Mother and child reunion

PREVENTING FETAL ALCOHOL SPECTRUM DISORDER BY PROMOTING WOMEN'S HEALTH

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Fetal Alcohol Syndrome Disorder (FASD) describes a range of physical and developmental problems affecting some children born to women who drink alcohol during pregnancy. The incidence rate in Canada is unknown, but in the United States it is estimated to be between .5 and 2.0 per 1000 births with some communities showing higher rates. Since the impact of FASD cannot be reversed, it is extremely important to focus efforts on prevention. In Canada the dominant approach to preventing FASD has been to focus on a single determinant, alcohol use, and on the impact on children's health. Yet evidence indicates this approach is too narrow and may actually be creating barriers for women who use substances during pregnancy and need help. This paper describes current knowledge about FASD and current prevention strategies and outlines an alternative, multiple-determinants approach to FASD prevention that would be more effective for both mothers and babies, more humane, and more cost-efficient.

What is Fetal Alcohol Spectrum Disorder? There is a spectrum of birth defects and developmental disabilities associated with alcohol use in pregnancy. There are three criteria used to describe the effects of prenatal alcohol exposure and to make a diagnosis of the full Fetal Alcohol Syndrome (FAS): a pattern of facial abnormalities, growth deficiencies and central nervous system impairment.^{2,3} The central nervous system impairment is often the most debilitating of the three areas of impairment and may include structural abnormalities of the brain; neurological problems such as impaired motor skills, poor coordination and visual problems; and behavioural and/or cognitive problems such as mental handicaps, learning difficulties, poor impulse control, problems in social perception, and problems in memory, attention, reasoning and judgment. Related conditions include partial FAS (pFAS) and Alcohol-Related Neurodevelopmental Disorder (ARND).^{4,5} Children born to mothers who drink heavily in 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 (ARBD). This continuum of problems is increasingly being referred to as Fetal Alcohol Spectrum Disorder (FASD).

The damage associated with alcohol use and related health risks during pregnancy is permanent and irreversible. However, early diagnosis and intervention with

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those affected can prevent common secondary disabilities such as mental health problems, disrupted school experience, inappropriate sexual behaviour, alcohol and drug problems, trouble with the law, problems with employment and problems with parenting.⁶

Maternal Drinking and FASD: Contributing Factors The range and severity of the impact of maternal alcohol use is related to variations in the timing of alcohol use, variations in the amount of alcohol used, use of more than one substance, malnutrition, poor overall health of the mother and many other contextual, individual and genetic factors. The range of contributing factors requires a response that goes well beyond a focus on alcohol use alone and a focus on the pregnancy alone.

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 in which partners often control their substance use and access to services.^{7,8} Designing and delivering an interdisciplinary and transdisciplinary response to women facing this level of burden is a critical component of an effective FASD prevention strategy.

Incidence and Prevalence of Maternal Drinking and FASD According to national data collected in the United States by the Behavioral Risk Factor Surveillance System (1999), 12.8% of pregnant women consumed at least one alcoholic drink during the past month, a decrease from 16.3% reported in 1995 in a study by the Centre for Disease Control.⁹ A total of 3.3% of pregnant women reported frequent drinking (at least 7 drinks per week) and 2.7% reported binge drinking (5 or more drinks on one occasion). Alcohol use and other drug use in pregnancy is higher in some high-risk neighbourhoods, and was found to be as high as 46% in Vancouver's Downtown Eastside in a study done in 1992.¹⁰

As some children born to mothers who drank alcohol during pregnancy are not affected, it is important to determine and describe the incidence of FASD, as well as maternal alcohol use. The authors of a recent review of the literature set the overall incidence rate for Fetal Alcohol Syndrome as between .5 and 2.0 per 1000 births in the USA.¹ These estimates of the occurrence of the full syndrome are in the range of other commonly recognized congenital birth defects, including Down syndrome and spina bifida. Estimates of the incidence and prevalence of the other disabilities in the FASD spectrum are made difficult by the lack of accessible, evidence-based diagnostic capabilities. Informal labeling, without medical or other professional assessment or confirmation of maternal alcohol use, has been common.¹¹¹ Such labeling can deprive those affected by FASD of the services they need and deserve and add to the stigmatization of birth mothers.

