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ajunnginiq centre

FETAL ALCOHOL SPECTRUM DISORDER:

An Environmental Scan of Services and Gaps in Inuit Communities

Ajunnginiq Centre
National Aboriginal Health Organization
2006

Based on research conducted in September 2004

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Fetal Alcohol Spectrum Disorder:
An Environmental Scan of Services and Gaps in Inuit Communities

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OAAPH [now known as the National Aboriginal Health Organization (NAHO)] receives funding from Health Canada to assist it to undertake knowledge-based activities including, education, research and dissemination of information to promote health issues affecting Aboriginal persons. However, the contents and conclusions of this report are solely that of the authors and not attributable in whole or in part to Health Canada.

Ajunnginiq Centre

The Ajunnginiq Centre of the National Aboriginal Health Organization shall promote practices that will restore a healthy Inuit lifestyle and improve the health status of Inuit, through research and research dissemination, education and awareness, human resource development, and sharing information on Inuit-specific health policies and practices.

The Ajunnginiq Centre's five main areas of focus are to:

- Improve and promote Inuit health through knowledge-based activities;
- Promote understanding of the health issues affecting Inuit;
- Facilitate and promote research and develop research partnerships;
- Foster participation of Inuit in the delivery of health care; and,
- Affirm and protect Inuit traditional healing practices.

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INTRODUCTION

Fetal Alcohol Spectrum Disorder (FASD) is a pressing health issue facing many Inuit communities. FASD is a permanent birth defect syndrome that can cause mental and emotional developmental handicaps, behavioural problems, memory and attention deficits, as well as certain physical defects. It is caused by maternal consumption of alcohol, and is therefore preventable. Due to the costs, availability and difficulty in testing and identifying individuals affected by FASD, actual rates among Inuit are not known. Anecdotal evidence leads most experts to believe that the rate among Inuit is many times higher than the national average.

To this end, the Ajunnginiq Centre at the National Aboriginal Health Organization and the Inuit Tapiriit Kanatami are participating in activities related to a Memorandum of Understanding (MOU) between Indian Health Services in the United States and Health Canada. This partnership pertains to sharing of information, identifying areas of common interest, and identifying and sharing models and approaches to addressing Aboriginal health issues at the community level. FASD was identified as a key area of activity of the MOU, and a working group was formed to initiate activities to address evidence-based practice models in Aboriginal communities.

One of the initial activities was an environmental scan of practices addressing FASD at the national, regional and community levels. In September 2004, the Ajunnginiq Centre conducted this environmental scan, and conducted two extensive literature reviews of mainstream and Inuit-specific resources on FASD. This document, therefore, presents a snapshot of services available in Inuit communities and gaps in services for Inuit at that time.

METHODOLOGY

To achieve maximum response rates and quality of information gathered from Inuit communities, an Inuit-specific environmental scan questionnaire was developed to ensure cultural relevancy. The questions were phrased to ensure the collection of data similar to that collected by other organizations involved in the joint United States and Canada MOU.

An extensive contact list of 44 individuals/organizations was developed. Informants represented the various levels of government, health care delivery organizations and departments, schools, NGOs, Regional Inuit Associations, and corrections organizations, nationally and in the six Inuit regions (Inuvialuit, Kivalliq, Kitikmeot, Qikiqtani, Nunavik, and Labrador). We attempted to contact informants in both the regional centres and a smaller community in each region; however, this was met with limited success.

Each informant was initially contacted by telephone to introduce the project. Questionnaires were then faxed or emailed, depending on the informant's preference. Follow-up calls were made 48 hours after sending the questionnaire. In total, 36 contacts responded with a completed survey – a response rate of 82 per cent.

A copy of the contact list and questionnaire are in Appendix A and B respectively.

The Ajunnginiq Centre also conducted two separate literature reviews. One examined Inuit-specific literature related to FASD; the other examined the mainstream literature on FASD. The Inuit-specific literature review focused on contacting officials in the Northwest Territories, Nunavut, Nunavik, and Labrador in the fields of health, education and corrections by phone and/or email. Only a few contacts were aware of Inuit-specific FASD literature or program resources targeting Inuit populations and these are annotated in the review. Many provided referrals to other contacts and potential sources that have been followed up to the extent possible.

A Google web search conducted on September 27, 2004 for "Inuit and fetal alcohol" resulted in 3,780 matches. Time constraints permitted only a very selective review of these matches. Over 30 sources have been annotated in the review, including published documents, research, audio-visual resources, unpublished program documents, resources under development, and so on. Northern newspaper archives contained over 80 articles from 1996 onwards. These have not been included in the review.

The mainstream literature review, utilizing Internet and published documents, focused on recommended practices for FASD prevention, as identified by Health Canada, Canadian and American medical associations and FASD-specific research. As Health Canada has already completed an extensive review and summary of recommendations related to FASD intervention, this document synthesizes and summarizes the general findings regarding prevention.

The literature reviews are in Appendix C and D.

FINDINGS: COMMUNITIES, REGIONS AND NATIONALLY

Raising awareness of and preventing FASD[1]

Activities related to prevention and raising awareness of FASD vary greatly across the four Inuit regions. Nunavut appeared to be very active with prevention and health promotion activities, whereas Labrador, Nunavik and the Inuvialuit Region appeared less active. Often, identified activities were not ongoing, co-ordinated programs, but individual events as funding was available or the extent of the need made an activity a priority. Overall, capacity building was identified as a key activity of many initiatives for raising awareness and supporting FASD-affected individuals and their families, in the form of workshops and presentations for frontline workers.

In the Inuvialuit Region, there was a range of answers to the question "What programs are currently available to Inuit communities to raise awareness of and to prevent FASD?" Some respondents said there were no programs available; others gave a list of current activities.

[1] Information is current as of September 2004.

These inconsistencies highlight the lack of co-ordination and the effective promotion of programs or activities.

Existing activities related to FASD prevention and awareness raising in the Inuvialuit Region included Community Health Representatives (CHR) in the communities engaging in health promotion to prevent FASD. Health Promotion Coordinators at the Regional Board of Health and Social Services also distribute information on FASD and set up workshops to update the health care providers in the communities. It was mentioned that occasionally a booth is set up to distribute information on FASD to the public. Some information is available from a group in Yellowknife that works on FASD prevention.

Although there is little activity in the Inuvialuit Region on FASD, it must be noted that the Inuvialuit Regional Corporation has been very active in advocating for funding for FASD prevention, and has proposed a training program for frontline workers in Tuktoyaktuk and Aklavik.

Across Nunavut, there was a range of answers to the same question, including “none that I have seen”, to identifying only national programs developed by Pauktuutit Inuit Women’s Association, to extensive lists of programs for FASD prevention and awareness raising. One community stated that the community health worker has “access to more info than we can use.”

The Department of Health and Social Services of the Government of Nunavut operates the Nunavut FASD Program with funding from the First Nations and Inuit Health Branch of Health Canada. It provides training opportunities and develops resources in the four languages spoken in Nunavut. This program is now developing community programs to support FASD affected individuals and their families.

In 2003/2004, the Nunavut FASD Program developed a number of awareness materials. Community workers were provided with training to give presentations on FASD, health care professionals were provided with funding to participate in a month-long online course on FASD, and awareness training was provided to teachers and home-care workers and nurses. A five-year goals document was developed in 2003/2004, which includes screening, diagnosis, services, and so on.

A pilot project in Kugluktuk sponsored by the Government of Nunavut through the Nunavut FASD Program (involving a number of departments, including Health and Social services, Justice and Education) began in 2003. It is a community-driven program where the community actively develops and carries out FASD awareness activities. Eventually, community members will be trained as part of this project to support and educate families affected by FASD. Implicit in this pilot project is capacity building, as it is intended to give the community the necessary resources to actively participate in FASD prevention activities. One respondent noted, “This is a community-based program which empowers the people.” There are plans to expand this project into two additional communities.

In the Kitikmeot region of Nunavut, there is a steering committee committed to raising awareness of FASD. Resource materials (primarily those developed by Pauktuutit) have been distributed to health centres and schools in the region, however, it is up to the local communities to use them. Workshops for teachers and health professionals have been held when requested. In March 2003, the Government of Nunavut sponsored a symposium that brought together community people and government officials to discuss and raise awareness of FASD.

Prenatal classes are often used to pass information on FASD to pregnant women. This was identified as an activity in Kugaaruk, Baker Lake and Cape Dorset. Presentations in schools, often by the CHRs, are also a common activity in Nunavut, with this activity occurring in Kugaaruk and Chesterfield Inlet, and are viewed as "effective." In Cape Dorset, information on FASD is communicated over the radio and in prenatal presentations. The Rankin Inlet Birthing Centre offers counselling to all women as part of the prenatal education and screening program. Two women in Rankin Inlet were trained by Pauktuutit to be community-based FASD resources.

