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*“Nine months is not a very long time but FASD is for a life time.”*



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**INUIT FIVE-YEAR STRATEGIC PLAN FOR  
FETAL ALCOHOL SPECTRUM DISORDER  
2010 – 2015**

## ACKNOWLEDGEMENTS

The development of this strategic plan was guided primarily by the results of focus group sessions conducted by Pauktuutit and by the outcomes of a strategic planning session that was held in Happy Valley-Goose Bay March 15 – 16, 2010. The focus groups and the strategic planning session were made possible with financial support from First Nations and Inuit Health Branch (FNIHB). Indian and Northern Affairs Canada (INAC) provided additional funding for the strategic planning session to ensure involvement of early childhood educators. .

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Tracy O'Hearn, Executive Director, Geri Bailey, Manager, Health Policy and Programs,  
Pitsulala Lyta, Project Coordinator, Ron Ryan, notetaker and Phillip Bird, consultant.

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2010 – 2015

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*“Nine months is not a very long  
time but FASD is for a life time.”*

Focus Group Participant  
(Puvirmituq, Nunavik, March 2010)

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## INTRODUCTION

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Pauktuutit Inuit Women of Canada works to foster greater awareness of the needs of Inuit women, to advocate for equality and social improvements and to encourage the participation of Inuit women in the community, regional and national life of Canada. This Inuit Five-Year Strategic Plan on Fetal Alcohol Spectrum Disorder (FASD) sets out a vision statement, mandate, priorities and strategic directions that will guide how Pauktuutit will collaborate with governments and other regional and local stakeholders over the next five years with respect to the problem of FASD within Inuit communities in Canada.

As a management tool, this Strategic Plan serves to focus Pauktuutit's efforts to promote healthier Inuit lives. There is a need to respond to the problem of FASD in the context of Inuit knowledge, attitudes and behaviours about pre-natal alcohol consumption and in the context of the changing northern health, social and economic environment. It is with these factors in mind that Pauktuutit has formulated the priorities and actions outlined in this Strategic Plan.

FASD is an umbrella term that includes a range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioural and learning disabilities with lifelong implications. Children with FASD often display such characteristics as extreme hyperactivity, aggressiveness, poor judgment and speech and language difficulties. The nature and extent of the damage to the baby depends on a number of factors such as when the mother drank during the pregnancy; the pattern and frequency of alcohol consumption (for example, binge drinking); the use of other drugs; and other biological features of the fetus and the mother.

Region	Percent Diagnosed
All Inuit in Canada	5%
Inuit Nunangat	4% *
Nunatsiavut	8% *
Nunavik	6% *
Nunavut	n/a **
Inuvialuit Region	n/a **
Outside Inuit Nunangat	12% *

\* Use with caution.  
\*\* Data suppressed due to confidentiality

Source: Aboriginal People's Survey, 2006.

Reliable data for FASD among Inuit are not readily available.<sup>1</sup> Results from the Census and from the Aboriginal Peoples Surveys (APS) are often suppressed for reasons of statistical

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1. A search for Inuit-related FASD research using the U.S. National Library of Medicine PubMed database provided 15 records; none were related to Canadian incidence rates or treatment.

reliability or confidentiality. For example, the 2006 APS data on FASD among Inuit children aged six -14 is suppressed for all Inuit regions due to the confidentiality requirements of the *Statistics Act*. However, the survey does report that five per cent of those Inuit living outside of Inuit Nunangat have been diagnosed with FASD. As an indirect measurement, the following table provides a regional comparison of Inuit children diagnosed with learning disabilities in 2006.

Another indirect measure for the potential for FASD is in terms of alcohol abuse. Binge drinking is a problem within Inuit communities, especially among young people. This behaviour is a risk factor in the spread of sexually transmitted infections, HIV/AIDS and Hepatitis C and may be a contributing factor for Inuit FASD. The results of the 2006 APS reveal that heavy drinking — defined as five or more drinks a day one or more times per week — are self-reported to be as high as 28 per cent among Inuit females in Nunatsiavut. In Nunavut, where eight communities have prohibited alcohol, the rate for heavy drinking is substantially lower. The following table summarizes the gender differences among heavy drinkers in each Inuit region.

**PERCENT OF ADULT INUIT (AGED 15+) WHO HAD FIVE DRINKS OR MORE ONCE A WEEK OR MORE OFTEN DURING THE PAST 12 MONTHS**

Region ↓		Percent ↓
All Inuit in Canada	% of Total	16%
	% among Males	18%
	% among Females	14%
Inuit Nunangat	% of Total	15%
	% among Males	16%
	% among Females	13%
Nunatsiavut	% of Total	31%
	% among Males	35%
	% among Females	28%
Nunavik	% of Total	18%
	% among Males	20%
	% among Females	17%
Nunavut	% of Total	11%
	% among Males	11%
	% among Females	10%
Inuvialuit Region	% of Total	15%
	% among Males	19% *
	% among Females	12% *
Inuit Living Outside Inuit Nunangat	% of Total	18%
	% among Males	22% *
	% among Females	15% *

\* Use with caution.

Source: Aboriginal People's Survey, 2006.

Inuit women have been concerned about the impact of FASD on their families and communities for more than a decade. This Strategic Plan is guided by Pauktuutit's long history of working in the area of early childhood development (ECD) and FASD. Since 1995, Pauktuutit has been engaged in the prevention and treatment of FASD among Inuit and has been an advocate for greater commitment among stakeholders to work towards eliminating FASD in Inuit communities. Pauktuutit is committed to enhancing prevention and access to diagnosis within Inuit communities and to supporting individuals and families coping with FASD. This effort has included participation on national advisory committees on FASD.

In 1996, Pauktuutit conducted an information-sharing and skill-building workshop on FASD. A report of this workshop was prepared. Also in 1996, Pauktuutit prepared a resource guide entitled *Fetal Alcohol Syndrome: A Resource for Inuit Communities to Understand What FAS is and What They Can Do to Help*. Another FASD resource guide was prepared in 1998 entitled *Ikajuqtigiinni* based on information gathered at a national Inuit FASD workshop.

In 2001, Pauktuutit completed a video entitled *Before I was Born* as a way to inform Inuit youth about the consequences of consuming alcohol during pregnancy and to provide support to families living with FASD. This video was part of a larger information kit that included a viewer's guide, a radio play and a poster. In 2003, an Inuit-specific FASD health promotion resource kit called *Children Come First: A Resource About FASD* was developed. The kit includes a flipchart and manual. Together the two resources have been used in a number of FASD prevention training workshops for frontline workers to help them engage community participation and to raise awareness. In 2004, Pauktuutit held an FASD train-the-trainers workshop, where Inuit facilitators received instruction in the delivery of Pauktuutit's four-day FASD training workshop. In 2005, these facilitators conducted Pauktuutit's FASD workshops for front-line workers in Iqaluit, Rankin Inlet, Puvirnituk and in Ottawa. Building Inuit capacity for the delivery of these programs is critical to ensuring that Inuit communities will be able to effectively address FASD-related issues. Also in 2005, a survey of FASD training opportunities within Inuit communities was conducted by Pauktuutit in partnership with the First Nations Child and Family Caring Society of Canada. The survey respondents identified the need for more attention to FASD in the communities, especially in the area of diagnosis and intervention training.

In 2006, Pauktuutit, in partnership with the National Aboriginal Health Organization (NAHO), designed an advanced FASD training workshop for frontline workers and other health care providers. *Katujjiqatigiitsuni Sanngini: Working Together to Understand FASD* focuses on strategies to support women at risk and is part of a larger strategy to assist communities to examine the broad determinants of health that impact the lives of pregnant women and women in their childbearing years who use alcohol or drugs. Regional workshops were conducted in Inuvik, Cambridge Bay, Kuujuaq and Inukjuak. In 2007, Pauktuutit formed a partnership with the Department of National Defence and the Canadian Junior Rangers to develop and conduct an advanced FASD training workshop for their trainers.

Pauktuutit has developed a manual for early childhood education entitled *Piarnut For Our Children: Quality Practices in Inuit ECD*. This resource includes a chapter on challenging behaviour, with particular attention to behaviours that may result from such factors as FASD, Attention Deficit Hyperactivity Disorder, learning disabilities and delays in speech and language skills. A key concept is the strength-based approach — the need to focus on the child's positive and unique strengths — in order to help the child develop appropriate behaviours. All Inuit children deserve the opportunity to grow and flourish in a nurturing environment. The strength-based approach assists those with challenging behaviours to succeed in Head Start programs, childcare and in school.

