

# Breaking taboos to improve prevention

FASD Bulletin 2021

**FA** fetal  
**SD** alcohol  
spectrum  
disorders

talk about it for better action







## CONTENTS

<b>Breaking taboos to improve children's health of and the well-being of Quebec families.....</b>	<b>3</b>
<b>Dive into the heart of the FASD.....</b>	<b>4</b>
<b>A behind-the-scenes look at the “During pregnancy, go alcohol-free” campaign .....</b>	<b>6</b>
<b>Together, we can go further .....</b>	<b>8</b>
<b>Do you network? The benefits of networking to form a united front against FASD.....</b>	<b>10</b>
<b>FASD: Should we prioritize needs or diagnosis? .....</b>	<b>11</b>

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## Editorial

# Breaking taboos to improve children's health of and the well-being of Quebec families



By **Isabelle Létourneau**,  
FASD Project Lead, ASPQ

**W**hile the pandemic continued to pose challenges throughout the year, the ASPQ kept up its efforts to gather information on Fetal Alcohol Spectrum Disorder (FASD) through data collection and publications. Our latest document, *Status of training on prenatal alcohol exposure and FASD*, confirms a number of shortcomings already documented in the Individual Interviews Report published this winter and suggests possible solutions. Among other things, better training and access to information would allow professionals to keep this disorder in mind during their practice and improve detection, prevention and support for pregnant women, mothers, and people with FASD.

This spring also saw the launch of *During pregnancy, go alcohol-free*, our first awareness campaign focusing on FASD and alcohol consumption during pregnancy. The

introduction of Charly, who's impact has reached as far as Europe, gives us an effective tool to raise awareness among young people aged 12 to 25, the general population, and health and social services professionals. If you didn't know already, Charly is a character living with FASD on a daily basis and is at the heart of our campaign – do check it out. Whether you are a professional working with pregnant women or a support person, this campaign offers many tools to help better understand and talk about FASD. This newsletter will take you behind the scenes to explore the issues and challenges behind its creation and evaluation.

These pages also contain a moving testimony by Vincent and Martin\*, respectively adoptive father and young man with FASD, who are still learning, on a daily basis, to live with this disabling disorder. Humanizing FASD allows us to open our hearts and work together to improve the lives of people with FASD and their families, help them reach their full potential, and improve prevention.

### FASD prevention concerns us all!

By expanding awareness about the dangers of alcohol consumption during pregnancy and FASD throughout all spheres of society, we can make a real difference in improving the health of unborn children in Quebec.

Getting informed, listening, adapting, showing empathy, diagnosing children early, recognizing this disorder, and working together: these are some of the ideas that permeate this second FASD newsletter, proudly presented to you by the ASPQ.

This next year, let's bring even more Quebecers together to make the best decisions to improve our children's health and the well-being of Quebec families! Together, we can break the taboos surrounding alcohol consumption during pregnancy and improve society's awareness on this issue.

**We hope you enjoy this newsletter and we look forward to hearing from you!**



\*fictitious names



# Dive into the heart of FASD

By **Isabelle Létourneau**,  
FASD Project Lead, ASPQ

**“IT’S A  
FUCKING PAIN  
TO LIVE WITH.”**

— Martin

**23** year-old Martin\* did not mince words when asked how he would describe living with Fetal Alcohol Spectrum Disorder (FASD) to the general public.

Martin has FASD. Without his adoptive family’s support and dedication, Martin’s educational struggles could have been even worse. Martin completed a Diploma of Vocational Studies (DVS) in roofing and works for a company in his field. He has been together with his girlfriend for a year, has also had to learn about his disorder and its effects.

Martin’s father, Vincent\*, says he is proud of his son’s accomplishments and the perseverance he shows on a daily basis as he deals with the difficulties associated with his disorder. Martin and his father both agree that FASD still lacks recognition in Quebec and that we need to turn things around.

These are the perspectives of a father-son duo to help us better understand the daily challenges of a person with FASD and their family, and what we can do, as a society, to facilitate their lives.

## What is it like living with FASD?

Martin: “It’s a fucking pain to live with. [...] I have to do things my own way. If someone pushes me or presses me, it goes against my way of doing things and I get completely disorganized.”

