

GOVERNMENT OF YUKON

**Yukon FASD Prevention Gap Analysis:
Summary of the Literature on
FASD Prevention - A Health Determinants Perspective**

March 2014

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1. Introduction

This literature review report is supplementary to *Evidence-Based Synthesis on the Effectiveness of Prevention Approaches for Fetal Alcohol Spectrum Disorders: A Systematic Review Update*, a document that was previously submitted to the Government of Yukon as part of the *Yukon FASD Prevention Gap Analysis* project. This report represents a non-exhaustive review of scholarly and grey literature on the underlying social conditions of FASD, and multilevel interventions which aim to address the social determinants of health in connection with FASD or health matters more broadly.

An expedited literature search strategy was used to locate annotated bibliographies, systematic reviews and primary research articles on these topics. Sources were mainly derived from Google and several EBSCO host academic databases, including Academic Search Complete, ERIC, MasterFILE, MEDLINE, SocINDEX, Family & Society Studies Worldwide, PsychINFO, Child Development & Adolescent Studies, CINAHL (Cumulative Index to Nursing and Allied Health Literature) Plus with Full Text, and Health Policy Reference Centre. The initial search explored the link between FASD and the social determinants of health using key terms such as, “social determinant*”, “social”, “economic”, “poverty”, “violence”, “class”, “education”, “unemployment”, “employment”, “income”, “work”, “job”, “first nation*”, “Inuit”, “Aboriginal”, “Métis”, “immigrat*”, or “minorit*”. The second search focused on system level FASD or health interventions with key terms including “intervention”, “policy”, “strategy”, “directive”, “framework”, “legislation”, “government”, “intersectoral”, or “initiative”.¹

The following sections describe what is known about FASD prevalence in Canada and in northern Canada more specifically. Subsequent sections delineate the sociodemographic and sociostructural factors that have been linked to FASD in the literature and program, and system level interventions which aim to address the social determinants of health.

1.1 Prevalence of FASD in the Canadian context

While no official data exists on the prevalence of fetal alcohol spectrum disorder (FASD) in Canada, this diagnosis is estimated to occur in 9 per 1,000 live births and affects approximately 1% of the population.² In Canada, there is a greater prevalence of FASD in “rural communities, foster care systems, juvenile justice systems and Aboriginal populations”.³ The rate of FASD in Aboriginal communities in

¹ Of note, Government of Yukon representatives suggested a few sources for inclusion in this review. Many sources were derived from *FASD prevention: An annotated bibliography, 2013* prepared for CanFASD by Rose Schmidt and Nancy Poole, BC Excellence for Women’s Health (January, 2014).

² Health Canada. (2006). *It’s your health: Fetal alcohol spectrum disorder*. Retrieved on February 18, 2014 from: http://www.hc-sc.gc.ca/hl-vs/alt_formats/pacrb-dgapcr/pdf/iyh-vsv/diseases-maladies/fasd-etcaf-eng.pdf

³ Jonsson, E., Dennett, L., & Littlejohn, G. (2009). *Fetal alcohol spectrum disorder (FASD): Across the lifespan – Proceedings from an IHE consensus development conference, 2009*. Retrieved February 18, 2014. p.175.

northern Canada is estimated to be higher than the national average.⁴ However, researchers have been challenged to provide a generalizable prevalence rates for this population because studies have drawn from a diverse range of research methodologies and have focused on different Aboriginal cultures with differing patterns of alcohol consumption.⁵ Muckle et al. have estimated that 47 per 1,000 live births “may result in children at risk for alcohol effects” among Inuit living in Arctic Quebec.⁶ Earlier literature reviewed by Chudley et al. revealed FASD rates (per 1,000 live births) of 25 (among native Canadian children in northern British Columbia); 46 (among nation Canadian children living in the Yukon); 190 (in an isolated Aboriginal community in British Columbia); and, 55-101 (in a First Nations community in Manitoba).⁷

Other research conducted by Stade et al. has focused on financial burden resulting from FASD.⁸ FASD entails considerable direct and indirect costs to those who personally experience this condition and to the health and social systems more broadly. In Canada, the annual costs associated with FASD are estimated to be \$21,642 at the individual level and \$5.3 billion at the system level (for individuals who are between 0 to 53 years of age). The costs of FASD are influenced by the severity of disability and corresponding need for specialized services, age corresponding with the kinds of supports that are available and accessed (generally more services are provided to children aged 0-3 years) and relationship to the child or adult with FASD (children in care incur the highest costs in seeking FASD supports; in comparison, biological and adoptive parents are generally less able to access and pay for these services).

Popova et al. compared provincial data to determine the number and associated costs of children (0-18 years) who are in care and have FASD in the Canadian child welfare system.⁹ In 2011, the highest prevalence of children in care (the national total in 2011 was 67,161) occurred in the Northwest Territories (31 per 1,000), Yukon (25 per 1,000) and Manitoba (24 per 1,000) had. The provinces with the highest prevalence of children with FASD who are in care included Ontario (612-1,060), Quebec (418-1,432) and Alberta (2,225-7,620). Popova et al. estimate that “the total number of children in care with

⁴ Health Canada. (2012). *It takes a community: Framework for the First Nations and Inuit fetal alcohol syndrome and fetal alcohol effects initiative. A resource manual for community-based prevention of fetal alcohol syndrome and fetal alcohol effects*. Retrieved on February 18th, 2014 from: http://publications.gc.ca/collections/collection_2012/sc-hc/H34-84-1997-eng.pdf

⁵ Muckle, G., Laflamme, D., Gagnon, J., Boucher, O., Jacobson, J., & Jacobson, S. (2011). Alcohol, smoking, and drug use among Inuit women of childbearing age during pregnancy and the risk to children. *Alcoholism: Clinical and Experimental Research*, 35 (6), 1081-91.

⁶ Ibid. p.1089.

⁷ Chudley, A., Conry, J., Cook, J., Loock, C., Rosales, T., & LeBlanc, N. (2005). Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. *Canadian Medical Association Journal*, 172 (5 suppl), S1-S21.

⁸ Stade, B., Ali, A., Bennett, D., Campbell, D., Johnston, M., Lens, C., Tran, S., & Koren, G. (2009). The burden of prenatal exposure to alcohol: Revised measurement of cost. *Canadian Journal of Therapeutics and Clinical Pharmacology*, 16 (1), 80-90.