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Current Prevention Context in Canada

Fetal Alcohol Syndrome was first identified in the American medical literature in 1973, yet it was the 1990s before momentum built on addressing the implications. Currently, within Canada, differences exist in uptake on FAS-related issues, with greater attention and action in the western provinces. The four western provinces and three territories are organized into a consortium called the Canada Northwest FASD Partnership, which is designed to support coordinated strategic action on FAS issues. Over the past nine years, federal government interest and action on Fetal Alcohol Syndrome have increased. Significant federal funding for FAS/FAE activities was allocated in the 2000 and 2001 federal budgets.¹²

The Canadian Centre on Substance Abuse has led several national projects designed to identify "best practices" on all levels of FASD prevention and intervention with those affected, as well as to identify all individuals, communities and governments working on these issues.^{13,14} The most recent listing of those involved in FAS-related activities on the community, regional, provincial and national levels in Canada has over 270 entries, a testament to the high level of interest and involvement in this issue.¹⁵

Two key national resources on FASD are the FAS/FAE Information Service ¹⁶ and clearinghouse function offered by the Canadian Centre on Substance Abuse, and the Motherisk Helpline, a phone line designed to provide "authoritative information and guidance to pregnant or lactating patients and their health care providers regarding the fetal risks associated with drug [and other] exposure during pregnancy."¹⁷

Evaluating Current Approaches

In spite of the high level of activity on FASD and the meritorious efforts to coordinate this activity on the national level, there are limitations to the current approach. There is a lack of understanding of the differing levels of prevention required and how they can be mutually reinforcing. In addition, the following four focuses have been limited and, in some cases, damaging.

Child-Centered Focus To date, FASD has been framed largely as a child health and welfare issue. Pediatricians, other child health professionals, foster parents and adoptive parents have led the way in pointing out the challenges in identifying, treating, educating and parenting children who have the range of birth defects and developmental disabilities associated with FASD. Awareness activities, literature 19 and research 20 have focused on understanding the impact of in-utero exposure and articulating the required interventions to address the needs of those affected by FASD and their caregivers.

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Much less effort has been made to understand women's substance use in pregnancy and to develop the interventions needed to prevent this use and/or mitigate the harms associated with it. Governmental leadership on FASD has also reflected this child-centered focus. In provincial governments, ministries associated with child welfare policy and programming have often been given responsibility for the issue. Health Canada's National Advisory Committee on FAS/FAE has no representation from the women's health or women's addictions treatment fields. This structural bias also leads to an imbalance in attention to the prevention of FASD as compared to strategies for working with those affected by FASD. For example, a recent document designed to solicit community input for a National Framework for Action on Fetal Alcohol Syndrome does not include a discussion of women's use of substances during pregnancy.²¹

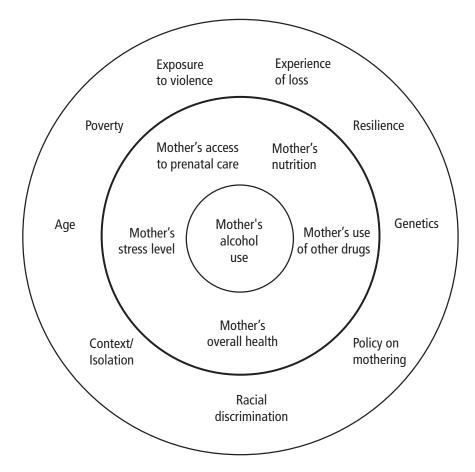
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Focus on Aboriginal Women Aboriginal communities are believed to have higher rates of affected children, yet limited research exists that has examined how rates of alcohol and other substance use vary across communities. ²² Studies that have determined prevalence rates in Aboriginal communities have involved communities where alcohol use was known to be high and prevalence rates were expected to be elevated. ²³ Bray and Anderson (1989) argue that research that examines demographic, socio-economic and sociocultural factors in relation to increased risk of FASD among Aboriginal populations would help to determine which Aboriginal populations are at increased risk. ²⁴ They recommend that community-specific information regarding alcohol consumption patterns of Aboriginal women be developed.