Vincent: “It’s all about routine. People with FASD need to have a routine. He has to do things a certain way. He knows that this way works. He needs this routine, and if we cut him off, he’ll tell himself that it won’t work anymore and then panic sets in. Because his condition is not well known, people don’t know how to deal with it. It’s like with blind people: we tend to speak to them loudly even though they are not deaf, they are blind. It’s the same with FASD, people don’t know how to take it, they don’t understand the problem. For Martin, the key to autonomy is to be accepted in his environment, it won’t happen on its own. He has to live in an environment where people are aware of his challenges and how to approach them, so that he can be functional and comfortable. People around him must know how to interact with him and what approaches can make things easier.”

## In addition to routine and adapting the environment, do you have any other tips to facilitate everyday life?

Martin: “When I’m working or driving, I absolutely need music because otherwise I can’t focus.”

Vincent: “To quote [French singer Michel] Sardou, his life is much easier when singing. He has an ease of learning through song, with music, with rhythms. Because there is a rhythm, it becomes like a series of steps. It’s the only time you’ll see someone with FASD thinking ahead, because they know the chorus is coming. In everyday life, they do not always have the reflex to anticipate.”

## How has the pandemic affected you?

Vincent: “The syndrome evolves with time [...] Martin is an adult now. His way of life is different. We’ve seen a clear improvement with his social skills, but there haven’t been many opportunities to socialize in the last year and a half... The more he’ll be able to socialize, the more he’ll learn, because he relies on the people around him to be like beacons. Being confined alone at home prevents him from moving forward.”

**“When you don’t know something, you distance yourself from it. [...] Due to ignorance, people will simply exclude him, stigmatize him. He senses this, and it makes him feel guilty even though it shouldn’t.”**

— Vincent

**Do you think FASD is sufficiently recognized by the general population?**

Martin: "If I met my biological mother, I would tell her that I forgive her because, honestly, FASD was not known 23 years ago in Quebec. And that's a shame, because it's still the case today. I don't wish this on anyone."

Vincent: "Society is not necessarily organized for people who are different, nor are its laws. Society doesn't know about FASD, so it's going to be up to him to talk about it, to take that step which does not come naturally for him, to be able to function and feel comfortable without being stigmatized. And that's a lot to put on a person's shoulders. I feel like this ignorance forces Martin to act as both an educator and someone who experiences the problem. It's a lot. He himself sometimes has a hard time expressing his feelings and how he experiences them, so imagine when he has to tell others and make them understand, when he has to live with other people. It's a bit heavy."

**What are the consequences of this lack of knowledge?**

Vincent: "When you don't know something, you distance yourself from it. [...] Due to ignorance, people will simply exclude him, stigmatize him. He senses this, and it makes him feel guilty even though it shouldn't. [Kids with FASD] are even diagnosed, but with the wrong diagnosis. So they are given inappropriate medication. The child feels sick, the medication makes them feel weird, so they stop taking it. One thing leads to another, and we end up with people who need different medications, different approaches to feel valued and feel that they can take their place in society, like Martin is doing right now. [...] When you ignore a problem, you can't solve it."

**What do you think of the current state of prevention and awareness?**

Vincent: "We don't talk about it, or very little. We don't even talk about it along with contraception. If birth control

didn't work, then you stop drinking. [...] Yes, things are improving, but very slowly. [...] People have heard of the term, but they still don't know what it really means. Instead of tackling the problem together to get rid of it, it feels like we are still sticking our heads in the sand. In the meantime, though, how many victims are there? I'm not just talking about children, but families as well. I'm talking about mothers who didn't know and who have a child with FASD. I blame companies who are hiding from this problem. The problem won't disappear just because you're keeping your eyes shut. Training programs should be implemented to raise awareness of the problem. Then, we'll start to see some movement."

**What do you think needs to change?**

Martin: "All pregnant women should avoid drinking and their partners should encourage them not to drink. [...] I told a colleague to go and buy non-alcoholic drinks, which are readily available, for his pregnant girlfriend."

