and schools. Assistance can be given to other providers to create opportunities to support children with FAS in their settings, e.g., a sensory integration facilitator or an educational consultant. If necessary, consider providing a facilitation role between parent and teacher, to promote consistency in approach between the home and school.

Emphasize to parents that their child has FAS or behaviours indicative of FAS, but has a unique personality. It is important to remember that FAS is just part of the child's life, and treat them the same as any other child, keeping in mind their limitations.

Developing written resources on FAS to guide other systems and providers is one support that can be given relatively easily. Resource packages can be prepared relatively easily and cheaply to cover the information relevant to the individual client's needs.

Assist parents in finding respite care, through agencies or through parent support groups. Respite care helps to reduce parental stress, and provides opportunities for the child to interact with other children and engage in new experiences in stable environments.

Providing or facilitating support to the family of an affected child

Being trustworthy will go a long way to supporting the family. Supports can be anything from interventions with the healthcare or educational system to providing basic needs support (e.g., transportation to and from appointments, or ensuring food by transporting families to food banks).

When supporting the family, watch for 'teachable moments' when key knowledge can be imparted and absorbed by the family. Reinforce messages about the affected child, remembering that people can only take in so much information and understanding of implications at one time.

Using developmental assessment can be a barrier. The result may not seem relevant to parents. It may be better with FAS families to use a functional assessment (how the child functions in its environment). Observing them in the larger context provides valuable information and allows you to work to improve that context, e.g., home environment, school/daycare environment, parents' environment.

Having a 0 to 6 mandate can be a barrier to providing consistent support to an FAS child. In many cases there are no further supports to a child that will need help throughout its life.

It can be difficult in many communities to find any agencies to provide supports for affected older children.

Working with parents who have FAS themselves provides unique challenges. More expertise is needed in working with adults with FAS. Far more reinforcement of messages is needed, and long-term support is essential.

Evaluation/monitoring activities

Evaluation and monitoring is essential if projects are to provide effective activities. However, it means spending time doing something that may not seem as important as other activities. All of the good practice projects emphasized the importance of evaluation and monitoring. This should be done in an ongoing way, and integrated into the overall work of the project. It helps to think about and plan for evaluation at the front-end, when designing the project activities.

Valuable feedback can be gained from participant satisfaction surveys, especially if participants are engaged in helping to design the evaluation. Participant surveys must be done in a personal and respectful way. Face to face interviews with participants are very important, particularly in cases of low literacy. Practice-based research can provide very useful information to projects. Waiting until participants leave the program to obtain feedback can be a problem. Sometimes families move away before they can be asked to help evaluate the program.

Always provide opportunities for clients to provide feedback and let them see the results of their feedback in the form of real change. Consider providing incentives to giving feedback, e.g., door prizes, and public acknowledgement of their input. Focus groups can provide valuable inputs, as can feedback from community consultations and training.

When eliciting feedback, try to allow an open-ended component. You can learn unexpected things about the impact the project has had. During the course of an interview with a former participant, one person stated, “I’ve learned that I shouldn’t leave my child alone.” The staff had never known that this was a problem, but could incorporate that into future educational components.

A number of the project managers interviewed have wrestled with how to do effective evaluation and monitoring. They have all worked out successful components to evaluation and monitoring, although some feel they can do better. Sharing this kind of information will be a valuable exercise for all of the projects.

Other advice

Taking a hard line, being critical, using scare tactics, intimidation, guilt, and pressuring clients are counter to achieving positive results. Similarly, creating fear of the consequences of substance use during pregnancy creates a situation where the client will withdraw, and may have the opposite effect to that which is intended.

Location of the program is important. It must be accessible with as few barriers as possible. It may be better to be near a clinic than to be located within one. Location near

needle exchange or friendship centres, and in the downtown core, can all facilitate outreach to clients. The physical environment is important. It should be welcoming and have familiar cultural referents.

How you name things, the language you use to describe yourself or your activities, will determine who comes to the table with you and how you're perceived in the community. A specific focus in the name can create a barrier by stigmatizing those using the program. Use something more holistic rather than just focusing on hard issues, e.g., 'empowerment and development group' rather than 'alcohol and drug group'.

Understand that this may be the only place a woman can go when she is using during pregnancy. She may go the program when she's not going to a doctor, addictions program, or health nurse. It is important to reduce social isolation, so attending group sessions can help women to connect and form healthy relationships.

Having the same staff person working with the family over time, and mediating between family and agencies is very useful. However, this has implications for the importance of retaining staff. Staff supports such as training, stress debriefing, and adequate compensation are essential to providing an ongoing advocacy role for a child and a family. Helping staff develop new skills or become specialists on issues strengthens the project and the community.

Active dissemination of information to create greater community awareness helps to bring the issue into the open. This includes working in schools starting at a young age, and using culturally sensitive materials. Materials that are visual, designed for low-literacy, and require less reading were judged to be the most effective. This can lead to greater involvement of the community, especially elders.

Selection of projects illustrating elements of good practice

Nominations of projects demonstrating one or more of the elements of good practice were solicited from project advisory committee members as well as from Health Canada regional program consultants. Ten projects were nominated and six projects were selected for interviews. The main consideration in selecting the final six to be interviewed was to obtain reasonably even distribution across program areas (i.e., prevention, identification and intervention) and across the country. All of those selected agreed to participate.

The selected projects received faxed letters of invitation to participate in the interviews, together with an interview guide including background to the project and the questions to be reviewed (see interview guide in Appendix 6B). Projects were informed of the elements of good practice on which they would be asked to comment, and were encouraged to consult with colleagues and others in their projects as preparation for responding to the interview questions. The program coordinator was interviewed in five of the projects; an FAS worker was interviewed in the other project.

The primary purpose of the interviews was to determine how the projects implement these elements in effective ways. The goal was to provide concrete information to others intending to develop and implement similar activities in their projects.