Aboriginal communities that have successfully implemented broad, community health actions to reduce substance use and address other determinants of health have received scant attention.²⁵ New research on the connections among substance use, FASD and the impact of residential schooling are just now becoming available and will be able to further support and guide such approaches.²⁶

This work may also serve to reduce the scrutiny directed to Aboriginal women, against whom the majority of punitive, legal actions have been taken for their use of substances during pregnancy, the Ms G case, concerning an Aboriginal woman at the centre of a legal case regarding mandatory treatment, being the most prominent among these.²⁷ It is important that all women be the focus of prevention efforts equally and that when Aboriginal women are struggling with alcohol and related problems in pregnancy, they receive supportive, health-enhancing assistance, not punishment.

Narrow, Simplistic Alcohol Focus Evidence shows that binge drinking ²⁸ creates the greatest risk of FASD ²⁹ and that other factors such as malnutrition, stress, use of other drugs, exposure to violence, and many other factors relating to women's health and well being have been shown to influence the risk of women giving birth to a child affected by FASD.² Prevention messages have tended to oversimplify this reality. They often focus only on alcohol use and imply that any level of alcohol use is highly dangerous. More critically, they often imply that it is a simple matter for all women to "just say no" to alcohol during pregnancy, ignoring the dynamics of addiction and the burden of other health and social problems that many women face. Finally, many prevention messages even imply that women are ignorant or callous when they are unable to stop using alcohol during pregnancy.



To be effective in FASD prevention efforts, we need to move from a focus on women's alcohol use alone to increased understanding of related health and social problems experienced by women that contribute to FASD, and to provide a network of supports that directly address these contributing factors. Community health policy that addresses broader determinants of health is also foundational to successful FASD prevention.

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The sole attention to alcohol use by individual women discourages a broader prevention approach focusing on the determinants of health. While the importance of taking a health determinants approach has been acknowledged in key policy documents as early as A Strategic Plan for Addressing Alcohol and Other Drug Related Developmental Disabilities in B.C. (1993), ³⁰ evidence-based policy and programming that address the multiple determinants of women's drinking have rarely been implemented. ^{31,32} Instead the trend has been to advocate for the labeling of alcohol bottles, instituting signage in bars, and other alcohol-specific initiatives that show little evidence of significant impact. ¹⁴ In fact, these and related policies may bias the general public against women who use substances and create misunderstanding of women's service needs. Mechanisms are critically needed to review and reform policies that cause harms such as these to women at risk and to those affected by FASD.

Judgmental Messages Societal attitudes towards substance use and addiction remain ambivalent. While the movement overall has been away from a moral and judgmental view, the shift towards seeing people with substance use problems as deserving of a comprehensive health care response has been slow to evolve. In the substance use literature there is agreement that stigma comes to bear heavily upon substance-using women ³³ and that the operation of this stigma is particularly strongly directed to pregnant women and mothers. ³⁴⁻³⁸

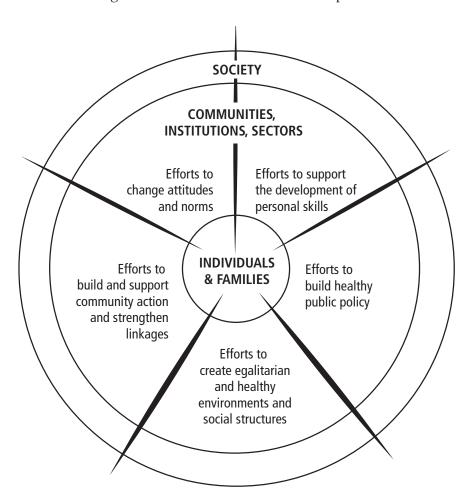
As a result, crucial barriers have emerged that hamper women's access to services, due to their feelings of shame, fear of losing custody of their children if they identify their need for help, and fear of being treated prejudicially on the basis of being mothers with substance use problems.³⁹ A range of service-level policies has created further barriers to care for women of childbearing years who have substance use problems. To give two examples: transition houses' refusal to accept women with substance use problems and a lack of protocols for withdrawal management of pregnant women in detoxification services.

FASD Prevention: Policy Recommendations

We know that the substance use of mothers of children with the full syndrome (FAS) has been influenced by a number of factors, such as histories of violence and trauma, serious mental health problems, and relationships in which the women's partners controlled their substance use and access to services. Factors such as malnutrition and the use of other drugs have also been shown to affect risk. An FASD prevention strategy that centres on improving women's health can succeed where other approaches have failed by addressing the multiple determinants of FASD and the dynamics of addiction in a coordinated, compassionate fashion. Three types of prevention are needed, each grounded in this approach

and each reaching different populations and involving different activities.^{2,40}

Level I Prevention The first level of prevention is public awareness, health promotion and community development activities. These are directed to, and can involve, all people in society. In the context of FASD prevention the goal is to increase understanding of how women come to have substance use problems, as well as to reduce inequities in health status. This level of prevention aims to shift negative attitudes towards women who have substance use problems, promote understanding of determinants of health, reduce organizational and systemic barriers to care, and bring people together to work on community-level solutions. This level forms the groundwork for the other levels of prevention.