In the Nunavik region, an FASD trainer has been traveling to all 14 communities to raise awareness of and talk about prevention activities for FASD with frontline workers in the mainstream health field. The FASD trainer was also teaching frontline workers how to set up a program for FASD prevention. Although the trainer is non-Inuk, she has an Inuk co-facilitator to assist in the FASD training. The training models used are from the south. In Inukjuak, a workshop on FASD was held with school staff.

In Puvirnituq, women are given information on FASD in their first trimester at their prenatal visits, both by the health centre and a midwife. FASD is addressed at prenatal classes when there is a sufficient budget to offer these classes. Both the health centre staff and midwives talk about FASD on the radio two to four times a year.

The addictions and public health agencies at Health Labrador developed a one-day FASD workshop that has been utilized throughout Labrador. In addition, there have been public awareness campaigns by Health Labrador, including posters, open houses, presentations at schools, articles in the newspapers, and so on. As in some communities in Nunavut and Nunavik, information on FASD is shared in Labrador on the radio.

The Labrador Inuit Health Commission (LIHC) held workshops with childcare workers, teachers, social workers and the RCMP. The LIHC also continues to disseminate information on FASD to parents and adults in the communities. Right Now-Training has been offered to front-line workers of the LIHC.

The Healthy Babies program of the Canadian Prenatal Nutrition Program (CPNP) operates in each of the Inuvialuit communities, and provides information on FASD prevention to pregnant women. CPNP also operates in many Nunavut communities and in Labrador. Although FASD is not the primary focus of CPNP, it is a topic that is addressed.

Pauktuutit has trained people from numerous Inuit communities on FASD awareness and prevention. This program uses a train-the-trainer model, and therefore the participants are expected to pass on the information they receive.

September 9 is FASD day, and a walk is held in many Inuit communities, as well as other activities to raise awareness.

Helping those affected by FASD[2]

There was also a wide spectrum of responses to the question "What programs are currently available to Inuit communities to help those affected by FASD?" In the Inuvialuit Region, no programs or activities were identified, except a program in Yellowknife (Learning and Living with FASD, sponsored by the Yellowknife Association for Community Living) and a radio information session. It was also mentioned that the reason there is no activity is because the Government of the Northwest Territories has not released any funding to the Inuvik Region for FASD.

In Nunavut, medical services for people affected by FASD are available through referrals from local community health centres. From there, a pediatrician can refer the patient for services outside the territory, if necessary. Currently there are few programs or services available for people affected by FASD in Nunavut. According to Nunavut Tunngavik Incorporated (NTI), "There is greater awareness – there is greater compassion – however as far as programs, there is very little." There is a position at the Government of Nunavut for an FASD employee, but at the time this scan was conducted, it had yet to be filled.

Lack of screening for individuals affected by FASD has an impact on the services available in communities. If there are no identified individuals in a community with FASD, there will be no programs offered. One of the responses was, "None, no one is diagnosed with FASD." This does not mean that FASD does not exist in these communities; rather, there are likely a number of affected individuals 'falling through the cracks'.

A similar situation was identified in Nunavik. There were no coordinated supports identified for people affected with FASD. In Kuujjuaq and in Inukjuak, if a child is diagnosed or is suspected to be affected by FASD, the schools will try to help, including Individual Path of Learning (IPL) services. IPL services are not FASD-specific.

A respondent from Nunavik identified that the problem is the lack of a qualified doctor/psychologist to diagnose people with FASD. Again, without diagnosed cases in a community, it is not likely that there would be programs for supporting an individual with FASD.

Labrador respondents had identified many more activities and programs than other Inuit regions; however, many programs are not FASD-specific, but have been modified to meet specific needs. One respondent from Labrador identified a Labrador FASD Advisory

[2] Information is current as of September 2004.

Committee. In Happy Valley-Goose Bay, an FASD support group was identified for any individuals affected by FASD as well as their family members.

In Hopedale, classrooms have been restructured (a pod system) to meet the educational needs of children with FASD. This is also planned for Nain. To accomplish this, the school board worked closely with LIHC. Furthermore, the school board has approved extra teachers to work with FASD children in Labrador. Changes were made at the daycare in Hopedale to provide a better environment for FASD children. For example, the colours of the walls of the daycare were changed to be less stimulating for affected children, and the setup of the daycare was changed as well. Education and training has been provided for parents, childcare providers with the Aboriginal Head Start Program and daycare providers to meet the special needs of children affected by FASD. The staff at the Labrador Correctional Centre has received training on FASD.

Two FASD workshops were held in Labrador, one sponsored by the Aboriginal Head Start program and the other by Health Canada. The latter workshop, developed by Pauktuutit, is called "Before I was Born", and was provided for Community Health Workers and Community Care Workers.

Although there is a fair amount of activity in Labrador, "much remains to be done. Schools are struggling to meet the needs of the present population. Attention is paid to FASD in a variety of school subjects, but we have a great deal to do before the population is fully aware of the significance of this problem," one respondent noted.

Gaps in addressing Inuit-specific FASD issues[3]

Respondents were asked to identify gaps in addressing Inuit-specific FASD issues, programs and services. Nationally, the need for diagnoses, services and programs were identified as gaps. Diagnosis, or lack of access to diagnostic procedures, was mentioned in all Inuit regions as a gap. A lack of awareness ("there needs to be more people talking about FASD") was identified in all regions.

FASD information and awareness were the primary prevention activities identified by respondents. No respondents mentioned ongoing counselling or addictions treatment for pregnant women who are drinking, although helping women stop drinking is the way to prevent FASD. Training in counselling women was also not mentioned.

In the Inuvialuit Region, lack of trained teachers to help children with special needs was identified as a gap, as was "a lot of denial in the communities." A lack of awareness of FASD symptoms, or the fact that "parents have not faced the fact that their child may be affected by alcohol" were also seen as gaps in addressing FASD. Smaller communities were seen as having fewer resources, or simply not having any resources to deliver strong messages about drinking when pregnant. The lack of alcohol and drug treatment centres, strategies for

[3] Information is current as of September 2004.

working with women at risk, and supports for people with FASD were identified as gaps in the Northwest Territories, as was the lack of a diagnostic team.

A respondent from the Inuvialuit Region recommended holding workshops in each community to "help parents face the fact that their kid may have FASD, and give them the help they need to deal with FASD." The reason the workshops should be held in the communities as opposed to a regional centre is because at the community workshops "you get the parents themselves dealing with the problem instead of just one person representing your community [at the workshops]."

In Nunavut, access to human service specialists and health professionals, such as pediatricians, audiologists, speech pathologists, rehabilitation specialists, and general practitioners with a background in FASD, was identified as a key gap in addressing FASD. "When families have to wait a long time for referrals, or don't even know they should be taking their child to the health centre to be checked, that significantly changes the health care the child is receiving and can receive." Also, the lack of community supports in communities to support the children and families affected by FASD is a gap territory-wide in Nunavut. If a child receives a diagnosis and then returns to their small home community, there are no supports for the family to develop routines, understand the child's behaviour and develop a plan for everyday living, nor is there any respite available for families. The pilot project in Kugluktuk was seen as addressing many of these gaps.

In the Kitikmeot region of Nunavut, a lack of awareness and "not knowing what to do once a diagnosis is received" were identified as gaps. All of the books on FASD were perceived to be in English, not Inuktitut, which would be an obvious barrier for unilingual Inuktitut speakers[4]. Many of the resources are brought up from the south, and are therefore predominantly in English and not culturally appropriate. For Inuit, culturally appropriate means Inuit-specific:

> "Because of the cultural difference there should be Inuit-specific, First Nations-specific workshops. Inuit and First Nations are very different and workshops should be presented in a different way. Inuit may be a strong people but they perceive information differently and may be in denial for an indefinite time."
>
> --Respondent

In Kivillaq and Qikiqtani, a lack of specific programs, including school counselling and social services available to deal with FASD, was mentioned. In fact, there is a perceived reluctance to diagnose FASD since there are few to no supports for people affected by FASD and their families. As in the Inuvialuit Region, a lack of support for pregnant women who want to quit drinking is seen as problematic in Iqaluit.

In Nunavik, lack of diagnosis/identification of children affected with FASD was raised, as was follow-up for the children who are diagnosed and for their families, especially a plan of action for both in and out of school. The respondent from Kuujjuaq also identified the need for an individualized service plan for each client and an integrated service plan between

[4] All of the Pauktuutit resources on FASD are in Inuktitut, including some in Inuinnaqtun.

organizations with a pivotal coordinator. Also in Nunavik, a lack of communication between community health professionals and the departments in health and social services, as well as other community organizations, was said to exist, further elucidating the lack of co-ordination between service organizations. Access to communication technologies in the smaller communities was viewed as a barrier to capacity building and service provision. Often, asking questions, getting updates, and maintaining contact with professionals in other communities is difficult without access to reliable means of communication.