Description of Projects

Food for Thought : Saskatoon, Saskatchewan (Pam Woodsworth, Program Coordinator)

Operating since August 1995, Food for Thought is funded by CPNP and is sponsored by the Nutrition Department of Public Health Services, Saskatoon District Health (SDH). It is a community-based outreach program, delivered through a partnership model, which assists high-risk, economically disadvantaged pregnant and parenting women to achieve a greater level of health. The project methodology focuses primarily around nutrition and cooking groups, although project staff meet with women individually as needed and refer them to appropriate support services when required. Milk and vitamin supplementation for women participating in Food for Thought is provided through the Healthy Mother, Healthy Baby Program.

Staffing for the project includes a project coordinator, a project nutritionist, a health aide, and peer leaders, who are graduates of the project. More recently, an addictions worker from one of the partner agencies has begun to work in the project. Program activities are offered at four sites: the Family Support Centre, the Westside Community Clinic, the Saskatoon Open Door Society, and the Saskatoon Tribal Council. Clients are largely First Nations or Métis women, and immigrant or refugee women.

FAS Community Action Project, Fetal Alcohol Syndrome Society of Yukon : Whitehorse, Yukon (Jeddie Russell, Coordinator)

The FAS Community Action Project received CAPC funding between November 1998 and March 2000. The project had three major elements. The first element was to create and distribute a prenatal bag, aimed at creating awareness of alcohol related birth defects and a high degree of hidden alcohol use in the community. The second element of the project involved the development of workshops on FAS. The development process was community-driven, and five First Nations communities participated in developing the content of six workshops. The third project element was parent support. The project sent four families to the parent support FAS conference in Anchorage, Alaska in 1998. The families' attendance at the conference resulted in the birth of a parent support group in Whitehorse.

The geographic mandate of the project was the Yukon Territory. Work was done to reach out to and link with other related resources and service providers. The FAS Community Action Project worked closely with the CPNP worker in the Territory, and supported and mobilized her with information in the area of FAS. The project linked individuals and families throughout the Territory with the CPNP worker.

Interagency Fetal Alcohol Syndrome/Effects Program: Winnipeg, Manitoba
(Deborah Kacki, Program Coordinator)

Operating since 1995, the Interagency Fetal Alcohol Syndrome/Effects Program is funded by CAPC and operates through a partnership of four agencies: Mount Carmel Clinic; Pregnancy Distress Family Support Services; New Directions for Children, Youth and

Families; and Winnipeg Child and Family Services. The partner agencies comprise the steering committee of the project. The project is located in the Manitoba Housing complex in the North End of Winnipeg, near the Mount Carmel Clinic.

The mandate of the project is to provide direct and support services within the City of Winnipeg to children aged zero to six who are affected by prenatal exposure to alcohol or other drugs. The service also extends to their families and secondary caregivers, e.g., childcare providers and teachers. Initially, the project provided support to women who were pregnant and using substances. Now that two other projects in Winnipeg are providing services to the prenatal population, pregnant, substance-using women are referred to them. If, for any reason, the referrals do not meet the specific criteria of the other projects, then the Interagency Fetal Alcohol Syndrome/Effects Program provides services to the prenatal participant as a priority. Seventy-two percent of participants in the project are of Aboriginal background.

Healthy Generations Family Support Program: Sioux Lookout, Ontario (Judy Kay, Program Coordinator)

Originally funded under CAPC, in 1994, the program's mandate for the first four years was to work with community residents and service providers to identify and respond to the needs for FAS information, education and support services in the Sioux Lookout and Red Lake communities. Primary, secondary and tertiary prevention activities were also undertaken. After the first 3-1/2 years of operation, there was a shift in mandate to a focus of offering frontline family support services around the issues of FAS/FAE and working with high-risk families with children 0-6 years. The geographic catchment area of the project is Sioux Lookout (pop. 5,000) and off-reserve communities in the surrounding area. Pregnant women from 32 remote northern communities arrive in Sioux Lookout six weeks prior to their due date to await the birth of their baby. Approximately 50% of project participants are First Nations people.

For the first four years of the project, the sponsoring organization of the project was the Patricia Centre for Children and Youth. Under the advice of Health Canada, the sponsorship was then transferred to the Equay Wuk (Women's Group), an Aboriginal organization whose mandate is to provide services to women and children in First Nations communities. The project operates in partnership with the Aboriginal Head Start Program, the Aboriginal CAPC program, the First Nation Health Authority, and the Child Health Network. A program coordinator staffs the project.

Children's Centre: Fort McMurray, Alberta (Ruby Canning, FAS Facilitator)

Fort McMurray is a city of approximately 45,000 people located 560km north of Edmonton. Two large oil sands projects attract a young and transient population without traditional family supports. Métis and aboriginal communities surround the city.

The Children's Centre has been operational since 1993, but received CAPC funding in November 1997. The Centre accepts children of any age, but manages programs for 0 to 6. It houses a gym and a resource centre. The Children's Centre offers prenatal classes to

young, low-income women and women at-risk of substance use during pregnancy. The Centre hosts a parent support group and organizes respite care for parents of FAS-affected children. The FAS facilitator prepares information packages, and does presentations to the local schools. The Centre works with Northern Lights Regional Working Committee on FAS.

Northern Family Health Society: Prince George, British Columbia (Marlene Thio-Watts, Program Coordinator)

The Northern Family Health Society developed out of a Pregnancy Outreach Program that originated in 1988. The Pregnancy Outreach component continues to be the core of the project, and FAS prevention and education to both participants and to the community has always been an integral part of the program. This core component was funded primarily through the Ministry of Health, with involvement from the Ministry of Alcohol and Drug Programs, and has been subsequently augmented by additional funding and services. The project had a close partnership with the Native Friendship Centre, who offered the project free space for eight years because their services were directed towards a common population. Forty-six percent of participants are First Nations or Métis.

