

FOETAL ALCOHOL SYNDROME A PREVENTABLE TRAGEDY

REPORT OF THE STANDING COMMITTEE ON HEALTH AND WELFARE, SOCIAL AFFAIRS, SENIORS AND THE STATUS OF WOMEN

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BARBARA GREENE, M.P. CHAIR

STANLEY WILBEE, M.P.
CHAIR
SUB-COMMITTEE ON HEALTH ISSUES

June 1992





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REPORT OF THE STANDING COMMITTEE ON HEALTH AND WELFARE, SOCIAL AFFAIRS, SENIORS AND THE STATUS OF WOMEN

PARABARA GREENE, M.P. CHAIR

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Issue No. 10

Thursday, June 11, 1992

Chair: Barbara Greene

CHAMBRE DES COMMUNES

Fascicule nº 10

Le jeudi 11 juin 1992

Présidence: Barbara Greene

Minutes of Proceedings and Evidence of the Standing Committee on Procès-verbaux et témoignages du Comité permanent de la

Health and Welfare, Social Affairs, Seniors and the Status of Women

Santé et du Bien-être social, des Affaires sociales, du Troisième âge et de la Condition féminine

RESPECTING:

Consideration of the Second Report of the Sub-Committee on Health Issues

Future Business

INCLUDING:

Fifth report to the House: Foetal Alcohol Syndrome

CONCERNANT:

Étude du deuxième rapport du Sous-comité sur les questions de santé

Travaux futurs

Y COMPRIS:

Cinquième rapport à la Chambre: Syndrome d'alcoolisme foetal

Third Session of the Thirty-fourth Parliament, 1991-92

Troisième session de la trente-quatrième législature, 1991-1992

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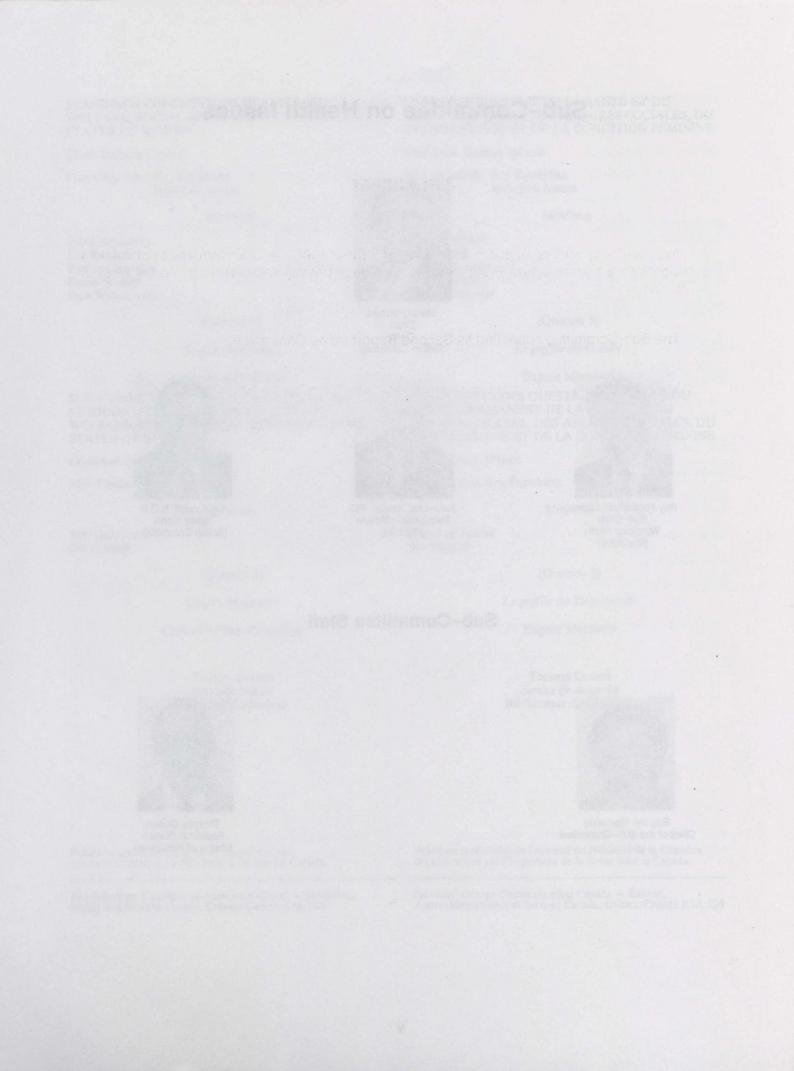
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The Standing Committee on Health and Welfare, Social Affairs, Seniors and the Status of Women has the honour to present its

FIFTH REPORT

In accordance with its mandate under Standing Order 108(1), your Committee established a Sub-Committee and assigned it the responsibility of examining the subject of Foetal Alcohol Syndrome.

The Sub-Committee submitted its Second Report to the Committee.

Your Committee adopted the following Report which reads as follows:

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LIST OF RECOMMENDATIONS

RECOMMENDATION NO. 1

The Sub-Committee recommends that the Minister of Health and Welfare Canada initiate discussions with the Provinces and Territories to create a National Advisory Committee on Alcohol and the Foetus. The Advisory Committee shall have a broad membership, including representatives from professional health-care organizations, social science and legal professions, government officials, parents' groups, and the beverage-alcohol industry. The Chairperson shall be elected by the Advisory Committee. The Committee shall report to the Minister of Health and Welfare Canada, whose department shall provide funding for the Committee. (page 11)

RECOMMENDATION NO. 2

The Sub-Committee recommends that the Minister of Health and Welfare Canada, in consultation with the Provinces and Territories, promptly establish a National Resource Centre on Alcohol and the Foetus, the purpose of the Centre being to coordinate and disseminate information across Canada on all aspects of Foetal Alcohol Syndrome (FAS) and Foetal Alcohol Effects (FAE). The Centre could most effectively and economically be developed from a currently active FAS/FAE resource group, such as The Canadian Centre on Substance Abuse. (page 12)

RECOMMENDATION NO. 3

The Sub-Committee recommends that the Minister of Health and Welfare Canada recommend to his provincial and territorial counterparts the establishment of Provincial and Territorial FAS/FAE Co-ordinators who will focus on prevention, identification of high-risk individuals and groups, clinical services for women of child-bearing age, early identification of affected offspring, and treatment and care facilities for FAS/FAE children. Wherever possible, the provincial/territorial co-ordinator should be employed with an established health-care centre with expertise in these areas. (page 13)

RECOMMENDATION NO. 4

The Sub-Committee recommends that Health and Welfare Canada, with the participation of the National Advisory Committee on Alcohol and the Foetus, organize and fund a National Conference on Foetal Alcohol Effects and Foetal Alcohol Syndrome for the purposes of information exchange, the stimulation of research and treatment activity, and to raise public awareness of this issue. The Conference should be held before the end of 1993. (page 13)

RECOMMENDATION NO. 5

The Sub-Committee recommends that the Minister of Health and Welfare Canada should amend the *Food and Drugs Act* and Regulations to require that containers for beverage alcohol sold in Canada, including beer, wine, and spirits, should carry an

appropriate warning label alerting all consumers that consumption of alcohol during pregnancy places the foetus at risk for Foetal Alcohol Syndrome (FAS) or Foetal Alcohol Effects (FAE). (page 16)

RECOMMENDATION NO. 6

The Sub-Committee further recommends that the form of the warning label on beverage-alcohol containers should be designed with appropriate regard for readability, perceptual prominence, colour contrast and impact. Also, the design and content of the warning label shall be approved by the Minister of Health and Welfare Canada on the recommendation of the National Advisory Committee on Alcohol and the Foetus prior to being adopted and used by the beverage-alcohol industry. (page 16)

RECOMMENDATION NO. 7

The Sub-Committee recommends that the Minister of Health and Welfare Canada initiate discussions with Provincial and Territorial Governments to develop appropriate warning signs for establishments serving and selling alcoholic beverages, or selling supplies for beer-and wine-making, to alert all consumers that consumption of alcohol during pregnancy places the foetus at risk for Foetal Alcohol Syndrome (FAS) or Foetal Alcohol Effects (FAE). The objective of this initiative is to implement a uniform program of warning signs at such outlets in all jurisdictions across Canada. (page 17)

RECOMMENDATION NO. 8

The Sub-Committee recommends that the Canadian Radio-Television and Telecommunications Commission amend the regulations under the *Broadcasting Act* and the "Code For Broadcast Advertising Of Alcoholic Beverages" to ban that type of advertising of alcoholic beverages, generally known as "lifestyle advertising", on radio and television in Canada. (page 18)

RECOMMENDATION NO. 9

The Sub-Committee recommends that the Minister of Health and Welfare Canada, in consultation with the Minister of Consumer and Corporate Affairs Canada and the Canadian Radio-Television and Telecommunications Commission, prescribe regulations to require that appropriate and effective warnings about the serious impacts of alcohol on the foetus be included as part of all advertising of alcoholic beverages in Canada. (page 19)

RECOMMENDATION NO. 10

The Sub-Committee recommends that Health and Welfare Canada, in cooperation with provincial and territorial health departments and with the National Advisory Committee on Alcohol and the Foetus, regularly review and evaluate current public awareness and education programs on the impacts of alcohol on the foetus. If current programs are judged to be appropriate and effective they should be maintained and expanded. If they are not, new programs should be developed and implemented to raise public awareness and knowledge of this issue. (page 21)

RECOMMENDATION NO. 11

The Sub-Committee recommends that the Federal Government, in cooperation with Provincial and Territorial Governments and with the National Advisory Committee on Alcohol and the Foetus, develop and implement awareness and education programs directed at Canada's primary and secondary school systems, the judiciary, and social and child-welfare services to increase awareness and understanding of Foetal Alcohol Syndrome and Foetal Alcohol Effects and of the unique problems and needs of individuals so-afflicted. (page 22)

RECOMMENDATION NO. 12

The Sub-Committee recommends that Health and Welfare Canada, in cooperation with professional health-care associations including, but not necessarily limited to, the Canadian Medical Association and the Canadian Nurses Association, take the lead and assist in upgrading the curricula of medical schools, schools of nursing, and other relevant health-care educational institutions, with respect to the impacts of alcohol on the foetus in particular, and on human health in general. (page 23)

RECOMMENDATION NO. 13

The Sub-Committee recommends that Health and Welfare Canada, in cooperation with provincial and territorial health departments, design and carry out an epidemiological study to determine the incidence of Foetal Alcohol Syndrome and Foetal Alcohol Effects in Canada, among the Canadian population in general and in target sub-populations known, or suspected, to be at higher risk for such conditions. (page 24)

RECOMMENDATION NO. 14

The Sub-Committee recommends that Health and Welfare Canada, with the cooperation of the National Advisory Committee on Alcohol and the Foetus, take the lead and assist in developing effective diagnostic tools for health-care professionals to identify and assess the special care and treatment needs of children born with Foetal Alcohol Syndrome or Foetal Alcohol Effects so that early and accurate diagnosis of these conditions might be made and appropriate treatment programs prescribed and applied. (page 25)

RECOMMENDATION NO. 15

The Sub-Committee recommends that Health and Welfare Canada, in cooperation with provincial and territorial health departments, initiate a program of research to develop more effective methods for the treatment, care and training of children with Foetal Alcohol Syndrome and Foetal Alcohol Effects, so that these individuals can maximize their intellectual and employment potentials as adults in Canadian society. (page 25)

RECOMMENDATION NO. 16

The Sub-Committee recommends that Health and Welfare Canada, in cooperation with provincial and territorial health departments, develop more appropriate, effective, and economical treatment-delivery programs for victims of Foetal Alcohol Syndrome and

Foetal Alcohol Effects. Such programs could include group homes or special treatment centres that recognize and provide for the unique problems and needs of these children. (page 26)

RECOMMENDATION NO. 17

The Sub-Committee recommends that the Minister of Health and Welfare Canada provide leadership and consult with his counterparts in the Provinces and Territories to develop and implement programs to subsidize adoptions of children with Foetal Alcohol Syndrome and Foetal Alcohol Effects and to provide income assistance to families with FAS and FAE children. (page 26)

RECOMMENDATION NO. 18

The Sub-Committee recommends that the Minister of Health and Welfare Canada and the Minister of Indian and Northern Affairs Canada, in cooperation with the Provinces and Territories, establish a Special Aboriginal Committee on Alcohol and the Foetus. The Special Committee should have representation from the various aboriginal communities in Canada and be represented on the National Advisory Committee on Alcohol and the Foetus. (page 27)