Level I prevention is public awareness, health promotion and community development activities.

This level of prevention can be alcohol- and drug-specific (for example, media campaigns and community awareness activities), as well as involve broader efforts to change health and social policy to address poverty, violence against women, discrimination and other factors that contribute to women's substance use. It is aimed at multiple levels of society and uses multiple strategies.

Level II Prevention The second level of FASD prevention activities is systematic, caring intervention with all women of childbearing years (including pregnant women) to inform them about the risks of substance use during pregnancy, and about the help that is available if it is difficult for them to reduce or stop their alcohol use and improve their health in this period. Physicians have long been recognized as important providers of this information, yet many other service providers who come into contact with women in many settings have also been found to be helpful when they assume this role.³⁹ Engendering commitment on the part of all these providers to engage in informed and compassionate discussion of substance use with all women, and not only Aboriginal women, poor women and others who are seen to be at more risk, presents significant challenges, but there are new Canadian resources available to support this work.⁴⁰⁻⁴³

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This level of prevention is provided by a coordinated infrastructure of services and is directed to all women of childbearing years. It involves education, brief motivational counselling, and in some cases referral to specialized pregnancy and substance use treatment services.

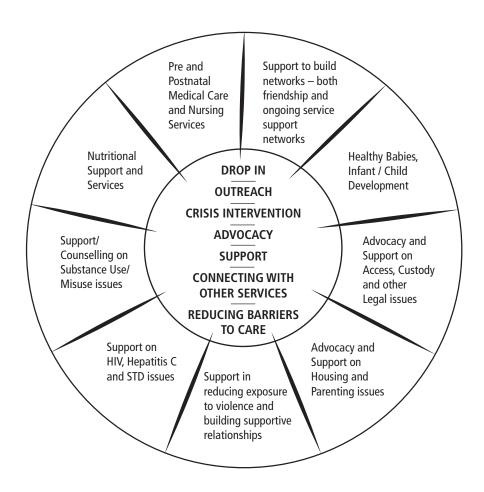
When this level of prevention is in place, all women are informed of the risks of drinking in pregnancy, women who are using alcohol in risky ways are helped to reduce or stop their alcohol use during pregnancy, and women with substantial alcohol and other health problems are linked to the comprehensive care described below.

Level III Prevention A third level of FASD prevention is delivered through a comprehensive constellation of services for pregnant women and mothers who have serious substance use problems and a range of other health and social problems. Across this network of services all contributing factors would be addressed. Critical to this level of FASD prevention is overcoming pervasive, systemic unwillingness to reduce barriers to access. Fundamental to this work is a holistic, nonjudgmental, harm reduction service orientation. Fundamental to this work is a holistic, nonjudgmental, harm reduction service orientation. Fundamental to this work is a holistic, nonjudgmental, harm reduction service orientation. Fundamental to this work is a holistic, nonjudgmental, harm reduction service orientation. Fundamental to this work is a holistic, nonjudgmental, harm reduction service orientation. Fundamental to this work is a holistic, nonjudgmental, harm reduction service orientation. Fundamental to this work is a holistic, nonjudgmental, harm reduction service orientation. Fundamental to this work is a holistic, nonjudgmental, harm reduction service orientation. Fundamental to this work is a holistic, nonjudgmental, harm reduction service orientation. Fundamental to this work is a holistic, nonjudgmental, harm reduction service orientation. Fundamental to this work is a holistic, nonjudgmental, harm reduction service orientation.

At this level of FASD prevention it is critical that women's fears about apprehension of their children are reduced.^{38,44} Women must know that a range of supports will be "wrapped around" the mother-baby pair, to help the mother create safety and health for herself and her child or children. In the Ms G case and in other cases that continue to arise, child welfare authorities have unsuccessfully tried forceful and mandatory approaches with women who have very serious substance use and other health problems.²⁷ In contrast, taking a welcoming, health-oriented approach, by increasing women's access to and the visibility of a range of networked health and perinatal services, is a more cost-effective, workable and respectful approach. The challenge at this level of prevention is to reduce territoriality and increase collaboration among agencies and across disciplines, which is achievable only when perinatal networks are adequately funded and supported.