Vincent: "Interventions at school should address this problem and professionals should be trained on the subject. It's exhausting to keep blowing snow forward in front of the snow blower, at some point it's hard to move forward. There is no support, there is no information. So we try to take it one thing at a time. Is it normal that we had to do so much education around us? Absolutely not. The information should have been there already. It shouldn't be a witch hunt. It's not about giving blame. We really just need to get together to find solutions for our children and for society as a whole. Society must come to realize how much it costs per year to have a child with FASD who is misdiagnosed. It costs a fortune. If we can't solve this problem and diagnose it properly, of course we will stay as we are. [...] The solution goes through education, through prevention, through services for those who are affected." ■

**"We really just need to get together to find solutions for our children and for society as a whole."**

— Vincent

# A behind-the-scenes look at the “During pregnancy, go alcohol-free” campaign

Last Spring, the ASPQ unveiled its first awareness campaign focused on FASD and alcohol consumption during pregnancy in Quebec, aimed primarily at teenage girls aged 12-17 and young women aged 18-25.

It was a huge challenge to take on. How can we talk frankly about such a taboo subject? How can we get our message to reach adolescent girls and young women who are still far from planning to start a family? How do we avoid stigmatizing and scaring mothers and future mothers who may have consumed alcohol during their pregnancy? How do we avoid stigmatizing people with FASD? Creating this campaign involved a whole lot of in-depth, rigorous, and heartfelt work to find the best possible way to inform and raise awareness among our target audience, the general population, and health and social services professionals throughout Quebec.

Here is a look back at the work that went into creating this groundbreaking awareness campaign.

## Knowledge about FASD in Quebec

Data and information collected since the start of this project have all pointed to a severe lack of awareness about FASD, even among future mothers. More than 28% of them don't know about FASD or its impact on the child's development<sup>1</sup>. Young people and future mothers both told us that they want to be better informed about FASD.

The data studied within the framework of this project revealed to us flaws that exist in pregnancy monitoring.

With nearly 50% of pregnant women claiming not to have discussed alcohol consumption with the health professional who follow their pregnancy<sup>2</sup>, it is worrying to note that few longitudinal follow-ups are made concerning this issue, especially knowing that stressful events (a pandemic, for example!) can change the women's situation during pregnancy.

During the confinement imposed between March 2020 and June 2020, more than 8% of future mothers indicated that they had increased their alcohol consumption during their pregnancy. There is reason to be concerned about the health of children born during the pandemic.

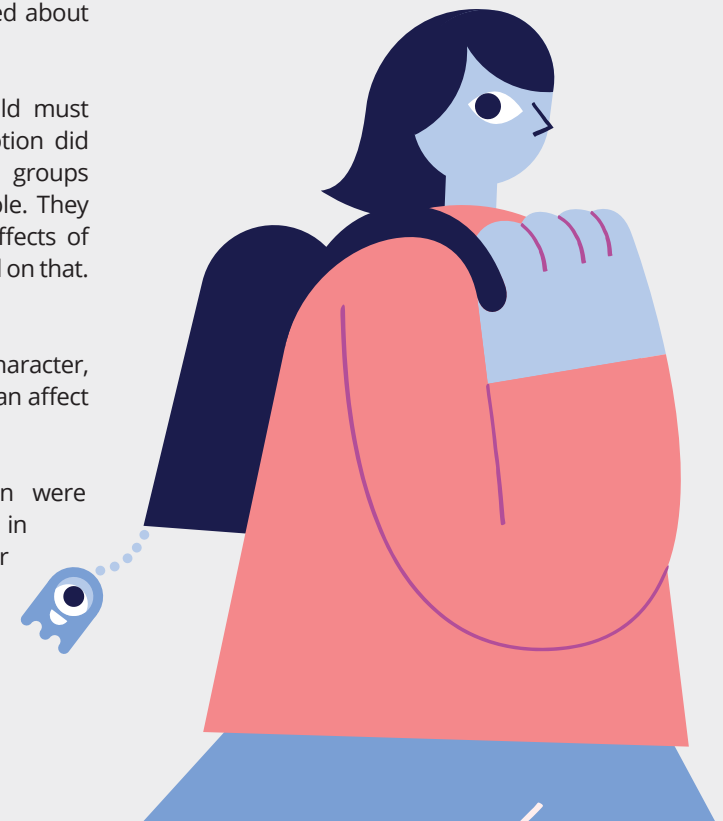
The toxic effect of alcohol on the unborn child must be clearly explained to the population. This notion did not seem to be well understood in discussion groups organized with future mothers and young people. They expressed a desire to better understand the effects of alcohol on the fetus's development. So we worked on that.

