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# **Report on the Symposium on Fetal Alcohol Syndrome and Fetal Alcohol Effects**

**Vancouver, British Columbia  
September 30th to October 2nd, 1992**

**Canada**

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*Opinions expressed in this report are those of the  
Symposium participants and do not necessarily reflect  
the official views or policies of the Department.*

# PREFACE

In June, 1992, when the Standing Committee on Health and Welfare, Social Affairs, Seniors and the Status of Women tabled its report, Foetal Alcohol Syndrome: A Preventable Tragedy, I made a commitment to bring together persons from across Canada to share perspectives, experience, and knowledge concerning this important issue. It was a pleasure to fulfil this commitment by convening a symposium in early October with representatives from the provinces, territories, First Nations, parents, professions, industry, and non-government community organizations. It is now with great pleasure that I present you with this report summarizing the work that took place during the two days of the symposium.

I would like to express my sincere appreciation to all those of you who participated and who helped us to meet the symposium objectives of sharing information, identifying priorities for action, and determining roles and mechanisms for addressing these priorities. Your insights have helped to increase our understanding of this serious problem and have ensured that the views of Canadians will be considered for the upcoming government response to the recommendations contained in the Standing Committee's report.

For those who were unable to attend, I would like to thank you for the effort and commitment you demonstrate daily in dealing with issues related to fetal alcohol syndrome. Although circumstances did not allow us to invite everyone to the symposium, I hope that this report on the proceedings will be useful to you.

I am heartened by signs of increased momentum within this field and trust that together, we can build on the energy and determination demonstrated at the symposium to reduce the incidence of fetal alcohol exposure with its related problems.

With every best wish,

**Benoît Bouchard**  
Minister of National Health and Welfare

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# INTRODUCTION

The Symposium on Fetal Alcohol Syndrome/Fetal Alcohol Effects (FAS/FAE), held September 30th to October 2nd, in Vancouver, British Columbia, marked the first time representatives from across the country have been able to address FAS/FAE in a Canadian context. With key sectors and all of Canada's regions represented, participants from provinces, territories, professions, industry, non-government organizations, First Nations, as well as foster and adoptive parents, were able to share information and discuss new directions and priorities in a comprehensive manner. Sponsored by Health and Welfare Canada, the Symposium on FAS/FAE attracted 110 experts and concerned individuals who, through intensive workshops and plenary panel discussions, were able to share current information and place FAS/FAE in a broader perspective.

Objectives of the two day symposium were:

- For all participants to gain a better understanding of an dimensions of the FAS/FAE issue by sharing perspectives and knowledge;
- To identify priorities for action; and
- To identify appropriate roles and mechanisms for moving forward.

## AN OVERVIEW OF THE SYMPOSIUM

This overview of the symposium summarizes the process of the two days. (See Appendix I for the Symposium Agenda.)

### **Minister's Welcome**

The symposium began on October 1 with an address by the Minister of National Health and Welfare, the Honourable Benoit Bouchard, whose hope was that the symposium would help to increase public awareness of FAS/FAE problems and would also help to "end the feeling of isolation many of you have had in the struggle to meet the special needs of individuals with alcohol related birth disorders." Mr. Bouchard also called upon delegates to share their insights and ideas with the government: "this will enable my department and I to develop a well-informed and comprehensive response to the report on Foetal Alcohol Syndrome: A Preventable Tragedy."

## **Introduction**

Dr. Heather Clarke opened the symposium and acted as chairperson throughout the two days.

## **Thematic Address**

The Minister of National Health and Welfare's introduction to the symposium was followed by a thematic address, presented by Dr. Geoffrey Robinson and Dr. Christine Look, which reviewed the history of the problem, its definition and the current situation, trends and future directions.

## **Panel Discussions**

The Day One panel discussion addressed "Canadian Perspectives on FAS/FAE" and consisted of spokespeople from different sectors, representing various stakeholder groups: families, Aboriginal peoples, community workers, industry and addiction/health care. The purpose of this panel was to present different perspectives on the FAS/FAE issue and to build an understanding and appreciation of its complexities. (See Appendix II for details.)

The Day Two panel, "Approaches That Are Working," which opened the second day of the symposium, highlighted several case studies illustrating successful, multi-faceted approaches. (See Appendix III for details.)

## **Overview of the Standing Committee Report**

Dr. Stan Wilbee, M.P. for Delta, British Columbia and chair of the Health Issues Subcommittee of the Standing Committee, then gave an overview of the 1992 Report of the Standing Committee on Health and Welfare, Social Affairs, Seniors, and the Status of Women, "Foetal Alcohol Syndrome: A Preventable Tragedy" including a brief summary of the Committee's recommendations.

## **The Workshop Process**

The Workshop process was the key focus of the symposium and involved the participants in active, information sharing sessions. The goal was to identify as many view points as possible and to determine priorities for action and appropriate roles and mechanisms to move forward.

Participants engaged in a series of workshops which addressed the following content areas:

- Prevention: Information, Awareness and Public Education Approaches;
- Mobilizing the Health Field: Research, Diagnosis and Sensitization of Health Care Professionals;
- Making Systems more Responsive: Sensitization and Change in Social Service, Criminal Justice and Education;
- Responding to Immediate Needs: Treatment and Support Services,
- At-Risk Groups: Targeted Approaches; and
- Building Momentum: Leadership and Networking.

On the first day of the symposium, delegates participated in small group sessions, each addressing one of the six content areas from the perspective of information sharing. The findings of the groups were then consolidated into reports on each topic area by volunteer rapporteurs from the working groups and presented to the plenary session on the morning of the second day. Delegates then participated in detailed planning sessions which identified priorities for action and began to address specific steps regarding implementation for each of the issue areas. The findings were presented in the final plenary session.

While consensus was not a goal of the workshops, the group sessions did provide the opportunity for participants to raise their individual concerns and, at times, find common ground on certain issues with representatives from other sectors. Group discussions could not always accommodate every individual viewpoint; therefore the workshop findings should not be interpreted to imply that conclusions were consistent with all participants' views.

### **Concluding Remarks**

The symposium concluded with a brief address by Chairperson, Dr. Heather Clarke. On behalf of the Minister of Health and Welfare, Benoit Bouchard, Dr. Stan Wilbee accepted the information gathered at the symposium and thanked participants for their efforts.

### **This Report**

This report begins with the keynote speeches of the symposium from the Honourable Benoit Bouchard, Dr. Robinson and Dr. Loock, followed by reports from the workshops. Each report begins with the issue brief used to stimulate the discussions and continues with notes from the workshop sessions. The workshop



notes are those reported on the flipchart sheets. While the notes should reflect the general direction and points discussed in the sessions, they are not a verbatim transcript of those discussions.

The Appendices include the symposium agenda, notes on the comments and views presented in the panel discussions, a statement from Aboriginal participants, the list of participants, and information on a future conference.

# THE OPENING PLENARY

## THE HONOURABLE BENOIT BOUCHARD, MINISTER OF NATIONAL HEALTH AND WELFARE

It is a great privilege for me to be here today to welcome you to Health and Welfare Canada's national symposium on fetal alcohol syndrome and other alcohol-related birth disorders.

For me, this gathering represents our country at its best. Participants have travelled from all parts of the land to share their knowledge and experience. You are collectively challenging a health problem that has serious implications for children and their families, as well as for afflicted adults.

The range of Canadian expertise represented here is as broad as the individual commitment is deep: natural and adoptive parents of children affected by alcohol-related birth disorders; health care providers; researchers; community activists; educators; representatives of social service organizations, Aboriginal organizations, women's groups; addiction and child care specialists; government policy makers; and representatives of the alcohol industry.

I am greatly impressed by the amount of commitment, compassion and effort displayed by so many, especially by those who have been working for a long period of time on this important issue.

It is my hope that this symposium will help to end the feeling of isolation many of you have had in the struggle to meet the special needs of individuals with alcohol related birth disorders.

The symposium will increase public awareness of these health problems. At present the special needs of afflicted children and adults are not yet well understood in the community at large.

The terms fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE), as you know, cover a variety of conditions that have many life-long consequences for both individuals and society as a whole.

Many observers believe that fetal alcohol syndrome, the most severe manifestation, is, in fact, the leading preventable cause of mental retardation.

These disorders are difficult to diagnose. We estimate - and it is a conservative estimate -- that between one and three cases of fetal alcohol syndrome occurs for every 3,000 live births in western countries.

Over one hundred babies may be born with FAS in Canada every year. The incidence of other alcohol-related birth disorders is thought to be much higher, but they are even harder to diagnose.

This two-day symposium is part of the federal government's immediate response to the report on Fetal Alcohol Syndrome by the Standing Committee on Health and Welfare.

I am pleased to say that the chair of the Standing Committee which produced the report, Dr. Stan Wilbee, is here with us today. His knowledge of this issue will benefit all of us.

As you may be aware, I will be tabling the government's response to recommendations contained in the report, Foetal Alcohol Syndrome: A Preventable Tragedy, in the House of Commons.

Before doing so, I want to hear what you have to say about this important issue.

Your insights, and the insight of others who are unable to attend the symposium, will increase our understanding of this serious problem. This will enable my department and I to develop a well-informed and comprehensive response to the report on Fetal Alcohol Syndrome.

The issue of alcohol and pregnancy has implications in a number of areas, including public education and awareness; professional education; directions in research; health and community services; justice and legislation. .

There are many avenues for action within Canada. Prevention is the key concern of the federal government. Our efforts to combat alcohol-related birth disorders are closely related to other broad initiatives.

Recently, Health and Welfare Canada has introduced two very important programs concerned with disease prevention and health promotion - Brighter Futures and Canada's Drug Strategy.

Healthy babies are a key focus of the Brighter Futures strategy. The strategy consists of government initiatives to aid the more than one million Canadian children at risk today because of poverty, ill health, unhealthy living conditions, neglect or abuse.

Our Drug Strategy recognizes that substance abuse is a complex social problem - a problem that can only be resolved through a long-term commitment to a comprehensive approach. The problem of alcohol-related birth disorders requires the same approach.

Within the Drug Strategy program, Health and Welfare Canada contributes to the support of Crabtree Corner, an FAS community project sponsored by the YWCA here in Vancouver.

Crabtree Corner strives to increase community and individual awareness about the potential hazards of drinking during pregnancy. The project also assists adult caregivers of children afflicted with alcohol-related birth disorders.

Health and Welfare Canada has also made contributions to several related projects in Aboriginal communities over the past decade.

In our efforts to prevent alcohol-related birth disorders, Health and Welfare Canada is committed to both research efforts and educational initiatives. Education is a valuable tool, since these disorders are completely preventable.

Educational efforts must be backed up with research efforts so that we can better target our efforts.

Today's meeting and subsequent workshops and discussions will help to further our research effort.

Presently, negotiations are underway with provincial and territorial colleagues about a shared pilot project on warning labels for alcoholic beverages. The pilot project would help us determine if mandatory warning labels would be an effective public information strategy.

Parents, teachers, health and social service workers, legislators and the public at large could all use more information about alcohol-related birth disorders.

We are preparing now an information sheet with these needs in mind. We expect you will want to adapt the information sheet, when available, for use in your specific communities.

At present our knowledge of the relationship between pre-natal alcohol exposure and birth disorders is incomplete. We need to know more about individual differences in susceptibility, the timing and amount of alcohol exposure at different stages of pregnancy, and patterns of drinking by women of reproductive age.

We do not know if there is a level of alcohol consumption in pregnancy that is safe for a developing fetus. Moreover, individual differences may preclude ever being able to offer advice about what amount may do no harm to an unborn baby.

As a result, we have adopted a policy of advising pregnant women, or women who are attempting to become pregnant, not to drink alcohol.

Women who drink should be encouraged to stop drinking at any time during pregnancy. This may prevent fetal damage or, at least, decrease its severity.

It is essential, of course, to convey this message with care to avoid instilling anxiety and guilt. I look forward to your workshop suggestions on how best to convey these messages within various communities.

It is also important to convey the message that the best way to prevent alcohol damage is for both partners to give up drinking during a pregnancy.

Moreover, it is much easier for a pregnant woman to abstain from drinking alcohol if her partner supports her choice and also stops drinking. We need to think about ways the community can help support these choices.

A significant development in the health field in recent years has been a change in public perception about the safety of substances that were once considered to be socially acceptable.

Tobacco is the leading example. What we did not know 30 years ago, and are increasingly becoming aware of today, is that it is unsafe to use any quantity of tobacco; even second-hand smoke poses a health risk.

Many observers feel this knowledge helped to influence the decline in the number of smokers in Canada. We know it has influenced the introduction of regulations to achieve smoke-free work environments and public spaces.

Likewise, most Canadians are now more aware of the hazards associated with drinking and driving and now view this behaviour as unacceptable.

The challenge we now face is to achieve a comparable level of awareness concerning the risks of consuming alcohol during pregnancy-

The task is formidable. Alcohol has only been scientifically identified as a cause of birth disorders within the past 25 years. Although Canadians may have a general level of awareness that alcohol during pregnancy can be harmful, many do not yet link alcohol consumption during pregnancy with possible life-long damage to their children.

