



FETAL ALCOHOL SPECTRUM DISORDER:  
A STRATEGIC PLAN FOR BRITISH COLUMBIA



BRITISH  
COLUMBIA

# A Strategic Plan to Address Fetal Alcohol Spectrum Disorder in British Columbia

## ***The Importance of Early Intervention***

Thousands of BC children have been affected by pre-natal alcohol exposure. It is estimated that more than three out of every 1,000 infants will be affected in some way by FASD. The loss in human potential is immeasurable. The financial cost is formidable. Each child affected by FASD may require an estimated \$1 million to \$2 million over the course of their lifetime to support remedial medical, educational and social costs.

## ***An Integrated, First-of-its-kind Plan for Improvement***

British Columbia has been a leader in the field of FASD since 1993. This work is the first comprehensive plan of its kind in Canada. It summarizes current research and identifies the provincial, federal and professional resources available in BC. It sets a framework for community ownership of the solutions and for the development of responses. My sincere appreciation goes to the staff at the BC Children's and Women's Health Center for their input and expertise, and to our colleagues in the federal government for their contributions to making this plan a reality.

## ***Building Community Partnerships***

Governments have a role to play in combating FASD. We have learned that the solutions lie in the networks of community supports available to at-risk women and their families. Every child matters. Every individual counts. And every community can make the commitment to the next generation of children so that every baby in our province has the potential to enjoy a glorious childhood.

Each of us need to make a commitment to prevent Fetal Alcohol Spectrum Disorder. It is an important task. It is a huge and far-reaching endeavour but together we will do it.



Premier Gordon Campbell



Honourable Linda Reid  
Minister of State for Early Childhood Development

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## Background

Fetal Alcohol Spectrum Disorder (FASD) has been identified as a major public health concern in both Canada and the United States. It is common, expensive and preventable. FASD is the most common form of preventable brain damage to infants in the Western world. The brain damage is irreversible and results in life-long challenges in learning, behaviour, employment, and socialization. Comprehensive strategic plans are needed provincially and nationally for directing policy, prevention, intervention, treatment and research.

FASD is a non-diagnostic term that covers a range of related birth defects resulting from prenatal alcohol exposure. Under this umbrella term, are several diagnostic terms such as Fetal Alcohol Syndrome (FAS), partial Fetal Alcohol Syndrome (pFAS), Alcohol Related Neurodevelopmental Disorder (ARND), and Alcohol Related Birth Defects (ARBD). Clinical definitions of these terms are provided in Appendix A.

The range and severity of the impact of maternal alcohol use is related to variations in the timing and amount of alcohol use, use of more than one substance that can cause fetal harm, malnutrition, poor overall health of the mother and many other contextual, individual and genetic factors (Stratton, Howe, & Battaglia, 1996). Mothers of children with the full syndrome have been found to have co-morbid histories of serious violence and trauma, serious mental health problems, and difficult relationships where partners control their substance use and access to services (Astley, Bailey, Talbot, & Clarren, 2000; Clarren, 1999).

According to the U.S. national data collected from 1995-1999 through the Behavioral Risk Factor Surveillance System, 12.8 per cent of pregnant women consumed at least one alcoholic drink during the past month, a decrease from 16.3 per cent reported in 1995 (CDC, 2002). A total of 3.3 per cent of pregnant women reported frequent drinking (at least 7 drinks per week) and 2.7 per cent reported binge drinking (5 or more drinks on one occasion). In the most recent *Canadian Community Health Survey*, less than 2 per cent of pregnant women reported using alcohol in the past week (*Canadian Community Health Survey, Cycle 1.1*, 2001). Other estimates, of the prevalence of maternal drinking at some point over the period of pregnancy for women in Canada, range from 7 to 25 per cent (Roberts & Nanson, 2000). Alcohol use and other drug use in pregnancy is higher in some high risk neighbourhoods, and was found to be as high as 46 per cent in Vancouver's Downtown Eastside, in a study done in 1992 (Loock et al., 1993).

Incidence and prevalence rates of FASD in Canada are poorly understood due to a lack of consistent diagnostic criteria and poor access, in many communities, to diagnostic services. Furthermore, diagnosis of FASD becomes more challenging as an individual's age increases. This occurs both due to the diminishing ability to rely on physical characteristics and the increase in the significance of other factors such as substance use, diminished mental capacity, mental disorders etc. A recent review of literature sets the overall incidence rate for the full syndrome (FAS) as between 0.5 and 2.0 per 1000 births in the USA (May & Gossage, 2001) with some communities showing higher rates. These estimates of the full syndrome are higher than other commonly recognized congenital birth defects, including Down Syndrome and spina bifida. Estimates of the incidence and prevalence of related disorders falling under the umbrella term of FASD are imprecise but may be as much as 5 to 10 times higher. In a recent report by the Provincial Health Officer (2001), concern was raised about high rates of FASD in some Aboriginal communities, however definitive rates are not known.

A range of secondary disabilities associated with FASD have been identified including mental health problems, drug/alcohol addictions, disrupted school experience, joblessness and homelessness, and involvement with the law (Streissguth & Kanter, 1997). However, the full lifetime extent of the health and other problems experienced by those affected by FASD is difficult to estimate and requires a flexible and co-ordinated response by service providers.

Without clear prevalence and incidence data, determining current and future resourcing implications remains extremely difficult. For example, if a conservative estimate of 3.5 per 1000 births is used as a rate for FASD, it means that out of the total of 40,000 live births per year in B.C., as many as 140 infants are born affected by prenatal alcohol exposure. The potential impact on society as a whole is potentially enormous. There are no reliable Canadian studies on life-long costs of FASD. One often quoted figure based on a study done by the Alaska government (1989) estimates that between \$1 and \$2 million is needed for extra health, education, and social supports, not including the loss of human potential and stress on families and communities.



