

Fetal Alcohol Syndrome: An Issue of Child and Family Health *A Policy Discussion Paper*

Canadian Centre on Substance Abuse (CCSA) National Working Group on Policy, 1994

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A. Background

1. Context

It has been widely demonstrated that there are significant adverse health effects associated with excessive alcohol consumption. Of particular recent concern are the effects of maternal and paternal alcohol consumption on the development and overall health of the fetus and the child. A variety of studies support the conclusion that heavy maternal drinking is a necessary causal factor in "fetal alcohol syndrome" (FAS). However, whether an individual child will have FAS appears to depend on a number of factors in addition to alcohol, including parental health, other drug use, lifestyle and other socio-economic factors. Therefore, FAS cannot and should not be considered in isolation from total concern for the health and well-being of children and their families.

2. Fetal Alcohol Syndrome (FAS) - Definition

FAS is a cluster of abnormalities occurring in children born of women having histories of relatively high levels of alcohol consumption during pregnancy. A diagnosis of FAS can only be made when signs of abnormality exist in each of the following categories. These criteria were developed for infants and may not always be appropriate for other age groups.

a) Growth retardation (prenatal and/or postnatal)

- weight or length below the 10th percentile when corrected for gestational age

b) Central nervous system involvement

- neurological abnormality (e.g. hearing disorders)
- developmental delay
- behavioral dysfunction or deficit
- intellectual impairment (e.g. learning disability, mental retardation) and/or structural abnormalities (e.g. brain malformations).

c) Characteristic face

- narrow eye openings (short palpebral fissures)
- elongated, flattened midface
- thin upper lip
- underdeveloped groove (philtrum) between the upper lip and the nose.

In addition to the pattern of abnormalities defining FAS, a number of individual features, often called Fetal Alcohol Effects (FAE) have been associated with drinking during pregnancy. FAE is not necessarily a milder form of FAS because the signs -- though fewer in number -- may be just as severe as in FAS. Examples of these include:

- learning problems (learning disabilities and/or mental retardation)
- behavioral problems (motor dysfunction, attention deficient disorder, hyperactivity, sleep disorder)
- hearing defects
- isolated birth defects

However, to date there is no universally accepted evidence that FAE is a definable entity and it would be unwise to apply it as a diagnosis, in part because of the risk of mislabeling. The individual symptoms may be found in children completely independent of alcohol consumption by the mother. Given these uncertainties, several authorities in the field have cautioned against use of the term FAE, and encouraged gaining a better understanding of individual alcohol-related birth defects. While this may be true, there is clearly reason to be concerned about potential fetal alcohol effects not included within the FAS diagnostic criteria.

3. Fetal Alcohol Syndrome (FAS) - Incidence

When considering the incidence of FAS it is important to remember that the estimates may be influenced by a number of factors.

- Diagnosis is difficult. Recognizing the facial features associated with the syndrome requires considerable experience. In addition, some of the features occur normally in different racial groups.
- Alcohol consumption is difficult to measure accurately at any time and is particularly difficult to measure during pregnancy when concerns about the consequences of drinking may lead to significant under-reporting of consumption. In addition, there is no consensus on what level, apart from very heavy drinking (e.g., five standard drinks or more per day), or what pattern of drinking (e.g., binge drinking) results in damage.
- Some of the individual features of FAS may also result from, or be exacerbated by, a variety of adverse influences (e.g., poor nutrition, family violence or substance abuse, mother's history of other health and obstetric problems) interacting with alcohol during pregnancy.

Because of these factors, estimates of the incidence of FAS are highly varied and controversial. One of the most recent estimates puts the rate for the general population at 0.33 cases per 1000 live births. This estimate is conservative and does not include minority groups such as aboriginals. Limited studies of aboriginal populations suggest that their rate may be 10 times higher, or more.

B. Issues

1. Unintended Harm

The current evidence supports the conclusion that women who drink heavily during pregnancy may produce children exhibiting features of FAS. In view of the potential damage to the fetus, some health care professionals have advised pregnant women to abstain from drinking. It has, however, not been consistently shown that low to moderate levels of maternal alcohol consumption (e.g., up to two standard drinks per day) cause harm to the fetus or the child. Despite the ambiguity relating to the impact of low alcohol consumption there is a

misconception among some health care practitioners, social service providers, and many members of the general public that FAS and individual abnormalities are inevitable even at low levels of consumption.