## Charly's daily life

In response to these needs, we created a character, Charly, to represent some of the disorders that can affect a person living with FASD.

Socialization, language and spatial orientation were among the most frequent challenges mentioned in our interviews with affected individuals and their families, as well as in literature. So we featured Charly in these different situations. Three short

video capsules and posters were produced and broadcast to our target audience, mainly on social networks (Instagram, Facebook and YouTube) and television as well as health and social services network partners. This fall, the campaign will extend to influencers and schools (high schools, vocational training establishments, and post-secondary institutions). Thanks to our partners, Charly is really taking off and we are thrilled about it!



1 Survey web Léger-ASPQ 2020

2 Survey web Léger

Another essential component of the campaign was to create effective tools to help professionals in the health and social services network and put FASD back on their “professional radar”. Thus, several tools were created and widely distributed, in particular through professional orders and publications (for example, the *Fédération des médecins omnipraticiens du Québec* and *Le Médecin du Québec*), in order to improve FASD awareness and knowledge. A webinar organized by the *Fédération des médecins spécialistes du Québec* was also presented to more than 650 medical specialists and remains available on their continuing education portal.

### A popular campaign

Following the campaign’s initial broadcast, we wanted to know how it was understood and received by our main target audience, women. The data collected in this first post-campaign survey is very encouraging!

### Léger-ASPQ survey, June 2021

N= 850 Quebec women aged 14 to 39

- Women who have seen the campaign have greatly appreciated it (approval score of 8/10)
- 77% of exposed women remembered and understood the message very well.
- 84% of women want to see more campaigns on this topic
- 71% of respondents said they felt positive emotions, including feelings of being touched, empathy, interest, need to act, and curiosity.

### One campaign, several tools to discover and share

If you haven’t seen our campaign, please do so here and share it widely. It is available in both French and English. For the general public, an Instagram account, which is intended as a virtual flyer for young people, has been created, at: [enceinte\\_sans\\_alcool/](https://www.instagram.com/enceinte_sans_alcool/) or [Alcohol\\_free\\_pregnancy](https://www.instagram.com/Alcohol_free_pregnancy). Posters and postcards, in both French and English, are also available free of charge. Here is the list of available tools for professionals and decision makers:

- **FASD Summary Papers**, September 2020;
- FASD Newsletter (1st edition), September 2020;
- **Awareness infographic**, which has also been available since spring 2021 on CHU Ste-Justine’s ABCDaire platform;
- **Portrait of excessive alcohol consumption** among young girls (12-17 years old) and women (18-44 years old) in Quebec, Spring 2021;
- **In-depth interviews** on the prevention of alcohol consumption during pregnancy and FASD, Winter 2021;
- **Status of FASD training** on prenatal alcohol exposure and FASD, June 2021.

### The FASD: More talk, more action project is keeping its momentum! ■

To comment, request more information or for any questions, contact Isabelle Létourneau, FASD project lead, *Association pour la santé publique du Québec (ASPQ)*.



# Together, we can go further



By **Annie Rivest**, teacher, mentor and new CEO of SAFERA.

**F**etal Alcohol Spectrum Disorder (FASD) is a neurodevelopmental disorder. We can sometimes perceive people who are affected as people with a lack of motivation, who have a tendency to provoke others or who refuse to adapt to various social and other situations. Because this disability is often invisible, those affected are often misunderstood and judged by others. However, if Quebec society were more aware of this preventable problem, there would probably be fewer people living with FASD and left to fend for themselves.

Fortunately, organizations like the ASPQ are stepping forward to inform the population. Their Charly videos are part of these awareness-raising efforts to reach the general public and reduce prejudices. These projects are essential because the FASD remains little known in Quebec: 50% of Quebecers have no knowledge of FASD<sup>3</sup>. This ignorance is a major obstacle to being able to address FASD without judgment or taboo.

