

**THE STATE OF FASD AND ALCOHOL USE DURING PREGNANCY
PREVENTION BEFORE THE IMPLEMENTATION OF THE
DURING PREGNANCY, GO ALCOHOL FREE AWARENESS CAMPAIGN
AND ITS RELATED TOOLS**



Results and findings from surveys and in-depth interviews conducted within the perinatal community, as part of the *TSAF: More talk, more action* project

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FOREWORD

The following report was created as a continuation of the Association pour la santé publique du Québec (ASPQ)'s "TSAF: *More talk, more action*" action research project, in order to establish a clear picture of existing prevention efforts in regards to alcohol use during pregnancy in Quebec, specifically within perinatal community settings and in the health and social services network, before the development of the *During pregnancy, go alcohol-free* awareness campaign and its accompanying tools. It also aims to assess the tools needed by health and social services professionals and other stakeholders in the field of perinatology to support better prevention and awareness of FASD and alcohol use during pregnancy.

It should be noted that alcohol use in pregnancy remains a major public health issue in Quebec. It is the leading preventable cause of intellectual disability and congenital malformations.^{1, 2, 3} The sequelae of prenatal alcohol exposure vary and are not systematic from one individual to another, hence the term Fetal Alcohol Spectrum Disorder (FASD), which encompasses all the consequences of alcohol exposure during pregnancy. FASD manifests itself mainly as neurodevelopmental delay, but sometimes also as physical signs.^{4, 5, 6} The prevalence of prenatal exposure to alcohol remains high, with a recent Public Health Agency of Canada study revealing that 11% of Canadian women consumed alcohol during their pregnancy in 2006.⁷ The numbers in Quebec are even higher than the national average, with the rate of alcohol use during pregnancy reaching 34.1%, according to a 2006 survey conducted by the *Institut de la statistique du Québec*.⁸ To address this serious public health issue, it is essential to develop prevention tools to help reduce alcohol consumption during the prenatal period. The ASPQ's action research project was launched with this objective in mind.

Previous phases of the research, carried out in 2019 and 2020,^{9, 10} highlighted the key role that health and social services professionals can play in preventing and raising awareness of this disorder. Unfortunately, they also revealed several barriers that greatly reduce their effectiveness, one of which is the current approach to discussing alcohol consumption with pregnant women. This is one of the elements that should be improved to better support the interventions of health professionals.

This report presents the results of a survey distributed within the perinatal community in the fall of 2020, as well as findings taken from a series of in-depth interviews conducted in November 2020 with 10 health professionals, alcohol and pregnancy experts, and FASD experts.

OBJECTIVE

The objective of this phase of the project was to establish a clear picture of the state of FASD prevention in healthcare establishments and community organizations. Data collection was carried out in the fall of 2020, before the creation of the *During pregnancy, go alcohol free* awareness campaign and its accompanying tools.

METHODOLOGY

In November 2020, a survey was sent to the 18 members of the *Réseau des Centres de ressources périnatale (CRP)*, an organization active in almost all regions of Quebec, and to other perinatal community organizations throughout Quebec. The questionnaire, written in French, was developed by the Project lead via Google Forms and included about twenty questions. The ASPQ then conducted a quantitative and qualitative analysis of the results.

In total, 21 organizations answered our questions and were included in our analyses, including eight CRPs and thirteen community organizations.

SAMPLE PROFILE

CRPs support over 2,500 families throughout Quebec. The number of families followed by participating CRPs varied between 100 and 950. As for community organizations, respondents reported supporting between 120 and 2,000 families. Our sample includes at least one respondent from twelve regions, while five regions are not represented at all.

| Regions covered | Regions not covered |
|-------------------------|-------------------------------|
| Bas-Saint-Laurent | Abitibi-Témiscamingue |
| Capitale-Nationale | Centre-du-Québec |
| Chaudière-Appalaches | Gaspésie-Îles-de-la-Madeleine |
| Côte-Nord | Nord-du-Québec |
| Estrie | Outaouais |
| Lanaudière | |
| Laurentides | |
| Laval | |
| Mauricie | |
| Montréal | |
| Montréal | |
| Saguenay-Lac-Saint-Jean | |

RESULTS

Ministry of Health and Social Services (MSSS) Public Health Notice on alcohol use during pregnancy

Awareness

The MSSS's Public Health Notice on alcohol use during pregnancyⁱ is known by the majority of the CRPs and by approximately 70% of the community organizations that took part in this survey (Table 1). Among those who replied that they knew about it, two establishments added that they would need more information to deepen their knowledge.