Receipt of CAPC funding, in 1994, allowed for the addition of an FAS worker to the project. The FAS worker is an alcohol and drug counsellor seconded from the detox in Prince George. Additional enhancements to the Pregnancy Outreach Program have been possible through CPNP funding. The project operates as a downtown outreach program, now located in a storefront beside the food bank, the needle exchange, and the native health clinic. The project is also engaged in community development, research and policy development related to FAS.

Conclusion

This project was initiated with the belief that Community Action Program for Children (CAPC), Canada Prenatal Nutrition Program (CPNP) and Aboriginal Head Start (AHS) projects held considerable potential in supporting the reduction of harm associated with substance use and pregnancy in their communities. The non-judgmental, respectful and culturally sensitive environment cultivated by these projects is fundamental to working with women and children on this issue. Moreover, the holistic, family approach taken by these projects, whether their program focus is pregnant women (as with CPNP) or young children (CAPC and AHS), situates them well to work with the broad family issues that usually arise when addressing alcohol and other substance use during pregnancy. The investigation confirmed that CAPC, CPNP and AHS projects, in fulfilling their basic mandate, do present a milieu that effectively engages high-risk families and is supportive of particular work on this issue.

In terms of activities beyond the basic mandate, CAPC and CPNP projects tend to be more involved with activities aiming to prevent substance use during pregnancy than activities aiming to identify and intervene with children affected by prenatal use. Particularly common prevention activities are those that require modest resources and expertise, such as disseminating information, providing referrals and supporting community awareness on the issue. More elaborate, "beyond basic" prevention services, that entail more resources and/or specialized knowledge, such as conducting screening or counselling with substance-dependent women tend to be less commonly available in these projects.

Similarly, the identification and intervention activities that projects are most likely to be involved with are those that require fewer resources, less specialized knowledge and that closely relate to their core mandate, such as providing referrals, and conducting home visits. Of the general activity areas (i.e., prevention, identification and intervention), projects appear to be least prepared to conduct intervention activities addressing the special developmental needs of children affected by prenatal substance use.

At the most advanced end of the spectrum of activities lies community development work. Progress with alcohol and other substance use issues in a community requires more than the involvement of CAPC, CPNP and AHS projects. Unfortunately, many human services professionals and agencies do not fully understand the special needs of mothers with substance use problems and their children. Where progress has been made, it is often the result of "advocacy" activity on the part of committed parents, and agencies that work to reorient and mobilize services to meet the multiple special needs of at-risk women and children affected by prenatal substance use (alcohol particularly). Advocacy activity, which requires strong knowledge, commitment and additional resources, is relatively rare among CAPC, CPNP and AHS projects.

There is a relatively clear east-west distinction (at the Ontario-Manitoba border) in the prevalence and nature of activities addressing substance use and pregnancy. More CAPC and CPNP projects give attention to this issue in the west and the activity tends to be more advanced in nature. While there are important exceptions, projects doing advanced work

on this issue tend to be located in the western and northern regions of the country. These projects go beyond their direct mandates to take a lead in community development and advocacy. They have attempted to incorporate staff with needed knowledge and skills into their projects (e.g., addiction workers, peers, and educational consultants), and some have been highly resourceful in seeking additional funding routes to enhance their work with this issue. A number are working with prenatally affected persons beyond their age mandate and with Fetal Alcohol Syndrome (FAS)-affected adults who are parenting children, sometimes with FAS.

While the prevalence of prenatal substance use and its effects in communities across Canada is poorly understood, and may indeed vary across the country, it appears that there is generally more that CAPC, CPNP and AHS projects could do, particularly in the provinces east of Manitoba, to adequately address the issue. There are a number of reasons—external to the projects and internal—that adequate attention to substance use and pregnancy issues may be hindered.

Health Canada's community projects do not operate in isolation. If there is little public awareness, professional concern or government support for this issue in a community or region, it is less likely that CAPC, CPNP and AHS projects will be involved. If there is no existing collaborative activity occurring among community agencies on this issue, initiating this kind of attention may appear to be a daunting task. If it appears that there are few agencies to which clients (i.e., mothers who may have substance use problems or children who may be affected by prenatal substance use) may be referred, projects will be justifiably hesitant to screen for these clients.

More internally, how broadly a CAPC or CPNP project perceives its mandate will be influenced by the level of funding available. If funding is only adequate to accomplish the basic mandate, particular attention to this issue is less likely. However, there are other mandate issues. Many respondents expressed a discomfort in identifying at-risk women and affected children. Some respondents felt they didn't have the right to ask women about their substance use or thought doing so would compromise the safe, trusting environment they strived for. Many felt they did not have the skills or tools to undertake such activity as screening clients for substance use-related problems.

How projects might enhance their FAS-related activity in the context of these external and internal issues will of course vary depending on the region and the community. In the 1999 Budget, the federal government announced increased funding for the expansion of the existing Canada Prenatal Nutrition Program to allow for a sustained focus on FAS/FAE. Funding of $11 million over three years was allocated to enhance various activities, including public awareness and education, FAS/FAE training and capacity building, early identification and diagnosis, coordination, integration of services, and surveillance. This funding should result in more projects considering this issue within their mandate regardless of where they exist.

Projects considering enhancement will need to review their mandate. In doing so, it is crucial they perceive that involvement with this issue is appropriate and will not compromise their overall work with high-risk families. It is clear from projects doing particularly strong work in this area that there are simple messages and measures that can

be taken to support at-risk women and affected children that do not compromise overall aims.

Enhancement should also involve attention to the broader community. At the most basic level this means raising awareness on this issue and supporting existing multi-agency work. More resources and skills are required to stimulate new interagency collaboration, more training, coordinate cases, advocate for appropriate services and push the broader community to give attention to upstream population health issues.