Working together with our partners - other jurisdictions, nongovernmental organizations and the private sector - we have made a significant difference on the impaired driving problem. We hope over time to have a similar impact in the area of alcohol-related birth disorders.

We won't eradicate the problem overnight.

While we work to diminish alcohol consumption during pregnancy, it is vital to maintain support for alcohol-affected children and their families. From infancy through adulthood, affected families need the support and understanding of health and social services, the educational system and society in general.

I am heartened, as I am certain you are, by the signs of increased momentum within this field in the last few years.

Each one of you has contributed to the strong foundation on which nation-wide prevention policies can grow. I particularly want to thank those remarkably dedicated individuals whose generous assistance made it possible to arrange this symposium on such short notice.

An extraordinary amount of energy and determination fills this room. I wish you all well, and I welcome your participation and contributions to this symposium over the next two days.

Thank you.

# THE EPIDEMIC OF THE FETAL ALCOHOL SYNDROME IN BRITISH COLUMBIA

Dr. Geoffrey C. Robinson, Professor Emeritus  
Dept. of Pediatrics, Sunny Hill Hospital, Vancouver, B.C.

## 1. Predisposing Causes

I have been asked to say something about the epidemic of FAS in this country during my lifetime. I begin with a review of predisposing causes: influence of legislation and other factors which have contributed to the availability and increased use of alcohol by women during child bearing years. Knowledge of these influences has important implications for prevention of FAS. This is followed by a brief review of the recognition and scope of FAS in British Columbia (the outcomes).

### *Influence of Legislation*

#### *Provincial:*

Prohibition was introduced in British Columbia in 1916. The Government Liquor Act (1921) authorized the sale of liquor at government liquor stores and the government became the province's primary liquor distributor. It has been suggested that the government was obliged to enact legislation to combat the excessive use of alcohol available on the Black Market! In addition the Act repealed the Prohibition Act. The Act also created the Liquor Control Board to supervise the administration and enforcement of the Act. Beer parlors were licensed with separate areas for Ladies and Escorts and Gentlemen and this increased the availability of alcohol to the general public.

In 1952 a plebiscite in B.C. asked the question "Are you in favour of the sale of spirituous liquor and wine by the glass in establishments licensed for that purpose?" and the majority voted yes. This was followed by a Liquor Inquiry Commission and a new Government Liquor Act (1953) which authorized the sale of spirituous liquors, vinous and malt liquor by the glass with meals" in a number of outlets (hotels, club restaurants, night clubs, trains and vessels). This further increased the availability of alcohol to the population.

#### *Federal:*

The federal Indian Act (1876) prohibited the consumption (except for medicinal purposes) and possession of alcohol by native Indians. The new Indian Act (1951) stated that Indians could drink in public places if the provincial government wished to extend this privilege to its native population. B.C. was the first province

in Canada to apply and this privilege came into force December, 1951. Similarly an amendment to the Act (1956) permitted Indians to purchase and consume "intoxicants" off Indian reserves in accordance with the laws of the province. B.C. applied for and was granted this privilege in 1961. The Indian is only allowed to take liquor to his home if the band has voted in favour of permitting liquor on reserve.

### *Influence of Other Factors*

#### *Social and Cultural:*

Drinking patterns of women have changed since World War II in the direction of increased consumption. In 1983 the National Symposium on Fetal Alcohol Syndrome in Winnipeg suggested an increase in the number of female drinkers. The ratio of male to female alcoholics had increased from 8 to 1 in 1960 to 1 to 1 in 1980. The reasons were the greater willingness to identify the problem in women and women's use of alcohol in dealing with their changing roles in society and the pressure and conflicts brought on by these new roles.

The use of alcohol is not part of traditional native Indian culture and their use of alcohol is generally attributed to the social and cultural breakdown of the Aboriginal people, one manifestation of which is alcoholism.

#### *Marketing:*

Women purchase a significant proportion of alcohol sales and as a result they are targeted by advertising and the cultural norms which have served to protect women are in danger of vanishing. Current advertising usually displays alcoholic beverages as a prominent part of the young lifestyle.

## **2. Outcomes**

It seems reasonable that greater access to alcohol and social and cultural issues noted above and marketing trends have combined to set the stage for alcohol related birth defects. During the 1950s and 1960s interest in the problem of drinking women was growing. The association between maternal alcoholism and growth retardation, mental deficiency and congenital anomalies was noted in France in the late 1960s and the term Fetal Alcohol Syndrome was introduced in 1973 by a team at the University of Washington in Seattle.

Clinical reports from pediatricians in B.C., notably Dr. D. F. Smith, Dr. P.M. MacLeod and Dr. K.O. Asante, followed and emphasized the high prevalence among Native Indians in British



Columbia. Dr. Asante also initiated epidemiological studies to address prevalence and promoted the introduction of preventive strategies.

Women with FAS children usually are socially and economically disadvantaged. An important at-risk group in our country are the Indian and Inuit people. The publication, *Achieving Health For All*, identifies this group and refers to the challenge for reducing inequities.

The importance of addressing related public policy issues - the marketing of alcoholic beverages directed at young women, child custody, neglect and abuse laws and highway safety policy - has recently been emphasized.

### **3. Responses**

#### *Provincial:*

The provincial government formed an Alcohol and Drug Commission in B.C. in 1973, (renamed Alcohol and Drug Program in 1982) and provided a population-based treatment program for alcohol and drugs.

The B.C. FAS Resource Group was started in 1984 (to become the B.C. FAS Resource Society in 1992) to advocate on behalf of FAS children and youth and their families and to promote education and research in the field.

In 1988 Alcohol and Drug Programs introduced a community awareness campaign followed by the TRY Campaign which included Counter Attack, Service it Right and Pregnancy Outreach Programs.

#### *Federal:*

Recognition of the presence of FAS in the Native Indian population was followed by the introduction of the National Native Alcohol and Drug Abuse Program (NNADAP) in the Medical Services Branch, National Health and Welfare to provide prevention and treatment for Indians on reserves in Canada. The following year a National Symposium on FAS was held in Winnipeg and sponsored by Health and Welfare Canada.

In 1986 *Achieving Health for All* was introduced and provided a framework to address the prevention of maternal alcoholism and alcohol-related birth defects. In 1987 the National Drug Strategy was introduced for five years and has been extended for a second five-year period.

The report of the Standing Committee on Health Issues submitted a report, Foetal Alcohol Syndrome: A Preventable Tragedy, in 1992. One of the recommendations was this symposium on FAS/FAE we are attending today. The forthcoming Brighter Futures and Child Development Initiative for at-risk children is a major advance for child health.

#### **4. Conclusion**

The purpose of this overview has been to suggest that a number of predisposing factors have contributed to the greater use of alcohol by women in the child bearing age and hence the occurrence of FAS. These include legislation, the changing role of women, the consequences of the social and cultural breakdown of the Aboriginal people, and contemporary marketing strategies.

These represent important barriers to the eradication of FAS. Efforts to understand the importance of these factors are central to the prevention of FAS.

# **FETAL ALCOHOL SYNDROME AND FETAL ALCOHOL EFFECTS: COMMON, EXPENSIVE, AND PREVENTABLE**

Dr. Christine A. Looock,

Assistant professor, Dept of Pediatrics at Sunny Hill Hospital,  
Vancouver, B.C. and Chair of the B.C. FAS Resources Society

## **Overview**

FAS. is common. Based on epidemiological studies world-wide, the incidence of FAS ranges from 1.1 /1000 live births to 2.9/1000, with an overall estimated rate of 1.9 cases/1000 live births (approximately 1 in 500 (Abel and Sokol, 1987). The incidence of FAE is estimated to be 5 - 10 times higher. Hence, FAS/FAE may be more common than Down Syndrome (1 in 600) and spina bifida (1 in 700) combined. Prevalence studies have shown that in some communities in B.C. and the Yukon, rates may be as high as 1 in 5 in the 0-18 age group (Robinson, 1987, Asante, 1981).

FAS is expensive. It is impossible to measure the cost to society of each FAS/FAE child. Added to the cost of health care for these children, are the direct costs of special education, foster care, financial assistance and social services, and indirect costs related to maladaptive behaviour, goods and services not produced, and most important, the loss of human potential. The estimated lifetime cost related to health and education for one child with FAS may exceed 1 million dollars (Hild, 1988). These costs are staggering considering that FAS and FAE are preventable.

Strategies for the prevention of FAS/FAE must be directed at all levels (primary, secondary and tertiary) with particular focus on improving reproductive health and pregnancy outcome. Prevention efforts must not target only women during their child bearing years, but also those who influence them, including their partners, families, and society.

Early diagnosis and intervention for individuals affected by FAS/FAE are also essential components of the action plan if the cycle of alcohol related birth defects is to be broken.

## **Key Questions**

Key questions related to FAS/FAE include the following:

1. What are the diagnostic criteria for FAS? (What is FAS?)
2. What is the epidemiology of FAS? (Where does FAS occur?)

3. How much alcohol is required to cause an effect? (How much is too much?)
4. When are the most critical times for the embryo/fetus for alcohol exposure? (When does alcohol have an effect?)
5. What are the important variables which impact on the teratogenic effects of alcohol? (Why aren't all individuals affected in the same way?)
6. How can we best identify pregnancies at highest risk for FAS/FAE? (Who is at risk?)
7. What are the essential elements in a prevention strategy for FAS/FAE? (How do we prevent FAS/FAE?)

The FAS Study Group of the Research Society on Alcoholism standardized the diagnostic criteria for FAS in 1980 and 1989. These include:

1. central nervous system involvement,
2. prenatal and/or postnatal growth retardation (below the 10th percentile), and
3. characteristic facial features (at least 2 of the following: short palpebral fissures (small eyes or short eye openings), a poorly developed philtrum (the groove above the upper lip), thin upper lip, short nose or flattened mid facial area).

The adverse effects of gestational alcohol exposure exist along a continuum with the full expression of FAS at one end of the spectrum and more subtle neurobehavioural effects on the other. FAE or possible FAE is a term used to describe children whose birth defects or developmental disabilities may be attributed to prenatal alcohol exposure but do not meet the full diagnostic criteria.

Alcohol Related Birth Defects (ARBD) is a broad term used to describe birth defects that have been correlated with prenatal alcohol exposure. These include congenital defects of the heart, neural tube (spina bifida), craniofacies (cleft lip and cleft palate), genitourinary system and the skeleton (cervical spine, digits, and elbows). Hence, FAS is a subset of ARBD.

Physical and developmental characteristics of alcohol exposed children may vary greatly from child to child and may depend on when and in what quantities the fetus was exposed, genetic makeup, maternal health, nutrition, and other compounding factors such as smoking and other drug use.

The brain develops throughout gestation, hence it may be susceptible to alcohol at any point during pregnancy. Growth retardation and neurobehavioural effects have also been reported to be associated with moderate and binge alcohol consumption (Streissguth et al, 1989; Barr, 1990; Day, 1990).

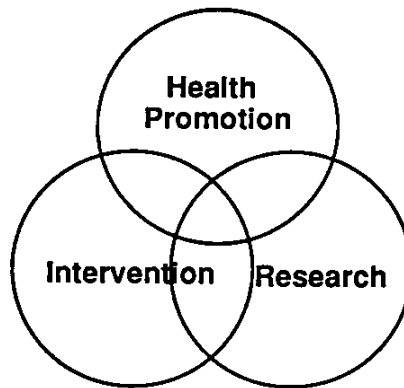
There is an urgent need to standardize the terms heavy, moderate, and binge alcohol use. A clear threshold has not been determined. Given the range of effects of alcohol on the fetus, defining a safe cut off point may be both unreasonable and unscientific. At this time, there is no known safe level of alcohol use in pregnancy.

### **Developing Art Action Plan**

In developing a successful action plan to prevent FAS/FAE, we must address 3 interlocking and interdependent spheres: health promotion, research, and identification/intervention strategies. Coordination at all levels of government beginning at the community level will ensure that all stakeholders are identified and appropriate priorities are set.

*Figure 1*

### **Prenatal Alcohol/Drug Prevention Strategy**



## **Health Promotion**

The following challenges and strategies outlined are consistent with the Framework for Health Promotion outlined by Epp (*Achieving Health for All*, 1986). In addressing FAS/FAE, the major challenges for our society will continue to be "reducing inequities, widening the prevention effort, and enhancing people's ability to cope" (Epp, 1986).

The four P's: poverty, poor nutrition, poor prenatal care, and poly drug use have a significant impact on reproductive health and developmental outcome. Among substance using women, alcohol and cigarettes are the most commonly reported drugs misused (Streissguth, 1991; Graham and Koren, 1991).

Health promotion strategies for FAS/FAE include:

1. fostering public participation; e.g. server intervention programs, train-the-trainer education programs, and community-based action groups (such as Crabtree Comer, YWCA, Vancouver).
2. strengthening community health services; e.g. hospital/community health partnerships and pregnancy outreach programs.
3. coordinating healthy public policy; e.g. comprehensive school health curriculum (such as the BC Learning for Living Curriculum), legislation involving labeling and lifestyle advertising, and accessibility as they apply to alcohol use in pregnancy).
4. coordinating policies between sectors; e.g. inter ministerial committees such as the BC Provincial FAS Forum with representation from Alcohol and Drug Programs, Ministries of Health, Social Services, and Education, and the Justice System.