Another relevant resource is *Born on the Land with Helping Hands – The Inuit Women’s Guide to a Healthy Pregnancy*. This practical pregnancy calendar incorporates important nutritional and medical knowledge about healthy pregnancies and information about traditional midwifery.

The development of this Strategic Plan has been guided by four focus group sessions conducted in early 2010 by Pauktuutit to understand better Inuit knowledge, attitudes and behaviours about FASD and to help identify the priorities for action in the years to come. The focus groups filled gaps in current knowledge and have contributed to developing the strategic directions that best address the needs of Inuit individuals, families and communities. Consultations culminated with a two-day FASD Strategic Planning Session that took place in Happy Valley-Goose Bay, Labrador in March 2010. Participants with a background in FASD, early childhood development and in childcare education gathered from across Inuit Nunangat to discuss the problem of FASD and to plan for the future.

## **GOVERNANCE**

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Since it was incorporated in 1984, Pauktuutit has proven to be a dynamic national Inuit organization that has a reputation for researching, developing and implementing projects and initiatives that meet the diverse needs of Inuit women, their families and their children. The organization has the experience and expertise to deliver timely and cost-effective initiatives.

Pauktuutit has a reputation for enhancing capacity and community awareness and for developing and delivering effective and appropriate community-level tools and resources. Many initiatives do not fall neatly under the heading of ‘women’s issues’ since many activities are not limited solely to gender. For example, violence, sexual health and injury prevention are multi-faceted problems where the solutions are not gender specific — the solutions lie with the entire community. Often Pauktuutit’s work has been groundbreaking in that it broaches subject areas that have not been addressed by other Inuit organizations.

Pauktuutit has strong democratic roots. It is governed by a 14-member Board of Directors, representing all Inuit regions in Canada. As well, youth and urban Board members contribute their perspective to Pauktuutit’s activities and mandate. Only Inuit women are eligible for Board membership. The Board is supported by a dedicated staff located in Ottawa who offer a broad range of subject matter expertise as well as administrative and financial expertise.

Pauktuutit’s strategy is to build community networks and advisory bodies that embrace broad and comprehensive Inuit input and expertise. This strategy ensures that the differing socio-economic and regional circumstances of Inuit are captured and incorporated during program and project development. The resulting initiatives are guided by Inuit women and this ensures the initiatives successfully meet their needs and those of their families and communities.

In terms of FASD, Pauktuutit continues to review its activities and initiatives to address the issue within Inuit communities. Resolutions passed during Annual General Meetings (AGMs) have continued to support the organization’s efforts. During the 2004 AGM, the FASD Prevention and Support resolution was passed which directs Pauktuutit to increase prevention and awareness of FASD in Inuit communities and to include support programs

for individuals, families and communities. During the 2008 AGM, the Healthy Pregnancy Promotion resolution was passed. During the 2010 AGM, delegates passed a parenting resolution that promotes, among other things, healthy living.

## **STRATEGIC DIRECTIONS**

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### **MISSION**

The mission of the Inuit Five-Year Strategic Plan on Fetal Alcohol Spectrum Disorder (2010 – 2015) is to enhance FASD prevention and diagnosis and to support the needs of individuals and families living with FASD in Inuit communities. This will be achieved through an inclusive, holistic and community-based approach that involves all stakeholders, builds upon existing strengths and knowledge, develops new partnerships and builds on the capacity to respond to the unique needs of Inuit women and their families and communities in a compassionate and respectful manner.

### **VISION**

This FASD Strategic Plan envisions Inuit affected by FASD, Inuit women, their families and their communities having the human and financial resources to access FASD diagnostic and treatment services and access to culturally appropriate care and support. Increased awareness that substantially reduces or eliminates FASD among Inuit is envisioned, as well as programming aimed at all stages in the life of an individual and which builds on their strengths in a manner that ensures all Inuit grow up to be healthy individuals.

### **GUIDING PRINCIPLES**

This FASD Strategic Plan builds on six guiding principles: respect, cooperation, understanding, compassion, hope and responsibility. These principles were first developed for the Nunatsiavut Government's FASD Program and were adopted during the March 2010 FASD Strategic Planning Session in Happy Valley-Goose Bay, Labrador as appropriate for this five-year Strategic Plan.

#### **Respect**

- For the abilities of those living with FASD;
- For the knowledge of those rearing children with FASD;
- For all Inuit communities in their efforts to address FASD;
- For the traditional values and practices of families and communities impacted by FASD;
- For the rights of women and families to make choices about their health and the health of their children; and
- For the ability of family and communities to support children and partners affected by alcohol.



**Cooperation**

- By recognizing the importance of building partnership within and among communities in addressing all aspects of FASD.

**Understanding**

- By informing ourselves of FASD issues, research and new information;
- By being conscious of our own attitudes and values;
- By being sensitive to the impact of a diagnosis on an individual, a family and a community; and
- By appreciating the importance of linking women to suitable supports and services.

**Compassion**

- By being sensitive to the needs of individuals with FASD and willing to understand both their strengths and difficulties; and
- By being sensitive to the situations of women with substance use problems.

**Hope**

- By recognizing that at whatever point a woman can stop or reduce her alcohol intake during pregnancy, there is hope for a healthier child;
- By acknowledging that however an individual is affected by FASD, supportive intervention can be effective; and
- By recognizing that with each positive action we take toward FASD prevention and awareness, a difference can be made.

**Responsibility**

- By recognizing our shared responsibility as community members to support healthy children, healthy women, healthy families and healthy communities.

**GOALS**

1. To work with pregnant women so that they make informed decisions and healthy choices;
2. To advocate for Regional FASD Coordinators in all Inuit regions by 2015;
3. To increase the number of FASD community workers;
4. To secure comprehensive and sustainable funding for FASD programs and services;
5. To have ongoing FASD programs and services that cover the life cycle of individuals with FASD that are appropriate to Inuit communities;
6. To reduce the occurrence of FASD from 2010 levels;

7. To establish links between communities and Inuit organizations for the exchange of information and for the development of strategies that counter and lessen the effects of FASD; and
8. To enlist champions who will assist in building awareness about the causes, prevention and treatment of FASD.

## **CURRENT OPERATING ENVIRONMENT**

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### **STRENGTHS, WEAKNESSES, OPPORTUNITIES AND LIMITATIONS**

A brief review of Pauktuutit's strengths, weaknesses, opportunities and limitations (a SWOT analysis) will demonstrate that the organization is well situated to meet the priority objectives detailed in this Strategic Plan.<sup>2</sup> It is important to identify the weaknesses and limitations faced by Pauktuutit in order to better strategize for the successful outcome of the Strategic Plan.

#### **Strengths**

Since it was incorporated in 1984, Pauktuutit has proven to be a dynamic national Inuit organization that has a reputation for researching, developing and implementing projects and initiatives that meet the diverse needs of Inuit women, their families and their communities. The organization has the expertise to deliver timely and cost-effective initiatives. Areas of strength for Pauktuutit include:

- Reputation for groundbreaking work on matters that have not been addressed by other Inuit organizations;
- Reputation for enhancing community capacity and awareness and for delivering community-level tools and resources. These include information and educational material, community-level workshops and train-the-trainer initiatives that are culturally appropriate and sensitive to regional differences;
- Record of addressing many health, social, economic and traditional issues that are not limited solely to gender. For example violence, tobacco use, alcohol abuse, sexual health and FASD are multi-faceted problems where the solutions must target all sectors of Inuit society — the solutions lie with the entire community;
- History of working on FASD and ECD issues within Inuit communities and an expressed commitment to make Inuit communities healthier;
- Experience conducting focus group sessions in different Inuit regions that served to assess Inuit knowledge, attitudes and behaviours about FASD and other topics;
- The capacity to effectively participate in policy-level discussions that ensure regional, community and gender-specific issues are articulated; and

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2. A SWOT analysis refers to strengths, weaknesses, opportunities and threats. However, the word "threats" has stronger negative connotations within Inuit culture and therefore the word "limitations" is preferred.

- The capacity and commitment to partner with Inuit women and with a wide variety of Inuit and non-Inuit organizations. This strength includes:
  - The priority to work with and to develop the capacity of women at the grassroots level of Inuit communities;
  - The capacity to undertake projects guided by Advisory Committees that are composed of qualified and experienced people who can exercise a critical role in the successful design and execution of programs;
  - A history of partnerships that have included Indian and Northern Affairs Canada (INAC), Health Canada, Status of Women Canada, the Public Health Agency of Canada (PHAC), Canadian Heritage, Correctional Service Canada, other federal departments and territorial and provincial governments; and
  - A history of close working relationships with Aboriginal organizations including Inuit Tapiriit Kanatami (ITK), Inuit Tuttarvingat at the NAHO, Inuit Land Claim Organizations (LCOs), Regional Inuit Associations (RIAs) and various First Nation and Métis organizations.