⁹ Popova, S., Lange, S., Burd, L., & Rehm, J. (2014). Canadian children and youth in care: The cost of fetal alcohol spectrum disorder. *Child and Youth Care Forum*, 43 (1), 83-96.

FASD in Canada, in 2011, ranged between 2,225 and 7,620” with associated overall costs ranging from \$57.9 to \$198.3 million.¹⁰ Higher costs were incurred for children between 11 and 15 years of age, followed by 6-10 year and 0-5 year age groups.

2. Maternal alcohol consumption during pregnancy

2.1 Sociodemographic variables

FASD is as much a social issue as it is a personal one and, therefore, must be understood in relation to the sociodemographic factors that influence alcohol consumption during pregnancy. The following sections describe reviewed literature and primary research findings concerning the personal and biographical determinants of prenatal alcohol use.

Zelner and Koren’s (2013) review of worldwide studies on alcohol consumption during pregnancy emphasized various risk factors that are linked with prenatal alcohol use.¹¹ Individual risk factors included maternal age (i.e., between 15 and 19 or over 35 years), being unmarried, having an unplanned pregnancy, and use of other substances while pregnant (i.e., tobacco and cocaine). In addition, inadequate nutrition, a history of physical and emotional abuse and paternal alcohol or drug use were also found to be risk factors for maternal alcohol consumption during pregnancy. Studies reviewed by Zelner and Koren also indicated that low levels of education attainment, “limited access to healthcare services and poor prenatal care” are associated with maternal alcohol use during pregnancy.¹²

Hutchinson et al. (2013) analyzed data from the 2005 Longitudinal Study of Australian Children to explore the sociodemographic backgrounds of mothers who reported alcohol use during pregnancy.¹³ Data were analyzed according to representative cohorts of families with infants (n=5,107) and families with children (n=4,983). Alcohol consumption during pregnancy was reported by 37.6% of mothers in the infant cohort and 27.1% of mothers in the child cohort. In both cohorts, prenatal alcohol use was positively linked with older maternal age, social and economic advantage (i.e., higher education and income), absence of health problems and smoking during pregnancy. The researchers suggest that public campaigns which aim to reduce maternal alcohol consumption during pregnancy should target women who are older, of higher socioeconomic standing, and who smoke tobacco.

¹⁰ Popova, S., Lange, S., Burd, L., & Rehm, J. (2014). Canadian children and youth in care: The cost of fetal alcohol spectrum disorder. *Child and Youth Care Forum*, 43 (1), 83-96. Popova et al. (2014). p.89.

¹¹ Zelner, I., & Koren, G. (2013). Alcohol consumption among women. *Journal of Therapeutics and Clinical Pharmacology*, 20 (2), 201-6.

¹² Ibid. p.203.

¹³ Hutchinson, D., Moore, E., Breen, C., Burns, L., & Mattick, R. (2013). Alcohol use in pregnancy: Prevalence and predictors in the longitudinal study of Australian children. *Drug and Alcohol Review*, 32 (5), 475-82.

Meschke et al. (2013) examined survey data from 9,004 pregnant women in north and central United States to determine risk factors for prenatal alcohol use across age groups.¹⁴ The findings suggested that younger women (20-25 years) were generally more at risk for maternal alcohol consumption during pregnancy compared to older women; however, women older than 35 years were more likely to engage in this behaviour. Risk factors that were associated with prenatal alcohol use included being white, unmarried, employed, having a first time pregnancy, smoking prenatally, having a depressed mood, and having more experience with alcohol use.

Leonardson and Loudenburg (2003) analyzed 4,767 questionnaires completed by women who had accessed prenatal care in Montana, Minnesota, South Dakota, and North Dakota.¹⁵ The study concluded that women at higher risk for alcohol use when pregnant tend to be “younger, less educated, single, and unemployed”.¹⁶ Other risk factors included past sexual or physical abuse, use of tobacco or other drugs, and association with other substance users (i.e., partners or friends). Factors that appeared to reduce risk for prenatal alcohol consumption included being married and a full-time housewife.

In a study of prenatal alcohol and tobacco use involving surveys of 1,591 pregnant women in Australia, Powers et al. (2013) found that “concurrent drinkers and smokers were younger, less educated and less likely to be married at the time of pregnancy” compared to women who did not concurrently smoke or drink prior to pregnancy.¹⁷ In addition, concurrent alcohol and tobacco use during pregnancy was more common among women who had less social support, experienced mental health problems, had more financial strain and experienced partner violence. The authors suggest that prevention and intervention efforts should emphasize the effects of both alcohol and tobacco use during pregnancy and target disadvantaged women and those who have experienced intimate violence in their lifetime.

Cannon et al. (2012) studied Fetal Alcohol Syndrome (FAS) Surveillance Network data in Arizona, New York, Alaska and Colorado to understand the sociodemographic characteristics of women (n=353) who gave birth to children FAS.¹⁸ Data from these groups were compared with state-specific and nationwide survey data. Mothers who gave birth to children with FAS “were more likely to be older, American Indians/Alaska natives, Black, not Hispanic, unmarried, unemployed, and without prenatal care, to smoke during pregnancy, to have a lower educational level, and to have more live born children”.¹⁹ The authors articulate that FAS prevention and intervention strategies should target all groups of women,

¹⁴ Meschke, L., Holl, J., & Messelt, S. (2013). Older not wiser: Risk of prenatal alcohol use by maternal age. *Maternal & Child Health Journal, 17* (1), 147-55.

¹⁵ Leonardson, G. & Loudenburg, R. (2003). Risk factors for alcohol use during pregnancy in a multistate area. *Neurotoxicology and Teratology, 25* (6), 651-8.

¹⁶ Ibid. p.651.

¹⁷ Powers, J., McDermott, L., Loxton, D., & Chojenta, C. (2013). A prospective study of prevalence and predictors of concurrent alcohol and tobacco use during pregnancy. *Maternal & Child Health Journal, 17* (1), 76-84. p.78.

¹⁸ Cannon, M., Dominique, Y., O’Leary, L., Sniezek, J., & Floyd, R. (2012). Characteristics and behaviours of mothers who have a child with fetal alcohol spectrum disorder. *Neurotoxicology and Teratology, 34* (1), 90-5.