In Kuujjuaq, over-crowding in family homes causes confusion concerning parenting roles and responsibilities, a respondent said. Although not mentioned by any other respondent, overcrowded housing is common across all Inuit regions, and leads to a variety of health and wellness problems.

Funding and Human Resources

In Labrador, funding was identified as the greatest barrier to addressing FASD. Lack of funding was identified as a barrier to diagnostic services. There is a genetic pediatrician willing to go to Labrador for three months to provide diagnosis, train physicians, develop community capacity and so on. Unfortunately, at the time this scan was conducted, there was no money available to pay his salary, despite the fact that Health Labrador will provide him with accommodations, office space, and medical supports. Without diagnosis, services and supports are not made available in communities.

Training and support for frontline workers was mentioned by a respondent from Happy Valley-Goose Bay as a gap.

In all regions, the need for funding to hire FASD co-ordinators was identified as a way to address many of the gaps in services/capacity building. In Labrador, the need for funding for community agencies to hire a FASD co-ordinator to work on prevention activities and to support people affected by FASD was mentioned. In the Inuvialuit Region, this was identified as a way to ensure that the needs of the smaller communities would be met. In Nunavut, it was proposed that this coordination position work closely with CHRs, nurses and Public Health to develop community awareness. One respondent stated, “Funding for a co-ordinator within each community would be the greatest asset. This would allow for increased communication/coordination between agencies, appropriate referrals, follow up and support for families, smooth transition between home/daycare and school.”

Many of the barriers identified in addressing FASD in the Arctic are ones that cut across many social issues, including: staff turnover in both health and education; the costs of travel and translation; the lack of funds to attend FASD-related events in the south; the need to build capacity (including more specialists, school counselors, social workers, training for frontline workers) as many activities are volunteer-based; the lack of infrastructure; and, the inequitable distribution of funding based on inadequate funding formulas.

Research

The need for more research was identified. This included addressing the lack of baseline data for Inuit, and the fact that research needs to incorporate culturally appropriate methodologies. Interestingly, research was mentioned in the interviews with informants from the corrections field as well. The "severe lack of statistically recognized and validated programming" has led to hesitancy on the part of government to develop or offer programming in the corrections field.

Stigmatization

A recurring theme from many respondents was related to the stigma FASD carries in Arctic communities. Some respondents find this stigma a downside to diagnosing children, as they are given a negative label. However, most respondents identified the need to "get people talking". In Rankin Inlet, it was stated that the regional Inuit associations need to take an active role promoting more discussion, and that "Elders need to speak up and share the message." Clearly, messaging needs to be delivered in the schools, as was mentioned by many respondents, "We need to talk about the effects of FAS and have people who the kids recognize come in to discuss how FAS affects them. This needs to happen at all levels of school and for adults."

Corrections and FASD[5]

"…a significant problem in the correctional community"

In the corrections field, no Inuit-specific programs for prisoners with FASD were identified. At the Saskatchewan Correctional Centre, all programs are open to all Aboriginal people, but they focus mainly on First Nations and Métis. At the Baffin Correctional Centre in Iqaluit, Nunavut, there are a number of Inuit-specific programs to address the correctional and social development needs of Inuit, but none focus on FASD affected prisoners. Although the Stony Mountain institution in Manitoba has no programs that address issues related to FASD, attempts to address it are made by being aware of each individual prisoner's circumstances, limitations and strengths. In Labrador there are no specific programs for individuals affected by FASD, but there are programs that may benefit them such as shop programs and education programs. All of the shop programs in Labrador encourage Inuit culture, such as carving and land-based activities.

Two of the respondents from the corrections field stated that they have no medically diagnosed individuals with FASD; rather they work with individuals who are suspected of being affected by FASD.

In the corrections field, very few capacity building initiatives were identified. At the Baffin Correctional Centre, all workers go through a 10-week intensive training program. One unit in

[5] Information is current as of September 2004.

that program deals with FASD. At Stony Mountain, officers are seen to be more culturally aware, but do not receive training specific to FASD. However, five of the seven respondents from the corrections field identified lack of training for staff as a gap in addressing FASD-related issues in a corrections environment.

A lack of diagnosis was identified as a gap as well. It was mentioned that current diagnosis is for children, not adults. And, with a lack of programs for FASD affected individuals, even if there were plans to provide diagnostic services, "there are no plans to provide the structured living environments persons having FASD require." This lack of resources for diagnosis, according to one respondent, was due to "the stigma attached to the diagnosis."

Without diagnosis and programming for individuals in the corrections system, there appears to be little available to address FASD in the corrections field. And, as one respondent stated, there are no community resources for individuals when they are released.

Although there is little activity on the frontline, FASD is recognized as an issue in corrections:

> "The area of FASD is relatively new to corrections and justice at both the federal and provincial levels. There has been some pressure to explore FASD with respect to identification and screening, diagnosis, and, to some degree, specialized programming and intervention." --Respondent

To address the gaps in services for FASD-affected prisoners, a clear theme emerged. Money to address these issues was identified as a need to provide training for corrections staff, to set up teams to diagnose individuals suspected of being affected by FASD and to create physical units for FASD prisoners. One respondent hoped that a screening tool that could lead to diagnosis could be developed; another that communities need to be educated about FASD. One respondent said that not only do individuals affected by FASD need assistance to address criminal offending patterns, but they also need basic life and social skills. The Correctional Service of Canada (CSC) does not offer life or social skills programming, and the respondent stated the CSC programming is not sufficient to address this issue "due to the sophisticated nature of [FASD]." Another area that was identified as a gap is that due to insufficient resources, there is a lack of transition planning between CSC and community agencies for these offenders once they are to be released.

Respondents from the corrections field recognized the time and effort that is required to deal with FASD. Recommendations to deal with the issue ranged from the need for diagnosis and treatment, to mandatory training for staff at corrections centres. It was strongly recommended that a life and social skills program be developed to address the deficits of FASD-affected individuals – one that is culturally appropriate and takes into account the factors that lead to incarceration.

CONCLUSION

A number of themes emerge from the data collected, including:

- a lack of funding and human resources;
- a need for Inuit-specific research;
- a need to raise awareness and address issues around stigmatization.

Clearly, the two major gaps in FASD services are a lack of co-ordination at all levels and funding for training, service provision, prevention and counseling. A national Inuit-specific strategy to address prevention and promotion, and to help individuals affected by FASD, is necessary to fill the co-ordination gap. However, the strategy must reflect the regional differences in levels of activity and be flexible to accommodate regional/community priorities and perspectives on FASD. Furthermore, the vast majority of prevention efforts identified in Inuit communities were promotion and awareness-raising of FASD. No one is actually working with women at risk - this emerges as the primary gap in prevention efforts. The only way to prevent FASD is to help women not to drink when pregnant. However, the capacity (human resource, financial, training) to reach and help women at risk does not exist in any Inuit region.

This was a national scan of FASD practices in Inuit regions and in the corrections field – it provides a 'snapshot' of activities and gaps at the time it was conducted. Clearly, each region is at a different place with regard to addressing FASD, each is looking at FASD from different perspectives, each has different priorities, and each works within different political and social environments. However, much has changed since 2004, and to be relevant, a scan needs to be conducted on a regular basis.

APPENDIX A: CONTACT LIST

Organization	Region
Nunavut Tunngavik Incorporated	Nunavut
Inuvialuit Regional Council	Inuvialuit
Hopedale - Labrador Inuit Health Commission	Labrador
Paulatuk Health Centre	Inuvialuit
Hopedale Nursing Station	Labrador
Chesterfield Inlet Health Centre	Kivalliq
Cape Dorset Health Center	Baffin
Kugaaruk Health Centre	Kitikmeot
Paulatuk - Angik School	Inuvialuit
Jens Haven Memorial School	Labrador
Inukjuak - Innalik School	Nunavik
Clyde River - Quluaq School	Baffin
Kugaaruk - Kuugardjuk Ilihakvik	Kitikmeot
Kitikmeot School Operation, Government of Nunavut	Kitikmeot
Healthy Baby Club - Center for Northern Families	NWT
Health Labrador Corporation	Labrador
Inuulitsivik Health Centre	Nunavik
Inuvialuit Regional Corporation	Inuvialuit
Nunavik Regional Board of Health and Social Services	Nunavik
Baker Lake Health Centre	Kivalliq
Government of Nunavut	Baffin
Rankin Inlet - Public Health	Nunavut
Iqaluit - Nakasuk School	Nunavut
Kivalliq Education Services	Kivalliq
Government of Nunavut	Nunavut
Aboriginal Head Start Program	Labrador

Government of the NWT, Health and Social Services	NWT
FASD Partnership	NWT
Clyde River - Quluaq School	Baffin
Labrador Inuit Health Commission	Labrador
Native Women's Association	NWT
Pauktuutit Inuit Women of Canada	National
Labrador Inuit Health Commission - Hopedale	Labrador
Government of Nunavut – Health and Social Services	Nunavut
Baffin Correctional Centre	Baffin
Yellowknife Correctional Centre	NWT
Department of Justice – Government of the NWT	NWT
Department of Justice – Government of Nunavut	Labrador
Yellowknife Correctional Centre	NWT
Correctional Service of Canada - Aboriginal Health	National

APPENDIX B: FASD SCAN OF BEST/BETTER PRACTICES IN INUIT COMMUNITIES

Introduction

The Inuit Tapiriit Kanatami and the Ajunnginiq Centre at the National Aboriginal Health Organization are participating in activities related to the Memorandum of Understanding (MOU) between Indian Health Services in the United States and Health Canada.

