

# Prevention of Fetal Alcohol Spectrum Disorder: Current Canadian Efforts and Analysis of Gaps



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## Supplementary Issue: Substance Use in Pregnancy

**ABSTRACT:** Effective prevention of risky alcohol use in pregnancy involves much more than providing information about the risk of potential birth defects and developmental disabilities in children. To categorize the breadth of possible initiatives, Canadian experts have identified a four-part framework for fetal alcohol spectrum disorder (FASD) prevention: Level 1, public awareness and broad health promotion; Level 2, conversations about alcohol with women of childbearing age and their partners; Level 3, specialized support for pregnant women; and Level 4, postpartum support for new mothers. In order to describe the level of services across Canada, 50 Canadian service providers, civil servants, and researchers working in the area of FASD prevention were involved in an online Delphi survey process to create a snapshot of current FASD prevention efforts, identify gaps, and provide ideas on how to close these gaps to improve FASD prevention. Promising Canadian practices and key areas for future action are described. Overall, Canadian FASD prevention programming reflects evidence-based practices; however, there are many opportunities to improve scope and availability of these initiatives.

**KEYWORDS:** alcohol, pregnancy, fetal alcohol spectrum disorder prevention, gap analysis, Delphi survey method

**SUPPLEMENT:** Substance Use in Pregnancy

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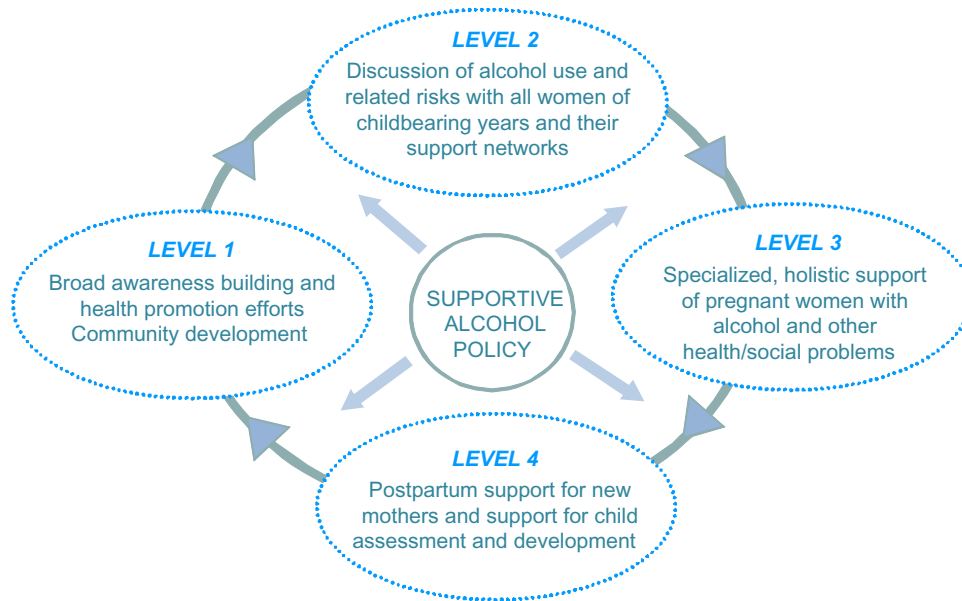
## Introduction

Fetal alcohol spectrum disorder (FASD) describes the range of harms that can result from prenatal alcohol exposure, including brain and central nervous system impairment, and concomitant cognitive, behavioral, and emotional disabilities.<sup>1</sup> FASD is the leading known cause of preventable developmental disability among Canadians, affecting approximately 1% of the Canadian population.<sup>1,2</sup> Over the past decade, Canadian health promotion and prevention specialists have been building knowledge about prevention of FASD, using multisectoral approaches tailored to the level of women's risk. To categorize this work, they have created a four-part framework of FASD prevention to capture the range of efforts required (Fig. 1),<sup>3</sup> developed in consultation with pan-Canadian prevention experts involved with the CanFASD Research Network, in a national project funded by the Public Health Agency of Canada (PHAC) in 2007/08.<sup>1</sup>

Beyond simplistic advice to not drink while pregnant, this comprehensive approach has demonstrated the benefits of helping women plan their pregnancies, obtain prenatal care, improve their nutrition, reduce stress in pregnancy, and, in some cases, access treatment. Ideally, all of these efforts,

in conjunction with alcohol policies that promote moderate use, are available and work together to contribute to improving women's health and reducing the risk of having a child affected by FASD.<sup>3</sup> However, there was no pan-Canadian picture of the state or level of services and initiatives being offered across Canada, prompting the need for the gap analysis described here.