RECOMMENDATION NO. 19

The Sub-Committee recommends that the Departments of Health and Welfare and Indian and Northern Affairs, in cooperation with the Special Aboriginal Committee on Alcohol and the Foetus, design and deliver aggressive public-information campaigns to heighten awareness of the association between Foetal Alcohol Syndrome and Foetal Alcohol Effects and alcohol use among aboriginal peoples. (page 27)

RECOMMENDATION NO. 20

The Sub-Committee recommends that Indian and Northern Affairs Canada and Health and Welfare Canada, in cooperation with the Special Aboriginal Committee on Alcohol and the Foetus, review and evaluate existing programs for the learning-disabled in aboriginal communities to develop more effective and appropriate community-based programs to deal with learning disabilities of individuals afflicted with Foetal Alcohol Syndrome or Foetal Alcohol Effects. (page 28)

Recommendation No. 21

The Sub-Committee recommends that Health and Welfare Canada, in cooperation with provincial and territorial health departments, design and implement a research program to develop diagnostic procedures to identify adults afflicted with Foetal Alcohol Syndrome and Foetal Alcohol Effects. This research initiative shall be the first step in a comprehensive program to provide assistance to adults whose lives have been blighted by alcohol-induced injuries. (page 29)

FOETAL ALCOHOL SYNDROME

INTRODUCTION

Alcohol has been described as the most widely used legal drug in the world. Health and Welfare Canada's "National Alcohol and Other Drugs Survey", carried out in 1989, found that 78% of adult Canadians were "current" drinkers; that is, they reported consuming alcoholic beverages at least once in the 12 months prior to the survey. An additional 16% of Canadians were "former" drinkers, having consumed alcohol at some time in their lives. Only 7% of Canadian adults reported that they had never consumed an alcoholic beverage. 1

The use of alcoholic beverages, in a variety of settings, is firmly entrenched in Canadian society. Also, the production and sale of beer, spirits, and wine comprise major industrial activities in Canada, as in other countries. Figures published by Statistics Canada show that sales of Canadian beer, spirits, and wine in Canada in 1988 amounted to a total of more than \$7.6 billion; sales of Canadian beer, at almost \$4.6 billion, accounted for more than half this total. When imported products are included, the total value of Canadian sales of alcoholic beverages for 1988 rises to almost \$9.6 billion. ²

The deleterious impact on the foetus of maternal alcohol consumption had been suspected by some medical practitioners and researchers for perhaps a century before foetal alcohol syndrome (FAS) was formally described and named in 1973. Many articles on FAS refer to citations in the Bible, the Koran, and Talmudic writings, suggesting that ancient civilizations knew of the association between alcohol and foetal injury. A critical review of these references by Dr. Ernest Abel, Professor of Obstetrics at Wayne State University, concludes that the ancient texts have been both misquoted and misinterpreted:

"To sum up, the Bible, the Talmudic fathers, and the Ancient Greeks and Romans were not aware of any dangers associated with drinking during pregnancy. These writers were all men and they were only interested in the effects of alcohol on themselves and on other men."

Today, there is no question that maternal alcohol consumption can have devastating impacts on the foetus. The basic fact is that when the pregnant woman drinks, her unborn child "drinks" also; that is, the alcohol in the mother's bloodstream circulates through the placenta into the bloodstream of the foetus. It is possible that the blood-alcohol level in the foetus will remain at an elevated level for a longer period than that of the mother because the immature foetal liver metabolizes the alcohol more slowly.

While much remains to be learned about foetal alcohol syndrome (FAS) and the related condition, variously called "foetal alcohol effects" (FAE) or "alcohol-related birth defects" (ARBD), enough is now known about both conditions for governments at all levels to take positive actions to

Health and Welfare Canada, *National Alcohol and Other Drugs Survey:* Highlights Report, Health Promotion Directorate, Health Services and Promotion Branch, June 1990, p. vii.

Statistics Canada, Beverage and Tobacco Products Industries 1988, Catalogue 32-251 Annual, Industry Division, November 1991, Table II.

K.L. Jones, D.W. Smith, C.N. Ulleland, and A.P. Streissguth, "Patterns of malformation in offspring of chronic alcoholic mothers", Lancet, No. 7815:1267-1271, 9 June 1973.

Ernest L. Abel, Foetal Alcohol Syndrome, Medical Economics Books, Oradell, New Jersey, 1990, p. 3.

attempt to prevent their occurrence and to deal more effectively and compassionately with the victims and their families. This report discusses the issues associated with these conditions. The testimony is to be found in Issues Nos. 6-16 of the Sub-Committee on Health Issues of the Third Session of the Thirty-Fourth Parliament.

FOETAL ALCOHOL SYNDROME

Since foetal alcohol syndrome was described in 1973, a growing body of evidence has indicated clearly that the full-blown syndrome is the major expression of a continuum of effects exerted by alcohol on the developing foetus. Diagnosis of FAS is made after a careful physical examination and a determination that the individual displays specific manifestations in each of the three categories described below:

- (a) Prenatal or postnatal growth retardation, below the 10th percentile.
- (b) Central nervous system abnormalities which may include tremulousness, poor sucking reflexes, abnormal muscle tone, hyperactivity, attentional deficits, or mental impairment (e.g., mental retardation).
- (c) At least two characteristic facial anomalies, including narrow eye width, "ptosis" (drooping of the upper eyelid), a thin upper lip, a short upturned nose with underdevelopment of the groove between the base of the nose to the top of the upper lip, and general underdevelopment ("hypoplasia") of the midfacial area resulting in a "flattened" facial appearance.⁵

One of the problems with FAS, and even more so with foetal alcohol effects or FAE, is the difficulty of making an early and accurate diagnosis. Dr. Oscar Casiro, Chairman of the Child Health Committee of the Manitoba Medical Association, made the following statement to the Sub-Committee:

"Full foetal alcohol syndrome does not always become evident right from the time of birth or during the first few months of life. There is no specific test we can do that will make a diagnosis without leaving any doubt. Diagnosis is made on a clinical basis, based on physical appearance, and babies with foetal alcohol effects don't have all the physical characteristics the ones with the full syndrome have. There is a spectrum of abnormalities, a spectrum of damage caused by alcohol. Foetal alcohol syndrome is at the end of this spectrum." ⁶

Dr. Casiro told the Sub-Committee that FAS is the leading cause of mental retardation in Canada and North America at the present time. ⁷ Wendy Kemp, a Clinical Nurse Specialist with the Alberta Alcohol and Drug Abuse Commission, stated that 50% of FAS victims suffer mental retardation and another 30% are borderline mentally retarded. ⁸ FAS is the major cause of mental retardation that is totally preventable.

Foetal alcohol syndrome children may suffer from a wide variety of physical and behavioural effects, in addition to the ones already described. One-fifth of FAS children have difficulty sleeping and are hyperactive. Many have severe learning disabilities and often are dyslexic. Congenital

Kenneth R. Warren and Richard J. Bast, "Alcohol-Related Birth Defects: an Update." Public Health Reports, Vol. 103, No. 6, November-December 1988, p. 639.

Minutes of Proceedings and Evidence of the Sub-Committee on Health Issues of the House of Commons Standing Committee on Health and Welfare, Social Affairs, Seniors and the Status of Women (hereafter, Proceedings), Issue 8, 20 February 1992, p. 19.

⁷ Ibid.

⁸ Proceedings, Issue 9, p. 22.

heart problems are more common than in normal babies, and genital-urinary problems also occur. An increased incidence of spina bifida, hip dislocation, and delayed skeletal maturation occurs among FAS children.

Neonatal death rates for FAS babies are higher than normal and this may be due to the fact that "the mother is intoxicated at the time of birth and the baby . . . then goes through withdrawal, which accounts for the higher mortality." Death rates in early infancy are also higher than normal, usually because of a failure to thrive. This may be due to poor parenting skills and a poor home environment which, itself, may be a result of parental alcohol use.⁹

Children with FAS have a higher-than-normal incidence of other health problems, including staggered gait in walking ("tremor ataxia"), speech impediments, dental problems, vision problems, and hearing difficulties. The organic cerebellar damage, which lies at the base of many of the FAS victim's health problems, produces the erratic behaviour and learning deficits, all of which interfere with mother-child bonding, making parenting very difficult.

FAS babies are very irritable when they are born, dislike being touched, and they have a very high-pitched crying. This may further complicate the mother-child relationship: "If the mother is also alcoholic and has a child who is very irritable and doesn't like being touched, then she also is an individual who has a lot of poor coping skills." In such a dysfunctional family situation, the FAS child may suffer significant physical, emotional, or even sexual abuse. Such abuse may account for a high mortality rate among FAS children in early infancy. ¹⁰

In many families where a child is born with foetal alcohol syndrome (or foetal alcohol effects), there are other complicating factors which may be included under the general heading of "environment". Where the family is in the lower socio-economic category, poverty and malnutrition, and general poor health of the mother may also be factors that affect the health of the child. Maternal smoking and the mother's use of other substances or drugs may also compromise the health of the offspring. If the father also is drinking, or using other substances, this will contribute to a dysfunctional family situation and affect the health of the child.

FOETAL ALCOHOL EFFECTS

Foetal alcohol effects, or FAE, is, on the surface, less severe than foetal alcohol syndrome in that the victims suffer fewer and less serious impacts from maternal alcohol consumption. In general, the individual's IQ is higher and is often in the normal range. Physical abnormalities are much fewer and less pronounced than those suffered by FAS victims. As Dr. Casiro stated, "babies with foetal alcohol effects don't have all the physical characteristics the ones with the full syndrome have."

Individuals with foetal alcohol effects do exhibit significant alcohol-related injuries, however. The testimony received by the Sub-Committee indicates that much of the damage suffered by FAE victims is neurological and is expressed as hyperactivity, behavioural problems, learning disabilities, and a general inability to function normally in a social milieu. Children with FAE may, in fact, face more serious problems in later life than will FAS children. Many of them suffer sufficiently severe neurological damage to make them socially dysfunctional, but their overall symptoms as infants are not often correctly diagnosed and early medical intervention will usually not happen.

⁹ Proceedings, Issue 9, p. 23.

¹⁰ Proceedings, Issue 9, p. 24.

Dr. Christine Loock of Sunny Hill Hospital in Vancouver, an expert on FAS and FAE, gave the following testimony, describing three of her young patients to illustrate the special difficulties of FAE victims:

"What is most concerning are these three children, who have foetal alcohol effects. Even to me they are not recognizable by their physical features. They are not small in size. They do not have any recognizable birth defects that are consistent enough to call it foetal alcohol syndrome. But they have severe learning disabilities. These are the children who, paradoxically, will likely do worse. They are all children of alcoholic birth mothers. If they are not recognized, then these are the children who end up as victims within our criminal justice system. They'll be victims within our school system for not receiving proper learning assistance related to their learning disability. They end up with very poor self-esteem, affective disorders and the loss of productivity."11

INCIDENCE OF FOETAL ALCOHOL SYNDROME AND FOETAL ALCOHOL EFFECTS

The incidence of FAS and FAE in Canada is not known with precision, principally because of the diagnostic difficulties. Testimony from Health and Welfare Canada stated that average FAS incidence rates "estimated from U.S. and European studies are from less than one to over three cases per thousand live births", with much higher levels in certain "sub-populations of heavy drinkers and certain disadvantaged social groups, including aboriginal and African American populations." Canada has no national data on FAS and FAE; the incidence rate of FAS in the general population is estimated by Health and Welfare Canada to be between one and two per thousand live births. ¹²

The Canadian Centre for Substance Abuse (CCSA) cited an estimate from a review of 19 epidemiological studies from around the world which indicated that the overall rate of FAS was 1.9 per 1,000 live births. A large-scale study in the United States by the Centers for Disease Control reported a rate of 1 per 1,000 live births. The CCSA testimony went on to state that:

"If this estimate was applied to Canada, it would indicate that between 400 and 500 children are born each year in Canada with FAS. This is, however, a very conservative estimate as it is based on the lowest estimated incidence rate and does not take into account the exceptionally high rate of FAS among aboriginal Canadians and possibly other socially disadvantaged groups." ¹³

In some communities, notably in remote, rural communities, and in some aboriginal communities, the incidence rates for FAS are several orders of magnitude higher than the rate for Canada as a whole. There is evidence also that the incidence rates in some poor, inner city communities are also very high. Dr. Richard Jock of the Assembly of First Nations quoted incidence rates from British Columbia and the Yukon: "Dr. Asante did a study several years ago, I believe in 1983 and 1984, which described the incidence in Yukon for aboriginal groups of 46 per 1,000 and 26 per 1,000 for aboriginal people in northern British Columbia." ¹⁴ Dr. Jock stated that the level of FAS and FAE among First Nations children represents a "crisis situation". ¹⁵

Ms. Betty MacPhee, Manager of the YWCA's "Crabtree Corner", an emergency day-care and family drop-in centre in Vancouver's downtown east side, presented testimony to the Sub-Committee on the incidence of FAS and FAE among the inner city population that forms the

¹¹ Proceedings, Issue 10, p. 20.