Currently, mothers of children with FASD are often stigmatized and accused of having consumed alcohol while pregnant. Yet 1 in 2 pregnant women (48%)<sup>4</sup> say that their alcohol use was not addressed by their healthcare professional during their pregnancy. And is it still the pregnant woman's sole responsibility when she is offered alcohol by a friend, a spouse or a colleague who trivialize or ignore the risks involved, without bad intentions?

## FASD affects everyone

FASD is an issue that affects us all. Many of us are directly or indirectly affected by this problem – sometimes without even knowing.

As parents, citizens, politicians, doctors, teachers, specialized educators, psychoeducators, educators, health professionals, foster families, caregivers, or others, you may feel the need to act and make a difference – but you have to get informed first. It is important to understand what FASD is, what causes it and how to avoid it, but also to be able to recognize it and know how to react, intervene and support people with FASD.

It is society's responsibility to adapt and to act differently, not the people affected. Visible disabilities are easier to accept and understand. Since FASD is in-

visible and difficult to detect, diagnosis is more complex. Sometimes misdiagnoses are made because of the other difficulties associated with FASD. In these cases, services offered are not always effective and the money invested is not maximized.

*“It is society's responsibility to adapt and to act differently, not the people affected.”*



3 Survey ASPQ Léger 2020  
<https://www.aspq.org/le-trouble-du-spectre-de-lalcoolisation-foetale-est-meconnu-de-la-moitie-des-quebecois-es-il-faut-en-parler-pour-mieux-agir>

4 Survey ASPQ Léger 2020  
<https://www.aspq.org/le-trouble-du-spectre-de-lalcoolisation-foetale-est-meconnu-de-la-moitie-des-quebecois-es-il-faut-en-parler-pour-mieux-agir>



To achieve this, we must know more about the subject in order to offer adequate services and adapt effectively when dealing with people with FASD. Effective and workable actions are needed to support people with this disability.

If we came together to increase awareness about FASD, if we worked together, if all the actors involved with this disability combined their efforts, FASD would emerge from the shadows and could finally be recognized. Quebecers are capable of great things, we must be better informed on FASD collectively in order to prevent it and intervene effectively. We must work to have FASD recognized by all institutions and ministries in Quebec, to improve training on FASD in various medical curriculums, to have the entourage of people with FASD recognized as caregivers, to allow SAFERA to continue supporting, informing, and training people with FASD, their entourage, and everyone else touched by this disability. All of these things won't happen on their own.

When we say loud and clear that we need recognition for FASD, more doors open. When the FASD community comes together, more people are able to receive appropriate services. The more we talk about FASD, the more we learn about the different aspects of this problem and the more our society becomes aware and involved. This is no longer a distant dream, we are at a crossroads and if we unite, we will get there, because together we go further. ■

## SOS FASD: A Social Emergency symposium

In order to help broaden Quebec society's awareness and knowledge of issues related to FASD, SAFERA will present, as part of Fetal Alcohol Spectrum Disorder Awareness Month, a virtual and bilingual symposium titled SOS TSAF: A Social Emergency, on September 17, 2021. This is the 2nd symposium organized by SAFERA on this subject.

Several speakers and other personalities will participate, including:

- **Ian Lafrenière**, Minister Responsible for Relations with the First Nations and the Inuit, and Repentigny MNA Lise Lavallée.
- **Guy Niquay**, deputy CEO of the CISSS de Lanaudière.
- **Isabelle Létourneau**, FASD project lead at the ASPQ.
- **Dr. Anne-Marie Goyette**, developmental and behavioural pediatrician.
- **Francine Lussier**, neuropsychologist, founder of Cenop.
- **Valérie Rouby M. Ps**, neuropsychologist.
- **Hélène Courchesne** and **Manon Kelso**, ABLE2ON managers.
- **Annette Cormier, B.Sc.N.** recipient of the Claudette Bradshaw Innovator Award.