## National Initiatives on FASD

In the 1999 budget, the federal government allocated funding of \$11 million over three years to enhance activities related to FASD, including public awareness and education; training and capacity development; early identification and diagnosis and assessment; co-ordination and sharing of information and best practices; surveillance; and a strategic project fund.

Health Canada's current FAS/FAE Initiative is led by the Population and Public Health Branch working in collaboration with other branches of the Department and regional offices. They have in place an inter-departmental Working Group, Federal/Provincial/Territorial Working Groups, a National Advisory Committee (NAC) and a National First Nations and Inuit CPNP/FAS/E Steering Committee. The NAC has formed a sub-committee on screening, diagnosis and surveillance. As part of its mandate, the committee is developing national standardized guidelines for diagnosis and assessment. B.C.-based researchers and advocates have played an advisory role in the development of national best practice documents such as *Enhancing Fetal Alcohol Syndrome (FAS-related Interventions at the Prenatal and Early Childhood Stages in Canada)* (Leslie & Roberts, 2001), *Best Practices* (Roberts & Nanson) and *Situational Analysis* (Legge, Roberts & Butler, 2000).

Health Canada is currently soliciting community input towards a National Framework for Action on Fetal Alcohol Syndrome. The ultimate goal of the framework is to develop a broad based collaborative effort to prevent FASD and improve the quality of life of people and families affected by the disability across Canada. At the time of this printing, the National Framework for Action was in development. Health Canada also provides funding to community organizations for FASD-related activities through programs such as Community Action Program for Children (CAPC), Canada Prenatal Nutrition Program (CPNP) and Aboriginal Head Start (AHS). For more information, see Appendix C.

The Department of Justice Canada has provided funding through the National Crime Prevention Strategy for at least 20 projects in British Columbia addressing FASD. The funding supports community-based activities such as public awareness, training, development of resources, curriculum development, early intervention pilot projects, and conferences. The intent is to raise awareness about the importance of preventing FASD and supporting individuals with FASD to prevent their involvement with the criminal justice system.

Human Resources Development Canada (HRDC) is addressing FASD issues through a wide range of activities. Work at the inter-governmental level includes FASD recognition within instruments such as the federal/provincial/territorial Early Childhood Development Agreement, and participation in a range of inter-governmental initiatives touching FASD, including federal-provincial committees and working groups, and the tri-partite Vancouver Agreement focusing on Vancouver's Downtown Eastside. HRDC provides funding to community organizations for FASD-related activities through programs such as SCPI (Supporting Community Partnerships Initiative), Youth programming, and the AHRDAs (Aboriginal Human Resource Development Agreements). HRDC also continues awareness-raising and networking activities within and beyond its staff members, including organizing workshops and conferences and participation in local and regional networks.

## Canada Northwest FASD Partnership

In 2001, B.C. joined the Prairie Northern FAS Partnership. Now called the Canada Northwest FASD Partnership, this is an alliance among the four western provinces and three territories. The goal is to partner in the development and promotion of an inter-provincial/territorial approach on the prevention, intervention, care and support of individuals affected by FASD. The partnership hosts biennial FASD conferences and symposia, and shares resources, expertise and best practices, thereby aiding effective and efficient use of resources. More information on the Partnership can be obtained through the Web site at [www.faspartnership.ca](http://www.faspartnership.ca).

## British Columbia Initiatives

British Columbia has been considered a leader in FASD prevention, support and intervention. There are key provincial initiatives launched by government in recent years such as the Aboriginal Early Childhood Development programs and Building Blocks programs located throughout the province. Non-governmental organizations working on prevention and support have provided strong leadership provincially and nationally, over the past 10 years. As well, many community-based networks and advocacy groups are in place, and it is at the community level where significant difference can be made. Examples of these programs are highlighted in Appendix C. A more complete listing can be found on the Canadian Centre on Substance Abuse (CCSA) Web site at [www.ccsa.ca/fasis/fasall.htm](http://www.ccsa.ca/fasis/fasall.htm).

British Columbia has research activity underway in the area of FASD. Researchers at University of B.C., University of Victoria, B.C. Children's and B.C. Women's Hospitals are working to co-ordinate and expand collaboration on FASD-related research, through the formation of the *FAS Research Network of B.C.* The B.C. Centre of Excellence for Women's Health is assuming a unique role in Canada, with its ongoing program of research designed to support policy and practice relating to health improvement on the part of substance-using mothers. The Centre of Excellence for Children and Adolescents with Special Needs: University of Northern British Columbia Task Force on Substance Abuse is a research institute concerned with substance abuse related special needs, including FASD. As part of its mandate, the institute pays particular attention to rural, remote and northern areas.

A cross-government Assistant Deputy Ministers' Committee on FASD has been formed in B.C. that includes representatives from provincial ministries and federal departments. This committee has overseen the development of this strategic plan and ensures the co-ordinated and effective use of available resources across ministries. (See Appendix B for more information on the roles of the provincial ministries in relation to FASD.)

Membership on this committee includes:

- Ministry of Children and Family Development (chair and secretariat support)
- Ministry of Public Safety and Solicitor General
- Ministry of Health Services
- Ministry of Health Planning
- Ministry of Education
- Ministry of Advanced Education
- Ministry of Human Resources
- Ministry of Attorney General
- Ministry of Community, Aboriginal, and Women's Services
- Health Canada
- Department of Justice Canada
- Human Resources Development Canada

## Strategic Plan on FASD for British Columbia

The Strategic Plan on FASD for British Columbia builds on work done in B.C. over the past ten years, including the first strategic plan in 1993 (Ministry of Health, 1993) and Delphi research to build consensus on strategic priorities (Legge, 1996). It also reflects the ongoing collaborative work by committed parents, persons affected by FASD, advocates, teachers, health and other service providers, other professionals and paraprofessionals, as well as governments on all levels in the province.