TABLE 1: Awareness of the MSSS's Public Health Notice on alcohol use during pregnancy

| Answers | CRPs (total n=8) | Community organizations (total n=13) | Total (%) |
|---------|---------------------|---|-----------|
| Yes | 7 | 9 | 16 (76%) |
| No | 1 | 4 | 5 (24%) |

Pros and cons

According to survey participants, using the MSSS's Public Health Notice has the advantage of supporting their statements, communicating preventive information, and creating an opportunity to address alcohol use during pregnancy and in general.

Among the disadvantages cited, respondents noted that the notice's message can be perceived as guilt-inducing for women who consume occasionally, but also for those with alcohol use disorders who make efforts to reduce their consumption. Some respondents also criticized the message for being negative, ineffective, and not suitable for women with addictions.

Among comments collected, it was noted that some pregnant women hide their alcohol consumption, hesitate to speak about it openly, and therefore may not seek help on their own. Moreover, one organization mentioned that it avoids including this message in its publications because it fears women will isolate themselves and that this message could create a breach of trust and result in women not using its services.

In our in-depth interviews report, which enabled us to gather the points of view of various stakeholders on this issue,¹¹ most health professionals also spoke of the risk of creating feelings of guilt and anxiety in pregnant women who have already consumed or whose consumption is the result of an addiction. It was also noted that some caregivers reported being uncomfortable bringing up this subject because they feared offending their patients, breaking their trust and harming their care relationship.

Another important element revealed by this report is that the 2016 Public Health Notice on alcohol use during pregnancy was not distributed optimally in the healthcare network, due to a combination of factors (e.g., incomplete distribution among health professionals, absence of a protocol to ensure optimal

ⁱMinistère de la Santé et des Services sociaux, « Avis de santé publique sur la non consommation d'alcool durant la grossesse », <https://publications.msss.gouv.qc.ca/msss/document-001763/>

distribution, heaviness of the document in both presentation and content). These various findings presented in the in-depth interviews report led us to conclude that the 2016 Public Health Notice has yet to be used to its full effect.

Although the majority of professionals met in individual interviews agreed on the fact that the Public Health Notice should be communicated and promoted systematically, it is also important to present the information in a way that minimizes guilt as much as possible. Professionals emphasized the importance of working with a motivational approach focused on harm reduction, openness and non-judgment.¹² This same approach could be applied in all settings to ensure the messages avoiding all alcohol during pregnancy remains coherent and effective.

Reactions of future parents

According to the survey's data, the Public Health Notice's message is received both positively and negatively. Parents are well aware of it, as well as the consequences alcohol use during pregnancy on the child. In some cases, it helps to initiate a conversation.

However, while the message may be obvious for some, others interpret as limiting their freedom: "one drink can't be that bad!"

There are also parents who do not fully understand the message's relevance, do not feel concerned, or would prefer to hear a different message, namely to drink moderately during pregnancy.

Some of the respondents wonder how to use this message, because unless the parents bring up the subject during an individual intervention, they are not sure if the message is understood and applied.

It was also noted that this message is known and understood by the mothers and that some spouses make the same choice out of solidarity. When this is not the case, it can sometimes create a rift between spouses, as women may then feel unsupported in their efforts and thus experience this deprivation alone.

Finally, several respondents noted that society has an influence on people's behaviour. **Today's society tends to de-dramatize "low consumption of alcohol" during pregnancy** (e.g., a small drink occasionally, a small sip from time to time)¹³ and there is much work to be done if we are to change the perception associating FASD only with heavy drinking and alcohol dependence.