In addition to sharing knowledge on the diagnosis of FASD, its distinction from other neurodevelopmental disorders, and its neuropsychological aspects, this event will also feature concrete strategies and effective interventions (school, social and others...). Several information capsules will also be offered. Finally, this symposium will be an opportunity to promote inspiring initiatives such as the ASPQ campaign, ABLE2ON's transition project for young adults with FASD, and the NB FASD Center of Excellence's Dream Catcher.

The SOS FASD: A Social Emergency virtual symposium is intended to be a moment of knowledge sharing that will allow people with FASD to be better served, supported, helped, and understood. By being more aware of this social emergency, we will be better equipped to face it.

To participate, visit: [colloquesostsaf.net](http://colloquesostsaf.net).



# Do you network?

## The benefits of networking to form a united front against FASD



By **Karolane Proulx**, M.Sc.  
Public Health Agency of Canada

**F**etal Alcohol Spectrum Disorder (FASD) is a complex issue: its differential diagnosis is largely underdiagnosed and often confused with other disorders. Its management requires the collaboration of professionals from multiple disciplines. In addition, multisectoral and holistic approaches have been shown to be effective for prevention<sup>5</sup>. It is essential that professionals and stakeholders supporting people with FASD be able to communicate with each other and share their knowledge and expertise. To do this, networking platforms are ideal.

There are currently various FASD sharing networks in the provinces and territories. At the national level, the Prevention Network Action Team on FASD Prevention from a Women's Health Determinants Perspective (pNAT) brings together partners working at the local, provincial and national levels. The monthly meetings, which take place in English, provide a forum for discussion and seek to advance research in FASD prevention

In 2009, in order to bring together professionals working on this public health issue, PHAC-QC also set up the Public Health Agency of Canada's Fetal Alcohol Spectrum Disorder Network — Quebec region (PHAC-QC FASD network). This network is comprised of twenty Quebec organizations from different disciplines, including health, social services, education, justice and research.

The PHAC-QC FASD network works in prevention to raise awareness about FASD, its manifestations, and its consequences, as well means of preventing it and improving care and services for people living with FASD. The network's objectives are to provide a place for networking and sharing expertise, to promote the mobilization of knowledge, and to promote and support promising initiatives and projects related to this public health issue.

Semi-annual meetings organized as part of the PHAC-QC FASD network inform members about recent data and studies on FASD as well as resources and promising practices, particularly in the Quebec context. These meetings are generally held in French, but participants can always intervene in English if they want.



Networking between professionals and stakeholders is important for discussing and aligning awareness messages, advancing knowledge on prevention and improving the management of people living with FASD. More talk, more action, more partnerships. ■

To learn more about FASD, you can consult the PHAC website at the following address: [www.canada.ca/en/public-health/services/diseases/fetal-alcohol-spectrum-disorder.html](http://www.canada.ca/en/public-health/services/diseases/fetal-alcohol-spectrum-disorder.html)

If you work on FASD and would like to join or learn more about the PHAC-QC FASD network, please do not hesitate to contact me at [karolane.proulx@phac-aspc.gc.ca](mailto:karolane.proulx@phac-aspc.gc.ca). I will be happy to discuss the network with you.

5 Public Health Agency of Canada (2008, march). La prévention de l'ensemble des troubles causés par l'alcoolisation fœtale (ETCAF) : Perspectives canadiennes (publication n° HP5-73/2008F-PDF). <https://www.canada.ca/fr/sante-publique/services/promotion-sante/enfance-adolescence/programmes-initiatives/ensemble-troubles-causes-alcoolisation-tale-etcaf/publications/perspectivescanadiennes.html#11>

# FASD: Should we prioritize needs or diagnosis?



By **Fabienne Saint-Cyr** T.S.M.S.s.  
and guardian mother of a child living  
with FASD

**A**In Quebec, there are no clinics offering treatment fetal alcohol spectrum disorder (FASD) and no teams trained to make such a diagnosis. This has led some professionals to wonder if it would not be more appropriate to focus on meeting the needs of children with FASD rather than diagnosing them.