FAS-related enhancements need to be sustainable, and this requires attention at several levels. It is important that CAPC, CPNP and AHS projects see FAS-related activity as central to their mandate or "core" services. Training and support needs to be available and ongoing to build and refresh skills and to avert burnout. This issue requires long-term commitment and the assurance of long-term funding at the outset of planning. Funding from multiple sources can help to sustain activity over the long term. A critical mass of parents, professionals and agencies with commitment to this issue can help to multiply resources and sustain attention to the issue in a community. Provincial/territorial and federal governments can support sustained project activity through long-term funding arrangements, by establishing policy that recognizes FAS as a distinct disability, by sponsoring research on the problem and effective responses, by promoting public awareness, and by fully committing to addressing the determinants of health.

The results of this project strongly confirm the value of locating FAS-related activities within Health Canada's community projects. These projects are ideally suited to prevent and reduce the harm associated with prenatal substance use and are, in many cases, currently doing so. The prospect for enhancement is great and will be fed by the genuine desire to learn and share that exists in the CAPC, CPNP and AHS networks.

Appendix 1: Key Resources and Training Needs

Resources

Print Resources Identified by Respondents

No. of mentions	Resource Name
11	Give and Take – Booklet, AWARE - Action on Women's Addictions Research and Education, 1996
8	FAS 100% Preventable, Saskatchewan Health and Health Canada
6	For Baby's Sake Don't Drink; SADAC, TRY, 1979
5	Precious Gift, Saskatchewan Institute for Prevention of Handicaps
5	Community Action Guide
5	Circle of Life, Paskwayak Productions, Winnipeg, MB, 1997
4	Pregnant? Did you know alcohol and hurt your baby? , BC Liquor Stores
4	It Takes a Community to Raise a Child, FNIHB, 1997
4	Fetal Alcohol Effects Booklets 1 – 5, Health Canada,: 1997
4	FAS Resource Kit,
4	Fantastic Antone Succeeds: Experiences in Educating Children with FAS, University of Alaska Press
3	Alcohol During Pregnancy (Drugs and Alcohol Pamphlets), ETR Associated, Santa Cruz, CA
3	Alcohol and Pregnancy - Keeping Your Baby Sober, W.R. Spence M.D., 1993
2	The Hangover that Lasts a Lifetime, Union of Ontario Indians, 1993
2	The Broken Cord, Michael Dorris, Harper Perennial
2	Stopping When You're Ready (smoking)
2	Parenting Children Affected by FAS (A Guide for Daily Living), Society of Special Needs Adoptive Parents, Vancouver B.C., 1998
2	Mama I Want to be Healthy, Childbirth Graphics 1992
2	Listen to the Inner Voice (poster), Saskatchewan Institute on the Prevention of Handicaps
2	Kick Butt For 2 : Brighter Futures for Children of Young Single Parents, 1997
2	Is it Safe for My Baby? Addiction Research Foundation,1991
2	Harmful Effect of Alcohol and Drugs on the Fetus and Infant (Poster), Directional Learning
2	Drugs during pregnancy, ETR Associates, Santa Cruz, CA
2	Celebrating Pregnancy, B.C., 1995
2	Alcohol Related Birth Defects, AADAC, 1999
2	Alcohol and Pregnancy: Know the Facts, BC FAS Resource Society
2	Alcohol and Pregnancy, Health Canada
2	Alcohol and Pregnancy (Flip Chart)
2	A New Start in Life: About Pregnancy and Smoking, Canadian Council on Smoking and Health

Videos Resources Identified by Respondents

No. of mentions	Resource Name
16	Precious Gift - Available from Saskatchewan Institute on Prevention of Handicaps, Saskatoon, SK, 1997
12	David with FAS - A story of Fetal Alcohol Syndrome, National Film Board of Canada, 1996
9	FAS 100% Preventable, Saskatchewan Health and Health Canada
8	One Drink Won't Hurt my Baby, Will It?, Association of Community Living, Winnipeg, MB
6	Drugs, Alcohol and Pregnancy, Human Relations Media (HRM Video), Pleasantville, NY, 1992
6	Caring Together, Native Physicians Association of Canada, Brewers Association of Canada
6	Circle of Life, Paskwayak Productions, Winnipeg, MB
6	Fetal Alcohol Syndrome & Fetal Alcohol Effects, Canadian Learning Company Inc., 95 Vansittart Avenue, Woodstock, ON, 1-800-267-2972
5	A Mother's Choice, Gryphon Productions Ltd., West Vancouver, BC, 1995
5	Babies in Waiting, Family Care Communications Inc., Eden Prairie, MN, 1992
4	The Fabulous FAS Quiz Show (target grades 6-8), March of Dimes, Birth Defects Foundation, 1993
3	Your Pregnancy, Your Plan - Project Future Series, Canadian Learning Company, Woodstock, ON
2	A Pregnant Woman Never Drinks Alone, Universal Health Association
2	An Avoidable Tragedy, CBC International Sales
2	Andrew's Story
2	FAS Resource Kit, CAPC Health Canada
2	Helping Children, Helping Families., Yellowknife Association for Community Living, 1996-1997
2	Mother's Choice, YWCA FAS Support Group

Other Resources Mentioned by Respondents

Motherisk Hotline: Toronto Sick Children’s Hospital, 1-877-327-4636 toll free. Based on research, they will provide clinical consultations. General Inquiries Hotline on Substance Abuse and Pregnancy, (416) 813-6780.

FAS/FAE Information Service, Canadian Centre on Substance Abuse, 1-800-559-4514.

Training needs

Projects were asked whether they felt that more staff training and development was needed. There was an overwhelmingly positive response to the need for more training (79%). Program managers are very interested in supporting FAS training needs. They unanimously agreed that projects need more training in regards to working with communities to prevent FAS and supporting children (and their families) who are affected by FAS.