¹² Proceedings, Issue 6, p. 5.

¹³ Proceedings, Issue 9, p. 5.

¹⁴ Proceedings, Issue 10, p. 4.

¹⁵ Ibid., p. 6.

centre's clientele. Eighty percent of Crabtree Corners' families are aboriginal and most are single mothers. Many have alcohol and drug-abuse problems. There the prevailing syndrome is often described as FAS/NAS, for "foetal alcohol syndrome/neonatal abstinence syndrome". In her brief to the Sub-Committee, Ms. MacPhee states that of "the 30 reported live births in the Downtown Eastside in 1990 15 have FAS/FAE/NAS", a prevalence rate of 50%. ¹⁶ Moreover, some of these women will have more than one baby, and the pattern of FAS/FAE/NAS is often repeated. The health of the offspring may be further compromised by maternal smoking, poor nutrition, and physical abuse.

Ms. MacPhee's statement that some women, who are problem drinkers, will have more than one child with FAS or FAE is supported by testimony from other witnesses. In some aboriginal communities in British Columbia and the Yukon, for example, heavy-drinking mothers have been reported to have more than one affected child:

"... there were multiple (FAS/FAE) births from single parents who were drinkers, very heavy drinkers. In other words, there were 10 children per mother and they were all FAS." 17

Where the father is also drinking, it will be even more difficult for the mother to break the cycle and abstain from alcohol when pregnant.

E.L. Abel is an American researcher who has studied the question of FAS/FAE in families. His review of a number of case reports has shown that the later-born children of alcoholics are at much greater risk for FAS and FAE than are their older siblings. His conclusion is that, even allowing for a wide latitude of error, "the estimated probability of a second FAS child in a family, given another sibling with FAS, is very high." ¹⁸

The Sub-Committee did not receive evidence that the siblings of an FAS/FAE child were likely to be similarly afflicted if the mother was a "social" drinker, rather than a problem drinker or an alcoholic. It is possible that the shock of having an FAS/FAE baby would alert a mother and father to the fact that even social drinking is unacceptable during pregnancy, and effect a change in maternal drinking behaviour during a subsequent pregnancy. A change in paternal drinking behaviour, in the direction of abstinence, would help the mother avoid alcohol during pregnancy.

The incidence rate for FAE births, and the numbers of FAE children born in Canada annually, also are not known. The Sub-Committee received a number of estimates in this area also. It is believed that there are many more FAE children than FAS children born in Canada each year. Dr. Casiro stated that FAE is "at least three times as frequent as the full foetal alcohol syndrome." ¹⁹

DOSE-RESPONSE RELATIONSHIP IN FAS AND FAE

There is no agreement in the medical community on exactly how much alcohol a pregnant woman may consume without producing a child with FAS or FAE. There is agreement that the amount of damage caused to the foetus will increase with the amount of alcohol consumed by the mother. Ms. Judy Ferguson of Health and Welfare Canada made the following statement:

Betty MacPhee, "Brief to the Sub-Committee on Health Issues", April 2, 1992, p. 7.

¹⁷ Proceedings, Issue 9, p. 26.

¹⁸ Abel (1990), p. 36.

¹⁹ Proceedings, Issue 8, p. 26.

"While there is still some question about the threshold in quantity and frequency of alcohol intake beyond which damage could occur to the foetus, there is no uncertainty about the dose response in more general terms, namely that risk of damage to the foetus increases as the level of alcohol to which the foetus is exposed increases . . . From a scientific viewpoint, no safe level of foetal alcohol exposure has been identified." ²⁰

Most witnesses agreed with the position that there is "no safe level" of alcohol that a woman can consume during pregnancy. The medical witnesses all recommended total abstinence by a pregnant woman to ensure that her baby would not be affected by either FAS or FAE. There was general agreement that greater amounts of alcohol are necessary to produce full-blown foetal alcohol syndrome than to produce foetal alcohol effects, or FAE.

It seems to be accepted that damage from alcohol can occur throughout the pregnancy, although the foetus is more susceptible during the first trimester. If the mother ceases drinking at any time during the pregnancy, there will be less risk of alcohol damage and the baby will be healthier than if she continued drinking throughout the nine months gestation period.

Dr. Oscar Casiro, representing the Manitoba Medical Association, made the following statement, agreeing that there is no safe amount of alcohol a pregnant woman can consume, suggesting at the same time that there might be a threshold for FAS, although it will not be the same for all women:

"... it appears (that) the end of the spectrum (of damage), the full-blown foetal alcohol syndrome, is caused when a woman drinks two to four drinks, or one to two ounces of absolute alcohol, a day during early pregnancy. There is no scientific evidence to show any amount of alcohol is safe for the foetus... heavy drinkers will have approximately 50% of their infants with foetal alcohol syndrome. Those mothers who drink two to four drinks a day have a 10% risk of having a child with foetal alcohol syndrome. We do not know why, with the same amount of alcohol, some babies will develop the full syndrome and others won't. That information is not available."²¹

In contrast to the testimony of medical witnesses, and of Ms. Ferguson from Health and Welfare Canada, the Association of Canadian Distillers (ACD) spoke of FAS in terms of consumption of "abusive amounts of alcohol during . . . pregnancy". ²² The Brewers Association of Canada (BAC) also associated FAS with "abusive levels of consumption of alcohol." ²³ The BAC stated also that questions still exist about moderate consumption of alcohol during pregnancy, citing a 1991 paper by Forrest and co-workers in the *British Medical Journal* suggesting that consumption of about one drink per day is safe for a pregnant woman. ²⁴

The paper by Forrest and co-workers states that "it is recommended that pregnant women should drink no more than eight units of alcohol a week, the equivalent of about one drink a day . . . and only as much as this if abstinence is not feasible." ²⁵ Dr. Casiro testified to the Sub-Committee that he believed the study by Forrest and co-workers had significant methodological flaws. The witness was concerned that 30% of the children were not followed for the full 18-month term of the

Proceedings, Issue 6, p. 4.

²¹ Proceedings, Issue 8, pp. 19, 27.

Proceedings, Issue 11, p. 4.

Proceedings, Issue 8, p. 4.

F. Forrest, et al, "Reported social alcohol consumption during pregnancy and infants' development at 18 months", British Medical Journal, Vol. 303, 6 July 1991, pp. 22-26.

²⁵ Ibid., pp. 22, 26.

study and that the diagnostic test used was not sensitive enough to detect subtle alcohol-induced damage in the children. Dr. Casiro stated that "I believe it is wrong and inappropriate to take that study based on those findings, to say that it is safe for a pregnant woman to have seven or eight drinks a week during pregnancy." ²⁶

The question of heredity and/or race as factors in higher or lower susceptibility to FAS or FAE was raised a number of times during our hearings. No witness was able to provide information that either heredity or race was a factor in the incidence of either condition. In his book on FAS, Abel notes that ethanol, the intoxicating component in alcoholic beverages, is primarily metabolized in the body to acetaldehyde through the action of the enzyme, alcohol dehydrogenase. The acetaldehyde itself is then broken down in a series of reactions.

It is known that alcohol dehydrogenase exists in a number of genetically different variants, resulting in different levels of acetaldehyde production after consumption of alcohol. Also, acetaldehyde is considerably more toxic to humans than is ethanol. Abel states that it is possible that "the genetic variations in acetaldehyde production or metabolism may be a critical maternal risk factor for foetal alcohol effects." It is not known, however, if this is a significant factor in the incidence of FAS or FAE in different social or racial groups.

In the absence of definitive evidence on the question of dose-response relationships in foetal alcohol syndrome and foetal alcohol effects, the Sub-Committee believes that a pregnant woman should abstain from alcohol throughout her pregnancy. We also believe that the father can assist the mother by also abstaining from alcohol during the pregnancy. We believe this position is particularly appropriate in the matter of foetal alcohol effects. It appears that FAE may be caused by smaller amounts of alcohol than is full-blown FAS.

The Sub-Committee received very pertinent testimony on this point from one of the witnesses who appeared before us:

"...I would like to tell you briefly of my own experience with FAE....in 1988 I began to come to the conclusion that my first born child was foetal alcohol affected.

"I worked throughout my pregnancy, ending my work day with a commute to my middle class home in the suburbs. During the meal preparation I often would have one drink. I was vigilant about not taking any medication, and had quit smoking prior to my pregnancy.

"During my pregnancy I asked my doctor about alcohol. In 1968-69 his knowledge was that a couple of drinks were fine. My son Jeff was born on February 11, 1969, a healthy baby. He appeared bright, and developmentally he kept up with his peers. His attention span was very short, however, and he was a very busy child. I rejected the term hyperactive.

"By the time he was three, he had had stitches three times. He was fearless, and did not seem to learn from his falls. In grade 2 he was identified as learning disabled, and he repeated grade 2. The painful years of testing, learning assistance, and special education classes began. During this time I worked very hard to be an advocate for him in the school system, and I also tried to help him maintain his self-esteem.

"He told me when he was 16 that, after watching a public broadcasting system program on learning disabilities, he sat and cried. With much support he completed high school at age 19. He began working in construction. His well-developed social skills, his charm and wit made hiring easy for him, plus he had a resumé at the ready that masked his grade 4 reading level.

Proceedings, Issue 8, p. 21.

²⁷ Abel (1990), pp. 39-41.

"He worked his way through the sub-trades, stating he wanted to build his own house some day, but he was often plagued with on-the-job accidents. Again, I suspect a lack of judgement. He fell off roofs, he put a nail through his hand with a nail gun, objects landed in his eye, etc. Through all this he maintained a cheerful attitude, often working 12 hours a day.

"On July 5, 1990, Jeff attended a friend's party in the suburbs where he lived. During the evening he took four prescription pills that were being passed around. The other kids took two pills. Jeff didn't read the label because he couldn't read it. The pills were slow acting morphine. He died of an accidental drug overdose. He was 21 years old.

"I have shared this very private story to emphasize this isn't an academic exercise for me. I, as a very conscientious pregnant mother, had the right to know alcohol could damage my child. I believe Jeff's death was connected to his birth. I urge you to use your position on this committee to advocate for the right of every parent to have the knowledge that when you are pregnant there is no safe amount of alcohol." ²⁸

ADOPTIVE CHILDREN WITH FAS/FAE

Evidence presented to the Sub-Committee indicates that many FAE children, and some FAS children, are adopted, their birth mothers being unable or unwilling to keep them. In many, perhaps most, cases, the adoptive parents are unaware that the children have been damaged by alcohol until the child is at least several years old, and perhaps not until he or she starts school. At that stage, their learning disabilities and their inherent socially dysfunctional traits will usually become obvious.

The adoptive parents then find themselves faced with a medical and social situation for which they are often totally unprepared. The Sub-Committee received testimony from two adoptive mothers of FAS and FAE children, Mrs. Shirley Joiner and Mrs. Lesley Carberry. Their testimony, often poignant and sometimes even shocking, deeply impressed the members of the Sub-Committee. Their testimony should be read by anyone wishing to appreciate and understand the immense difficulties encountered by parents — adoptive or natural — who must cope with the rearing of children afflicted by FAS and FAE. Excerpts from their testimony are presented below.

Mrs. Shirley Joiner and her husband, Dennis, adopted a boy with FAE:

"Eleven years ago we adopted a five-year-old boy named Ethan . . . Last year my 15-year-old son spent over 100 days in prison. He is no longer in prison, but he is not free either. He is serving a life sentence for consumption of alcohol before birth . . . When we adopted Ethan we knew he was hyperactive. Lots of kids are, so we didn't pay too much attention to that . . . When he started Kindergarten, that is when his problems started.

