



**STATUS REPORT ON FETAL  
ALCOHOL SYNDROME IN QUÉBEC**

INSTITUT NATIONAL DE SANTÉ PUBLIQUE DU QUÉBEC



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# STATUS REPORT ON FETAL ALCOHOL SYNDROME IN QUÉBEC

DIRECTION DU DEVELOPPEMENT DES INDIVIDUS ET DES COMMUNAUTES

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- Persons responsible for substance abuse services in the Agences de développement de réseaux locaux de services de santé et de services sociaux

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## LIST OF ACRONYMS AND INITIALISMS

ADRLSSSS	Agence de développement de réseaux locaux de services de santé et de services sociaux ( <i>agency for the development of local health and social services networks</i> )
AHS	Aboriginal Head Start
ARBD	Alcohol-Related Birth Defects
ARND	Alcohol-Related Neurodevelopmental Disorders
CAGE	Cut down – Annoyed – Guilty – Eye-opener (alcohol dependency screening test)
CAPC	Community Action Program for Children
CCHS	Canadian Community Health Survey
CCSA	Canadian Centre on Substance Abuse
CEECD	Centre of Excellence for Early Childhood Development
CHUL	Centre hospitalier de l'Université Laval ( <i>hospital centre</i> )
CHUM	Centre hospitalier universitaire de Montréal ( <i>hospital centre</i> )
CHUQ	Centre hospitalier universitaire de Québec ( <i>hospital centre</i> )
CIHR	Canadian Institutes of Health Research
CLSC	Centre local de services communautaires ( <i>local community services centre</i> )
CPLT	Comité permanent de lutte à la toxicomanie ( <i>standing committee on substance abuse control</i> )
CPNP	Canada Prenatal Nutrition Program
CRAN	Centre de recherche et d'aide pour les narcomanes ( <i>drug addiction research and assistance centre</i> )
DPJ	Direction de la protection de la jeunesse ( <i>youth protection branch</i> )
DSMIV	Fourth edition of the Diagnostic and Statistical Manual of Mental Disorders – American Psychiatric Association
FAQ	Association des femmes autochtones du Québec ( <i>Aboriginal women's association</i> )
FAS	Fetal Alcohol Syndrome
FAS/FAE	Fetal Alcohol Syndrome / Fetal Alcohol Effects
FASD	Fetal Alcohol Spectrum Disorder
FNICCI	First Nations and Inuit Child Care Initiative
FNIHB	First Nations and Inuit Health Branch

FNQLHSSC	First Nations of Quebec and Labrador Health and Social Services Commission
GRASP	Groupe de recherche sur les aspects sociaux de la santé et de la prévention ( <i>research group on the social aspects of health and prevention</i> )
GRIP	Groupe de recherche sur l’inadaptation psychosociale chez l’enfant ( <i>research group on the social maladjustment of children</i> )
INSPQ	Institut national de santé publique du Québec ( <i>national public health institute</i> )
MSSS	Ministère de la Santé et des Services sociaux ( <i>Québec department of health and social services</i> )
NIAAA	National Institute on Alcohol Abuse and Alcoholism
NIICHRO	National Indian & Inuit Community Health Representatives Organization
NNADAP	National Native Alcohol and Drug Abuse Program
OLO	“Eggs, milk and orange juice coupons” program
pFAS	Partial Fetal Alcohol Syndrome
RISQ-CIRASST	Recherche et intervention sur les substances psychoactives Québec – Collectif en intervention et recherche sur les aspects sociosanitaires de la toxicomanie ( <i>research and intervention on psychoactive substances – intervention and research collective on the socio-sanitary aspects of substance abuse</i> )
RRSSS	Régie régionale de la santé et des services sociaux ( <i>regional health and social services board</i> )
T-ACE	Tolerance – Annoyed – Cut down – Eye-opener (screening test for at-risk alcohol consumption)
TWEAK	Tolerance – Worry – Eye-opener – Amnesia – Cut down (screening test for at-risk alcohol consumption)

## **INTRODUCTION**

The consumption of alcohol during pregnancy is likely to cause what is considered the most frequent preventable birth defect. This defect is fetal alcohol syndrome (FAS), which is a complex problem closely related to alcoholism and substance abuse among women. Described for the first time some 35 years ago, this syndrome has since been the subject of many studies conducted for the purpose of providing insight into its specific nature, documenting its prevalence or identifying ways to prevent it and help those who are afflicted with it. This research was conducted primarily in North America, but also in some European countries. Canada's contribution to developing knowledge in this area should be pointed out.

## **MANDATE**

In December of 2003, the Institut national de santé publique du Québec was mandated by the Minister of Health and Social Services to produce a status report on FAS. In response to this request, this report describes the current state of knowledge in Québec, and its situation and achievements in this area.

## **METHODOLOGY**

Considering the objectives set forth, a combination of methods was used. These methods call upon several sources of information, i.e. survey of available literature and documentation, interviews with key informants and analysis of survey data. Once the information gathered was put together, it was possible to provide an overview of the problem and situation in Québec.

A review of the scientific literature first made it possible to identify a number of excellent summaries describing research results from the past thirty years. Among the summaries dealing with the effects of alcohol on the foetus, there were those published by the Institute of Medicine, the American Academy of Pediatrics and the US Department of Health and Human Services (1-3). In addition, in 2003, the Centre of Excellence for Early Childhood Development of the Université de Montréal made available on its website a series of research papers on FAS written by prominent researchers (4). The more general problem of women's alcohol consumption and its effects is analyzed in a book by Wilsnack and Wilsnack, with the contribution of several scientists (5). With regard to services for children suffering from FAS, the Canadian Paediatric Society drafted a position statement on FAS describing methods to identify and diagnose problems and provide assistance to children affected (6). Finally, Health Canada has produced a review of literature that brings together extensive, up-to-date research on practices. Entitled "Best Practices," this work covers the range of measures designed to prevent, identify and deal with fetal alcohol syndrome and fetal alcohol effects (7). These references and other original articles deemed mandatory served as the basis of this report, along with a review of recent publications. These publications were found using a keyword-based search in three databanks, i.e. PsycINFO ("Pregnancy" AND "Alcohol"), PubMed ("Alcohol" AND "Pregnancy" AND "Fetal Alcohol Syndrome") and Sociological Abstracts ("Pregnancy" AND "Alcohol"). Publications dating after 1997 were used.

Furthermore, available documentation, such as brochures, association-based publications and various ads, were examined to see what type of information was given to the general public. Several websites were consulted to better understand how various institutions and associations in the world address the issue.

Along with this literature survey, interviews were conducted with some thirty key respondents. These persons were selected for their expertise in one or other of the fields and for their experience at the places of practice targeted by the report. As a whole, the people met represented a wide range of interests, expertises and training relevant to the topic. The interviews lasted about 90 minutes. Their purpose was to determine the expertise of people consulted, the research or intervention carried out in their field of expertise and place of practice and also their opinion with regard to various aspects of the problem of alcohol consumption during pregnancy and fetal alcohol syndrome.

Finally, certain variables of the Canadian Community Health Survey (Cycle 1.1) by Statistics Canada were used to describe the consumption of alcohol in women of childbearing age. Survey data were collected in 2000-2001. Analyses were done using the public-use microdata file (PUMF).

## **REPORT PRESENTATION**

This report is subdivided into three main parts: Part one focuses on problem elements. Its main aim is to document the importance of FAS, in terms of seriousness and frequency, and to provide an overview of the alcohol consumption of Québec women of childbearing age: frequency, alcohol consumption patterns and perceptions, profile of women who have problems related to alcohol and drug abuse. In part two, the focus is on intervention. The chapter begins with a description of Health Canada's *Initiative* on FAS, which is a reference model used by several countries. Projects that were put in place during this Initiative are also described. This is followed by a presentation of the prevention strategies aimed at the general public and alcoholic and substance-abusing mothers, along with a description of the services available for affected children and their families. This second part ends with a general look at the practices of professionals to highlight places where their actions are required and requested. Finally, part three is reserved for discussing and analyzing the information gathered, and presenting recommendations.

## **PART ONE: PROBLEM OVERVIEW**

This part lays out the scientific knowledge on the spectrum of disorders caused by *in utero* alcohol exposure. In a first section, the effects of alcohol on fetal development are presented. The range of nomenclature used in scientific papers on all fetal alcohol-related disorders is then introduced. A third section is devoted to FAS epidemiology, namely problem prevalence and populations at-risk.

A document on FAS cannot in good conscience fail to examine the state of the knowledge concerning the consumption of alcohol by pregnant women. For this purpose, and within a perspective of public health, the second section is devoted to various problems related to alcohol consumption. The focus is on the context in which various alcohol-related problems occur. The prevalence of alcohol consumption among pregnant women and women of childbearing age is also examined as well as the knowledge about and patterns of alcohol consumption of most Québec women. Lastly, special attention is paid to the profile of a minority of women suffering from alcohol-related problems since the abusive or chronic consumption of alcohol is considered as a major risk factor for giving birth to a child with FAS or other fetal alcohol-related disorders.

### **1.1 FETAL ALCOHOL SYNDROME AND DISORDERS CAUSED BY PRENATAL EXPOSURE TO ALCOHOL**

#### **1.1.1 Effects of alcohol on fetal development**

The effects of alcohol on fetal development have been of interest to scientists for some 35 years. In 1968, a pediatrician from Brittany published the first study on the harmful effects of fetal exposure to maternal alcoholism. In this case study, Paul Lemoine described the anomalies observed in 127 children of alcoholic parents (8). These children had abnormal facial features, severe growth retardation and psychomotor retardation with behavioural disorders. In 1973, Jones and Smith introduced the term “fetal alcohol syndrome” to describe these abnormalities in children born to mothers who drank large amounts of alcohol (9). Following this American publication, a number of studies clearly proved the teratogenic effects of alcohol and, in 1980, the syndrome’s diagnostic criteria were defined (10). In Québec, in 1982, physicians specializing in genetics published a first paper where they presented two cases of fetal alcohol syndrome (FAS) (11).

The extent of the teratogenic effects of alcohol depends on various factors, both biological and environmental, such as the quantity of alcohol consumed by the mother, the period during which the foetus was exposed, the frequency and length of exposure, the biological susceptibility of the mother and foetus, the combination of alcohol with other teratogens, the mother’s situation, her nutritional, health and socio-economic status, her obstetrical care and living conditions (1). It is also worth mentioning that not all children exposed to alcohol will necessarily develop FAS. However, a woman whose firstborn has FAS and who continues to drink during a second pregnancy greatly increases the risks of effects on the foetus (12).

During embryonic development, alcohol can interfere with the formation of several organs and cause heart defects, bone abnormalities, kidney disorders and vision and hearing problems (1). The brain is the organ most sensitive to alcohol. Since it forms throughout pregnancy and even after birth, it is highly vulnerable and as a result can be affected at different developmental stages (1). Alcohol is also a neurotoxic product with the property of causing central nervous system defects and neurobehavioural sequelae (1). Exposure to this substance interferes with the proliferation, migration and survival of nerve cells (3). Imaging techniques show smaller brains along with specific damage to the central part of the brain, namely the corpus callosum, the cerebellum, the basal ganglia and the hippocampus, whereas other regions are not affected by alcohol exposure (3;13). These anomalies also have consequences for the child in terms of psychomotor, cognitive and socioemotional development (3;13;14).

Psychomotor problems vary depending on age. Children may experience impaired fine motor skills and have poor balance and coordination (2). Sensorineural hearing loss can also be present with the syndrome (2).

With regard to cognitive performance, a study found reduction of the average IQ in French children whose mothers drank at least three glasses of alcohol per day during pregnancy (15). In a study by Streissguth (16), the average IQ of affected children was 68, but not all children with FAS were mentally impaired. These children may also have attention deficits, learning and memory problems, and difficulties with their executive functions (14). An attention deficit is found in over 70% of children with FAS (or partial FAS), and this problem appears to be 17 times more frequent in these children than in the general population (17). The type of deficit is different, i.e. children with attention deficit hyperactivity disorder (ADHD) have very short attention spans whereas those with FAS have trouble when they are distracted or subjected to sensory stimulation (noise, light) (3;18). Impaired memory is also specific to these children. They have difficulty processing new information, but then manage to retain it (3). When it comes to deficits in executive function, which involves abstract thinking and the ability to coordinate, plan and properly react to stimuli, they show up as trouble learning arithmetic and carrying out routine tasks with sequential steps (3).

These children also suffer from socioemotional, behavioural and social complications (14). Studies conducted in Germany to define a FAS “behavioural phenotype” showed that these manifestations are present, regardless of intelligence (19). Problems are primarily emotional in nature. Persons afflicted with FAS often suffer from anxiety, among other things when their routine is disrupted (19;20). Then, compared with a control group of children without FAS, they are most often anti-social, disruptive and self-centred, with autistic-type behaviours and communication problems (19;20).

These deficiencies persist or worsen during adolescence (21;22). According to a study conducted in British Columbia, it is possible that children with FAS and other problems related to prenatal alcohol exposure have more run-ins with the law (23). It is also possible that drinking-related problems in young adults are the result of alcohol exposure during pregnancy (24).

All these alcohol effects were documented by looking at children suffering from FAS or exposed to large amounts of alcohol. The consumption of large amounts of alcohol in one occasion would be more harmful than the consumption of equivalent amounts spread out over several sittings (22). However, researchers also report that some effects on the development and behaviour of children may be associated with

exposure to moderate quantities of alcohol (25). The term “moderate” is far from clear. It is generally used to describe the consumption of a quantity of alcohol deemed acceptable by society, regardless of what that may mean. According to the studies reviewed, this quantity varies widely. For instance, a French study qualifies as moderate the consumption of 1.5 oz of pure alcohol per day (roughly three glasses) during pregnancy, even if this quantity is associated with a lower IQ among children (15). In their literature survey, Jacobson and Jacobson (14) reported that developmental problems were observed among children whose non-alcoholic mothers occasionally drank alcohol. In a study conducted by these authors and reaching these same conclusions, the moderate consumption of alcohol is defined as drinking from seven to fourteen glasses per week<sup>1</sup> (25). This study showed that these consumption levels are much more harmful when the mother drank this quantity in one sitting rather than drinking one or two glasses a day over several days. Furthermore, among most children with developmental problems, their mothers drank on average five glasses or more in one sitting (25).

Australian researchers, who looked into the effects of light (less than a half a glass per day) or moderate (one half to one glass per day) drinking on physical growth, did not find any effects on a child’s weight or head circumference at birth and at five years of age (27).

Danish studies on the influence of alcohol intake on pregnancy outcomes concluded that the consumption of more than five glasses of alcohol during pregnancy might increase the risk of spontaneous abortion during the first trimester. The risk of stillbirth (at 28 weeks or more of gestation) tripled at these consumption rates, regardless of the mother’s socio-economic status or smoking habits, and would appear to be due to feto-placental abnormalities rather than congenital defects (28;29).

The heavy consumption of alcohol during pregnancy clearly contributes to increased risks for the unborn child. The potential effects of such drinking are wide-ranging: spontaneous abortions, growth retardation, developmental problems, more subtle behavioural problems, congenital defects and FAS. A child is at greater risk of having problems associated with the mother’s alcohol consumption if this mother drinks large quantities in one sitting.