### **Weaknesses**

- Lack of financial support is a limiting factor. Generally, projects are financed on an annual project-by-project basis. An investment in human resource capacity may be lost once a project is complete;
- Finding funding and having the resources to develop proposals in the time frames available are major time-consuming challenges. This results in less work being done to address the issues at hand and more time allocated to administration and paper work;
- A general problem is the recruitment and retention of staff. An investment in building human resource capacity may be lost to other employers who constantly seek skilled Inuit and who can offer secure full-time employment;
- Staff turnover can have a major impact on programming capacity. Within a small organization considerable knowledge becomes invested in the staff. As staff work closely together and know the ins and outs of the project, staff turnover can result in considerable disruptions and delays;
- Working with northern communities takes time, patience and flexibility as unforeseen circumstances can disrupt planning. Weather and local community events and crises can delay the planned arrival of individuals for meetings and the scheduling of workshops, symposiums or forums. Pauktuutit must always be prepared to adjust programs and plans on short notice. This, however, can take a toll on staff in terms of heavy workloads, long hours and stress;
- Often a lack of funds limits the ability to conduct face-to-face meetings with those who sit on the project steering committees. Instead, teleconferences are held when advice and guidance are required and these limit the ability to establish trust and relationships;
- It is increasingly more difficult to find volunteers or organization-sponsored input. People often are not available for meetings and sometimes Pauktuutit does not have the funds to pay honoraria for those who are not organization-sponsored; and
- In some communities there are limited funds to hire FASD workers. In others, FASD workers are only part-time.

## Opportunities

- Inuit women are becoming more aware of how alcohol can have a negative effect on the developing fetus. The opportunity exists to build on this knowledge and to establish the linkages between the prevention, diagnostic, care, treatment and social support services that must complement public awareness and the willingness to act;
- Pauktuutit's earlier *Children Come First* train-the-trainer initiative already has established some community-level human resources for future FASD work. Some communities already have had some awareness programming;
- FASD prevention initiatives have been undertaken in Nunavik and Nunatsiavut. Pauktuutit can partner with the Nunatsiavut government and the Inuulitsivik Centre to build on this work which can serve as models and promising practices for initiatives in all Inuit regions; and
- Positive relationships have been established with different federal, provincial and territorial government departments on a wide-range of topics and projects. These can serve as opportunities for future partnerships and sources of financial support. At the federal level, potential partners include:
  - Correctional Service Canada;
  - Health Canada's First Nations and Inuit Health Branch (FNIHB);
  - Human Resources and Skills Development Canada (HRSDC);
  - INAC; and
  - PHAC.
- The opportunity exists to coordinate FASD activities with the Government of the Northwest Territories (GNWT) and the governments in Nunavut, Nunavik and Nunatsiavut. Relevant departments and agencies include:
  - GNWT Department of Education, Culture and Employment;
  - Government of Nunavut Department of Culture, Language, Elders and Youth;
  - Government of Nunavut Department of Education;
  - Government of Nunavut Department of Health and Social Services;
  - GNWT Health and Social Services;
  - Kativik Regional Government;
  - Kativik School Board;
  - Nunatsiavut Government Department of Education and Economic Development;
  - Nunatsiavut Government, Department of Health and Social Development; and
  - Nunavik Regional Board of Health and Social Services.
- The LCOs and other Inuit organizations offer opportunities for support and collaboration. These include:
  - AnânaKatiget Tumingit (Nunatsiavut Women's Association);
  - Inuit Tapiriit Kanatami;
  - Inuit Tuttarvingat of the National Aboriginal Health Organization (NAHO);

- Inuulitsivik Centre;
- Inuvialuit Regional Corporation;
- Kakivak Association (Qikiqtaaluk, Nunavut);
- Kitikmeot Economic Development Commission;
- Kitikmeot Inuit Association;
- Kivalliq Inuit Association;
- Kivalliq Partners in Development;
- Makivik Corporation;
- Nunavut Tunngavik Incorporated;
- Qikiqtani Inuit Association; and
- Qullit Nunavut Status of Women.

At the community level, potential partners include:

- Aboriginal Head Start programs;
- Child development centres;
- Community Health Representatives and Workers (CHR/Ws);
- Childcare centres;
- Family counselling centre;
- Health centres;
- Men’s and women’s groups;
- Nurses;
- Schools and school boards;
- Wellness coordinators;
- Women and children’s centres; and
- Women’s shelters.

### **Limitations**

- There is limited data about the incidence of FASD among Inuit and about the social and economic impact of FASD within Inuit communities;
- Within the corrections system the number of inmates with FASD is unknown. Staff may not be trained to handle inmates with FASD;
- Inuvialuit, Nunavut and Nunavik have limited access to FASD diagnostic services;
- There is insufficient FASD training for Inuit and great disparity across Inuit Nunangat;
- Within Inuit communities there are limited health care personnel and fewer services. Inuit must often travel great distances for specialized health services, including diagnostic testing and long-term care;
- Linkages between various service providers are limited;
- Cultural barriers — language, the absence of Inuit knowledge within the health care system and the lack of cultural awareness — limit the ability of health care professionals to effectively meet the needs of Inuit patients;

- Recruitment and retention of health practitioners is a challenge due to lack of a local skilled workforce, isolation and the high cost of living;
- The Inuit population is dispersed over a wide geographic area across multiple jurisdictions; and
- Information material and training must be provided in multiple Inuit dialects.

## INUIT-SPECIFIC FASD FOCUS GROUPS

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Pauktuutit conducted focus group sessions in the four Inuit regions to gauge Inuit knowledge, attitudes and behaviours with respect to FASD. The results have contributed to the development of this Strategic Plan. A total of 39 participants attended the sessions in Inuvik, Puvirnituq, Hopedale and Iqaluit. All participants were women. Almost two-thirds of the women were under 40 years of age, a third were between 21 and 30 years and almost 18 percent were under 20 years. Virtually all of the participants have children.

The focus groups revealed that even among participants who had received some previous FASD training (almost 75 per cent of all participants), there were still persistent gaps in behaviour among some. Though awareness and attitudes have changed, some continued to undertake high-risk behaviour. Participants understood the general characteristics of FASD and its causes. It appears younger Inuit continue to be less informed.

The focus group participants felt there was a need to get at the root of why Inuit women drink while pregnant. It was suggested that teens who are pregnant and continue to drink may be trying to fit in. Some noted the lack of services for addiction and that it can be difficult to give support to those suffering from addiction. The prospect or intent to give the newborn up for adoption may foster a lack of responsibility by the mother. Concern was expressed that teens affected with FASD are getting pregnant — their lack of knowledge about FASD and their ability to manage alcohol and other substances may be impaired and this may foster risk behaviour.

The focus group participants provided some important insights that are relevant to the design and delivery of community-level programs and services. These include:

- Mothers and children with FASD may experience stigma, regret, guilt, shame and rejection;
- Mothers may become overwhelmed and fail to properly raise their child;
- Family members must help;
- The need to identify and counsel mothers at risk;
- Support and counselling for mothers is needed because young mothers may lack parenting skills and may find it difficult to provide the necessary constant care and attention;
- The lack of services for addiction;

- For reasons of confidentiality, the child and family services may not share information about a child's FASD condition with foster parents;
- Church, exercise, watching videos, teen dances, spa nights for women, getting men involved and greater awareness were cited as alternate activities from drinking during pregnancy;
- Inuk-to-Inuk knowledge transference is valuable — learning from a parent with an FASD-affected child is an effective way to inform and change awareness, attitudes and behaviour;
- More publicly available information needs to be translated and it must avoid blaming the mother;
- More information and workshops are needed;
- A role for doctors, hospitals and leadership needs to be identified (many participants indicated they had little in-depth contact with doctors while pregnant);
- Medical advice was limited about the dangers of drinking while pregnant (some doctors suggest a little alcohol is OK, others say nothing); and
- In Nunavik, midwives were praised for their FASD counselling.

## **FASD STRATEGIC PLANNING SESSION**

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In March 2010, Pauktuutit organized an FASD Strategic Planning Session in Happy Valley-Goose Bay, Labrador in advance of a scheduled National Inuit Early Childhood Education Gathering. The planning session provided an opportunity to develop a more coordinated approach to FASD with the participation of the Inuit Early Childhood Development Working Group and others working on FASD. Outcomes of the planning session included a draft vision statement for dealing with FASD, a statement of goals and guiding principles and a discussion of next steps and actions.