"These kids have no fear of danger. I remember even when he was five years old . . . (he) would climb trees as high as they grow them in British Columbia without any fear at all of falling . . . They can never relate behaviour to consequences. If they suffer consequences in one situation, they cannot transfer that information to another situation.

"These kids need 24-hour supervision. You'd think by the time they reached adolescence you could back off a bit, but it's exactly the opposite. It seems as though they need even closer supervision in their adolescence, more so even than when they're toddlers.

"... one of the rules we (had) established was that my bedroom was my refuge and he had no business coming in there when the door was locked. Consistently he'd force his way in. It just seemed as though he delighted in tormenting me. A few months later we discovered that during this

Proceedings, Issue 13, pp. 27-28.

time he had had a powerful pistol stored in the attic above his closet and enough ammunition to blow away the whole neighbourhood . . . By the end of December (1990) my health was not doing well at all, the stress was just so unbearable . . . Finally, on January 15 (1991), when he had threatened three times to kill Dennis and acted as if he would, I called the police and they finally responded." ²⁹

Mrs. Joiner and her husband endured years of enormous stress, and confusion about why their adopted son behaved the way he did, because he was not correctly diagnosed until quite recently. Special education was not available through the school system, counselling and other expenses were extremely high, and the overall strain put their marriage in jeopardy. Ethan, however, is now living in foster home in a small community and "doing much, much better." 30

After a local newspaper ran a story on Ethan, Mrs. Joiner made contact with other families in a similar situation and a support group has been formed:

"This support group offers us an opportunity to exchange information, for instance which doctors to avoid, which ones may be sensitive to and informed about foetal alcohol syndrome, and which social worker might listen. It gives an opportunity to share frustrations and support each other in crisis. Most of these families are just hanging on by their fingernails." ³¹

Mrs. Carberry, who is from Whitehorse, gave testimony which had many themes in common with Mrs. Joiner's. For parents, extreme fatigue is a constant fact, and the strains on a marriage are very great. The need for continuing support at all levels is very important. Mrs. Carberry is a member of the Alcohol-Related Birth Defects Committee of her local Association for Community Living. The committee has compiled a kit which is sent to every pregnant woman in the Yukon. The kit has information on a healthy pregnancy, including the effects of drinking on the foetus. Funding for this program initially came from a grant from Health and Welfare Canada, but that funding has now been discontinued.³²

Foetal alcohol syndrome and foetal alcohol effects are major problems in the Yukon, particularly among aboriginal peoples. The Yukon government has prepared an action plan on FAS and FAE and also requires warning labels on containers of beverage alcohol, the only jurisdiction in Canada to do so.

Some of Mrs. Carberry's comments are quoted below:

"...my first point is that the impacts on an individual... are really multi-dimensional. They are ... the foetal alcohol effects, the birth defects, the mental disabilities in some cases, many, many physical problems ... The second (point) that I think we cannot overstate is what happens when children are separated from their families ... there's separation from their culture if they're native children ... there are the effects of abuse and neglect. For my children, all of those things are apparent. It's not just the foetal alcohol effects that are creating problems for them. It's the separation from their family, it's the poor foster care that they got, the impacts of sexual abuse, physical abuse, neglect and everything else.

"... the demands on care-givers — whether they're birth families, foster families, extended families, adoptive — are enormous.

²⁹ Proceedings, Issue 12, pp. 4, 9, 12, 13.

³⁰ Ibid., p. 9.

³¹ Ibid., p. 20.

Proceedings, Issue 12, p. 26.

"The third (point) is that we really don't know enough . . . What we know is the end result, children and adults who have incredible problems trying to manage in society.

"The fourth (point) I think, is implications for the ways that our systems work in terms of providing help to mothers who are drinking before their children are born, to the children themselves, to the care-givers. We don't know enough about how to provide help to people who have a mental disability and have been abused.

"The early months after a child is born are absolutely critical to the future for that child. The need for good assessment, the need for knowing what (the) prognosis would be, and the need for realistic supports, especially with moms who are struggling with alcoholism and many other issues . . . We need, I believe, to work toward keeping these children in their families and with their communities . . . The removal of the child (from the community) impacts on the child in terms of the attachment. It impacts on the mom and dad in terms of, what's the point of getting better if you've lost your child? It impacts on the family because they're losing one of their family members. It impacts on the community because of lessening their accountability.

"You're told that all these kids need is love and a good home. That's not enough. It's not enough for them. It's not enough for the parents. There's no shortage of love for these children . . . You have foster and adoptive parents who are very eager. They want to be the best parents ever . . . They're very optimistic. They think, "We're going to fix this kid. They just need a better situation in life and everything's going to be okay.

"We're often really naive and very uninformed about our particular child's history, as well as the impacts of foetal alcohol . . . If you look at it from the kid's point of view, they're scared. They've been moved around often. They're hurt. They're angry . . . You have super parents on the one hand and very traumatized children on the other. It's a time bomb waiting to go off, and it's a time bomb that people don't know about . . . I believe the struggle is to rescue this (situation) before the kids get dumped on or before the parents dump on themselves or go under financially . . . many marriages break up over this.

"Society monitors kids more when they start to reach 12 or 13. The Young Offenders Act kicks in which is a real concern for most of us . . . We may not have noticed it earlier, but by the time these kids enter adolescence, particularly middle adolescence, that poor judgement really begins to stand out . . . it is a real volatile time. For many people, I believe the child is not able to remain in the home at that point. The key is for professionals not to then say well, you've had an adoption breakdown. What we've had is a really tough situation and we need to find a way to manage that for everybody.

"The other thing I think that really comes in in adolescence is that we parents begin to get really, really concerned about the long-term future for our children. What are they going to do? How are they going to be supported? How are they going to work? . . . The challenges are to find appropriate school placements, to find an accepting social network for practical non-judgemental support . . . Long-term struggles are employment, leisure activities, independent living and finances and the whole notion of what will happen (to our children) after we die . . .

"I think as a society we're not quite prepared to look at the costs of what we're doing and what our behaviour is doing to our children. I believe these children will force the issue for us and make us look at it. I think we have some real tough questions to answer."33

³³ Proceedings, Issue 12, pp. 28-30, 32, 34-35.

RECOMMENDATIONS

Foetal alcohol syndrome, or FAS, is an important health issue in Canada, and in Western nations generally where alcohol is widely consumed by adults of both sexes. Although the evidence for Canada is that fewer women than men consume beverage alcohol, drink less often, and consume smaller amounts, many women of child-bearing age are "social drinkers" and a small but significant number may be described as "problem" or "abusive" drinkers.

It is tempting for some to suggest that FAS is a threat only to the latter group, a small minority of women of child-bearing age, and it is certain that problem drinkers or alcoholics who are pregnant will place their unborn children at greater risk for FAS than occasional or social drinkers. The fact remains, however, that there is no known safe level of alcohol for a pregnant woman. There is a suggestion that some individuals may be more susceptible to foetal alcohol problems than are others.

The Sub-Committee has learned that foetal alcohol effects, or FAE, is much more prevalent than FAS, and is caused by a lower level of alcohol consumption by the mother. Individuals with FAE often encounter immense problems throughout their lives as a consequence of alcohol-induced brain damage. As the testimony presented to us shows, many have learning disabilities and severe behavioural problems and often run afoul of the criminal-justice system.

We believe that the problem of maternal drinking and impacts on the foetus is probably much more serious than many Canadians suspect. We feel it is important for Canadians, women and men, to understand that even moderate alcohol consumption during pregnancy places the child at risk. The principal conclusion we have reached on the basis of the evidence that we have seen and heard is that complete abstinence is the appropriate course for pregnant women.

The Sub-Committee has formulated twenty-one recommendations.

(A) NATIONAL ADVISORY COMMITTEE ON ALCOHOL AND THE FOETUS

All witnesses before the Sub-Committee stated emphatically that alcohol consumption during pregnancy is a very serious issue and that the potential risks to the foetus merit a high profile. Several witnesses, including the Brewers Association of Canada, the Assembly of First Nations, and the Association of Canadian Distillers, believed that a National Action Committee on FAS and FAE should be formed. Such a committee could give a high profile to this issue, and could focus diverse energies and activities more effectively than is currently the case.

The Sub-Committee believes that a National Advisory Committee on Alcohol and the Foetus should be formed. Representation should be decided after consultation with the provinces and territories and with non-government organizations. We believe it is appropriate to have a national committee to concentrate on alcohol problems separate from drugs and other substances of abuse, because beverage alcohol is a legal product, its use deeply ingrained in our society and culture, and one whose use is widely advertised in the media. Because alcohol presents special problems, its use and abuse requires a special approach.

RECOMMENDATION NO. 1

The Sub-Committee recommends that the Minister of Health and Welfare Canada initiate discussions with the Provinces and Territories to create a National Advisory Committee on Alcohol and the Foetus. The Advisory Committee shall have a broad

membership, including representatives from professional health-care organizations, social science and legal professions, government officials, parents' groups, and the beverage-alcohol industry. The Chairperson shall be elected by the Advisory Committee. The Committee shall report to the Minister of Health and Welfare Canada, whose department shall provide funding for the Committee.

(B) NATIONAL RESOURCE CENTRE ON ALCOHOL AND THE FOETUS

As our public hearings progressed, it became apparent that there is a need for a national resource centre to deal with the many issues associated with FAS and FAE. Such a centre could make a valuable contribution in this area, operating perhaps in the manner of a "centre of excellence" both for studies on FAS/FAE, development of treatments for victims and drinking mothers, and for coordinating information for dissemination across Canada.

The Canadian Centre for Substance Abuse in Ottawa operates a national clearing-house for information on drugs and other substances, including alcohol, and could participate directly or indirectly in the development and operation of a national resource centre on alcohol and the foetus. An existing centre of excellence in this area is the British Columbia FAS Resource Group at the University of British Columbia Department of Pediatrics and the Sunny Hill Hospital for Children in Vancouver.

The Sub-Committee believes that existing resources should be used to the maximum extent in creating a national centre.

RECOMMENDATION NO. 2

The Sub-Committee recommends that the Minister of Health and Welfare Canada, in consultation with the Provinces and Territories, promptly establish a National Resource Centre on Alcohol and the Foetus, the purpose of the Centre being to coordinate and disseminate information across Canada on all aspects of Foetal Alcohol Syndrome (FAS) and Foetal Alcohol Effects (FAE). The Centre could most effectively and economically be developed from a currently active FAS/FAE resource group, such as The Canadian Centre on Substance Abuse.

(C) PROVINCIAL CO-ORDINATORS FOR FOETAL ALCOHOL SYNDROME AND FOETAL ALCOHOL EFFECTS

There is a need for improved provincial coordination of resources, programs and activities to deal with the many complex issues associated with FAS and FAE. First, it is necessary to make the public more aware of the risks to the foetus posed by maternal consumption of alcohol. The education and counselling of pregnant women is a priority and the resources for this could be effectively organized and coordinated at the provincial or territorial level. The early diagnosis of FAS and (especially) FAE children would be enhanced if there were a central source of information and expertise in each province and territory which health-care professionals could contact. Provincial and territorial resources and expertise for the treatment, care and education of FAS and FAE victims could be more efficiently managed and dispensed by a central coordinating office. Similarly, a provincial or territorial co-ordinator could assist families in organizing and contacting support groups, which have been shown to be very effective in assisting parents and families to deal with the many problems associated with FAS and FAE.

A recurring theme in the testimony of parents of alcohol-damaged children, particularly FAE children, was that the problems they had to deal with were the result of bad parenting, when in fact these problems were due to injuries inflicted on the foetus by alcohol. We received much testimony indicating that health-care professionals, social welfare agencies, educators, and officers of the judicial system were often unaware of the existence of FAS and FAE and, therefore, insensitive to the special needs of alcohol-damaged children and their parents. The Sub-Committee believes that provincial and territorial co-ordinators can provide resources, leadership and guidance to the various agencies and institutions of government to help resolve these problems.

RECOMMENDATION NO. 3

The Sub-Committee recommends that the Minister of Health and Welfare Canada recommend to his provincial and territorial counterparts the establishment of Provincial and Territorial FAS/FAE Co-ordinators who will focus on prevention, identification of high-risk individuals and groups, clinical services for women of child-bearing age, early identification of affected offspring, and treatment and care facilities for FAS/FAE children. Wherever possible, the provincial/territorial co-ordinator should be employed with an established health-care centre with expertise in these areas.