¹⁹ Ibid. p.90.

including those who appear to have fewer risk factors (based on those outlined above), have previously given birth to a child with FAS qualities, and drink high or moderate amounts of alcohol.

Ethen et al. (2009) analyzed data from the National Birth Defects Prevention Study of eight states (Arkansas, California, Georgia, Iowa, Massachusetts, New Jersey, New York and Texas) involving 4,088 women who completed structured telephone interviews before and during their pregnancy.²⁰ The findings suggested more frequent alcohol consumption among women who are older and have higher levels of income and education. In addition, “women with unintended pregnancies, women who smoke cigarettes, non-Hispanic white women, and women with higher incomes” and education are more likely to consume alcohol prenatally.²¹

As part of a longitudinal fetal alcohol syndrome (FAS) primary prevention study, Astley et al. (2000) explored the sociodemographic profiles of women (n=80) who had given birth to child with FASD.²² The majority of women had not completed high school (61%), earned less than \$10,000 USD annually (78%), had experienced physical or sexual abuse in their lifetime (95%), and had one or more mental health disorders (96%) (e.g., post-traumatic stress disorder and simple phobias). In addition, most of the women reported a history of tobacco (84%) or illicit drug use (86%) near the time of their child’s birth.

Kvinge et al. (2003) conducted a case-control study of Northern Plains Indian mothers to describe the characteristics of women who gave birth to children with FAS or children who presented with FAS characteristics.²³ Mothers of children with FAS (n=43) and mothers with children who had characteristics of FAS (n=35) were compared to women with children who did not have FAS. Compared to the control mothers, women with children with some form of FAS “had significantly fewer prenatal visits, had more pregnancies, had more children before the index child, and were older”.²⁴ In addition, mothers with children with FAS or FAS characteristics had less education and more often reported histories of alcohol use in the family, experiences with sexual abuse and mental health problems compared to the control group.

²⁰ Ethen, M., Ramadhani, T., Scheurle, A., Canfield, M., Wyszynski, D., Druschelm C., Romitti, P. (2009). Alcohol consumption by women before and during pregnancy. *Maternal & Child Health Journal*, 13 (2), 274-85.

²¹ Ibid. p.281.

²² Astley, S., Bailey, D., Talbot, C., & Clarren, S. (2000). Fetal alcohol syndrome (FAS) primary prevention through FAS diagnosis: II. A comprehensive profile of 80 births mother of children with FAS. *Alcohol & Alcoholism*, 35 (5), 509-19.

²³ Kvinge, V., Leonardson, G., Borzelleca, J., Brock, E., Neff-Smith, M., & Welty, T. (2003). Characteristics of mothers who have children with fetal alcohol syndrome or some characteristics of fetal alcohol syndrome. *Journal of the American Board of Family Medicine*, 16 (4), 296-303.

²⁴ Ibid. p.297.

A study conducted by Muckle et al. (2011) aimed to determine substance use prevalence and risk factors among 208 pregnant Inuit women in Arctic Quebec.²⁵ The data revealed that 61% of the women consumed alcohol, 92% smoked cigarettes, and 36% had used marijuana during pregnancy. Alcohol use and binge drinking during pregnancy were linked with higher socioeconomic status (suggested by less crowded living conditions and ability to speak English or French), alcohol consumption and binge drinking prior to pregnancy and use of illicit drugs. Binge drinking also occurred more frequently among women who were single, had fewer previous pregnancies, and experience maternal symptoms of depression.

Across reviewed sources, there is agreement on the connection between maternal alcohol consumption during pregnancy and variables pertaining to age, marital status, socioeconomic status (i.e., achieved education and income levels), employment, ethnicity, concurrent substance use (i.e., tobacco or other drugs), mental health status and past experience with violence or trauma. However, the research findings appear to diverge when conclusions are made about age and socioeconomic status as risk factors for prenatal alcohol consumption. Some studies suggested that low maternal age and socioeconomic status are associated with increased risk for prenatal alcohol consumption, where as other studies indicated that older women and women with higher socioeconomic standing appear to use alcohol more frequently while pregnant.^{26,27,28,29,30,31,32,33,34,35} A few studies highlighted that risk

²⁵ Muckle, G., Laflamme, D., Gagnon, J., Boucher, O., Jacobson, J., & Jacobson, S. (2011). Alcohol, smoking, and drug use among Inuit women of childbearing age during pregnancy and the risk to children. *Alcoholism: Clinical and Experimental Research*, 35 (6), 1081-91.

²⁶ Zelner, I., & Koren, G. (2013). Alcohol consumption among women. *Journal of Therapeutics and Clinical Pharmacology*, 20 (2), 201-6.;

²⁷ Meschke, L., Holl, J., & Messelt, S. (2013). Older not wiser: Risk of prenatal alcohol use by maternal age. *Maternal & Child Health Journal*, 17 (1), 147-55.;

²⁸ Leonardson, G. & Loudenburg, R. (2003). Risk factors for alcohol use during pregnancy in a multistate area. *Neurotoxicology and Teratology*, 25 (6), 651-8.;

²⁹ Powers, J., McDermott, L., Loxton, D., & Chojenta, C. (2013). A prospective study of prevalence and predictors of concurrent alcohol and tobacco use during pregnancy. *Maternal & Child Health Journal*, 17 (1), 76-84.

³⁰ Astley, S., Bailey, D., Talbot, C., & Clarren, S. (2000). Fetal alcohol syndrome (FAS) primary prevention through FAS diagnosis: II. A comprehensive profile of 80 births mother of children with FAS. *Alcohol & Alcoholism*, 35 (5), 509-19.;

³¹ Kvinge, V., Leonardson, G., Borzelleca, J., Brock, E., Neff-Smith, M., & Welty, T. (2003). Characteristics of mothers who have children with fetal alcohol syndrome or some characteristics of fetal alcohol syndrome. *Journal of the American Board of Family Medicine*, 16 (4), 296-303.