## **Research**

FAS has begun to receive the attention of researchers since its description in 1973; however, research in Canada continues to be limited to a few major centres. Expanded research programs are required to address issues relating to epidemiology (e.g. screening, surveillance, incidence, and prevalence studies), basic science questions, and effective prevention, clinical, educational, and legislative interventions.

## **Early Identification/Intervention**

Early identification can assist in accessing appropriate interventions which may mitigate many of the physical, emotional, social, and educational problems faced by children with FAS/FAE. Early identification may also result in an opportunity to intervene with an at-risk mother and her support network prior to future pregnancies.

Although FAS/FAE cannot be cured, early and ongoing interventions may reduce the social, economic, and personal consequences of this lifelong disability. Important strategies include

1. regionalized FAS/FAE assessment programs with outreach to smaller communities;
2. routine TACE questionnaire screening of pregnant women and risk assessments in hospital obstetrics;
3. priority addiction treatment for pregnant women (sensitive to gender specific issues including childcare responsibilities and history of abuse/family violence);
4. a continuum of special needs daycare services and educational support services,
5. supportive living arrangements (for youth and adults);
6. support groups, respite, and home support for families;
7. education for social service workers, daycare workers, educators, court workers, addiction counsellors, police, Crown counsel, judges, etc.

## **Coordination**

To ensure coordination between health promotion, research, and early identification/intervention strategies, FAS/FAE communication networks must be established at all levels: federal, provincial/territorial, and community. It is my hope that you will return to your communities and establish provincial/territorial FAS Resource Groups and encourage the formation of inter-ministerial forums.

## **Conclusion**

The 1992 Standing Committee on Health and Welfare, Social Affairs, Seniors and the Status of Women should be recognized for

their contribution toward our common goals in FAS/FAE. They were the first to develop comprehensive recommendations regarding FAS/FAE at a national level.

We look forward to the recently announced federal initiative Brighter Futures as an important part of a federal FAS/FAE plan; and at the provincial level in British Columbia to the new Thanks for Caring FAS/FAE resource.

Our challenge over the next two days will be to gain a better understanding of FAS/FAE by sharing our many perspectives, experiences, and knowledge, and to identify priorities, roles, and mechanisms for action.

FAS is common, expensive, and preventable.



# **WORKSHOP REPORTS**

## **Introduction**

Participants were pre-selected to workshop groups to ensure that each group had representation from all of the sectors participating in the symposium. On Day One, participants received briefs summarizing six content areas to guide workshop discussions. These briefs are provided at the beginning of each workshop report below.

On Day One, workshop participants were requested to discuss the strengths and challenges in the six content areas and to establish priority concerns and directions for action. In each of the Workshop Reports contained here, Day One Discussion is the point form notes made by the volunteer group rapporteur reflecting this discussion.

On Day Two, participants self-selected content areas of their choice. In each content area, participants expanded on the discussion of Day One by examining what needs to be done by whom and how all players can work together. Day Two Discussion is again the notes of the group rapporteur.

While the workshop notes reflect the general direction of the discussion in each group, they are not a verbatim transcript of those discussions.

## **CONTENT AREA # 1: PREVENTION**

### **INFORMATION, AWARENESS AND PUBLIC EDUCATION APPROACHES**

#### **ISSUE BRIEF**

Prevention is the first line of defense in health care, particularly in the case of FAS/FAE - a preventable problem. Prevention involves providing relevant and persuasive factual information to guide decision-making concerning alcohol consumption, during pregnancy. However, more than information-giving is required in order to create behaviour change. A range of mechanisms may be needed in order to create a new social norm around drinking during pregnancy.

This content area focuses on a continuum of approaches, activities and tools for reaching the general public with effective messages about the dangers of drinking during pregnancy. The continuum includes information-giving approaches (labelling, distribution of fact sheets, signs and warnings); awareness-raising (use of media, community-based approaches); and public education and social marketing programs aimed at changing attitudes and behaviour (school-based education programs, counselling programs, national campaigns).

## **DAY ONE DISCUSSION**

### **Overview**

- FAS/FAE is part of a larger constellation of problems that result from the misuse or abuse of substances;
- use of alcohol occurs in social/cultural context that includes poverty/violence/racism/sexism  
e.g. "this will drive me to drink;"
- approaches have to be multifaceted/comprehensive to address underlying or root factors.

### **Awareness with a Goal of Behavioural and Attitude Change**

- educate people about the detrimental effects of alcohol to the fetus;
- long-term consequences - social/family;
- targeted at pregnant women for a better chance at behaviour change;
- fathers;
- alcohol is a drug
- local/community effort (native leaders/elders);
- educate doctors about FAS/FAE and alcoholism (diagnosis);
- educate the male population;
- not to induce guilt in delivery of message;
- use a positive approach;
- target the risk population;
- social services;
- probation officers/justice system.

### **Tools that bring about changes**

- positive approach;
- know the behaviour and risk factors;
- targeted at high risk population;
- fathers;

- alcoholics;
- built on models that have proven to be effective;
- wellness perspective - healthy lifestyle (holistic).

#### **Mass media**

- publicity;
- advertising;
- labeling;
- promotional efforts;
- testimonials

#### **Specific educational efforts**

- Prevention Programs K-12

#### **Legislative products,**

- labeling (symbolic);
- advertising restrictions - enforcement of existing legislation (sport and alcohol);
- pricing increase or higher taxes to reduce the availability of alcohol.

#### **Networks/Partners**

- concerted effort - national;
- industry should be part of the solution;
- better networking (Information. Brokers).

## **DAY TWO DISCUSSION**

### **Information, Awareness And Public Education**

The workshops identified three specific areas for FAS/FAE awareness efforts:

- Awareness activities with a goal of behavior and attitude change:
  - general awareness through mass media and advertising; and
  - community-based, local programs.
- Specific formal educational programs:
  - in schools and post-secondary educational institutions; and
  - in medical schools;
- Tools that bring about change, such as:
  - legislation that imposes restrictions on advertising and establishes labels on alcoholic beverages; and

— the involvement of networks and other systems such as justice.

### **Awareness Activities**

Awareness activities were divided into two major categories: general awareness through mass media and community-based local programs. These two categories should be addressed simultaneously. Target audiences should include two broad groups:

- those who don't know about FAS/FAE, such as sexually active men and women; and
- those who may know but are unable to stop consuming alcohol.

#### *General Awareness*

While the general public may be aware that alcohol consumption during pregnancy can be harmful to the fetus, few are aware of the specific effects of FAS/FAE. Furthermore, many people believe that alcohol in moderation is acceptable. This perception should be checked and the general public needs to be made aware of Fetal Alcohol Syndrome.

Many participants recognized the important role that the alcoholic beverage industry can play in facilitating awareness of FAS/FAE, and acknowledged the efforts the industry has made on other social issues such as drinking and driving. The industry has considerable marketing resources and expertise and should be a partner in conveying general awareness information. The labeling of alcoholic beverages was also believed to be a significant tool for awareness, although there was considerable debate whether it could influence behavior.

Other industry groups should also be approached to serve as partners in FAS/FAE awareness. The manufacturers of pregnancy test kits could distribute information with their products. Distributors of alcoholic beverages such as pubs and bars could assist with the posting of FAS/FAE signage (signs should be posted in both the Men's and Ladies' rooms).

The federal government should also coordinate and fund mass media campaigns as is has for smoking, Participation and AIDS. An effective federal government campaign would also provide support to local initiatives.

#### *Community-Based*

Localized, community-based programs were identified as being very successful for targeting high risk groups. Examples, such as

the Crabtree Corners "Bottle Feeding/Needle Work" programs in Vancouver as well as AIDS programs in Edmonton, Alberta and elsewhere were cited. Community-based programs can also more effectively address cultural barriers to awareness and information: i.e. language and literacy problems experienced in the Northwest Territories can be better addressed locally than through national programs (when dealing with Aboriginal people the role of "healers" should not be underestimated). Health care professionals or people administering health care are an important group for these types of programs.

Community-based initiatives need financial support and a mechanism by which they can share information, such as a national FAS/FAE network

### **Educational Programs**

Education programs should include awareness on FAS/FAE from elementary through to post-secondary school. It was also recommend that considerable education be given through in-service programs particularly for doctors and professional health care providers.

FAS/FAE could be linked to other programs dealing with health effects of drugs and particularly dealing with education on pregnancy. The program should be comprehensive. This issue also raised calls for a uniform health education program in Canadian Schools.

Post-secondary and in-service programs should be targeted at doctors, nurses, social workers, community health workers, and native leaders. Specific groups involved could include: Canadian Medical Association', Canadian Nurses Association (and provincial counterparts), Native Physicians of Canada, College of Family Physicians, Provincial Alcohol and Drug Commissions, Canadian Association of School Health, Canadian Teachers Federation (and provincial counterparts), national parent associations. The programs should also be expanded to provide awareness and education to professionals in the justice and penal system.

It was recommended that a central body be established to provide leadership, funds and to undertake activities such as needs assessments and research. Its goal could be to develop a societal norm regarding the use of alcohol during pregnancy.

## **Tools for Change**

The focus of this discussion was primarily on legislative initiatives. There was general agreement that a starting point could be the promotion of the Standing Committee's Report on FAS "A Preventable Tragedy" and that this document could serve as basis for discussion with key stakeholder groups on the implementation of the sub-committees recommendations.

### *Labeling*

While there was no consensus on the efficacy of labeling as a deterrent to FAS/FAE, there was general agreement that it could be very effect as an awareness tool. Many suggested that labeling of alcohol beverages should proceed and that its impact should be studied. The labels should address not only FAS other alcohol related health problems. The use of labels in the United States was cited as a possible direction for Canada. Furthermore, it was noted that many Canadian firms currently manufacture products for the US market with warning labels. It was also generally agreed that another forum is required to deal with the specific issues on labeling.

### *Advertising*

Consensus was achieved on the need for responsible advertising as regards the consumption of alcohol, however, there was no consensus on restrictions of the banning of advertising similar to those now being called for on tobacco products. The debate revolved around that fact that the consumption of alcohol is not necessarily dangerous, but only if abused or used during pregnancy. There was debate over the CRTC guidelines not being enforced and some confusion about "life-style" advertising.

Some participants identified an immediate need for a national symposium to formulate clear and enforceable guidelines for advertising and promotion.

### *Changes to the Mental Health Act*

There was strong argument made by several individuals for the need to involuntarily institutionalize a woman who is pregnant and cannot stop consuming alcohol. Furthermore, there is a need for more appropriate detoxification facilities for women in Canada. This position was not supported by the group in general as many people had concerns about human rights and the ability of the community to enforce sanctions against an individual.

## **CONTENT AREA # 2: MOBILIZING THE HEALTH FIELD**

### **RESEARCH, DIAGNOSIS AND SENSITIZATION OF THE HEALTH CARE PROFESSIONALS**

#### **ISSUE BRIEF**

The health field, including doctors, nurses, researchers, mental health professionals, pharmacologists, and numerous other specialties have a great deal to contribute in terms of better identifying, understanding, and meeting the needs of FAS/FAE children, adults and their families. While some progress has been made since FAS was first diagnosed in the 1970s, the health field needs to play a major role in understanding why and how FAS/FAE occurs, and how FAS/FAE children, adolescents and adults can be better identified and helped. Perhaps most importantly, health care practitioners are a highly credible information source in the eyes of the public and therefore have a large role to play in the front line of awareness-raising and education around FAS.

This content area focuses on health care issues related to FAS/FAE, including what further research is required to understand the magnitude of the problem and why and how it occurs; what tools and systems need to be developed to assist health care practitioners in diagnosing FAS/FAE; incorporating FAS education into health care curricula, and sensitizing and enlisting those working in the health field to raise awareness about the dangers of drinking alcohol during pregnancy.

#### **DAY ONE DISCUSSION**

##### **Education Of Health Professionals**

- target all types and levels of health care professionals;
- knowledge of alcohol and effects, skills, tools (diagnosis, treatment, prevention, promotion and cultural sensitivity);
- behaviour and attitude changes promoted;
- evaluation process "built
- multi-disciplinary approach to education.

##### **Research (Clinical And Basic)**

- epidemiological baseline for Canada (e.g. applied research in prison system);
- national mechanism for FAS/FAE research findings;
- clinical research on extent of disabilities and abilities;

- basic research on biological marker FAS/FAE (including low doses);
- basic research on a biological marker for alcohol intake during pregnancy,
- connect research with the community and clinics to permit input and two-way communication flow.

### **Resources**

- access to community diagnostic/coordinating centres need to be created across the country,
- shared research effort by industry, government and academic community;
- treatment centres for child and mother (family-centered)
- respite centres;
- coordination with community resources;
- increased funding for research, education and resources;
- identify and build on existing resources.

## **DAY TWO DISCUSSION**

Three broad policy directions emerged from the group discussion of Day One. They were:

- The need for a comprehensive national mechanism to address alcohol and other drug use effects on gestation;
- The need for a shared FAS/FAE research effort support jointly funded and supported by industry, government, and the academic community. This research effort to include basic, clinical and applied (e.g., health promotion, research);
- The need to enhance the education and knowledge of health professionals about FAS/FAE.