Researchers affirm that exposure to moderate quantities of alcohol may also have effects on the child’s development. These effects were observed following the drinking of seven or more glasses of alcohol per week (corresponding to six standard drinks in Canada). The consumption of large quantities in one sitting is more harmful for the foetus than the consumption of equivalent quantities over several days.

### 1.1.2 Terminology of disorders caused by fetal alcohol exposure

A diagnosis of FAS is only established based on clinical observations of specific characteristics: unique facial anomalies (thin palpebral fissure, flat face, thin upper lip and flat or absent nasolabial fold), growth retardation and anomalies of the central nervous system. This diagnosis is possible with or without confirmation of alcohol exposure (1).

<sup>1</sup> Seven standard glasses or drinks in the United States correspond to six standard drinks in Canada. In the United States, a standard drink contains 11.671 g of alcohol and in Canada it contains 13.456 g (26).

Disorders may appear in more or less intense form, ranging from the classic form of FAS at one end of the spectrum, to psychological or behavioural manifestations without visible anomalies at the other end. The expression “fetal alcohol effects” (FAE) was adopted to describe prenatal alcohol exposure accompanied by an incomplete pattern of clinical FAS manifestations.

In 1996, due to the imprecise definition of FAE and resulting controversy, the American Institute of Medicine proposed a new diagnostic nomenclature (1). Other than FAS with or without confirmation of alcohol exposure, the following diagnoses are possible:

- *Partial FAS*: confirmation of alcohol exposure and evidence of some components of the pattern of characteristic facial anomalies;
- *Alcohol-Related Neurodevelopmental Disorders (ARND)*: confirmation of alcohol exposure, evidence of anomalies of the central nervous system and cognitive problems. By anomalies of the central nervous system, the Institute of Medicine means: 1) decreased cranial size at birth; 2) structural brain abnormalities; 3) neurological signs (e.g. impaired fine motor skills and coordination, neurosensory hearing loss). There must also be evidence of cognitive problems. It is a “complex pattern of behaviour or cognitive abnormalities that are inconsistent with developmental level and cannot be explained by familial background or environment alone”;
- *Alcohol-Related Birth Defects (ARBD)*: confirmation of exposure to alcohol and evidence of congenital anomalies potentially linked to alcohol: cardiac, skeletal, renal, ocular and auditory defects (1).

Confirmation of alcohol exposure is one of the criteria required to diagnose these disorders. Alcohol exposure is confirmed when the mother drank a large quantity of alcohol during pregnancy, either on a regular basis, or during drinking binges. The appearance of medical, social legal problems or signs of alcohol dependency are other elements used to confirm exposure (1).

Finally, the expression “Fetal Alcohol Spectrum Disorder” (FASD) was recently proposed to describe the range of disorders caused by fetal alcohol exposure (30). This expression is not a medical diagnosis and has no clinical value for the moment. Increasingly, Health Canada is using it in its policy statements. In French the expression is translated as “ensemble des troubles causés par l’alcoolisation fœtale” (ETCAF) (30).

The diagnosis of alcohol-related disorders other than the classic case of FAS is difficult to make and the debate on the best nomenclature to use is probably not over. We have presented the terminology found in literature on the topic since the first descriptions of FAS. It is generally agreed that the expression FAS/FAE is becoming obsolete. This is why, in this status report, we will use the term FAS to describe the syndrome alone and FASD for the range of disorders caused by fetal alcohol exposure, including FAS. Acronyms and initialisms such as pFAS, ARND and ARBD (diagnoses of the Institute of Medicine) are for specific disorders.



### 1.1.3 FASD epidemiology

#### *Prevalence*

A number of studies document the frequency of FAS. Clinical studies give prevalence data, but these studies are often conducted in American public hospitals that provide service to a poor urban population or minority ethnic groups (31-33). Consequently, their results are not representative of the general population and may have a tendency to overestimate prevalence.

There are also passive monitoring systems, such as the American FASNET, which have the advantage of covering large populations (34;35). However, data are often limited because of the problem of underdiagnosis (36-38). This can be explained by the fact that clinical characteristics are sometimes rudimentary, that no biological tests exist to confirm FAS and that it is not always possible to know the extent of alcohol exposure. The prevalence is also underestimated because of the inadequate reporting of diagnoses and subsequent recording in administrative files. The Canadian Perinatal Surveillance System (CPSS), through the Canadian Congenital Anomalies Surveillance Network (CCASN), reports the frequency of various anomalies, but does not give FAS-related data, probably due to the same difficulties (39). With the current state of knowledge, the pooling of all studies makes it possible to estimate that FAS is found in 0.5 to 2 children out of 1000 live births in North America (32).

Researchers at the University of Washington, highly active in fetal alcohol research, used the results of a longitudinal study to estimate the incidence of Fetal Alcohol Spectrum Disorder (FASD) (including FAS), which appears to be three times higher than FAS alone (33). According to this same study, the prevalence of FASD is 9.1 cases per 1000 live births in Seattle. In the absence of Canadian data on FASD, this rate of 9 cases/1000 is the one used by Health Canada (30).

In Québec, FAS prevalence is still not documented. It would probably be more prudent to apply the rates generally used in North America to Québec rather than the particularly high ones found in the Seattle study. As a result, on the premise that prevalence is 0.5 to 2 per 1000, the number of children born with FAS would range from 36 to 144 out of the 72,200 live births for the year 2002. If the FASD rate is triple that of FAS, the total number of new children affected would be 108 to 432 cases during that same year (from 1.5/1000 to 6/1000). For comparison purposes, in 1999, the prevalence rate of trisomy 21 (Down's Syndrome) at birth was 1.3/1000 and that of neural tube defects was 0.5/1000 in Québec (39).

The absence of statistics for Québec does not mean there is an absence of cases. The three physicians consulted for this report said they regularly make diagnoses, but data is not systematically collected and no studies are conducted to document the number of people affected.

#### *Populations at risk*

The persons interviewed maintain that FAS, but more often alcohol-related neurodevelopmental disorders (ARND) are found in children whose mothers have multiple additions. As a result, it is not always possible to determine alcohol exposure during pregnancy and to make a diagnosis.

FAS is also found in some children adopted from Eastern Europe where alcoholism is a serious social problem. According to Chicoine *et al.* (40), who wrote a book on children adopted from around the world, between 100 and 200 children out of 1000 live births in Russia suffer from FAS. These authors also pointed out that because alcoholism and violence are rampant in that country, alcohol would be the cause of the institutionalization of some 100,000 children per year. There is no study that documents the percentage of children affected among those adopted in Québec, but physicians revealed that they regularly see such cases. As is the case for children adopted from mothers with multiple addictions, the absence of information on prenatal exposure complicates the diagnosis.

FAS is found more often in some Aboriginal communities and minority groups, both in the United States and in Canada. American surveillance systems show that the incidence of FAS is clearly higher among Aboriginals and black populations in certain states (35). These results are supported by active FAS case finding conducted in Aboriginal communities in the United States, Alaska and Canada. In these studies, FAS rates, while wide-ranging and hard to compare due to the use of different methods, are very high (37;38;41;42). A community in British Columbia is the most dramatic example with 22 cases out of 116 children examined, some mothers having more than one child with FAS or FAE (14 mothers gave birth to 22 affected children; among those mothers, 5 had a total of 12 children) (42). In northeastern Manitoba, the prevalence of FAS appears to be at least 7.2 cases for every 1000 births (37).

No Aboriginal community in Québec was the subject of a specific study on the prevalence of FAS. Currently, a project, which would be carried out by the public health research unit of the CHUL (CHUQ), is planned for Nunavik communities to determine the phenotypic characteristics of FAS-affected Inuit children. Not only will this study establish diagnostic criteria for facial anomalies in Inuit children, but it will also make it possible to document the extent of the phenomenon of prenatal alcohol consumption and to better grasp the incidence of this syndrome in these communities.

## **1.2 ALCOHOL CONSUMPTION AND PREGNANCY**

### **1.2.1 General information on alcohol consumption**

#### ***Alcohol consumption in a population***

The consumption of alcohol is part of daily life, but can be harmful and cause a number of social, health and safety problems (accidents, suicides and other types of intentional and unintentional traumas) (43). Alcohol is a major cause of mortality and morbidity in the world (44).

In a population, the prevalence of problems is associated with the overall amount of alcohol ingested and the patterns of consumption. As a result, any increase in the average consumption of alcohol also means an increase in the proportion of the population who drinks a quantity of alcohol associated with problems, and an increase in the number of problems associated with alcohol. A decrease in the average consumption has the opposite effect (45;46). Time series studies in Europe showed a relationship between the variations in the average consumption of alcohol and death due to liver cirrhosis, traffic accidents, other accidents, homicides and coronary heart disease (47). However, drinking cultures somewhat mitigate these effects and, for certain problems, variations are wider in countries where binge drinking

occurs. For instance, death by accident or homicide increases with average alcohol consumption, but this increase is higher in countries where binge drinking is a common way to drink (48;49).

### ***Alcohol's mechanisms of action***

On an individual basis, the mechanisms that partly explain the appearance of social and health problems along with traumas are: toxicity, intoxication and dependence (50).

Alcohol is a toxic substance. Among some children whose mothers were chronic or binge drinkers, it is the action of this toxicity on embryonic cells that is responsible for fetal alcohol-related problems. Liver cirrhosis is another example of alcohol toxicity (50).

Alcohol is also a psychoactive substance that affects motor skills and judgment if ingested until the person is intoxicated. Alcohol intoxication is primarily associated with traumas, early death and major social problems whose nature is also influenced by social and cultural norms (50). In the majority of Canadian statistical studies on population health, the indicator chosen for intoxication is the consumption of five or more standard drinks per occasion.

Finally, alcohol is a substance that can cause dependency (50). Dependency is a medical diagnosis described in the DSM-IV (forth edition of the *Diagnostic and Statistical Manual of Mental Disorders* published by the American Psychiatric Association) (51). This diagnosis is based on the presence of cognitive, behavioural and physiological symptoms indicating that the person continues to consume the substance despite serious problems related to its use.

### ***Low-risk consumption of alcohol***

Alcohol is not all bad for one's health, it may also protect against coronary disease in people aged 40 years and over (50). In Canada, organizations specializing in substance abuse and professional associations produced a series of low-risk drinking guidelines based on the best scientific evidence available in 1999 (52). In short, it is recommended that women not consume more than nine standard drinks per week on a regular basis and men not more than fourteen. No one should consume more than two standard drinks per day and non-drinkers should not start consuming alcohol just for its protective effects against coronary disease. Lastly, certain people should not drink alcohol, namely women who want to become pregnant and those who are pregnant or breastfeeding their baby (52).

### ***Definition of a standard drink of alcohol***

In Canada, a standard drink is defined as containing 13.5 g or 17 ml of pure alcohol (26). This corresponds to a 341-ml or 12-oz bottle of beer (5% alcohol); a glass of wine containing 142 ml or 5 oz (12% alcohol); a 43-ml or 1.5-oz spirits-measuring jigger (40% alcohol); and 85 ml or 3 oz of fortified wine (18% alcohol) (52). The pure alcohol content of a standard drink varies from one country to the next. It is 8 g in Great Britain and 12 g in the United States and in France (26).

### **1.2.2 Prevalence and patterns of consumption of Québec women of childbearing age**

In Québec, the majority of young women of childbearing age drink alcohol. According to the Canadian Community Health Survey (CCHS, Cycle 1.1) by Statistics Canada, conducted in 2000-2001, slightly over 85% of Québec women aged 15 to 44 years drink. This proportion varies from about 80% among 15 to 19 year-olds to about 88% among 25 to 34 year-olds (Table 1), however this variation is statistically not significant.

Among Québec women aged 15 to 44 years who drink alcohol, close to 94% drank less than ten glasses in the week preceding the survey, which corresponds to a low-risk quantity. Therefore, 6% of Québec women consume ten glasses or more per week. Variations were noted depending on age, however they were statistically not significant (Table 1).

Binge drinking is considered having five or more glasses of alcohol per occasion. Among women aged 15 to 44 years who drink alcohol, 27% drank five glasses or more during a single sitting, but less than once a month, and close to 14% binge drank one or more times per month. This behaviour is more common among younger people (Table 1).

Finally, the survey questions make it possible to estimate the risk of becoming dependent, which would be 1.3% of women aged 15 to 44 years. The results given per age category lack precision and cannot be used.

The survey provided comparative Canadian data showing that, compared with women in the rest of Canada, a significantly higher proportion of Québec women consume alcohol (Table 2). However, the same proportion of women drinkers consume amounts of alcohol above low risk thresholds (6.5%) (Table 2). Again when compared with women from the rest of Canada, a higher proportion of Québec women drinkers never binge drink (58.9% vs. 53.3%). Furthermore, binge drinking, at a frequency of at least once a month, is less common among women drinkers in Québec (Table 2). The dependency rate is low in both Québec and the rest of Canada. It is however, slightly lower in Québec (Table 2).

On a last note, the Groupe de recherche sur les aspects sociaux de la santé et de la prévention (GRASP) of the Université de Montréal is taking part in the Canadian component of an international study on alcohol consumption. Data collection will be completed in 2005. The results, which will be available one year later, will provide international comparisons along with information on patterns, contexts, cultural factors and consequences of alcohol consumption.

**Table 1 Alcohol consumption indicators – in percentage and by age group among Québec women aged 15 to 44 years who drink alcohol**

Indicators	Age Groups						
	15-19	20-24	25-29	30-34	35-39	40-44	Total 15-44
<b>Proportion of women drinkers</b>	79.9	87.2	87.6	87.6	86.0	84.5	85.5
<b>Among women drinkers</b>							
Consumption above low-risk thresholds (10 or more drinks per week)	8.4	7.0	5.3	4.9	4.7	8.1	6.4
Binge drinking at least once a month (5 or more drinks per occasion, at least once a month)	23.5	19.7	10.4	9.7	12.1	9.7	13.8

Source: Canadian Community Health Survey, Cycle 1.1.

**Table 2 Alcohol consumption indicators among women aged 15 to 44 years, for Québec and the rest of Canada**

Indicators	Québec		Rest of Canada		
	%	C.I. 95%	%	C.I. 95%	
<b>Proportion of women drinkers</b>	85.5	(84.1-86.8)	78.1	(77.4-78.9)	Significant difference at 95%
<b>Among women drinkers</b>					
Consumption above low-risk thresholds (10 or more drinks per week)	6.4	(5.4-7.4)	6.5	(6.0-7.0)	
Binge drinking at least once per month (5 or more drinks per occasion, at least once a month)	13.8	(12.4-15.2)	17.1	(16.3-17.8)	Significant difference at 95%
Risk of dependency	1.3*	(0.9-1.7)	1.8	(1.6-2.1)	Significant difference at 95%

Source: Canadian Community Health Survey, Cycle 1.1.