³² Hutchinson, D., Moore, E., Breen, C., Burns, L., & Mattick, R. (2013). Alcohol use in pregnancy: Prevalence and predictors in the longitudinal study of Australian children. *Drug and Alcohol Review*, 32 (5), 475-82.;

³³ Cannon, M., Dominique, Y., O'Leary, L., Sniezek, J., & Floyd, R. (2012). Characteristics and behaviours of mothers who have a child with fetal alcohol spectrum disorder. *Neurotoxicology and Teratology*, 34 (1), 90-5.;

³⁴ Ethen, M., Ramadhani, T., Scheurle, A., Canfield, M., Wyszynski, D., Druschel, C., Romitti, P. (2009). Alcohol consumption by women before and during pregnancy. *Maternal & Child Health Journal*, 13 (2), 274-85;

factors exist across different age groups and socioeconomic positions.³⁶ An emergent theme concerns the complexity of biographical and personal characteristics in relation to FASD and recognition that many subpopulations of women should be targeted by FASD prevention and awareness initiatives.

2.2 Sociostructural variables

Beyond the sociodemographic factors that influence patterns of maternal alcohol consumption during pregnancy, it is also important to consider the social environment that enable or mitigate FASD outcomes. Literature reviewed by Nathoo et al. (2013) “strongly suggests that the women most likely to have a child with FASD are those who will be least likely be able to respond to awareness messages about the potential harms of consuming alcohol during pregnancy because of the overwhelming social conditions within which they live”.³⁷ Such sociostructural conditions include, but are not limited to, poverty, homelessness, cultural connectedness, violence, trauma, and a history of colonization.

Thanh et al. (2013) argue that FASD and poverty (i.e., low socioeconomic status) are connected, but it is unclear whether FASD contributes to or is caused by poverty.³⁸ Individuals with FASD and their families experience financial burden because of direct costs (i.e., travel, accommodations, missed work, insurance) and indirect costs (i.e., physical, behavioural and mental health problems) that are associated with FASD. In effect, FASD can negatively impact the earning potential of individuals and families, thus forcing them “into poverty from which they hardly escape”.³⁹ Thanh et al. indicate that a similar poverty trap process occurs among individuals families who experience other forms of intellectual disability.

Badry and Felske (2013) highlight the relationship between other sociocultural factors and FASD in the Northwest Territories.⁴⁰ Women who took part in a participatory action research project (n=30) described ways in which the health of women in the north is closely tied to land and traditions, housing and poverty, food security, physical and mental health, experiences of trauma, and ability to travel and

³⁵ Muckle, G., Laflamme, D., Gagnon, J., Boucher, O., Jacobson, J., & Jacobson, S. (2011). Alcohol, smoking, and drug use among Inuit women of childbearing age during pregnancy and the risk to children. *Alcoholism: Clinical and Experimental Research*, 35 (6), 1081-91.

³⁶ Zelnor, I., & Koren, G. (2013). Alcohol consumption among women. *Journal of Therapeutics and Clinical Pharmacology*, 20 (2), 201-6.; Meschke, L., Holl, J., & Messelt, S. (2013). Older not wiser: Risk of prenatal alcohol use by maternal age. *Maternal & Child Health Journal*, 17 (1), 147-55.;

³⁷ British Columbia Centre of Excellence for Women’s Health, 2008 and Poole, 2008 as cited in Nathoo, T., Poole, N., Bryans, M., Dechief, L., Hardeman, S., Marcellus, L., Poag, E., & Taylor, M. (2013). Voices from the community: Developing effective community programs to support pregnant and early parenting women who use alcohol and other substances. *First Peoples Child & Family Review*, 8 (1), 93-106.

³⁸ Thanh, N., Jonsson, E., Moffatt, J., & Dennett, L. (2013). Fetal alcohol spectrum disorder – Poverty trap? *Journal of Population Therapeutics and Clinical Pharmacology*, 20 (1), 63-66.

³⁹ Ibid p. 64-5.

⁴⁰ Badry, D. & Felske, A. (2013). An examination of the social determinants of health as factors related to health, healing and prevention of foetal alcohol spectrum disorder in a northern context – the brightening our home fires project, Northwest Territories, Canada. *International Journal of Circumpolar Health*, 72, 1-6.

access health services. Drawing on this research, Badry and Felske (2013) developed a model for FASD prevention in the northern Canadian context. The model brings together trauma, alcohol abuse and child welfare involvement as three overlapping factors associated with FASD. The authors suggest that FASD prevention initiatives should consider how alcohol use stems from a history of colonization, residential schooling, trauma, and breakdown in families and communities in the north.

In an ethnographic study of northern Aboriginal mothers of children with FASD in British Columbia (n=8), Johnston and Boyle (2013) explored FASD as an intergenerational pattern “related to the historical and collective emotional injury Aboriginal peoples have experienced as a result of colonialism”.⁴¹ Mothers who participated in the study were themselves affected by FASD and also had family members with this condition. Alcohol use, among other unhealthy ways of coping with trauma, had been passed down through generations and was accompanied conflicting feelings of acceptance and shame among the women. Johnston and Boyle delineate how intergenerational patterns of alcohol use and FASD are connected with sociostructural elements, including lack of support for addressing unresolved personal trauma, racial stereotyping, and stigmatizing notions of Aboriginal motherhood, lack of opportunity to learn childrearing skills, “poverty, unemployment, isolation, and lack of education”.⁴²

The above literature builds connections between the sociodemographic variables and broader social forces that influence women’s use of alcohol during pregnancy. In the northern Canadian context specifically, FASD risk factors of age, income, education level, experience with violence and trauma are compounded by deeper issues related to the intergenerational effects of colonization, poverty, availability of health services in communities, racism, and stigma.^{43,44}

3. Health interventions

A targeted literature review of program and system level interventions pertaining to the social determinants of health was conducted. The literature search uncovered a structured literature review of program models delivering services to socioeconomically disadvantaged women who use substances and may be pregnant or parenting. Further research and evaluation data were available for two such programs. Adding to these findings are system level systematic reviews and strategies which have been summarized in subsequent sections.

⁴¹ Johnston, S. & Boyle, J. (2013). Northern British Columbian Aboriginal mothers: Raising adolescents with fetal alcohol disorder. *Journal of Transcultural Nursing*, 24 (6), 60-7. p.63.

⁴² Ibid. p.65.