### **Specific Action Steps**

For each of the above noted policy directions, several specific action steps were identified. A short description of these is contained below.

#### ***Policy Direction 1: National Mechanism***

- Identify an appropriate model for the national mechanism. One possibility might be the Cystic Fibrosis Foundation. It is important that the mechanism be independent of government;



- Obtain seed money from the federal government to establish the mechanism;
- Obtain additional seed money from other key stakeholder groups;
- Establish a permanent secretariat for the foundation. Again, this secretariat must be independent of government,
- Create a mission statement for the foundation based on health promotion, research, and intervention;

Activities of the proposed foundation could include:

- Promote and fund centers for excellence across the country which are built on existing resources;
- Connect research with the community and clinics to permit two-way input;
- Reconvene a national forum/symposium in two years to track progress.

***Policy Direction 2: Shared Research***

- Initiate joint discussion between industry, government and the academic community to develop a plan for an appropriate funding mechanism (during the group's discussions, the industry representative indicated that they would be interested in an arms-length mechanism whereby they provided funding for, but did not become actively involved in sponsoring, research);
- Conduct clinical research on the extent of disability and ability of individuals affected by FAS/FAE;
- Conduct basis research on possible biological markers for FAS/FAE (including the need to be sensitive to low doses);
- Conduct basis research on possible biological markers to assess alcohol intake during pregnancy;
- Establish collaboration between basis and clinical research on the "natural course" of FAS/FAE;
- Conduct epidemiological research to gather relevant information for Canadian situation. This research should include screening, surveillance, and epidemic/endemic considerations;

- Ensure that evaluation processes are inherent in all forms of research.

### ***Policy Direction 3 - Education of Health Professionals***

- As a starting point, create national standards for alcohol/drug use during pregnancy;
- Disseminate information about FAS/FAE through the various professional associations. This could include newsletters, continuing education, etc.;
- Revise the curriculum including knowledge, skills and attitude for all health professionals' training programs, at the undergraduate or entry level, the graduate level, and the continuing education level. In addition to the "traditional" curriculum, there was an identified need to include skill development in areas such as interpersonal communication and conflict management for practitioners in the FAS/FAE area;
- Provide knowledge for health professionals about related support and resources available to them in treating FAS/FAE. This could include support and resources geared to diagnosis, intervention and prevention of FAS/FAE.
- Encourage and support First Nations students who want to enter health professions.

### **Other action items and priorities**

In addition to the above noted priority directions and action steps, several other items were also identified as needing attention. Unfortunately, due to time constraints, they were not developed as fully as the above. The group indicated that they wanted them to be mentioned in the report. These include:

### ***Priority Direction 4 - Provision of Services (Interventions)***

- Create a series of regionalized, community-based diagnostic centers across the country, utilizing a trans-disciplinary approach;
- Create a continuum of gender-sensitive addiction treatment centers on a provincial basis;
- Direct the Minister of Health and Welfare Canada to place the FAS/FAE recommendations in the Wilbee report and the

recommendations of this Symposium on the agenda for the next meeting of Health Ministers and get a commitment to action.

## **CONTENT AREA # 3: MAKING SYSTEMS MORE RESPONSIVE**

### **SENSITIZATION AND CHANGE IN SOCIAL SERVICE, CRIMINAL JUSTICE AND EDUCATION**

#### **ISSUE BRIEF**

FAS/FAE children and adults often slip between the cracks of some of the major systems in our society. A large part of the problem is that FAS/FAE children and adults are not appropriately identified and assisted. Instead they become labelled as "problems" in social service, justice, education and other systems that do not recognize or have appropriate provisions to meet their needs.

This content area deals with how various societal systems (other than health which is the focus of area #2) could be more accessible, be sensitized to, and respond better to the needs of FAS/FAE children, adults and their families. This includes better systems of identifying FAS/FAE individuals, the modification of existing programs to accommodate FAS/FAE individuals or the development of new programs.

#### **DAY ONE DISCUSSION**

##### **Social/cultural factors**

- different reasons for drunkenness;
- conventional stereotypes need to be broken;
- conflict between maternal and fetal rights;
- traditional views of women (e.g. onus not only on pregnant women);
- families with special needs members tend to be isolated - all need community support.

##### **Diagnosis**

- need national standards;
- needs to take place as soon as possible;
- is critical to programming and planning.

**Cross disciplinary nature of service**

- justice, social services, education, recreation, employment, voluntary agencies, care-givers, families and community all need to work together,
- many people with FAS/FAE have other difficulties (sexual and physical abuse, attachment, poverty, etc.) which need to be addressed in planning and service;
- traditional approaches need to be re-thought;
- planning and service need to be comprehensive and long term, and include work, housing, socialization, etc.;
- planning and service need to reflect of FAS/FAE and not reflect judgment, blame or guilt;
- improved access to and sharing of information among all players (persons with FAS/FAE, care-givers, professionals);
- client centered, not program control service.

**Education/training for professionals/service providers;**

- need for information and training for all professionals and paraprofessionals,
- need for research into programs that work;
- need for research into learning patterns/needs of people with FAS/FAE;
- training needs to address service for children and adults;
- need to acknowledge many professionals are over stretched, training should help reduce this, e.g., justice workshop in Yukon, manual in B.C., information package.

**Programming;**

- needs to be lifelong;
- needs to reflect specific learning needs of FAS/FAE people, other existing programs don't work (i.e. learning disabled);
- behaviour management, not behaviour modification;
- need to develop appropriate "life skills" training;
- subsidized work environments.

**Cost**

- funding for appropriate education attached to child, not program;
- financial support for care-givers (e.g. disability pensions, subsidies);
- practical, emotional supports - respite;
- insurance program supported by the alcohol industry.

**General**

- need for national clearing house;

- need for national focus with local response;
- need to assess programs for effectiveness,
- Systems need to be:
- proactive, not reactive
- coordinated
- comprehensive
- community driven
- community based
- culturally responsive.

## DAY TWO DISCUSSION

### **Sensitization and Change in Social Service, Criminal Justice and Education**

The following statements were presented to the plenary session.

#### *Practical, Emotional Supports for Families*

- Establish national recognition that FAS/FAE exists as a problem in Canadian society that requires long term solutions and short term interventions.
- Establish a federal-provincial cost share program to make funds available immediately to families with special needs children for respite (implemented provincially to ensure equal access), extraordinary child care costs (medical, housing, education, therapy) and support information networks.
- Undertake incidence studies in adult, adolescent and child populations (in, for example, the justice and education systems).
- Establish funds for case advocate services.

#### *Funding Support for People with FAS/FAE*

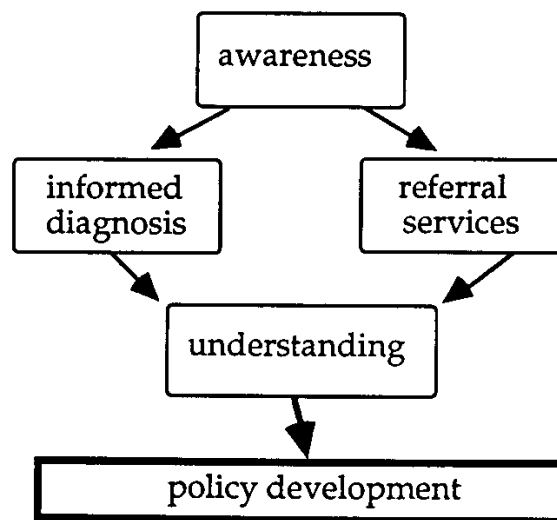
- A national group with vested interest should lobby the federal government to develop comprehensive policies that will direct provincial and municipal governments to address funding issues for people with FAS/FAE. Federal responsibilities should include awareness building, research and program coordination.
- Suspected cases of FAS/FAE should be diagnosed immediately, as diagnosis allows creation of a blueprint for life long care for people with FAS/FAE and their caregivers.

- In order to access existing funding, front-line workers need to play the institutional games necessary to receiving funding.

### *Diagnosis*

- Physicians, psychologists and assessment centre personnel should be informed and trained in FAS/FAE. Implications for a medical training core curriculum, in-service training, the accessing of information, and directories of services, should be considered.
- In order to address cross-disciplinary concerns, a mechanism should be established to ensure policy, information and services coordination. Provincial health departments should take the lead in this, but input should come from families and social services, education, justice, employment and voluntary agencies.
- The mechanism should address the accessing of information, core and in-service training, services directory establishment and funding. The various agencies should provide feedback and direction on appropriate programming and work to legitimize the advocacy role of the parents and other care givers of people with FAS/FAE.

This sub-group tried to represent its understanding of cause and effect with the following diagram:



## **CONTENT AREA # 4: RESPONDING TO IMMEDIATE NEEDS TREATMENT AND SUPPORT SERVICES**

### **ISSUE BRIEF**

FAS/FAE children may suffer from a wide variety of physical and behavioural problems that put enormous stress on birth parents, foster or adoptive parents. Often caregivers find themselves dealing with medical and social situations for which they are totally unprepared. This is compounded by the fact that educational and other systems cannot adequately meet either their needs or their children's needs. While making a place for FAS children within these systems is necessary, it is a slow process and, in some cases, may not be as effective as developing new, targeted programs specifically designed to meet the needs of FAS children and their families.

This content area covers the range of programs and services that are needed to provide better support and treatment for FAS/FAE children and adults. Three major sub-headings are: services for women (alcohol and drug treatment programs specifically designed to meet the needs of alcohol-dependent pregnant women, pre-natal, post-natal); programs for families (financial support, adoption counselling, long-term planning, support groups); and services for children and adults with FAS/FAE (treatment, behaviour modification, etc.). Particular emphasis will be given to community-based approaches.

### **DAY ONE DISCUSSION**

#### **Needs and Challenges**

- Accessible treatment programs, including residential centres that are appropriate for women with families:
  - women-only detoxes
  - protocols to give priority to pregnant women.
- Coordinated continuum of services including pre- and postnatal services, targeted appropriately.
- Respite with appropriately trained care-givers that are:
  - accessible

- pro-actively available
- funded
- Need for coordinated information collection and dissemination about programs, services, resources, funding at national, regional and community levels;
- Need to recognize strengths of individuals and families, but ensure that services don't exclude people because of them i.e. services based on diagnosis, not IQ.
- Accessible diagnosis is an integral part of treatment and support.
- More information on medical treatment of associated problems.
- Financial support needs to be available for pregnant women, birth and adopted families - adoption subsidies should reflect the true cost of raising the child.
- Need for continuum of services targeted specifically to adolescents and adults, because of special needs.
- Need for recognition that FAS is a lifelong disability with unique developmental, emotional and physical effects.

## **DAY TWO DISCUSSION**

### **Treatment And Support Services**

#### *General Principles*

The group consensus was that there were specific over-riding principles that prefaced all recommendations made on this subject. They were:

- All services should be equally accessible to all Canadians.
- Need for recognition that FAS is a life long disability with unique developmental, emotional and physical effects.
- It is important that all services be culturally and gender sensitive
- FAS must be recognized as a specific disability with the same services as other recognized disabilities.



## **Priority #1**

### **Accessible Treatment Centres and Programs**

There should be a coordinated continuum pre- and post natal services available throughout the life of the FAS/FAE victim. Women-only detox centres should be created with programs specifically geared to their special needs. These centres should:

- be family centred;
- have sufficient beds available;
- provide accommodation for children;
- have women staff, perhaps recovered alcoholics;
- favour a holistic approach.

Any program could be centred around existing centres available for women, and should include:

- an outreach component to reach women who did not complete the program;
- better follow up for the woman going back to the community to ensure that the problem does not begin again once she has returned to the environment,
- a protocol that gives priority to pregnant women. This could be based on existing U.S. protocols.

#### *Responsibility:*

Provincial Ministries of Health should develop policies to allow such centres to be established and funded. The federal government must develop the same program for Aboriginal peoples.

#### *Other services to be established*

- Mental Health Services;
- Grief counseling;
- Medical services hospital programs for multi-substance abuse or for multi-disease;
- Methadone Program;
- Attitude and value training for health and social service professionals;
- Outreach programs, including linkages between hospitals and communities;
- Treatment options that go beyond traditional medical models, including spiritual and holistic approaches;
- Support groups for recovery;
- Role models for people in recovery;
- Second stage housing for recovering mothers;
- Community and advocacy support: the goal should be to maintain the child with its birth family (should be 24 hour

service available). This would be a reversal of the current trend which is to apprehend the child; and

- Advocacy groups for children going into care, to make sure that they are appropriately placed so as not to have to move them frequently.

### **Priority #2**

#### **Respite with appropriately trained caregivers**

There should be a range of options made available for parents of FAS children. A program should be set up to use existing elite trained skilled care givers to train others in local communities. Candidates for this training should be screened. Local social services should be responsible for running these respites, with parent support groups. Social work and human services students should have practical placements in the respites.

### **Priority # 3**

#### **training for prospective foster and adoptive families.**

Various demonstration projects should be developed in each region as a model for the desired approach. These should be the responsibility of all relevant ministries of provincial governments. Health and Welfare Canada must develop concept of associate families for alcohol damaged children, adapting existing models, for example, those for the physically handicapped.