In our in-depth interviews report,¹⁴ experts reported different experiences when meeting with parents. Some women react rather well, because they expect this message and to be questioned about their alcohol consumption. In contrast, other experts, especially those working with women with alcohol use disorders, observed strong feelings of guilt when informing parents of the potential effects of alcohol on the fetus. It may sometimes even be necessary to reassure them without minimizing the risks, because they can panic.

For most experts, the correct way to approach this subject with pregnant women is to assume that all patients consume alcohol, whether currently or before pregnancy. Discussing alcohol consumption can also be an opportunity to address other contributing factors (e.g., violence, stress, isolation, loneliness, anxiety, lack of resources, etc.)¹⁵

Recommendations in terms of alcohol consumption

All CRPs who give prenatal classes and birth preparation classes use the zero alcohol recommendation during pregnancy. Some mention that, while they stress it as much as possible, in cases where it is too difficult to apply they may advise reducing alcohol consumption and suggest organizations to accompany women in their efforts.

In most perinatal community organizations, pregnant women are advised not to consume alcohol. One organization that meets women at the end of their pregnancy explains that this subject is discussed with pregnant women if they consume alcohol, in which case the organization works with the future mother to see if they could stop for the rest of their pregnancy. However, one organization among the respondents to our survey offered contradictory messages. The incoherence can cause misinformation, create confusion for parents, and even minimize certain risks.

FASD

Knowledge and use of the term FASD

The term FASD is used more in community organizations than in CRPs. In fact, more than half of the organizations use this term whereas it is only used in a quarter of participating CRPs (Table 2). One of the CRPs explains to us that they avoid the term, because it refers to a scientific concept that is poorly understood by people who have not received training on the subject of FASD.

TABLE 2: Knowledge and use of the term FASD

| Answers | CRP (n=8) | Community organizations (n=13) | Total (%) (n=21) |
|---------|--------------|-----------------------------------|---------------------|
| Yes | 2 | 7 | 9 (43%) |
| No | 6 | 6 | 12 (57%) |

When the term FASD is not used, respondents reported using the following terms:

- Fetal Alcohol Syndrome;
- Effects on fetal and child development;
- Problems for the unborn baby, characteristic traits related to alcohol use during pregnancy and syndrome;
- Adverse effects on the baby if there is general alcohol consumption.

Discussion of FASD during prenatal classes

Three out of four respondents reported discussing FASD-related issues. However, this proportion was higher among community organizations (Table 3).

TABLE 3: FASD-related issues are discussed during prenatal classes

| Answers | CRP (n=8) | Community organizations (n=13) | Total (%) (n=21) |
|---------|-----------|--------------------------------|------------------|
| Yes | 5 | 11 | 16 (76%) |
| No | 3 | 2 | 5 (24%) |

Among those who do not discuss FASD, reasons cited include the fact that the need is not present among their clientele or that they have never had clients with risky behaviours.

Another organization indicated that it does not feel equipped to talk about this subject and that it has little time to do so, while another said it lacked the knowledge to talk about it.

Finally, a CRP reported it is not currently offering prenatal or birth preparation classes.

Workshops on the prevention of alcohol use during pregnancy and FASD

While all CRPs are required to offer perinatal activities, 62% of community organizations reported offering such activities.

During these perinatal activities, only one CRP and one community organization reported offering specific workshops/meetings on the prevention of alcohol use during pregnancy and FASD (Table 4).

TABLE 4: Specific workshops on the prevention of alcohol use during pregnancy and FASD are offered

| Answers | CRP (n=8) | Community organizations (n=8) | Total (%) (n=16) |
|---------|-----------|-------------------------------|------------------|
| Yes | 1 | 1 | 2 (13%) |
| No | 7 | 7 | 14 (87%) |

For those who do not offer specific workshops on the prevention of alcohol use during pregnancy, 64% of respondents, in similar proportions in the two groups surveyed, said they broached this subject while discussing other themes.