We based our study on the four-part framework developed to organize and clarify the complex continuum of interventions involved in FASD prevention. Level 1 prevention is focused on broad awareness building and health promotion and includes prevention campaigns, pamphlets, warning signs and labels, and other forms of public education.<sup>3</sup> Such public awareness of FASD is foundational to the other levels of FASD prevention. Studies examining the effect of educational campaigns generally report increased knowledge about the effects of alcohol during pregnancy after the intervention.<sup>4–7</sup> However, this awareness does not always translate into changes in attitude or behavior.<sup>5</sup> Similarly, studies of alcohol warning labels report having moderate<sup>8</sup> to high support,<sup>9</sup> but these labels have little effect on the beliefs of risks associated with alcohol use<sup>10</sup> or changes in alcohol use.<sup>11</sup>



**Figure 1.** Four-part framework of FASD prevention.

Level 2 prevention involves collaborative discussion of alcohol use and related risks with all women of childbearing age and with their support networks.<sup>3</sup> Discussions on the available prenatal supports, contraception and pregnancy planning, and the ways to cope without alcohol are also included in Level 2 prevention, as is brief counseling.<sup>3</sup> Brief interventions (BIs) have been demonstrated to be a low-cost, effective treatment alternative to promote alcohol reduction among nondependent women and to facilitate referral to specialized alcohol treatment programs among alcohol-dependent women.<sup>12–15</sup> Interventions that include counseling on contraceptive use, in addition to alcohol, may be particularly effective in reducing the risk of alcohol-exposed pregnancies.<sup>16–23</sup> However, it has been identified that health-care providers are not consistently providing brief support on the topic of alcohol use during pregnancy,<sup>24</sup> nor are all providers aware of the evidence regarding FASD.<sup>25</sup>

Interventions offered in the preconception period to women before they are pregnant are aimed at supporting women to reduce or stop using alcohol when pregnant and avoiding alcohol when trying to conceive. Most of these interventions reflect methods that are similar to Level 2 interventions, such as BIs, and are considered a subcategory of Level 2 in the four-part framework. While preconception care and planning for the pregnancy are associated with lower self-reported alcohol use during pregnancy,<sup>26,27</sup> the majority of women do not receive such preconception interventions.<sup>27</sup>

Level 3 prevention is designed to reach women and girls at highest risk for alcohol-exposed pregnancy.<sup>3</sup> It can be provided through outreach and *one-stop* drop-in services and/or through a network of community-based services. Research in this area has found that intensive interventions, such as case management, can successfully reduce alcohol use in pregnancy

and improve maternal and fetal outcomes.<sup>28,29</sup> Using trauma-informed and harm reduction approaches<sup>30,31</sup> to overcome pervasive stigma and other barriers to service access is critical to this level of FASD prevention.<sup>32</sup> Interventions that address social and environmental factors that affect a woman’s ability to attend treatment (eg, housing, childcare, and transportation) tend to be more effective in engaging women with services. There is evidence for improved outcomes for mothers and infants when accessible, women-centered, substance use treatment is offered, in conjunction with prenatal care, for pregnant women who are willing to engage in treatment.<sup>31</sup>

Level 4 prevention involves postpartum support for mothers with alcohol problems. These services support new mothers to maintain the changes they have been able to make during pregnancy, and/or to begin to make changes in cases where women were unable to reduce their substance use during pregnancy.<sup>3</sup> Nurse home visiting and long-term paraprofessional advocacy or mentorship interventions such as the Parent–Child Assistance Program (PCAP) are examples of evidence-based postpartum interventions. Studies suggest that home visitation can impact outcomes such as decreased alcohol use,<sup>33–35</sup> increased treatment completion,<sup>33</sup> increased housing stability,<sup>34</sup> and decreased rates of maternal incarceration.<sup>34</sup> Women who engage with mentorship programs have demonstrated a reduced risk of future alcohol-exposed pregnancy, as a result of decreased alcohol use and increased family planning methods.<sup>33,34</sup>

The goals of this study were to draw a picture of current FASD prevention efforts in Canada. In particular, we wanted to identify current promising FASD prevention efforts in each of the four levels outlined in the framework, determine gaps relative to evidence-based practice, and promote reflection by experts on how to close the gap between promising practice and



current practice. To reach these goals, we employed a structured group communication process to extend the currently available evidence in the academic literature. This process structured and distilled the wisdom and informed judgment<sup>36,37</sup> of Canadian experts working at various levels in the field of FASD prevention to create a set of agreed-upon policy solutions for moving FASD prevention efforts forward.

## Methods

The study had two components: (1) a scoping review of academic literature to provide an evidence base for FASD prevention interventions and (2) a structured group communication process (gap analysis) with Canadian experts working in the area of FASD prevention. This article reports primarily on the results of the gap analysis.

**Scoping review.** A scoping literature review, guided by the five-step framework outlined by Arksey and O'Malley,<sup>38</sup> was used to identify and summarize recent evidence related to FASD prevention. The following databases were searched for articles published between January 2004 and August 2014: Academic Search Complete, Bibliography of Native North Americans, Family and Society Studies Worldwide, Cumulative Index of Nursing and Allied Health Literature (CINAHL), MEDLINE, PsycINFO, Social Work Abstracts, and Women's Studies International. All searches were limited to peer-reviewed articles published in English and with human subjects. We located 2,248 references, and after excluding duplicates and screening the titles for relevance, a sample of 114 papers remained. Each abstract was then read and screened for inclusion independently by two reviewers (RAS and NH). Our final sample included 58 papers. As the goal was to summarize all available evidence, and typical of scoping reviews, we did not formally assess the quality of the included studies.<sup>39</sup> The data were extracted in Microsoft Excel including the following information: a summary of the paper, the study population, the type of intervention, outcome measures, the study design, limitations of the study noted by the authors, and suggested directions for future research. The research team discussed the data extraction and identified themes in the existing literature and gaps in available evidence. The data extraction was then narratively summarized to form the basis of the first round of data collection for the gap analysis (described below).