Participants to the strategic planning event were presented the results of the four FASD focus group sessions conducted by Pauktuutit. The participants then identified a number of FASD issues. These include:

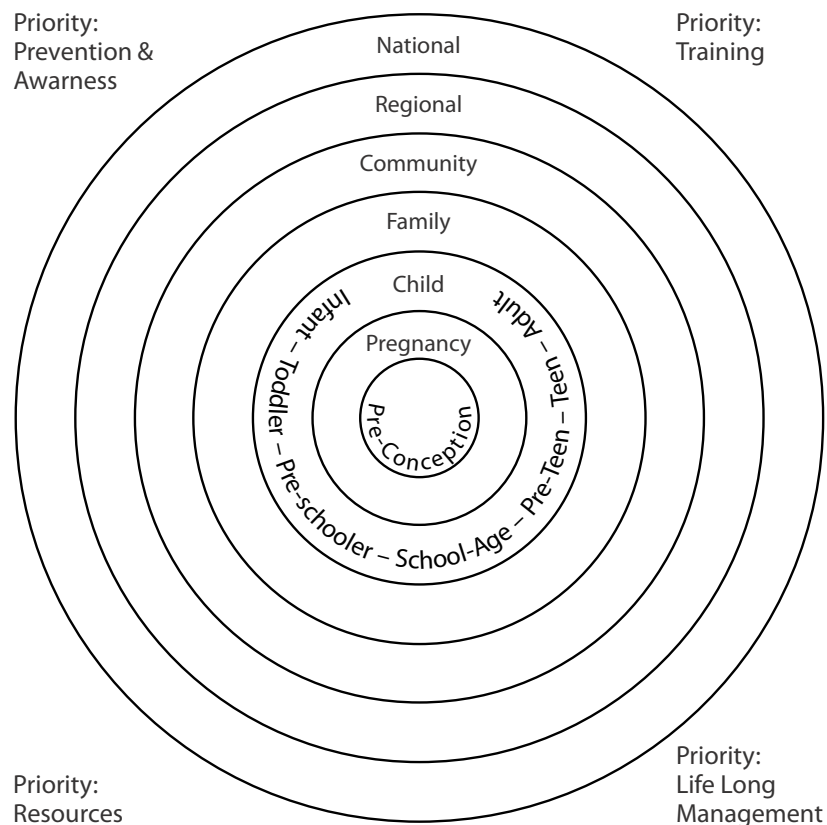
- Awareness building about FASD is long overdue;
- Education about the effects of alcohol during pregnancy and breast feeding needs to be communicated and this material should be translated into Inuktitut;
- Challenges linked to changing Inuit attitudes about drinking during pregnancy include:
  - The view that the newborn will be adopted so it does not matter;
  - That the mother's other children are OK despite having drunk alcohol during pregnancy so it is OK to drink; and
  - Abusive relationships may foster high risk behaviours;

- In many cases, foster parents are unaware their foster child is affected by FASD;
- Doctors are not always providing a consistent message about drinking during pregnancy;
- There is an important role for addiction workers in FASD prevention; and
- Without additional FASD programs and services, a generation of Inuit could be lost, resulting in the loss of Inuit culture and way of life.

In terms of next steps, the FASD Strategic Planning Session identified two main objectives. These are:

1. To undertake two or three FASD pilot awareness projects in Inuit communities during the 2010-2011 fiscal year in order to build the capacity of the communities to conduct their own FASD awareness activities. It was recommended that these pilot projects take place in communities located in the Inuvialuit Settlement Region, Nunavut and/or Nunavik.
2. Conduct an environmental scan on what has been done on FASD in terms of training, awareness building and promotion, prevention, diagnosis, support and treatment. The intent is to look beyond what has been done with respect to women at risk, the prenatal period and for infants through to preschool. There is a need for an environmental scan of FASD initiatives for school age children, youth and adults. This should include the identification of programs and material, an assessment of its suitability for Inuit and the identification of promising practices.

## LEVELS OF ACTION





This Strategic Plan acknowledges that FASD lasts a lifetime. Interventions must begin before conception and must focus on pregnant women and on the health of the unborn children. The support needed for children with FASD evolves over time and will vary depending upon the severity of the disorder. At each stage in life, different institutions and services are relevant and these must have the necessary resources to respond. An adult with FASD also needs support. Not only must the parents and families adjust to raising a child with FASD, but so must the childcare services, Aboriginal Head Start programs, schools, community members, community and regional health and social services, justice system and ultimately the policies and services provided at the national level.

This Strategic Plan seeks to work collaboratively at all levels of action — pre-conception, pregnancy, the lifecycle of the FASD-affected individual, the family, the community, the region and at the national level. Work must continue to focus upon awareness and prevention across Inuit Nunangat in order to prevent alcohol-affected births, to improve the outcomes for individuals already affected by FASD and to support their families, caregivers and their communities.

Current FASD-related activities have largely focussed upon the action levels of pre-conception, pregnancy and the early years. This Strategic Plan aims to direct activities across all action levels and throughout the lifespan of the individual affected by FASD. Without support for the later years, the progress made during early childhood development will be lost. Support for FASD-affected children cannot end once they enter school. It must continue in various forms throughout their lives.

The following table illustrates this Strategic Plan’s objective to promote a more balanced approach to FASD activities in Inuit Nunangat. The current emphasis on pre-conception, pregnancy and early childhood development would shift to a more holistic approach that acts at all levels — pre-conception, pregnancy, the FASD-affected individual, the family, the community and at the regional and national level. As well, the strategy seeks to balance actions to meet the changing needs of an individual affected by FASD as they get older.

<b>COMPARISON OF CURRENT AND PLANNED FASD ACTIVITIES</b>															
Current Focus of FASD Action	Ideal Focus of FASD Action														
Pre-conception and Pregnancy	Pre-conception and Pregnancy														
<table border="1"> <tr> <td style="text-align: center;">Individual (0 to six years only)</td> <td style="text-align: center;"> <table border="1"> <tr><td style="text-align: center;">Infant</td></tr> <tr><td style="text-align: center;">Toddler</td></tr> <tr><td style="text-align: center;">Preschooler</td></tr> </table> </td> </tr> </table>	Individual (0 to six years only)	<table border="1"> <tr><td style="text-align: center;">Infant</td></tr> <tr><td style="text-align: center;">Toddler</td></tr> <tr><td style="text-align: center;">Preschooler</td></tr> </table>	Infant	Toddler	Preschooler	<table border="1"> <tr> <td style="text-align: center;">Individual</td> <td style="text-align: center;"> <table border="1"> <tr><td style="text-align: center;">Infant</td></tr> <tr><td style="text-align: center;">Toddler</td></tr> <tr><td style="text-align: center;">Preschooler</td></tr> <tr><td style="text-align: center;">School age</td></tr> <tr><td style="text-align: center;">Pre-teen</td></tr> <tr><td style="text-align: center;">Teen</td></tr> <tr><td style="text-align: center;">Adult</td></tr> </table> </td> </tr> </table>	Individual	<table border="1"> <tr><td style="text-align: center;">Infant</td></tr> <tr><td style="text-align: center;">Toddler</td></tr> <tr><td style="text-align: center;">Preschooler</td></tr> <tr><td style="text-align: center;">School age</td></tr> <tr><td style="text-align: center;">Pre-teen</td></tr> <tr><td style="text-align: center;">Teen</td></tr> <tr><td style="text-align: center;">Adult</td></tr> </table>	Infant	Toddler	Preschooler	School age	Pre-teen	Teen	Adult
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School age															
Pre-teen															
Teen															
Adult															
Family	Family														
Community	Community														
Regional/National	Regional/National														

## **PRE-CONCEPTION**

Healthy pregnancies may be planned in advance and there is a need to link FASD programming to the knowledge, attitudes and behaviour of Inuit men and women in advance of conception. Unfortunately, many pregnancies are unplanned and a woman may be two, three or more months pregnant before she finds out.

Awareness about the dangers of FASD before conception is one solution. There is a need for Inuit-specific material about the importance of planned pregnancies. This material can be provided to community health and social service providers and to Inuit community members. Alternatively, there is the opportunity to avoid unplanned pregnancies. There is a need to link awareness about safe sex practices to planned pregnancies and to FASD prevention. Pauktuutit already works in the area of sexual health within Inuit regions and can adapt its material and some awareness activities to draw attention to FASD. Prevention and awareness should be provided to young adults on a regular and ongoing basis.