This strategic plan is intended to provide policy makers, service providers, community groups, and researchers a map of the multi-layered and multifaceted work involved in the prevention and intervention and support for FASD. Where appropriate, separate yet complementary Aboriginal strategies will need to be identified and supported.

This document is designed to generate discussion with community partners with the view to consolidate priorities for action by all sectors for 2003-2006.

## Vision

The achievement of the vision relies on a co-ordinated and complementary approach across all sectors.

- British Columbians are aware of the disabilities related to Fetal Alcohol Spectrum Disorder and the risks associated with the use of alcohol and other substances during pregnancy.
- Women are effectively supported in reducing or stopping alcohol and other substance use during pregnancy, and in achieving improved health in related areas known to reduce risk. As a result, a decreased number of infants will be born affected by prenatal alcohol exposure.<sup>1</sup>
- Individuals affected by FASD and related birth defects/disabilities are identified in a timely manner, and secondary disabilities are minimized. Children, youth and adults with FASD and their families/support networks have access to a comprehensive and life-long range of supports.
- Individuals affected by FASD will be managed by the justice system consistent with other mentally disordered offenders. The objective is to provide responses that access appropriate health and social welfare treatment services while not jeopardizing community safety.
- Research to guide improved prevention, early intervention, diagnosis, assessment, planning, service delivery and policy is supported.

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<sup>1</sup> Baseline incidence rates of FASD in B.C. are not known and many cases currently go unidentified. Should diagnostic capacity increase in the province, more cases of FASD would likely be reported which could be misinterpreted as a rise in incidence.

**Respect, Compassion and Cultural Sensitivity** - Respect and compassion are shown toward all those at-risk and affected. Aboriginal peoples and other cultural groups are involved in determining approaches that are responsive to the needs of their communities.

**Comprehensiveness** – Prevention strategies include efforts to change attitudes and norms, support the development of personal skills, build and support community linkages and action, build healthy public policy and create egalitarian and healthy social structures and environments. Intervention efforts are interdisciplinary, matched to the level of risk, and responsive to needs across the life span.

**Collaboration, Inclusion and Capacity Building** – To achieve the desired ends, collaboration takes place among all levels of governments and between government and non-governmental partners. Mechanisms are in place to support information sharing and collaboration by services and community groups across regions. The planning and delivery of initiatives are sensitive to the geographical differences in the province.

**Balance** – Efforts are directed equally to FASD prevention through provision of support to women, and to intervention through provision of support to those affected and their families.

**Evidence based** – Prevention and intervention efforts are grounded in best available evidence, and ongoing research and evaluation is supported to continuously add to the evidence base and to support decision making by policy makers.

## Key Components of a Provincial Strategy

- Community development, health promotion and public awareness strategies to raise awareness of FASD as a life-long disability and the risks associated with alcohol and substance use during pregnancy.
- Early identification and intervention/support for all pregnant women who use alcohol and their partners/support systems.
- Focused intervention with high risk pregnant and parenting women and their partners/support systems
- Timely diagnosis, assessment and planning for children, youth and adults affected by FASD.
- Comprehensive and lifelong intervention and support for children, youth and adults affected by FASD and their families/support systems.
- Leadership and co-ordination of FASD initiatives at the community, regional, provincial and national levels.

The following table (pages 7 – 9) maps the broad territory involved in prevention and intervention related to FASD across many different sectors including communities, service providers, researchers and policy makers. Given the limited budget, not all activities can be funded exclusively by provincial government sources. It is therefore necessary to select priorities for strategic government investment on an annual basis.

## OPTIONS FOR FASD STRATEGIC INITIATIVES

	<b>Individual/Community Level</b> (building individual skills and responsibility and community capacity)	<b>Service Providers and Health Educators</b> (building skills of service providers and educators in planning/delivery of services and health education)	<b>Policy</b> (improving the public policy response from government, regional authorities, and community/local level)	<b>Research</b> (identifying and expanding needed research that supports the other 3 levels)
<b>COMMUNITY DEVELOPMENT, HEALTH PROMOTION AND PUBLIC AWARENESS STRATEGIES TO RAISE AWARENESS OF FASD AS A LIFE-LONG DISABILITY AND THE RISKS ASSOCIATED WITH ALCOHOL AND SUBSTANCE USE DURING PREGNANCY</b>	Support involvement in community-based education efforts, and community development activities that influence determinants of health and raise awareness of the disability.	<p>Promote the awareness of service providers about FASD and the importance of altering practice accordingly.</p> <p>Promote awareness of service providers who come into contact with youth and women at risk.</p> <p>Support and co-ordinate development and provision of practical materials that support transferability of prevention messages to students, patients and clients.</p>	<p>Promote the development of public health policies addressing the social determinants that place women at risk of prenatal alcohol use.</p> <p>Undertake ongoing, co-ordinated national/provincial awareness campaigns, evaluated for their effectiveness.</p>	Evaluate community development, education and awareness strategies and undertake research designed to guide further health promotion, disability awareness, community development, and prevention work.
<b>EARLY IDENTIFICATION, INTERVENTION AND SUPPORT TO ALL PREGNANT WOMEN WHO USE ALCOHOL AND THEIR PARTNERS/ SUPPORT SYSTEMS</b>	<p>Enhance visibility of and access to healthy pregnancy groups offered through health clinics and community centers.</p> <p>Make information on risks of alcohol use during pregnancy readily available through pregnancy helplines, internet sites on healthy pregnancy, and related strategies</p>	<p><b>Selected Priority:</b> Train physicians and other health care and social service professionals in discussing alcohol use during pregnancy and brief motivational interviewing to support change (when necessary) in alcohol use and in other health areas on the part of women, and those in a position to support them.</p> <p>Provide information through B.C. Reproductive Care Program and others that support screening and withdrawal management efforts on the part of perinatal service providers.</p>	Ensure curriculum on ethical and best clinical practice with pregnant women, women of child bearing age and their partners/social support networks is in place in medical, nursing and social work schools and other professional training contexts (midwifery, infant development, mental health, early childhood development, etc.)	<p>Research on effective early intervention methods with women, understanding women's barriers to change, etc.</p> <p>Research to determine incidence of alcohol and other drug use by pregnant women by region.</p>