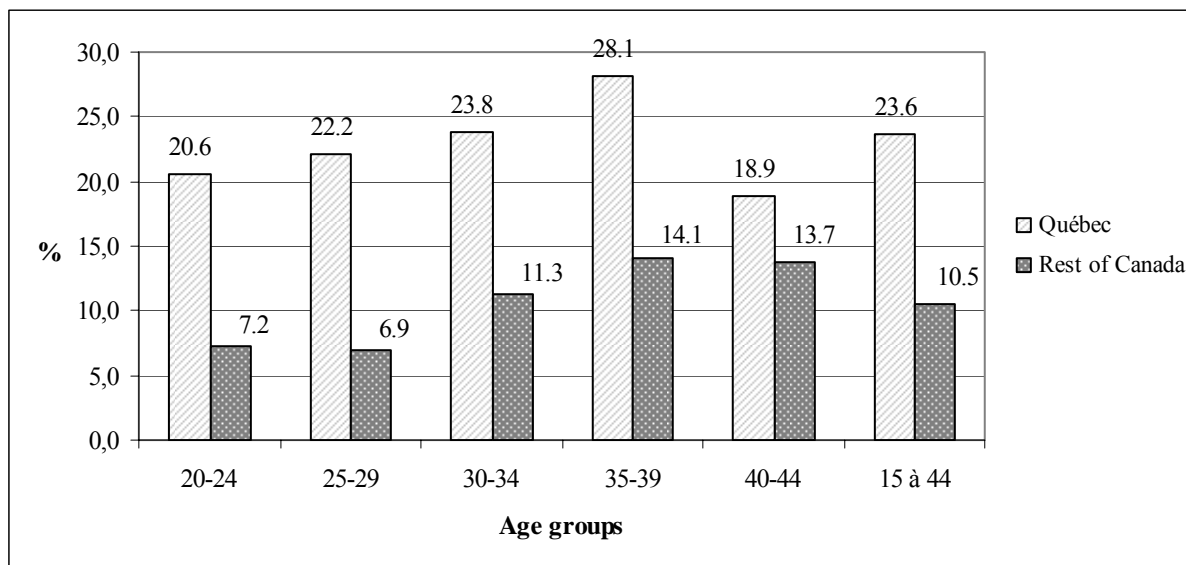
\* Note: Coefficient of variation between 16.6 and 33.3; to be interpreted with caution.

### 1.2.3 Prevalence and patterns of alcohol consumption during pregnancy

#### *According to the Canadian Community Health Survey (CCHS)*

One of the questions included in the CCHS was to see if women having given birth in the last five years drank alcohol during their last pregnancy. Although this information could be biased due to memory problems or social desirability, it is one of the rare sources of data on alcohol consumption in pregnant women. It was possible to learn that one Québec woman out of four said she drank alcohol during her last pregnancy (Figure 1). In the rest of Canada, this proportion is one out of ten. The Survey does not provide information regarding the quantity of alcohol or drinking patterns during pregnancy and it is not known if the pregnant Québec women who do drink consume more or less alcohol than the other Canadian women.

**Figure 1 Consumption of alcohol during the last pregnancy, by age group, for Québec and the rest of Canada**



Source: Canadian Community Health Survey, Cycle 1.1.

***According to two Québec hospital studies***

Studies on the consumption of alcohol among pregnant women were conducted in two hospitals in the Lanaudière region by the public health and evaluation branch of the regional health and social services board (53).

In the first study, dating back to 1997 and 1998, 22% of women said they drank alcohol during their pregnancy. In 2000 and 2001, in another of the region’s hospitals, this proportion was 32%. Although these data cannot be generalized for Québec’s population as a whole, they are the only data, to our knowledge, that provide information on the incidence of alcohol consumption during pregnancy. The majority of women drinkers, or 56%, had less than one drink per week. Therefore, some 44% of these women consume alcohol on a weekly basis: 31% had one drink per week, 7.4% had two and 5.4% had three or more (53). Compared with the whole population, this means that 14% of pregnant women drank alcohol each week (44% x 32%).

***In three Nunavik communities***

A team from the public health research unit of the CHUL (CHUQ) conducted a study on child development in three Nunavik communities (54). The 248 pregnant women who took part in the study were questioned about their use of tobacco, alcohol and drugs, at three different times (midway through pregnancy and one month and eleven months after giving birth) (55). Overall, 60% of participants said they drank alcohol during their pregnancy and the average amount of alcohol ingested was six glasses per drinking occasion. The alcohol drinkers said they reduced the number of drinking occasions from one day out of six before the pregnancy to one day out of twenty-five during the pregnancy (55).

Close to half the women drinkers (49%) binge drank, i.e. 30% of the pregnant women studied. These binges occurred on average ten times. When this happened, the average consumption was twelve drinks

(the maximum was thirteen drinks). Among the study's participants, 5% drank at least 0.5 oz of pure alcohol per day during pregnancy – an amount that has proven to have harmful effect on the foetus (55).

The RISQ (Recherche et intervention sur les substances psychoactives – Québec) is piloting a major research project on the consumption of alcohol in Nunavik's Inuit communities. Started in 2004, this study will provide information on the consumption patterns of young people and families along with a better understanding of the beliefs about drinking alcohol as well as its consequences in these communities. In addition, the National Public Health Institute of Quebec and the Public health research unit of the CHUL (CHUQ) are currently preparing a survey on Inuit health in fourteen Nunavik communities. This survey will contain questions on their lifestyles, including alcohol consumption. Data collection will start in September of 2004. These two projects are carried out in conjunction with the Nunavik Regional Board of Health and Social Services.

#### **1.2.4 Awareness of the effects of alcohol use during pregnancy and FAS**

In late 1999, a nation-wide survey ordered by Health Canada was conducted among 902 women and 303 men (56). The survey examined awareness of the effects of alcohol use during pregnancy and of FAS and FAE. According to our scientific literature review, it is the only study that presents the beliefs and knowledge of women, both Quebecers and Canadians, on the topic.

The findings suggest that Québec women perceptions differ from those of women outside Québec when it comes to the effects of alcohol consumption during pregnancy. Québec women are more likely to think a small amount of alcohol consumed during pregnancy would not lead to serious harm to the unborn child. They are also less likely than other Canadian women to think that smaller amounts of alcohol will be harmful and less likely to believe that alcohol use during pregnancy can lead to life-long disabilities in a child. They are less likely to cut back or stop alcohol use to increase the likelihood of having a healthy baby. It should be mentioned that the survey does not go into detail about what constitutes "safe consumption" for Québec women. Québec men are also different from men from other provinces. Québec men are less willing to encourage their spouse or partner to stop alcohol use during pregnancy or to stop alcohol consumption themselves (56).

It should also be pointed out that a lesser proportion of Québec women (56%) recall seeing information on the effects of alcohol use compared with Canadian women as a whole (72%). When it specifically comes to fetal alcohol syndrome, 32% of Québec women recall having heard about it, compared with 71% of Canadian women. However, all women have difficulty providing a detailed description of the syndrome (56).

In terms of methodology, it should be noted that since the size of the Québec sample in this survey is unknown, it is not possible to judge results for their real value and representativeness. Furthermore, the report that was made available does not always give tables with actual numbers so that Québec women's answers can be compared to those of Canadian women. We therefore cannot analyze for ourselves the interpretation of survey results that highlight Québec differences. It should be noted that these results date back five years and many changes may have occurred since then.

There are only partial data relating to the beliefs, knowledge and behaviours of women and alcohol consumption during pregnancy and its effects. However, the results of the Health Canada study lead us to believe that in 1999, Québec women were more tolerant when it comes to the consumption of alcohol during pregnancy. These findings are in line with the results of the CCHS in which a larger proportion of women said they consumed alcohol during their last pregnancy.

One might wonder about the elements that could explain the differences between Québec women and Canadian women when it comes to alcohol consumption:

- Do the beliefs and behaviours of Québec women stem from a lack of knowledge on the risks associated with alcohol consumption during pregnancy?
- Are the answers provided by Québec women the reflection of a more tolerant consumption culture that removes social desirability biases when women are asked about their alcohol use during pregnancy?

### **1.2.5 Profile of women with problems related to the consumption of alcohol or drugs**

In Québec, in conjunction with the RISQ-CIRASST, researchers recently looked into the issue of maternity and substance abuse. They first conducted a survey of the literature published by the Comité permanent de lutte à la toxicomanie (CPLT) (57). They then conducted research combining mixed research methods, i.e. that are both quantitative and qualitative, which made it possible to describe the events in a pregnant woman's life that have led her to abuse alcohol or drugs (58).

A similar approach, exploring maternity and addiction, was also taken by Tait and Contois (59). Their work focused on health issues linked to substance abuse by Aboriginal women. The qualitative methodology pursued, along with the ethnographic methods used, made it possible for these authors to establish a profile of Canadian Aboriginal women, mainly those living in Québec's urban areas and those in Saskatchewan.

In general, the profile of women that emerged is comparable to that of other North American studies. When describing the female population at risk for consuming alcohol or drugs during pregnancy, socio-demographic characteristics such as being unmarried, poorly educated and unemployed are often mentioned (57;58;60).

Women's dependency on alcohol and drugs is associated with their past as victims of violence and several authors agree that being or having been abused, whether sexually, physically or psychologically, is common among women who are regular alcohol or drug users (58-63).

Finally, according to some authors, the simultaneous use of other drugs and tobacco also contributes to a mother's risk of alcohol consumption during pregnancy (60;63). Research by Guyon *et al.* (58) shows a similar reality in Québec. In their study conducted with a sample group of 54 women from five hospitals in Québec, only one mother did not have problems caused by at least two substances. Québec caregivers dealing with women having alcohol consumption problems also suggest that multiple drug use is



increasingly widespread. Many women consume various drugs (cocaine, heroine, ecstasy, PCP, methadone) in combination with alcohol. In Québec, among women with substance-abuse difficulties, alcohol is rarely taken alone and becomes a prelude to illegal drug abuse or a consequence of it.

This general portrait of women may however be biased. A literature survey, done in Québec by Guyon *et al.* (57), points out that research on the profile of women taking psychoactive substances often encompasses vulnerable groups from extremely poor environments. While poverty is part of the daily lives of many pregnant alcoholic women, it is important to remember that sometimes even well-off women may have substance abuse problems. Both in privileged and underprivileged areas, there are women who hide their condition and remain vulnerable in several respects, according to the health care workers met. These women are isolated, often having broken off ties with their family. Having oftentimes spent their childhood in a dysfunctional family has deprived them of good parental role models (58). Their close relationships in adulthood are just as dysfunctional. In short, as stated by a health care professional, substance abuse is not an accident in their lives. Women use alcohol and drugs to self-medicate so they can temporarily block out their emotional pain, manage their stress and traumatic experiences, satisfy their need for thrills, relieve boredom, feel less rejected and get through the hard times (58;64).

We have provided a portrait of women who are chronic abusers of alcohol, a phenomenon that is known and documented. However, another way of drinking alcohol is also known to have harmful effects on fetal development. It is what is commonly called “binge drinking” or sporadic episodes of excessive drinking (five or more standard drinks per occasion). Except for a Canadian study that is highly biased when it comes to the women who participated,<sup>2</sup> very few studies seem to have specifically looked at what causes binge drinking in pregnant women (65). According to various informants working with the Inuit in Nunavik and Québec’s Aboriginal populations, this type of drinking is most typical for these groups.

When it comes to Aboriginal women experiencing alcohol-related difficulties, their profile is shaped by a distinctive cultural and historical context. The respondents questioned have said time and again that, for the Aboriginal people, the problem of alcohol consumption belongs to the whole community and cannot be considered just a personal problem. Alcohol consumption problems cannot be disassociated from the multitude of factors that put Aboriginal women at risk. According to Tait and Contois (59), who looked at Aboriginal women in Canada, in addition to the factors shared with most women drinkers, Aboriginal women face great poverty, socio-economic marginalization, racism, language barriers, distrust of non-Aboriginal social workers, the risk of disease and accidents and the consequences of having been placed in residential homes when they were young (59;64). Still, for Tait, heavy drinking is not really a choice, but is rather rooted in different variables (environmental, physiological, psychological) that act together to cause substance abuse. Despite the above, studies rarely take a real close look at the social, economic, political and cultural factors that have a bearing on alcohol consumption among pregnant Aboriginal women (64).

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<sup>2</sup> The sample comprises all women who, between 1985 and 1994, phoned the consultants at the Motherisk program in Toronto to seek help for their drinking binges during pregnancy. The women’s binges were, in 67.7% of cases, accidental (65). The study therefore provides little information on the profile of women who repeatedly binge drink.

## PART TWO: INTERVENTION

Addressing fetal alcohol syndrome means getting involved upstream to prevent cases and downstream to deal with the problem once it arises. In this section, various prevention and intervention strategies are presented along with thoughts on these strategies. We will first provide a description of the Health Canada Initiative, upon which Québec and Aboriginal communities have based many of their FAS-related activities. In our presentation of the Initiative, we will explain what has already been done in Canada and in Québec, which consequently brings to light the lesser-dealt-with aspects of intervention. Then, since alcohol consumption is frequent among Québec women of childbearing age, the second section will deal with FAS prevention in the general population, and specifically among pregnant women and women of childbearing age. Thirdly, we will look at intervention among women with problems related to alcohol consumption as a FAS prevention strategy. The fourth section outlines current strengths and weaknesses in health care and services offered to affected persons, their families and their communities. Indeed, much of what has been learned about Québec's health care needs comes from the daily experience of parents with affected children and the clinical experience of professionals. This part finishes with a section on how health professionals perceive their caregiver role when it comes to FAS and alcohol consumption by pregnant women.

### 2.1 HEALTH CANADA INITIATIVE

#### 2.1.1 Description of the Canadian FAS Initiative

Despite the fact that the federal government had already launched a framework to address the prevention of maternal alcoholism and alcohol-related birth defects as early as 1986, it was really in June of 1992, with the publishing of a report on fetal alcohol syndrome by the Standing Committee on Health and Welfare, Social Affairs, Seniors and the Status of Women, that Health Canada truly began to focus on this problem (66). That is when Health Canada launched a campaign for the prevention of FAS/FAE.<sup>3</sup>

That same year, the first Canada-wide symposium on the issue was organized by Health Canada and held in Vancouver (66). People from across the country and from various backgrounds, along with workers and specialists in the field, came together to share their knowledge and propose priorities for action. Starting then, FAS/FAE was integrated into different Health Canada programs. Conferences, workshops and working groups on the issue were funded across the country (66). In 1994, a national information centre, with a major databank and a reference service and phone line, was set up at the Canadian Centre on Substance Abuse and was made available to the public, especially for use by health care professionals, caregivers, educators and researchers (67). In 1996, Health Canada, the Canadian Paediatric Society and close to twenty national associations adopted the *Joint Statement: Prevention of Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE) in Canada*, which, with the support of health care professionals, aims to reduce fetal alcohol-related disorders (67).