(D) NATIONAL CONFERENCE ON FOETAL ALCOHOL SYNDROME AND FOETAL ALCOHOL EFFECTS

In 1988, a conference on Alcohol and Child/Family Health was held in Vancouver, with funding support from the Government of British Columbia, the University of British Columbia and Health and Welfare Canada. The Sub-Committee believes that it would be appropriate to hold a national conference on alcohol and the foetus, preferably before the end of 1993. Not only would such a conference facilitate information exchange among professionals involved with the many facets of FAS and FAE, and stimulate research in this area, but, with effective publicity and media coverage, the conference could significantly raise public awareness of this important subject.

RECOMMENDATION NO. 4

The Sub-Committee recommends that Health and Welfare Canada, with the participation of the National Advisory Committee on Alcohol and the Foetus, organize and fund a National Conference on Foetal Alcohol Effects and Foetal Alcohol Syndrome for the purposes of information exchange, the stimulation of research and treatment activity, and to raise public awareness of this issue. The Conference should be held before the end of 1993.

(E) WARNING LABELS AND WARNING SIGNS

Perhaps the most contentious issue the Sub-Committee has dealt with during its consideration of FAS and FAE is the matter of warning labels on containers of beverage alcohol. The witnesses were sharply, but not evenly, divided on this matter. The two industry groups who offered testimony, the Brewers Association of Canada and the Association of Canadian Distillers, were opposed to the inclusion of warning labels on bottles and other containers. Virtually every other witness supported the proposal. The witnesses from Health and Welfare Canada stated that the Department was reviewing the available evidence on the effectiveness of warning labels, before making any decision. The Sub-Committee has considered carefully the testimony of all witnesses.

Industry's position is that general public awareness of foetal alcohol syndrome is very high, that warning labels are not effective in raising awareness in any case, and that funds that would be necessary to develop and print warning labels on containers would be better spent on other, more useful, programs for preventing alcohol-related problems. The two industry witnesses testified that the industry is already very active in promoting the responsible use of beverage alcohol and in alerting the public to the dangers of alcohol consumption while driving or working, or by pregnant women.

In 1986, the brewing industry in Canada decided to launch a national campaign through the Brewers Association of Canada to encourage the responsible use of beverage alcohol:

"The campaign included television and radio messages, outdoor advertising, print advertising, posters in retail outlets, and a variety of support materials, such as brochures, buttons, refrigerator magnets; anything to raise awareness of the issue . . . our campaign focuses on family and children as the key reason for drinking responsibly." ³⁴

In addition to the industry-wide campaign, Canada's two national brewers, Labatt and Molson, have sponsored their own multi-media "responsible use" campaigns. In total, Canada's brewing industry spends about \$10 million per year on such campaigns. 35

Other programs supported by Canadian brewers include the Alcoholic Beverage Medical Research Foundation (with American brewers), and an FAS program developed with, and endorsed by, the College of Family Physicians of Canada. This program urges women who are pregnant or who are contemplating pregnancy to consult a physician for advice on alcohol use. The key line in the message is: "At a time like this, drinking responsibly may mean not drinking at all." ³⁶ In addition to the association's FAS program, Molson Breweries sponsors its own program in this area.

Canada's distilling industry, through the Association of Canadian Distillers, has also sponsored public-awareness and education programs. One initiative is the Information Council on Beverage Alcohol which was created to fund community groups to help promote the responsible use of beer, wine and spirits through educational programs.³⁷

The Sub-Committee acknowledges the efforts of the beverage-alcohol industry to promote responsible use of their products and we agree with their general thrust that increasing public awareness and promoting public education on the FAS/FAE issue will require a variety of initiatives, programs and methodologies to reach a very heterogeneous consuming public. We are obliged to point out, however, that the \$10 million per year that Canada's brewing industry spends on "responsible use" campaigns is less than 10% of the brewing industry's expenditures on product

³⁴ Proceedings, Issue 8, pp. 4-5.

³⁵ *Ibid.*, p. 5.

³⁶ Ihid

Proceedings, Issue 11, p. 7.

advertising which promotes consumption of beverage alcohol. Overall, the Canadian alcohol industry spends huge sums on product advertising and promotion. Professor Gurprit Kindra of the University of Ottawa provided the following statistics to the Sub-Committee:

"The beer and ale industry of Canada spends about 6.9% of their sales on advertising. Molson Breweries spent \$65 million on advertising in 1991 and Labatt was among the top 10 in Canada, with a 1991 expenditure of \$50 million. Health and Welfare estimates the entire alcohol industry in Canada spends \$250 million on advertising, promotion, and sponsorships." 38

Almost all of the non-industry witnesses who appeared before us testified that warning labels on alcoholic products should be part of the overall strategy to raise public awareness of the risks posed to the foetus by maternal alcohol consumption. Most witnesses, in part, based their support for warning labels on the consumers' right to know that the use of a product carries certain risks. Dr. Oscar Casiro:

"I strongly support and recommend the labelling of all alcoholic beverage containers. It is our duty to inform people of the dangers of drinking during pregnancy at the time they are going to have their drink. This label should be clear and should be in contrasting colours and in large print." ³⁹

In 1989, the Canadian Medical Association's (CMA) General Council passed a resolution that "the CMA urge governments in Canada to enact legislation requiring that all alcoholic beverages sold in Canada be labelled with warnings on the hazards from the consumption of alcohol during pregnancy." Dr. Richard Jock of the Assembly of First Nations stated that "implementing a labelling initiative would send a clear message to the public that (FAS/FAE) is a concern."

An irony that has not escaped the Sub-Committee's notice is the fact that the United States Government requires warning labels on containers of beverage alcohol sold in that country, and has done so since 1989. Canadian distillers, and to a lesser extent Canadian brewers, market their products in the United States. All of these products contain warning labels. Mr. Guy Paquet of the Association of Canadian Distillers stated:

"As an industry, we meet all the regulations required of us in the countries where we sell our products. Indeed, in the United States we put warning labels specified by the federal government in the U.S. on the products we export from Canadian manufacturers to the U.S." 42

This incongruity also was not overlooked by the witnesses who appeared before us. Mrs. Shirley Joiner, an adoptive mother of an FAE boy made the following statement:

"It's my understanding that all the alcohol produced in Canada and exported to the United States does carry that labelling. Don't we deserve the same education on our beverages, all alcoholic beverages? Such legislation could be instrumental in preventing alcohol-related birth defects." 43

Proceedings, Issue 14, p. 16.

Proceedings, Issue 8, p. 24.

⁴⁰ Proceedings, Issue 13, p. 6.

Proceedings, Issue 10, p. 6.

⁴² Proceedings, Issue 11, p. 11.

⁴³ Proceedings, Issue 12, p. 17.

Ms. Betty MacPhee, Manager of Vancouver's Crabtree Corner, stated:

"I have great difficulty understanding the reluctance of the alcohol industry to label their products . . . Every woman has the right to be an informed consumer. Every woman should know there is no known safe amount of alcohol to drink when you are pregnant. It seems ludicrous that alcohol beverages exported from B.C. and the rest of Canada to the U.S.A. have had warning labels for two years, but the same bottles in our stores do not." 44

The Sub-Committee believes that the reluctance of the beverage alcohol industry to include warning labels on containers is at least partly related to the importance that labelling has in the marketing of alcoholic products and product image. Dr. Gurprit Kindra, Associate Professor of Marketing at the University of Ottawa, offered the following testimony on this point:

"Information on the label and the nature of the package can enhance or damage the overall product offering. Information on the package plays the role of a salesperson. Information that appears on the label can also be viewed as an advertisement. So, warning labels in a way imply forced de-marketing from the brewers' and distillers' point of view. Labelling is part of an extremely delicate balance of the product mix .. (which) . . . is based on dreams, aspirations and desired lifestyles. A warning label of any kind will ruin the fun theme that is generally associated with beer and alcohol." ⁴⁵

The Sub-Committee is aware, as were most of our witnesses, that warning labels on containers of alcoholic beverages will not, by themselves, completely solve the problem of FAS and FAE, nor will they effectively reach all segments of society. Problem drinkers and alcoholics will probably not be sensitive to label warnings. The design and presentation of a warning label is vitally important to its effectiveness. The Sub-Committee has examined several examples of warning labels on alcohol products from the United States. In all cases, the warnings were generally inconspicuous and difficult to read. It is essential that warning labels adopted for Canadian products not emulate the United States examples, but be carefully designed for maximum visibility and impact. We believe that warning labels, properly designed and printed, are an essential part of a comprehensive strategy for increased public awareness and education about the risks that maternal alcohol consumption poses for the foetus.

RECOMMENDATION NO. 5

The Sub-Committee recommends that the Minister of Health and Welfare Canada should amend the *Food and Drugs Act* and Regulations to require that containers for beverage alcohol sold in Canada, including beer, wine, and spirits, should carry an appropriate warning label alerting all consumers that consumption of alcohol during pregnancy places the foetus at risk for Foetal Alcohol Syndrome (FAS) or Foetal Alcohol Effects (FAE).

RECOMMENDATION NO. 6

The Sub-Committee further recommends that the form of the warning label on beverage-alcohol containers should be designed with appropriate regard for readability, perceptual prominence, colour contrast and impact. Also, the design and content of the warning label shall be approved by the Minister of Health and

⁴⁴ Proceedings, Issue 13, p. 26.

⁴⁵ Proceedings, Issue 14, p. 18.

Welfare Canada on the recommendation of the National Advisory Committee on Alcohol and the Foetus prior to being adopted and used by the beverage-alcohol industry.

Label warnings on containers of beverage alcohol can only be effective if the consumer actually sees the container at the time he or she takes a drink. Obviously, this will not always be the case. A significant amount of alcohol is consumed in bars and taverns, in restaurants, or in other public places where the consumer may not actually see or handle the container. Moreover, many Canadians make their own wine and beer at home for personal and family consumption.

The Sub-Committee believes, and our opinion is supported by some of the witnesses who appeared before us, that warning signs directed toward the risks that alcohol poses for the foetus should be displayed in all places where alcohol is served or sold. The paper and plastic bags used by provincial liquor outlets often contain warnings: as an example, the bags used by the Liquor Control Board of Ontario display the clear warning, "IF YOU DRINK, DON'T DRIVE", in prominent red lettering. An equivalent warning could be used to alert consumers to the risks of FAS and FAE.

As a Sub-Committee of the House of Commons, it is outside our purview to make recommendations to provincial or municipal governments who have the authority to require warning signs in bars and restaurants and in sales outlets for liquor and beer, or in retail outlets where supplies are sold for home-brewing or wine-making. It is, however, quite appropriate for us to recommend that the Minister of Health and Welfare Canada take the initiative and raise this matter with his provincial counterparts, since the purpose is to promote a health policy in the national interest.

RECOMMENDATION NO. 7

The Sub-Committee recommends that the Minister of Health and Welfare Canada initiate discussions with Provincial and Territorial Governments to develop appropriate warning signs for establishments serving and selling alcoholic beverages, or selling supplies for beer-and wine-making, to alert all consumers that consumption of alcohol during pregnancy places the foetus at risk for Foetal Alcohol Syndrome (FAS) or Foetal Alcohol Effects (FAE). The objective of this initiative is to implement a uniform program of warning signs at such outlets in all jurisdictions across Canada.

(F) ADVERTISING OF ALCOHOLIC BEVERAGES

The advertising of alcoholic beverages is obviously related to the Sub-Committee's concerns about the drinking behaviour of women of child-bearing age, and the attendant risks of FAS and FAE. A number of witnesses raised concerns about the advertising of alcoholic beverages on television, particularly the use of "lifestyle" advertising for beer, which is directed to young persons in the general age range of 18 to 25 years. While it is not our intention to delve into the theory and practice of advertising, the testimony of some witnesses is worth noting.