This partnership pertains to sharing information, identifying areas of common interest, and identifying and sharing models and approaches to addressing Aboriginal health issues at a community/regional level. Fetal Alcohol Spectrum Disorder (FASD) was identified as a key activity of the MOU and a working group was formed to develop a workplan that will address evidence-based practice models in Native communities.

The MOU will benefit Inuit by sharing information and collaborating with Native communities in Alaska and the mainland United States, as well as First Nation communities in Canada. The working group is conducting an environmental scan of best and promising practices, as well as key challenges faced by people affected by FASD throughout their life span. A template for this scan has been prepared by the FASD working group and will be used to group information collected.

To help us develop the scan with accurate information relevant to Inuit regions, please complete the following questions. Please use a separate sheet if necessary.

1. **What programs are currently available to Inuit communities to raise awareness of and to prevent FASD? Which programs are most effective? Please describe in detail.**

_____
_____
_____
_____
_____
_____

2. **What programs are currently available to Inuit communities to help those affected by FASD? In particular, what programs are geared specifically towards children, parents and adults living with FASD?**

_____
_____
_____

3. **Are any of these programs Inuit-specific?**

4. **Are there specific capacity building initiatives that are related to FASD in Inuit communities? What are the strengths and weaknesses of the current initiatives?**

Strengths:

Weaknesses:

5. **What gaps do you see in addressing Inuit-specific FASD issues, programs and services?**

6. **How could these gaps be addressed, including increased capacity building?**

7. **Is there anything you would like to add?**

_____
_____
_____
_____
_____
_____

APPENDIX C: INUIT-SPECIFIC FASD LITERATURE REVIEW[6]

Search methods and what is included in this review:

The Inuit-specific literature review focused on contacting officials in the Northwest Territories, Nunavut, Nunavik and Labrador in the fields of health, education and corrections by phone and/or email. Given the time constraints for this project, the writer assumed that contacts working in these three fields were the most likely to be aware of relevant documents. In the future, the review could be expanded to other fields such as social services and employment in order to find program documents or guidelines assisting fieldworkers with clients affected by FASD.

Review contacts were asked if they were aware of any literature, program documents, resource materials or research that contained Inuit-specific content and/or that targeted Inuit populations. Only a few contacts were able to offer documents or materials and these are annotated in the review. Many provided referrals to other contacts and sources North and South, including several researchers. These contacts and potential sources were followed up to the extent possible. Overall, the phone and e-mail contacts totaled approximately 40. Contact information is attached in the Appendix. An estimated 10-15 additional calls to similar contacts in the North would have ensured a more thorough process.

In addition to and separate from this review, a survey was developed as part of the Inuit-specific environmental scan of FASD practices. Findings from this scan are reported elsewhere in the National Aboriginal Health Organization - Ajunnginiq Centre's submission. A revised version of this survey that was sent to contacts in corrections across the country included a request for literature. This review includes one entry that resulted from the corrections scan.

A Google web search conducted on September 27, 2004 for 'Inuit and fetal alcohol' resulted in 3780 matches. Time constraints permitted only a very selective review of these matches. At least a week or two more would be needed to thoroughly review these matches for relevant documents.

Northern newspaper archives (*Nunatsiaq News* and *Northern News Services On-line*) contained over 80 articles from 1996 onwards. An e-mail providing several articles was also received from *The Labradorian*. These articles likely serve as the most frequent source of easily and regularly available information in the public view. They are without doubt an important tool for building public awareness of the issues and of initiatives and for stimulating public debate. The articles reported on a range of local and regional activities in the North including conferences. They provided factual information, called for political action and announced the availability of resource materials. Summaries of these articles have not been included in the review.

[6] Information is current as of September 2004.

In total, over 30 sources have been annotated in this review including published documents, research, audio-visual resources, unpublished program documents and resources under development.

Discussion of findings:

In spite of the limitations of the literature review described above, the results are somewhat encouraging.[7] There are a few existing and emerging initiatives addressing certain aspects of prevention, diagnosis and support. The few research activities located focus on diverse subjects. One is a study of congenital heart malformations and whether maternal alcohol consumption during fetal development may be a factor. Another relates to the development of Inuit-appropriate screening and prevention tools. Inuit and other organizations have developed or are developing a handful of Inuit-specific multi-media resources. More recent federal funding, flowed through provincial and territorial funding mechanisms, has greatly increased the level of regional activity concerning the development of processes and community friendly resources. The range of resources uncovered in this review are a beginning point for meeting a wide range of needs related to FASD prevention and the life-span issues of people affected by FASD.

Given that most of the work uncovered is less than a decade old, it is understandable that in the area of better and best practices in Inuit communities, there is very little available. One would presume that the Aboriginal Nurses Association of Canada's framework and resource manual document for First Nations and Inuit included in this review is based on better and possibly best practices in relation to Aboriginal peoples. Input from those with experience in First Nations and Inuit communities was widely sought before its publication.

Apart from Pauktuutit Inuit Women's Association (Pauktuutit) initiatives, no other information on evaluation was uncovered. Although not summarized in this review, the evaluations (three of them) concern the development of FASD awareness resources, the subsequent training activities and participant follow-up in their own communities. One can presume that the Government of Nunavut's pilot project underway in Kugluktuk, Nunavut will be carefully evaluated. This would be particularly important in relation to the asset-mapping work that is to be replicated shortly in additional communities and concerning the youth CD-ROM initiative. Other Inuit regions could greatly benefit from evaluation information collected on initiatives in Inuit jurisdictions. Evaluation is increasingly becoming a requirement for federally funded projects. While costly, there are many advantages. The lack of evaluation data constrains the building of better and best practices. A project that compiles and disseminates the findings of any evaluations relating to FASD initiatives would help build better and best practices for Inuit.

[7] It must also be kept in mind that contacting regional officials will not necessarily assist a review of this kind in capturing individual or organizational initiatives that take place purely at the community level. This is especially true when these initiatives, and the resources they may develop, are not shared with a larger network. A means of encouraging this kind of dissemination might significantly increase the number and range of resources available.

There appears to be a fair amount of generic FASD information reproduced in a variety of formats. Packaging it in Inuit-friendly and Inuit-reviewed formats may increase its usefulness. It is known best practice that involving the target population in the development of any health promotion or prevention initiatives that affect them is an integral component to success. This has been the practice of Pauktuutit. Steering committees composed primarily of Inuit are gathered from the Inuit regions to guide initiatives and any resources that they develop. While a professional video from southern Canada or the US can be a great addition to a northern kit on FASD, materials that feature Inuit, are in dialects of the Inuktitut language and are developed with Inuit input must be considered as invaluable. Ownership for issues, increased learning and skill-building of participants, and creative, culturally relevant processes and solutions can emerge from this approach.

Awareness materials and initiatives, however, do not get at the core of prevention issues. While awareness activities may convince some women of childbearing age not to drink during pregnancy, they are not enough. The Status of Women Council of the Northwest Territories summarized this in their statement "Family and community support are the keys to helping women and teen girls who have substance abuse problems."

Other than a brief mention in the Korhonen paper cited, the review did not uncover any Inuit-specific materials for use in Inuit communities relating to working with women at risk of bearing children affected by FASD. Pauktuutit is considering the development of counselor training materials and a training pilot to complement and provide the next step after its *Children Come First* training workshops.

It must be stressed that many more resources for program and outreach work in effective prevention are needed to reduce the need for the huge downstream investments that are required over the life-span of an FASD affected individual.

When the mainstream, Aboriginal and Inuit-specific literature are considered as a whole, there appears to be a sizeable amount. After the many discussions with the contacts involved in this review, it would appear that a much greater emphasis and investment is needed in the areas of program development and the associated human resources over the coming years. Greater implementation at the community level of existing materials such as the RCMP Guidebook or the Grade 8 unit cited in this review could also be helpful.

While developing a full range of FASD initiatives (including but not limited to identifying and working with women at-risk, screening/diagnosing/assisting those affected, or conducting research into FASD related issues) are all very much needed, avoiding stigmatization of Inuit in general and at-risk women and those affected by FASD specifically is crucial. Researchers and the literature appear to be fairly cognizant of this.

