



Information Sheet

Women-centred approaches to the prevention of FASD

Barriers to accessing support for pregnant women and mothers with substance use problems

Women who are pregnant or mothering and who have substance use problems experience multiple barriers to accessing support to improve their health and reduce the risk of FASD in their children. These barriers are linked to broad determinants of health and require collaborative action among women with substance use problems, service providers, policy makers, and researchers. We often place the burden of FASD prevention solely on the shoulders of pregnant women. Yet research and the experiences of women and those who work with them point to the need for multi-level, multi-sectoral responses.

Barriers to treatment and other needed supports and services fall into three categories:

- 1) System-level barriers that make it difficult to develop and link comprehensive programs for health care, addictions treatment, harm reduction, housing, nutritional supports, transportation, child care, and other supports for women;
- 2) Program-level barriers, such as agency policies and practices, that make it difficult for women to access and coordinate care in their communities;
- 3) Personal and social barriers, such as negative societal attitudes and depression, that affect women's ability to identify and benefit from prevention and support services ¹.

The stigma surrounding women who are pregnant or mothering and using substances is a common thread in each of these barriers. Public discourse surrounding mothers who drink, smoke, or use drugs when they are pregnant has been fundamentally blaming, judgmental, and unsympathetic ²⁻¹⁰. These judgmental attitudes persist: the media continues to portray women with substance use problems unsympathetically ¹¹; and pregnant women who use substances are still being sent to jail in Canada ¹².

In this context of blame and shame, efforts to implement changes in policy and programs to reduce barriers to care and increase the range of supports available to women struggling with substance use problems have often been frustrated. Although effective for improving a wide range of health and social outcomes, harm reduction approaches to substance use in pregnancy have received uneven and insufficient support ¹⁰. Lack of attention at the policy level to the role of stigma, shame, cultural insensitivity and blame in perpetuating barriers to care means that services are often fragmented, operating with conflicting mandates and models of care ^{9,13,14}.

1. System level barriers

Barriers related to child welfare and mothering policy – To date, most Canadian policies and programs have underscored the dangers that women with substance use



problems pose to the health of their children, families, and communities while neglecting the wellbeing of mothers themselves. In many jurisdictions, child welfare policy is enacted in a way that positions maternal substance use as evidence of bad mothering. As a result, mothers with substance use problems are frequently denied the right to parent their children. This in turn means that women are often afraid to ask for the help they need and deserve.

Research has repeatedly demonstrated that fear of losing one's children is one of the most significant barriers pregnant women and mothers face in asking for and receiving help for substance use problems^{5,7,9,15}.

Moreover, although women who are able to bring their children to treatment with them are more likely to complete treatment and have better outcomes, few treatment programs are equipped to meet this need. As a result, while system wide attention is increasingly being directed to prevention, intervention, and support for FASD in Canada, little of this attention has been directed to assisting women in jointly accessing treatment and supporting their capacity to mother.

Service integration barriers – Women with substance use problems generally carry the burden of multiple intersecting problems, including experiences of violence and abuse in their relationships, mental health concerns, trauma, physical health problems, housing instability, social isolation and legal issues^{3,13,15}. However, programs that serve pregnant women often have narrow mandates and may even have policies that result in women being turned away based on the 'complexity' of their situation⁸. To

illustrate, most housing options for women fleeing violence will not admit women with substance use problems, and many community-based withdrawal management facilities will not admit women who are pregnant. Many facilities that come in contact with pregnant women presenting while intoxicated are unprepared to provide supportive services without displaying judgment or blame⁹. Yet homeless women, who experience the most severe substance use, medical, social/family and mental health challenges, are at higher risk for not accessing services and have poorer treatment outcomes than women with stable and safe housing¹⁶.

Many system level barriers are due to poorly integrated policies and service philosophies¹⁰. Successfully addressing these barriers will require a policy integration process that is informed by a thorough appreciation of how current policies affect women.

2. Program-level barriers

Program level barriers include agency-level capacity, structures, policies and practices that make it difficult for women to access and coordinate care in their communities¹⁷.

Service policies that create additional harms for women needing treatment and support must be addressed.

Program criteria – Many services for pregnant women and mothers with substance use problems, have long wait lists or restrictive criteria that exclude some women wishing to access care^{5,8}. For some women, programs that require 30 days of abstinence prior to admission create barriers to accessing timely support. Wait lists may make it difficult for mothers to retain custody,



as the clock related to children's attachment and placement and the clock relating to mothers' treatment and recovery are often not in synch¹⁷.

Providers are increasingly recognizing that women wishing to access prevention, treatment, harm reduction, and related supports for substance use in pregnancy may themselves have FASD. Yet treatment programs may restrict access to women who are affected by FASD. Increasing service providers' awareness of the needs and concerns of pregnant and parenting women who have FASD, including efforts to tailor programming to anticipate and accommodate the disabilities experienced by women with FASD, can reduce barriers to care and encourage retention in supportive programs¹⁸.

Service fees - In Canada, women are more likely than men to live in poverty and to work in low-wage employment¹⁹ which limits attempts at care seeking. When programs have fees, mothers with low incomes, without extended health benefits or support from social services cannot pay user fees for treatment or childcare while in treatment¹³.

Transportation costs - Travel and transportation barriers can also be problematic for women who must travel outside their communities to access services^{4,7} or who must travel through several zones within urban centres on crowded buses accompanied by children and strollers. Day treatment programs that offer support for transportation and childcare have been found to reduce barriers to mothers²⁰.

