



INDIVIDUAL INTERVIEWS ON THE PREVENTION OF ALCOHOL CONSUMPTION DURING PREGNANCY AND FETAL ALCOHOL SPECTRUM DISORDER (FASD)

EXECUTIVE SUMMARY

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EXECUTIVE SUMMARY

This summary is part of the report entitled *Individual interviews on the prevention of alcohol consumption during pregnancy and fetal alcohol spectrum disorder (FASD)* released by the Association pour la santé publique du Québec (ASPQ) in December 2020.

OBJECTIVES:

This qualitative section is part of the data collection for the action research the ASPQ is currently conducting in order to create an awareness campaign about FASD and abstaining from alcohol during pregnancy. The goal of this section was to gather points of view from the various people involved in the issue: health professionals, people living with FASD and their families, vulnerable people who have drinking problems. Prenatal exposure to alcohol is still a major public health issue in Québec and is the most avoidable cause of birth defects. It is therefore essential to understand how the different populations concerned perceive FASD and drinking during pregnancy so that we can design an awareness campaign building on their lived experiences, one that is also in tune with everyday realities.

METHODOLOGY:

We carried out 21 semi-structured interviews with: 10 health and social services professionals who were experts on FASD and alcohol consumption during pregnancy; 10 people living with FASD and their family members; and one vulnerable young woman who has a drinking problem. Each interview lasted about an hour and followed an interview grid. After that we analyzed the answers to draw out the principal themes.

FINDINGS:

DRINKING DURING PREGNANCY: A DIFFICULT TOPIC

The health and social services professionals who were experts on FASD and alcohol consumption during pregnancy ("the experts") said that, even though drinking during pregnancy is a relatively well known topic within the health and social services network, the 2016 public health message promoting "zero alcohol"¹ during pregnancy has not been widely disseminated since that time. Women may be exposed to a whole range of messages on the topic during pregnancy, however, from both health professionals and their own entourages. Our experts also told us that the topic was still taboo in the health and social services system, and that some professionals found it hard to bring up because they were afraid of breaking the trust relationship with their patients. They also said those professionals do not necessarily have the time to ask women about drinking while they monitor their pregnancies.

All the experts agreed that it is important to review the way questions about drinking are put to pregnant women. It should be done with greater openness, less judgement and no moralizing. It should also be based on the premise that all women consume alcohol. The experts recommended using questions like:

¹ <https://publications.msss.gouv.qc.ca/msss/document-001763/>[in French only]

"[How much] are you drinking now? Did you have [any] information on fetal alcoholism? Would you like some? [...] Were you planning to stop? [How] do you plan to stop? "

Ms. Wagner, nurse specializing in addiction

The experts also called for more help as they look after women who drink, either to spot the habit or to steer those women toward the proper resources. Here again, more services are needed for women who need help cutting down on their drinking or stopping completely.

INSUFFICIENT TRAINING AND NO CONNECTION BETWEEN THE PREGNANT MOTHER'S RECORD AND THE CHILD.

All the experts agreed that there is a serious lack of training about FASD in the health professionals' basic curriculum. According to them, the topic should be presented systematically and in greater depth so that future care givers can be aware not only of the disorder but how to spot it, prevent it and help the patients concerned by it (pregnant women, mothers and people with FASD). Our experts also raised the failure to make connections between the pregnant mother's record and the child's record. Even when information is available about alcohol consumption during pregnancy, it is very rarely mentioned in the newborn's record. As one expert told us:

"It's as if we put all our focus on the pregnancy, then after the baby is born we don't have the information any more [...]."

Ms. Lavandier, perinatal social worker

That could slow down screening, diagnosing and caring for the child. The experts therefore recommended setting up a systematic connection between the mothers' records and their children's records, particularly for key information like this.

The FASD experts raised the difficulty of diagnosing children affected by FASD when the medical history of some adopted children is unknown, as well as the lack of knowledge on the part of health professionals who may confuse it with other disorders or syndromes (especially ADHD). Those experts also emphasized the need to diagnose these children and start caring for them and their families quickly, with a focus on prenatal assistance. They recommended increasing resources (human, financial and material) so that care and proper services can be provided to children living with FASD, who are usually in classrooms that do not meet their needs and do not always get appropriate care and services.

LACK OF INFORMATION ABOUT FASD AMONG THE PUBLIC AND THE EDUCATION AND HEALTH NETWORKS

The people living with FASD and their families also acknowledged that the general public does not know much about FASD, nor do the education and health networks. The parents often have to explain things to teachers and care givers and provide information. FASD is very demanding and hard on parents on a daily basis, exposing them to a variety of behaviours. As one parent said:

"[...] it's a surprise package. There's been something new every day for 14 years. It takes a great deal of adjustment. With lots of difficulties from day to day."

M. L., adoptive father of two children with FASD

The learning process is long and hard for several young people because they have difficulty retaining information. It is also hard for some of them to manage their emotions, because they cannot always describe what they are feeling, and they may resort to violence as a way of communicating. One mother told us:

"it's like the house is full of bombs and you never know when they will go off, or why. You have to be on your guard all the time, and hyper vigilant [...]."

Ms. B., adoptive mother of a child with FASD

Many parents also pointed out that the crying shortage of resources adapted to their children's needs makes them feel alone with the problem. They are both physically and psychologically exhausted. They want the provincial government to recognize FASD as an independent diagnosis and they want dedicated, adapted resources for help and guidance put in place to help their children develop and become autonomous when they are adults.

The vulnerable young woman pointed out that many factors may drive a pregnant woman to drink, and that all those factors need to be dealt with in addition to the drinking itself. According to her:

"[...] it's all the little things that make you want to drink or get you to the point where it would do you good to forget. [...] I don't drink unless there's a trigger. I don't drink when I want to have a good time."

Lastly, all the participants decried the general lack of public knowledge about prenatal exposure to alcohol and FASD, and they all agreed that there is a need for more widescale awareness. They recommended talking about the consequences of drinking, because they know the public is generally well informed about the fact that alcohol should not be consumed during pregnancy. They said information is needed on "why you shouldn't drink." They all agreed that young people—especially teenage girls—need to be made aware at school. They suggested addressing the topic in courses like Ethics and Religious Culture, where it can be linked to contraception, drinking and driving and other issues presented to adolescents. They also recommended an open, non-judgemental approach, bringing in people living with FASD to share their experiences. They were in favour of an awareness campaign aimed at teenage girls as well as a wider audience. They wanted the emphasis to be on collective and societal responsibility, not just on pregnant women; they called for more inclusive awareness campaigns.

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