⁴³ Badry, D. & Felske, A. (2013). An examination of the social determinants of health as factors related to health, healing and prevention of foetal alcohol spectrum disorder in a northern context – the brightening our home fires project, Northwest Territories, Canada. *International Journal of Circumpolar Health*, 72, 1-6.;

⁴⁴ Badry, D. & Felske, A. (2013). An examination of three key factors: Alcohol, trauma and child welfare: Fetal alcohol spectrum disorder and the Northwest Territories of Canada. *First Peoples Child & Family Review*, 8 (1), 131-43.

3.1 Program level interventions

The FASD research described earlier emphasized the significance of sociodemographic factors (i.e., age, ethnicity, employment status, educational level, mental illness, substance use, and history of violence or trauma) and sociostructural factors (i.e., poverty) in women’s experiences with alcohol during pregnancy. The literature highlighted multiple subpopulations of women who are at risk for prenatal alcohol consumption. One subpopulation concerned women who are socially disadvantaged, use multiple substances and have experienced trauma in their lifetimes.

A recently published literature review (2012) examined the effectiveness of program level supports for street-involved pregnant and parenting women.⁴⁵ The backgrounds and socioeconomic dispositions of this group are similar to those described for at-risk groups in the FASD literature. The document highlights that socially marginalized women who may be pregnant and who are using substances are less likely to access health services due to structural barriers of stigma and negative public attitudes, feelings of shame or guilt, fear of losing their children, mental illness and low self-esteem, inability to access information, and mistrust of health providers. Community-based programs are challenged to connect this group to health supports that could positively impact maternal and infant health outcomes.

The literature review explored best practices for providing services and supports to street-involved pregnant and parenting women. The author compared sixteen program types (detailed in table 1), including resource centres and community centres, drop-in healthy baby programs, residential programs, home visitation or mobile outreach programs, and one stop or single access models of service delivery.

Table 1. Service delivery program name, location and model⁴⁶

Program Name	Location	Model of Service Delivery
Sheway	Vancouver, Canada	“One-stop” or single access model
Breaking the Cycle	Toronto, Canada	“One-stop” or single access model
Maxxine Wright Place Project for High Risk Pregnant and Early Parenting Women	Surrey, Canada	“One-stop” or single access model
HerWay Home	Victoria, Canada	“One-stop” or single access model
The Mothering Project	Winnipeg, Canada	“One-stop” or single access model
New Choices	Hamilton, Canada	“One-stop” or single access model
Homeless Prenatal Program	Seattle, USA	“One-stop” or single access model

⁴⁵ Brower, K. (2012). *Best Practices: Services and Supports for Street-Involved Pregnant and Parenting Women – A Review of the Literature*. Report prepared by Charis Management Consulting for the Alberta Centre for Child, Family and Community Research, Calgary, AB.

⁴⁶ Ibid.p.10.

Program Name	Location	Model of Service Delivery
Toronto Centre for Substance Use in Pregnancy	Toronto, Canada	“One-stop” or single access model/ Hospital comprehensive care
Homeless At-Risk Prenatal Program	Toronto	Home visitation/mobile outreach
KidsFirst	Saskatchewan, Canada	Home visitation/mobile outreach
First Steps Fetal Alcohol Spectrum Disorder (FASD) program	Edmonton, Canada	Home visitation/mobile outreach
Parent-Child Assistance Program	Washington, USA	Home visitation/mobile outreach
St. Michael’s My Baby and Me Infant Passport Program	Toronto, Canada	Hospital comprehensive care
First Steps Housing Project Inc.	Saint John, Canada	Residential
Supportive Housing for Young Mothers	Halifax, Canada	Residential
Villa Rosa	Winnipeg, Canada	Residential

Programs which appeared to positively influence client knowledge, behaviour and lifestyle were those that:

- Incorporated drop-in or mobile outreach services;
- Offered centralized, integrated, comprehensive and multidisciplinary services;
- Addressed women’s immediate needs (i.e., food, shelter, clothing, transportation) and more complex needs (i.e., pregnancy, mental illness, addiction);
- Provided primary health care, such as basic medical support, prenatal and postnatal care and health counselling;
- Encouraged client involvement in decisions about which services and supports would best help them to reach their goals;
- Emphasized hopeful, non-judgemental, harm-reduction approaches;
- Focused on both maternal and infant health outcomes; and,
- Included an advocacy component to increase client access to resources, information, education and social supports.

Challenges experienced across all program types included funding and space availability, expanding outreach services to assist more women, implementing creative and culture-based activities, extending program capacity to provide lengthier postnatal support to clients, and broadening scope of services offered in relation to employment and education, as well as treatment and support for multiple substance use.

Nathoo et al. (2013) note that community-based organizations and others are evolving “within a context of greater awareness of issues like FASD, harm reduction approaches, cultural safety, and violence and trauma-informed care”.⁴⁷ These authors describe best practices and lessons learned from four Canadian single access programs (the Maxxine Wright Place Project in Surrey, BC; the Healthy, Empowered and Resilient (H.E.R.) Pregnancy Program in Edmonton, AB; HerWay Home in Victoria, BC; and, Manito Ikwe Kagiikwe in Winnipeg, MB) that serve pregnant and parenting women who use alcohol and other substances. Successful elements of these programs include:

- Informal engagement and outreach activities to allow greater flexibility in reaching women in several locations and overcome challenges related to transportation or fear or formalized institutions;
- A harm reduction approach that encourages women to engage in healthier behaviours (i.e., reduced substance use rather than abstinence or developing positive relationships with counsellors or partners);
- Creating a safe programming environment with culturally relevant, trauma-informed care to facilitate trust-building between service providers and women who have experiences with violence or trauma;
- Addressing the needs of the mother and fetus or child; and,
- Cross-sectoral partnerships with other service providers, particularly child welfare services.

The authors discuss some of the challenges the four programs have encountered in relation to meeting high demands for service with limited staffing and funding, adapting to cross-sectoral changes and fragmentation and addressing stigma and misconceptions about mothering and alcohol or substance use in the public domain.