Need for pragmatic, holistic programming
– Women's pathways into and experiences

of problematic substance use and addiction are different from those of men. Gender informs "needs and expectations regarding health care services"²¹. For example, women more often than men change doctors because of dissatisfaction with the quality of doctor-patient communication²². Women with substance use problems interact with health care and welfare systems more than men, yet women are less likely to access substance use treatment⁸. Women's motivation to access care for substance use problems tends to be linked with pragmatic concerns, such as child custody, health concerns, or needs to improve their income, housing, education, or employment situation⁹. Women-centred, "one stop" services where women can work with a range of providers to create their own goals for change and access a wide range of health and social services, can be effective in supporting recovery and reducing harm from addictions²³.

Need for comprehensive, women-centred care - Substance use treatment designed for women is associated with: treatment completion, length of stay, decreased use of substances, reduced mental health symptoms, improved birth outcomes, employment, self-reported health status, and HIV risk reduction^{24,25}. Women seek comprehensive, women-only treatment for many reasons: a desire to parent and care for their child, to have a healthy pregnancy, to escape violence or abuse, to engage in healthier eating, a need for social and cultural affiliation, to access information on breast-feeding, and to access food vouchers^{4,8}. Education in coping mechanisms and practical life skills (such as nutrition,



budgeting and parenting) empowers women to focus on self-care and reduces stress²⁶. For women attending residential addictions treatment programs, post-treatment follow-up is an important component of relapse prevention that is not readily available^{16,26}. Women who attend women-only programs are more than twice as likely to complete treatment compared with women in mixed-gender programs²⁷. However, such programs are scarce in Canada.

Integrated gender and cultural competence - Gender and cultural competence are important aspects of treatment and prevention programming for pregnant women and mothers. Treatment can assist women in linking their use of substances with experiences of racism, colonization, and of discrimination as women and mothers. Culturally sensitive programs for women are scarce, and there are additional barriers for on- and off-reserve First Nations women⁹.

Provider training and awareness barriers – Outreach and treatment access is impeded when service providers are unaware of special issues and concerns faced by women with multiple barriers, such as safety, violence, and trauma issues, prenatal care, needs for care and advocacy support when interacting with child welfare systems, mental health, transportation and accessibility options, and conflicts with the criminal justice system³. Service providers (such as physicians) are in a key position to support pregnant women and mothers in accessing treatment and support, yet providers report a lack of awareness of these services and

supports²⁸. Inconsistent information on referral services, cultural insensitivity, and discontinuity of care discourage women from identifying themselves and their family to “the system”^{7,13}. Providers report they need assistance with applying harm reduction-oriented care⁹.

3. Social / personal barriers

Social support barriers – A lack of peer and spousal support increases the likelihood that women are unable to access²⁹ and remain in treatment^{4,5}. Abused pregnant women report a higher prevalence of alcohol use issues, social/family and mental health challenges¹⁶ - all of which increase isolation and barriers to care. Drug-using male partners are less likely to offer support for their partners' efforts to reduce substance use and recover from addiction¹⁶. A non-judgmental, confidential provider who instills confidence and encourages engagement in support services⁵, and supportive family, and friends are all motivations for women to seek help^{7,15,16,30}.

Fear and trust barriers – A lack of confidence in and dissatisfaction with the quality of care received are deterrents to seeking treatment^{5,9}. Women have reported receiving threats and warnings about custody loss and incarceration when they present to hospitals for treatment and are pregnant⁸. As a result, women may avoid seeking treatment, or withhold information out of fear for negative consequences that could result from disclosing a substance use problem – particularly fears their children will be apprehended^{5,7,9,15}.



Recommendations

The following recommendations to meet the service needs of pregnant women and mothers with substance use problems are proposed:

- The most important aspect of service provision is a supportive, non-judgmental environment addressing fear, stigma, misinformation, and prejudice. Training for providers in cultural competence, legal issues, FASD and other disability issues, violence and trauma issues can reduce stigma and misinformation.
- The health and safety of both children and mothers needs to be a common goal of child welfare and women's health policy. Treatment services, including shelters, need to be equipped to support and accessible to perinatal women who present while intoxicated. Efforts to keep women and children safely together by providing childcare facilities and other integrated health and social supports improves access to care, and can reduce harmful consequences of prenatal substance exposure.
- "One stop" programs that provide a comprehensive range of services (e.g. maternity care, well-baby and well-woman care, nutrition supports, mentor programs, outreach services, harm reduction, stopping the violence counselling, and family support programs) increase opportunities for women and their children to access the care they need, and provide the basis for continuity of post-treatment follow-up to reduce the risk of relapse.
- Advocacy by contact agencies and programs (prenatal and primary health care, pregnancy outreach programs, addictions treatment, harm reduction, housing, violence and trauma services, housing) is essential for continuing to draw attention to and encourage action on the unmet needs of women who use substances.
- Providing both trauma-informed and trauma-specific services, that are integrated with substance use treatment will address a key factor that prevents women from being able to reduce or stop their harmful substance use.
- Providing FASD-informed services so that treatment providers understand FASD as an invisible, neurobehavioural disability, and develop and/or review their services using an FASD-lens can improve health access and outcomes for women and their children.
- Harm reduction policies which focus on reducing substance use, reducing substance-related harms, and acknowledge women's individual agency, strengths, and choices- make engagement possible when abstinence is not desirable or attainable.
- Culturally appropriate and gender-sensitive services can offer frontline support to high-risk women; conducting regular gendered assessments of gaps, barriers to, and adequacy of treatment can increase services' reach to vulnerable groups.
- Developing efficient and collaborative referral networks (of child welfare, pregnancy programs, addictions services, housing supports, and anti-violence services) supports women to identify meaningful, realistic options for improving their wellbeing in collaboration with service providers.
- Outreach services, such as culturally-appropriate mentorship programs, supported by comprehensive referral networks can use the message of community wellness to provide support for women who are isolated socially and geographically.



Coalescing on Women and Substance Use

Linking Research, Practice and Policy

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