ANNOTATED SOURCES:

Published print material

Aboriginal Nurses Association of Canada. It Takes a Community: Framework for the First Nations and Inuit Fetal Alcohol Syndrome and Fetal Alcohol Effects Initiative / A Resource Manual for Community-based Prevention of Fetal Alcohol Syndrome and Fetal Alcohol Effects. Ottawa. Revised 2001.
Summary:
This document includes both a framework and a manual in both Inuktitut syllabics and English versions. The framework provides: First Nations and Inuit historical background; guiding principles; vision, goals and objectives; and information on the initiative's components, eligibility, funding and implementation. Objectives focus on raising awareness, reaching those at risk, working with those affected and creating linkages, all in relation to the needs of First Nations and Inuit communities. The framework was developed with input from First Nations and Inuit communities across Canada during information-sharing and feedback discussions.

The manual "is intended to help people prevent FAS/E and guide those who want to make their community a caring and supportive place for individuals and families already living with this condition." It includes a broad range of factual and practical information, interventions and suggested reading lists. A Bibliography is provided and ten reproducible fact sheets accompany the document. This publication appears to be the most comprehensive document of its kind targeting First Nations and Inuit.
Available at: www.hc-sc.gc.ca/fnihb/cp/fas_fae/publications/it_takes_community.pdf and www.hc-sc.gc.ca/fnihb/cp/fas_fae/publications/it_takes_community_inuktitut.pdf

Arbour, Laura et al. "Heart Defects and Other Malformations in the Inuit in Canada: A baseline study." International Journal of Circumpolar Health. 63:3 2004.
Summary:
From the Conclusion (p. 264): "A five-year chart review of children born to Inuit parents on Baffin Island and in Arctic Quebec between 1989 and 1994 revealed a significantly higher rate of birth defects than expected for the population's size. Although several birth defect categories were increased significantly, the greatest health care impact is probably secondary to the high rate of congenital heart defects. Further study is needed to determine if the high rate of congenital malformations, and particularly congenital heart malformations, in the Inuit results from 1) a diet with sub-optimal folic acid and/or Vitamin A intake, 2) a genetic predisposition altering nutrient status and/or heart formation, and 3) exposure to alcohol intake, which may alter both folic acid and vitamin A status. Further study is also needed to determine how contributing factors may be altered through public health efforts to reduce the rates of birth defects by, for example, optimizing the vitamin status of women during their child-bearing years."
Contact: larbour@cw.bc.ca

Archibald, Linda. Report on the Fetal Alcohol Syndrome and Substance Abuse Workshop. Pauktuutit Inuit Women's Association: Ottawa. 1996.
Summary:
This information-sharing and skill-building workshop included a presentation (including slides) prepared by Dr. Nicole Chatel, a pediatrician working in Yellowknife at the time. The document reports on participants' discussions concerning FAS challenges, barriers and solutions. Two resolutions resulted. The first included training Inuit to educate their communities about FAS. Pauktuutit has since actioned this recommendation through front-line worker FASD training workshops focusing on presentation skills.
Available at: pauktuut@pauktuutit.ca

Boland, Fred J. et al. "The challenge of Fetal Alcohol Syndrome in adult offender populations." Reintegration. 61-64. Correctional Service of Canada. No date available.
Summary:
The article focuses on diagnosis and screening issues, related gaps and the need for appropriate tools to use within the correctional system. It points to other relevant research. While the article is not Inuit-specific, it mentions a collaboration with the First Nations and Inuit Health Branch of Health Canada.
Available at: www.csc-scc.gc.ca/text/pblct/forum/v14n3/v14n3a19e.pdf

Canadian Paediatric Society. "Fetal alcohol syndrome." Paediatrics and Child Health. 2002; 7(3): 161-174. Reference No. II02-01
Summary:
This is a Position Statement (II 2002-01) of the Indian and Inuit Health Committee of the Canadian Paediatric Society and is available on their website. While the statement mentions the high prevalence in First Nations and Inuit communities, the content is generic. Topics include: prevalence, etiology, maternal factors, clinical manifestations, newborn, early childhood, diagnosis and management, intervention and funding. The recommendations are comprehensive, stress the need for culturally-centred programs and approaches and call for services to be available to all Canadians regardless of ethnicity or status. A variety of screening strategies are described. Screening tools are included for: women who are not pregnant, women who are pregnant, newborns, 18-24 month old children and 4-5 year old children. Extensive references are provided.
Available at: www.cps.ca/english/statements/II/ii02-01.htm

First Nation and Inuit Regional Health Survey. First Nation and Inuit Regional Health Survey National Steering Committee: 1999.
Summary:
(Multiple authors – no lead listed.) In the section on Children's Health, the report states that "due to limitations in the number of questions [1997 Survey] concerning children's health, no information about tobacco use, alcohol or substance abuse was collected." While there is a brief discussion on the validity of studies on FAS and Native versus non-Native children, there is no Inuit-specific FAS or FASD information presented.
Available at: www.hc-sc.gc.ca/fnihb-dgspni/fnihb/aboriginalhealth/reports_summaries/regional_survey_ch1.pdf

Government of the Northwest Territories – Education. "Alcohol and Other Drugs Program – A Prevention Program for Schools: A unit of the School Health Program – Grades 7 – 9." No date – likely mid-1980s.
Summary:
At the time of writing, this Unit was in current use in Nunavut and is used to some extent in other Inuit regions. (A Nunavut school health curriculum is under development.) The Grade 7 unit of this program focuses on: alcohol and its path and effects on the body; decision-making steps; and internal and external influences. The Grade 8 Unit consists of: historical information; responsible use of alcohol including not drinking when pregnant; decision-making steps; progressive symptoms of alcoholism; social problems for teenagers; major characteristics of Fetal Alcohol Syndrome; and common techniques used by advertisers. In Grade 9, students learn about: offences under the NWT Liquor Act; consumption levels; the Criminal Code of Canada; the Young Offender's Act; and criminal acts and consequences.

Korhonen, Marja. Alcohol Problems and Approaches: Theories, Evidence and Northern practice. Ottawa: National Aboriginal Health Organization, 2004.
Summary:
"The purpose of this paper is to provide essential information about alcohol problems, theories about causes and evidence-based best practices in alcohol problem treatment and prevention. Treatment practice in Inuit communities is also examined so gaps in service can be identified." While not specifically on FASD, the paper includes discussion of a variety of problem-resolution approaches and addresses special needs groups such as women at risk of having FASD children. A range of resources is included in the Appendices and the Bibliography is extensive.
Available at: www.naho.ca/english/pdf/alcohol_problems_approaches.pdf

McGrath, Janet. Fetal Alcohol Syndrome: A resource for Inuit communities to understand what FAS is and what they can do to help. Pauktuutit Inuit Women's Association: Ottawa. 1996.
Summary:
This Inuktitut syllabics/English booklet was developed in consultation with Pauktuutit's National Inuit Working Group for FAS and targets "community members, families, mothers and anyone interested in learning about FAS." Inuit women who gave input to the booklet, stressed positive approaches, provided "do's and don'ts" for supporting those attempting to stop drinking, gave ideas for activities to replace drinking, suggested a variety of ideas for community members and workers and shared personal anecdotes. Along with other factual information, many suggestions and strategies for caregivers of babies or children affected with FAS are also provided.
Available at: pauktuut@pauktuutit.ca

McGrath, Janet. Ikajuqtigiinniq: A resource for fetal alcohol syndrome prevention and intervention work. Pauktuutit Inuit Women's Association: Ottawa. 1998.
Summary:
This resource was based on information gathered at a national Inuit FAS/FAE workshop. It includes the following topics from an Inuit perspective: FAS/FAE across the North; barriers to progress; special issues and considerations (including the role of elders, men, youth and community workers); action planning, activity ideas and a long list of materials that could be developed. The appendices contain several information resources.
Available at: pauktuut@pauktuutit.ca

Muckle, Gina et al. "Smoking, Alcohol, and Drug Use During Pregnancy Among Nunavik Inuit Women." Poster presentation, 12th International Congress on Circumpolar Health. Nuuk, Greenland. September 2003.
Summary:
This soon to be published study reports "descriptive data on smoking, alcohol and drug use in Nunavik for the periods of pregnancy and the year prior to pregnancy." "The study indicated that frequency and amount of alcohol consumption during pregnancy represent a risk for growth, developmental and behavioral effects in Nunavik children (personal communication)." The study also looks at predictors of alcohol consumption by pregnant women. The data show that "a large proportion of Nunavik Inuit women reported smoking, drinking alcohol and using illicit drugs, mainly marijuana, during pregnancy and the year prior to pregnancy" and among other expected and unexpected conclusions, the authors "suggest that binge drinking during pregnancy is intercorrelated with stronger maternal distress and use of domestic violence postnatally."
Contact: gina.muckle@psy.ulaval.ca