The multi-faceted Sheway program in Vancouver is an example of how perinatal networks can function to solve problems of access to care and support women's health in a way that prevents FASD. Sheway works in partnership with innovative providers of withdrawal management services at BC Women's Hospital, with child welfare services, with the YWCA Crabtree Corner program, and many other community-based providers of housing, children's, Aboriginal, violence, nursing and other services. Many smaller communities are creating perinatal support networks that are workable for smaller numbers of women served, also based on a compassionate and comprehensive service orientation.

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This level of prevention is delivered through a coordinated infrastructure of perinatal services and is directed to women at high risk of having a child affected by FASD. Services can be colocated, as with the Sheway program, or linked on the community level through an organized perinatal services network. Such services address known barriers to access and work proactively to support change at a pace that supports retention and increased control over life circumstances.

Summary

A truly effective approach to managing FASD in Canada requires a concerted effort to prevent FASD as well as to care for those who are affected. Policy makers working on women's health issues and women's health researchers and advocates need to assume a leadership role on FASD prevention in concert with those working on intervention with those affected. A balance and respect for the health of both children and mothers is needed.

Components of this strategy to prevent FASD and improve the health of women of childbearing years include: 1) efforts on the community level to address

multiple determinants of health; 2) system-wide, brief intervention with all women of childbearing years to inform and assist them; and 3) coordinated networks of perinatal services to reach high-risk women and their families. All three levels of prevention need to be grounded in health-enhancing and non-blaming approaches that counter the stigma directed at substance-using women and mothers.

The three levels of prevention activities are interconnected, mutually reinforcing and based on improving women's health. A key principle for policy makers is to regard the mother and child as the unit of care, affecting a "Mother and Child Reunion" in policy and prevention.

A truly effective approach to managing FASD in Canada requires a concerted effort to prevent FASD as well as to care for those who are affected.

Notes

- 1. May PA, Gossage JP. Estimating the prevalence of Fetal Alcohol Syndrome: A summary. Alcohol Research and Health 2001;25 (3).
- 2. In 1996 the Institute of Medicine issued the most comprehensive definitions of the spectrum of defects and disabilities associated with maternal alcohol use. The descriptions included in this paper are adapted from these formal definitions. See Stratton K, Howe C, Battaglia F. Fetal Alcohol Syndrome: Diagnosis, epidemiology, prevention and treatment. Washington: National Academy Press; 1996.
- 3. The facial characteristics may include: small eye openings; flat midface (cheekbones); flattened groove between nose and upper lip (philtrum); thin upper lip. The growth deficiencies may include: low birth weight; decelerating weight over time, not due to malnutrition; disproportional low weight to height; height and weight below the 10th percentile.
- 4. 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. FAE (Fetal Alcohol Effects) is another less specific term that has been used to describe what are now known as pFAS and ARND. For a discussion of the rationale for using the more specific terms see Note 5.
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- 8. Clarren S. Keynote presentation. Prairie Provincial Conference on FAS; 1999; Calgary, Canada.
- 9. Centers for Disease Control and Prevention. Alcohol use among women of childbearing age United States, 1991-1999. Morbidity/Mortality Weekly Report 2002;51 (14):273-276.
- 10. Loock CA, Kinnis C, Robinson GC, Segal S, Blatherwick FJ, Armstrong RW. Targetting high risk families: Prenatal alcohol/drug abuse and infant outcomes. Vancouver (B.C.): Department of Pediatrics, Faculty of Medicine, University of British Columbia; 1993.
- 11. Greaves L, Cormier R, Poole N. Fetal Alcohol and women's health: Setting a womencentred research agenda. Vancouver: British Columbia Centre of Excellence for Women's Health; 2002.