## **CONTENT AREA # 5: AT RISK GROUPS TARGETED APPROACHES**

### **ISSUE BRIEF**

In some communities, notably in remote, rural, and some Aboriginal communities, the incidence rates for FAS have been estimated as being several orders of magnitude higher than the rate for Canada as a whole. There is evidence that the rates are also higher in poor, inner-city communities. Another group of particular concern are women with alcohol and drug-abuse problems. Women in lower socioeconomic groups may also be at somewhat higher risk, as the health of their offspring may be further compromised by poor nutrition and living conditions.

This content area focuses on ways of reaching and influencing behaviour change among particular at-risk groups. This requires developing awareness, education and support programs that are

built on an understanding of the particular social, economic, health, geographic and other circumstances and needs of these groups, and utilizing the most effective and culturally appropriate communications channels and messages. Particular focus in this content session is on awareness-raising programs, community-based approaches, and support services.

## **DAY ONE DISCUSSION**

### **General**

- need to address underlying issues related to alcohol abuse;
- cuts across all groups but not clear who is high risk;
- more work needs to be done to identify high-risk groups and determine why they are high risk to enable appropriate intervention;
- target groups only if it will be beneficial to those groups; groups currently thought of as high risk or requiring special attention:
  - families with FAS/FAE
  - those with FAS/FAE
  - adolescents
  - Aboriginals
  - women in correctional system
  - business/professional women
  - women in armed forces
  - poor women
  - sexually/physically abused women
  - women with other substance abuse problems
  - any woman of child-bearing age

### **Community-based approach**

- programs sensitive to culture, language;
- outreach facilities (Health Action Centre);
- involvement of target groups in developing group-specific programs (empowerment);
- services:
  - counseling for families
  - support for those with FAS/FAE
  - services for women with alcohol problems (pregnancy outreach, daycare)
  - better assessment tools;

- need to evaluate existing programs for effectiveness;
- developing strategies to improve sense of self-worth of the individual

## DAY TWO DISCUSSION

### Priorities

At the close of discussion, the following were identified as priorities:

1. Address the underlying issues that cause alcohol abuse
  - pressure from peers, partner, family
  - isolation as a consequence of stopping drinking
  - sexual abuse/violence
  - alcohol abuse by women as a new phenomenon
  - lack of political and economic power for poor women
 Actions recommended to address this issue:
  - gender specific treatment programs
  - increase welfare payments
2. Development of a comprehensive national strategy for prevention, treatment and support with an underlying principle of respect for the spiritual and cultural diversity of individuals, family and community.

This strategy would involve creating a broad based national Action Committee which would:

- serve as a clearing house for resource information,
- evaluate existing programs,
- have commitment and authority (money), and
- be accountable to the Government and interested parties.

It was recommended that the Terms of Reference for this group be developed and presented within one year.

3. Development of generic "Community based" programs from which individual communities/groups could develop their programs. These programs would contain items such as communications material, action plans, basic factual information and contacts for the communities.

It was indicated that the items outlined in the last two points could either be addressed within the framework of the National Action Committee or could stand alone. And, although it was not mentioned in the final presentation, this group also supported the recommendations of the Aboriginal Committee as presented.

## **Major issues**

The rapporteur session on Thursday afternoon identified the following additional items as important to high risk groups:

- Recognizing that FAS cuts across all groups and acknowledging that it is not clear who is at high risk;
- Recognizing the fact that more work needs to be done to identify high-risk groups and determine why they are high risk to enable appropriate intervention; and
- Developing broad and targeted, community-based programs.

### ***High-risk group identification***

Discussion centred on the fact that if those groups currently widely accepted as high risk (Aboriginals, poor women) were the only ones placed in this category certain legitimate high risk groups would be missed. Groups currently thought of as high risk or requiring special attention were identified as:

- families with FAS/FAE;
- those with FAS/FAE;
- adolescents;
- Aboriginals;
- women in the correctional system;
- business/professional women;
- women in armed forces;
- poor women;
- sexually/physically abused women;
- women with other substance abuse problems;
- any woman of child bearing age.

### ***Identifying high-risk groups***

Discussion centred on the fact that there are many segments of society who are exposed to alcohol on a regular basis (business women) but do not fit the popular definition of high risk (Aboriginals, poor women). It was suggested that health care professionals who see middle class women may be reluctant to diagnose them.

It was agreed that until all groups are identified, effective prevention and treatment programs can not be developed; and that there was no need to publicly target groups unless it could be proved to be beneficial as targeting could focus the problem on the group being targeted.

A community based approach was seen as being especially important for the Aboriginal communities. These programs offered the following advantages:

- programs sensitive to culture, language;
- outreach facilities (Health Action Centre);
- involvement of target groups in developing group specific programs (empowerment).

### ***Accessible services***

More specific yet wide-reaching, community-based programs must be developed. These would include:

- counseling for families (this would include pre adoption/fostering training specific to drug and alcohol affected children, pre-marriage counseling, and pre-natal care);
- support for those with FAS/FAE;
- services for women with alcohol problems (such as pregnancy outreach, daycare, etc.);
- better assessment tools.

The group felt that there may be enough money already targeted to FAS/FAE but that programs should be evaluated to ensure that money was being directed to where it would have the greatest positive effect. The group concluded that until the self-esteem of women at risk was increased, prevention and treatment programs will not be successful.

### **Additional points**

Further points raised during the two sessions included:

- In addition to educational material for high risk groups being cultural and language sensitive, it was also recognized that different mediums of delivery would have to be used in view of the high percentage of functionally illiterate people in the current target groups;
- A holistic approach to the problem was essential;
- FAS/FAE is not a woman's issue but rather a societal issue; and
- As with drinking and driving, to drink while pregnant must be made socially unacceptable.

## **CONTENT AREA # 6: BUILDING MOMENTUM LEADERSHIP AND NETWORKING**

### **ISSUE BRIEF**

There is a need to ensure networking and coordination among the many individuals and organizations active in addressing the FAS/FAE issue, including improved provincial and national coordination of resources, programs and activities to deal with the many complex issue areas.

This content area concentrates on what needs to be done in order to work more effectively together and to ensure that momentum is maintained in the many "action fronts" associated with the FAS/FAE issue. What needs to happen to make sure coordination and networking occurs between the various sectors or systems, governments, other stakeholder groups and front-line community programs?

### **DAY ONE DISCUSSION**

#### **Success Is...**

- community-based and culturally attuned tentacles in federal and provincial;
- focused:
  - third party (non-government, non-profit); and
  - coordinate and synergize programs;
- continued awareness of problem:
  - regional mini-symposia of multiple stakeholders; and
  - alcohol awareness week and mothers' day,
- network:
  - data and information base sharing, and
- adequately and appropriate funding.
- finding ways to move and change barriers

#### **Overcome Restraining Elements by:**

- empowering at risk groups;
- stop passing the problem around between educators, social services, health, parents, etc. - work together;
- acknowledge and highlight - bring into public purview the extent of the problem;
- work on understanding and dealing with the roots of the problem
- fund the parent groups, support groups, etc., to manage and administer their own programs;
- fund the research;

- take the problem step by step within the whole picture;
- support, care for, include those affected - love is non judgmental and unlimited;
- work with rather than against industry (part of the solution), it wants a positive image;
- take women's drug/alcohol dependency issues seriously work on them.

### **Build On Driving Elements**

- the energy of the dedication of the families;
- the concern of high risk communities;
- the existing support groups;
- the willingness to act:
  - political
  - community
  - care-givers
- recognition of the social and economic costs;
- more women in positions of influence (e.g. Md.'s, politicians, etc.).

## **DAY TWO DISCUSSION**

### **Three Priority Actions:**

- Create, as soon as possible, a National Advisory Committee (call it what you will);
- Create a National Clearing House, which may be build from existing agencies such as CCSA, the B.C. group or others or a combination of these; and
- Establish the role of Provincial/Territorial (Regional) Coordinators

### **National Advisory Committee**

A National Advisory Committee must be created as soon as possible. This must include representation from multiple stakeholders, including:

- Aboriginal Peoples
- Families
- People with FAS/FAE



- Researchers (Behavioural and Health and ?)
- Provincial (Regional) Concerns
- Federal Strategists
- Beverage Alcohol Industry
- Judicial System
- Educators
- Social Service Workers

The National Advisory Committee mandate must include a time dimension, for example, first year, second year, report and decide on continuity. The committee must focus on the complexity of the issue, it must initiate additional symposia, both regionally and on various topics, and it must include advocacy for people with FAS/FAE, for families, and for others.

The National Advisory Committee must engage the media on this issue, it must clear jurisdictional hurdles (federal, provincial and local), and it must focus spending the new money that may be needed.

### **National Clearing House**

A National Clearing House may be built from existing agencies such as CCSA, the B.C. group or others, or any combination of these. Its mandate should include:

- share information
- publish a newsletter
- engage the media
- interlink with other related issue groups
- be a think tank
- identify expertise (and introduce experts personally to each other)
- co-ordinate, present symposia

Funding for this facility should come from the federal government and from the beverage alcohol industry, and others. It should report to the National Advisory Committee (or whatever it is called), and also use the Children's Bureau and the National Drug Strategy and Children's Initiative Agencies.

### **Provincial/Territorial (Regional) Co-ordinators**

The role of Provincial/Territorial (Regional) Co-ordinators must be established (this may need an additional clarification of the role of Aboriginal Governments). Their mandate should be to focus efforts locally, and assure that whatever is done complements and builds on grass root initiatives, the local situation, and is culturally

attuned. The primary role of the regional coordinators would be service co-ordination on a day-to-day basis. Such a person might initially be already working in the field, e.g. a director of public health nursing, or a superintendent of education, or a director of social services. But likely, this would become a full time job.

## **CONCLUDING REMARKS**

Chairperson Dr. Heather Clarke addressed the symposium briefly, observing the energy exhibited during the two days and noting the increased knowledge, awareness, and sensitization that had taken place.

Participants received an invitation from Lethbridge, Alberta delegates to attend the FAS conference there in May, 1993. (See Appendix VI for details.)

Marilyn Van Bibber read a statement on behalf of the Aboriginal participants at the symposium. (See Appendix IV for details.)

On behalf of Minister Bouchard, Dr. Stan Wilbee concluded the symposium by accepting the information gathered at the symposium and thanking participants for their efforts in taking one step further, the process he started as Chair responsible for the Standing Committee Report.



# APPENDIX I

## AGENDA

### SYMPOSIUM ON FAS/FAE

Sheraton Landmark Hotel  
Vancouver, British Columbia  
September 30 to October 2, 1992

#### Wednesday, September 30th

6:30 Pre-Symposium Evening Reception

#### Thursday, October 1st

8:00 Registration and Continental Breakfast  
9:00 Opening Session  
Introduction of Benoit Bouchard, Minister of National  
Health and Welfare  
Minister Bouchard's Remarks  
Introduction to the Symposium  
Chairperson: Dr. Heather Clarke  
9:45 Thematic Address  
Dr. Geoffrey Robinson  
Dr. Christine Loock  
10:45 "Canadian Perspectives on FAS/FAE"  
Moderator: Dr. Stan Wilbee  
(Plenary Panel Discussion)  
11:45 Overview of Standing Committee Report  
Dr. Stan Wilbee  
(Plenary Presentation)  
1:30 Defining the Issues  
(Concurrent Multi-Stakeholder Workshops)  
4:30 Rapporteur Working Sessions  
7:00 Networking Evening

#### Friday, October 2nd

8:45 "Approaches That Are Working"  
Moderator: Dr. Kwadwo Asante  
(Plenary Panel Discussion)  
10:00 Reports from Yesterday's Workshops  
(Plenary Session)  
11:00 Priorities for Action  
(Concurrent Topic Workshops)  
1:00 Reports from Workshops  
(Plenary Session)  
2:30 Closing Session  
Dr. Heather Clarke  
Dr. Stan Wilbee, M.P.

## APPENDIX II

### DAY ONE PLENARY CANADIAN PERSPECTIVES ON FAS/FAE

#### PANEL DISCUSSION

*Dr. Stan Wilbee, moderator*

*Jackie Herbert*

*Françoise Parent*

*Joyce Paul*

*Dr. Julie Conry*

*Dr. Jo Nanson*

*Serge Perreault*

#### JACKIE HERBERT

*Jackie Herbert is a nurse from Brandon, Manitoba, and is a mother of two adopted FAE and possibly FAS girls.*

Thank you, Mr. Moderator, for that introduction and as you said I am a nurse by training and a mother by profession, myself and my husband are the parents of three daughters - one biological, and two adopted daughters with FAE and probably FAS. I will try to share with you the 10 years of torment in the life of our 16-year old daughter, but I can only highlight some of the factors which have shaped our understanding of her problems, and the many deficiencies in our educational and remedial facilities for our child, who for want of a better term has been described as learning disabled, hyperactive, a street kid, a "drop out", a "shopping mall rat," and in the terminology of social workers, the ultimate fantasy parent-child conflict.