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<sup>3</sup> At that time, Health Canada used the term FAS/FAE

All this effort has led to what is now called the *Health Canada Initiative on Fetal Alcohol Syndrome and Fetal Alcohol Effects (FAS/FAE)*. In 1999, the federal government announced more funding for the Canada Prenatal Nutrition Program (CPNP) to focus more attention on FAS/FAE (68). This increase brought the funding envelope to \$11 million over three years. The Initiative sponsors many activities designed to provide better understanding of the situation in Canada and better intervention and adaptation of the orientations to come<sup>4</sup> (68). Here are a few examples:

- Studies
  - Surveys of the general public on their knowledge and attitudes concerning the effects of alcohol during pregnancy and fetal alcohol syndrome (56).
  - Situational analysis (69).
  - Literature review on "Best Practices" (7).
  - Surveys of physicians on their knowledge and attitudes concerning fetal alcohol syndrome (70).
- Consultation
  - Consultation of agencies funded by the Community Action Program for Children (CAPC), the Canada Prenatal Nutrition Program (CPNP) and the Aboriginal Head Start Program (AHS).
  - Consultation of Health Canada's "regional" representatives.
- Creation of committees, including the National Advisory Committee.
- National awareness and information campaigns.
- Organization of workshops and conferences.

Certain organizations and groups are following in Health Canada's footsteps and proposing research and publications on fetal alcohol syndrome. One example is the Position Statement published by the Canadian Paediatric Society in 2002 (6).

Recently, at the end of 2003, Health Canada proposed a *Framework for Action* to guide and support provinces, territories, agencies and communities wishing to plan and implement activities involving what Health Canada has now termed FASD (Fetal Alcohol Spectrum Disorder) (30).

Since the start of the Initiative, Health Canada, through the First Nations and Inuit Health Branch, has clearly established the public health priority that FAS/FAE represents among certain Aboriginal communities. Already in 1997, the document *It Takes a Community* was drafted, specifically focusing on the Initiative of First Nations and Inuit communities in the area of fetal alcohol syndrome and fetal alcohol effects (71).

Health Canada's fetal alcohol syndrome team uses mostly a perinatal prevention-based approach, whether among Aboriginal people or population in general. However, the persons interviewed state that concerted action with other sectors is also important. Such collaboration has been achieved with the education sector and the Drug Strategy and Controlled Substances Program, but would also be welcome in the legal

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<sup>4</sup> See Appendix 1 for access to Health Canada's reference documents and reports.

and correctional systems, disabled persons services, front-line services for the homeless and the Royal Canadian Mounted Police.

### 2.1.2 Projects in Québec

Since the very beginning of the Canadian Initiative, FAS has come under the CPNP. In Québec, the Initiative has given rise to various projects:

#### *FAS Day: September 9*

The first activities began in 1999 when the person hired to oversee the FAS issue in Québec decided to bring the province up to par with other Canadian provinces. Since then, activities are planned for FAS Day every year on September 9.

#### *SAFERA*

In 2002, Health Canada's FAS/FAE strategic project fund was made available to the Québec organization called SAFERA for a three-year period.<sup>5</sup> The project was designed to create a toolbox on fetal alcohol syndrome: brochures, a website, a newsletter, a video and a conference.<sup>6</sup>

#### *Translation of training material*

The French translation of reference material on fetal alcohol disorders is among Health Canada's priorities. Among the translated materials, the most important ones are the following two training documents:

- *Understanding FAS* is a training manual and video for professionals and family support groups (72). It was widely used in training sessions offered in seven Québec cities. Some 200 representatives were reached from CAPC/CPNP projects along with the Fédération des organismes familiaux and certain professionals from the Agences de développement de réseaux locaux de services de santé et de services sociaux.
- *Supporting change* is a training program for physicians about pregnancy and alcohol (73). It is available upon request but has not yet been systematically distributed, which is something that could be done in coming years. The document mainly focuses on intervention, counselling and medical approaches. Many references are given on the telephone help line Motherisk,<sup>7</sup> now bilingual, that among other things provides FAS-related information, both to the general public and to health care and social services professionals.

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<sup>5</sup> In fact, two projects have been funded: the other is an Aboriginal project, about which we have little information.

<sup>6</sup> The activities of SAFERA are described later on, at 2.2.1

<sup>7</sup> Motherisk is a Toronto-based agency (Hospital for Sick Children), composed of a multi-disciplinary team of clinicians and researchers (pharmacology, genetics, nutrition, obstetrics, preventive medicine and psychology), associated with the University of Toronto.

### **2.1.3 Projects of the First Nations and Inuit of Québec**

FAS is more prevalent in First Nations and Inuit communities. Activities in these communities emphasize local efforts and initiatives to deal with the problem. The Initiative's impact on Aboriginal communities is important. The First Nations and Inuit Health Branch (FNIHB) subsidizes several projects mainly involving information and prevention:

#### ***First Nations and Inuit Health Branch***

The FNIHB mainly acts as a funding agency for other organizations, which carry out the activities. For example, the Association des femmes autochtones du Québec (FAQ) received funding for a conference. A grant was also provided for a health forum. Other funds were provided so four Native women could take *Community Learning Asset Mapping*.<sup>8</sup> Some activities are also carried out by the branch. The agency provides material to pregnant women, in the form of a kit, and annually contributes to FAS Day.

#### ***Cree Regional Authority***

In 2000-2001, the Cree Regional Authority obtained a grant from the Initiative to carry out a training activity on FAS, which should be proposed to all Native communities in Québec. This training seems to be a major event in Québec, since a number of respondents mentioned this activity.

Since 2002, more than 75% of Québec's First Nations and Inuit communities have received training. In February 2004, eight visits to Inuit communities and six to other communities in the south were scheduled. The three-day training is given to a group of people from the community who are concerned by FAS. This group may be made up of elected officials, professionals from the health, social services and early childhood fields, caregivers, teachers and parents. A half-day is devoted to devising a community action plan tailored to the community visited. The instructor also proposes individual meetings during the evening. Once the training is over, the action plan has no definite follow-up, unless it is unofficial.

#### ***The First Nations of Québec and Labrador Health and Social Services Commission (FNQLHSSC)***

The FNQLHSSC, which represents all 54 communities of the First Nations of Québec and Labrador (including Cree and Inuit), is also very active when it comes to FAS. In 2001-2002, a directory of resources available on the Internet was translated (FNQLHSSC). In 2002-2003, the Commission conducted a needs analysis and produced a FAS kit especially for first-line workers, health care providers, caregivers and educators. A flip chart was also translated into French. Many other activities are scheduled in the action plan prepared by the FNQLHSSC, and are designed, among other things, to detect and manage cases. They are however contingent on funding.

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<sup>8</sup> This training is designed to make participants (one Health Canada employee and three First Nations members working at a day-care centre and at the FNQLHSSC) apt at giving workshops on *Community Learning Asset Mapping* among First Nations communities. *Community Learning Asset Mapping* helps communities become aware of their strengths, and to subsequently lean on those strengths to devise a plan aimed at reducing FAS and other fetal alcohol disorders in the community (Health Canada, FNIHB).

### ***First Nations Education Council***

This project stems from the First Nations Education Council in Wendake. It contributes to providing training and creating tools and methods for special education teachers. Front-line workers and young people are also targeted: the former to increase their expertise and documentary resources, the latter to become more knowledgeable on the subject. A thousand people have been reached by this project (74).

### ***Research in Nunavik***

The research project, presented above and designed to establish the morphological criteria of FAS among the Inuit, was possible through a grant from the Health Canada Initiative.

## **2.2 FAS PREVENTION IN THE GENERAL POPULATION**

### **2.2.1 FAS information**

Providing the general public with information on FASD is a very specific prevention activity.

A Québec organization, SAFERA, focuses specifically on the prevention of FAS and other fetal alcohol disorders. This private not-for-profit organization was created in 1998 by the adoptive parents of a child affected with FAS and by a teacher.<sup>9</sup> Since that time, members give lectures and offer training and information in several Canadian provinces and numerous regions in Québec. They also maintain contacts with international researchers and publish a quarterly newsletter. The mission of SAFERA also involves participating in written and televised media events and making elected officials more aware of the problem.

As previously mentioned, SAFERA received a grant from Health Canada, in September 2002, for a three-year project aimed at developing a FAS toolbox. The first year, the agency's members prepared brochures, improved their website and broadened the distribution of their newsletter. The year 2003-2004 was devoted to making a video, which was launched in April 2004. The last year's project was to organize a conference, in December 2004. The Ministère de la Santé des Services sociaux of Québec also contributed to the conference. It was Québec's first FAS conference. Persons interviewed from Health Canada pointed out that all Canadian provinces have had a conference on the subject and that Québec had been the exception to date. Without knowing all the details of their involvement, it is expected that members from the First Nations will also participate in this event.

SAFERA's staff also plans to organize support groups for the parents of affected children starting in 2004. They are also working on other projects, especially for training, since they feel that service providers do not have enough knowledge of the problem.

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<sup>9</sup> Source: SAFERA website at <http://www.safera.qc.ca/menu.html>

There are other isolated training and information activities for the public and workers in the field offered by people with expertise or vast personal experience on the issue. These persons work in conjunction with agencies or health care professionals to carry out their activities.

Internet also offers a wealth of information on the subject of FAS. The main websites are listed in Appendix 1.

### **2.2.2 Measures to prevent alcohol-related problems in the general population**

The problem of alcohol consumption among women of childbearing age is part of a larger context, that of the alcohol consumption of the general population or the community in which the women live. Other than individual factors, the main influences pertaining to alcohol consumption are social norms, physical access to the product, price and access to alcohol-related social and health care services (75).

It is important to define what these contextual elements are. On the one hand, it makes it possible to view the problem of alcohol consumption as a social responsibility and avoid having women carry the burden of the problem alone. On the other hand, it makes it possible to identify prevention strategies that can have an impact the general public, including women of childbearing age.

Research over the last three decades has made it possible to identify prevention measures based on actual data. A synthesis of work done was first published in 1994, and then again in 2003, by a group of some fifteen international scientists (75;76). Price increase, through taxation, is very effective in reducing alcohol consumption and associated problems (75), although just up to a certain point, if the black market becomes involved and counters those effects (75). Measures that control physical and legal access have also proven effective: limits on the hours and days of sale, limits on the number of sales outlets, minimum age for purchasing alcohol, greater restrictions on drinks with higher percentages of alcohol and rationing purchase amounts per person (75). The choice of strategies must be tailored to the specific context of the society and community and must be implemented with the public's approval. One of the first strategies is therefore to develop public support for implementing such measures (77).

Drinking-driving countermeasures and early treatment programs are also effective in reducing the harmful consequences of alcohol consumption (75). In the United States, labels on alcoholic beverages are designed to inform the public of the dangers of drunk driving and of the risk to the foetus when pregnant women drink. Evaluations to date show increased public awareness, but very little change in behaviour (75). Information programs in schools and colleges do not seem to affect drinking habits (75).

### **2.2.3 Information on alcohol consumption during pregnancy**

#### ***Information provided in different countries***

Following the first studies involving fetal alcohol syndrome in the United States, the National Institute on Alcohol Abuse and Alcoholism called for the prevention of alcohol-related birth defects (78). In 1981, it was the Surgeon General's turn to get out the message, advising all women who were pregnant or planning to get pregnant to abstain from drinking alcohol while pregnant (78). The warning even covered food or medicine that might contain alcohol. Still in the United States, in 1989, legislation was enacted to

attach warning labels to all alcoholic drinks sold in the country (79). The United States embarked upon an information campaign targeting the general public and, specifically, pregnant women and women of childbearing age. These policies were criticized by some American authors who felt that the scientific data did not support the idea that there is no safe alcohol level during pregnancy (12;80). They suggest that American policies are based on value judgements and a moral approach to the problem, arising from different social and historical contexts (80).

A special issue published by the French magazine *Alcoologie et Addictologie* on alcohol use during pregnancy provided an overview of the official recommendations on alcohol consumption during pregnancy in various countries (81). The most common message is that of abstinence. Along with the United States, that is the case for Austria, Ireland, Sweden, France, Germany and Australia. Great Britain and Denmark have opted to advise "extreme moderation." Great Britain presents two slightly different messages. That of the Royal College of Obstetricians and Gynaecologists "is based on a methodology of evidence-based medicine" and suggests that prudence would be to "limit oneself to a maximum of one standard drink per day." The Department of Health, along with the message of abstinence, suggests a maximum of one to two alcoholic drinks not more than twice a week. Lacking scientific evidence, Denmark, which promoted abstinence up until 1999, now suggests that women should avoid drinking as much as possible while pregnant. In the event they do drink, they should not exceed one glass per day, and not drink every day (81).

### *Canadian message*

In Canada, the message advanced by Health Canada is abstinence (82). It is considered that the risks of damage to the health of the foetus when a woman consumes a small amount of alcohol during pregnancy are unknown. Since we cannot know for sure, prudence is advised and abstinence is recommended:

"Alcohol consumption during pregnancy – any amount of alcohol – could be a sentence of lifetime disability for an unborn child. [...] As researchers have not been able to determine a safe level of drinking during pregnancy, there's only one safe course if you are pregnant or wish to become pregnant: don't drink alcohol. Even moderate alcohol consumption during pregnancy can have serious, long-term adverse effects on the foetus and child. Some studies have shown that children born to mothers who have on average one to two drinks per day, or may occasionally have up to five or more drinks at a time, are at increased risk for learning disabilities and other cognitive and behavioural problems" (82).

### *Situation in Québec*

The data on the habits of Québec women, shown in Table 1 of this report, show that close to 86% of women aged 14 to 44 drink alcohol and that some 19% of them consume excessively at least once a month. That means that 16% of all women of childbearing age have adopted this behaviour. If they become pregnant, it is likely that some of them will drink before their pregnancy is confirmed, and possible that some of them will drink abusively and expose the foetus to large amounts of alcohol.



Recommendations to pregnant women concerning alcohol consumption during pregnancy were jointly made by the Collège des médecins du Québec and the Ministère de la Santé et des Services sociaux (MSSS) in conjunction with Éduc'alcool. They are available in a question answer form, in a brochure entitled: *Pregnancy and Drinking: Answers to Your Questions*<sup>10</sup>. The brochure is distributed mainly by physicians. It is inserted in the pregnancy handbook *Nine months for life*<sup>11</sup> which also talks about alcohol consumption during pregnancy.

The brochure emphasizes that avoiding alcohol during pregnancy is a safer choice. However, occasional drinking, cutting down on drinking or drinking moderately remain other options for pregnant woman. The term "moderate" however is not defined in the brochure:

Drinking moderately and on occasion is the responsible line of behaviour during pregnancy. Avoiding drinking is the safest choice [...] The risks of affecting the foetus are greatly reduced when a woman drinks moderately (a glass or two).

In the pregnancy handbook, the issue of alcohol is addressed along with other lifestyle habits (for example, taking folic acid, using tobacco and being exposed to infections). The message again suggests that abstaining from all alcohol consumption is a safer choice. However, the tone with which the risks to the foetus and the mother's lifestyle habits are addressed is uneven. Recommendations on other lifestyle habits are more directional than those involving alcohol, which could result in trivializing alcohol consumption.

Certain individuals interviewed for this report consider that moderate or occasional consumption should be no cause for alarm and assert that women should make their own decisions in matters of alcohol consumption. They also underscore the fear that excessively alarmist messages might impose a burden of guilt upon women who drank at the beginning of their pregnancy.