Topics and Skills

In the survey, projects were asked to identify topics and skill development that they would find most useful. The responses can be grouped into the following areas:

- Doing identification and assessment
- Doing intervention and counselling
- Developing supports during recovery and reducing use
- Dealing with difficult clients, working with affected children
- Communications skills, and techniques for asking questions, especially during intake; best communication vehicles and messages
- Cultural awareness
- Building community awareness
- Teaching parenting skills and coping skills
- Harm reduction, dealing with blaming, shaming, denial
- Effects of alcohol and other drugs during pregnancy; FAS/FAE information
- Building specialized capacity in staff teams (e.g., special knowledge of court system or social security or housing)

Training Activities

Projects were also asked about their training needs. They identified several training activities that they have found useful:

- Workshops and spending time with speakers. One region had just completed a series of capacity building workshops. The informant was anxious to ensure that there was more broad-based training that addressed root causes.
- Training through partner organizations, tapping into what already exists in the service system, and having a lot of partners in the community. Linking with others for in-kind training
- CAPC/CPNP regional conferences

Concerns

A common theme from the informants was the wide variation of training needs. There was also recognition of a need for training opportunities to be placed along a continuum based on existing level of awareness and capacity, in order to ensure a comfortable fit for all.

Concerns were expressed about dominant perceptions not being respectful of other cultural norms. Some felt that Aboriginal communities could teach non-Aboriginal communities many lessons, including how to approach and lessen judgment when working with families.

A couple of people emphasized that training without follow up is an incomplete process.

> *"The mayor of (name of town removed) …had just attended a workshop on FAS and said that he is now aware that 70% of the children in our school have FAS. He had attended a workshop and that is what he had come away with and we do nothing with it… I think that (in regards to) prevention we need to leave them with something that people can do within the context of…a community …otherwise you have people walking away from it, thinking that it is too big for them to handle..."*

Several informants had concerns about just how much projects would be expected to take on.

> *"We are still trying to reach our goals and have a quality program for children that are at risk, living in poverty, disadvantage, but now we get FAS thrown on top of this. Even within the…program the people who are actually working there are starting to expect that from themselves…by now putting special needs on top of that, we are putting communities at great disadvantage and we are almost setting them up for failure."*

> *"When these programs were designed to promote cultural and parental involvement, it was also recognized that some families were at risk. And perhaps even guessing at the fact that some of them would have special needs. But from what I am seeing and hearing the need is huge and we probably underestimated the numbers of children that would come to this program or the parents of these children that have these problems."*

Potential and limitations of Internet-based learning

Informants were asked about the potential for Internet-based training to meet training needs. Overall, they were very positive about using the Internet for training. Internet training was viewed as a logical next step for Health Canada's Connectivity Initiative. Some of the concerns expressed were whether all projects had received computers, and whether Internet was readily available within more remote communities.

There were a number of suggestions relevant to the design of an Internet training site, including having a good table of contents, site map, and navigation features; ensuring that information can be accessed at different levels, allowing individuals to choose the level of information needed; providing a mechanism by which individuals can assess their

progress; incorporating personal stories and experiences; and ensuring that the resource is culturally sensitive.

Appendix 2: Key Learnings Regarding Good Practices

Role within the community

- Working upstream in order to address some of the root causes and underlying reasons why women use alcohol during pregnancy; broad determinants of health must be addressed.
- Building capacity within the community; not just providing or contributing to a continuum of services.

Foundational program characteristics

- Using a grass-roots, bottom-up approach to development, with multiple sources of funding in order to ensure that the program has a broad basis, including strong associations with other community groups and working in partnership with families
- Providing a seamless, integrated program with substance use and pregnancy as one component of a more comprehensive service.
- Incorporating the cultural, linguistic and social values of the communities where they are located.
- Using a multi-pronged, flexible approach to meet families where they are, as opposed to a packaged program with one way to work with all families.
- Developing a trusting, non-judgmental relationship with women, accepting them where they are.

Preventing substance use during pregnancy

- Providing one-on-one support, counselling and teaching.
- In the context of a supporting, non-judgmental relationship, using a brief screening instrument to help women recognize when their alcohol or substance use is at high risk levels.
- Incorporating a motivational counselling approach to help women to recognize their substance use and to seek support.
- Accepting that women may not be able to quit but can only reduce harm.
- Incorporating a peer support component as part of the model.
- Providing early identification of children affected by substance use during pregnancy.
- Advocating for the child and family with other agencies in the community.
- Providing a stable program environment for an affected child and supporting stability at home.
- Providing or facilitating support to the family of an affected child.

Appendix 3: Glossary

Definitions and Terms

FAS-related for the purpose of this project refers to:

(a) Fetal Alcohol Syndrome:

Category 1-FAS with a documented history of alcohol involvement by mother

Category 2-FAS without a documented history of alcohol involvement

(b) Fetal Alcohol Effects:

Category 3—partial FAS with a history of alcohol involvement

Category 4-ARBD- physical anomalies only

Category 5-ARND – neurodevelopmental disorder

(c) Other Drug Effects: effects of use of opiates, cannabis, hallucinogens, inhalants, stimulants and sedatives during pregnancy.

Prevention: activities that occur up to the birth of the child and are intended either to prevent alcohol and other drug use while a woman is pregnant or reduce the harm arising from substance use during pregnancy. These activities include primary, secondary or tertiary measures and can be broad based, policy-related and/or targeted. For example, primary prevention focuses on the general population rather than on risk populations, and includes such activities as public awareness campaigns, warning labels, school curriculum and programs for young mothers. Secondary prevention activities focus on groups that are viewed as being of higher risk (e.g. women of child bearing age who are heavy drinkers). Tertiary prevention focuses on alcohol dependent women of child bearing age, particularly those having had an affected child, and would involve support and treatment.

Identification: activities that identify the drug affected person—either as newborns, children, adolescents, or adults—through identification or diagnosis by a physician; and support screening by intermediaries (i.e. public health nurses, teachers, social workers and others) for referral and possibly case managing.