**Delphi gap analysis.** The Delphi survey method was used to involve expert advisors working in the field of FASD prevention in Canada in reflection and consensus building through an iterative process, involving multiple rounds of data collection and analysis interspersed with feedback.<sup>37,40</sup> This technique is a way to structure and process information gathered from experts and is beneficial when the goal of a project is improving the understanding of a problem, as well as investigating the solutions for the problem.<sup>36,37</sup> This study involved three rounds of data collection. After consenting to participate, the participants (1) completed an online survey

about current prevention efforts in the Canadian framework categories, (2) ranked and provided feedback on an overview of the preliminary findings, and (3) provided feedback on a written summary of the results of the previous two rounds and final recommendations for moving prevention efforts forward. The study received ethics approval from the University of British Columbia's Office of Research Ethics.

The first round of a Delphi process typically begins with an open-ended questionnaire, and the results of this questionnaire are used to develop the second more structured questionnaire.<sup>41</sup> In some cases, particularly when there are condensed timelines, such as the present study, a structured questionnaire based on a literature review is used instead of having an open-ended first round.<sup>41</sup> After reading a summary of evidence on current evidence-based practice from the academic literature, based on the results of the scoping review described above, participants answered questions on current program responses in their region, their opinions of gaps in programming and knowledge, and suggestions for improvements. The survey was completed online using a secure web survey application and used a combination of an open-ended, yes/no, and five-point Likert-style questions. In the second online survey, participants were asked to rate the lists of barriers and opportunities (on a scale of 1–5) on their relative importance to understanding FASD prevention in Canada. Participants were also presented with a table describing approaches for each level of prevention and asked to indicate their agreement or disagreement with each approach. The materials in round two were created by summarizing the responses from round one. For the third round of data collection, participants received a summary of the scan of available prevention efforts in their region (as indicated in round 1) and a narrative summary of recommended approaches (compiled from the previous two rounds). Both documents were provided for participants to make further clarifications, suggestions, and comments.

**Data analysis.** Open-ended responses and comments from survey one and two were thematically coded using the qualitative data analysis software NVivo 8. Major themes related to barriers and opportunities for each level of prevention and recommended approaches for moving forward FASD prevention in Canada were identified. Three consolidated lists were created; duplicate responses were removed and ideas, language, and terminology were combined across the responses. A qualitative summary of the current prevention efforts across Canada was also created. Frequency tables for all dichotomous and the Likert-style responses were created.

In round two, the proportion of participants agreeing with each approach was calculated, and more than 75% agreement was considered consensus.<sup>42</sup> For each barrier and opportunity, the median and interquartile range (IQR) of each item's ranking were determined. An IQR of one or less is found to be a suitable consensus indicator for 4- or 5-unit scales,<sup>42</sup> indicating



that at least 50% of the responses are within one point on the scale. All quantitative analyses were conducted in SPSS 23.

The third round of data analysis was qualitative only. Typically, the final round of a Delphi methodology would ask the participants to rerate any item that did not reach a convergence of opinion,<sup>37</sup> but due to the time constraints of the participants, we opted to focus the third round of data collection on refining the recommended approaches for moving forward that had already reached at least 75% agreement. Comments on the scan of services were incorporated into the table, and suggestions and additional recommendations were incorporated into the recommended approaches.

**Participants.** Invitation letters were sent to 50 potential participants. Federal civil servants working in nine regional offices of the PHAC were asked to identify three representatives working in the area of FASD prevention from their region of Canada who worked as: (1) a researcher or evaluation expert, (2) a health practitioner from the health care or addiction field, and (3) a community-based service provider. Participants were required to have expertise in the field of FASD prevention, which was defined as “having knowledge and practical engagement with the issue under investigation”.<sup>36</sup> The PHAC regional consultants were chosen to identify participants as they were deemed to be consistently knowledgeable about the experts working in their region and to ensure that participants were identified from all regions of Canada. In addition to these invited participants, PHAC regional consultants and 14 members of the Prevention Network Action Team (NAT) of the CanFASD Research Network were invited to participate in the Delphi survey process. Thirty-six participants agreed to participate (72% response rate). Table 1 indicates the response rate and provinces represented by the panelists in each round of data collection.

The ability of participants to participate in an asynchronous manner is an important feature of the Delphi method, as it allows experts to choose to participate when they feel they want to, and they may choose to contribute to the aspects for which they feel most qualified.<sup>36</sup> As such, all participants were sent all rounds of data collection, even if a participant did not complete the previous round. Despite this, our response rate decreased over subsequent rounds of data collection. The potential for low response rates, particularly as there are multiple rounds of feedback required for participants, is an identified limitation of the Delphi method.<sup>40,41</sup> Participants identified by the PHAC consultants were most likely to complete all three rounds of data collection (62%, compared with 38% of PHAC consultants and 33% of NAT members).

## Results

In the first survey, participants were asked to indicate their perceived level of importance (on a scale of 1–5) of each level of prevention. Most indicated that they thought every level was “very important”; however, slightly more indicated that Level

1 was “somewhat not important,” “somewhat important”, or they were “neutral” compared with every other level, indicating slightly less perceived importance for general awareness raising. Compared with all the other levels of prevention, the highest percentage of participants (97%) saw Level 3 prevention as “very important” in the prevention of FASD (Fig. 2). Note that in each round of data collection questions on preconception interventions were included as a subset of Level 2. As many of the themes that emerged from Level 2 and preconception were the same, the results have been combined in the sections below. However, in the first survey, participants were asked to rate the perceived level of importance for preconception interventions, and as such, it is reported as a distinct category in Figure 2.