National Indian and Inuit Community Health Representative Organization. "FAS/FAE-Fetal Alcohol Syndrome/Effects". In Touch Magazine. Vol. 21, Winter 2001.
Summary:
This issue of *In Touch* covers a range of factual information about FAS and FAE. Included is a list of Universal Protective Factors that if actioned lessen the challenges FAS/FAE affected individuals face. One article also contains a list of the potential impacts of alcohol use during three stages of fetal development. Diagnostic services and contact information are listed by province. The newsletter has Aboriginal content. While it also targets Inuit CHRs, it contains no Inuit-specific information. It lists an Aboriginal Nurses Association of Canada resource for First Nations and Inuit (included in this review).
Available at: www.niichro.com/library.html#anchor328972

Rojas, Aluki. Children Come First: A resource about Fetal Alcohol Spectrum Disorder (FASD). Pauktuutit Inuit Women's Association: Ottawa. 2003.
Summary:
This kit contains a manual in Inuktitut syllabics, Inuinnaqtun and English and a visual flipchart with no text. The two items are to be used in concert. Each flipchart page has a corresponding page in the manual that provides some background to the visual and several suggested activities to do with groups. Manual topics fall generally under the following three categories: prevention of FASD; facts about FASD; and ways to support those with FASD

and their families. An Inuk writer and researcher developed the kit in consultation with a steering committee in Nunavut. It is a training resource for Inuit front-line workers to use in delivering presentations and promoting discussion in their communities.
Available at: pauktuut@pauktuutit.ca

Rojas, Aluki. Children Come First: FASD Workshop Report. Pauktuutit Inuit Women's Association: Ottawa. 2004.
Summary:
A workshop was developed in 2002 for Inuit front-line workers to familiarize themselves with the *Children Come First* manual and flipchart described above along with Pauktuutit's *Before I Was Born* kit, also included in this review. The workshop increases knowledge, skills and confidence and provides an opportunity for participants to practice giving presentations based on the activities and information. The workshop has been repeated in several Inuit regions. At the time of writing, several more are planned. Independent evaluations (2004) of two of the workshops have been conducted and are available at Pauktuutit.
Available at: pauktuut@pauktuutit.ca

Royal Canadian Mounted Police. Fetal Alcohol Spectrum Disorder – FASD Guidebook for Police Officers. RCMP: 2002.
Summary:
(A majority of Inuit communities are served by the RCMP. Inuit are regularly recruited to work with the RCMP.) This guidebook provides a wide range of factual FASD information for police officers. Highlights include: possible effects on the fetus (covers several street drugs and alcohol); common strengths of some individuals affected by FASD; and a section on FASD Profile and Law Enforcement (understanding and exerting legal rights; conducting interviews and taking statements; re-planning your investigation; and an investigation checklist). This practical Guidebook encourages community networking including the use of cultural supports and diversionary practices. A resource list and bibliography are included.
Available at: www.asantecentre.org/pdf/latestfasguide.pdf

Single, Eric et al. Horizons 1994: Alcohol and other drug use in Canada. Health Canada and the Canadian Centre on Substance Abuse. 1994.
Summary:
This research publication includes information on the Northwest Territories before division. It mentions limitations in the availability of data on substance abuse for the North, although it provides data on alcohol sales. In a section on *Women, Drugs and Fetal Growth,* the report mentions a 1992 study of pregnant women in northern NWT that included 56 Inuit women out of the 162 studied. Of the total 162, "34 per cent of the women drank during pregnancy. Smoking, caffeine use, and binge drinking were most frequent among the Inuit and Indian mothers. … Alcohol use, and especially binge drinking, was significantly associated with decreased head circumference."
Available at: www.hc-sc.gc.ca/hecs-sesc/cds/pdf/hor_e.pdf

Status of Women Council of the NWT. Keeping Women and Communities Strong: Women, Substance Abuse and FAS/FAE, an NWT Needs Assessment. May 1996.
Summary:

The study conducted 56 interviews with aboriginal women in the NWT (before division) and input was received from a number of other respondents concerning "the experience of women and girls who have abused alcohol and/or drugs and their experiences when seeking help or treatment. … Frontline workers say peer pressure seems to be the major reason teen girls begin using substances. The workers believe family violence is the most important reason why adult women begin to drink. Most women say they started drinking in their early teens." One-third of the interviewees with children said they drank while pregnant. A range of issues are discussed in the Report including: awareness; prevention; treatment; diagnosis; frontline coordination and cooperation; training; and initiative evaluation. An action plan and 13 detailed recommendations are presented. "Family and community support are the keys to helping women and teen girls who have substance abuse problems." (Inuit-specific information or recommendations are not identifiable from the Executive Summary reviewed.) In addition to the English report, the Council produced a plain language summary in English and Inuktitut syllabics, referred to as "Keeping Women and Communities Strong - the Short Report" with the same date.
Contact: marsha@statusofwomen.nt.ca

Stout, Roberta. Before I Was Born: Preventing FAS/FAE in Inuit communities.
Pauktuutit Inuit Women's Association: Ottawa. 2001.
Summary:
This kit was developed with the input of a national Inuit steering committee and the technical assistance of many Inuit. It contains: video versions in English, Inuvialuktun, two dialects of Inuktitut, and French; a printed viewing guide and poster in English, Inuktitut syllabics, Inuinnaqtun and French; and radio play versions on CD in English, Inuinnaqtun, Baffin and Labrador Inuktitut and French. The viewing guide includes: factual information on FAS/FAE; background to the video; a facilitator's guide to the video including scene summaries; a true and false quiz with answer guide and explanations; and a resource list. The 26-minute video, featuring Inuit actors and various health personnel, is a docudrama filmed in Iqaluit. The 7-minute radio play contains content similar to the drama enacted in the video. An independent evaluation (2001) of this project is available at Pauktuutit.
Available at: pauktuut@pauktuutit.ca, http://www.pauktuutit.ca/main_e.html or http://209.217.87.67/FAS/index.html (website under reconstruction 2004-2005)

Soon-to-be-published research

Egeland, Grace et al. "Age Differences in Vitamin A Intake Among Canadian Inuit." Canadian Journal of Public Health. In press.
Summary:
(A draft was not available at the time of writing.) The paper includes a discussion on "vitamin A and alcohol and that high amounts of alcohol may increase the toxicity of too low Vitamin A exposures."
Contact: grace.egeland@mcgill.ca

Other documents/research

Beddard, Janice M. "Fetal Alcohol Syndrome: Educator's Knowledge and Needs." Master's Thesis. Queen's University, Kingston. September 1996.
Summary:
"This exploratory study surveyed or interviewed educators in Ontario and the Northwest Territories [before division] to ascertain their knowledge about fetal alcohol syndrome (FAS) and their experience and needs related to working with students with FAS. … Northern educators consistently responded with more information than southern educators and had more concerns about the community impact of FAS." A range of recommendations to "improve the educational response of educators and the prognosis of students with FAS" were gathered in the study.
Contact: jbeddard@qikiqtani.edu.nu.ca

Godel, John et al. "Fetal Alcohol Syndrome and Effect: Following of northern infants at risk." Approximately 1997.
Summary:
(No publication of this research was found at the time of writing.) The locations for this study included several Inuvialuit communities in the western Northwest Territories. Elementary school children were assessed using several methods in the schools or health centers. "… Parents were informed of their children's results." The results underline "the need for prevention and remedial programs."

A News North article with no date was also received during this review. Without the date, it is unclear whether the information concerned an earlier study or if the following results were part of the study above. Also, there is no information provided on sampling methods: Of "Godel's 90-student survey," 29 were Inuit students. "Of these, 11 (or about 38 per cent) were diagnosed with having symptoms of fetal alcohol syndrome or effects (FAS/FAE)." The results "point to an epidemic of learning problems."
Sources: www.nwtresearch.com/media/comp9697.pdf; "Study finds FAS rampant." News North. No date on photocopy.

Kits/audio-visual/other resources

"Fetal Alcohol Spectrum Disorder Resource Kit." Compiled by the Northwest Territories Literacy Council.
Summary:
At the time of this review, it was not determined whether this kit contained any Inuit-specific material. "Each kit comes in a sturdy plastic container and has a selection of books, videos, audio tapes, CD-Roms, and other resources. The NWT Literacy Council will ship it to you by Canada Post or air freight and borrowers are responsible for the cost of shipping the kit back to the NWT Literacy Council."
Available at: www.nwt.literacy.ca/catalogue/resrckit.htm

Government of the Northwest Territories – Social Services. "Alcohol." Alcohol and Drug Services pamphlet series. No date – possibly mid-1980s.
Summary:
This pamphlet provides a description of alcohol use, patterns and problems in the context of the Northwest Territories (likely well before division created Nunavut). It mentions the issue of drinking in pregnancy and the potential damage to the unborn baby, but does not refer to FAS, FAE or FASD.