## A diagnosis that presents challenges

FASD is the leading cause of developmental disorders and intellectual disabilities in Canada, despite the fact that in the majority of cases IQ is measured within normal limits<sup>1</sup>. A study based in Toronto estimated the prevalence of FASD at 2 to 3%<sup>2</sup>. Given the lack of studies on FASD in Quebec, we do not currently have data on the prevalence of FASD in this province.

By its name, FASD infers the notion of spectrum. This one is very wide, including children who are affected physically, intellectually or neurologically. In fact, over 400 different health conditions have been observed<sup>3</sup>. The harm to the child depends on the amount and nature of the mother's alcohol use throughout pregnancy, the stage of pregnancy at the time of alcohol consumption, the mother and child's respective genetics, as well

as the health and nutritional status of the mother<sup>4,5</sup>. This damage is permanent and therefore irreversible. The good news is that FASD is completely preventable, as long as the mother does not consume alcohol during pregnancy.

For the majority of children, no characteristic facial features are observed at birth. These morphological characteristics are found in 10% of people with FASD<sup>6</sup>. Some children have damages to their vital organs. For these two types of damage, diagnosis will usually be given at birth, especially if alcohol consumption in utero has been declared by the mother. For all other children with FASD, which is to say the majority, their disability will go undetected at birth.

Although the central nervous system is sensitive to the harmful effects of alcohol throughout pregnancy, it is difficult to predict whether the baby will have brain damage during the first months of life. Rather, the impacts will manifest themselves in subsequent years. Thus at the birth of the child, we face a blank page for the majority of cases, because the spectrum unfolds along with cerebral maturation. During the first years of life, symptoms appear one by one and the spectrum begins to unfold.

With the difficulties usually comes the need to implement strategies and means to help development, to overcome or compensate for the deficits. Vigilance and medical follow-up must be intensified if there is a suspicion of prenatal alcohol exposure or if the mother has declared alcohol consumption during pregnancy. Without this vigilance, there is a great risk of issuing a false

or late diagnosis, thus compromising the development of the child, because they will not receive the help required for their neuroatypical condition.

## The importance of early diagnosis

Although meeting the child's needs is necessary for developing language, gross motor skills, and social awareness, it would be risky to ignore where these needs originate. Once established, a FASD diagnosis helps to better understand the child and to define expectations during possible interventions. Ideally, the diagnosis should be established in the first years of life so that the child can receive the intensity of services they need. Not putting words on what they are going through unfortunately means running the risk of having a second trauma. Making a diagnosis as early as possible then becomes a way of restoring justice for these children whose development has been compromised. The diagnosis brings with it an understanding of how they function.

**“During the first years of life, symptoms appear one by one and the spectrum begins to unfold.”**



Recent studies have demonstrated that children's brain plasticity, that is to say the ability of the brain to reorganize to function differently, means that early stimulation can lead to better outcomes for the five spheres\* of development. This is also true for a brain damaged by alcohol in utero. It is urgent that professionals involved with children identify those who may have been exposed to alcohol during their intrauterine life. "The plasticity of the brain combined with affective compensation will allow a form of reconstruction of the neural network on the condition that the child is given more time compared to a child without brain damage"<sup>7</sup>. The earlier the support, the greater the chances of helping the child develop to his or her full potential. It therefore becomes essential to diagnose FASD early in order to set up teams encompassing several professions.

**"Putting words on what they are going through is also a way of restoring justice for these children..."**

To make this possible, children need the involvement of several key people, including family doctors, pediatricians and child psychiatrists, as well as multidisciplinary teams. Child psychiatry centers are proving to be a gateway for diagnosing and treating these children, because they benefit from multidisciplinary teams. They can thus assess the child as recommended by Canadian

standards<sup>8</sup>. The genetic reference may also be appropriate for making a differential diagnosis when intrauterine alcohol consumption is unknown.

### **An unwanted label?**

Some allege the danger of stigmatizing people by diagnosing FASD. In fact, the risk of stigmatization by early or even late diagnosis is a false debate. Not knowing what a person has and, above all, why they have such difficulty functioning, means exposing them to shame and high levels of anxiety. This can also lead to incomprehension, exclusion or even ill-treatment from those around them

It would be dangerous not to diagnose, because not only will the child be misunderstood during early childhood, but this could also cause harm to their schooling. Understanding the child and knowing what they have makes it possible to put the right strategies in place to promote their development.