**Current prevention efforts.** This section summarizes the trends in prevention efforts in Canada that participants reviewed in the third round of data collection, which was informed by the responses in round one. Results of the quantitative questions asked in round one are also incorporated in these summaries.

*Level 1.* All provinces and territories represented in the study have undertaken awareness raising activities. Primarily, these activities involved the creation and distribution of posters or pamphlets. Billboard, radio and TV advertisements, workshops for youth, and targeted presentations were reported less often, and in fewer provinces. In some regions, prevention materials have been distributed through partnerships with governmental liquor distribution branches with a social responsibility mandate. Alcohol warning labels on bottles are not in place in any jurisdiction covered in the gap analysis. However, there are other warning initiatives (eg, warning signs at licensed establishments) in some areas of Canada. The majority of participants (84%) saw value in consolidating efforts for FASD awareness campaigns, rather than each jurisdiction developing their own. Most participants saw how these materials if developed, could then be adapted to local contexts.

*Level 2.* Screening, brief intervention, and referral (SBIR) is not provided universally or systematically in any area of Canada. BI activities are commonly undertaken by care providers such as physicians, midwives, nurse practitioners, and public health nurses, but can also be provided by practitioners delivering mental health and addiction, violence, and sexual health services. Participants identified that SBIR on alcohol and pregnancy was not a routine practice among most medical professionals. Participants identified a few specific practices designed to identify and support women who were using alcohol, but less than half of the participants (40%) identified practices in places that identify and support particular subgroups of women or girls in their region. An exception was Project CHOICES in Manitoba, a BI program for young women who are sexually active, using substances and currently not pregnant. Project CHOICES focuses on decreased alcohol consumption as well as increased contraceptive use using an evidence-based motivational interviewing

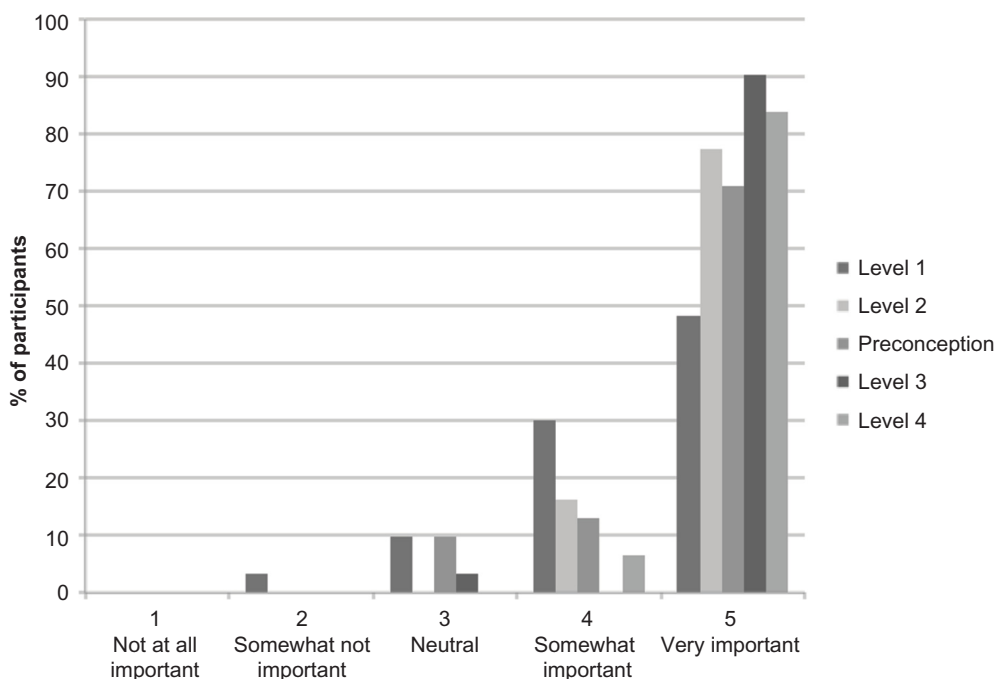
**Table 1.** Participants in each round of data collection, by province.

	INVITED	CONSENT	ROUND 1	ROUND 2		ROUND 3	
			ONLINE SURVEY	RECOMMENDED APPROACHES	BARRIERS AND OPPORTUNITIES	PROVINCIAL SCAN	RECOMMENDED APPROACHES
Alberta	5	4	4	2	3	3	3
BC	10	8	6	4	6	2	2
Manitoba	6	4	4	1	2	2	1
New Brunswick	1	1	1	1	1	1	1
Nova Scotia	4	4	4	3	3	1	1
Newfoundland	2	2	2	0	0	0	0
NWT	2	1	1	0	0	0	0
Nunavut	2	0	0	0	0	0	0
Ontario	5	5	4	3	4	2	1
PEI	1	1	0	0	0	0	0
Quebec	5	2	1	1	1	1	1
Saskatchewan	4	3	3	3	3	3	1
Yukon	3	1	1	1	1	1	1
Total	50	36	31	19	24	18	13

approach. The majority of participants (84%) could identify some education or training initiatives for health-care providers on having empowering conversations about alcohol use, which had been offered in their region. However, it was emphasized how rare and how important it is to follow-up on such educational initiatives, to determine the extent and effectiveness of application to practice.