Professor Kindra offered the following comments on lifestyle advertising of brewers' products:

"One particularly powerful type of advertising is referred to as lifestyle advertising. This type of advertising is often employed for products that are more or less undifferentiated or similar in nature. In the case of beer, for instance, once you go beyond the lager versus ale split, they really are all the

same . . . most people in blind taste tests cannot tell the difference between various brands of beer. Selling beer really means selling an image, a certain lifestyle, a fantasy if you will . . . Lifestyle is a consumer's mental mosaic of his or her desired activities, interests and opinions, a mosaic that is consistent with the person's needs and values . . . The consumer is then presumed to buy the product which through promotion for the most part reflects the lifestyle he or she wishes to lead."⁴⁶

A number of witnesses expressed concern that the promotion of moderate drinking and a healthful lifestyle in general, whether advocated by government or by industry, is overwhelmed by the amount of product advertising by industry, particularly the lifestyle advertising on prime-time television. The Canadian Medical Association (CMA) has taken a strong position for a number of years on the advertising of alcoholic beverages, and particularly on lifestyle advertising. In 1989, the CMA requested the federal government to ban all advertising of alcoholic beverages on radio, television, and in printed material. In 1991, the association requested the Canadian Radio-Television and Telecommunications Commission (CRTC) to enforce existing regulations with regard to lifestyle advertising of alcoholic beverages. The regulations are detailed in the "Code for Broadcast Advertising of Alcoholic Beverages", as shown in Appendix A.

The CMA made the following statements to the Sub-Committee on the matter of beverage alcohol advertising:

"... until shown otherwise, we must recognize that there is massive prime-time advertising of alcoholic beverages in society and this must encourage consumption...

Education has to start as young as possible and it is very difficult to start educating children in elementary school about the adverse effects of alcohol consumption, and then the same children will see on the hockey broadcasts that alcohol is a great thing to use . . .

The lifestyle commercials, in which everybody is running around partying and having a good time and is very comfortable with alcohol and it seems to be a necessary social event, are directly targeted at introducing young people to the product in general and making them comfortable with it and instilling it as a core part of any social occasion."

The advertising of alcoholic beverages is a very difficult and contentious issue. On the one hand, we live in a market economy and the advertising of products is an accepted part of our economic and social system. On the other hand, governments have the responsibility to enact regulations in the public interest, and the regulation of product advertising is an established role for governments. Government restrictions on the advertising of tobacco products have been challenged by the industry and the issue is currently before the courts. Nevertheless, the Sub-Committee believes that the advertising of alcohol products is an important matter and should be re-examined by the federal government in the context of a national health policy.

RECOMMENDATION NO. 8

The Sub-Committee recommends that the Canadian Radio-Television and Telecommunications Commission amend the regulations under the *Broadcasting Act* and the "Code For Broadcast Advertising Of Alcoholic Beverages" to ban that type of advertising of alcoholic beverages, generally known as "lifestyle advertising", on radio and television in Canada.

⁴⁶ Proceedings, Issue 14, p. 17.

⁴⁷ Proceedings, Issue 13, pp. 6, 10, 14.

Advertising for alcoholic products appears in numerous formats, including magazines and newspapers, on radio and television, on billboards and posters, and other media. The Sub-Committee believes that it is important to include effective warnings about the serious impacts of alcohol on the foetus on all forms of advertising for alcoholic products.

RECOMMENDATION NO. 9

The Sub-Committee recommends that the Minister of Health and Welfare Canada, in consultation with the Minister of Consumer and Corporate Affairs Canada and the Canadian Radio-Television and Telecommunications Commission, prescribe regulations to require that appropriate and effective warnings about the serious impacts of alcohol on the foetus be included as part of all advertising of alcoholic beverages in Canada.

(G) PUBLIC AWARENESS AND EDUCATION

The issue of public awareness and education is important because prevention of disease is the first line of defense in health care. This is particularly true in the matter of FAS and FAE. Both conditions are totally preventable. If a woman abstains from consumption of alcohol during the period of her pregnancy, her baby will be protected from alcohol damage. Although all witnesses agreed that public awareness was essential, there was sharp disagreement on the current state of awareness of the Canadian public. Industry witnesses argued that general public awareness of the FAS/FAE issue has already been achieved. Other witnesses argued that public awareness is not as high as industry claims.

The Canadian Brewers Association presented the results of an Angus Reid Group survey suggesting that "92% of the population were aware that excessive consumption of alcohol by women during pregnancy increased the potential for birth defects among children." ⁴⁸ The survey also indicated that awareness among women of conventional child-bearing age was 95%. The Angus Reid survey was conducted by telephone, and did not include either the Yukon or the Northwest Territories.

Based on the results of this survey, the Brewers Association believes that general public awareness of the FAS/FAE issue has been achieved and that only 3% of the general population remains to be made aware:

"Of the general (Canadian) population, 5% did not answer the question, 3% were unaware (of the risk)... more can be done to reach the 3% of the population unaware of the danger of excessive (alcohol) consumption... We believe the audience yet to be reached includes the native population and lower-income, inner-city residents. We have been reviewing ways in which we can reach these people, and frankly, it's a difficult problem. Two of the problems may be language barriers and illiteracy." 49

The Association of Canadian Distillers stated that Decima Research had conducted a survey for them in 1990 which:

"...showed that 88% of Canadian women already believe that pregnant women should not consume any alcohol beverages at all during the term of their pregnancy. Furthermore, when probed on the seriousness of a range of concerns associated with beverage alcohol consumption,

⁴⁸ Proceedings, Issue 8, p. 6.

⁴⁹ Ibid., pp. 6-7.

9 out of 10 - that is, 90% - Canadians describe drinking while pregnant as a serious concern. Fully two-thirds, which is 68%, of the population and almost 8 in 10 women, which is 79%, of the population describe it as a very serious concern."⁵⁰

The Decima survey also found that among women in the 18 to 24 year age group, 93% describe drinking while pregnant as a "very serious concern".⁵¹

If these survey results are accurate and representative of the general Canadian population, they would indicate a high level of awareness among Canadians that drinking during pregnancy has definite risks for the foetus. The Sub-Committee has some concerns about these statistics, however.

First, if the Reid and Decima surveys are compared on the question of the perceived advisability of abstinence from alcohol during pregnancy, there is some difference in the findings. In the Angus Reid survey, when asked if any consumption of alcohol would harm a woman's baby, 62% of female respondents replied in the affirmative (50% of males, 56% of Canadians overall). ⁵² The Decima survey, as noted above, found that 88% of Canadian women believe that no alcohol should be consumed during pregnancy. Although the two survey questions were not identical, the 26% difference between the responses of women in the two surveys raises concern about their accuracy and representativeness.

The nature of the questions asked in the Reid Survey also raise some concerns in the minds of Sub-Committee members. The initial question posed in the Reid survey was: "To the best of your knowledge, does the excessive consumption of alcohol by a woman during pregnancy increase the potential for birth defects in her child, or not?" In our view, there are a number of cues in this question which will tend to influence the response. The phrase "excessive consumption of alcohol" would, we feel, trigger a strong negative reaction from the respondent; the subsequent phrase, "increase the potential for birth defects" strongly suggests that alcohol may damage the foetus and, in our view, encourages the respondent to answer the question in the affirmative.

Dr. Eric Single of the Canadian Centre for Substance Abuse commented on the Reid Group survey and on the question of public awareness:

"...there are certain methodological problems (with the survey), and I guess you have also considered them. If you ask people whether they are aware of something, and given almost any statement, you will probably get close to 90% saying yes. So you have to look at that in detail. I am not necessarily saying the 92% is wrong.

"The other points would be that, first of all, there are degrees of awareness. Just being aware of it, do they really understand exactly what the nature of the problem is. There is the fact that we are not even sure about the risks involved with even very low-level drinking which might carry certain risks.

Proceedings, Issue 11, p. 5.

⁵¹ Ibid.

Angus Reid Group, "National Reid Poll (1-555-23)", September 1991.

⁵³ Ibid.

"The other point is that even if it were completely true and we did have a very high level of awareness, I am not sure 92% of the people is the figure we should be shooting for. I am not sure that is enough. It is still leaving quite a large number of people vulnerable. I think it should be 100%."54

Most witnesses who appeared before us believed that public awareness of FAS and FAE needs to be increased, particularly the latter. As we noted earlier, FAE typically presents a more subtle panoply of symptoms which are often not diagnosed, or not diagnosed correctly. Children born with FAE are damaged for life and, although some individuals will be able cope with their handicaps and live independent and productive lives, many will not. Dr. Casiro commented on this point:

"When you talk to people, what they seem to be aware of is that drinking excessive amounts of alcohol — heavy drinking — is damaging to the foetus. From my personal experience, people I've talked to don't seem to be aware that there is no known safe amount, that even small amounts of alcohol during pregnancy may be damaging to the foetus. There's a misconception, I believe, that only heavy drinking will affect the baby. That stems from the fact that for full-blown foetal alcohol syndrome to occur you need about two to four drinks a day, but a lesser amount of alcohol causes foetal alcohol effects. That's what people don't know about."

The Angus Reid Group survey appears to provide support to Dr. Casiro's position on public awareness. As noted above, 62% of women responded that any level of alcohol consumption would damage a baby; the corollary is that 38% of Canadian women may believe that some level of alcohol consumption by a pregnant woman is both acceptable and safe. The Reid survey found that 13% of Canadian women believe that "only excessive consumption" will harm the baby, while 23% of those surveyed believe that "moderate consumption" (defined as one or two drinks a day) will not harm the baby.⁵⁶

The Sub-Committee believes that these statistics from the Angus Reid survey are not reassuring about the level of awareness in Canadian society about FAS and FAE. The unanimous opinion expressed by the medical witnesses who appeared before us, including Health and Welfare Canada, is that there is no known safe level of consumption of alcohol for a pregnant woman. Until proof is forthcoming that there is an absolutely safe level of consumption, we hold with the majority view that a pregnant woman should abstain from alcohol for the entire course of her pregnancy.

The Sub-Committee makes two recommendations in this area, expressing our belief that more public awareness and education are required to deal with the risks posed to the foetus by maternal alcohol consumption.

RECOMMENDATION NO. 10

The Sub-Committee recommends that Health and Welfare Canada, in cooperation with provincial and territorial health departments and with the National Advisory Committee on Alcohol and the Foetus, regularly review and evaluate current public awareness and education programs on the impacts of alcohol on the foetus. If current programs are judged to be appropriate and effective they should be maintained and expanded. If they are not, new programs should be developed and implemented to raise public awareness and knowledge of this issue.

Proceedings, Issue 9, p. 17.

⁵⁵ Proceedings, Issue 8, p. 20.

⁵⁶ Angus Reid Group (1991)

Awareness of the special nature of FAS and FAE needs to be developed at many levels in Canadian society, commencing with the school systems. Use of beverage alcohol is deeply ingrained in most segments of Canadian society. The responsible use of alcohol was stressed by many witnesses, particularly by the beverage-alcohol industry. Information about alcohol and its effects on human health, especially foetal health, should be dispensed early in a child's formal education.

It seems clear, also, that many institutions and persons who come into contact with FAS and FAE children and adults are not aware that the problems these persons face are due to foetal alcohol exposure. Various witnesses made reference to the fact that even professionals in social services agencies, members of the judiciary, and even persons working with child welfare services are unaware that "problem" children often are victims of Foetal Alcohol Effects, or even that such problems exist.

Unless persons in positions of societal responsibility are made fully aware of the special problems and needs of FAS and FAE children and adults, their difficulties will be compounded and no-one will be well-served.

RECOMMENDATION NO. 11

The Sub-Committee recommends that the Federal Government, in cooperation with Provincial and Territorial Governments and with the National Advisory Committee on Alcohol and the Foetus, develop and implement awareness and education programs directed at Canada's primary and secondary school systems, the judiciary, and social and child-welfare services to increase awareness and understanding of Foetal Alcohol Syndrome and Foetal Alcohol Effects and of the unique problems and needs of individuals so-afflicted.

(H) HEALTH-CARE CURRICULA

A recurring theme during our public hearings was that health-care professionals, particularly family physicians, were not well enough versed in the impacts of alcohol on the foetus to provide accurate and effective advice and guidance to pregnant women. There was also a frequently expressed concern that the diagnosis of FAS, and particularly FAE, children was often delayed because the attending physician was unfamiliar with the symptoms. Delayed or incorrect diagnoses can greatly complicate treatment programs for these children, and the uncertainty thus created adds to the distress of parents and children alike.

To some extent, the testimony we have received about health-care professionals reflects the situation a decade or more in the past. Foetal alcohol syndrome was only described in 1973 and the recognition of FAE developed somewhat later. Over the last decade, the level of knowledge and understanding in the health-care community of the impacts of maternal alcohol consumption presumably has increased somewhat.