## OPTIONS FOR FASD STRATEGIC INITIATIVES

	<b>Individual/Community Level</b> (building individual skills and responsibility and community capacity)	<b>Service Providers and Health Educators</b> (building skills of service providers and educators in planning/delivery of services and health education)	<b>Policy</b> (improving the public policy response from government, regional authorities, and community/local level)	<b>Research</b> (identifying and expanding needed research that supports the other 3 levels)
<b>FOCUSED INTERVENTION WITH HIGH-RISK PREGNANT AND PARENTING WOMEN AND THEIR PARTNERS/SUPPORT SYSTEMS</b>	<b>Selected priority:</b> Enhance visibility and reach of all community-based prenatal support programs including Pregnancy Outreach Programs designed for high risk pregnant substance using women. Promote collaboration among related prenatal services across sectors to ensure a “safety net” of care is created for high-risk women.	<p>Expand community-based services that offer holistic, harm reduction-oriented, interdisciplinary care and strategies to increase access to such services.</p> <p>Support all maternity and pediatric facilities in providing withdrawal management for high risk women and transfer knowledge on practice, that is based on wrapping services around the mother-child pair.</p> <p>Increase availability of residential programs that support the recovery of pregnant women and women and their infants in the postnatal period.</p> <p>Support for case management and the development of perinatal service networks that ensure a co-ordinated response to high risk pregnant women at the community level.</p>	Mechanism to examine existing policy that may increase barriers to access to care, and support policy action to reduce those barriers.	Research on effective interventions with this population and evaluation of existing services.
<b>TIMELY DIAGNOSIS, ASSESSMENT, AND PLANNING FOR CHILDREN, YOUTH AND ADULTS AFFECTED BY FASD</b>	<p>Enhance visibility and reach of support networks for birth, foster and adoptive parents.</p> <p>Support training by and for caregivers on the identification and care of those affected.</p>	<p>Training to addictions, health care, education, social work, justice and other professionals, on recognizing those who may be affected and on making referrals for diagnosis, assessment and intervention planning.</p> <p><b>Selected priority:</b> Expand diagnostic, assessment and case planning capacity at the provincial, regional and community levels and support provincial reporting of diagnoses to Vital Statistics.</p> <p>Develop provincial practice guidelines, including hospital discharge and outpatient management protocols.</p>	Ensure curriculum on ethical and best clinical practice for diagnosis and assessment, early developmental interventions, treatment and support of affected individuals and their caregivers is in place in medical and nursing schools and other relevant educational settings.	<p>Research to identify incidence and prevalence of FASD</p> <p>Research on screening and diagnostic tools.</p> <p>Evaluation of impact of medical education, increased diagnostic capabilities and protocol implementation</p>

## OPTIONS FOR FASD STRATEGIC INITIATIVES

	<b>Individual/Community Level</b> (building individual skills and responsibility and community capacity)	<b>Service Providers and Health Educators</b> (building skills of service providers and educators in planning/delivery of services and health education)	<b>Policy</b> (improving the public policy response from government, regional authorities, and community/local level)	<b>Research</b> (identifying and expanding needed research that supports the other 3 levels)
<b>COMPREHENSIVE AND LIFELONG INTERVENTION AND SUPPORT FOR CHILDREN, YOUTH AND ADULTS AFFECTED BY FASD AND THEIR FAMILIES/SUPPORT NETWORKS</b>	Support parent/ community groups in their efforts to provide peer counselling and support on diagnostic, assessment, respite and care issues.	<p>Promote, with professional schools and training bodies, the inclusion of information about FASD in their curriculums for service providers (eg. schools/faculties of nursing and medicine, social work, education, etc.).</p> <p>Development of services and supports to meet the needs of offenders with FASD within the justice system and as they reintegrate within the community.</p> <p>Increase availability of community-based living support options for affected youth and adults, both integrated and independent of the justice system.</p> <p><b>Selected Priority:</b> Ensure justice personnel, educators and other service providers have current information on the nature of FASD and services available to children, youth or adults affected by FASD and their families.</p>	<b>Selected priority:</b> Explore options to enhance accessibility and suitability of current programs and services in areas relevant to the comprehensive needs of affected children, youth, adults and their families/support systems. As funding becomes available, provide improved access to services for affected children, youth, adults and their families/support systems.	<p>Improve access to best practice research regarding current intervention models in education, justice, mental health and other settings.</p> <p>Engage experts in the field of FASD service provision as partners in identifying and communicating best practices.</p> <p>Identify and encourage further research needed on best practices and the nature and impact of secondary disabilities.</p> <p>Research on how to adapt or modify interventions by practitioners throughout social, educational and health service fields to address the needs of those affected.</p> <p>Research on, and evaluation of, community-based support options.</p>
<b>LEADERSHIP AND CO-ORDINATION OF FASD INITIATIVES AT THE COMMUNITY, REGIONAL, PROVINCIAL AND NATIONAL LEVELS</b>	<b>Selected priority:</b> Create opportunities for the sharing of resources, best practices and expertise, through FASD Consultation Group, program mentoring, and/ or other mechanisms.	Support co-ordination of those providing services to women at risk, and to individuals affected by FASD and their families/support networks – including those working on mental health, addictions, contraception, parenting, schooling, employment, recreation, housing, corrections, sexual health, spiritual health, cultural health, violence and other related issues.	<b>Selected Priority:</b> Work with provincial ministries and federal partners to share knowledge, co-ordinate funding of services, and implement joint initiatives. Where possible, seek strategically-funded partnerships from the private, not-for-profit and public sector.	Expand the work of the FAS Research Network of B.C. and explore additional opportunities to increase research in this area, to enhance collaboration among researchers working in different disciplines and to co-ordinate research in B.C.