Health Canada. "Stop Fetal Alcohol Syndrome/Fetal Alcohol Effects (FAS/FAE) – Healthy Parents – Health Babies." Poster and pamphlet in English and Inuktitut syllabics versions featuring Inuit. No date – Approximately 2002.
Available at: http://www.hc-sc.gc.ca/fnihb/cp/fas_fae/publications/stop_fas_fae.pdf
http://www.hc-sc.gc.ca/fnihb/cp/fas_fae/publications/stop_fas_fae_inuktitut.pdf
http://www.hc-sc.gc.ca/fnihb/cp/fas_fae/publications/stop_fas_fae.htm

Rojas, Aluki. Children Come First: A resource about Fetal Alcohol Spectrum Disorder (FASD). Pauktuutit Inuit Women's Association: Ottawa. 2003.
See above for kit description.

Stout, Roberta. Before I Was Born: Preventing FAS/FAE in Inuit communities.
Pauktuutit Inuit Women's Association: Ottawa. 2001.
See above for summary of kit contents.

Yellowknife Films for Yellowknife Association for Community Living. "Helping Families - Helping Children." 29 min. Video.
Summary:
(These videos are multi-ethnic but may contain Inuit content.) The first video is for parents of children up to six years affected by FAS/FAE. It includes concrete ways for parents to support their children to develop to their full potential. The video explains problems to expect and gives strategies for managing. "Helping Families - Helping Children: Part 2" focuses on children affected by FAS and partial FAS with their families and in the elementary school system. It demonstrates ways that they can be supported to achieve success. This video targets parents and teaching and health professionals.
Available at: nwtacl@ssimicro.com

Kits/audio-visual/other resources under development

Education/Health

Government of Nunavut. CD ROM on FASD. Kugluktuk, Nunavut. 2004-2005.
Summary:
The FASD Pilot Project Team in partnership with Dept. of Education, Kitikmeot School Operations, and Dept. of Health and Social Services, Government of Nunavut, is producing an educational interactive CD ROM on FASD. The Kugluktuk FASD Pilot Project Team has designed this project in collaboration with a range of community and other partners as part of their Community Action Plan. A local youth has been hired to coordinate the project. The CD is an educational tool created by youth for use with children and youth in schools, youth centers, awareness centers, Canada Pre-natal Nutrition Programs and other relevant community programs to increase understanding, awareness and acceptance about FASD. The CD will feature culturally relevant interactive stories, poems, messages, games, puzzles, posters, and projects to illustrate what FASD is, how to prevent it, secondary disabilities and crime prevention associated with FASD. This material will also be incorporated on a website in the future.
Contact: april_pigalak@kitikmeot.edu.nu.ca or ross_learn@kitikmeot.edu.nu.ca

Young, Barbara. "Fetal Alcohol Spectrum Disorder: A unit of study on FASD prevention for Grade 8 students." Draft under review. Iqaluit, Nunavut. April 2004.
Summary:
The unit includes: guidelines for using the unit; rationale; general learning outcomes; 10 Lesson Plans; a resource list; numerous resources for the lessons; and a series of 11 overheads. The Lesson Plan categories are: learning outcomes; recommended materials; key words; suggestions for teaching; and assessment strategies. Learning outcomes range from students being able to produce factual information and have discussions on a number of FASD related topics to expressing their personal viewpoints. The final lesson has students, individually or in groups, produce an information brochure, poster, song, skit or video (if a camera is available) on FASD for sharing with the public. The unit has been tested with Grade 8 students at Inuksuk High School in Iqaluit and is being reviewed by Department of Education officials with the Government of Nunavut.
Contact: byoung@qikiqtani.edu.nu.ca

Unpublished program/internal documents

Corrections

Government of Nunavut – Department of Justice. "Alcohol Related Disorders: Fetal Alcohol Syndrome/Fetal Alcohol Effect—Considerations for Corrections." Iqaluit, Nunavut. June 2001.
Summary:
Prepared by Psychological Services, Corrections Branch, this document provides definition of ARD and FAS/FAE and lists the characteristics and behavior anomalies of FAS/FAE. An outline of the positive aspects of people affected by FAS/FAE is provided. People

management strategies related to work, self-esteem, discipline, behaviour, hyperactivity and providing structure along with general strategies are listed.
Contact: wpodmoroff@gov.nu.ca

Podmoroff, Wayne and Kim Ross. "Kaatak Program—For Special Needs Inmates at BCC". Iqaluit, Nunavut. Proposal - No date.
Summary:
Kaatak is the Inuktitut word for 'the way in or out'. "If we were to combine the populations of current mental health disorders, substance use disorder, intellectual disability and Fetal Alcohol Spectrum Disorder (FASD) our population at BCC [Baffin Correctional Centre] would be all inclusive." This BCC program is designed to meet the correctional goal of promoting wellness in the broad sense and to meet the needs of inmates diagnosed with psychotic disorders, mental disability, FASD and/or organic impairment. The global treatment model is based on Social Skills Training within a controlled, predictable and constant but flexible environment. Based on Nunavut's Bathurst Mandate and *Pinasuaqtavut*, the program emphasizes self-reliance seeking to work within available means, incorporates traditional activities and values into new strategies and builds on existing strengths. Screening processes, staffing issues, a residential self-contained Kaatak Living Unit, security issues and other elements of the program are described.
Contact: wpodmoroff@gov.nu.ca

Education

John Strutynski. "FAS – A Workshop for Teachers". Kivalliq School Operations, Nunavut. September 2002.
Summary:
This workshop document contains: workshop activity instructions; a description of FAS characteristics from the Saskatchewan Institute on Prevention of Handicaps; and a series on education techniques by Valborg Kvigne, Judy Stuck, Ellen Engelhart, and Tracy West. Education techniques are categorized by school level: pre-school; elementary; and junior and senior. Each category covers a range of techniques such as the instructional environment, the alphabet, language development, reading, math, sensory stimulation, short attention span, social behaviour, managing hyperactivity, eye hand coordination, vocational education and evaluation. The workshop has participants review the material, select an appropriate age level and complete and share a lesson plan for a child affected with FAS emphasizing what the child will learn and practice and how the child's work will be evaluated.
Contact: j_strutynski@kivalliq.edu.nu.ca

Kativik School Board. Course materials. Montreal.
Summary:
The KSB is responsible for K - Secondary V education in Nunavik (Northern Quebec) and it provides training for its Inuit teachers. Course material for three regular courses that these teachers complete includes content on FASD: symptoms, causes and ways of working with affected children. Courses available for special education teachers focus more on the teaching aspect of FASD. The course materials are available in Inuktitut. Courses designed for the student counselors (Inuit – one in each school) also include information about FASD. School

personnel have attended FASD workshops where print and visual materials in all three languages (Inuktitut, English and French) described elsewhere in this document were used.
Contact: Judy Macarthur (514) 482-8220 ext. 406

Health

Government of Nunavut – Department of Health and Social Services. "FASD Program Workplan 2004-2005". Iqaluit, Nunavut.
Summary:
Program objectives cover the following topics: health promotion/prevention; asset mapping; coordinated community approach: building community strength for healthy moms and babies; training for professionals working with FASD affected individuals; telehealth education series for community and professionals; and Canada Northwest Partnership and Research Network. Program outcomes, descriptions and partners for each objective are listed. An FASD steering committee brings together multi-sectoral representatives from health, social services, education, early childhood development and corrections. A coordinated approach to FASD involving the establishment of multi-disciplinary teams and pilot communities is underway. Plans relating to Inuit-specific data collection and the establishment of norms for the development of an FASD screening and diagnosis program are featured. Resources being developed include: a Nunavut adaptation of an asset-mapping training manual; a CD-ROM (see Under Development below for a description); an FASD poster; an FASD general information brochure; and an FASD community 'scribbler' sheet for posting events.
Contact: wgovereau@gov.nu.ca

Korhonen, Marja. "Report – Breaking the Cycle: Moving Forward from Evaluation – FASD Conference." National Aboriginal Health Organization – Ajunnginiq Centre: February 2004.
Summary:
Conference "content focused on providing an understanding of at-risk women and explanations of effective processes and strategies for getting them involved in change." The report provides a summary of the key information obtained including information on early identification, early intervention, and important factors for engaging and keeping women in programs to prevent the birth of FASD children.
Contact: mkorhone@naho.ca

Korhonen, Marja. "Report: Canada Northwest Fetal Alcohol Spectrum Disorder Conference." National Aboriginal Health Organization – Ajunnginiq Centre: November 2003.
Summary:
The conference, held in Winnipeg in November 2003, was a product of an FASD partnership among the governments of several provinces and the three territories. Participants from a range of disciplines and backgrounds received "the latest information regarding: etiology and diagnosis; strategies for home and classroom; strategies for community organization, awareness and education; counseling with FASD individuals and families; and sharing of experiences." Key learnings in prevention, research and diagnosis are presented in the report. Conference presentations are expected to be posted on the Conference website. As a follow-up, NAHO-AC expects to prepare FASD Fact Sheets for inclusion on the NAHO-AC website.