Martha Bradford of Stoney Creek, Ontario is attempting to establish a national Foetal Alcohol Support Network for parents of FAS/FAE children. Mrs. Bradford cited the experience of one of her group members who searched for 13 years before finding a medical practitioner who was knowledgeable about FAS and FAE:

"The story of (a) member of our group is typical. (Her) son has been a patient or client of three MDs, two paediatricians, four psychologists, two psychiatrists, two neurologists, two speech pathologists, one occupational therapist, one audiologist, six special-needs special-education

teachers, two special-education consultants, and four social workers. He is in his second residential treatment centre. Not one of these professionals identified the foetal alcohol drug damage." ⁵⁷

The Canadian Medical Association testified that in 1989 a national conference was held at Niagara-on-the-Lake on "Preventing Alcohol Problems: the Challenge for Medical Education". The conference was organized by two departments in the Faculty of Medicine at the University of Toronto, in collaboration with the Addiction Research Foundation of Ontario and the Canadian Medical Society on Alcohol and Other Drugs. Financial support for the conference was provided by Labatt Breweries of Canada. Each of Canada's 16 medical schools was represented. The conference goal was "to ensure that Canadian physicians acquire the knowledge, attitudes and skills needed to prevent alcohol problems in clinical practice and to play leadership roles in community efforts to prevent alcohol problems". The proceedings of the conference were published in a special supplement of the Canadian Medical Association Journal in October 1990.

The CMA witnesses testified that "... most of the strategies have been identified, and we're now in the follow-up phase."⁵⁹ It is encouraging that Canada's faculties of medicine have recognized the problem and have taken steps to modify and enlarge medical school curricula to provide better education for medical students about the impacts of alcohol on human health. As the conference organizers noted, however, "... enhanced opportunities for continuing education in this area are also important and require the attention of the entire profession".⁶⁰

The Canadian Nurses Association recommended to the Sub-Committee that "... information on foetal alcohol syndrome and alcohol-related birth defects be included in the curriculum of health professions and that training and upgrading include practical knowledge of the evaluation and counselling of alcohol use in pregnancy".⁶¹

The Canadian Centre on Substance Abuse observed that few medical professionals have received formal training on the effects of alcohol during pregnancy and that the federal government should fund programs aimed at the development of appropriate curriculum materials for the training of health-care professionals. The federal government should further ensure that such material is adopted by educational institutions. ⁶²

RECOMMENDATION NO. 12

The Sub-Committee recommends that Health and Welfare Canada, in cooperation with professional health-care associations including, but not necessarily limited to, the Canadian Medical Association and the Canadian Nurses Association, take the lead and assist in upgrading the curricula of medical schools, schools of nursing, and other relevant health-care educational institutions, with respect to the impacts of alcohol on the foetus in particular, and on human health in general.

⁵⁷ Proceedings, Issue 15, p. 15.

Mary Jane Ashley, et al, "Preventing alcohol problems: the challenge for medical education", Canadian Medical Association Journal, Vol. 143, 1990, p. 1041.

⁵⁹ Proceedings, Issue 13, p. 7.

⁶⁰ Ashley (1990), p. 1042.

⁶¹ Proceedings, Issue 14, p. 6.

⁶² Proceedings, Issue 9, p. 8.

(I) RESEARCH REQUIREMENTS FOR FAS/FAE

Most witnesses who appeared before the Sub-Committee stated that additional research needs to be done on the many aspects of FAS and FAE in Canada. The need for additional research is, to some extent, a truism in any field of science, medicine included. There are a number of areas which stand out, however.

The first point of concern is that the incidence of FAS and FAE in Canada is not known with any accuracy. Health and Welfare Canada cited statistics generated in other countries to suggest that the incidence of FAS in Canada is between one and two cases per 1,000 live births. A number of studies have shown that the incidence of FAS is much higher among certain sub-populations, notably among some First Nations communities and in certain inner-city groups. The incidence of FAE is generally thought to be much higher than FAS, at least three times as high, according to Dr. Casiro.

Our first recommendation is that Health and Welfare Canada should develop better information on the incidence of both FAS and FAE in Canada, in the population generally and among high-risk populations.

RECOMMENDATION NO. 13

The Sub-Committee recommends that Health and Welfare Canada, in cooperation with provincial and territorial health departments, design and carry out an epidemiological study to determine the incidence of Foetal Alcohol Syndrome and Foetal Alcohol Effects in Canada, among the Canadian population in general and in target sub-populations known, or suspected, to be at higher risk for such conditions.

The diagnosis of foetal alcohol effects, in particular, is said to be very difficult because the affected children do not show the overt physical symptoms that characterize FAS children. Nonetheless, these children may be seriously affected with learning disabilities and behavioural problems. If the underlying cause of the problems is not identified, treatment will be delayed, to everyone's cost and disadvantage.

Ms. Wendy Kemp, a Clinical Nurse Specialist with the Alberta Alcohol and Drug Abuse Commission, told the Sub-Committee that accurate diagnosis of FAE children was necessary in order to be able to give them optimum help.

Assessment tools are necessary for health-care professionals to determine whether a patient is afflicted with FAE, or is suffering from some other illness:

"We have a lot of dual-diagnosed individuals, perhaps depression plus addiction, or substance abuse or sexual abuse — that's what I mean by dual-diagnosed. We need to be able to screen and figure out how we can best help these individuals. Before we can do that, we have to find out what it is we're working with. Are they personality disordered or are they FAE? It makes a big difference in how we treat them." 63

An assessment tool which health professionals can use to make accurate diagnoses of FAE individuals is essential to the determination of correct treatment and care. Assessment tools are questionnaires used to supply necessary information on which to base treatment programming. A universal screening tool would facilitate accurate diagnoses at different treatment centres.

⁶³ Proceedings, Issue 9, p. 32.

RECOMMENDATION NO. 14

The Sub-Committee recommends that Health and Welfare Canada, with the cooperation of the National Advisory Committee on Alcohol and the Foetus, take the lead and assist in developing effective diagnostic tools for health-care professionals to identify and assess the special care and treatment needs of children born with Foetal Alcohol Syndrome or Foetal Alcohol Effects so that early and accurate diagnosis of these conditions might be made and appropriate treatment programs prescribed and applied.

There was a general sentiment expressed by witnesses before the Sub-Committee that treatment of FAS and FAE victims is typically inadequate and not uniform across the country. Many of these victims have little to look forward to beyond a life in a protected environment; in the worst situations, individuals will be institutionalized and, in the case of many FAE individuals, life will be a revolving door in and out of the prison system. Individuals vary in their potential to be educated and trained but, if the parents who appeared before us are credible, and we believe them to be so, much remains to be accomplished in the development of effective treatment and training programs so that FAS and FAE individuals can maximize their potentials and their contribution to society.

RECOMMENDATION NO. 15

The Sub-Committee recommends that Health and Welfare Canada, in cooperation with provincial and territorial health departments, initiate a program of research to develop more effective methods for the treatment, care and training of children with Foetal Alcohol Syndrome and Foetal Alcohol Effects, so that these individuals can maximize their intellectual and employment potentials as adults in Canadian society.

(J) TREATMENT DELIVERY

The development of treatment and training methods for persons with FAS and FAE will be useful only to the extent that they can be delivered to persons in need. One of the major needs is for financial assistance to parents, particularly adoptive parents, who find that their child is either FAS or FAE. In many cases, the family does not qualify for special education funding because the child does not fall into an established category mandating that special education is necessary. Similarly, many FAE children have been through a series of foster homes, or come from dysfunctional family environments, and many have been severely abused. Such children may need extensive psychiatric care or psychological counselling but, again, may not qualify for established medical programs.

Several witnesses stated that supervised group homes are an appropriate solution for FAS and FAE children because their needs and demands are such that parents cannot cope with them. This may be especially relevant with older children whose adoptive parents no longer have the personal resources, financial or otherwise, to handle their complex needs and increasingly disruptive behaviour. Such parents simply become exhausted and need relief and respite.

Although health-care delivery clearly is a provincial responsibility, the federal government, through Health and Welfare Canada, can play a leading or co-ordinating role to assist the provinces to develop treatment-delivery programs.

RECOMMENDATION NO. 16

The Sub-Committee recommends that Health and Welfare Canada, in cooperation with provincial and territorial health departments, develop more appropriate, effective, and economical treatment-delivery programs for victims of Foetal Alcohol Syndrome and Foetal Alcohol Effects. Such programs could include group homes or special treatment centres that recognize and provide for the unique problems and needs of these children.

An important component of the treatment of children with FAS or FAE is a stable home environment and a sense of security and parental caring. The testimony that we have received indicates that many children suffering from alcohol damage are born into dysfunctional family situations. Many are removed from the birth family into foster care or become adopted. In the case of many FAE children, as discussed earlier in this report, the adoptive parents are unaware of the alcohol damage that their adopted children have suffered.

Elspeth Ross is Executive Director of the Adoption Council of Canada. She and her husband are the adoptive parents of two FAE children. In her testimony to the Sub-Committee, Ms. Ross emphasized the importance of a stable home environment for alcohol-damaged children:

"... these children are adoptable and more should be adopted... It takes them out of the foster care system and provides a permanent, stable home for them, with strong advocates. Our experience shows they do better with this care." 64

In many foster homes, such children do in fact receive good care and, if the financial situation of such foster homes were more favourable, many foster parents would adopt these children. These children do have special needs for medical and psychological care, and educational assistance, and the associated costs are often too high for the average family. A program of subsidized adoptions would enable more families to adopt FAS and FAE children. Although such a program would require additional government expenditures, money would almost certainly be saved over the long term.

First, family care is less costly to the state than is institutional care. Second, the children will benefit from a stable, caring home environment and will be more likely to mature into healthy, productive citizens. In the case of FAE children, in particular, there may be a reduced probability that the individual will come into contact with the criminal justice system.

Although adoption issues lie within the provincial domaine, we believe the Minister of Health and Welfare Canada can provide leaderhsip in this area by initiating discussions with his provincial and territorial counterparts. The matter of income assistance to families with FAS and FAE children should be included in these discussions.

RECOMMENDATION NO. 17

The Sub-Committee recommends that the Minister of Health and Welfare Canada provide leadership and consult with his counterparts in the Provinces and Territories to develop and implement programs to subsidize adoptions of children with Foetal Alcohol Syndrome and Foetal Alcohol Effects and to provide income assistance to families with FAS and FAE children.

⁶⁴ Proceedings, Issue 15, p. 6.

(K) ABORIGINAL PEOPLES

The Sub-Committee received testimony from Dr. Richard Jock, Director of the First Nations Health Commission, to the effect that FAS and FAE are major problems in some First Nations communities, an observation discussed above. One of Dr. Jock's recommendations to the Sub-Committee was for:

"... (a) high-profile action committee that would serve to stimulate and maintain interest in various sectors of the country to deal with FAS. I would also recommend that there be a special aboriginal committee set up which would focus on this because of the special and urgent nature of the problems facing aboriginal peoples." 65

The Sub-Committee agrees with Dr. Jock's suggestion and we make the following recommendation.

RECOMMENDATION NO. 18

The Sub-Committee recommends that the Minister of Health and Welfare Canada and the Minister of Indian and Northern Affairs Canada, in cooperation with the Provinces and Territories, establish a Special Aboriginal Committee on Alcohol and the Foetus. The Special Committee should have representation from the various aboriginal communities in Canada and be represented on the National Advisory Committee on Alcohol and the Foetus.

Public awareness of the effects of alcohol on the foetus needs to be increased in Canada generally, particularly the possible effects of moderate amounts of alcohol in the etiology of FAE. Dr. Jock suggested that the level of awareness of FAS and FAE among aboriginal peoples was about half that in Canadian society generally. ⁶⁶ Dr. Jock suggested that an "aggressive social marketing plan" is needed to make people aware of the risks of maternal alcohol consumption. Simply stating that alcohol may cause FAS or FAE would not be sufficient.

Based on Dr. Jock's comments, we make the following recommendation.

RECOMMENDATION NO. 19

The Sub-Committee recommends that the Departments of Health and Welfare and Indian and Northern Affairs, in cooperation with the Special Aboriginal Committee on Alcohol and the Foetus, design and deliver aggressive public-information campaigns to heighten awareness of the association between Foetal Alcohol Syndrome and Foetal Alcohol Effects and alcohol use among aboriginal peoples.