It is impossible in so short a time to describe the full impact our daughters' behaviour has had on our family, so I will quote from some of the reports and statements made by various authorities with whom we have been in contact while searching for some help for our daughter.

*"You cannot put any brains where there are none - but we will try and get her a teachers' aide for a while to see if that will help with her learning."*

— Director of Special Education

*"Academically this girl has progressed at a pace that would be expected from her language skills, but socially and emotionally her behavioural irregularities which arise are probably related to frustration, caused by sensing at an emotional level that something is wrong and being unable to transfer those thoughts or feelings into words."*

— School Psychologist

*"She is a 12-year-old girl of average height with long dirty straight hair, dressed in the style of a street wise adolescent, possibly with some mild brain dysfunction for whom I would recommend foster home placement. It is not unlikely that once placed there she will never return home, but it will be important for her to maintain some consistent contact with her parents no matter where she ends up."*

— Consultant Psychologist

*"I am the expert here. There is nothing wrong with your daughter this is simply a parent-child conflict. I will hand her over to CFS because you cannot care for her properly."*

— Psychiatrist

*"I do not know what to tell you, if you still insist that she needs therapy, I would suggest you move to Ontario."*

— Second Psychiatrist

*"You are bad parents, you cannot raise you daughter properly because you are both shift workers."*

— Social Worker

Those are just a few of the statements that were made about our daughter, and as you can see from the above quotes, she has travelled a long hard road already and she is only 16. When we adopted her she was two months old and we thought the world was our oyster. She was a beautiful, happy bright-eyed child who was a delight to have around. She was full of laughter, loving, and she was very active (at the time, I rejected the term "hyperactive", but in retrospect, she was hyperactive, and I had to supervise her constantly). She was always on the move, and even as a toddler she would run away because she did not have the fear that she might get lost or get injured while on the move. She wanted to see what was up the road, or to go visit a friend any time — night or day. She loved running and climbing and fell often — she even suffered a few broken bones. She was people-oriented and talked a lot. Her behaviour was the same for all the activities she attended — whether it was ballet lessons, music lessons, art classes, Sunday school, swimming, gym or nursery school.

Kindergarten was not fun because she was disruptive in class, and refused to participate in the Christmas concert. In grade two her

teacher told me she was writing backwards. She was then diagnosed as dyslexic, with other learning disabilities. This, of course, was the beginning of her problems and from the earlier quotes you can understand what has happened to her since then.

As I watched the movie *The Broken Chord* I was amazed — it was like watching my own life in slow motion. I then realized that my daughter was not to blame for her behaviour, because she could not help it, and neither were we, her parents, to blame. As I read the literature which I received after the movie, and the book by Michael Dorris, I wondered how many other children and parents have suffered in ignorance, because they had no idea what was wrong with their children. I decided to do something about this and that is how FAST started in my hometown — Brandon, Manitoba. We are a small group at the moment, but according to the response we have received so far, there is need for support group in Brandon, and I am sure that need exists in many other places in Canada. Thank you.

## **FRANÇOISE PARENT**

*Françoise Parent is Director of Communications and Public Relations for the Association of Canadian Distillers. She spoke on behalf of the Beverage Alcohol Industry.*

Thank you, Dr. Wilbee, ladies and gentlemen. It is a pleasure to be here today to share with you the beverage alcohol industry's perspectives on fetal alcohol syndrome. It is unusual for one person to be speaking on behalf of the brewers, the distillers and the vintners given the competitive nature of our business. But despite our commercial differences, the three industry groups share common expectations from this conference:

We want to learn what others have to say, we want to contribute to what we have learned, we want dialogue. All of this with the objective of finding effective ways of reducing the incidence of fetal alcohol syndrome.

It is this common objective that allows us to accommodate the request of the symposium organizers - that only one industry representative speak during this plenary panel discussion. My colleagues from the brewers and vintners are here and will be participating in the workshops and other symposium events.

I hope that by the time the symposium ends tomorrow afternoon that this gathering will have reached some consensus on how best

to proceed in tackling this problem which has captured public attention in the last few years.

We have read and studied the report of the House of Commons Subcommittee on Health Issues. The industry's separate views were shared with the Sub-Committee. On the whole the beverage alcohol industry is supportive of an integrated approach to dealing with FAS.

Our disappointment with the Committee's report is that it failed to indicate the industry's willingness to be part of the solution, part of the effort to change attitudes and behaviour with respect to the consumption of alcohol during pregnancy.

It is important that everyone here knows that the industry shares your concerns over FAS. It is equally important that you accept the sincerity of this statement especially as we prepare to sit down in smaller groups to address this issue and share views.

The one disagreement we have with the committee's report centres on the undue priority and attention given to health warning labels and the curtailment of freedom of commercial speech as an effective means of dealing with FAS.

The subject of health warning labels will be discussed at this symposium. The beverage alcohol industry's concern over labels on bottles and warnings in advertising is that the introduction of such warnings may well shut the door to other more effective measures. We hope that we will concentrate over the next two days, on flushing out more comprehensive and potentially more effective approaches.

We will not voluntarily put warning labels on any alcohol produced in Canada for consumption in Canada because such a measure, although easy enough to implement, is not effective and, therefore, does not satisfy our sense of responsibility. We would rather be a partner in providing sound alcohol education to those who need it. Education is the action required.

Proponents of warning labels advance that they are effective at raising awareness. There is evidence to demonstrate that there is already a high awareness of the risks associated with drinking during pregnancy. We do not need more efforts directed, at raising awareness. We need more efforts directed at changing behaviour.

We have faced the challenge before with drinking and driving. The concerted efforts of government, law enforcement, interest groups and the beverage alcohol industry have made drinking and driving socially unacceptable. That behaviour is not tolerated.



And as a result, the incidence of impaired driving charges has dropped by more than one-third over the past decade.

The problem is not gone nor is the concerted effort aimed at discouraging people from drinking and driving.

The beverage alcohol industry was a key player, right from the onset in the battle against drinking and driving. For instance, Hiram Walker Brands adapted a concept originating in Sweden and introduced it as Canadian Club Designated Driver Program. This program encouraged participation by licensed drinking establishments and by individual responsible hosts. The designated driver program received widespread public support and in fact has become part of our everyday vocabulary.

Campaigns against drinking and driving have been endorsed by such groups as the Canadian Association of Chiefs of Police, Mothers Against Drunk Drivers and People to Reduce Impaired Driving Everywhere. Initiatives were expanded to include point of sale programs, such as the electronic advertising for the CounterAttack Programs in B.C.

Before long, drinking and driving campaigns were everywhere. The challenge to reduce impaired driving has been taken up by all levels of government, special interest groups, law enforcement and the industry.

The Brewers of Canada sponsor a variety of programs jointly through their Association and as individual companies, such as Molson's "Take Care" and Labatt's "Know When to Draw the Line". The programs all encourage the responsible and appropriate consumption of alcoholic beverages. The industry's commitment to participate against the misuse of our products is not limited to drinking and driving. The industry is involved in a range of other programs dealing with the responsible consumption of alcoholic beverages, including drinking and the family, drinking and education, drinking and the workplace.

Messages have been developed in cooperation with the medical community. For example, an FAS awareness campaign by the Brewers is endorsed by the College of Family Physicians of Canada, whose members participate through the display of information materials in their offices.

The distillers and the Canadian Wine Institute are the key supporters of the Information Council on Beverage Alcohol. The Council was created to fund community groups, to help them promote the responsible consumption of beer, wine and spirits

through educational programs. The goal of the Council is to promote positive community initiatives that can bring about effective results.

So when we say that we want to devote ourselves to finding and participating in effective ways of fighting against the misuse of alcohol during pregnancy - we mean it.

And the last thought that we would like to leave with you is that there is actually a lot of consensus on which priorities will lead to effective approaches and solutions.

Here's where we agree and where consensus can be built:

- No one person or group alone can solve this problem;
- FAS is not just a woman's issue,
- More research is required to determine the levels of incidence of FAS, to develop effective methods of diagnosis, assessment and treatment;
- Natural and adoptive parents of FAS children need support; Accurate and effective medical advice and guidance to all women is a must;
- Fetal Alcohol Syndrome is a problem which merits a high profile and the coordinated focus of diverse activities and energies.

The alcoholic beverage industry is committed to working to reduce the incidence of FAS and FAE. We are willing to work with a coalition of groups on the development of effective and focused preventive programs to reach those who are at risk. This symposium and the discussions that will flow from the workshops are an excellent first step in the right direction

## **JOYCE PAUL**

*Joyce Paul is a native Indian and Director of the Rising Sun Rehabilitation Centre in Newcastle, New Brunswick. She also works with the N.B. Native Women Association.*

My name is Joyce, and I'm an alcoholic. I have to acknowledge where I'm coming from for you to understand where I am today. Some people have a hard time with this — but I'm not saying it to shock you. This the way I have chosen to address myself.

I'm a mother of six children who are now all adults; fortunately for them I wasn't drinking during my pregnancies or during the first couple of years of their lives.

My experience as a front-line social worker started eight years ago when my community initiated the first steps towards self-government. It is important for me to address myself in a very respectful manner since I am not here to speak for all my people but to speak of my experience and the experience of my neighbours and my friends. One thing which sets me apart from many social workers is that where I work I'm dealing with my own people, not strangers. After listening to the comments regarding Natives this morning I can say that things are different where I come from. Someone here told me it was okay to be angry at some of the things that were said but I've decided to respect your opinion — I have to accept what I can't change.

Alcohol is relatively new to our culture, but being told how to run our lives in a disrespectful manner isn't so new. Educating our people and trying to accept others in our Medicine Wheel fashion helps us heal ourselves. That's the avenue that I take today providing the new born with the potential to be anything he or she wants to be in a healthy way. I could really identify with the pain of a parent who spoke earlier. I can see that the pain won't go away until we address the guilt, the helplessness and hopelessness that some of the parents with FAS/FAE children go through.

In my job I often deal with non-Native parents who have adopted Native children. The frustration these parents have to go through when the children started going to school is awful. The adopted child is usually passed around like a buck (not only the dollar but the two-legged version!). If the parents lived on a reserve they would automatically qualify for financial assistance — this is very frustrating. Because of this, adoptive parents are worried of what will happen to their children when there is no one left to care for them — when the parents pass on. What are the long-term educational and living issues?

I try to help these people — I explain to them it would be different if they lived on the reserve but yet I also get frustrated and I'm living on the reserve, working with my own people.

I've seen many alcohol abuse cases as a social worker and it seems to me that there are many similar events that happen in cycles. These cycles need to be broken, they need to be stopped. One of the most common outcomes is that as FAS/FAE children mature they seem to get into trouble with the law, some of them become followers and the teachings they are getting from the leaders are not very good and healthy. And outside help isn't always the answer.

When that 12- or 13-year-old kid gets into trouble, he or she does not need incarceration, a child needs treatment. The family needs treatment. But in my experience, when you try to get money for this treatment, we are told "you have to do it this way, you have to do it that way." Another problem is that we have limited facilities compared to what's available in the East. Often, a person who tries to be a solution becomes a problem because the community looks at you and asks "what are you going to do?"

It's a vicious circle, and parents get so frustrated that they end up putting the children into foster care and there is no specialized foster home to deal with these teenagers. No one wants to deal with them. So the children who are really affected are the ones to suffer and pay the price.

My dream as a child-protection worker has always been starting intervention right at conception. FAS and FAE affects all of us, we all suffer, one way or another. I could say a lot more about my feelings regarding this issue but one thing is certain — I am very encouraged.

## **DR. JULIE CONRY**

*Dr. Conry is a psychologist with the Faculty of Education, University of British Columbia, in Vancouver.*

### **CANADIAN PERSPECTIVES ON FAS/FAE: CHALLENGES WITHIN THE EDUCATION SYSTEM**

The stated goals of the Ministry of Education in British Columbia, for its intermediate students, reflect responsibility (or shared responsibility) for the development of social-emotional maturity, social responsibility, physical skills, intellectual skills and creative/artistic talent of its students. At the secondary level, these are elaborated and extended to include preparation of the students to become productive members of society.

These goals pose extraordinary challenges for children with FAS/FAE, requiring the cooperative and supportive efforts of teachers, families, and interdisciplinary teams of professionals within the school and community. The school becomes the focal point for 13 years of the child's life; the groundwork that is laid during these years has the potential to affect, for better or worse, what some of the outcomes may be.

Key issues are:

1. Early diagnosis/assessment of FAS/FAE leads to early intervention, and a better outcome.
  - a. Children who show early developmental delay become eligible for services such as speech/language therapy and occupational therapy, special needs preschools, and early learning assistance.

Example: a child who had a positive school experience, and coped reasonably well during adolescence ("a success story") was a child who was first seen for serious medical problems and by happenstance, fell into speech and occupational therapy services. On an anecdotal basis, it seems that students in urban centers who have had access to resources may be functioning approximately two grade levels ahead of students living in more isolated areas which lack these resources.

- b. Diagnosis cannot always be made definitively at a young age. Children, who at a young age are not obviously FAS can be identified as being "at-risk", (due to known prenatal alcohol exposure, affected siblings, etc.). Although they may not demonstrate serious developmental problems they should also receive special services on a preventative basis. We know what the potential problems are likely to be. We know that the child will not simply "outgrow it."