## Setting Priorities 2003-04

For 2003-2004, \$400,000 is available for FASD strategic government initiatives, which are determined by the cross-government Assistant Deputy Ministers' Committee on FASD. The Ministry of Children and Family Development chairs the ADMs' Committee and administers the funds.

Seven priorities from the table have been selected for consideration. **They are not in order of priority.** These were derived with consideration to current initiatives and the limited funding available (see footnotes). Community-driven initiatives complement the government priorities, and both are best informed by current research.

- Expand diagnostic, assessment and case planning capacity of the provincial, regional and community levels and support provincial reporting of diagnoses to Vital Statistics.<sup>1</sup>
- Ensure justice personnel, educators and service providers have current information on the nature of FASD and available services for children, youth, adults and their families affected by FASD.<sup>2</sup>
- Explore options to enhance accessibility and suitability of current programs and services in areas relevant to the comprehensive needs of affected children, youth, adults and their families. As funding becomes available, provide improved access to services for affected children, youth, adults and their families/support systems.
- Train physicians and other health care and social service professionals in discussing alcohol use in pregnancy and in brief motivational interviewing to support change (when necessary) in alcohol use and in other health areas on the part of women, and those in a position to support them.<sup>3</sup>
- Enhance visibility and reach of all community-based prenatal support programs including Pregnancy Outreach Programs<sup>4</sup> designed for high-risk pregnant substance using women.<sup>5</sup> Promote collaboration among related prenatal services across sectors to ensure a "safety net" of care is created for high-risk women.
- Create opportunities for the sharing of resources, best practices and expertise, through FASD Consultation Group, program mentoring and/or other mechanisms.<sup>6</sup>
- Work with provincial ministries and federal partners to share knowledge, co-ordinate funding to services and implement joint initiatives. Where possible, seek strategically funded partnerships from the private, not-for-profit and public sector.<sup>7</sup>

This document is designed to generate discussion with community partners with the view to consolidate priorities for action by all sectors for 2003-2006.

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<sup>1</sup> A planning document has been completed for the Vital Statistics Agency, outlining a training and service model for consistent, province-wide diagnosis and assessment for FASD.

<sup>2</sup> Development of an on-line course is currently funded for development during 2003 – 2004.

<sup>3</sup> Training for service providers working with at-risk women is currently funded and will be delivered during 2003 – 2004.

<sup>4</sup> In this document, the term "Pregnancy Outreach Programs" include prenatal programs funded by Health Canada and/or Health Regions.

<sup>5</sup> Will be integrated into training provided for service providers working with at-risk women.

<sup>6</sup> Enhanced through community events held in Spring 2003.

<sup>7</sup> Currently occurs through ADM's Committee, Interministry Working Group and Canada Northwest FASD Partnership with minimal funding.

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## APPENDIX A: DEFINITIONS OF DIAGNOSTIC CATEGORIES UNDER THE UMBRELLA TERM “FETAL ALCOHOL SPECTRUM DISORDER”

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There is a spectrum of alcohol-related birth defects and developmental disabilities included in what is now being referred to as Fetal Alcohol Spectrum Disorder:

***Fetal Alcohol Syndrome (FAS)*** is a condition affecting some children born to women who drink alcohol during pregnancy. There are three criteria used to describe the effects of prenatal alcohol exposure and to make a diagnosis of FAS: a pattern of facial abnormalities, growth deficiencies and central nervous system impairment. The central nervous system impairment many include structural abnormalities of the brain; neurological problems such as impaired motor skills, poor co-ordination and visual problems; and behavioural and/or cognitive problems such as mental handicap, learning difficulties, poor impulse control and problems with social perception, memory, attention, reasoning or judgment.