They will focus on diagnostic issues and prevention, areas in which Inuit communities have indicated a need for more information.
Contact: mkorhone@naho.ca

Muckle, G. and Déry, S. (from the French) "Alcohol Consumption and FAS in Nunavik – Activity Report 2003-2004 and Workplan 2004-2005." Kuujjuaq, Nunavik.
Summary:
The workplan describes the context of minimal information available on alcohol consumption in Nunavik. The workplan includes: gathering epidemiological information (see Muckle, G. et al. study above); the development and validation of effective, prevention screening tools for Inuit women at risk; the development of Inuit-specific FAS diagnostic tools; and the development and piloting of a preventative intervention in an Inuit community in Nunavik. A committee composed of Inuit experts and other professionals will be formed to advise on the design of the intervention. The plan hopes that findings from the various activities in Nunavik will also prove useful to other Canadian Inuit jurisdictions.
Contact: gina.muckle@psy.ulaval.ca

APPENDIX D: FASD SCAN OF BEST PRACTICES[8]

Mainstream Literature Review: FASD Prevention

Good/best practice recommendations for FASD prevention and intervention were reviewed through a search of documents from:

- Health Canada
- Institute of Medicine (United States)
- University of Northern British Columbia's Centre of Excellence for Children and Adolescents with Special Needs
- British Columbia Centre for Excellence for Women's Health
- Canadian Centre on Substance Abuse
- National Institute on Alcohol Abuse and Alcoholism (United States)
- Canadian Paediatric Society
- Alberta Medical Association and Alberta Partnership on FAS
- Best Start: Ontario Maternal, Newborn and Early Child Development Resource Centre

While further research is essential, current evidence and consensus indicates benefits of specific interventions and activities, especially as a flexible and comprehensive continuum of programs and services.

Prevention of FASD requires three levels of effort and activity:

- Primary prevention focuses on preventing/decreasing the occurrence of FASD through activities that lead to the systemic, environmental and behavioural changes that result in healthy lifestyles and healthy choices: public education and awareness, health promotion, community development, policies, etc. Although evidence of effectiveness is limited, activities should include:
  - ⇨ school/community-based programs for youth
  - ⇨ both general and women-specific substance education strategies
  - ⇨ highly visible community-based prenatal support programs
  - ⇨ training of health and social service providers in discussing alcohol use and providing advice
  - ⇨ evaluation of awareness/education strategies in order to assess effectiveness and enable modifications
  - ⇨ policies and programs that address the determinants of substance problems

  However, research has shown that knowledge alone is not necessarily enough to bring about changed drinking behaviour among all women.

- Secondary prevention activities focus on women of child-bearing age, both pregnant and not pregnant. Effective programs should include:

[8] Information is current as of September 2004.

- ⇨ early identification of at-risk women in a variety of settings (health centres, housing, social services, etc.) through screening (which may include the use of screening tools such as TACE or simple conversational questions)
- ⇨ full, accurate (and non-fear-raising) information and awareness activities
- ⇨ non-judgmental respectful outreach services emphasizing harm reduction (women at risk may not seek help for fear of blame, judgment and stigma)
- ⇨ cognitive-behavioural brief interventions by health and social service providers
- ⇨ services such as change motivation, harm reduction information and strategies (decreasing or stopping drinking), nutrition counselling, and skills development
- ⇨ holistic services that include partners and family, and deal with all levels of needs
- ⇨ contraceptive counselling
- ⇨ respectful, non-judgmental culturally-appropriate interactions

- Third-level prevention activities are oriented to pregnant women and mothers who already have substance abuse problems…those for whom fetal damage is a real possibility and/or who already have a child affected by fetal alcohol. The goals are to prevent or reduce damage to the foetus, help mothers control their alcohol abuse after giving birth (in order to minimize the risk of further FASD births and to maximize her ability to manage her/her child's care), and enable the mother to better care for a child who may be/has been born with FASD.
    - ⇨ flexible respectful culturally-aware services oriented to harm reduction
    - ⇨ recognition/acceptance of each woman's level of readiness for change, and allowing for client input
    - ⇨ involvement of partners/family members when possible
    - ⇨ contraceptive counselling
    - ⇨ referral for withdrawal and intensive treatment when necessary
    - ⇨ consistent contact and relationship/trust-building
    - ⇨ continuation of service and support immediately after birth
    - ⇨ coordinated case management and comprehensive package of prenatal care, substance abuse counselling, coping and skills development, housing and medical care advocacy, relationship counselling, etc.

Minimization of the secondary disabilities of FASD individuals depends on early identification and diagnosis. The possibility of fetal alcohol effects should considered soon after birth for a woman who has been at risk, and supports and interventions put in place to enable the best possible child development and parental coping/caring skills. Intervention (including involvement of family and community resources) should begin even if a definitive diagnosis has not yet been made. Diagnosis and intervention services should be coordinated and multidisciplinary, involving medical, educational, psychological and community resources.

Specific gaps in service have been identified across Canada and are especially lacking in remote and rural areas:

- Routine and sustained ongoing screening/early identification and brief intervention is not generally happening in health and social service settings.
- Although both early and intensive services for women are necessary for prevention, such services for women are inadequate both in numbers and in the range of needed services and modalities (harm-reduction, withdrawal and intensive treatment, outreach, supports, etc.) Poole (2003) states that emphasis has been on FASD as a child welfare issue – after the fact - rather than on services to women which would decrease the incidence of FASD.
- FASD assessment and diagnostic tools are not well-developed or readily available, and early identification/diagnosis of children is too often not done, especially in rural and remote areas, meaning that children are at high risk of secondary disabilities.
- Communities, individuals and even professionals still lack awareness and understanding of the full cognitive, social and personal effects of FASD across the lifespan. Children, adolescents and adults therefore may not get the supports, understanding and services necessary for optimal development socially, emotionally and cognitively.
- Evaluation and evidence as to effectiveness of programs and approaches is inadequate.
- There is lack of coordination of services.

SOURCES

Alberta Medical Association. "Recommendations: Prevention of Fetal Alcohol Syndrome (FAS)." Alberta Clinical Practice Guidelines. April 1999. http://www.albertadoctors.org

Best Start. "Keys to a Successful Alcohol and Pregnancy Communication Campaign." Ontario's Maternal, Newborn and Early Child Development Resource Centre. 2003. http://www.beststart.org/resources/alc_reduction/keys.pdf

Canadian Centre on Substance Abuse. "FAS Toolkit." http://www.ccsa.ca/toolkit/introduction.htm

Canadian Paediatric Society. "Fetal Alcohol Syndrome." CPS Statement: II-2002-01. Paediatric Child Health 7(3), March 2002: 161-174. http://www.cps.ca/english/statements/II/II02-01.pdf

"Prevention of Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE) in Canada." Position Statement. Paediatric and Child Health 1997, 2(2): 143-145. Reaffirmed March 2004. http://www.cps.ca/english/statement/FN/cps96-01.htm

Hankin, J.R. "Fetal Alcohol Syndrome Prevention Research." Alcohol Research and Health 26 (1), 2002: 58-65. National Institute on Alcohol Abuse and Alcoholism. http://www.niaaa.nih.gov/publications/arh26-1/58-65.htm

Health Canada. "Fetal Alcohol Spectrum Disorder (FASD): A Framework for Action. 2003. http://www.hc-sc.gc.ca/dca-dea/publications/fasd-etcaf/frameowk_e.html

Legge, C., Roberts, G., Butler, M. “Situational Analysis: Fetal Alcohol Syndrome/Fetal Alcohol Effects and the Effects of Other Substance use During Pregnancy.” Health Canada, December 2000.

Leslie, M., Roberts, G. “Enhancing Fetal Alcohol Syndrome (FAS)-related Interventions at the Prenatal and Early Childhood Stages in Canada. Canadian Centre on Substance Abuse, 2001. http://66.46.215.135/docs/capc-cpnp/monograph.htm

Poole, N. “Mother and Child Reunion: Preventing Fetal Alcohol Spectrum Disorder by Promoting Women’s Health.” British Columbia Centre of Excellence for Women’s Health, Policy Series. June 2003.

Roberts, G. and Nanson, J. “Best Practices: Fetal Alcohol Syndrome/Fetal Alcohol Effects and the Effects of Other Substance use During Pregnancy.” Health Canada, December 2000.

Stockburger, J. “Substance Abuse Related Special Needs in Canada: Best Practices for Prevention.” University of Northern British Columbia Substance Abuse Task Force, Health Canada Centre of Excellence for Children and Adolescents with Special Needs. 2003.

Stratton, K., Howe, C., Battaglia, F., eds. *Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention and Treatment*. Institute of Medicine, Committee to Study Fetal Alcohol Syndrome. National Academies Press, 1996.