Example: one young student was referred as preschooler, but did not receive speech/language intervention because it was thought that "modeling" and home stimulation would be sufficient. Then, in K and grade 1, it was clear that speech/therapy was necessary; was valuable time lost?

- c. Some professionals question the usefulness of the diagnosis and disapprove of "labeling" children. If an FAS child is not labeled as such, he will surely receive another label: such as "lazy" "stubborn" "conduct disordered" "schizophrenic". The diagnosis of a neurologically-based learning disability, is in my opinion, constructive. We see FAS not so much as a label but as a blueprint for planning.

2. With "remedial" and "preventative" interventions in place, the student's progress needs to be closely monitored. As with most neurologically-based learning disabilities, a short-term intensive learning and behavior intervention may appear successful, but once the extra support is removed, the student does not continue to develop at the same rate as his peers and again slips behind. The learning disability is life-long and there needs to be continuity of support.

3. Assessments and re-assessments should be done at key transition points in the student's educational career. Within the continuum of effects for FAS/FAE, problems may arise at any of the major transition times:
  - a) school entry
  - b) intermediate grades
  - c) junior/senior secondary school.
4. Psychologists and counselors need to be informed regarding the patterns of behaviour and learning that are commonly observed among FAS/FAE students. Assessments need to include evaluation of the abilities, achievement, and adaptive behaviour. As the student grows older, adaptive behaviour may be a more important dimension to assess than academic skills: can he count money? would he trade his mountain bike for a pack of cigarettes? would he be approachable by a stranger on the bus? Systematic social skills interventions are of critical importance.
5. Teachers in-training, and through in-service, need to be informed about the educational needs and appropriate expectations for children with FAS/FAE.

Example: Many of our traditional ideas about how children learn do not hold with FAS/FAE children. A classroom environment that is stimulating to a normally achieving student can be disastrous to the learning of an FAS child. Teachers need support and consultative services.

6. Specialized educational placements and services need to be more readily available to these children. Mainstreaming may not be a good plan for some of these children who have poor adaptive skills; smaller classrooms, 1 - 1 teaching and other adaptations are needed. Some special classes (e.g., for children with behavioral disorders) are not appropriate because the FAS/FAE children are like behavioral chameleons; they seem to learn by modeling inappropriate behaviour more easily than appropriate behaviour.

Teachers need to be identified who enjoy the challenge the FAS/FAE children present. In my experience, many parents mention a teacher their child has had who was particularly effective — and that made for a "good year." (We need more of those.)

7. The greatest need is at the junior/senior secondary level. Perhaps as early as grade 8, a placement in a pre-employment and life-skills program is appropriate. Programs in place for

mentally handicapped students are not appropriate for the majority of FAS/FAE students, who are not mentally handicapped. (although they are functionally handicapped).

8. FAS/FAE is a life-long disability. As we focus on the older adolescent or young adult with FAS/FAE, we see the families reaching a crisis point. They have struggled and coped with their children for 20 years, they now come to the realization that their son or daughter will not be able to live independently. As parents, they may be simply unable, financially or emotionally, to assist them indefinitely. Planning for adulthood for FAS/FAE is our greatest need. The young people may not easily fit the disabled classifications that now exist which would allow them to access resources. Extended education, supervised work experiences and assisted living arrangements are a top priority, and we need to be planning for this throughout the child's school career.
9. Challenges within the education system, also include education of our young people about FAS/FAE — I'll leave that for the specialists in "prevention."
10. Lastly, I have the multiple perspectives of psychologist, educator and researcher. I took as a compliment, a comment from a parent attending one of my workshops when she said "the way you speak, you must have an FAS child." I don't. I would like to acknowledge that most of what I know about FAS, I have learned from the families. I want to thank them for that, because it has helped me to help others. Through a cooperative effort of families, teachers, other professionals, and agencies, we will come to a greater understanding of how to effectively help these children enjoy satisfying and productive lives.

## **DR. JO NANSON**

*Dr. Jo Nanson is a psychologist at the Kinsmen Children's Centre of the Department of Pediatrics, Royal University Hospital, Saskatoon.*

As researchers, there are five areas of secure knowledge and four areas for research development. First, FAS/FAE is a preventable tragedy. Second, we know that alcohol is a major cause of disability and that it is also a significant contributor to fetal and infant mortality. Third, FAS/FAE is costly. Fourth, it affects different social groups disproportionately (the poor, native bands, etc.). Fifth, alcohol is the only teratogen that is widely available without a prescription, and is socially acceptable.

What don't we know? We don't know the teratogenic mechanisms that operate with FAS/FAE. It is very complex and we are pessimistic about medical intervention to prevent effects. Second, we have very little information about prevalence of FAS/FAE in Canada outside of B.C. and the Yukon/NWT. We are grateful about funding from the Saskatchewan government for research into this. Third, we know very little about teenagers and older children; we know a lot about young children. Our clinic in Saskatoon is being flooded with teenagers who are now suspected of suffering from FAS/FAE.

Fourth, we fail to understand why knowledge about alcohol fails to translate into behavioural change. Very few biological parents are not aware of the syndrome affecting their children. We lack alcohol treatments that are family-oriented. Women often have to choose between alcoholism treatment and caring for their children.

Finally, I think there should be more money from HWC and recognition of the need for research into FAS/FAE - there are many people willing and able to answer these question by research.

## **SERGE PERREAULT**

*Serge Perreault is a substance abuse coordinator in Cornwall, Ontario.*

What do service providers do? They have to act as a network between the different support services, cases have to be coordinated. Case workers need to be trained and educated about the physical, behavioural, social and cognitive manifestations of FAS/FAE; identification of needs and how to meet those specific needs with appropriate intervention and treatment.

Awareness is the big word. The needs of FAS/FAE children evolve from childhood to adulthood, and we need therapeutic modules that will provide a continuum of services that respond to those changing needs.

Diagnosis and early identification are very important for efficient intervention for symptoms relating to health and motor, language, and behavioural skills. Education programs must be devised for:

1. Doctors, teachers, child care workers, social workers, health care workers, probation officers and at risk-parents;
2. Parents — parenting skills and strategies, information about physical and psycho social needs of infant or child with FAS/FAE;



3. FAS/FAE children and adults — special education programs to teach independent living skills, exploring one's strength, and if required, vocational training.

There also is a need for support for FAS/FAE families in terms of counseling, respite, finances, therapeutic foster homes, training for foster parents, parent relief program and residential care (group homes).

Networking is very important between agencies and treatment for alcoholic mothers needs to be improved. Hopefully, we will be able to answer some of these questions through this symposium.

## APPENDIX III

### DAY TWO PLENARY APPROACHES THAT ARE WORKING

#### PANEL DISCUSSION

*Dr. Kwadwo O. Asante, moderator*  
*Martha Bradford*  
*Betty MacPhee*  
*Dr. Oscar Casiro*

#### MARTHA BRADFORD

*Martha Bradford is an adoptive mother of a diagnosed FAS child, who lives in Stoney Creek, Ontario. Martha Bradford helped to establish the Fetal Alcohol Support Network.*

In February of this year, a TV critic from Hamilton, Ontario featured an article on The Broken Chord movie debut. The Broken Chord, by Michael Dorris, presented a family's ongoing struggle with a virtually unknown condition — Fetal Alcohol Syndrome. Since the publication of this book in 1989 and a subsequent 20/20 segment on FAS, caregivers have started to put the clues together of this great mystery — what is wrong with my child? The stark reality is alcohol can cause organic brain damage in the developing fetus resulting in emotional and behavioural problems.

As an adoptive mother of a diagnosed FAS child, I had desperately sought for information and for another parent or caregiver to share my struggles with. I welcomed the TV critic's article as a springboard to find other parents. The Hamilton Spectator did a wonderful job — full page, full color article on my son and my quest to find a support group — on the front page of Friday's Entertainment Section.

The initial response to the article was overwhelming. We received many calls and letters from as far away as the Yukon. One month later, our phone number was telecast nation-wide on CTV's *Shirley Show*, dealing with the issue "Should Women Drink During Pregnancy?" The people that manned the phones that day were thankful for previous distress line training.

That same month the *Ottawa Citizen* did a full page article regarding FAS, and the subcommittee hearings and mentioned

our support network. When the *Toronto Star* presented an article on an adolescent FAS child in our area who could not access services because he was too old or too young, too retarded or too high functioning, in the wrong catchment area, too violent, too medicated and had not participated in any criminal behaviour, our group announced an information meeting for the Toronto area, attended by 35 people.

In those first three months we were contacted by over 66 caregivers mainly from Ontario. The statistical breakdown from that time frame is as follows:

- 57 per cent of the victims were diagnosed mainly by out-of- province doctors, 43 per cent were undiagnosed,
- 18.5 per cent were identified as Native people (92 per cent of these Native people were diagnosed);
- 14 per cent\* of the diagnosed victims were living with their biological mothers; this group had the hardest time obtaining a diagnosis;
- 6 per cent\* of diagnosed victims lived with their biological fathers, alcohol being a major contributor to the marriage breakdown,

(\*Note: 20 per cent of the victims were living in foster care and 60 per cent were living with adoptive parents.)

- the age variance in our contacts was between 1 and 40 years old with an average age of 12.

From this evidence the greatest needs that we encountered were for:

- general information on FAS by caregivers, educators, public health workers, social workers;
- a diagnosis especially for adolescents and adults;
- specialized residential and educational facilities for adolescents with FAS;
- qualified and available respite care; and
- on-going emotional support for caregivers.

At our first meeting in Hamilton we carefully chose three basic information articles on FAS and showed the video, What is FAS? We had hoped to empower parents to keep on struggling with the overwhelming burdens of everyday living, that together we could survive. However, we were naive. Parents went home and promptly went into grief; there is a great need for grief therapy for

the caregivers, the siblings and the affected child. Many parents did not want their child diagnosed, but they wanted help. They did not want to be televised, or for their children to know their suspicions. Several parents who were the most adamant on these issues have since been informed that their adopted children were identified early and the material had been stamped "do not show to parents," or the medical information had purposely been withheld.

As a group we have the following goals:

- providing emotional support and encouragement for caregivers;
- providing access to research and programs in this field;
- providing a register of professionals specializing in the field of FAS and FAE — currently we have a list of who not to go to;
- providing a public awareness campaign as to the effects of alcohol on the unborn child with emphasis on prevention;
- our dream, creating programs and facilities for the FAS/FAE adolescents and adults.

An example of what our network is about happened last week when an adoptive family in Alberta who is being transferred to Halifax called wanting to know the name of a doctor and groups or someone else they could talk to. During that phone conversation we told her about the upcoming conference in Lethbridge, in their area. They were very excited to know what was happening in their own province and then to find out what else was happening in Canada.

Perhaps the greatest public awareness campaign happens when the caregiver tells his/her story and shares information or research with teachers, special ed. consultants, the school psychologist, the social workers, the probation officers, the lawyers, the family physician, the eye doctor, the orthodontist, the sexual abuse counselors and the family or marriage therapist that we all get sent to by other agencies.

As caregivers our story can be powerful as we have the passion and the channeled energy to want to see that there are no more victims of FAS. We live with it, it shouldn't have to happen. We do not lack for opportunities to tell our story of alcohol-related birth defects — once we recognize that our living experience is common from coast-to-coast, that the issues remain unchanged nation-wide. Together we can be empowered to face the challenges of the systems — be it in government, other organizations, or the alcohol industry — that are put in our way. As each community meets, it has unique opportunities and goals to work on. The isolated family will be able to tap into the same network of

support via phone calls, newsletters, electronic mail and mini-conferences sponsored in different regions.

Our purposes include co-operating with other similar interest groups. But we stand firm — taking a proactive role in establishing the recognition of FAS/FAE as a major medical and societal concern.

The Fetal Alcohol Support Network is becoming a truly Canadian organization not because of our imagination or design — but because of the vacuum that exists. Caregivers themselves are the front-line workers and they need immense support. Together with our strengths and our weaknesses we can support each other and we can give caregivers hope that the FAS victim whom we love and advocate for will have a meaningful existence and that their life will not be in vain. As a parent coming here, I have a feeling that we are all working together on this, lay people and professionals. We all know why this must be prevented.

## **BETTY MACPHEE**

*Betty MacPhee is a registered social worker and manager of Vancouver YWCA Crabtree Corner, situated in the Downtown Eastside of the city.*

I would like to talk about YWCA Crabtree Comer, the community and the children and women that we serve including the barriers these women face, and our FAS/NAS Prevention Project.

Vancouver YWCA began in 1897. In 1985 the Downtown Eastside community (Vancouver's inner city) identified the need for emergency daycare. The community approached the City of Vancouver, and the Ministry of Social Services for funding, and the YWCA to sponsor the project. Our doors opened in 1985. In 1991, we had 456 individual children, ages 6 weeks to 6 years attend our centre, with an additional 248 children using our family drop-in and over 2000 women accessing our services.

Our emergency daycare is the only licensed daycare of its kind in Vancouver and I believe in B.C. We have 20 spaces a day. Our staff are multi-cultural reflecting the ethnic diversity of the community. Some of our staff live in the Downtown Eastside. I think these things contribute to the effectiveness of the program. Because we are an integrated service we provide many services for both women and children — which I won't go into now because I have only 10 minutes!