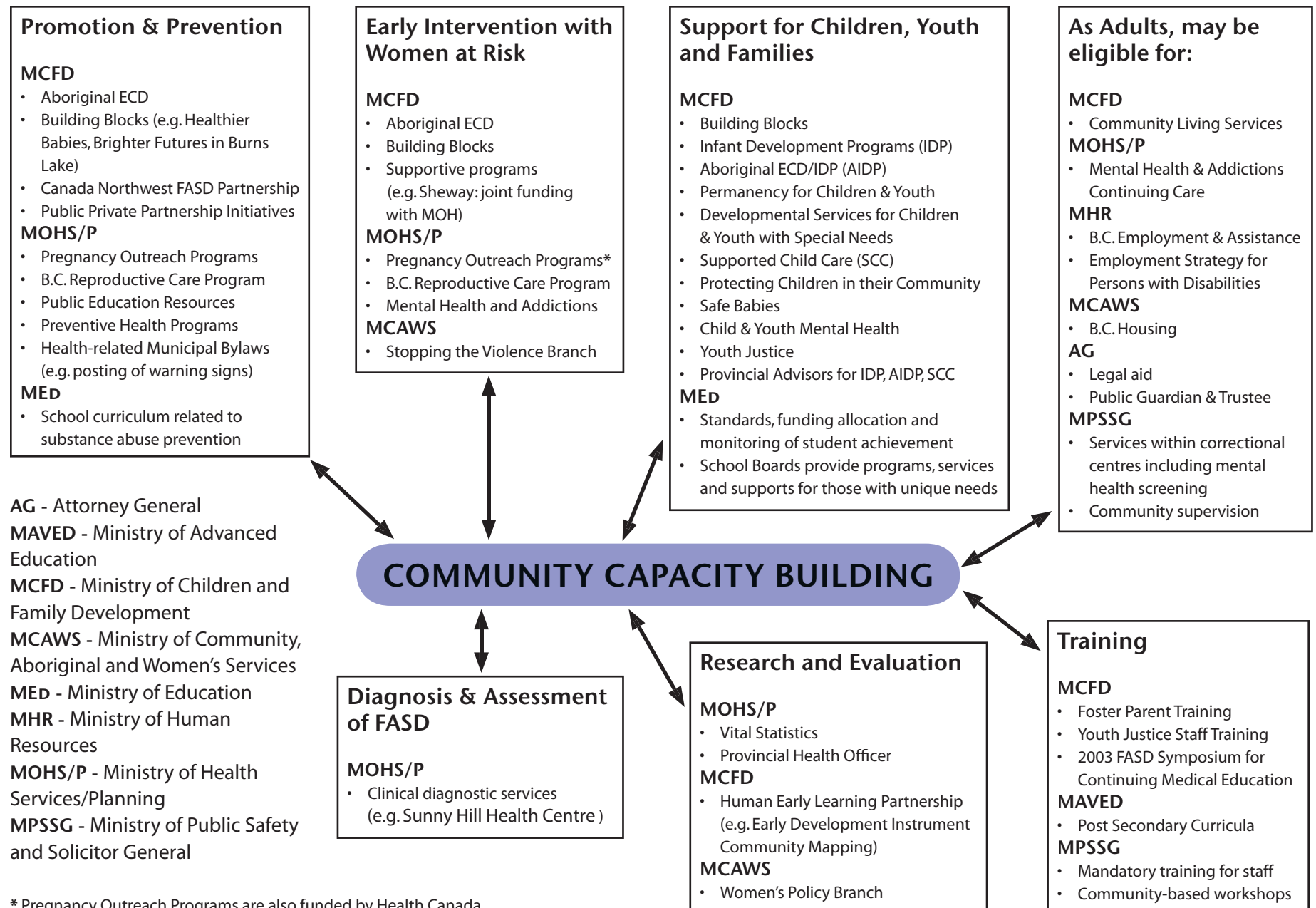
***Partial FAS (pFAS)*** is the recommended term used to describe those children born with evidence of some of the characteristic facial abnormalities associated with FAS and evidence of one other component (growth deficiency or central nervous system impairment) when it is known that there was significant prenatal exposure.

***Alcohol Related Neurodevelopmental Disorder (ARND)*** describes the presence of the structural or neurological brain abnormalities and/or the behavioural and cognitive problems associated with FAS, without the characteristic facial or growth abnormalities, when it is known that there was significant prenatal exposure.

***Alcohol Related Birth Defects (ARBD)*** Children born to mothers who drank heavily during pregnancy may also have congenital birth defects such as skeletal abnormalities, heart defects, cleft palate and other craniofacial abnormalities, kidney and other internal organ problems and vision and hearing problems. These are known as Alcohol Related Birth Defects.

The National Advisory Sub-Committee on screening, diagnosis, and surveillance has closely examined the differences between the diagnostic models outlined by the Institute of Medicine and the University of Washington 4-digit diagnostic code. Because each model offers some strengths in the development of national guidelines for diagnosis and assessment, the committee is currently exploring how to best harmonize the two models.

## APPENDIX B: FETAL ALCOHOL SPECTRUM DISORDER - PROVINCIAL MINISTRY CONTRIBUTIONS



## APPENDIX C: HIGHLIGHTS OF PROGRAMS IN BRITISH COLUMBIA

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The following is a selection of FASD-related community, regional and provincial based programs in British Columbia. This list is intended to support an understanding among policy makers of the wide range of work being done in the area of FASD across the life span. This is not an exhaustive list as new and emerging programs and action groups are developing every year in British Columbia. A more complete listing can be found on the Canadian Centre on Substance Abuse (CCSA) Web site: [www.ccsa.ca/fasis/fasall.htm](http://www.ccsa.ca/fasis/fasall.htm).

### ABORIGINAL EARLY CHILDHOOD EDUCATION INITIATIVE

The Aboriginal Early Childhood Education Initiative focuses on developing innovative, culturally responsive community-based approaches to supporting early childhood development for Aboriginal children prenatal to age 6 and their families. FASD prevention is a key component of the strategy. To date, 37 initiatives have been funded. Community capacity is being enhanced through the development of collaborative FASD Prevention Committees, FASD awareness campaigns and community-based support circles for pregnant and parenting women.

**Contact:** Dena Carroll, Aboriginal ECD Consultant  
Early Childhood Development Branch  
Ministry for Children and Family Development  
PO Box 9719 Stn Prov Govt  
Victoria, B.C. V8W 9S1  
Tel: (604) 387-9538

### ALBERNI VALLEY FASD ACTION TEAM

The Alberni Valley FASD Community Action Group is a volunteer community coalition that advocates for the development of a spectrum of services over the life span of affected individuals and their families/support networks. The group provides a monthly forum from which to initiate co-ordinated action with respect to FASD and includes foster, adoptive, and birth parents as well as employees or board members of agencies in the community.

**Contact:** Ron Jorgenson or Penn Thrasher  
Tel: (250) 723-7123  
E-mail: [ronpenn@shaw.ca](mailto:ronpenn@shaw.ca) or [chekask@shaw.ca](mailto:chekask@shaw.ca)

## APPENDIX C: HIGHLIGHTS OF PROGRAMS IN BRITISH COLUMBIA

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### THE ASANTE CENTRE FOR FETAL ALCOHOL SYNDROME

Administered by the Greater Vancouver Fetal Alcohol Society, the Asante Centre provides standardized multidisciplinary diagnostic, assessment and family support for individuals of all ages affected by fetal alcohol spectrum disorder. Additionally, the centre provides educational workshops to health and human service providers, educators, and families who care for children, youth and adults with FAS. The multidisciplinary team at the Asante Centre assists communities in developing strategic plans for addressing the complex issues of FAS and emphasizes a prevention message.