*Level 3.* The widely available Community Action Program for Children (CAPC), Canada Prenatal Nutrition Program

(CPNP), and Aboriginal Head Start (AHS) deliver community-based programs to many vulnerable pregnant women and families across Canada. However, it was unclear to the participants to what extent these three programs include alcohol education and support, as it is not an explicit focus of any of these programs. In some communities, PCAPs, which are evidence-based services, that involve flexible, personal, and intensive case management by paraprofessional mentors<sup>33,35</sup> work with vulnerable mothers both before and after they give



**Figure 2.** Perceived importance of each level of intervention to prevent FASD.



birth, supporting connection to a service support network as well as abstinence from alcohol.

A few specialized programs for high-risk pregnant women with alcohol problems and related health and social concerns were identified, largely in large cities. Some provide outreach services, some offer drop-in programs, and some a combination of these approaches. Their key feature is to focus on the full range of determinants of health, using trauma-informed, harm reduction-oriented, and culturally relevant approaches. This specialized programming also brings a focus to support the mother-child unit.

Across the country, it was identified that pregnant women are given priority access to substance use treatment, yet this priority access does not translate into tailored treatment for pregnant women. The lack of access to gender-responsive and pregnancy-focused substance use treatment across the country was seen as a significant gap in services. Additionally, participants noted that access to treatment is very challenging for women who live in rural areas, because of the expectation that they will leave their family and children and travel to attend treatment. It was reported that gender-specific substance use treatment was not available for women in two jurisdictions, and in fact, only a handful of addiction treatment programs tailored for pregnant women and mothers with young children could be identified across the country.

*Level 4.* Despite the perceived importance of Level 4 services, access to postpartum interventions and support for new mothers with alcohol problems varies greatly across the country. The specialized Level 3 services located in large cities often support women and children until the children are aged 18 months to 3 years. The PCAPs available in five provinces play a significant role in supporting vulnerable mothers and their children, with a focus on advocacy and supporting connection to a range of needed services. Home visitation programs were identified in several jurisdictions, although it was noted that these did not have a specific focus on alcohol use.

**Barriers and opportunities.** This section summarizes the barriers and opportunities that in round two of data collection received a median rating of 4 (somewhat a barrier or opportunity) or 5 (very much a barrier or opportunity) and had an IQR of one or less, meaning at least half of the responses were within 1 point on the scale, which indicates a convergence of the participant's opinions.

*Level 1.* Among other barriers, participants noted the challenge arising from the conflicting messages in the media about the safety of consuming alcohol during pregnancy and the effects of moderate consumption, and how these conflicting messages can cause women and practitioners to doubt the overall messaging about the risk of alcohol use in pregnancy. They also noted concerns about how awareness campaigns can contribute to the further stigmatizing and isolating (the *othering*) of mothers who use substances, by exaggerating risk, focusing on fetal harm, using exploitative imagery, and not identifying how women can access nonjudgmental support.

While respondents saw general awareness campaigns as important to undertake as part of a comprehensive approach to FASD prevention, they underlined the challenges of creating messaging that is respectful of women, can encourage friends and family to provide support to pregnant women and women of childbearing age who drink alcohol, and can be tailored as needed to young women and men, and for specific contexts.

*Level 2.* Participants identified that women often do not feel safe about disclosing their use of alcohol out of fear of judgment by health providers and of child removal by child welfare authorities. Participants also identified the barrier that service providers may lack the skills and confidence to effectively converse with women about alcohol and to connect women to needed services. Participants were concerned that screening and discussion of alcohol is not conducted systematically and that typically only women who are perceived to be at high risk are screened. This constellation of barriers was also seen as an important opportunity to enhance FASD prevention, since women are receptive to support from health-care providers and evidence-based approaches to identification, BI, and support are available for uptake. Participants also agreed that a key barrier (and opportunity for uptake) for effective alcohol interventions with women *planning* to become pregnant is the lack of emphasis and guidelines on preconception care.

*Level 3.* There was strong consensus among participants that there is insufficient capacity for holistic, tailored Level 3 type programming to meet the support and treatment needs for pregnant girls and women at highest risk. Limited resources for these programs, including limited funding, space, and professional staff, were rated as a significant barrier. Other barriers for women accessing Level 3 services included the fear of involvement of child protection and the lack of access to safe and affordable housing, which could impede the ability to address all other issues, including those related to substance use. Participants agreed it was a barrier that there are currently limited supports available for women who themselves have FASD and consequently are at higher risk for having an alcohol-exposed pregnancy and not effectively engaging with services. At the same time, program evaluations support the positive impact of these multifaceted interventions. It was seen as an opportunity that these services work from a framework of harm reduction where small steps are considered successes, which can contribute to the self-efficacy of the women accessing services. Participants also agreed that efforts could be made to connect the already existing services to provide more comprehensive care.