Finally, Dr. Jock suggested that existing programs for the learning-disabled funded and administered by Indian and Northern Affairs Canada should be examined to determine if there are "more effective and more appropriate community-based ways of dealing with learning disabilities, of which FAS is the major portion of demand." 67

A community-based approach to alcohol-induced birth defects, abusive drinking and related problems was suggested by a number of witnesses. The rationale is that the problems themselves are essentially based in the manner in which the individual relates to his/her social milieu and, therefore, the most effective solutions to the problem will derive from the community itself, rather than being imposed from outside.

Proceedings, Issue 10, p. 6.

⁶⁶ Ibid., p. 14.

⁶⁷ Ibid., p. 7.

RECOMMENDATION NO. 20

The Sub-Committee recommends that Indian and Northern Affairs Canada and Health and Welfare Canada, in cooperation with the Special Aboriginal Committee on Alcohol and the Foetus, review and evaluate existing programs for the learning-disabled in aboriginal communities to develop more effective and appropriate community-based programs to deal with learning disabilities of individuals afflicted with Foetal Alcohol Syndrome or Foetal Alcohol Effects.

(L) ADULTS WITH FAS AND FAE

While the bulk of this report appropriately focuses on children with FAS or FAE, it is necessary and important to consider that there are many adults in Canadian society who are afflicted with these conditions. The actual numbers can never be known with precision but, based on the estimated incidence rates discussed above, there could be tens of thousands of FAS and FAE adults living in Canada today.

Most of these individuals have never been correctly diagnosed and few, therefore, will have received any treatment or care. Many of the most seriously damaged, those who are mentally retarded, probably are living in a variety of institutions, including mental hospitals. Many others, particularly those who suffer from FAE and have significant behavioural and learning problems, probably eke out an existence on the margins of Canadian society. From the testimony we have received on FAE children, it seems likely that many FAE adults will have come into contact with the criminal justice system. We suspect that a significant number end up in prison for part of their lives.

These individuals, damaged by alcohol before birth, have had little if any possibility of developing independent and productive lives. They are victims in the deepest and most tragic sense of the word. The question is, what can be done to assist them at this point in time?

The Sub-Committee has received little testimony on this aspect of the FAS/FAE issue, and most of the testimony we did receive focused on the development of programs, workshops and homes to assist FAS/FAE children as they grow into adulthood. The plight of undiagnosed FAS/FAE adults has not received much attention. We believe this is an important aspect of the overall problem, however, and should not be ignored.

This is an area where a great deal of research is needed before any programs can be contemplated. The first priority must be the development of effective and efficient methods to diagnose adults who suffer from FAS or FAE. We propose this research initiative as the first step in a comprehensive program to assist people whose lives have been blighted by alcohol-induced prenatal injuries.

If and when effective diagnostic procedures for adults have been developed, it will be necessary to develop programs of assistance for these individuals in a variety of areas, including treatment and care, and education and training where this is feasible. Group homes, sheltered workshops, and income assistance, possibly in the form of disability pensions, are among the options that should be explored.

Recommendation No. 21

The Sub-Committee recommends that Health and Welfare Canada, in cooperation with provincial and territorial health departments, design and implement a research program to develop diagnostic procedures to identify adults afflicted with Foetal Alcohol Syndrome and Foetal Alcohol Effects. This research initiative shall be the first step in a comprehensive program to provide assistance to adults whose lives have been blighted by alcohol-induced injuries.

APPENDIX A

OF ALCOHOLIC BEVERAGES

This Code applies to radio and television commercial messages, as the case may be, for alcoholic beverages ("product").

For the purposes of this Code, "portray" means "depict or refer to, visually or in sound". Such messages shall not:

- (a) attempt to influence non-drinkers to drink;
- (b) portray an unrealistic or excessive number of cases or containers;
- (c) show or use language that suggests, in any way, product misuse or product dependency;
- (d) refer to the feeling and effect caused by alcohol consumption or show or convey the impression that the people involved are under the influence of alcohol;
- (e) portray persons with any such product in situations in which the consumption of alcohol is prohibited;
- (f) associate the consumption of any such product with the operation of any motorized vehicle, e.g. by suggesting or implying that any such product is or should be consumed prior to or during the operation of a motor vehicle;
- (g) associate the consumption of any such product with any activity requiring a significant degree of skill, care or mental alertness or involving an obvious element of danger until such activity has been clearly completed, e.g. by suggesting or implying that any such product is or should be consumed prior to or during any such activity; -- a flat label or symbol associated with a brand or brand name reference, used for brand identification, will not in itself be considered to suggest consumption of that brand;
- (h) be directed at persons under the legal drinking age, associate any such product with youth or youth symbols, or portray persons under the legal drinking age or persons who could reasonably be mistaken for such persons in a context where any such product is being shown or promoted;
- attempt to establish any such product as a status symbol, a necessity for the enjoyment of life, or an escape from life's problems;
- (j) imply directly or indirectly that social acceptance, personal success, business or athletic achievement may be acquired, enhanced or reinforced through consumption of any such product;

- (k) contain an endorsement of any such product, personally or by implication, either directly or indirectly, by any person, character or group who is or is likely to be a role model for minors because of achievement, reputation or exposure in the mass media;
- (I) contain scenes in which any such product is consumed or give the impression, visually or in sound, that it is being or has been consumed;
- (m) portray any such product, or its consumption, in an immoderate way; and
- (n) exaggerate the importance or effect of any aspect of the product or its packaging.

APPENDIX B

List of Witnesses

Associations and Individuals	Date	Issue
Adoption Council of Canada: Elspeth Ross , Executive Director.	Thursday, April 30, 1992	15
Alberta Alcohol and Drug Abuse Commission: Wendy Kemp, Clinical Nurse Specialist.	Thursday, February 27, 1992	9 1
Angus Reid Group: Dr. Angus Reid.	Thursday, February 13, 1992	7 0
Assembly of First Nations: Richard Jock, Director, First Nations Health.	Thursday, March 12, 1992	10 7
Association of Canadian Distillers: Françoise Parent, Director of Communications & Public Relations; Guy Paquet, Chairman, Social Responsibility Committee.	itistine Loodic by of Ottowas upfit Kindra	
Bradford, Martha, Individual.	Thursday, April 30, 1992	15
Brewers Association of Canada: Howard Collins, Acting General Manager.	Thursday, February 20, 1992	8
Pamela C. Fralick, Acting Chief Executive Officer; Dr. Eric Single, Director, Policy and Research.	Thursday, February 27, 1992	9 /
Canadian Medical Association: Dr. David Walters, Director, Health Care and Promotion; Dr. Barry Adams,	Thursday, April 2, 1992	13

Chairman,

Council on Health Care and Promotion.

Associations and Individuals	Date	Issue
Canadian Nurses Association: Judith Oulton, Executive Director; Jill Courtemanche, Registered Nurse, CHEO.	Thursday, April 9, 1992	14
Carberry, Lesley, Individual;	Thursday, March 26, 1992	12
Crabtree Corner: Betty MacPhee, RSW, Manager, YWCA Crabtree Corner.	Thursday, April 2, 1992	13
Department of Health & Welfare: Judy Ferguson, Director General, Policy and Information Directorate.	Thursday, February 6, 1992	6
Joiner, Shirley, Individual.	Thursday, March 26, 1992	12
Manitoba Medical Association: Dr. Oscar Casiro, Chairman, Child Health Center.	Thursday, February 20, 1992	8
Sunny Hill Hospital: Dr. Christine Loock.	Thursday, March 12, 1992	10
University of Ottawa: Dr. Gurprit Kindra.	Thursday, April 9, 1992	14
University of Toronto: Dr. Donna Stewart, Associate Professor of Psychiatry.	Thursday, April 30, 1992	15

List of Individuals and Organizations having submitted Briefs

Alcohol-Drug Education Service

10

Canadian Bar Association

Canadian Wine Institue

Habbick, Brian F. (University of Saskatchewan)

Learning Disabilities Association of Canada

VV

Pakozdy, Judith Joanne (Yukon Association for Community Living)

REQUEST FOR GOVERNMENT RESPONSE

Your Committee requests that the Government table a comprehensive response to this report.

A copy of the relevant Minutes of Proceedings and Evidence (Issue No. 10, which includes this report) is tabled.

Respectfully submitted,

BARBARA GREENE, Chair.

REQUEST FOR GOVERNMENT RESPONSE

Your Committee requests that the Government table a complehentive response to this report.

A copy of the relevant Minutes of Proceedings and Evidenus (Issue Mo. 18, which includes misseport) is tabled.

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BARZARA GREENE Challe

Minutes of Proceedings

THURSDAY, JUNE 11, 1992 (13)

[Text]

The Standing Committee on Health and Welfare, Social Affairs, Seniors and the Status of Women met *in camera* at 9:45 o'clock a.m. this day, in Room 371, West Block, the Chair, Barbara Greene, presiding.

Members of the Committee present: Edna Anderson, Barbara Greene, Barbara Sparrow, and Stan Wilbee.

Acting Members present: Dawn Black for Jim Karpoff and Shirley Mahey for David Walker.

In attendance: From the Research Branch of the Library of Parliament: Odette Madore, Tom Curren and Sandra Harder, Research Officers.

The Chair presented the Second Report of the Sub-Committee on Health Issues.

It was agreed, - That the Committee ask the Chair to present the Second Report of the Sub-Committee on Health Issues as the Fifth Report of the Standing Committee to the House of Commons.

It was agreed, - That pursuant to Standing Order 109, the Committee request that the Government table a comprehensive response to this Report.

It was agreed, - That the Committee print 3,000 copies of this Report, in tumble bilingual format, with a distinctive cover page.

At 9:47 o'clock a.m., the Committee adjourned to the call of the Chair.

Eugene Morawski Clerk of the Committee

Minutes of Proceedings

11+URSPAY, JUNE 11, 1998 (13)

Parell |

The Standing Committee on Nichth and Weltzre, Social Milato, Benigs and the Crans of Women net in camera at 975 b clock a an triaday, in Room, 371, West Black, the Chat, Beneral Greene, presiding

Membersof the Cumilities overeith Baha Andreich, Berturt Greene, Barbara Spaniow, and Stan Wildes

Acting Members proced Dasa black for Jim sarped and Shiney Managriot David Walker.

In attendance: From the Rases of Brench of the Library of Parisonals Odella Mudera, Tom
Junen and Sondra Farder, Research Odelcara.

The Chair green and the Second Report of the Sub-Committee on Health Insules.

It was agreed, "That the Committee are the Chair to present the Second Report of the Sub-Committee on Health feetier as the suit Payor of the Clar ing Committee to the House online Commons

If was nowed. - That germant to Sauding Crew 10s, the Domintes request that the Government takes a compenhansive recomment to the Report.

It was somed. - That the Committee print 3,000 replac of this Report, in remble billingted tomat, with a distancing dover plug.

At 9 47 o'clost, a.m., the Consmittee edjourned to be date of the Units

Cugeno Monavide Cleak of the Committee

Proced-verbal

LE JEUD(-11 JUIN 1992 (13)

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Le Comité permanent de la santé et du bler-être social, des affaires sociales, du troisieme âge et de la condition férminine se réunit à huls clos à 8 h 45, dens la salle 371 de l'adifice de l'Ouest, sous la présidence de Barbara Greene (présidente).

Membres du Comite pressots: Edna Anderson, Barbara Greene, Barbara Sparrow, Stati Wilbee.

Membres suppleants presents: Dawn Biack remplace Jim Kerpoff, Shirley Mehou remplace David Walker.

Aussi presents: Du Service de recherche de la Bibliothèque du Parlement. Tom Cunen. Sandra Harder et Odette Madore, attachés de recherche.

La présidente presente le deuxième rapport du Sous-comité des questions de santé.

Il est convenu. – Que le Comité demande à la présidente de présenter à la Chambre le deuxième rapport du Sous-cernité des questions de santé, comme cinquieme rapport du Comité permanent.

Il est convenu. —Ou en application de l'article 109, le Comité demande au gouvernement de déposer une réponse globale à son rapport.

Il est convenu. - Que la Comité lasse arer son rapport à 3 000 exemplaires, format bilingue tête-bêche, avec couverture distinctiva.

À 9 h 47, le Comité s'ajourne jusqu'à nouvelle convocation de la présidente

Le greffier du Comité

Eugene Morawski