## **PREGNANCY**

Pregnancy is a critical focus of FASD awareness and prevention. Social and economic support often targets women at risk in order to help them make informed and positive choices about their health and the health of their families. Pauktuutit has a history of engaging frontline workers and community members in FASD awareness. A great deal of effort has been directed at harm reduction during pregnancy and in helping Inuit to identify and manage the challenging behaviours often associated with FASD.

In order to reduce the incidence of FASD there is a need to engage more than just the mother. Couples often have similar drinking habits and they tend to socialize with others with similar lifestyles. As such, efforts to promote abstinence during pregnancy require the support of fathers, families and friends.

## **INDIVIDUALS WITH FASD**

FASD lasts a lifetime. Strategic planning and actions must include those stages in life that follow pregnancy and early childhood in an effort to avoid disabilities that an individual was not born with. The potential for these secondary disabilities can be reduced if individuals are diagnosed early, if they grow up in a stable and nurturing home that does not change every few years, if they do not experience sexual or physical or other abuse and if they receive appropriate health, educational and social services.

As an Inuk with FASD gets older, they will encounter many situations and will come in contact with many services and institutions where their condition may be a factor. What are labelled challenging behaviours in their childhood and youth may be at the root of future problems in school, with employment, with their own families and potentially with the legal system.

Individuals who do not display the physical manifestations of FASD are difficult to diagnose. However, professional FASD diagnostic and screening services are limited in Canada but are virtually nonexistent in Inuit Nunangat.<sup>3</sup> Inuit children and youth who are suspected of being affected by FASD need access to diagnostic and screening services that are outside the Inuit regions. Even without formal diagnosis, children, youth and adults who exhibit challenging behaviours should receive support from physicians, psychologists, early childhood educators, teachers, social service professionals, family therapists, nurses and community support circles.

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3. FASD screening is available in Nunatsiavut under special arrangement with the Janeway Children's Hospital located in St. John's. FASD specialists travel to the region to provide FASD screening services.

At this stage, it is difficult to strategically plan and to define priority actions for all stages in the life of an Inuk with FASD. Current programs and services are primarily geared for infants, toddlers and Aboriginal Head Start children. Programs and services for grade school, high school students and for adults are less developed. Inuit high school students with FASD may face bullying and substance abuse, may become sexually active and/or may come into conflict with the law. As an adult, an Inuk woman with FASD may have her own children and may be repeating the cycle of FASD. If they are within the justice system, they may not fully appreciate the consequences of their actions and may, therefore, become repeat offenders. In total, all these programs, services, institutions and circumstances call for a complex coordinated multidimensional plan of action.

## **FAMILY**

Parents of children with FASD, as well as foster parents and adoptive parents need support to help them raise their family and to help them cope with the challenges they face. For young parents, they may not be prepared to deal with the challenging behaviours associated with their child. Some adoptive and foster parents may not be immediately aware of their child's condition. Parents need training on how best support an FASD-affected child. It is important that fathers become involved in the parenting and education of their child. Respite care services and support groups need to be established to help parents better cope with the difficulty of raising an FASD-affected child.

From a strength-based perspective, support programs and services are needed that meet the needs of mothers, children, partners and communities impacted by FASD. Young women, new mothers and fathers can meet to build stronger networks of relations. In a group context, they can share understandings, concerns and strategies in a manner that builds on every person's strengths.

## **COMMUNITY**

Action at the community level is critical to the problem of FASD in Inuit Nunangat. Human and infrastructural resources need to be in place to properly screen and diagnose the disorder and to provide the health, social and educational support to ensure FASD-affected Inuit live full and productive lives. The community is a key focal point for multidisciplinary action in the form of awareness and prevention, training, resources and life-long management of FASD.

Ideally, a community-based FASD coordinator is needed to manage awareness and prevention and to liaise with other agencies and services. In practical terms, a visiting or part-time FASD coordinator is more realistic in the smaller Inuit communities.

Effective action within the community requires local physicians, nurses, CHR/Ws, wellness coordinators, substance abuse workers, psychologists, early childhood educators, teachers, social workers, family therapists and law enforcement officers having the training to recognize FASD-affected individuals and to understand the behaviours they may encounter. They also need to be aware of the support services that are available to help FASD-affected individuals.

Health care providers are the primary line of defence in awareness and prevention. They also play an important role in the preliminary identification of infants and children who may be affected with FASD or have Attention Deficit Hyperactivity Disorder, Attention Deficit Disorder, Oppositional Defiant Disorder, Reactive Attachment Disorder or Autism Spectrum Disorder. As such, there is a need for health care providers to be familiar with the determinants

of health that promote risk behaviour and to recognize potential FASD-related behaviour. Critical is the need for health care providers, as well as teachers and other social service providers, to avoid projecting guilt upon the mothers. This will inhibit disclosure and will limit the provision of care and services.

In the schools, teachers and staff must be trained to recognize potential FASD-related behaviour and must have the skills and programs to ensure that students who exhibit challenging behaviours are able to participate fully. Special education programs may be required. A key principle is to value the strengths in all individuals. As well, schools must educate the general student population about the impact of alcohol use during pregnancy.

Communities also need to examine the policies that guide access to alcohol. Some Inuit communities limit access and some are dry communities. What actions are communities taking to enforce their alcohol laws and how effectively are they being enforced?

## **REGIONAL**

FASD action at the regional level will largely be in the form of policies, training and financial and infrastructural support. Regional governments are key partners in a coordinated strategy to address FASD within Inuit Nunangat. Relevant focal points are the departments of health and social services, the departments of education and school boards and the departments of justice and local policing.

Regionally coordinated awareness campaigns are needed. Messaging should be consistent across different regions. Access to FASD diagnostic and screening services requires the support of the regions. The capacity for schools to support FASD-affected students and to include FASD education as part of the curriculum requires regional support. Adjustments to the way police and the courts handle FASD-affected individuals require intervention at the provincial, territorial and federal level. Programs and services are needed to accommodate the disproportionate number of Inuit with FASD, mental health disorders and substance use disorders within the correctional system. Within police services, there is the need for officers to have the training and knowledge to effectively respond to FASD-related behaviours when working in the communities and to be able to make the appropriate referrals for either the accused or victim who may be FASD-affected.

## **NATIONAL**

The true cost of FASD is difficult to assess. Costs range from those related to medical, educational and social services to the costs related to police responding to the actions of FASD-affected individuals, correctional services, lack of employment and/or dependence on social services and overall loss of productivity. The severity of an FASD-affected person's condition, their age and where they live are significant determinants of costs.<sup>4</sup> These costs will always be higher in Inuit Nunangat than elsewhere in Canada. In addition, the extent that FASD is under-diagnosed will reduce the estimated economic burden of FASD on Canadian society. National policies and disease management strategies need to be based on a reasonable estimate of the real cost of FASD.

Policy-makers need to be aware of the long-term economic impact of FASD and should recognize the financial burden this places on parents — especially those with low incomes — and upon small isolated communities. Support is needed so that local health professionals

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4. Stade, B., et al., *The Burden of Prenatal Exposure to Alcohol: Measurement of Cost*. JFAS Int 2006; 4: e5 Feb. 2006.

and educators can implement health promotion strategies that reduce or eliminate the incidence of FASD. Though health care is largely in the domain of the provinces and territories, FASD-affected individuals are likely to place some economic burden on Health Canada's Non-Insured Health Benefits program. These economic costs need to be evaluated in order to guide policy and program development.

Within the justice system, a large proportion of Inuit inmates are likely to have some form of FASD. This condition can foster high rates of recidivism because the FASD-affected individual may not link their actions to consequences and, therefore, may not learn from their prison experience.<sup>5</sup> Ideally, FASD-affected youth should be diverted from the prison system and those suspected of FASD should undergo FASD assessment in advance of sentencing.

Overall, national policies and programs need to be reviewed and assessed to identify promising practices and their potential relevance to Inuit.

## **PRIORITIES**

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Ideally, a woman should stop drinking before conception. However, not all pregnancies are planned. Therefore, the sooner a woman stops drinking the better the long-term outcomes for her baby. FASD is preventable but solutions must consider both the addiction and the socioeconomic factors that contribute to the disorder. These latter factors include reduced access to prenatal and postnatal care and services, inadequate nutrition, paternal drinking and a poor developmental environment (for example stress, abuse and neglect). FASD is therefore a complex public health and social problem.

This Strategic Plan recognizes that a mother and her family — as well as any foster parents, adoptive parents and social support workers — will need information, guidance and training. All of this only can happen in a community that has the facilities and the personnel to meet the challenge. As well, the community childcare centers and schools must provide support. All of this requires support at the regional and national level.

A fundamental element of all of these priorities is the need for collaboration. All actions require working relationships with parents, with community-based organizations and with territorial, provincial and national organizations, agencies and governments. There is a need to establish collaborative relationships that encourage the identification and sharing of promising practices and the sharing of information and planning.