Thus the messages concerning prevention proposed in Québec and in Canada differ from one another, and the people we met emphasized that this constitutes a problem. A number of Québec service providers have received fetal alcohol syndrome training promoting zero consumption during pregnancy from the *Canada Prenatal Nutrition Program* and the *Community Action Program for Children*. The service providers also affirm that they repeat this non-consumption message in their own practices. The fact that various health care professionals receive and convey different messages makes the advice given to women concerning alcohol consumption during pregnancy confusing. A number of people interviewed for this report worry about the inconsistencies of the views expressed and believe that it is necessary to speak with one voice. Without uniformity, there is a risk that individuals will look for or hear only what suits them. In this regard, we have been told about how future parents, during prenatal courses, will insist on receiving the consent of a health care professional when it comes to consuming moderate quantities of alcohol during pregnancy.

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<sup>10</sup> In 2001, the Collège des médecins and the MSSS promoted this publication among physicians. In 2002, two advertisings were broadcast on the radio, as a means of publicizing the brochure among the general public. The website is at: <http://www.edualcool.qc.ca/doc.cfm?Ca=297&Doc=625>

<sup>11</sup> Collège des médecins *Nine months for life*.

Obviously, regardless of the points of view, the goal of the messages is always to avoid exposing the foetus to harmful quantities of alcohol. As is the case for any teratogen, these alcohol levels may be derived from studies of animals and humans (1). However, uncertainty still remains as to the individual vulnerabilities of the pregnant woman and the foetus (1). Given these unknowns, the recommendation to avoid drinking alcohol during pregnancy, being one hundred percent safe, is the one generally adopted by national and professional organizations.

Nevertheless, adopting another approach might make it possible to address this issue and decide upon the message to convey. For instance, in the area of occupational and environmental health, when the risk exposure level for a given product is known, it is divided by a safety factor which would be of low risk for the entire population, above and beyond individual vulnerabilities. A factor of ten is usually applied. This approach is, moreover, discussed in an article where it is shown that the consumption level at which children present development difficulties is seven consumptions per week (six standard consumptions in Canada) (25). When these authors apply a protection factor of ten, they come to consider the consumption of 0.7 glass per week, or one glass every ten days, to be safe (25). Establishing a low-risk level based on scientific evidence would have the advantage of keeping the debate from focusing only on values that are not always explicit, and that seem, up until now, to explain both abstinence and moderate consumption.

However, whether the prevention message promotes abstinence, as is the case in a number of countries and in the rest of Canada, or includes tolerance of low-risk alcohol consumption at a level that needs to be defined, the message must be consistent and must also present accurate information enabling women of childbearing age to make informed choices regarding their own alcohol consumption.

Lastly, we must accept the fact that despite all the efforts to provide information, it is likely that such an endeavour will have no effect whatsoever on the drinking patterns of women belonging to the group at highest risk. More intensive services are required to encourage the latter to decrease their consumption of alcohol and other drugs. The information material distributed to all pregnant women is nevertheless an appropriate instrument for informing these women at risk as to the existence of professionals and services that can help them.

## **2.3 PREVENTION OF FAS AMONG WOMEN WITH ALCOHOL-RELATED PROBLEMS**

### **2.3.1 Identification of the problems and brief interventions**

#### *Difficulties encountered*

Some research suggests that with the motivation accompanying the arrival of a child, the support of a partner, concern for one's own health, and professional support, pregnancy represents an opportunity for the pregnant woman to consider changing lifestyle habits that may be detrimental to her health, and/or to the health of her foetus (58). Nevertheless, many obstacles still remain.

Pregnant women who consume alcohol or drugs face tremendous social stigmatization that imprisons them within the confines of their problem (62). Yet, a number of them are aware that their consumption jeopardizes the healthy development of their child. They experience a feeling of guilt and shame, which makes them afraid of losing their children and may cause them to distance themselves from health care personnel (58). Delays in going for prenatal care may be caused by a number of factors: drug consumption can cause amenorrhoea and thus delay recognition of the pregnancy; the onset of pregnancy may give more power to a violent man (the future father of the child); the women are afraid of being forced to undergo treatment; and access to clinics may sometimes be difficult (babysitting and/or transportation problems) (62). As a result, women with alcohol- or drug-consumption problems are slow to turn to resource persons for addiction treatment or obstetrical care (62;83). Certain Québec service providers working in the perinatal field speak of women arriving at the clinic during their fourth or even fifth month of pregnancy.

This sort of guilt and distrust has other effects during their contacts with professionals. It is difficult to establish a bond of trust, and the slightest judgment or suggestion that their child may be removed from the home causes them to become withdrawn and remain silent about their drinking (57).

### ***Questionnaires about alcohol consumption among pregnant women***

Since 1994, the Canadian Task Force on Preventive Health Care (formerly the Canadian Task Force on the Periodic Health Examination) has recommended that physicians “include screening procedures (self-administered questionnaires, interviews, or clinical judgment) to identify the drinking patterns of pregnant women” and offer them counselling (recommendation B). However, the task force realizes that “obtaining specific information concerning the alcohol consumption of certain patients is a real diagnostic feat” (84).

For their part, the service providers interviewed insist that every little clue should be taken into consideration when it comes to identifying alcohol abuse among pregnant women. Given that alcohol is often consumed in conjunction with other drugs (tobacco, illegal drugs, methadone, etc.), any use of psychoactive substances should lead to questions about alcohol consumption; one must not wait until a drunken woman arrives for a prenatal care appointment. Comments such as “there’s no more beer coming into my house now” or “as soon as I learned that I was pregnant, I stopped doing cocaine” or “I’m only a social drinker” should be cause for concern and be dealt with seriously during a more extensive discussion with the patient. In order to obtain the most accurate information possible about the drinking patterns of the women consulting them, professionals have to put them at ease, ask specific questions and, above all, avoid making them feel guilty (85).

In order to facilitate the work of professionals who see pregnant women, the use of standardized questionnaires is being recommended more and more frequently to detect cases (86). The T-ACE and the TWEAK are two tests recommended for the screening of high-risk alcohol consumption among pregnant women (87). These tests include four and five questions respectively and take less than one minute to administer. They focus on the consequences, behaviour patterns and perceptions associated with high-risk alcohol consumption, and not on the amount consumed (85). Both tests have a good track record in detecting high-risk consumption among pregnant women (85;88-90). The Alcohol Use Disorders Identification Test (AUDIT) is another test used for screening high-risk alcohol consumption and which has shown its effectiveness in the general population and which can also be used with pregnant women

(87;91). It does, however, have ten questions, which may make it rather long to complete for someone who is not seeking help for this problem. The T-ACE and TWEAK tests, being shorter, are probably easier to use in a perinatal care context.

The decision to use a screening test is based not only on its validity but also on the prevalence of the problem being sought since even for a test with a proven track record, there is a very high proportion of false positives when the prevalence level is low (85). As a result, these tests are not useful for diagnostic purposes, and for this reason a positive result should never be interpreted as definitive. For a clinician, physician or other health care professional, these tests instead provide an opportunity to open the lines of communication with the woman in question in order to better understand her drinking habits and then to intervene in an appropriate manner.

### ***Brief interventions***

In a climate of trust, a health care professional is able to intervene in a simple manner in order to help individuals become aware of the risks that their consumption entails and to give them advice as to how to reduce this consumption. The acronym FRAMES summarizes the strategy (92).

**Feedback:** review the problems that the person is experiencing due to alcohol consumption and pass on comments;

**Responsibility:** consider that changing is always the person's own choice and responsibility;

**Advice:** provide advice concerning how to reduce consumption or stop drinking;

**Menu:** propose various means of changing the behaviour in question;

**Empathy:** use an empathetic, encouraging approach; and

**Self-efficacy:** strengthen the person's confidence in her/his own capacity to change.

This intervention lasts only a few minutes. Sometimes the clinician hands out reading material such as guides and folders. This approach is often called bibliotherapy (92). A multicentric study conducted in ten countries by the World Health Organization (WHO) has proven the effectiveness of screening and counselling for people who drink too much, and a recent meta-analysis has confirmed these conclusions (93;94). There are few studies on the effectiveness of brief interventions among pregnant women. However, according to a recent literature review on the subject, it is possible that they are effective for this population group (95).

The "motivational approach" is a type of brief intervention designed to increase the capacity for change by resolving a person's ambivalence (96). It involves a counselling approach through which the professional explores the pros and cons of consumption (or of the behaviour to be changed) with the person in a non-confrontational atmosphere of trust and respect (96). A large-scale research project (*Project MATCH*) has demonstrated that this method is as effective as other treatment approaches in terms of reducing alcohol consumption and associated problems (97). In addition, it seems that neither the length nor the intensity has any bearing on the results and that "more is not necessarily better" (96). When the approach was tried with pregnant women, changes in drinking patterns were observed (98). The results of a preliminary study administered by the Centers for Disease Control (*Project CHOICES*) show

that the method has also produced promising results with respect to reducing prenatal exposure to alcohol (99;100). It was carried out among women of childbearing age who drink and who, following the intervention, chose either to use contraception or to reduce their alcohol consumption. An experimental study with a control group is currently underway to verify these results (99;100).

Studies of brief interventions therefore suggest that an evaluation of alcohol consumption involving a pregnant woman or a woman of childbearing age, carried out with empathy and without value judgment, can help the woman in question recognize the problem and find solutions in order to initiate a change in habits (101).

### **2.3.2 Perinatal and early childhood interventions**

Several women go to their neighbourhood CLSC to get nutritional advice and food supplements under the OLO program (coupons for eggs, milk and orange juice) and the Canada Prenatal Nutrition Program (CPNP). Some attend prenatal classes. Others seek consultation to have access to social or medical services. The perinatal and early childhood services offered can be excellent opportunities to identify women who have problems related to alcohol or drug consumption, and guide and support them in an effort to steer them toward change.

CLSCs also dispense “integrated perinatal and early childhood services” to families living in vulnerable situations. These services target pregnant women and new mothers under 20 years of age and older women who have not had much schooling and who live in extreme poverty (very little formal education with family incomes below the low-income threshold). The services have two major components: supportive care of families and the creation of environments conducive to good health. The first consists of home visits by a specially trained caregiver (“a Navigator”) who fosters a relationship of trust with the parents and is in charge of following up on the child until school age. The caregiver serves as the link between the family, the services and the community. A relationship of trust and continuity is therefore the basis of intervention with vulnerable families.

Since pregnancy can also be a time for women who are grappling with alcohol and drug issues to take charge of their lives and, since they need assistance to do so, such “integrated services” can also provide support throughout the prenatal period and the first few years of the child’s life. They were not designed specifically for alcoholic and drug-addicted women, but for all those who live in difficult situations. Women experiencing problems with alcohol and drug consumption might then be included under this umbrella of services.

American studies maintain the hypothesis that such a model of services could indeed help them. Since the 1990s, at least two comprehensive US programs were set up to lend support to alcoholic or drug-dependent pregnant women or new mothers (102;103). These programs include a home visit component, inspired by the same research as that which supported the development of Québec’s “integrated services” (104). The first such program, conducted in Seattle, had effects on the integration of treatments of the women, on their use of contraception methods, on the child’s well-being and on links with services. The outcome appeared to be better among women who were monitored the longest (102;105). Of the women who were reached for a study that was carried out after home visits had ceased, an average of 2½ years later, the effects on abstinence and contraception were maintained (106). The

second project, conducted in Baltimore, reduced referrals to child protection services and had a moderate effect on improving the results of cognitive and motor development tests on 18-month-old toddlers (107;108).

The assessments of these two randomized tests, despite having certain methodological limitations, support the hypothesis that Québec's "integrated services" could be useful for alcohol and substance-abusing women as well. This is supported by the fact that, compared to the situation observed in Anglo-Saxon settings (United States and Great Britain), women drug addicts in Québec made use of perinatal services more often (58). In addition, since teenage pregnancies are often accompanied by alcohol/drug abuse and dependence problems, these young women likely find themselves in the "integrated services" of the CLSCs, providing other opportunities to identify their problem and support them in their child-bearing role (109). Therefore, the perinatal services staff must be skilled and trained first in recognizing these women and then in providing care to them (110).

Community outreach programs are also useful for marginalized female alcohol and drug addicts. In Québec, there are no such programs specifically designed for pregnant women. The Sheway Project in Vancouver is one such model. With an approach aimed at "harm reduction," comprehensive services are proposed to the women during their pregnancies and until their child is 18 months old. The qualitative and quantitative assessments of the project show that this approach succeeds in improving prenatal and postnatal services, improving the quality of the mother's living quarters and nutritional status, and helping them keep the custody of their child (111).

Since an excessive consumption of alcohol often comes within a context of multiple substance abuse, perinatal services for drug-addicted women dispensed in Montréal hospitals contribute to the prevention of problems related to fetal exposure to alcohol or drugs. Hôpital Saint-Luc (CHUM) takes care of following up pregnant women who are alcohol or drug-dependent or who participate in a methadone substitution program. The creation of a perinatal and addiction committee, integrated into the birthing centre, makes it possible to support women through a multidisciplinary approach (paediatricians, child psychiatrists, nurses, general practitioners, female social workers). During the prenatal period, one social worker makes sure the woman's pregnancy is followed by a physician at the hospital, works on stopping or curbing the woman's consumption, offers psychosocial support and helps in preparing for the baby's arrival. The women are asked to consult every week at the outpatient services. After giving birth, those who so desire can keep on being followed up.

Because the caregivers at Hôpital Saint-Luc believe that a relationship of trust must be developed between the health care professional and the patient, they foster informal networking with the various agencies that the women frequent. As a result, the first person from the community organization, CLSC, DPJ (youth protection agency) or CRAN (drug addiction research and assistance center) who comes into contact with the woman will be the person who introduces her to the hospital team. Without being a resource specifically dedicated to treating drug abuse, Hôpital Saint-Luc at least offers a pregnancy follow-up specifically adapted to the reality of pregnant women who have alcohol or drug problems.

The health care professionals at Hôpital Saint-Luc also point out the importance of ensuring the continuity of prenatal and postnatal care. To that end, they submitted a project for a perinatal and family drug abuse centre to the *Agence régionale de développement de réseaux locaux de services de santé et de services sociaux* (regional agency for the development of local health and social services networks). The aim of the project is to centralize the follow-up services at the hospital with the help of the CLSCs and other agencies granted to the families (mother, father and child). A multidisciplinary team would be responsible for assessing each family member and proposing the relevant care needed until that child has reached school age. Through the project, the health care workers also wishes to ensure that the children whose prenatal exposure to alcohol or drugs is known receives the proper care.

### **2.3.3 Treatment and rehabilitation of alcohol and drug dependency**

#### ***Characteristics of the treatment and rehabilitation of women***

Much of the literature describes the approaches used in treating women who are dependent on alcohol. In terms of this report, we will not dwell on a review of this. However, we will underline the importance of providing services that are gender based. In fact, the former Addiction Research Foundation, (now CAMH, Centre for Addiction and Mental Health), in a book specifically dedicated to women's drug addictions, advances that, in general, the treatment programs have always been “designed by men, for men” (112). For some women, such an approach geared specifically to them is beneficial in several ways (113).