Published research data pertaining to program level health interventions were available for Sheway in Vancouver, British Columbia⁴⁸ and the H.E.R. Pregnancy Program in Edmonton, Alberta.⁴⁹ Sheway is a single-access pregnancy outreach program that provides integrated health and social supports to pregnant and parenting women who use alcohol or other substances. The program is guided by harm reduction philosophy that encourages clients to decide which services and staff members should be involved in their care and personal decision making. The Sheway staff team consists of many different

⁴⁷ Nathoo, T., Poole, N., Bryans, M., Dechief, L., Hardeman, S., Marcellus, L., Poag, E., & Taylor, M. (2013). Voices from the community: Developing effective community programs to support pregnant and early parenting women who use alcohol and other substances. *First Peoples Child & Family Review*, 8 (1), 93-106. Page 94.

⁴⁸ Marshall, S., Charles, G., Hare, J., Ponzetti, J., & Stokl, M. (2005). Sheways' services for substance using pregnant and parenting women: Evaluating the outcomes for infants. *Canadian Journal of Community Mental Health*, 24 (91), 19-33.

⁴⁹ Wodinski, L., Wanke, M., & Khan, F. (2013). *Impact Evaluation of the H.E.R. Pregnancy Program – Final Summary Report*. Retrieved on March 1, 2014 from the CanFASD Research Network: <http://fasdprevention.files.wordpress.com/2014/02/her-final-summary-report-2014.pdf>

professions (i.e., counsellor, dietician, social workers, outreach workers, infant development consultants, nurses, and physicians) from multiple agencies and government ministries.

A study was conducted to determine the impact of Sheway's services in relation to maternal health and infant outcomes. The researchers carried out statistical analysis of 1,247 client files collected over a 9.5 year period. Most program clients self-reported as being in their mid-twenties (average age is 26 years) and of Aboriginal descent (between 64 and 81% throughout program operation). Over time, program clients increasingly reported "inadequate housing, income, or access to food as well as mental and/or physical health problems".⁵⁰ The authors suggest that increased reporting in these areas may relate to trust building between the program and clients and staff ability to provide clients with a safe environment. The researchers examined client prenatal and postnatal health indicators, such as birth weight, Apgar scores, infant withdrawal symptoms, infant mortality and rates of child apprehension. Available data demonstrated positive correlation between infant birth weight and longer prenatal care ($r=.14$, $p<.01$) and receipt of food supports ($r=.12$, $p<.01$) from Sheway. The data also demonstrated fewer preterm infant births and instances of low birth weight infants over the program's operating years, but increases were recorded for these outcomes in the last few years of data collection (2000-2003). Sheway did not appear to influence the rate at which children were removed from maternal care. The authors conclude that the program has improved or maintained client prenatal or postnatal health indicators over time.

The H.E.R. Pregnancy Program, like Sheway, is a community-based program that serves socioeconomically disadvantaged pregnant and parenting women who may struggle with alcohol or substance use issues. The H.E.R. Pregnancy Program is based on a single access model of service delivery and is guided by principles of women centeredness, peer support, harm reduction, and health promotion and primary care. The program employs pregnancy support workers who have street knowledge and experience, as well as a registered nurse and social worker who connect women to health and social services before during and after pregnancy. The H.E.R. Pregnancy Program staff team connects with women at its onsite location and through outreach efforts in the community. Staff help clients with accessing addictions support, crisis intervention, health services, health education, housing and income supports. Staff also accompany and advocate on behalf of clients in larger institutional settings (i.e. health, social and judicial systems).

The H.E.R. Pregnancy Program underwent an impact evaluation that involved a modified photovoice approach, program data analysis, staff focus groups, stakeholder key informant interviews and surveys, and social return on investment (SROI) analysis. Program data were collected for 134 pregnancy program clients and 139 pregnancies over a 2.5 year period. For most pregnancies, clients were between 20 and 29 years (55%) and of Aboriginal descent (83%). Substance use (excluding tobacco) was recorded for 60% of client pregnancies and suspected in 16% of pregnancies.

⁵⁰ Marshall, S., Charles, G., Hare, J., Ponzetti, J., & Stokl, M. (2005). Sheways' services for substance using pregnant and parenting women: Evaluating the outcomes for infants. *Canadian Journal of Community Mental Health*, 24 (91), 19-33. p.30.

The evaluation determined that the H.E.R. Pregnancy Program was successful in helping women access social and health supports during their pregnancy. Program data demonstrated that clients were highly connected to the program; on average, pregnant women visited the program 29 times from preconception to the baby's due date. Most clients (78%) who had a second pregnancy returned to the program within the first trimester. Clients most often accessed general supports (100%), health education (94%), referrals (75%), health services (74%), and advocacy support (74%). Clients most frequently accessed the following program products: milk coupons (69%), personal incentives (e.g., food and hygiene products) (69%), bus tickets (64%), and vitamins (44%).

Evaluation data suggested that the H.E.R. Pregnancy Program helped pregnant clients to eliminate (40%) or reduce (26%) substance use or use substances more safely (37%), although increased substance use was reported for 37% of client pregnancies. Some clients (42%) reported engaging in safer sexual practices while connected with the program.

The H.E.R. Pregnancy Program also helped clients to maintain custody of their infants. Available data indicated that for over half (53%) of client pregnancies the women maintained care of their infant, 8% of pregnancies results in the baby going into the care of a family member or friend; 32% of pregnancies resulted in the baby being placed into care. Before connecting with the H.E.R. Pregnancy Program, the four women who participated in the photovoice project collectively had 14 children taken into care. Three of the four women kept their subsequent child after receiving support from the H.E.R. Pregnancy Program staff team.

While connected to the H.E.R. Pregnancy Program women reported increased feelings of empowerment (48%). In key informant interviews, staff observed and clients confirmed heightened feelings of safety and confidence in women's decisions about the outcome and care of their children. Children's Services had involvement in half (50%) of client births. In 70% of these cases, the client was involved in child placement decisions.

Program stakeholders indicated that the H.E.R. Pregnancy Program is an additional community support for women during pregnancy, as "existing prenatal services are generally offered through traditional modes of health service delivery may not be acceptable or feel welcoming to women who are deeply immersed in street culture".⁵¹ The program appears to be well integrated among existing health and social services in the community. Staff members discussed their role in bridging pregnant and parenting women toward accessing supportive health and social programs. The SROI analysis of the H.E.R. Pregnancy Program estimated that every dollar invested in the program amounts to \$8.24 in social value and entails system level costs savings related to child apprehension and foster care processes, homelessness, substance use, and treatment for sexually transmitted infections.