This perception can result in a number of undesirable outcomes including:

- labeling children incorrectly, leaving them with a life-long stigma.
- causing parents to feel guilt that drinking small amounts of alcoholic beverages caused anomalies that were actually due to other factors.
- causing undue anxiety in pregnant women and their families.
- decreasing the credibility of information about the other known adverse health effects of heavy drinking.
- supporting interventions that may be minimally effective, at the expense of programs for groups that could benefit from preventive programs and appropriate treatment.

On the other hand, there is a need to take appropriate action on FAS. Otherwise there might be:

- more FAS children born unnecessarily
- inadequate diagnosis, treatment, and support of FAS children and their families
- missed opportunities for pregnant women with alcohol or other drug problems to access addictions treatment.

In the absence of a scientifically established threshold of consumption above which there is significant risk to the fetus, service providers are unable to offer consistent, valid advice to women and their partners regarding "safe" levels of alcohol consumption. Presently, service providers suggest anything from abstinence to "light" drinking, depending on their personal views, without being able to reference a scientifically validated continuum of drinking and risk of harmful effects. Clients often find this situation less than helpful and, as noted above, even the most conservative advice carries the potential of causing unintended harm to the mother, child, or family.

Nevertheless, pregnant women, women planning pregnancy and their partners should not exceed the drinking limits suggested for all drinkers. If they want to avoid all risks of fetal alcohol effects, less drinking is better and none is best.

2. A Narrow Focus on Alcohol

While it is apparent that children who meet the criteria for FAS are born only to those mothers who consume alcohol during pregnancy, it is also evident that these mothers are subject to other adverse conditions which are major factors in many cases. These include: poor nutrition, poverty, tobacco use, illicit drug use, violence, history of obstetric problems, lack of prenatal care, among others. Thus, FAS is not simply an issue of alcohol abuse but a complex issue rooted in the underlying social and economic conditions which influence all aspects of maternal and child health.

3. A Narrow Focus on Women

In many cases of FAS where information on the father is available, the father has been described as a heavy drinker or alcohol-dependent. Thus, some of the factors contributing to FAS may be male-mediated. This may occur biologically through damage to the sperm, or physically and psychologically through violence or other abuse to the mother. In addition, the

positive influences that males can have on their partners' drinking need to be recognized and encouraged.

C. Policy Recommendations

1. Fetal Alcohol Syndrome should be addressed as a community health problem that results from the interaction of a variety of adverse conditions, including excessive alcohol consumption. Within this context, resources should be directed toward pregnancies at high risk of FAS within high risk families. In addition, adequate resources should be available to treat children with FAS and to provide caring and compassionate support to their families.
2. Prevention and education programs must provide information that is scientifically valid and pragmatic. Care must be taken to ensure that guidance provided with respect to drinking during pregnancy does not result in more harm than good.
3. All health care professionals should receive appropriate and scientifically valid training on preventing, diagnosing and treating FAS and other alcohol related birth defects.
4. Prevention and education programs should be relevant and targeted to prospective fathers and other significant persons in addition to mothers.
5. Research should be undertaken to:
 - (a) establish a set or sets of agreed-upon criteria for diagnosis of FAS at all age levels,
 - (b) more accurately determine the incidence of FAS and other alcohol-related birth defects in all populations,
 - (c) determine the relationship between alcohol consumption levels and patterns of use and birth defects,
 - (d) determine the relationships between alcohol use and other factors affecting fetal and child health,
 - (e) determine the most effective programs for the prevention of FAS and other alcohol-related birth defects, and
 - (f) determine the most effective treatment and support for those diagnosed as having FAS and their families.
6. Addictions professionals should coordinate their efforts regarding FAS with those of service providers concerned with prenatal and reproductive care, maternal and child health, and other health care professionals. Their intent should be to improve networking and communications among service providers and to ensure mutually supportive initiatives for both women and their partners in prevention, treatment and research aimed at the full spectrum of factors affecting maternal, fetal and child health.