Another aspect of the treatment that merits closer consideration is its accessibility for mothers with children. A number of caregivers have insisted on the urgent need to make residential treatments accessible for mothers and their children. According to them, many women will refuse detoxification treatment because no accommodations are available and consequently they must be separated from their baby.

#### ***Services in Québec***

In Québec, services to treat drug addiction are provided by: (1) public addiction treatment centres; (2) private centres and centres with government agreements; (3) community and private organizations; and (4) treatment centres culturally adapted to First Nations.

The public addiction rehabilitation centres are mainly geared toward day treatments. They are located in all the administrative regions and dispense services free of charge. For the purposes of this status report, the National Public Health Institute of Québec asked the *Fédération québécoise des centres de réadaptation pour personnes alcooliques et autres toxicomanes* (Québec federation of rehabilitation centres for alcoholics and other addicts) to survey their members on the priority access of pregnant women for treatment. Of the twenty or so existing public centres, all – without exception – replied they gave priority to pregnant women. A few programs also provide women, even pregnant women and mothers of young children, with services that are specifically designed for them. One such project is the “*Trip de cœur*” offered by the Centre André-Boudreau. This centre sees women drug addicts at its outpatient counter; in addition, Centre Jean-Patrice Chiasson/Maison Saint-Georges has a specific program aimed at pregnant women and the mothers of young children.

Private centres and centres with government agreements are organizations that are financially backed by the public and private sectors, and offer their services free of charge. Portage is one such organization. In one of the Portage centres located in Prévost in the Laurentides region, a one-of-a-kind treatment program is proposed to addicted mothers and their children. Its clientele is composed of both teenagers and adults, and as part of the group the women take part in a therapeutic community rehabilitation, without being separated from their children. To do so, they are lodged with their offspring in small cottages on the site. The children benefit from access to daycare at the centre or, if they are older, to the local school. Furthermore, the mothers participate in a number of activities aimed at instilling a heightened sense of responsibility in them as mothers. In addition to their usual activities, workshops and leisure activities with their children aim at reinforcing their capabilities and their role as parents are part of the especially designed program. Finally, an intensive and extended follow-up enables them to better resume their everyday life after living at the centre for approximately one year. The CRAN, mentioned earlier, is another private centre with a government agreement. Partnering with Hôpital Saint-Luc, it supports pregnant women through its perinatal service. This organization also offers a methadone substitution program. This program is in constant development and will eventually integrate nursing care component into the psychosocial support services that are already offered.

One hundred or so community and private organizations provide substance abuse treatment in Québec. Most of them offer residential treatments for their clientele undergoing treatment. A short while ago, the Québec Ministère de la Santé et des Services sociaux issued certification standards for those organizations. To date, 32 centres have been certified. Four of them are solely or specifically addressed to a female clientele. They are presented in Appendix 2.

The *National Native Alcohol and Drug Action Program* (NNADAP) funds many substance abuse treatment centres, both Canada-wide and across Québec. In Québec, six centres offer services that are completely dedicated to the Native population. None of them, however, are devoted solely to women or families, but all included in the treatment certain cultural activities (e.g. sweat lodge, purification ceremony, elders, language). Of these six centres, half offer only residential treatments, one of which is specifically focused on teenagers who abuse solvents. The other half combines day treatments with residential treatment. In terms of a Canadian inventory of drug addiction treatment resources subsidized by NNADAP, the First Nations and Inuit Health Board gives detailed information on its website as to the features of each Aboriginal centre<sup>12</sup>.

According to people surveyed in the north, the need for treatment in Inuit communities is urgent. In fact, only two centres treating drug addiction in Nunavik are known, one for adults in Kuujuaq, and another for young people in Inukjuak.

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<sup>12</sup> For more information: [http://www.hc-sc.gc.ca/fnihb-dgspni/fnihb/cp/nnadap/treatment\\_centres/index.htm](http://www.hc-sc.gc.ca/fnihb-dgspni/fnihb/cp/nnadap/treatment_centres/index.htm)



## **2.4 CARE AND SERVICES FOR PEOPLE WITH FAS AND THEIR FAMILIES**

### **2.4.1 Identification of suspected cases**

The earlier FAS and its associated problems are identified and the sooner effective management begins, the higher the chances that treatment will decrease the harmful effects of these problems (6). However, a definite diagnosis of FAS is difficult to make and, as a result, according to physicians consulted for this status report, only those who are very knowledgeable in this area are able to make one. It is also important that only experienced physicians make such diagnoses since both false positives and false negatives are prejudicial. In this context, the role of most health care professionals is rather to detect suspected cases and direct them toward specialized services that can make a definite diagnosis. If the diagnosis is confirmed by specialists, some of the health care professionals will be able to provide follow-up services and assistance to the children and their families.

Knowledge of the mother's alcohol consumption habits during pregnancy is needed to identify cases in children. This underscores the importance not only of recognizing alcohol-related problems during a woman's pregnancy or when she gives birth, but also of getting information on the biological mother's lifestyle when children are adopted or put in foster care (1;40).

Based on the experiences shared by the persons surveyed for this report, it is often the parents who have a feeling that something is wrong with their child. However, getting a diagnosis remains difficult, especially when it comes to alcohol-related neurodevelopmental disorders (ARND). According to the Canadian Paediatric Society (CPS), professionals in the education system, namely psychologists, could also suspect problems among children who have specific learning disabilities or behavioural problems and could possibly take part in their assessment (6). The people consulted also mentioned that it is sometimes hard for education professionals to know where to send parents who want a medical diagnosis for their child. Furthermore, the diagnosis is even harder to make when the child's exposure to alcohol is not known.

According to the parents surveyed for this report, it is very difficult to diagnose older adolescents and adults. Because of behavioural problems that develop during adolescence, it is highly probable that several adolescents and adults find themselves in youth protection centres and in trouble with the law. A Canadian study suggests, however, that this problem is rarely diagnosed in the Canadian correctional system (114). To our knowledge, the situation in youth protection centres has not been assessed.

### **2.4.2 Diagnosis and evaluation**

A diagnosis of FAS is based on clinical manifestations and no specific test exists to confirm it (6). Researchers have criticized the lack of precision in diagnostic criteria for FAS, partial FAS and neurological disorders and birth defects related to fetal alcohol exposure, as defined by the Institute of Medicine, and have proposed a new diagnostic method (4-digit diagnostic code) (115). This method has the advantage of being more reliable, however, it lacks sensitivity (6). In addition, in its current state of development, it is not very practical for physicians and should be improved (116). It seems that the Institute of Medicine's criteria are still the ones most often used.

In addition to these difficulties, the physicians consulted pointed out that the differential diagnosis of FAS is complex and special expertise is required to distinguish FAS from other syndromes (e.g. Fragile-X), attention deficits, learning disabilities and socio-affective disorders. There are also external factors in addition to alcohol exposure. Children generally live in socio-economically underprivileged environments where substance abuse and violence puts them at risk for multiple developmental problems. When it comes to children who are adopted or in foster care, bonding difficulties and socioemotional problems also complicate the clinical picture. As for children adopted from other countries, they often have impaired growth resulting from being born prematurely or having suffered malnutrition.

As reported in the literature survey conducted by Roberts and Nanson (7), the diagnosis is based on a medical assessment by a paediatrician or dysmorphologist and an in-depth psychological evaluation. According to the physicians interviewed, specialized medical examinations are often required to determine the presence of congenital anomalies (cardiac, orthopaedic and renal). Additional evaluations in the areas of audiology, speech-language pathology, physiotherapy, occupational therapy and social services are often requested. After having established the diagnosis and evaluated the extent of related problems, the specialists send intervention protocols to the professionals who are responsible for following the child in his or her environment, whether medically, psychologically or pedagogically.

According to the people interviewed, the medical diagnosis and clinical evaluation therefore require medical and multidisciplinary expertise. This recommendation is of critical importance according to consensus of experts (7). The Alberta Medical Association states:

“A multi-disciplinary team for care and management could include, at minimum, two or three professionals, depending on need and availability within the area; and could be comprised of the following professionals: physicians, nurses, psychologists, speech pathologists, occupational therapists, educators and social workers” (*Guideline for the Diagnosis of Fetal Alcohol Syndrome* (117).

According to the physicians consulted, there is such a multidisciplinary team associated with the CHUQ’s genetic medicine clinic. It is made up of various specialists, including a psychologist and a nutritionist, since experience has shown that children with FAS have specific nutritional needs. However, despite the expertise and will, resources are rare. The professionals on this team must meet numerous patients referred to them by their colleagues in other hospital departments. Consequently, they have very little time to transfer knowledge, which is done on a case-by-case basis, and cannot provide training to professionals in the regions. It would be very practical to have one person to coordinate intervention plans. Access to certain services is also sometimes delayed because of waiting lists, primarily for speech therapy.

Informants from the Outaouais region said that this region’s population can have a FAS investigation done in Ontario. In Montréal, physicians are able to make diagnoses, but it seems that existing teams are currently not able to do the evaluation and draw up the intervention protocol for children suspected of having FAS or other related disorders. Sometimes parents are advised to use certain private services to avoid waiting lists, sometimes long, before getting an appointment. Access to speech therapy services seems to be particularly difficult.

Lastly, one of the physicians stated that the organization of services for people with FAS must be part of a global framework of services for disabled persons. However, access is often difficult due to a lack of resources and the absence of coordinated services for this clientele.

### **2.4.3 Intervention to help persons with FAS and support for their families and living environments**

Children with FAS and other fetal alcohol-related disorders have many needs that are described in the Canadian Paediatric Association (CPS) position statement (6) and by the members of the organization called SAFERA. These children are oversensitive to stimulation and, consequently, it is important to avoid bright lights, noise and sudden movements when they are around. In addition, they don't adapt well to change and it is crucial that they have a strict routine. They also have trouble performing more complex tasks that require self-organization, like getting dressed, and it is often necessary to put up lists or drawings to make these tasks easier. They only understand clear and concrete instructions, since they have poor abstract thinking. Since they are not able to foresee the consequences of their actions, they must be reminded of the rules. Because of their lack of judgment in social situations, they can be overly friendly with strangers and be exploited. At school, parents and teachers must have realistic expectations for them. According to one parent interviewed, inappropriate sexual behaviours during adolescence cause many problems at school. When these children become adults, delinquency and alcohol and drug abuse also enter the picture.

Studies on effective intervention for children with FASD are at the early stages (118). The similarities and differences between children suffering from these problems and those who suffer from other deficits are not clear. It is also not known which interventions should specifically target children with FASD (118). Although research is needed to address these issues, it is necessary to offer services based on the experience of affected children's parents and caregivers, along with the consensus of experts. Interventions implemented should also be evaluated (119).

Meeting the needs of these children is very demanding and both the CPA (6) and the individuals consulted say that parents need respite services. Parents also want practical advice on how to take care and educate their child and have expressed the need for "recipes" to help them cope with difficult situations. The production of practical guides would indeed improve the situation. Currently, parents help each other out informally, namely through Internet discussion forums. Telephone helplines, like the one at SAFERA, are also sources of information. This organization also plans to set up group meetings for parents.

One of the mothers consulted mentioned the need for parents to receive guidance from experienced caregivers, which corresponds to the CPA's (6) proposal "to train specialists to deal with behavioural abnormalities in early childhood intervention programs [...] and these services could be supplemented by well-trained volunteers who could do home visits and supply family support." Lastly, both this mother and the CPA propose "that foster families have specific training or experience in caring for children with FAS."

For this status report, we have only scratched the surface of the situation in Québec schools. However, the information gathered makes it possible to state that professionals are interested in being part of the intervention team. Furthermore, according to the physicians interviewed, school psychologists play an important role in following up children and want to have a good grasp of the problem. The few experiences related during the interviews suggest that when they go to school, affected children face various hurdles, but their parents succeed in finding support and qualified resources. According to one informant, children suspected of having FAS benefit from specialized educational support, but not specifically geared to their affliction. These children, like other disabled children, receive follow-up services for their learning disorders and the development of social skills.

Experiences in other parts of Canada have led to the definition of approaches for teaching affected children. Manitoba's Department of Education published a document outlining educational strategies for children "who are alcohol-affected." This document contains, among other things, means for creating a positive school climate, learning strategies, classroom behavioural strategies and strategies to foster family and community involvement in the school (120). This document appears to be a well-known and used resource since it was brought up time and again during interviews. Also, in Manitoba, one elementary school has a special program for children with FAS. Because of its renown, now worldwide, a video summarizing the various techniques used by teaching personnel was made available to the public.<sup>13</sup>

#### **2.4.4 Knowledge and attitudes of health care professionals**

The previous sections highlight the need for the expertise of health care professionals to be invested in all aspects related to the problem of FAS. The people interviewed repeatedly emphasized the role that professionals have to play, specifically that of physicians. They found certain difficulties, due to a lack of knowledge, and insist on the need to provide training on FAS and alcohol consumption.

Physicians from the University of Calgary recently concluded a study conducted among 2216 Canadian health care professionals (paediatricians, psychiatrists, midwives, family physicians and obstetricians) to ascertain their knowledge of and attitudes toward alcohol consumption during pregnancy and FAS (70). In Québec, 348 health care professionals took part in the study, which represents a participation rate of 39% of the professionals initially sampled. It is possible that the participants showed special interest in the problem and that the results paint a picture that is somewhat rosier than it actually is in reality.

Study findings reveal that three quarters of Québec health care professionals recommend that women abstain from drinking alcohol during their pregnancy. Most of them, or 95%, ask the women how much and how often they drink alcohol during pregnancy, and 85% of them use standard questionnaires. For this last item, they are different from professionals in other provinces, who only use the questionnaires in 62% of cases (70).

Furthermore, 65% of them consider that it is the health care professionals' role to deal with alcohol consumption issues in their practice. Some 46% say they are prepared to take care of pregnant women who suffer from alcohol abuse or dependence and 65% believe they are ready to direct them toward other resources (70).

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<sup>13</sup> The video is called "Teaching Children With Fetal Alcohol Syndrome."

In Québec, 92% of health care professionals agree with the statement that prenatal exposure to alcohol can cause permanent brain damage. The majority of these professionals are aware of the main clinical manifestations of FAS (55% to 83% depending on characteristics). The possibility of inappropriate sexual behaviours is a lesser known problem (15%) (70).

When it came to the question on the kinds of support they deem to be very useful, Québec health care professionals answered: clinical practice guidelines for diagnosis of FAS-FAE (61%); materials or training on FAS-FAE (53%); registry of specialists available for consultation about FAS-FAE (53%); literature on the impact of alcohol use during pregnancy (49%); referral resources for women of childbearing age with alcohol problems (47%). Few of them consider useful: Internet resources (39%); pregnancy history checklists including terms on alcohol use (38%); assistance with diagnosis of FAS/FAE through telemedicine (26%); training on addiction counselling (23%) (70).