**Contact:** Audrey Salahub, Centre Coordinator  
22326A McIntosh Ave.  
Maple Ridge, B.C. V2X 3C1  
Tel: (604) 467-7101  
E-mail: [info@asantecentre.org](mailto:info@asantecentre.org)  
Web site: [www.asantecentre.org](http://www.asantecentre.org)

### B.C. ABORIGINAL HEAD START

Aboriginal Head Start, funded by Health Canada, is an early intervention program for First Nations, Métis and Inuit children and their families. The goal of the initiative is to demonstrate that locally controlled and designed early intervention strategies can provide Aboriginal children with a positive sense of themselves, child development and school readiness, a desire for life-long learning and opportunities to develop as successful young people. AHS project serves 78 communities in B.C.

**Contact:** Rose Sones, AHS off reserve  
Population and Public Health Branch  
440F-757 West Hastings  
Vancouver, B.C.  
Tel: (604) 666-9917  
Web site: [www.ahsabc.ca](http://www.ahsabc.ca)

Christine Burgess, AHS on reserve  
Program Manager  
540-57 West Hastings  
Vancouver, B.C. V6C 3E6  
Tel: (604) 666-3284  
Web site: [www.hc-sc.gc.ca/fnihb/cp/ahsor/index.htm](http://www.hc-sc.gc.ca/fnihb/cp/ahsor/index.htm)

### B.C. ABORIGINAL NETWORK ON DISABILITY SOCIETY (BCANDS)

Provides advocacy and support to Aboriginal people with disabilities, including FASD. BCANDS operates the Native Health Resource Centre lending library, which includes a wide variety of videos, manuals and other related material on FASD.

**Contact:** June Wylie  
1179 Kosapsum Crescent  
Victoria, B.C. V9A 7K7  
Tel: (250) 381-7303  
Web site: [www.bcands.bc.ca](http://www.bcands.bc.ca)

## APPENDIX C: HIGHLIGHTS OF PROGRAMS IN BRITISH COLUMBIA

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### **B.C. ASSOCIATION OF PREGNANCY OUTREACH PROGRAMS (BCAPOP)**

BCAPOP fosters accessible, quality, non-judgmental, perinatal support to improve the well being of pregnant women; their infants and families through leadership, advocacy, community collaboration, education and research promotion for pregnancy outreach programs in B.C. There are currently over 40 such programs in the province. Some are funded through health authorities and Health Canada's Canada Prenatal Nutrition Program.

**Contact:** Louise Fraser  
Comox Valley Family Services  
Tel: (250) 338-7575  
Web site: [www.bcapop.ca](http://www.bcapop.ca)

### **B. C. WOMEN'S HOSPITAL – FIR SQUARE PROGRAM**

B.C. Women's Fir Square Combined Care Unit provides five antepartum and six postpartum beds for women wishing to stabilize or withdraw from drug use during pregnancy. In the post partum period, mothers room in with their babies where possible. There is also a centralized nursery for babies in need of specialized treatment. This program is designed to assist substance-using pregnant and early-postpartum women in achieving an optimum level of pre and postnatal health in order that the effects of alcohol, drugs, malnutrition and neglect, on women and their infants may be minimized. It is also designed to improve both health and social outcomes for infants exposed to drugs.

**Contact:** Fir Square Program  
B.C. Women's Hospital  
4500 Oak Street  
Vancouver, B.C. V6H 3N1  
Tel: (604) 875-2000

### **BUILDING BLOCKS**

Building Blocks were established in 1997 to build parental capacity to support the healthy development of children from preconception to age 6. Building Blocks programs across the province provide a variety of supports such as family home visiting, parent support groups, parent education and FASD prevention.

**Contact:** The Ministry of Children and Family Development office in your region  
Online: [www.mcf.gov.bc.ca/roc/](http://www.mcf.gov.bc.ca/roc/)  
By phone: Enquiry BC – Vancouver: (604) 660-2421, Victoria: (250) 387-6121, Toll-free in B.C.: 1 800 663-7867

## APPENDIX C: HIGHLIGHTS OF PROGRAMS IN BRITISH COLUMBIA

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### COMMUNITY HEALING AND INTERVENTION PROGRAM (CHIP)

Provides holistic, culturally sensitive support services to Aboriginal children (birth to 12 years) and Aboriginal youth (13 to 29 years) who are identified as being affected by FASD and who reside in the East Kootenay region of British Columbia. CHIP facilitates FASD workshops, partners with the College of the Rockies to provide a lending library of FASD resources, and produces FASD materials (e.g. posters, pamphlets, T-shirts, manuals, newsletters).

**Contact:** Lynnette Wray  
7468 Mission Road  
Cranbrook, B.C. V1C 7E5  
Tel: (250)489-3373  
E-mail: chip@cyberlink.bc.ca

### CRABTREE CORNER (YWCA) FAS/NAS PREVENTION PROGRAM

Located in the Downtown Eastside, Crabtree Corner provides a support group for women caring for children affected by prenatal alcohol/drug exposure. The program also provides training workshop in the community, advocacy, referral and support to women. In Fall 2003, Crabtree Corner and Sheway will be colocating in a new facility, which will include 12 transition housing units for Sheway clients.

**Contact:** Nola Harper/Nancy Cameron  
101 E. Cordova Street  
Vancouver, B.C.  
V6A 1K7  
Tel: (604) 689-2808

### COWICHAN VALLEY FAS ACTION TEAM SOCIETY - ACTION FOR INCLUSION PROJECT

This is a two year educational project funded by the National Crime Prevention Centre to build capacity in community organizations to accommodate people living with FASD. In this project, persons living with FASD work under the guidance of project staff to conduct on-site assessments of community organizations, to identify the physical and social factors that impact accessibility and service provision for people with FASD. Project team members then develop and deliver in-service training modules that meet the specific needs identified in the assessment of each organization. A Web site and network are being developed to share information, resources and best practice.