*Level 4.* Participants agreed that the barriers to access Level 4 programs were very significant, including fear of losing custody of children, existing systemic barriers to accessing supports (eg, lack of affordable housing, childcare, and transportation), fear of self-identifying as someone who had an alcohol-exposed pregnancy, and lack of trust in the service system by women who had had very difficult lives. It was agreed that lack of continuing support for women between



Level 3 and Level 4 interventions added to the challenges. Participants agreed that there is currently a lack of understanding of the benefits of such programs among service providers and limited understanding on the part of policy makers as to their cost savings and return on investment. Furthermore, participants agreed that there is limited understanding that some women who have alcohol-exposed pregnancies themselves have FASD, and few Level 4 programs are tailored to their needs (are FASD informed). There was a strong agreement that Level 4 services are well positioned to work with women who may be mistrustful of health-care providers and respond in a tailored and trauma-informed way. Participants agreed on the opportunities provided by Level 4 interventions as: tailoring services to the specific needs of each woman; interventions that can increase social support; and those that both help women reduce the need for child welfare involvement and support early attachment and positive mothering experiences.

**Recommended approaches.** Table 2 includes all the promising strategies that received at least 75% agreement from the participants in round two of the survey process. The next section summarizes the key themes of these promising strategies and reflects the input that the participants provided on the summary created for round three.

*Level 1 – coordination, clarification, innovation, and beyond pregnancy.* Level 1 prevention efforts build general awareness and are foundational to all other levels of prevention. However, Level 1 prevention needs to take on the challenge of reducing the powerful stigma attached to alcohol use during pregnancy, create overall evidence-informed messaging, and, in some cases, tailor messaging to subgroups. Broad awareness campaigns can be expensive, and current efforts are not nationally coordinated. The survey respondents made recommendations related to overall messaging, both broad and narrow campaigns, tailored educational initiatives that allow for education within the agency context, and for coordination.

For example, when designing campaigns, respondents noted it is important to incorporate the gendered pressures to drink alcohol and suggest remedial action that may empower girls and women. Many participants noted how challenging this is to achieve in campaigns. Other suggestions for improving Level 1 prevention included: providing information within campaigns about how to access support; learning from successful public health campaigns on related health issues such as those on sexually transmitted infection prevention; focusing on low-risk drinking by women's overall (not only in pregnancy); and linking broad campaigns to simultaneous educational work with professional organizations so that increased awareness is matched with increased responsiveness.

*Level 2 – facilitation, coordination, barrier reduction, and improving evidence.* Level 2 prevention refers to BIs by a wide range of professionals and paraprofessionals, with all women on issues related to alcohol use and pregnancy. Educational work with physicians and other health and social care

**Table 2.** Proportion of participants agreeing with recommended approach for each level of FASD prevention.

PROMISING STRATEGY	AGREEMENT (%)
<b>Level 1</b>	
Recognize and address the pressures on girls to drink when designing campaigns, so girls and women are empowered to negotiate social pressure.	100.0
Build in and tailor FASD education in service delivery models of agencies working on justice, substance use, disability, shelter, and women's health.	100.0
Make available resources designed to provide practical assistance to health care service providers with the aim of increasing their capacity to discuss alcohol use with women.	100.0
Create campaigns that do not stigmatize, focus on negative/what not to do, nor have an "anti mothering in there approach" when doing FASD prevention messaging.	100.0
Use blogs and other social media mechanisms to provide information on FASD and alcohol use.	94.7
Offer campaigns that provide simple facts and ways to seek support, include a call to action and where to go for further information.	89.5
Have positive focus to campaigns. Eg Focus broadly on healthy pregnancies, include ideas such as making mocktails.	89.5
Support small, community based, grassroots campaigns, as well as the broad ones.	89.5
Support campaigns designed by and for high school and university students.	89.5
Design campaigns aimed at girls and women in preconception period that are linked to birth control.	89.5
Use provincial or national groups to coordinate the development and follow-up of resources.	88.9
Partner with liquor distribution branches to support awareness – especially if the materials are developed collaboratively with FASD prevention experts.	84.2
Offer province-wide campaign strategies employing multiple tools – bus ads, signage for restaurants, posters, TV ads, magazines, brochures etc.	84.2
Offer longer-term campaigns (eg not just in September/around September 9).	84.2
Use online learning including sessions on women's health and substance use and FASD prevention.	84.2
Create bystander campaigns, and use messages that engage women in supporting each other.	78.9
Have a national campaign with the option to make it regionally specific.	78.9
Expand the use of Low Risk Drinking Guidelines to educate about alcohol overall, to raise awareness about the risks of alcohol to women's health outside of pregnancy and lessen the risk for those who have unplanned pregnancies.	78.9
Use face-to-face methods involving people with lived experience such as conferences, workshops, and open discussions with youth.	78.9

(Continued)



Table 2. (Continued)