Through the support of the Vancouver North Health Unit, we also have half day weekly pediatric time provided by Dr. Loock. She has identified 25 per cent of Crabtree's children as "special needs" with developmental delays and of that group 25 per cent demonstrate the effects of maternal use of alcohol and drugs.

Now I'd like to talk to you about the women and children who attend Crabtree and about the barriers these women face because too often we don't hear about this.

The families who attend Crabtree are among the poorest in Canada. Stats Canada in 1991 identified postal code V6A, the Downtown Eastside of Vancouver, as the lowest per capita income in Canada. The majority of Crabtree's Downtown Eastside women are frequently shelterless, severely economically and socially disadvantaged and they may be handicapped physically, mentally and educationally. Many of the women appear to be suffering from FAE themselves and increasingly more often win discuss this with us. Psychologically they suffer the effects of multiple traumas including multiple family deaths, physical, sexual and emotional abuse, as well as blatant racism and sexism. Their health is also impacted by lifestyle factors including multiple partners, injectable drug use, and alcohol abuse which puts these women at a high risk for HIV infection, Hepatitis, STD's, TB, and a variety of other health problems.

Many of Crabtree's clients are single mothers. They and their children live in hotel rooms, rooming houses or they share space with several families in one- and two-bedroom suites — all substandard housing where violence is very common. High rent means less money for food. A lack of money, cooking and refrigeration facilities all mean poor nutrition. During the third week of each welfare cheque month, Crabtree has a long waiting list as mothers try to get their children into daycare so the children will be fed and clothed.

Child poverty in the Downtown Eastside is the norm. Poor children have poor health and they are susceptible to infection and disease. Hungry children do not learn well. Many of these children are born with low birth weight. High risk families do not use existing health care services for a variety of reasons including mistrust and/or lack of education and understanding of medical services. Women in the Downtown Eastside receive very little prenatal care accessing the medical system usually twice — once for the confirmation of their pregnancy and then at the time of delivery.

Many pregnant women who are using alcohol and drugs will not seek medical attention during their pregnancy because they fear a possible "apprehension" of their newborn baby if they are identified as an alcohol and drug user. There is therefore little medical monitoring or intervention during the pregnancy.

The reality is these women probably will have their babies apprehended. There appears, according to these women and it's been my experience, to be little or no grief counseling after the apprehension. A high percentage will be pregnant within the year to replace their "lost child." Only this time their alcohol and drug use will have accelerated to numb the pain of their loss. Each subsequent baby will be born more and more damaged. Without intervention this pattern will be repeated.

Now I'd like to talk a little bit about our Prevention Project.

First of all we have only one paid worker, and I think that's really important to mention. Her name is Mary Ellen Johnston. Mary Ellen and I worked together on this project.

The first step in our project was to identify the barriers for high-risk women seeking treatment. This is our list of these barriers (a short version of it):

- no protocols or prioritizing of services for pregnant women in detoxes or treatment centres (pregnant women only have nine months, they can't wait);
- no FAS/FAE information available;
- no women-only detox beds (many of these women have been sexually abused and they do not want to use services that include men);
- no area alcohol and drug services;
- no pre- and post-natal programs;
- no safe, affordable housing for pregnant women with alcohol and drug problems;
- no community-based services for pregnant women to provide coordinated and comprehensive care;
- no support for birth parents of children with FAS/FAE;
- and finally, there seemed to be a lack of sensitivity to the cultural and literacy needs of these women.

Our FAS/FAE Prevention Project, funded in 1990 by Health and Welfare Canada for three years, had a total budget of \$141,000. That breaks down to \$47,000. a year, which included Mary Ellen's salary, her benefits, office equipment, program expenses — as you can see, there wasn't very much money.

Our five goals for the Project were:

- facilitate community educational programs;
- spearhead a community FAS/FAE committee,
- develop a video and print resource library readily available to the community;
- provide client resources and referral information and;
- produce an FAS/FAE prevention manual.

So let's talk a little bit about what your tax dollars did...

When our Prevention Project began we contacted detox and treatment centres to determine their protocols for pregnant women. There were none. We also surveyed hospitals and alcohol and drug programs to establish what FAS brochures and information they had available to the public. Again, the information was almost non-existent. I believe that our questions have produced some changes.

A search in the U.S. and Canada for FAS/FAE materials produced very little so we decided to produce our own FAS/FAE prevention brochure and poster which Dr. Look showed earlier. The brochure and poster design was a Crabtree community effort involving the women who use Crabtree Corner.. the volunteers, students and staff. It has proven to be an excellent means to begin discussing this important issue.

A media news release was also developed. This fact sheet on FAS was distributed to a wide variety of media with excellent response and interest. They contacted us and we gave them information; (often we would refer them to the B.C. FAS Resource Group) and it was a way of getting the issue into the newspapers.

A 50-member FAS Prevention Advisory Committee was formed with representatives from a wide variety of groups. We decided to choose a wide variety — we knew that a lot of the people were not particularly interested but we also thought that if they got the information, somebody would read it and we hoped it would educate people.

Sharing of resources, information and education has occurred. The group developed a multi-cultural warning sign for pubs, bars and restaurants which has been widely distributed. And I might also add that when we walk in we're not always welcome, but none the less, we continue to walk in and put up our little signs and hope that they will be well-received.

The Advisory Committee is also working on a treatment model. Another offshoot of the Advisory Committee is the FAS/FAE



Community Conference to be held next Thursday, October 8, at Ray Cam Centre. This one-day conference is for the area's community residents, parents, caregivers, and front-line workers. It is \$10 for professionals and free for everyone else. To date I think we have close to 175 registered. I think this is one of the first community-based conferences and I'm very excited about that. Partial funding for the conference comes from the B.C. Ministry of Health, Alcohol and Drugs.

Our Project Coordinator, Mary Ellen, has provided referrals, resource information and support to 192 women. She has also presented 35 sessions to more than 600. These sessions provide an opportunity for community health nurses, community workers, teens, students, teen moms, single mothers, and provincial pregnancy outreach coordinators to become familiar with the FAS/FAE symptoms, the barriers for the women, resources and prevention strategies. Dr. Loock has provided valuable medical resource information for us to share with community groups and has attended some of our sessions which has been very helpful.

Our FAS/FAE video and print library has very up-to-date information and it is frequently used by students, public health nurses and members of the community. Crabtree's FAS/FAE/NAS Guides will be available in January 1993. They are a:

- Community Action Guide;
- Caregiver's Guide; and
- Resource Guide.

Additional funding from the B.C. Ministry of Health will allow us to develop an FAS/FAE Resource Kit and expand our guides.

We have provided information to all three levels of government including the Federal Government Standing Committee on FAS. We have submitted articles on FAS/FAE which have been published in national magazines — after which we are inundated with phone calls from readers about our Prevention Project.

I believe an essential element to the success of our project is establishing the program in an already existing and respected service where the trust and networking is well established. We have learned a great deal during this process. We are anxious to continue so that our knowledge and impetus will not be lost. To this end we are now actively searching for the necessary resources to continue a project we feel has made a difference both to the women we serve and the community we live in.

## **DR. OSCAR CASIRO**

*Dr. Casiro is Director of the Newborn Follow-Up Program, Health Sciences Centre, and is Associate Professor, Department of Pediatrics, University of Manitoba, and Chairman, Child Health Committee, Manitoba Medical Association.*

In early 1990 the Child Health Committee of the Manitoba Medical Association decided to develop and mount a public awareness campaign on the risks of drinking alcohol during pregnancy. The campaign consisted of a 30-second television commercial played 700 times in English, French and Cree throughout the province of Manitoba over a ten-week period beginning June 17, 1991. The essential message was that there is no known safe amount of alcohol consumption during pregnancy and that regardless of age or race, any drink containing alcohol will reach the fetus and put it at risk.

The Board of Directors of the Manitoba Medical Association provided funds to cover the entire cost of this project. After reviewing the current medical literature on this topic, we consulted with local medical experts on fetal alcohol syndrome and epidemiology, prevention and education consultants from the Alcoholism Foundation of Manitoba, Native health educators, representatives of television networks and the Broadcaster's Association of Manitoba.

To evaluate the effectiveness of this campaign we designed a pre-and post-campaign survey consisting of five questions on alcohol and pregnancy and five unrelated questions, added to disguise the intentions of the questionnaire. The pre-campaign questionnaire was administered in the waiting rooms of 30 physicians to 1,577 female patients aged 15 to 45 years. The sample was stratified for subspecialty (into family practice, pediatrics, obstetrics, community clinics) and also was stratified by geographic location (into inner city, urban, rural and the North). The same methodology and physicians were used to administer the post-campaign survey to a similar group of 1,392 female patients, followed by a comprehensive data analysis for pre and post differences.

In addition, members of the Child Health Committee and representatives from the Alcoholism Foundation of Manitoba (AFM) developed a brochure, which was distributed to all Manitoba physicians just prior to the televised campaign, to ensure that they were prepared for inquiries from their patients. The AFM also developed a brochure suitable for the general public.

The proportion of correct answers to the five questions that were unrelated to alcohol were no different before and after the campaign. There were significant differences in the responses to the alcohol and pregnancy questions, showing a post-campaign increase in awareness that alcohol can cause mental, physical and behavioural abnormalities in the baby, and that even small amounts of alcohol can place the baby at risk. Although most people knew that alcohol would cross the placenta and reach the baby, the more specific the questions we asked, the less knowledge was revealed. Also, a significantly higher proportion of post-campaign responders chose "television" as their source of information obtained to answer the questionnaire.

Our findings suggest that a TV campaign effectively increased the level of awareness of a population at risk. Television seems to be an effective way to promote awareness of the risks of drinking alcohol during pregnancy.

## **DR. KWADWO O. ASANTE, MODERATOR**

*Dr. Asante is a Clinical Assistant Professor of Pediatrics, University of British Columbia, Vancouver, B.C.*

Dr. Asante commented on another prevention program, the B.C. provincial government system to get information out to high-risk communities in the province. The Pregnancy Outreach program had two main objectives, with an emphasis on Native women:

- to reduce risk behaviour and improve pregnancy outcome by improving nutrition, decreasing the use of alcohol, drugs and tobacco, and encouraging breast-feeding; and
- to inform physicians and other health-care professionals about FAS/FAE and other drug effects on pregnancy.

As a result of the many outreach visits and workshops, there is early evidence that their project has helped in reducing alcohol use in pregnancy, in addition to achieving their own objectives. In the long term, it is felt that the program will be successful in reducing risk behaviours in pregnancy.

## APPENDIX IV

### REPORT FROM THE ABORIGINAL PARTICIPANTS

*submitted by Marilyn Van Bibber*

We applaud the recommendations coming from the many workshop sessions, and hope that this is a good first step towards the development of a national strategy to address FAS/FAE.

We agree that FAS/FAE is a national problem affecting all segments of the Canadian population, however there are dynamics surrounding FAS in Aboriginal populations that are different.

We recommend the development of an Aboriginal strategy to prevent FAS/FAE and to deal with the problems associated with FAS/FAE amongst individuals, their families and their communities. This is a complex issue requiring a comprehensive multi-disciplined strategy.

Such a strategy should adequately and appropriately respond to the challenge of addressing FAS/FAE in Aboriginal populations, it must recognize First Nation governments as the third level of government in Canada, and therefore must be done in collaboration with Aboriginal governments and organizations.

We have urgent needs to be dealt with prior to developing and implementing this strategy.

Therefore we recommend interim measures to address urgent immediate needs;

- develop health promotion material appropriate for Aboriginal populations, including funding for videos;
- access to assessment;
- immediate support and treatment services for mothers and families, i.e.:
  - alcohol treatment services
  - access for all families with children with development problems to available services offered by health, education, and social services (Infant Development Programs provided by Provincial health are not available to people living on reserves);
- resources (funding) for special needs education, and
- resources for a national symposium or conference focusing on all Aboriginal peoples in Canada.

## APPENDIX V / APPENDICE V

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# APPENDIX VI

## FUTURE CONFERENCE

### FETAL ALCOHOL SYNDROME/EFFECTS: COMMUNITY PERSPECTIVE

May 5, 6,7,1993  
Lethbridge, Alberta

Speakers to include:  
Sterling Claren, MD.  
Robin La Due, Ph.D.  
Sandra Randels, RN, M.S.N.  
Donna Burgess, Ph.D.

#### TOPICS

*focus on medical, psycho-social,  
educational and family issues*

Identification of FAS/FAE  
Preparation for Assessment  
Growth and Development Issues  
Psycho-social Aspects of Different Ages  
Psychological Testing Assessment  
Behaviour Management

#### Cross-cultural Issues

Identification, Parenting and Education

#### Educational Issues and What Works

Partnership Issues: Schools and Community  
Effects on the Family and Community  
Coping Strategies for the Family

All speakers are at the forefront  
in the developing area of  
Fetal Alcohol Syndrome/Fetal Alcohol Effect.  
A specialist in dealing with cross-cultural issues  
is yet to be confirmed.

**Conference Brochure will be available in January 1993.**

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