This Strategic Plan rests on four key priorities: prevention and awareness, training, resources and life-long management. Each of these priorities must be articulated at all life stages of an individual with FASD — as an infant, toddler, pre-schooler, student, pre-teen, teen and as an adult. As well, each priority is relevant at all action levels — before conception, during pregnancy, within the family, the community and at the regional and national levels.

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5. M.Waage, 2008. *Lethbridge Community Justice Project Supporting Individuals with FASD*. Lethbridge Regional Police Service. PowerPoint presentation, Second National Roundtable on the Development of a Canadian Model for Calculating the Economic Impact of FASD: Youth Justice Component, Vancouver, February 2008.

## PREVENTION AND AWARENESS

Current prevention and awareness activities tend to focus on the action levels of preconception, pregnancy and the pre-school years of an individual affected by FASD. Though harm reduction during pregnancy and the diagnosis and early intervention of FASD are critical activities, there is a need to expand awareness about the lifelong challenges associated with an individual affected by FASD. This must take place not just among community members, but also among professionals in a wide range of fields.

FASD is a community-based issue so awareness and education about FASD is essential at this action level. Much of Pauktuutit's work has been in the area of training frontline workers and CHR/Ws about FASD. A train-the-trainer model is an effective way to bring FASD awareness into each community and to establish the capacity for ongoing awareness and prevention activities.

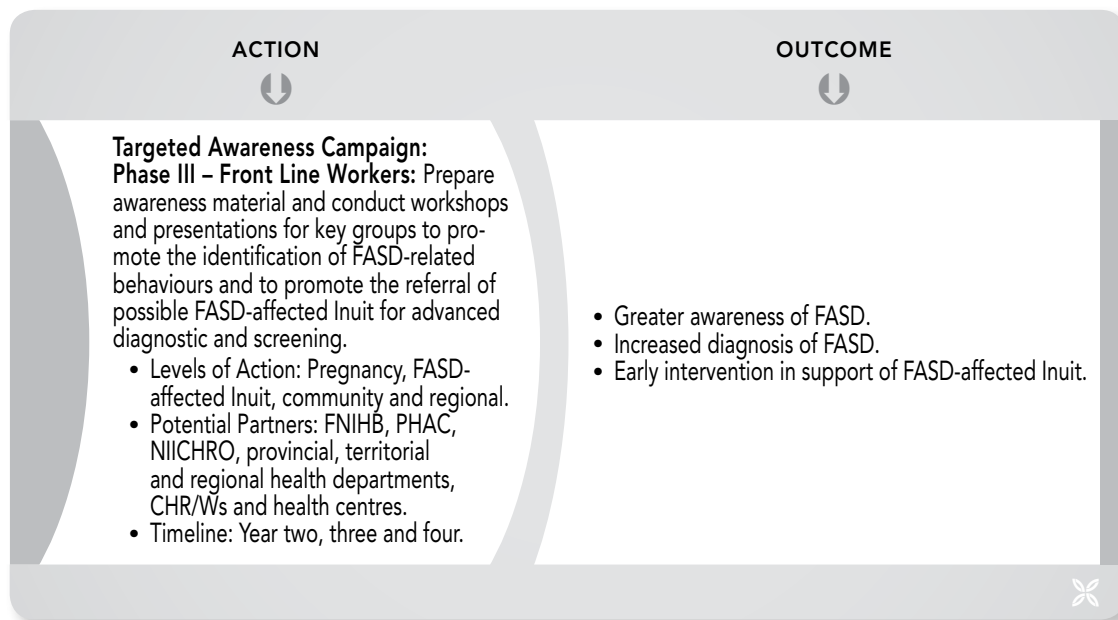
Awareness campaigns must cater to different audiences. There is a need for clear and consistent messages. There is a need for broad-based campaigns that raise public awareness. A campaign is needed for girls and women of childbearing years and another for Inuit women who are at high risk. All frontline professionals need awareness and understanding of FASD so that they can recognize high-risk women and the symptoms of those affected by FASD and can then help these individuals access the services and support they may need.

The following table summarizes prevention and awareness action items proposed to be undertaken over the next five years. Each activity identifies the level of action targeted by the activity, lists partners that could potentially collaborate in completing the action and notes the proposed timeframe for the action.

ACTION	OUTCOME
<p><b>Pregnancy Planning:</b> Prepare Inuit-specific material that empowers individuals to make informed decisions about conception and pregnancy. Provide material to community health and social service providers and to Inuit community members.</p> <ul style="list-style-type: none"> <li>• Levels of Action: Pre-conception, pregnancy, community and regional.</li> <li>• Potential Partners: PHAC, FNIHB, provincial, territorial and regional health departments, CHR/Ws, health centres and family counselling centres.</li> <li>• Timeframe: Year one and ongoing.</li> </ul>	<ul style="list-style-type: none"> <li>• Reduced incidence of FASD.</li> <li>• Harm reduction.</li> <li>• Informed and healthy decision-making.</li> </ul>
<p><b>Consistent Messaging for Pregnant Women:</b> Develop resource material for health service providers in Inuit Nunangat that promotes a consistent message of alcohol reduction/abstinence during pregnancy.</p> <ul style="list-style-type: none"> <li>• Levels of Action: Pregnancy, community and regional.</li> <li>• Potential Partners: NAHO, PHAC, FNIHB, provincial, territorial and regional health departments and health centres.</li> <li>• Timeline: Year one and two.</li> </ul>	<ul style="list-style-type: none"> <li>• Consistent advice across Inuit Nunangat by health professionals for pregnant women about reduced or zero alcohol during pregnancy.</li> <li>• Reduced incidence of FASD.</li> <li>• Harm reduction.</li> </ul>

ACTION ↓	OUTCOME ↓
<p><b>Link FASD to Sexual Health and Safer Sex Practice Campaigns:</b> Adapt existing safer sex material geared for Inuit to include the dangers of FASD as a consequence of unsafe sex.</p> <ul style="list-style-type: none"> <li>• Levels of Action: Pre-conception, pregnancy, community and regional.</li> <li>• Potential Partners: ITK, PHAC, provincial, territorial and regional health departments and health centres.</li> <li>• Timeframe: Year one and ongoing.</li> </ul>	<ul style="list-style-type: none"> <li>• Reduced incidence of FASD.</li> <li>• Harm reduction.</li> <li>• Greater awareness of the link between unsafe sex and FASD.</li> </ul>
<p><b>Link FASD to Other Substance Abuse Prevention Efforts:</b> Identify and adapt existing Inuit-specific substance abuse prevention material to include the dangers of unplanned pregnancies and FASD.</p> <ul style="list-style-type: none"> <li>• Levels of Action: Pregnancy, community and regional.</li> <li>• Potential Partners: PHAC, FNIHB, provincial, territorial and regional health departments, schools and school boards and health centres.</li> <li>• Timeframe: Year one and ongoing.</li> </ul>	<ul style="list-style-type: none"> <li>• Reduced incidence of FASD.</li> <li>• Harm reduction.</li> <li>• Greater awareness of the link between substance abuse and FASD.</li> </ul>
<p><b>Targeted Awareness Campaign: Phase I – High Risk Women:</b> Develop and disseminate awareness material that targets Inuit women at risk.</p> <ul style="list-style-type: none"> <li>• Levels of Action: Pregnancy, community and regional.</li> <li>• Potential Partners: PHAC, FNIHB, provincial, territorial and regional health departments, schools and school boards and health centres.</li> <li>• Timeframe: Year one and ongoing.</li> </ul>	<ul style="list-style-type: none"> <li>• Greater community-level awareness of FASD.</li> <li>• Reduced incidence of FASD.</li> <li>• Harm reduction.</li> </ul>
<p><b>Targeted Awareness Campaign: Phase II – Teens and Youth:</b> Develop and disseminate awareness material that targets Inuit teens and youth.</p> <ul style="list-style-type: none"> <li>• Levels of Action: Pre-conception, pregnancy, community and regional.</li> <li>• Potential Partners: PHAC, FNIHB, provincial, territorial and regional health departments, schools and school boards and health centres.</li> <li>• Timeframe: Year one and ongoing.</li> </ul>	<ul style="list-style-type: none"> <li>• Greater community-level awareness of FASD.</li> <li>• Reduced incidence of FASD.</li> <li>• Harm reduction.</li> </ul>





## TRAINING

There is a need within Inuit regions and communities for on-going training about FASD. As well, there is a need for adequate resources to support these training efforts. The subject matter and the audience for this training are diverse. They include those working in the health care field, education, social services, child welfare, corrections and in law enforcement as well as families and community members. Ideally, training is community driven, culturally relevant and led by committed, well-trained facilitators.