Clinical practice guidelines were thought to be the most useful. Medical organizations have produced such tools. For instance, the position statement of the Canadian Paediatric Association contains guidelines for the diagnosis and management of alcohol-exposed children and the Alberta Medical Association also produced a guide, somewhat shorter, on diagnosing fetal alcohol syndrome (6;117).

Training tools designed for physicians and caregivers are also available. As previously presented, a training kit was developed in Ontario and translated into French by Health Canada to help physicians develop skills to question, guide and assist women when it comes to alcohol consumption and pregnancy (73). The professionals do not want to be trained in counselling on alcohol abuse. However, being able to ask mothers about their alcohol consumption is an integral part of the skills required to diagnose FAS. Once tailored to meet the needs of participants, this training could be offered to interested persons.

One caregiver brought up the need for training CLSC nurses on alcohol consumption. The training material on Understanding fetal alcohol syndrome, designed for first-line caregivers, could possibly be adapted to the context in which CLSCs provide perinatal care (72).

Lastly, the production not only of referral resources to know where to send women with problems associated with alcohol consumption, but also of lists of physicians and specialized teams that can be consulted on FAS and related disorders, would meet some of the needs expressed by health care professionals.

## **PART THREE: DISCUSSION AND RECOMMENDATIONS**

If a number of issues emerge unresolved from this report, it nonetheless clearly highlights the complex topic of fetal alcohol syndrome (FAS). Part three aims to summarize the literature survey and the interviews held with health care professionals from Québec working in the field of FAS or other related fields.

The first section is presented as a discussion that takes another look at the problem areas giving rise to questions or various thoughts. The second section presents findings on the specific situation in Québec. On the one hand, the recommendations stemming from these findings involve FAS prevention and take into account the situation of alcohol consumption among women who are pregnant or of childbearing age, and on the other hand, they reiterate the importance of intervention and the necessity to offer the services and support required by affected people and their families. Five sectors are targeted in the recommendations – information, professional practices, organization of care and services, improvement of knowledge and coordination of actions.

### **3.1 DISCUSSION**

Fetal alcohol syndrome is an embryopathy that greatly affects child development. Even though the harmful effects of consuming alcohol during pregnancy have been widely documented, a diagnosis is still hard to make. The constraints related to establishing a diagnosis and the fact that it is not possible to be supported by accurate sources of information are the reasons why no study clearly exposes the prevalence of fetal alcohol disorders in Québec. Estimates nonetheless suggest FAS rates of 0.5 to 2 out of 1000 live births in North America. Applying these rates to measure the extent of the problem in Québec gives, for 2002, from 36 to 144 cases of FAS among all live births. Considering that the number of cases of Fetal Alcohol Spectrum Disorder (FASD), including FAS, is three times that of FAS alone, this number would have been from 108 to 432 during the same year. These figures are hypothetical, but regardless what they are, the individuals interviewed reported several cases in Québec. These cases are primarily found among children from certain Inuit and First Nations communities, children adopted from countries where alcoholism is widespread and children born in Québec to mothers with multiple substance abuse problems. The congenital anomalies from which they suffer along with the difficult living conditions and abandonment to which they are subjected have the combined effect of hindering their development and social adaptation. These children and their biological and adoptive families need assistance and support, which presupposes that the problem be recognized, that a diagnosis be made and that secondary complications be evaluated. Access to these services is sometimes difficult, especially when it comes to evaluating *Alcohol-related neurodevelopmental disorders* (ARND) and individuals having reached adolescence and adulthood.

Fetal alcohol syndrome (FAS) can be prevented if measures are implemented. This syndrome is caused by significant exposure to alcohol during pregnancy. Disorders associated with alcohol consumption also appear when the foetus is exposed to lesser amounts, which are considered to be low risk among women who are not pregnant. A discussion on FAS therefore involves looking at a second problem, which is the consumption of alcohol when women are of childbearing age or when they are pregnant. In this area, if the frequency and patterns of alcohol consumption among women of childbearing age are relatively well

known, there is much to be done when it comes to the consumption of alcohol by pregnant Québec women. According to a study by Health Canada, there is a higher number of these women who believe there is a “safe amount of alcohol” that can be drunk without causing harm to the foetus, however, their consumption behaviours have not been studied.

A literature survey along with two studies have provided a detailed profile of Québec and Aboriginal women who have drinking problems during pregnancy. In general, these women have had a difficult childhood, were victims of violence and abuse and the consumption of alcohol and drugs is a way for them to ease their suffering. Yet, for some of them, pregnancy represents hope and an opportunity to put their life in order, but many hurdles remain in their way. First, their problem has to be identified if they are to receive counselling on their alcohol consumption and support to meet their needs. This help, provided without judgement by a person whom they can trust, has proven to be effective in reducing alcohol consumption or, at the very least, to limit the consequences. Access to treatment adapted to the needs of mothers of young children is often suggested in the literature. The effectiveness of this treatment has not been assessed, but its relevance is generally recognized by organizations with expertise in substance abuse, such as the Centre for Addiction and Mental Health.

Health Canada has developed a major *Initiative* on fetal alcohol syndrome. However, in Québec it seems that this problem continues to be the concern of just a few researchers, parents and health care and social service professionals. Projects stemming from the *Initiative* focus on public awareness campaigns, the creation of information and training tools, and training in Inuit and First Nations communities. It appears that these efforts have not yet enabled Québec’s population to better understand fetal alcohol syndrome. Consequently, additional efforts need to be made in several areas.

It is worth mentioning that this work is exploratory and has its limits. Despite interviewing many people, it is not possible to accurately describe the whole situation in Québec with the necessary subtleties. The situation in Québec’s education sector has been barely examined. As a result, what people in this sector know and do when it comes to FAS is unknown. Furthermore, the information gathered for this report is not complete enough to provide an overview of the situation in Québec’s youth protection centres, whether for children under the Youth Protection Act or those under the Young Offenders Act. According to recent research, adolescents and adults with FAS most often end up incarcerated. The problem in Québec’s prison system was not studied either in this status report.

Nonetheless, the situation appears to be sufficiently clear to present the following findings and ensuing recommendations.

## **3.2 FINDINGS AND RECOMMENDATIONS**

### ***Informing the public***

The message saying that it is best to abstain from drinking alcohol during pregnancy is conveyed by all Québec and Canadian authorities concerned by the issue. However, there are some differences. While Québec officials accept to put out a message recommending a moderate consumption of alcohol, for most Canadian organizations, such a notion of moderation does not exist for pregnant women and all alcohol

consumption is deemed risky. In addition, the term “moderate” is not defined in Québec guides for pregnant women and this is probably a source of confusion. Women must decide what this “moderate” means or listen to advice from health care professionals who have not been given clear guidelines on the subject.

Also, very little attention is paid to awareness in the general public and environments that may have to deal with children with FAS, namely foster families and adoptive families.

RECOMMENDATIONS:

- Formulate a clear and consistent message regarding alcohol consumption during pregnancy.
- Make the general public and foster and adoptive families aware of FASD.
- Support organizations that provide information on FAS to the public.

***Improving professional practices***

Health care and social service professionals along with perinatal and early childhood workers are in a good position to identify problems related to alcohol consumption among pregnant women, to give these women advice, conduct brief interventions, and refer them to treatment services. These workers are also in a position to recognize the consequences of drinking on child development and identify cases of FAS. A survey carried out among health care professionals revealed that they consider clinical practice guidelines and specialized referral resources lists practical, whether the topic is substance abuse or the expertise available to diagnose FAS. The majority of respondents do not want training on counselling in the area of dependence, but several of them would like to receive materials or training on FAS.

RECOMMENDATIONS:

- Provide health care and social services professionals and personnel working in perinatal and early childhood services with clinical tools to deal with alcohol consumption.
- Offer training on identification and brief interventions in substance abuse to interested groups.
- Provide professionals with clinical practical guidelines and lists of resources dealing with the treatment of alcoholism and substance abuse.
- Offer training and clinical practical guidelines on FAS to health care and social services professionals and also perinatal and early childhood workers.
- Offer registry of specialists to whom children can be sent so a definitive diagnosis and intervention plan can be made.



### ***Organizing care and services***

#### *...for women with alcohol consumption problems*

Perinatal services are special opportunities for providing assistance to pregnant women with drinking and drug problems. CLSC services such as *Integrated perinatal and early childhood services for families living in a context of vulnerability* are a promising way to help alcohol and drug addicted women on their way to becoming mothers. Pregnancy follow-up programs designed specifically for alcohol and drug addicted women also exist in Montréal hospitals and professionals would like to see ongoing care once the baby is born, in conjunction with other service providers in the area.

Even if public treatment and rehabilitation centres for alcohol or drug addicted persons offer, without question, priority to pregnant women, it remains that very few of them offer programs that meet the specific needs of these women (gender-based approach, daycare services, acceptance of children during residential treatment). Organizations dedicated to helping Aboriginal people offer treatment that is culturally adapted to Aboriginals, but none of them has a specific approach for women.

#### RECOMMENDATIONS:

- Develop approaches within existing perinatal services that are adapted to the situation of alcohol and drug addicted women.
- Make treatment and rehabilitation services accessible to women with children.
- Make culturally adapted treatment services accessible to Inuit and First Nations women with alcohol and drug problems.

#### *...for children with FAS and their family*

Parents, various professionals and scientific literature maintain that early identification and intervention can minimize the harmful consequences of problems related to prenatal alcohol exposure. To our knowledge, in Québec, children are evaluated and diagnosed by specialized teams in urban centres (genetic clinics, development clinics). However, these teams don't have enough resources to evaluate children and cannot ensure that knowledge will be transferred to service providers in the regions who will be following up these children. The most urgent needs are to have professionals who are able to evaluate a child's development and contribute to the diagnosis of alcohol-related neurodevelopmental disorders (ARND) and to have speech pathologists to correct language and communication problems. As for parents, they need respite and practical assistance.

#### RECOMMENDATIONS:

- Provide specialized medical teams with the necessary resources to diagnose and evaluate persons suspected of having FAS or other disorders caused by fetal alcohol exposure.
- Ensure that intervention plans are carried out.

- Put in place respite services and support activities for parents and people in the living environment of affected children.
- Develop practical how-to guides for parents of affected children.

### ***Increasing knowledge and fostering research***

Problems related to alcohol consumption during pregnancy and FAS are still misunderstood in certain respects. In addition, the possible contribution of professionals in the education sector and in youth protection centres should be pointed out when it comes to identifying probable FAS cases and other disorders related to fetal alcohol exposure and when it comes to working with affected children. Finally, the situation of affected adults is not very well known.

#### RECOMMENDATIONS:

- Study the perceptions of women regarding prevention-based messages on alcohol consumption during pregnancy.
- Study alcohol consumption patterns of pregnant women.
- Gather detailed information on the characteristics and needs of affected people and their family and those in their living environment (early childhood centres, schools, youth protection centres).
- Conduct an exploratory study on the incidence of FAS and other disorders caused by fetal alcohol exposure.

### ***Coordinating actions***

There are many needs when it comes to FAS prevention and other disorders caused by fetal alcohol exposure, the provision of services for alcohol and drug addicted women, or the follow up of affected children. It is important to take ongoing action in all areas of services.

#### RECOMMENDATION:

- Ensure leadership and coordination of services and programs for fetal alcohol spectrum disorders in Québec.

### SUMMARY TABLE OF RECOMMENDATIONS

STRATEGIES	PREVENTING FAS	REACTING TO FAS
<b>INFORMING THE GENERAL PUBLIC</b>	<ul style="list-style-type: none"> <li>· Formulate a clear and consistent message regarding alcohol consumption during pregnancy.</li> </ul>	<ul style="list-style-type: none"> <li>· Make the general public and foster and adoptive families aware of FASD</li> <li>· Support organizations that provide information on FAS to the public.</li> </ul>
<b>IMPROVING PROFESSIONAL PRACTICES</b>	<ul style="list-style-type: none"> <li>· Provide health care and social services professionals and personnel working in perinatal and early childhood services with clinical tools to deal with alcohol consumption.</li> <li>· Offer training on identification and brief interventions in substance abuse to interested groups.</li> <li>· Provide professionals with clinical practice guidelines and lists of resources dealing with the treatment of alcoholism and substance abuse.</li> </ul>	<ul style="list-style-type: none"> <li>· Offer training and clinical practice guidelines on FAS to health care and social services professionals and also perinatal and early childhood workers.</li> <li>· Offer registry of specialists to whom children can be sent so a definitive diagnosis and intervention plan can be made.</li> </ul>
<b>ORGANIZING CARE AND SERVICES</b>	<ul style="list-style-type: none"> <li>· Develop approaches within existing perinatal services that are adapted to the situation of alcohol and drug addicted women.</li> <li>· Make treatment and rehabilitation services accessible to women with children.</li> <li>· Make culturally adapted treatment services accessible to Inuit and First Nations women with alcohol and drug problems.</li> </ul>	<ul style="list-style-type: none"> <li>· Provide specialized medical teams with the necessary resources to diagnose and evaluate persons suspected of having FAS or other disorders caused by fetal alcohol exposure.</li> <li>· Ensure that intervention plans are carried out.</li> <li>· Put in place respite services and support activities for parents and people in the living environment of affected children.</li> <li>· Develop practical how-to guides for parents of affected children.</li> </ul>
<b>INCREASING KNOWLEDGE AND FOSTERING RESEARCH</b>	<ul style="list-style-type: none"> <li>· Study the perceptions of women regarding prevention-based messages on alcohol consumption during pregnancy.</li> <li>· Study alcohol consumption patterns of pregnant women.</li> </ul>	<ul style="list-style-type: none"> <li>· Gather detailed information on the characteristics and needs of affected people and their family and those in their living environment (early childhood centres, schools, youth protection centres).</li> <li>· Conduct an exploratory study on the incidence of FAS and other disorders caused by fetal alcohol exposure.</li> </ul>
<b>COORDINATING ACTIONS</b>	<ul style="list-style-type: none"> <li>· Ensure leadership and coordination of services and programs for fetal alcohol spectrum disorders in Québec.</li> </ul>	

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**APPENDIX 1**  
**ELECTRONIC RESOURCES ON FAS**

## APPENDIX 1 ELECTRONIC RESOURCES ON FAS

### QUÉBEC RESOURCES

#### Centre of Excellence for Early Childhood Development (CEECD)

GRIP-Université de Montréal  
C.P. 6128, succursale Centre-ville  
Montréal, Québec H3C 3J7  
Telephone: (514) 343-6111, Extension 2541 / Fax: (514) 343-6962  
E-mail: cedje-ceecd@umontreal.ca  
Website: <http://www.excellence-earlychildhood.ca/theme.asp?id=6&lang=EN>

Description: The CEECD is an organization whose mission is to improve scientific knowledge of the development of young children between the ages of 0 and 5 and to disseminate this knowledge. On its website it offers a theme-based encyclopaedia on early childhood development which contains scientific articles. The topics available respond to three main inquiries: 1) How important is it? 2) What do we know? 3) What can be done? One of the topics in the encyclopaedia is fetal alcohol syndrome.