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- 12. In January 2000, Health Canada began a three-year, \$11 million, Fetal Alcohol Syndrome/Fetal Alcohol Effects (FAS/FAE) Initiative. This funding has been allocated to enhance FAS/FAE activities related to: a) public awareness and education, b) training and capacity development, c) early identification and diagnosis, d) coordination, e) surveillance, and f) a strategic project fund designed as a first step towards supporting existing FAS/FAE activities across the country as well as creating new ones where no previous activity or capacity exists. The 2001 federal budget included \$25 million dollars in new funding for FAS prevention efforts on reserves.
- 13. Legge C, Roberts G, Butler M. Situational analysis: Fetal Alcohol Syndrome/Fetal Alcohol Effects and the effects of other substance use in pregnancy. Ottawa (ON): Health Canada; December 2000.
- 14. Roberts G, Nanson J. Best practices Fetal Alcohol Syndrome/Fetal Alcohol Effects and the effects of other substance use during pregnancy. Ottawa (ON): Health Canada; 2000.
- 15. Canadian Centre on Substance Abuse. Directory of FAS/FAE information and support services in Canada, Fourth Edition. Ottawa (ON): Canadian Centre on Substance Abuse; May 2002.
- 16. Through a toll-free line, 1-800-559-4514, bilingual information on FAS/FAE is provided to caregivers, educators, social workers, health care and treatment professionals, members of the legal community, policy makers and planners, researchers and the general public. Information on FAS/FAE is also provided at www.ccsa/fasgen.htm.
- 17. Phone 1-877-327-4636. The phone line is reinforced by a website, www.motherisk.org.
- 18. As with many FAS conferences, only 5% of workshops at the February 2003 "FASD Doing What Works Conference" sponsored by the University of British Columbia, BC Women's and Children's Hospitals and the FAS Parent Support Network of B.C., addressed prevention of FAS by working with women. Awareness posters commonly depict babies or fetuses miraculously speaking out on pregnant women's positive or negative behaviour, and/or focus on women's wombs only (depicting women's torsos or uteruses only).
- 19. Books such as *The Broken Cord*, *Fantastic Antoine Succeeds*, and *The Challenge of Fetal Alcohol Syndrome*: *Overcoming Secondary Disabilities*, all of which deal with the challenges and triumphs of living with and working with those affected, have been rallying points for the field. Books discussing the problems associated with punitive approaches to working with substance-using mothers, such as *Misconceiving Mothers* (see Note 36), *Mothers and Illicit Drugs*: *Transcending the Myths* (see Note 37) and *Pregnant Women on Drugs*: *Combating Stereotypes and Stigma* (see Note 38) remain obscure.
- 20. Over 80% of nationally-funded research projects between 1998 and 2002 were of a biomedical nature and only 2% focused on a women's health research agenda. (Source: speech made by Dr. Aubrey J. Tingle to The Prairie North West FASD Partnership, February 23, 2003.)
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- 22. May PA. The epidemiology of alcohol abuse among American Indians: The mythical and real properties. American Indian Culture and Research Journal 1994;18 (2):121-143.
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- 25. An example is the Community Healing Intervention Program, Cranbrook, B.C., programming also offered on the Big Cove reserve in Nova Scotia.
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- 28. A large number of drinks on an occasion: for women this is considered to be 5 or more drinks.
- 29. Maier S, West J. Drinking patterns and Alcohol-Related Birth Defects. Alcohol Res Health 2001;25 (3):168-174.
- 30. British Columbia Ministry of Health. A strategic plan for addressing Alcohol and other Drug-Related Developmental Disabilities (ADRDD), including Fetal Alcohol Syndrome (FAS) and Neonatal Abstinence Syndrome (NAS) in British Columbia. Victoria (B.C.): Government of British Columbia; 1993.
- 31. A key exception is the work of the Northern Family Health Society in Prince George, B.C., which since 1987 has been building a comprehensive community development strategy based on grassroots participation. (See Note 32.)
- 32. Northern Family Health Society. Our northern FASD process. Prince George (B.C.): Northern Family Health Society; 2003.
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- 34. Finklestein N. Treatment Issues for alcohol and drug dependent pregnant and parenting women. Health Soc Work 1994;19 (1):7-15.
- 35. Gomez LE. Misconceiving mothers: Legislators, prosecutors, and the politics of prenatal drug exposure. Philadelphia (PA): Temple University Press; 2000.
- 36. Murphy S, Rosenbaum M. Pregnant women on drugs: Combating stereotypes and stigma. Piscataway (NJ): Rutgers University Press; 1999.
- 37. Boyd SG. Mothers and illicit drugs: Transcending the myths. Toronto (ON): University of Toronto Press; 1999.

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