**Contact:** Jennifer Kyffin  
204-111 Station Street  
Duncan, B.C. V9L 1M8  
Tel: (250) 748-0236  
E-mail: info@cvfasd.org

## APPENDIX C: HIGHLIGHTS OF PROGRAMS IN BRITISH COLUMBIA

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### FAS/E SUPPORT NETWORK OF B.C.

The Support Network operates a Warm Line, which provides consultation, support, and advocacy for parents/caregivers/partners of FASD affected individuals. Training workshops are provided throughout the province to caregivers and professionals on the effects of prenatal alcohol exposure and effective prevention strategies.

**Contact:** 13279 72<sup>nd</sup> Ave  
Surrey, B.C. V3R 8X8  
Tel: (604) 507-6675  
Web site: [www.fetalalcohol.com](http://www.fetalalcohol.com)

### HEALTHIER BABIES - BRIGHTER FUTURES (HBBF)

HBBF is a Building Blocks program. Located in Burns Lake, this program provides individual support to high-risk pregnant women and their families, including advocacy, education and group activities. Community mobilization is also a key component and has resulted in partnerships with local liquor vendors providing pregnant women with free non-alcohol beverages and the local mill providing FASD-awareness events on company time.

**Contact:** Anne Price  
College of New Caledonia  
P.O. Box 5000  
Burns Lake, B.C. V0J 1E0  
Tel: (250) 692-1700

### NORTHERN FAMILY HEALTH SOCIETY

The NFHS provides co-ordination of the North Central CAPC Fetal Alcohol and Drug Effects Resource Coalition ( 8 communities) and to the Prince George FAS Network formed in 1997. The society has a Family Resource Centre Library and a Web site that provides education and resources related to community development, community based research and education and training resources related to FASD and related issues. NFHS programming includes a Pregnancy Outreach Program (Northern Health Authority, CPNP and CAPC), Employment Program for young parents with multiple barriers (Human Resources Development Canada), and a community-based research project MIRRORS promoting social competency for adolescent young girls through mentoring (Medical Services Fund- Vancouver Foundation).

**Contact:** Marlene Thio-Watts, Executive Director  
1010-B Fourth Ave  
Prince George, B.C. V2L 3J1  
Tel: (250) 561-2689  
E-mail: [postmaster@nfhs-pg.org](mailto:postmaster@nfhs-pg.org)  
Web site: [www.nfhs-pg.org](http://www.nfhs-pg.org)

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### PACIFIC LEGAL EDUCATION ASSOCIATION (PLEA)

PLEA offers community alternatives to custody that incorporate specialized intensive support and supervision services, drug and alcohol counselling and, where appropriate, specialized residential placements tailored to the needs and characteristics of individual youth. As part of a 2-year pilot project, PLEA and the Asante Centre are developing and implementing a best practice service delivery model addressing the needs of youth suspected of having an alcohol-related diagnosis, and who are before the courts under the *Youth Criminal Justice Act*. The pilot project is funded through the Department of Justice Canada Youth Justice Renewal Fund.

**Contact:** Ray Hartley, Manager  
3894 Commercial Street  
Vancouver, B.C. V5N 4G2  
Tel: (604) 871-0450  
E-mail: info@plea.bc.ca

### PERINATAL CONNECTIONS

Perinatal Connections offers co-ordination of services when assisting families during pregnancy, birthing and early infancy, so that families are not disconnected from community services. Services include provision of lists of resources available, collaboration with other professionals who are knowledgeable about how to assist high-risk families, and other services designed to facilitate positive outcomes for clients.

**Contact:** Susan Cuumming  
North Shore Health Unit  
Kamloops, B.C.  
Tel: (250) 312-6232

### SHEWAY

Sheway (Coast Salish word meaning *growth*) is a pregnancy outreach/drop-in program for very high-risk pregnant women and women with infants under 18 months who live in or frequent the Downtown Eastside of Vancouver. The focus of the program is to support women dealing with alcohol and drug use issues, through a very broad scope of health and social services, to help them have healthy infants and positive parenting experiences.

**Contact:** Monica Stokl, Program Co-ordinator  
Sheway  
369 Hawks Ave  
Vancouver, B.C. V6A 4J2  
Tel: (604) 658-1221

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### **SOCIETY FOR SPECIAL NEEDS ADOPTIVE PARENTS (S.N.A.P.)**

S.N.A.P. provides assistance for special needs adoptive families through mutual support, information, sharing and advocacy. S.N.A.P. produces "FAS: A guide For Daily Living" and features articles on FASD in the S.N.A.P. newsletter.

**Contact:** Brad Watson, Executive Director  
205 - 409 Granville Street  
Vancouver, B.C. V6C 1T2  
Tel: (604) 687-3114  
Web site: [www.snap.bc.ca](http://www.snap.bc.ca)

### **SUNNY HILL HOSPITAL, SUBSTANCE EXPOSURE RESOURCE TEAM**

Within the province of B.C., Sunny Hill provides outpatient services to children (up to 19 years of age) and their families where questions have arisen around the possible impact of prenatal exposure to alcohol and/or other drugs. Services may take the form of consultation and initial linking to available community resources, diagnosis and developmental assessment, education and advocacy with community education being a vital component of clinical outreach.

**Contact:** Sunny Hill SERT Team  
3644 Slocan Street  
Vancouver B.C. V5M 3E8  
Tel: (604) 453-8300

### **WHITECROW VILLAGE CHILDREN'S CAMPS**

Whitecrow Village, located outside Burns Lake, provides a positive experience to families and individuals with FASD. The goal is for children and families to have fun, participate in ordinary and traditional camp activities such as hiking, boating, nature lore, and crafts. The camp also provides training, speakers, consultation and support for parents, family members and caregivers.

**Contact:** Kee Warner  
Whitecrow Village  
Box 75  
Burns Lake, B.C. V0J 1E0  
Tel: (250) 695-6635

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the Government of British Columbia and Children's and  
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