Prevention tools to talk about alcohol use during pregnancy

The various organizations surveyed used leaflets and informational documents, rather than PowerPoint presentations, as tools for discussing alcohol during pregnancy (Table 5).

TABLE 5: Prevention tools used to talk about alcohol use during pregnancy

| Answers | CRP (n=8) | Community organizations (n=13) | Total (%) (n=21) |
|----------------------|-----------|--------------------------------|------------------|
| Leaflet | 4 | 5 | 9 (43%) |
| Informative document | 3 | 6 | 9 (43%) |
| PowerPoint | 1 | 2 | 3 (14%) |

Three CRPs and five community organizations (38% of our sample) mentioned that they lacked tools to address alcohol use during pregnancy and FASD prevention.

Most community organizations would like to have a pamphlet on the subject. However, the Covid-19 pandemic caused many meetings to take place virtually. Digital documents would therefore be more appreciated by many organizations.

Other suggestions include:

- Pamphlet created by the Montreal Dispensary;
- Short documentary videos on living with FASD;
- Small readymade workshops including tools;
- Trainings.

Our in-depth interviews report¹⁶ suggested:

- Updating the information in the *From Tiny Tot to Toddler* guide;
- Posters to put in hallways and offices of community and health facilities;
- A helpline to centralize information on available help resources.

Prevention training (alcohol, pregnancy and FASD)

Less than 20% of respondents told us that they had received training on the subjects of alcohol, pregnancy and FASD. These trainings appear to be more common in CRPs, where 60% of respondents reported having received training (Table 6).

TABLE 6: Training on the topics of alcohol, pregnancy and FASD

| Answers | CRP (n=8) | Community organizations (n=13) | Total (%) (n=21) |
|---------|--------------|-----------------------------------|---------------------|
| Yes | 3 | 1 | 4 (19%) |
| No | 5 | 12 | 17 (81%) |

The training courses followed by the participants are:

- The CAPC Symposium (**Community Action Program for Children**) offered by the Public Health Agency of Canada;
- Effects of drugs and alcohol on people in general, on women in the perinatal period, and on their babies;
- The fetal alcohol spectrum;
- Understanding Fetal Alcohol Syndrome.

In our report on prenatal alcohol exposure and FASD training among health professionals,¹⁷ we noted that continuing education on these topics was almost non-existent among Quebec's various associations, federations and professional orders. While certain education programs do include some information on alcohol use and FASD (e.g., 1st cycle in nursing sciences, internships in medicine, 1st cycle in social work, etc.), students are rarely exposed to it more than one hour during the course of their studies.

In conclusion, training on prenatal alcohol exposure and FASD remains rare among health professionals, healthcare establishments and community organizations.

Future mothers dealing with alcohol consumption problems: where to refer

More than 80% of our respondents told us they know where to refer an expectant mother who has alcohol consumption problems (Table 7).

Table 7: Know where to refer future mothers dealing with alcohol problems

| Answers | CRP (n=8) | Community organizations (n=13) | Total (%) (n=21) |
|---------|--------------|-----------------------------------|---------------------|
| Yes | 7 | 10 | 17 (81%) |
| No | 1 | 3 | 4 (19%) |

Here are the people and places mentioned as resources:

- CISSS or CIUSSS:
 - Local resource
 - Perinatal nurse
 - Perinatal team
 - Youth program
 - CLSC
- Doctor
- Midwife
- Street worker
- Addiction center
- Support group for alcohol-related disorders
- Professional (e.g., psychologist, social worker, nutritionist)

Most therefore refer to the resources of their regional CISSS or CIUSSS, but some do not hesitate to follow up with the pregnant woman's family doctor or other health professionals.