PROMISING STRATEGY	AGREEMENT (%)
<b>Level 2</b>	
Work with physicians on SBIR (eg make available standard drink examples, develop an educational PowerPoint for health and social service providers that provides evidence and methods for universal screening, offer ongoing teaching of BI strategies such as MI).	100.0
Include information on women and alcohol into Alcohol, Mental Health and Addictions and Sexual Violence Strategies.	100.0
Use preconception approach's that pair alcohol use screening, MI and birth control counseling together to make an impact on alcohol exposed pregnancies.	100.0
Modify CAPC and CPNP programs to include education on alcohol during pregnancy in a nonjudgmental way, providing support to the participants in the program.	100.0
Offer curricula in professional education contexts (nursing schools, medical schools, etc.) on FASD and SBRI.	94.7
Increase use of Indigenous approaches (eg, encourage empowering conversations done by Elders.)	94.1
Use gender-specific university and college campus programs to improve the response to mental health and substance use concerns for students.	83.3
<b>Level 3</b>	
In smaller communities have outreach programs to assist women to access services.	100.0
Link through formal partnerships: a) programs for pregnant women with substance use problems, b) trauma-informed addiction treatment for mothers and c) child welfare.	100.0
Provide intensive, individualized support to women who are living in conditions of risk, offered by workers who are able to address basic needs of women and are trained to provide strength based, FASD and trauma informed service.	100.0
Use a relational approach that links child mental health programming with women's and children's programming.	94.7
Expand linkages of hospital delivery programs with substance use treatment programs and community-based programs.	94.7
Expand access to one stop, holistic, harm reduction oriented program.	94.4
Offer substance use treatment for pregnant women who may have FASD themselves.	84.2
Offer more women specific substance use treatment.	78.9
<b>Level 4</b>	
Offer PCAP and other mentoring programs that support women and children at the community level to access the supports they need over an extended period.	100.0
Expand programs that focus on infant attachment, child development and parenting.	100.0
Expand home visitation programs for mothers and fathers to learn health and attachment skills.	94.7

(Continued)

Table 2. (Continued)

PROMISING STRATEGY	AGREEMENT (%)
Link multiple levels of prevention.	89.5
Develop additional outpatient counseling or day treatment programs that work with mothers/families that include programming for children, child care, and a focus on recovery and parenting.	86.7

providers on SBIR was seen as essential, requiring considerable commitment and facilitation by professional bodies, educational institutions, and governments. Sample *conversation starters* and tools such as standard drink size examples could make this more concrete and doable for health-care providers. Given the highly stigmatized nature of this topic, training in motivational interviewing and working in a trauma-informed way are important to support this screening and identification, so that they are done through collaborative and safe discussions. Participants agreed that there is significant opportunity for pairing advice on low-risk drinking and birth control counseling, to reduce alcohol-exposed pregnancies. All in all, the need is to better understand the barriers and opportunities to enhance uptake of BIs on alcohol and pregnancy and proactively identify specific strategies for addressing these.

*Level 3 – consolidation, collaboration, and cooperation.* Level 3 prevention is designed to reach and support women at high risk of drinking heavily, before and during pregnancy, and in the postpartum and interconception periods. Level 3 alcohol preventative interventions are delivered in a range of settings, usually integrated with interventions on related health and social issues.

Participants commented on various models for delivering this type of programming. In urban centers, it was felt that access to one-stop, holistic, harm reduction-oriented programs, such as Sheway in Vancouver, HerWay Home in Victoria, Breaking the Cycle in Toronto, Maxxine Wright in Surrey, The Mothering Project in Winnipeg, and the HER Program in Edmonton enact evidence-based practice. In smaller communities, outreach programming, linked services, and PCAP programming can be used to reach and support pregnant women with multiple burdens. Strengthening the linkage of community programming with women's addiction treatment, supportive child welfare policy, and innovative hospital delivery programs was seen as important. Whether formal or informal, these linkages between service types have the potential to form a key net of support for positive change and recovery. Training for health professionals on trauma-informed, gender transformative, and FASD-informed approaches would increase the sensitivity and effectiveness of maternity care. Women-centered addiction treatment is a critical gap in the work to prevent FASD, and more substance use treatment programs tailored to the needs of pregnant women and mothers are needed in Canada.





*Level 4 – extension, coordination, and evaluation.* To support women and children postpartum, participants saw the relevance of programs that support women and children at the community level. At the same time, it was noted that there is a need to eliminate the limits on participation (eg, age and number of pregnancies) that typically accompany these programs. Mother–child and early years programs that focus on the mother’s health and resilience, child health and resilience, and supporting mother–child relationship (parenting and attachment) are critically important,<sup>43</sup> and the evidence base for such programming needs to be expanded. More addiction outpatient counseling and day treatment programs that work with mothers/families, which include programming for children, childcare, and a focus on recovery and parenting, are needed. Participants thought that it was important to link all levels of support, from awareness to Level 4 programming.

## Discussion

Canada has made considerable contributions to the understanding of and action on FASD prevention over the past decade. This project confirmed the usefulness of the four-level framework identified by Canadian leaders in FASD prevention for organizing the complex continuum of interventions involved in FASD prevention. The multisectoral participants in this study identified many initiatives underway at all levels of prevention.

And yet significant barriers remain to a coordinated, compassionate, evidence-informed, and systematic approach to prevention tailored to the needs of women at differing levels of risk and their families. For example, women’s fear of child apprehension or lack of options for childcare can be significant barriers for disclosing, and seeking, treatment for substance use.<sup>44</sup> Key barriers relate to systemic policies such as child welfare policies that mandate reporting of alcohol use during pregnancy and act to separate children from substance using mothers at birth, as opposed to generating opportunities for engagement by wrapping support around the mother–child unit in order to strengthen parenting and attachment and support harm reduction efforts.<sup>45,46</sup> Such policies can create a climate of mistrust and fear, which may result in women being less likely to disclose alcohol use to the health-care providers or to disengage from prenatal care.<sup>47</sup> Supportive child welfare policy and protocols outlining how collaborative support can be achieved among primary care, addiction treatment, and harm reduction-oriented community-based services serving women will be important to achieving FASD prevention goals.