### **Getting the right services and support IN DAYCARE OR AT SCHOOL**

Childcare establishments and schools need to know in order to understand and be able to accompany these children adequately. With a diagnosis, the child with FASD has a better chance of obtaining the educational services they will need throughout their academic journey. Indeed, the school network does not operate in terms of needs, but with codes related to levels of services related to diagnoses. The Ministry of Education allocates codes of difficulty to children with special needs for which an intensity of services is attached. These codes appear in the nomenclature of difficulties listed in the "organization of educational services for students at risk and students with disabilities or social maladjust-

ments or learning difficulties (EHDAAY)". Although the FASD diagnosis is not there, certain codes can be given to the child depending on the case, including:

- Code 53: disorder relating to psychopathology;
- Code 33: mild motor impairment;
- One of the codes for intellectual disability based on assessment results;
- Code 99, a temporary code for a student awaiting the conclusion of the diagnostic evaluation.

These codes make it possible to secure academic or specialized support to promote learning. Therefore, the child's practical challenges and needs of the child are not enough: for one of these codes to be granted to the child, a diagnosis is necessary. It should be noted here that these codes are an invaluable asset for schooling. They allow the integration or maintenance of FASD children in the school network under good conditions<sup>9</sup>.

### **AT HOME**

Currently, many parents of children with FASD are in limbo. They struggle to implement strategies that usually work with normal children. However, for these neuroatypicals, learning is longer and more laborious. Damage to short-term memory, immaturity, and poor judgment are just a few of the characteristics of FASD.

Unfortunately, diagnosis often comes very late in the child's life. In the meantime, parents start to doubt their own parenting abilities (or judgment...). These issues could, in many cases, be avoided if the diagnosis was recognized and identified. This would release and devote the parents' energies to more beneficial purposes for the child and the parent-child relationship. As hard as

\*The spheres of development are: language, physical and motor, social, cognitive and affective development.

this reality is, knowing is the beginning of a long process of accepting the disability and learning to support the child. Knowing and understanding a child's neurodevelopmental damage will provide invaluable answers for many biological parents, adoptive parents, guardians, and foster families.

#### FOR THE DOCTOR AND PHARMACIST

Diagnosing FASD in children can also help in pharmacological dosing. For the majority of children with FASD, who are also diagnosed with ADHD, this disorder with or without impulsivity will be more complex to treat. Medication dosage will be more complicated if the FASD diagnosis is not established.

Vigilance is required, because these children often react too strongly or are refractory to medication. When we know a child has FASD, outcomes are usually better. As we know, the algorithm for pharmacologically treating a FASD child is often different from children with ADHD alone. These people have a damaged brain which must be taken into account in the trial and dosage of medication. Although anyone may react differently to medication, FASD makes it more likely<sup>10</sup>.

**“As a society, we have a colossal responsibility to collectively recognize the danger of alcohol consumption during pregnancy...”**

#### Understanding your own reality

There are benefits to telling the child why they are different. Knowing the origin of their difficulties does not lessen them, but it does give them an understanding of why they must work so hard to establish “paths in their brain”. Knowing early may also help them avoid the anger related to their diagnosis and, in time, walk through life at their pace. Accepting reality, even if it is unfair, is a step towards the acceptance of one's own difference. Some will be more resilient than others and will be lucky enough to meet people to help them express their pain and anger and meet the challenge of learning to be independent.

In short, diagnosis is essential to respond early to the needs of these children. With a diagnosis, the child is more likely to receive services that will help them de-

velop to their full potential. As a society, we have a colossal responsibility to collectively recognize the danger of alcohol consumption during pregnancy, to improve the diagnosis of FASD and to offer services to those affected. Although very disabling, FASD is not officially recognized in the nomenclature of disabilities or disorders giving immediate access to services offered by the health network. It is hoped that with more diagnoses issued for FASD, the prevalence and its impact will be more recognized in Quebec. Then, families living with FASD will no longer be denied the services necessary for their children's rehabilitation and well-being. ■

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