⁵¹ Wodinski, L., Wanke, M., & Khan, F. (2013). *Impact Evaluation of the H.E.R. Pregnancy Program – Final Summary Report*. Retrieved on March 1, 2014 from the CanFASD Research Network: <http://fasdprevention.files.wordpress.com/2014/02/her-final-summary-report-2014.pdf> p.10.

3.2 System level health interventions

Single-access programs like the H.E.R. Pregnancy Program and other similar program models represent program level, community-based strategies for addressing the social determinants of health impacting social marginalized women who may drink alcohol or use substances. While these interventions may prove successful in reducing risk for maternal alcohol consumption during pregnancy, broader system level interventions would contribute further solutions to this complex issue.

To help reduce risk of alcohol consumption during pregnancy and FASD, Tough (2010) recommends a community health perspective and system oriented approach for addressing the underlying issues of alcohol dependence more broadly.⁵² She highlights the roles multiple sectors can play in identifying and preventing risk of fetal alcohol exposure during pregnancy. For instance, child welfare monitoring may be used to identify children at risk for substance dependence later in life and introduce appropriate interventions, such as parenting programs and income, education and employment or skills training supports that would help parents overcome substance use and acquire basic needs for their families. In light of research suggesting that substance using women are more likely to come into contact with social welfare, justice and health systems, Tough argues that these sectors may offer integrated interventions to help reduce alcohol exposed pregnancies.

Given that many women have reported consuming alcohol before learning they are pregnant,⁵³ Tough (2010) emphasizes a need to provide interventions to all women before and during pregnancy. She suggests supporting physicians to have an increased role in identifying, screening and offering interventions to women who are at risk for alcohol-exposed pregnancy. A low cost option might involve yearly physician administrated prenatal alcohol-exposure clinical interviews or routine screening assessments for all women, rather than just those who are pregnant. In addition, Tough asserts that women should receive consistent messages about maternal alcohol consumption during pregnancy in a variety of contexts, such as when couples obtain a marriage licence, new home warranty and mortgage.

Three additional documents emerged from a literature search of evidence based, system wide strategies to address the social determinants of health in general. Petticrew et al. (2009) reviewed a collection of systematic reviews and primary studies of health interventions across sectors (i.e., health and social services, unemployment and welfare, housing, education, and others) in OECD countries.⁵⁴ Selected housing interventions to promote mixed housing, housing mobility policies and improved housing conditions appear to improve health and healthy behaviours, but further research is needed to validate these outcomes. Work environment interventions that aimed to increase employee job control and

⁵² Tough, S. (2010). Dispelling myths and developing a framework for reducing the risk of alcohol-exposed pregnancies. *Forum on Public Policy, 1, Special section p1.*

⁵³ Ibid. p.7.

⁵⁴ Petticrew, M., Bambra, C., Gibson, M., Sowden, A., Whitehead, M., & Wright, K. (2009). Tackling the wider social determinants of health and health inequalities: Evidence from systematic reviews. *Journal of Epidemiology and Community Health, 64*, 284-91.

work-life balance and introduce smoking bans and safety prevention legislation helped to improve mental health and healthy behaviours and reduce injury among workers. In contrast, organizational privatization that could result in job insecurity and unemployment negatively impacted employee mental health. Welfare rights interventions and supported employment programming did not yield outcomes pertaining to health. Culturally sensitive health care interventions did not result in improved health outcomes; however, outreach health services which aimed to increase patient access to care did positively influence health outcomes. Agricultural and food security interventions which aimed to increase availability of health foods did not have an effect on health outcomes. Petticrew et al. did not find any systematic reviews or studies of educational interventions to improve adult health.

The authors conclude that evidence for social determinant health interventions is somewhat limited, particularly in relation to outcomes among different social groups; however, there is preliminary evidence to suggest that housing and employment interventions positively influence health inequalities. Thus, housing and employment represent two key areas where health interventions may have the greatest impact on reducing inequalities and require further research and evaluation efforts.

In addition to Petticrew et al.'s work, the National Collaborating Centre for Determinants (2012) conducted a systematic review of intersectoral actions to address social determinants of health and health inequalities.⁵⁵ The review brings together key outcomes of 17 intersectoral initiatives that ranged according to:

- Approach (i.e. universal programming vs. unique programming for specific groups);
- Populations served (i.e., socioeconomically disadvantaged individuals and communities, racialized groups, refugee and/or immigrant populations, Aboriginal communities, and people with disabilities);
- Intervention setting (i.e., community, school or workplace locations); and,
- Intervention level (i.e., upstream, midstream or downstream).

Upstream interventions include “reform of fundamental social and economic structures and involve mechanisms for the redistribution of wealth, power, opportunities, and decision-making capacities” and “typically involve structural and system-level changes”.⁵⁶ The systematic review included two upstream interventions occurring in the fields of housing and employment. The review also included eight midstream interventions involving “employment and working conditions, early childhood development, housing, physical and social environments, and food security”.⁵⁷ These initiatives took place at the community or organizational level and aim to reduce risky behaviours and improve health in relation to

⁵⁵ National Collaborating Centre for Determinants of Health. (2012). *Assessing the impact and effectiveness of intersectoral action on the determinants of health and health equity: An expedited systematic review*. Antigonish, NS: National Collaborating Centre for Determinants of Health, St. Francis Xavier University. Retrieved from: http://nccdh.ca/images/uploads/ISA_Report_EN1.pdf

⁵⁶ Ibid. p.6.

⁵⁷ Ibid. p.10.

living and working conditions. The seven downstream interventions included in the review sought change at the individual or micro level by increasing access to health care services.

All interventions included in the systematic review emphasized intersectoral action between the public health sector and “governmental and non-governmental sectors outside of health”.⁵⁸ Various groups participated in social determinant of health interventions, including primary care providers, academia, nonprofit agencies, teaching and training personnel, coalition groups, advisory councils, as well as community partners and organizations.

The systematic review described a number of tools and strategies used for initiating and implementing intersectoral actions to address the social determinants of health.⁵⁹ These mechanisms comprised of written agreements between interagency partnerships; meetings with stakeholders, community members, and program partners; leadership personnel to help champion key messages and changes in policy or legislation; working committee or advisory groups; partnerships with academics and research institutions to facilitate initiative research and evaluation, and building from the initiatives of existing partnerships or programs. According to the authors, none of the reviewed studies provided evidence to suggest the effectiveness of these strategies.