#### First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC)

250, place Chef Michel Laveau  
Wendake, Québec G0A 4V0  
Telephone: (418) 842-1540 / Fax: (418) 842-7045  
E-mail: fvincent@cssspnql.com; ngroslois@cssspnql.com; msioui@cssspnql.com  
Website: [http://nexus.webnet.qc.ca:8080/cssspnql/ui/health/HealthFAS.jsp?section=link\\_sante&lang=en](http://nexus.webnet.qc.ca:8080/cssspnql/ui/health/HealthFAS.jsp?section=link_sante&lang=en)

Description: The purpose of the FNQLHSSC is to ensure the health and well-being of First Nations and Inuit communities and to provide assistance when it comes to health and social services. Within the framework of the Health Canada Initiative, the FNQLHSSC produced a resource guide on FAS/FAE. It provides references to written documents (educational manuals, books, articles, newsletters, etc.) and to centres or associations offering services in the area of fetal alcohol syndrome.

#### SAFERA

845, chemin du Bord-de-l'Eau  
Saint-Henri-de-Lévis  
Lévis, Québec G0R 3E0  
Telephone: (418) 882-2488 or 1 866 272-3372 / Fax: (418) 882-6373  
E-mail: info@safera.qc.ca  
Website: <http://www.safera.qc.ca/menu.html> (In French only)

Description: SAFERA is a private, not-for-profit organization entirely devoted to fetal alcohol syndrome. It has produced a toolbox with resources, such as a website providing detailed information, in French, on this topic. Also on this website is a section containing links to various resources and the possibility of becoming a member of a discussion forum.

## OTHER RELEVANT QUÉBEC RESOURCES

### **Le monde est ailleurs - Meanomadis**

10, 51<sup>e</sup> Avenue, bureau 01

Notre-Dame de l'Île Perrot, Québec J7V 7L8

Telephone: (514) 453-6967

E-mail: [info@meanomadis.com](mailto:info@meanomadis.com)

Website: [http://www.meanomadis.com/content/show\\_articles.asp?ID=92](http://www.meanomadis.com/content/show_articles.asp?ID=92) (In French only)

Description: “Le monde est ailleurs” (the world is elsewhere) is an organization that specializes in new media, namely the creation of recreation-education portals, and scientific resource portals, with a perspective on children’s health and rights throughout the world. The section “Abandon, Adoption, Autres Mondes” (abandonment, adoption, other worlds) lets visitors read excerpts from a book by Jean-François Chicoine, Patricia Germain and Johanne Lemieux called “L’enfant adopté dans le monde en quinze chapitres et demi” (the child adopted in the world in fifteen and a half chapters) (Éditions de l’Hôpital Sainte-Justine, 2003). One of the chapters deals with fetal alcohol syndrome in relation to international adoption.

## CANADIAN RESOURCES

### **Canadian Centre on Substance Abuse Information on FAS and FAE**

75 Albert Street, Suite 300

Ottawa, Ontario K1P 5E7

Telephone: (613) 235-4048, Extension 223 or 1 800 559-4514 / Fax: (613) 235-8101

E-mail: [fas@ccsa.ca](mailto:fas@ccsa.ca)

Website [www.ccsa.ca](http://www.ccsa.ca)

Description: The CCSA proposes various resources, mostly Canadian, on alcoholism and addictions. It offers information services (website, e-mail, telephone) and one website section is entirely devoted to fetal alcohol syndrome:

- CCSA’s website page with FASD information and references  
<http://www.ccsa.ca/index.asp?ID=17>
- National database of FASD and substance use during pregnancy resources.  
<http://www.ccsa.ca/fas>
- Directory of FAS/FAE Information and Support Services in Canada  
<http://www.ccsa.ca/pdf/ccsa-008036-2003.pdf>
- FAS toolkit  
<http://www.ccsa.ca/toolkit/introduction.htm>
- Calendar of events on FASD  
<http://www.ccsa.ca/index.asp?mode=Calendar&fas=true>

### **FASworld**

1509 Danforth Ave.  
Toronto, Ontario M4J 5C3  
Telephone: (416) 465-7766 / Fax: (416) 465-8890  
E-mail: [fasworldcanada@rogers.com](mailto:fasworldcanada@rogers.com)  
Website: <http://www.fasworld.com/help.ihtml#resources>

Description: FASworld is an organization co-founded by American (Arizona) and Canadian (Ontario) volunteers (parents) and professionals. This alliance is international in scope. Although the website is only in English, one section lists various sources of useful information.

### **Best Start**

Best Start: Ontario's Maternal, Newborn and Early Child Development Resource Centre  
c/o Ontario Prevention Clearinghouse  
180 Dundas Street West, Suite 1900  
Toronto, Ontario M5G 1Z8  
Telephone: (416) 408-2249 / Fax: (416) 408-2122  
E-mail: [beststart@beststart.org](mailto:beststart@beststart.org)  
Website: [http://www.beststart.org/resources/alc\\_reduction/index.html](http://www.beststart.org/resources/alc_reduction/index.html)

Description: Best Start supports service providers across the province of Ontario working on health promotion initiatives to enhance the health of expectant and new parents, newborns and young children. One of its website sections provides resources related to alcohol during pregnancy (also available in French).

### **Motherisk**

The Hospital for Sick Children  
555, University Avenue  
Toronto, Ontario M5G 1X8  
Telephone: 1 877 327-4636 (Alcohol and Substance Use Helpline)  
E-mail: [momrisk@sickkids.ca](mailto:momrisk@sickkids.ca)  
Website: <http://www.motherisk.org/alcohol/index.php>

Description: Motherisk offers information and counselling to women who have questions about their pregnancy, especially on the risks and illnesses that may occur during this period. It is possible to drop by the clinic, visit its website or phone its helpline (service is bilingual). Motherisk's website provides a link to an electronic publication called "Journal of FAS International" and also proposes a variety of resources on fetal alcohol syndrome.

### **National Indian and Inuit Community Health Representatives Organization (NIICHRO)**

C.P. 1019  
1, chemin Roy Montour  
Kahnawake, Québec J0L 1B0  
Telephone: (450) 632-0892 / Fax: (450) 632-2111  
E-mail: [niichro@niichro.com](mailto:niichro@niichro.com)  
Website: <http://www.niichro.com/fresources%20cat2004.pdf>

Description: NIICHRO is a non-governmental organization and one of its goals is to upgrade the quality of care provided to First Nations and Inuit people across Canada. Among its activities, it produced a catalogue of community health resources. Each health-related theme has a training kit with resources. One of them (kit no. 7) deals with fetal alcohol syndrome.

## **Health Canada**

I.A. 0900C2

Ottawa, Ontario K1A 0K9

Telephone: (613) 957-2991 / Fax: (613) 941-5366 / TDD: 1 800 267-1245

E-mail: [info@hc-sc.gc.ca](mailto:info@hc-sc.gc.ca)

Website: <http://www.hc-sc.gc.ca/english/index.html>

Description: Health Canada offers a few websites that list the department's own resources along with resources offered by various organizations, committees, associations, etc.

- Fetal Alcohol Syndrome/Fetal Alcohol Effects  
<http://www.hc-sc.gc.ca/english/lifestyles/fas.html>
- FOR ALL (Information sheets, national newsletter and summaries)  
[http://www.phac-aspc.gc.ca/dca-dea/programs-mes/fas-fae\\_main\\_e.html](http://www.phac-aspc.gc.ca/dca-dea/programs-mes/fas-fae_main_e.html)
- Community programs: Fetal Alcohol Syndrome and Fetal Alcohol Effects  
[http://www.hc-sc.gc.ca/fnihb/cp/fas\\_fae/index.htm](http://www.hc-sc.gc.ca/fnihb/cp/fas_fae/index.htm)

<b>RESOURCES IN OTHER COUNTRIES</b>
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## **Fetal Alcohol and Drug Unit**

180 Nickerson Street, Suite 309

Seattle, Washington 98109

Telephone: (206) 543-7155 / Fax: (206) 685-2903

E-mail: [fadu@u.washington.edu](mailto:fadu@u.washington.edu)

Website: <http://depts.washington.edu/fadu/>

Description: The Fetal Alcohol and Drug Unit (FADU) is an American research centre that comes under the Department of Psychiatry and Behavioral Sciences of the University of Washington School of Medicine. It specializes in the prevention, management and treatment of fetal alcohol syndrome. In addition to listing its publications, FADU also offers Internet users access to a FAS resource index.

## **National Institute on Alcohol Abuse and Alcoholism (NIAAA)**

5635 Fishers Lane, MSC 9304

Bethesda, Maryland 20892-9304

E-mail: [niaaaweb-r@exchange.nih.gov](mailto:niaaaweb-r@exchange.nih.gov)

Website: <http://www.niaaa.nih.gov>

Description: As an institute whose mission is to reduce alcohol-related problems, NIAAA conducts and supports research on fetal alcohol syndrome. By doing a search with the keyword FAS or FASD, it is possible to access numerous publications produced by this institute.



**APPENDIX 2**  
**SUBSTANCE ABUSE TREATMENT CENTRES**

## APPENDIX 2 SUBSTANCE ABUSE TREATMENT CENTRES

### Centres or programs for women

#### EXTERNAL RESOURCE IN AN URBAN CENTRE

##### **Centre hospitalier de l'Université de Montréal**

Outpatient substance abuse clinic – Saint-Luc Pavilion  
1058, rue Saint-Denis  
Montréal, Québec H2X 3J4

#### REHABILITATION CENTRES FOR ALCOHOLICS AND OTHER ADDICTS

##### **Centre André Boudreau**

“Trip de cœur”  
910, rue Labelle  
Saint-Jérôme, Québec J7Z 5M5  
Telephone: (450) 432-1395 or 1 888 345-1395 / Fax: (450) 432-8654  
E-mail: [centredoc.cab@sss.gouv.qc.ca](mailto:centredoc.cab@sss.gouv.qc.ca)

##### **Centre Jean-Patrice Chiasson/Maison Saint-Georges**

1270, rue Galt Ouest  
Sherbrooke, Québec J1H 2A7  
Telephone: (819) 821-2500 / Fax: (819) 563-8322

N.B. For a detailed description of all centres, please log on to the website of the Fédération québécoise des centres de réadaptation pour personnes alcooliques et autres toxicomanes (Québec federation of rehabilitation centres for alcoholics and other addicts): <http://www.fqcrpat.qc.ca/membre> (In French only except section for the SAAQ Driver Evaluation Program)

#### PRIVATE CENTRES AND CENTRES WITH GOVERNMENT AGREEMENTS

##### **Centre d'accueil le Programme de Portage inc.**

Treatment program for addicted mothers and their children  
1790, chemin du Lac Écho  
Prévost, Québec J0R 1T0  
Telephone: (450) 224-2944 / Fax: (450) 224-8673

##### **Centre de recherche et d'aide pour les narcomanes**

110, rue Prince-Arthur Ouest, 3<sup>e</sup> étage  
Montréal, Québec H2X 1S7  
Telephone: (514) 527-6939 / Fax: (514) 527-0031  
E-mail: [info@cran.qc.ca](mailto:info@cran.qc.ca)  
Website: [www.info-sam.qc.ca](http://www.info-sam.qc.ca)

<b>COMMUNITY AND PRIVATE ORGANIZATIONS</b>
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**La Maisonnée de Laval inc.**

2255, rue Bienville  
Laval, Québec H7H 3C9  
Telephone: (450) 628-1011 / Fax: (450) 628-8383

**Maison de thérapie l'Entre-Temps**

1011, Chantal Poulin  
Sainte-Béatrix, Québec J0K 1Y0  
Telephone: (450) 883-8191 or 1 877 883-8191 / Fax: (450) 883-8191

**Maison du nouveau chemin**

4171, rue Rolland  
Sainte-Adèle, Québec J8B 1E2  
Telephone: (450) 229-8044 / Fax: (450) 229-8189  
E-mail: maison.nchemin@qc.aira.com

**Résidence Le Portail**

1240, route de Fossambault Nord  
Saint-Augustin-de-Desmaures, Québec G3A 1W8  
Telephone: (418) 878-2867 / Fax: (418) 878-3668  
E-mail: resleportail@globetrotter.net

N.B. To obtain the list of organizations certified by the Ministère de la Santé et des Services sociaux (MSSS) log on to: [http://www.msss.gouv.qc.ca/sujets/prob\\_sociaux/liste-org-certi.pdf](http://www.msss.gouv.qc.ca/sujets/prob_sociaux/liste-org-certi.pdf) (In French only). To find out about other centres that are not yet certified by the MSSS, log on to the website of the Association des intervenants en toxicomanie du Québec inc.: <http://www.aitq.com/membres/orgmem.htm>

## Centres with a cultural vocation

<b>TREATMENT CENTRES CULTURALLY ADAPTED TO FIRST NATIONS</b>
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**Centre de réadaptation Miam Uapukun inc. (Malioténam)**

P.O. Box 389  
Moisie, Québec G0A 2B0  
Telephone: (418) 927-2254 / Fax: (418) 927-2262  
E-mail: cebtreka@globetrotter.net

**Centre de réadaptation Wapan**

P.O. Box 428  
La Tuque, Québec G9X 3P3  
Telephone: (819) 523-7641/7642 / Fax: (819) 523-7513  
E-mail: wapan@lino.sympatico.ca  
Website: [www.wapan.com](http://www.wapan.com)

**Mawiomi Treatment Services**

P.O. Box 1068  
Maria, Québec G0C 1Y0  
Telephone: (418) 759-3522 / Fax: (418) 759-3048  
E-mail: mawiomi@globetrotter.net

**Onen'to: Kon Treatment Services**

380 St. Michel P.O Box 3819  
Kanehsatake, Québec J0N 1E0  
Telephone: (450) 479-8353 / Fax: (450) 479-1034

**Walgan Centre- First Nations Youth Rehabilitation Centre (solvent abuse)**

P.O. Box 1009  
Gesgapegiag, Québec G0C 1Y0  
Telephone: (418) 759-3006 / Fax: (418) 759-3064  
E-mail: fnyrc@globetrotter.net

**Wanaki Centre**

P.O. Box 37  
Maniwaki, Québec J9E 3B3  
Telephone: (819) 449-7000 / Fax: (819) 449-7832  
E-mail: wanaki@ireseau.com

N.B. To consult the Treatment Centre Directory of the *National Native Alcohol and Drug Abuse Program* (NNADAP) and the *National Youth Solvent Abuse Program*, log on to the website of the First Nations and Inuit Health Branch:

[http://www.hc-sc.gc.ca/fnihb-dgspni/fnihb/cp/nnadap/treatment\\_centres/index.htm](http://www.hc-sc.gc.ca/fnihb-dgspni/fnihb/cp/nnadap/treatment_centres/index.htm)

<b>TREATMENT CENTRES CULTURALLY ADAPTED FOR INUIT</b>
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**Anarrapik Group Home General Delivery**

Inukjuak, Québec J0M 1M0  
Telephone: (819) 254-8887 / Fax: (819) 254-8605

**Isuarsivik Treatment Centre**

P.O. Box 749  
Kuujjuaq, Québec J0M 1C0  
Telephone: (819) 964-2592 / Fax: (819) 964-2041