Comprehensive, multidisciplinary, holistic, community driven and culturally relevant FASD training is needed to support FASD awareness, diagnosis, prevention and life-long care in a multifaceted and inter-agency manner. Training must prepare communities to manage FASD throughout the lifespan of the individual. Training must be designed to place FASD in the context of substance abuse. Teachers involved in ECD, education and childcare need training to help them manage and support children affected by FASD and to help parents to get involved in education planning and to link to other agencies and services. The topic of FASD needs to be incorporated into elementary and secondary teacher training and included as on-going training for all school personnel. Law enforcement personnel need to learn more about FASD among adults and how difficult behaviour may be rooted in the disorder.

Within Inuit regions, an increased capacity to have access to FASD diagnostic and screening services should be a priority. Community health care professionals need specialized training to aid in the diagnostic process. This would benefit from input by FASD specialists. FASD training must include specialized training about women-at-risk, including assessment, relationships and intervention/change strategies.

Train-the-trainer workshops are valued among Inuit because they contribute to, and enhance, self-determination and capacity building within communities. This is especially important for rural, remote and isolated communities. Given the personal and sensitive nature of FASD, FASD training and related materials must meet the cultural and linguistic needs of the community. Trainers must be fluent in Inuktitut or interpretation services must be available.



The following table summarizes training-related action items proposed for the next five years. Each activity identifies the level of action targeted by the activity, lists partners that could potentially collaborate in completing the action and notes the proposed timeframe for the action.

ACTION	OUTCOME
<p><b>Pilot Community Training Sessions:</b> Utilize community mobilization and community development approaches to assist two communities to develop grassroots plans that empower community members to raise awareness about FASD.</p> <ul style="list-style-type: none"> <li>• Levels of Action: Community and regional.</li> <li>• Potential Partners: FNIHB, PHAC, CHR/Ws and health centres.</li> <li>• Timeline: Year one.</li> </ul>	<ul style="list-style-type: none"> <li>• Increased community-level training capacity.</li> <li>• Greater community-level awareness of FASD.</li> <li>• Establish community-level FASD action plans.</li> <li>• Reduced incidence of FASD.</li> </ul>
<p><b>FASD Training for Pregnant Women, Young People, Parents and Families:</b> Train-the-trainer for direct community level capacity building for parents and families affected by FASD.</p> <ul style="list-style-type: none"> <li>• Levels of Action: FASD-affected Inuit, family, community and regional.</li> <li>• Potential Partners: FNIHB, PHAC, provincial, territorial and regional health departments, CHR/Ws and health centres.</li> <li>• Timeline: Year two and ongoing.</li> </ul>	<ul style="list-style-type: none"> <li>• Increased community-level training capacity.</li> <li>• Increase capacity among parents and families to raise FASD-affected Inuit.</li> </ul>
<p><b>Targeted Training for Professional Groups:</b> Prepare and conduct training for police and probation/parole officers, judges, lawyers, corrections workers, physicians, psychologists, teachers and school staff.</p> <ul style="list-style-type: none"> <li>• Levels of Action: Community, regional and national.</li> <li>• Potential Partners: FNIHB, PHAC, provincial, territorial and regional health departments, schools, school boards, police departments, Department of Justice and Correctional Service Canada.</li> <li>• Timeline: Year three and ongoing.</li> </ul>	<ul style="list-style-type: none"> <li>• Increased awareness about FASD.</li> <li>• Increased sensitivity to the needs and challenges facing FASD-affected Inuit.</li> </ul>



## RESOURCES

There is a critical need to develop an Inuit-specific integrated system of support and resources that links all levels of action together into an effective holistic strategy. This requires leadership, direction, partnerships and collaboration at the national, provincial/territorial and community level working together to prevent FASD and meet the needs of FASD-affected Inuit and those caring for them.

In Inuit Nunangat, there has not been a systematic assessment of the programs and services related to all aspects of FASD. To a large extent, there are only limited Inuit-specific FASD resources beyond those related to pre-conception, pregnancy and infancy. There needs to be an assessment of what resources are available to FASD-affected Inuit across the lifespan: pre-schoolers, students, teens, adults as well as those who may in conflict with the law, who have substance abuse issues and who may be a parent. In addition, there is a need to assess the extent and patterns of binge drinking in Inuit Nunangat, the capacity of communities to support Inuit with substance abuse problems and to assess the strategies used by communities, if any, to enforce limits on access to alcohol.

It is essential to conduct an environmental scan to map relevant FASD resources in all Inuit regions and communities. There is a need to identify the resources, skills and knowledge that already exist at all levels — in families, communities, regions, governments, private industry and non-government organizations — and to filling in the gaps with additional awareness and prevention training, sharing of promising practices, knowledge and additional resources. Through the identification of resources, skills and knowledge that already exist, a multi-disciplinary, systemic and coordinated response to FASD can be developed at all levels. Immediate outcomes of an environmental scan include the identification of promising practices for parenting Inuit with FASD and an Inuit-specific database for FASD resources.

The following table summarizes immediate resource-related action items proposed for the next five years. Each activity identifies the level of action targeted by the activity, lists partners that could potentially collaborate in completing the action and notes the proposed timeframe for the action.

ACTION ↓	OUTCOME ↓
<p><b>Advisory Committee:</b> A National Inuit Advisory Committee on FASD to provide leadership and direction on the implementation of the Strategic Plan.</p> <ul style="list-style-type: none"><li>• Levels of Action: Community, regional and national.</li><li>• Potential Partners: ITK, provincial, territorial and regional health departments.</li><li>• Timeline: Year one and ongoing.</li></ul>	<ul style="list-style-type: none"><li>• Leadership and direction for implementation of the Strategic Plan.</li><li>• Local, regional and national advice about FASD.</li></ul>

**ACTION****OUTCOME**

**Environmental Scan:** Conduct a systematic mapping of FASD-related programs and services available within Inuit communities and regions, including: awareness and prevention, access to diagnosis\* and screening, training, support services and groups, education, justice programs, etc. The scan must encompass all those programs and services that support FASD-affected Inuit throughout their entire life.

- Levels of Action: Pre-conception, pregnancy, FASD-affected Inuit, family, community, regional and national.
- Potential Partners: ITK, FNIHB and PHAC.
- Timeline: Year one.

- Regional comparison of services and programs.
- Identification of gaps in programs and services.
- Identification of promising practices.
- A baseline data set to better target training, programming, prevention, awareness and FASD screening and diagnostic services

**Inuit-Specific Gathering to Validate the FASD Environmental Scan:** Organize and conduct a follow-up meeting to the environmental scan to validate the resources identified and to measure progress and successes following the scan.

- Levels of Action: Community, regional and national.
- Potential Partners: ITK, FNIHB and PHAC.
- Timeline: Year two.

- Validation of environmental scan findings.
- Identification of resources and services of high value.
- Identification of ongoing gaps in existing resource and services.

**Establish FASD Community Coordinators:** Establish full-time or visiting positions for FASD coordinators to maintain a multidisciplinary approach to FASD training and services at the community level.

- Levels of Action: Pre-conception, pregnancy, FASD-affected Inuit, family, community and regional.
- Potential Partners: FNIHB, PHAC, INAC, LCOs, provincial, territorial and regional health departments.
- Timeline: Year two and ongoing.

- Community-level FASD focal point.
- Region-wide coordination of programming and services.
- Increased community capacity.
- Increased FASD awareness and prevention.
- Reduced incidence of FASD.

**Inuit-Specific Gathering of FASD Coordinators:** Organize and conduct a meeting of FASD coordinators to share stories, experiences and promising practices.

- Levels of Action: Community, regional and national.
- Potential Partners: ITK, NAHO, FNIHB, PHAC, INAC, LCOs, provincial, territorial and regional health departments, CHR/Ws, health centres, schools and school boards.
- Timeline: Year four.

- Increased community capacity.
- Increased FASD awareness and prevention.
- Reduced incidence of FASD.
- Improved coordinated response to FASD.
- Revised inventory of promising practices.

\* Currently, no FASD diagnostic services are permanently located within Inuit regions.



## LIFE-LONG MANAGEMENT

FASD lasts a lifetime. There is a need for a range of permanent, holistic, responsive support services for families and FASD-affected Inuit. These may include respite, home visits, recreational activities, independent living, resource lending, intervention and employment services. A mechanism should be established to share leading edge information, promising practices and other resources across Inuit Nunangat.