SUMMARY

- The MSSS's Public Health Notice alcohol use during pregnancy is known by the majority of CRPs and community organizations surveyed. However, it was poorly distributed in the health network and its formatting makes it difficult to use as a resource.
- The Public Health Notice's message is known and usually well received by the majority of women and parents, but can be guilt-inducing for women who consume alcohol occasionally and for those with alcohol use disorders.
- This message can also lead to women hiding their alcohol consumption rather than talking about it openly and seeking help, hence the importance of presenting the information in a way that minimizes the guilt as much as possible.
- The majority of participating organizations (CRPs and community organizations) recommend that pregnant women should not consume alcohol during pregnancy.
- 57% of organizations surveyed do not use the term FASD.
- 75% of organizations surveyed discuss issues related to FASD. However, this proportion is greater among community organizations.
- 87% of the organizations in this sample do not have workshops/meetings specific to the prevention of alcohol use during pregnancy and FASD, but 64% of the organizations address this subject within other themes.
- The various organizations surveyed use pamphlets and informational documents as a prevention tool to talk about alcohol use during pregnancy, but many would like to have other or more tools.
- Less than 20% of respondents had received training on the subjects of alcohol, pregnancy and FASD.
- More than 80% of the respondents in the sample know where to refer an expectant mother who has alcohol consumption problems.

RECOMMENDATIONS

Review and streamline the questionnaires given to future mothers about alcohol use during pregnancy

The experts consulted in the in-depth interviews suggested a “turnkey” guide that would include a series of questions to help the various stakeholders in the health and social services network and in community organizations.

Among what was mentioned during the series of in-depth interviews last fall, **“it is important to reconsider how we talk to pregnant women about alcohol consumption and what questions we ask. We must be more open, less judgmental, and avoid being moralistic. It should also be assumed that all women consume alcohol. Experts recommend using this type of question:**

*“[What is] your current consumption?
Have you received [any] information on fetal alcohol disorder?
Would you like some?*

*[...] Do you intend to stop?
[What is] your plan to quit? »*

Improve the training of health and social services professionals

In order to improve the training of health and social services professionals who work in perinatal settings, we refer to the proposals made in our two reports^{18,19}. Several respondents mentioned the potential benefits of developing a toolkit on FASD (overview, prevention, screening, diagnosis, management, support, etc.). This type of kit could be an interesting solution for healthcare institutions and community organizations. In addition, publicizing the various FASD training courses, such as those offered by the SAFERA organization could also be beneficial.

Develop an FASD awareness tool for future parents

The need to better inform parents about FASD is very apparent in our data collection. It would be interesting to develop a simple, clear and non-judgmental tool about FASD, which could be distributed to pregnant women and their entourage as a complement to the *From Tiny Tot to Toddler* guide, in order to raise awareness about FASD and alcohol use during pregnancy. To support healthcare professionals, a poster-like tool could be created and displayed in healthcare facilities and community centers.

Continue raising awareness about alcohol use during pregnancy

Our survey of perinatal community organizations and CRPs revealed that more than a third of organizations surveyed do not address the prevention of alcohol use during pregnancy within their perinatal workshops and have no specific workshop on the subject. Knowing that more than 50% of the general population does not know about FASD and that nearly 30% of pregnant women do not know about it either,²⁰ it is recommended to continue efforts to disseminate and promote messages avoiding all alcohol during pregnancy. Additionally, several young people, future mothers, and mothers in the focus groups indicated that they wanted to know more about the impact of alcohol on the development of the unborn child. Our *During pregnancy, go alcohol-free* campaign and its accompanying tools can help raise awareness among young people (adolescents and young adults) before they become parents, and society in general.

CONCLUSION

In conclusion, the MSSS Public Health Notice on alcohol use during pregnancy is known by the majority of healthcare establishments and community organizations surveyed, but has not been well disseminated. However, reluctance to use it persists for fear of making women feel guilty, especially those with substance abuse disorders. Moreover, more than half of the various community organizations questioned do not use the term FASD and the majority do not have a specific workshop on the prevention of alcohol use during pregnancy. In addition, only a minority of workers have received training on the topics of alcohol, pregnancy and FASD. Our actions to raise awareness about FASD and to create better prevention tools is therefore very important and relevant, and could, in the medium and long term, contribute to improving the health of children and the well-being of families. Several recommendations were suggested in this report, some of which will be further explored as part of this action research project.

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