Intervention: activities that are intended to prevent and reduce harms associated with primary and secondary disabilities of alcohol or other drug exposed persons. Includes measures directed to individuals with FAS as children, adolescents, adults and management of the FAS child, parenting, family support, school issues, vocational training, young offender and criminal justice issues.

Best practice: refers to policies, programs and practices that are in keeping with the best possible evidence about what works and why.

Values: In collecting and analyzing the data special attention will be paid to the values that may be associated with specific practices (e.g., women-centred, family-centered, etc.).

Appendix 4: List of contributors

Advisory Committee and Project Associates

Ms. Mary Pia Benuen
Community Health Nurse
P. O. Box 406
North West River, Labrador, NF A0P 1M0
Tel: (709) 497-8423
Fax: (709) 497-8366

Ms. Adele Crocker
Program Consultant
Children's Programs
Population & Public Health Branch
18th floor, 1920 Broad Street
Regina, SK S4P 3V2
Tel: (306) 780-6944
Fax: (306) 780-6207
Email: Adele_Crocker@hc-sc.gc.ca

Ms. Bernice Dubec
Shkoday Abinojiiwak Obimiwedoon
R.R. # 11
1610 John Street Road, Site 6-33
Thunder Bay, ON P7A 4P7
Tel: (807) 768-2342
Fax: (807) 768-9509
Email: tbahs@norlink.net

Mme Marie-Paule Duquette
Dispensaire diététique de Montréal
Counselling nutritionel individualisé Méthode Higgins
2182, avenue Lincoln
Montréal, PQ H3H 1J3
Tel: (514) 937-7452
Fax: (514) 937-7453
Email: ddmdd@qc.aira.com

Ms. Lorraine Green
Program Coordinator/Committee Member
Capital Health Authority
Health for Two
Suite 300, 10216 - 124 Street
Edmonton, AB T5N 4A3
Tel: (780) 413-7972
Fax: (780) 482-4203
Email: lgreen@cha.ab.ca

Ms. Élise Lavigne/Andrea Corbett
Program Officer
Community Based Programs Section
Childhood and Youth Division
Jeanne Mance Building, 9th Floor
Tunney's Pasture
Ottawa, ON K1A 0K9
Tel: (613) 957-3955
Fax: (613) 952-5955
Email: Elise_Lavigne@hc-sc.gc.ca

Ms. Margaret Leslie
Program Manager
Breaking the Cycle
761 Queen Street West
Toronto, ON M6J 1G1
Tel: (416) 920-3515, ext. 103
Fax: (416) 920-5983
Email: Mleslie@mothercraft.org

Ms. Della Maguire
Drug Abuse and FAS Counsellor
MicMac Native Friendship Centre
Mi'kmaq Youth Program
2158 Gottingen Street
Halifax, NS B3K 3B4
Tel: (902) 420-1576
Fax: (902) 423-6130
Email: della@ns.sympatico.ca

Brenda McIntyre
Health Promotion Specialist, Nutrition
Department of Health & Social Services
Government of Nunavut
PO Bag 1000, Station 1000
Iqaluit NU X0A 0H0
Tel: 867-975-5729 / 5700
Fax: 867-975-5780
Email: bmcintyre@gov.nu.ca

Mr. Alan Ogborne
Senior Scientist
Centre for Addiction and Mental Health, ARF Division
100 Collip Circle, Suite 200, UWO Research Park
London, ON N6H 3P4
Tel: (519) 858-5000
Fax: (519) 858-5199
Email: ogborne@julian.uwo.ca

Ms. Kimberly Resch
Program Consultant
CAPC - AHS Program Consultant
Winnipeg, MB
Tel: (204) 984-0677
Fax: (204) 983-8674
Email: kimberley_Resch@hc.sc.gc.ca

Mr. Gary Roberts
Senior Associate
Canadian Centre on Substance Abuse
75 Albert Street, Suite 300
Ottawa, ON K1P 5E7
Tel: (613) 235-4048 ext 225
Fax: (613) 235-8101
Email: groberts@ccsa.ca

Ms. Jeddie Russell
Coordinator
FAS Community Action Project
Fetal Alcohol Syndrome Society of Yukon (FASSY)
707 Cook Street
Whitehorse, Yukon Y1A 2R7
Tel: (867) 633-3051
Fax: (867) 393-4950
Email: Jeddie Russell: russell@polarcom.com

Ms. Marlene Thio Watts
Executive Director
Healthiest Babies Possible
Northern Family Health Society
1010 B 4th Avenue
Prince George, BC V2L 3J1
Tel: (250) 561-2689
Fax: (250) 563-0924
Email: twatts@uniserve.com

Key Informants

Teresa Jeffery & Beth Sherwood
Program Consultant
Aboriginal Headstart Programs
Health Canada
Halifax, Nova Scotia
B3J 3V4
PH: (902) 426-7148
Teresa_Jeffery@hc-sc.gc.ca
Beth_Sherwood@hc-sc.gc.ca

Suzette Jeanotte
Santé Canada, Direction generale
De la promotion et des programmes de la sante
Complexe Guy-Favreau, 2e etage, Tour est, Bur.212
Montreal (Quebec) H2Z 1X4
PH: 514-496-9626
FX: 514-283-3309
EM: Suzette_jeonette@hc-sc.gc.ca

Margaret Zubert
Health Canada Sudbury Field Office
Room 314 19 Lisgar Street
Sudbury, Ontario, Canada P3E 3L4
PH: (705) 670-6593
FX: (705) 670-6441
EM: Margaret_zubert@hc-sc.gc.ca

Kimberley Resch
Health Canada
Health Promotion And Programs Branch
Suite 420 391 York Avenue
Winnipeg, Manitoba, Canada R3C 0P4
PH: (204) 983-0677
FX: (204) 983-8674
EM: Kimberley_Resch@hc.sc.gc.ca