FASD-affected individuals need a stable home, a responsive school system and the support of family and friends. To reach their full potential they need to feel a part of the community. Parents of children with FASD need connections with the community as well. Raising a child with FASD is a demanding job. Parents may require help dealing with their own addictions, along with poverty, low self-esteem and/or limited parenting and employment skills.

Supportive environments are important in reducing the chances that FASD-affected individuals will come into conflict with the law. A large percentage of Inuit offenders in federal and provincial/territorial prisons are there because of family violence and/or sexual assault. There may be a link between FASD and violence.

Through increased capacity gained through community training sessions, local FASD action plans can be developed to meet the life-long needs of FASD-affected individuals and their families.

ACTION ↓	OUTCOME ↓
<p><b>Establish Home, School and Community Support Groups:</b> Establish and maintain support groups for FASD-affected Inuit and their families.</p> <ul style="list-style-type: none"> <li>• Levels of Action: Family, community and regional.</li> <li>• Potential Partners: LCOs, CHR/Ws, health centres, schools and school boards, provincial, territorial and regional health departments.</li> <li>• Timeline: Year two and ongoing.</li> </ul>	<ul style="list-style-type: none"> <li>• Focal point for awareness, training and interventions.</li> <li>• Greater support for families affected by FASD.</li> <li>• Greater community awareness about FASD.</li> <li>• Promote community-level FASD action plans.</li> </ul>
<p><b>Employment Training:</b> Provide employment-training opportunities for FASD-affected Inuit.</p> <ul style="list-style-type: none"> <li>• Levels of Action: Family, community and regional.</li> <li>• Potential Partners: ITK, LCOs, INAC, HRSDC, schools, school boards, post-secondary institutions, provincial, territorial and regional governments, regional economic development corporations and northern businesses.</li> <li>• Timeline: Year three and ongoing.</li> </ul>	<ul style="list-style-type: none"> <li>• Reduced costs to support FASD-affected individuals.</li> <li>• Improved life chances for FASD-affected individuals.</li> <li>• Better integration into community.</li> </ul>
<p><b>FASD Among Inuit Inmates:</b> Conduct an environmental scan about what is known about FASD among Inuit inmates. Review diversion programs and presentencing assessment options.</p> <ul style="list-style-type: none"> <li>• Levels of Action: FASD-affected Inuit, family, community, regional and national.</li> <li>• Potential Partners: ITK, Correctional Service Canada, federal, provincial and territorial departments of justice, INAC and FNIHB.</li> <li>• Timeline: Year three.</li> </ul>	<ul style="list-style-type: none"> <li>• Reliable assessment about FASD among Inuit inmates.</li> <li>• Inventory of local, regional and federal programs that supports FASD.</li> <li>• Identification of promising practices.</li> <li>• Identification of gaps.</li> </ul>



## SUMMARY OF PRIORITIES, ACTIONS, TIMEFRAMES AND POTENTIAL PARTNERSHIPS

INUIT FIVE-YEAR STRATEGIC PLAN FOR FETAL ALCOHOL SPECTRUM DISORDER , 2010 – 2015  
Summary of Priorities, Actions, Timeframes, and Potential Partnerships/Collaborations

Year 1	Year 2	Year 3	Year 4	Year 5
<b>PREVENTION AND AWARENESS</b>				
<p><b>Pregnancy Planning →</b></p> <ul style="list-style-type: none"> <li>• Levels of Action: Pre-conception, pregnancy, community and regional.</li> <li>• Partnerships: PHAC, FNIHB, provincial, territorial and regional health departments, CHR/Ws, health centres and family-counselling centres.</li> </ul>				
<p><b>Consistent Messaging for Pregnant Women →</b></p> <ul style="list-style-type: none"> <li>• Levels of Action: Pregnancy, community and regional.</li> <li>• Partnerships: NAHO, PHAC, FNIHB, provincial, territorial and regional health departments and health centres.</li> </ul>				
<p><b>Link FASD to Sexual Health and Safe Sex Practices →</b></p> <ul style="list-style-type: none"> <li>• Levels of Action: Pre-conception, pregnancy, community and regional.</li> <li>• Partnerships: ITK, PHAC, provincial, territorial and regional health departments and health centres.</li> </ul>				
<p><b>Link FASD to Other Substance Abuse Prevention Efforts →</b></p> <ul style="list-style-type: none"> <li>• Levels of Action: Community and regional.</li> <li>• Partnerships: PHAC, FNIHB, provincial, territorial and regional health departments, schools and school boards and health centres.</li> </ul>				
<p><b>Targeted Awareness Campaign: Phase I – High Risk Women →</b></p> <ul style="list-style-type: none"> <li>• Levels of Action: Pregnancy, community and regional.</li> <li>• Partnerships: PHAC, FNIHB, provincial, territorial and regional health departments, schools and school boards and health centres.</li> </ul>				
<p><b>Targeted Awareness Campaign: Phase II – Teens and Youth →</b></p> <ul style="list-style-type: none"> <li>• Levels of Action: Pre-conception, community and regional.</li> <li>• Partnerships: PHAC, FNIHB, provincial, territorial and regional health departments, schools and school boards and health centres.</li> </ul>				
<p><b>Targeted Awareness Campaign: Phase III – Front Line Workers →</b></p> <ul style="list-style-type: none"> <li>• Levels of Action: Pregnancy, FASD-affected Inuit, community and regional.</li> <li>• Partnerships: FNIHB, PHAC, NIICHR0, provincial, territorial and regional health departments, CHR/Ws, health centres.</li> </ul>				



Continued

Year 1	Year 2	Year 3	Year 4	Year 5
<b>TRAINING</b>				
<b>Pilot Community Training Sessions →</b> <ul style="list-style-type: none"><li>• Levels of Action: Community and regional.</li><li>• Potential Partners: FNIHB, PHAC, CHR/Ws and health centres.</li></ul>				
	<b>FASD Training for Pregnant Women, Young People, Parents and Families →</b> <ul style="list-style-type: none"><li>• Levels of Action: FASD-affected Inuit, family, community and regional.</li><li>• Partnerships: FNIHB, PHAC, provincial, territorial and regional health departments, CHR/Ws, health centres.</li></ul>			
		<b>Targeted Training for Professional Groups →</b> <ul style="list-style-type: none"><li>• Levels of Action: Community, regional and national.</li><li>• Partnerships: FNIHB, PHAC, provincial, territorial and regional health departments, schools, school boards, police departments, Department of Justice and Correctional Service Canada.</li></ul>		



Continued

Year 1	Year 2	Year 3	Year 4	Year 5
<b>RESOURCES</b>				
<b>Advisory Committee →</b> <ul style="list-style-type: none"><li>• Levels of Action: Community, regional and national.</li><li>• Partnerships: ITK, provincial, territorial and regional health departments.</li></ul>				
<b>Environmental Scan →</b> <ul style="list-style-type: none"><li>• Levels of Action: Pre-conception, pregnancy, FASD-affected Inuit, family, community, regional and national.</li><li>• Partnerships: FNIHB and PHAC</li></ul>				
	<b>Inuit-Specific Gathering to Validate the FASD Environmental Scan →</b> <ul style="list-style-type: none"><li>• Levels of Action: Community, regional and national.</li><li>• Partnerships: ITK, FNIHB and PHAC.</li></ul>			
<b>Establish FASD Community Coordinators →</b> <ul style="list-style-type: none"><li>• Levels of Action: Pre-conception, pregnancy, FASD-affected Inuit, family, community and regional.</li><li>• Partnerships: FNIHB, PHAC, INAC, LCOs, provincial, territorial and regional health departments.</li></ul>				
			<b>Inuit-Specific Gathering of FASD Coordinators →</b> <ul style="list-style-type: none"><li>• Levels of Action: Community, regional and national.</li><li>• Partnerships: ITK, NAHO, FNIHB, PHAC, INAC, LCOs, provincial, territorial and regional health departments, CHR/Ws, health centres, schools and school boards.</li></ul>	



Continued

Year 1

Year 2

Year 3

Year 4

Year 5

LIFE-LONG MANAGEMENT

**Establish Home, School and Community Support Groups →**

- Levels of Action: Family, community and regional.
- Partnerships: LCOs, CHR/Ws, health centres, schools and school boards, provincial, territorial and regional health departments.

**Employment Training →**

- Levels of Action: Family, community and regional.
- Partnerships: ITK, LCOs, INAC, HRSDC, schools and school boards.

**FASD Among Inuit Inmates →**

- Levels of Action: FASD-affected Inuit, family, community, regional and national.
- Partnerships: ITK, Correctional Service Canada, federal, provincial and territorial departments of justice, INAC and FNIHB.