In this study, the importance of addressing the barriers to uptake of brief alcohol interventions with pregnant women and women who may be planning pregnancies was identified. Recommendations from the literature for increasing SBIR in primary care settings include education with medical students and residents using curriculum that incorporates the latest guidelines, recommendations, and research<sup>24</sup> and providing continuing medical education on how to overcome barriers

such as patient resistance to treatment and insufficient referral resources.<sup>25</sup> Kennedy et al.<sup>48</sup> used multiple methods including staff training and a BI protocol and decision tree to motivate staff to provide SBIR to all pregnant women in routine prenatal care. They found, after the intervention, that 77% of women who screened positive for at least one risk factor were provided a BI during their routine office visit and concluded that SBIR can be implemented effectively in prenatal care by building on existing resources and providing training and resources to staff. In systemwide implementation of alcohol BIs in Scotland, factors such as using a pragmatic, collaborative approach that fit with the context, establishing practical reporting systems, and “establishing close working relationships with frontline staff including flexible approaches to training and readily available support” were important in implementation outside of primary care.<sup>49</sup> National collaborative action with health professional bodies, such as the Women Want to Know campaign (<http://www.fare.org.au/women-want-to-know/>) done in Australia, could promote the use of BIs that use an empowering approach, sensitive to the guilt and fear of child apprehension faced by mothers who find it difficult to stop drinking alcohol when pregnant. It was stressed by respondents in this project that such SBIR approaches need to be assessed from the perspectives of both women and practitioners.

The scarcity of substance use treatment tailored to pregnant women and new mothers is another key barrier to an effective systemic approach to prevention. Women who are pregnant and who have substance use problems often face barriers such as judgment from health-care providers in a position to refer them to treatment, lack of childcare, lack of transportation, and limited family or social support, all of which limit their ability to participate in treatment.<sup>50</sup> Pregnant women who continue to use alcohol often face a number of interconnected barriers to seeking treatment, may be anxious about the attitudes of health-care providers, and overwhelmed by the involvement of multiple agencies.<sup>51,52</sup> Services for alcohol using pregnant women should integrate care from different services, be respectful, nonjudgmental, comprehensive (include prenatal support), and harm reduction oriented.<sup>3,51,52</sup> Childcare, parenting supports and classes, referral to treatment for past trauma, and assessment and treatment for underlying mood disorders are essential components to women-specific treatment.<sup>53</sup> While several model substance use treatment programs were identified in this study, such programming needs to be greatly expanded if we are to be successful in preventing alcohol-exposed pregnancies.<sup>54</sup> In addition to the expansion of treatment availability, Canadian practitioners working in all types of services that engage pregnant women and new mothers need to continue to discuss and enact service delivery principles, to ensure women-centered, trauma-informed approaches are in place to engage women and their support networks.<sup>32</sup>

Overall, the study served to promote recognition of and reflection on the extensive work being done toward prevention



of FASD across Canada. It provided the opportunity to consider how these efforts fit together, to ensure an effective continuum of effort, consistent with the evidence for effective practice. It also identified many opportunities for coordination, collaboration, consolidation, innovation, barrier reduction, improving of evidence, evaluation, and expansion of effort. These ideas are now being shared widely with funding bodies, researchers, practitioners, and policy advocates.

**Strengths and limitations.** Due to cost, time, and geographical separation, using a Delphi method made it possible to convene a group of experts for this study that would not have been possible through another type of group communication process.<sup>36</sup> Anonymity is a key feature of the Delphi method, and since the summaries did not identify who proposed which idea, participants were allowed to more freely express their judgments and opinions without social pressure often experienced in group consensus building. The anonymous nature of the Delphi process can also minimize some of the issues related to other methods of group consensus building (ie, influences of dominant individuals, and group pressure for conformity)<sup>37</sup> and facilitated collecting information from experts working at various levels of FASD prevention including federal employees, researchers, and service providers without conflicts or influencing the outcomes.

Despite the benefits of the Delphi method, it is subject to some limitations that may have impacted the results of our study. For example, the potential for low response rates, particularly as there are multiple rounds of feedback required of participants. Not all provinces, territories, or regions of the country were represented in the gap analysis. Specifically, there were no participants from Nunavut or Prince Edward Island, and there was only one participant each from New Brunswick, Quebec, NWT, and Yukon. Therefore, some regions are better described in the study than others, and it is difficult to determine if the summary of current prevention efforts is generalizable to all regions of Canada.

## Conclusion

This study aimed to draw a picture of current FASD prevention efforts in Canada, which has a mix of federal, provincial, and territorial governments, each responsible for different elements of health initiatives and public health efforts. The study combined promising practice evidence from the literature with input from experts to determine the level of activities and to identify barriers and opportunities in closing the gap between promising practices and current practices. Overall, current Canadian practices do reflect the evidence-based practices described by the research. However, services are unevenly distributed across the country and require action to improve access, availability, and integration with other areas of service delivery. There are also many opportunities identified by those in the field and in policy arenas, to improve scope and availability of education and support, and to better generate integration with other areas of health promotion and prevention.

## Author Contributions

Conceived and designed the study: NP, RAS. Analyzed the data: RAS, CG. Wrote the first draft of the manuscript: RAS. Contributed to the writing of the manuscript: NP, RAS. Agreed with manuscript results and conclusions: NP, RAS, CG, NH. Jointly developed the structure and arguments for the paper: NP, RAS. Made critical revisions and approved the final version: NH, CG. All the authors reviewed and approved the final manuscript.

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