Sophie Stalely
Health Canada
Health Promotion And Programs Branch
1975 Scarth Street
Regina, Saskatchewan S4P 2H1
PH: (306) 780-5356
FX: (306) 780-6207
EM: Sophie_Staely@hc-sc.gc.ca

Liz McDougall
Health Canada, Health Promotion And Programs Branch
620, 220-4th Ave, SE
Calgary, AB T2G 4X3
PH: 403-292-4971
FX: 403-292-6696
EM: Liz_McDougall@hc-sc.gc.ca

Lianna Zimmer
Health Canada
Health Promotion And Programs Branch
440 F 757 West Hastings
Vancouver, BC V6C 1A1
PH:
FX: 604-666-8986
EM: Lianna_zimmer@hc-sc.gc.ca

Roslyn Woodcock, Program Consultant
Health Promotion and Programs Branch
Yukon Department of Health and Social Services
P.O. Box 2703
Whitehorse, YT Y1A 2C6
Roslyn_Woodcock@hc-sc.gc.ca

Elsie De Roose & Lona Hegeman
Health and Wellness, Health and Social Services
Box 1320 Yellowknife, NWT X1A 2L9
PH: PH: 867-920-8032
FX: 867-873-7706
EM: Elsie_deroose@gov.nt.ca
Lona_Hegeman@gov.nt.ca

Carole L'Oiseau, Program Consultant
Health Canada
Health Promotion and Programs Branch
For Nunavut
PH: (780) 495-7357
Carole_Losieu@hc-sc.gc.ca

Appendix 5: The Sponsoring Organizations

Breaking the Cycle

Breaking the Cycle (BTC) is a community-based early identification and prevention program designed to reduce risk and enhance the development of substance-exposed children (prenatal to 6 years) by addressing maternal addiction issues and the mother-child relationship through an integrated, cross-sectoral model. Funded by Health Canada's Community Action Program for Children since 1995, Breaking the Cycle operates through the efforts of a partnership that includes the Canadian Mothercraft Society, the Jean Tweed Centre, the Hospital for Sick Children's Motherisk Program, the Children's Aid Society of Toronto, the Catholic Children's Aid Society of Toronto, and the City of Toronto Department of Public Health. Each of the partners participates in Breaking the Cycle at three different levels: 1) they comprise the Steering Committee of the organization and are responsible for administration and policy development; 2) they deliver consultation services to front-line staff; 3) they provide direct service to support programs offered at Breaking the Cycle. Services are offered through a single-access model in which mothers and children can access addiction, health, developmental and parenting services through an integrated, trans-disciplinary approach at one location in downtown Toronto.

Since 1995, Breaking the Cycle has provided services to almost 300 women and their children. An evaluation of Breaking the Cycle's first 2.5 years of operation indicated that the primary drugs of abuse of mothers at BTC are alcohol and crack cocaine. The evaluation demonstrated that participation in BTC has contributed to: healthier birth outcomes, better maternal health ratings, fewer health concerns, fewer parenting breakdowns resulting in separation of children from their mothers, and fewer maternal developmental concerns. Because of their involvement at BTC, young children did not experience the developmental lags often reported in the literature for those who have been substance-exposed.

Canadian Centre on Substance Abuse

The Canadian Centre on Substance Abuse is Canada's principle national NGO addressing substance abuse. Established by an Act of Parliament as an arm's length organization, the Centre's mandate is to lend support and leadership to activity preventing and reducing the harms associated with substance abuse. Funded by Health Canada, the Solicitor General and through its own revenue-generating efforts, the Centre:

- promotes informed debate on substance abuse issues and encourages public participation in reducing the harm associated with drug abuse
- disseminates information on the nature, extent and consequences of substance abuse
- supports and assists organizations involved in substance abuse treatment, prevention and educational programming.

The Centre is structured as a corporation, with a chair and a board of directors. It employs a staff of 13 (full- and part-time), and has an annual budget of approximately $2 million, approximately one-quarter of which is core funding with the remainder derived from contracts and projects.

A core service of the CCSA is the National Clearinghouse on Substance Abuse. The Clearinghouse has a full- and part-time staff of six. Staff time is divided between two major efforts: development of information products, and provision of information services. One of the primary reasons for the creation of the Clearinghouse was to fill the gaps in substance abuse information in Canada, and to disseminate that information to those needing it. To that end, the Clearinghouse coordinates the Canadian Substance Abuse Information Network that links the major substance abuse related libraries in the country.

The Centre is heavily engaged in the development of best practice advice, having managed major initiatives to arrive at guidelines for treatment and rehabilitation, tobacco cessation, workplace practices (including small business issues), youth prevention, and practices pertaining to FAS/FAE and other substance use and pregnancy issues.

The Centre provides support to the public, parents and practitioners on substance use and pregnancy issues through its FAS/FAE Information Service and the Online FAS Tool Kit.

Appendix 6: Survey instruments

(A) Key Informant Interview Guide

Background

In Canada, Fetal Alcohol Syndrome and Fetal Alcohol Effects (FAS/FAE) are a leading cause of birth defects and developmental delay that constitute a life-long disability to those affected. The use of other substances during pregnancy also presents concerns.

Although FAS/FAE and the effects of other substance use during pregnancy are preventable, these problems are complex and multi-faceted. It is generally acknowledged that they can only be addressed effectively through the collaborative efforts of many groups, including governments, non-governmental organizations, professional associations, Aboriginal organizations and the private sector working together with affected individuals, families and communities.

The close to 1,000 Community Action Program for Children (CAPC), Canada Prenatal Nutrition Program (CPNP), Aboriginal Head Start (AHS) projects across the country represent a significant effort to support pregnant women and young children at risk. These projects hold great promise in preventing and reducing the harms associated with FAS/FAE and the effects of other drug use—hence this is a priority issue for Health Canada national CAPC/CPNP funding.