The authors comment that “upstream or structural interventions are likely to have the greatest impact in terms of reducing health inequities because they change the underlying conditions in which people live, work, and play”; however, the two reviewed upstream initiatives had either moderate or no effect on the social determinants of health in the targeted populations.⁶⁰ In contrast, several midstream interventions appeared positively impact social determinants of health and health inequities (i.e., efforts to improve employment supports and working conditions; early childhood interventions; policies which aim to access to healthy foods in low-income groups; and, school-based obesity prevention programming). Moderate health impacts were documented for downstream interventions; in particular, initiatives which aimed to increase health care access, reduce emergency visits and improve personal management of health conditions.

The authors conclude that the effects of the reviewed intersectoral initiatives to improve health outcomes are moderate and further research is needed to determine health equity differences between socioeconomically disadvantaged and more privileged populations.⁶¹ There is also a dearth of information pertaining to system level interventions that might reduce health inequalities in different settings (i.e., schools and workplaces) and regions.

⁵⁸ National Collaborating Centre for Determinants of Health. (2012). *Assessing the impact and effectiveness of intersectoral action on the determinants of health and health equity: An expedited systematic review*. Antigonish, NS: National Collaborating Centre for Determinants of Health, St. Francis Xavier University. Retrieved from: http://nccdh.ca/images/uploads/ISA_Report_EN1.pdf. p.2.

⁵⁹ Ibid.

⁶⁰ Ibid. p.18.

⁶¹ Ibid.

In 2008, the National Treatment Strategy Working Group developed a system oriented framework to help address substance use in Canada.⁶² This key document has been included in the Yukon FASD Prevention Gap Analysis supplementary literature search because it emphasizes the importance of intersectoral collaboration to address the social determinants of health in substance use treatment and prevention efforts. The framework describes the complex and interacting nature of sociostructural factors (i.e., stigma and discrimination, housing instability, inability to access to basic needs, experiences with violence and intergenerational trauma) and sociodemographic characteristics (i.e., ethnicity, gender, parenting status, and location) in patterns of substance use.

Drawing on similar models implemented in other jurisdictions (i.e., Quebec, United Kingdom and Australia), the framework presents a tiered model of services and supports that involves multiple systems to help address substance use problems in Canada. The model consists of a continuum of services and supports across five tiers:

- Tier One services and supports exist at the community-level and may be accessed by all individuals, families, and communities.
- Tier Two services and supports consist of brief interventions and referrals from service providers in a range of sectors (i.e., primary care, public health, social services, and community mental health). Tier Two services focus on early interventions for people who use substances.
- Tier Three services and supports consist of emergency services, standardized assessments and referrals, and treatment programs for people who currently use substances and are at risk for further harms (i.e., illness or victimization).
- Tier Four services and supports are designed to be more intensive than those provided in Tier Three and may draw on expertise from multidisciplinary teams.
- Tier Five services and supports target individuals with “highly acute, highly chronic and highly complex substance use and other problems, for whom lower-tier services and supports are inadequate”.⁶³

In the recommendations section of the framework, the National Treatment Strategy Working Group articulates that service users should be able to access support in all sectors and each tier. In addition, the model emphasizes the importance of “intersectoral collaboration and co-ordination in planning and delivering services and support, including the development of shared service protocols, agreed service and support pathways, and interdisciplinary, collaborative models of service delivery”.⁶⁴

⁶² National Treatment Strategy Working Group. (2008). *A systems approach to substance use in Canada: Recommendations for a national treatment strategy*. Ottawa: National Framework for Action to Reduce the Harms Associated with Alcohol and other Drugs and Substances in Canada. Retrieved from: <http://www.nts-snt.ca/2012%20Document%20Library/nts-systems-approach-substance-abuse-canada-2008-en.pdf>

⁶³ Ibid. p.19.

⁶⁴ Ibid. p.22.

4. Conclusion

What is clear from the above literature is the need to consider complex patterns of sociodemographic and sociostructural phenomena that influence maternal alcohol use during pregnancy. Our understanding of the lives of women who give birth to children with FASD lies in the intersection of personal history and social circumstance. In addition, there does not appear to be a single category of women who are more likely to consume alcohol during pregnancy; rather, many women with varying personal histories and socioeconomic backgrounds engage in this behaviour.

The existing literature on the effectiveness of intersectoral action to address social determinant of health seems to be fairly limited, yet researchers have voiced their support for this approach and drawn attention to the need for closer outcome monitoring and analysis of system level interventions in relation to health inequities.^{65,66,67,68} There appears to be support and opportunity for many government policy sectors beyond health (i.e., child welfare, housing, income support, education and employment) to share responsibility for public health inequality and FASD prevention and awareness.

⁶⁵ Petticrew, M., Bambra, C., Gibson, M., Sowden, A., Whitehead, M., & Wright, K. (2009). Tackling the wider social determinants of health and health inequalities: Evidence from systematic reviews. *Journal of Epidemiology and Community Health, 64*, 284-91.

⁶⁶ Ospina, M., Moga, C., Dennett, L. & Harstall, C. (2011). An overview of systematic reviews on the prevention, diagnosis, and treatment of fetal alcohol spectrum disorder. In S. Clarren, A. Salmon & E. Jonsson. (Eds.). *Prevention of fetal alcohol spectrum disorder FASD: Who is responsible?* Wiley-Blackwell.

⁶⁷ National Collaborating Centre for Determinants of Health. (2012). *Assessing the impact and effectiveness of intersectoral action on the determinants of health and health equity: An expedited systematic review*. Antigonish, NS: National Collaborating Centre for Determinants of Health, St. Francis Xavier University. Retrieved from: http://nccdh.ca/images/uploads/ISA_Report_EN1.pdf.

⁶⁸ National Treatment Strategy Working Group. (2008). *A systems approach to substance use in Canada: Recommendations for a national treatment strategy*. Ottawa: National Framework for Action to Reduce the Harms Associated with Alcohol and other Drugs and Substances in Canada. Retrieved from: <http://www.nts-snt.ca/2012%20Document%20Library/nts-systems-approach-substance-abuse-canada-2008-en.pdf>.