Through National Project Funding, Breaking the Cycle (BTC), Toronto in partnership with the Canadian Centre on Substance Abuse (CCSA), Ottawa, have undertaken a project to support and strengthen the efforts of CAPC, CPNP, AHS projects in addressing FAS-related issues among pregnant women, young children and their families.

The aim of the project is to develop a profile of the extent and nature of FAS-related activity and to describe initiatives reflecting good practices among these projects. This information will be compiled in a print monograph and key learnings sheets and will form the basis of an Internet learning environment being created for CAPC, CPNP and AHS project staff.

The information is being gathered through written mini-surveys that were distributed to all CAPC, CPNP and AHS projects, detailed surveys sent to those responding to the mini-survey and interviews with approximately 20 key informants identified through a nomination process involving the project advisory committee. Informants are of two sorts: those with a broad knowledge of FAS-related activity among CAPC, CPNP and AHS projects in their jurisdiction and those closely associated with projects reflecting good practice.

This project is operating in parallel and collaboration with another Health Canada project conducted by the Canadian Centre on Substance Abuse that is investigating best practices as well as current overall FAS-related activity in the country. The CAPC, CPNP and AHS project will provide information crucial to the preparation of the overall national profile. The findings from both projects will be an important reference for planned collaborative

national action on this issue. It is also hoped that the projects will generally contribute to research agendas, policy development, enhanced training and strengthening of practice across Canada.

Preparing for the Interview

All interviews will be conducted by telephone, taking approximately 90-120 minutes to complete. A set of questions and definitions of key project terms are outlined below and on the third page.

You are asked to review these questions and terms prior to the interview. If you need to consult with others in your jurisdiction to arrive at a broad understanding of CAPC, CPNP and AHS activity, you may wish to share these questions with them.

When answering the questions below, please remember to respond from a broad, jurisdictional perspective and distinguish as fully as possible between CAPC, CPNP and AHS activities.

Interview Questions

1. Describe the current extent and nature of FAS-related activity among CAPC, CPNP and AHS programming.

2. What are the project level challenges to conducting FAS-related activity?

3. What are the challenges or gaps at the broader, systems level?

4. What (if anything) appears to be working (and why) at the project level? Has progress been made?

5. What (if anything) appears to be working at the broader systems level of activity in your jurisdiction (and why)? Has progress been made?

6. Is more FAS-related training necessary for staff in these networks? If so, what knowledge or skills should be viewed as priorities?

7. Do you have any suggestions or cautions for those developing an Internet learning environment to support enhanced FAS-related programming among CAPC, CPNP and AHS projects?

8. If you haven't already been asked, you are invited to identify any CAPC, CPNP or AHS projects that, in your opinion, reflect good practices.

(B) Good Practice Interview Guide

The Interview Questions

1. Briefly describe your project: how are you funded; what is the mandate of your project; what is the target population of your project; describe your community partnerships.

2. Describe how key project activities/practices contribute to the success of your work with pregnant, substance-using women and their children.

3. Describe the development of the key activities/practices, including: factors which facilitated the development of these activities/practices, barriers or challenges that were encountered in the development of the activities/practices, and how they were overcome

4. Describe any monitoring or evaluation activities that provide information on the impact of these key activities/practices on children and families.

5. Describe how staff support and staff training needs are addressed in relation to the key activities/practices.

6. Do you have any additional comments for other groups who may consider developing such activities/practices in their projects?

7. Do you have any suggestions or cautions for those developing an Internet learning environment to support enhanced FAS-related programming among CAPC, CPNP and AHS projects?

(C) FAS Mini-Survey

We are writing to ask for your help on a project of importance to you and other CAPC/CPNP/AHS* projects. Recently many CAPC/CPNP/AHS projects across the country indicated to Health Canada that the effects of drinking or other drug use during pregnancy on children is an important issue for them. So, Health Canada has asked us-the Canadian Centre on Substance Abuse and the Breaking the Cycle Program in Toronto-to learn more about how you and others view this issue and are addressing it. The information gained from this work will be made available in a booklet and through workshop sessions.

We ask you to help us by taking a couple of moments to respond to the following questions:

[a] Does your project do something-anything at all-to address substance use during pregnancy with your clients (even giving out pamphlets and nothing more)?

Yes No

[b] How important is the issue of substance use during pregnancy for your agency/project?

One of the top five issues One of many issues Not much of an issue

[c] How aware of this problem are health and social service practitioners in your community?

Greatly aware Moderately aware Largely unaware Don't know

[d] Do you wish to receive the final project booklet and information on the workshop sessions?

Yes No

** Community Action Program for Children (CAPC); Canada Prenatal Nutrition Program (CPNP); Aboriginal Head Start (AHS)*

(D) FAS Full Survey

COMMENTS PLEASE…

Once you have had a chance to read this report please take a few moments to complete this short questionnaire and to return it by fax or mail to Gary Roberts at the Canadian Centre on Substance Abuse.[5]

Please use the following scales to indicate you overall impressions of the report. (Check one box ( ) for each scale.)

	Strongly Agree	Agree	Not sure	Disagree	Strongly Disagree
The report was easy to read					
The report was well organized					
The report was comprehensive					
The recommendations will be helpful to people in my community					

If you wish, please explain your ratings:

Other comments and suggestions:

Please also tell us if you work with FAS/FAE children, or with women at risk of having FAS/FAE children. Check ( ) any that apply.

I work directly with women at risk for having children with FAS/FAE

I work directly with women who have had children with FAS/FAE

I work directly with children who have FAS/FAE

Thank you for your interest in this report. Your comments will be used to plan future projects of this kind.

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[5] **CCSA, 75 Albert Street, Suite 300, Ottawa, Ontario, K1P 5E7. Fax: 613-235-8101**