

Submission to Inquiry into Foetal Alcohol Spectrum Disorder

Public Health Association of Australia
Northern Territory Branch

Our organisation has the mission:

“To improve the health of all people in the Northern Territory through public health, advocacy and action addressing health inequities.”

We recognise alcohol as a key contributor to poor health outcomes and health inequity in NT. Action on alcohol is one of five key issues on which we focus our advocacy.

In relation to your inquiry's terms of reference:

1. **Prevention** – We support education campaigns, product warnings and other mechanisms to raise awareness of the harmful effects of alcohol consumption during pregnancy. However the effectiveness of these strategies is limited while consumption of alcohol is normal for young people including women at risk of pregnancy.

Alcohol can affect fetuses from 6 weeks after conception. This is often well before women are aware that they are pregnant. Strategies that aim to change drinking behaviour only of women who know that they are pregnant cannot prevent these effects.

Therefore a comprehensive FASD strategy must ensure that women are alcohol free throughout pregnancy. At the most fundamental level, and recognising the gender discrimination inevitably involved, we acknowledge that there are two ways this can be done:

- a. Ensure that all women drinking alcohol are protected from pregnancy
- b. Ensure that all women who are pregnant do not drink alcohol

These strategies require societal change.

The first requires increased awareness of the risks of pregnancy among women who drink alcohol, and increased access to effective contraception. Australian women should have access to safe, effective and easy to use contraception, and this must be promoted. Risks of hormonal contraception are often overstated, since the risks to women using contraception are compared with the risks to women not using contraception rather than the risks of pregnancy. When risks to unborn fetuses including risks from alcohol are considered, the relative risk of contraception is even lower. The possibility of making contraception – such as emergency contraception and oral contraceptive pills, in addition to condoms – available in supermarkets and alcohol outlets should be considered. “Unforgettable contraception” in which no action is required at the time of sexual intercourse may be much more effective in preventing FASD than methods that require planning and application at the time of intercourse which may be affected by alcohol.

The second requires society to accept that it is normal and healthy to abstain from alcohol. This poses a challenge to our society in which drinking of alcohol occurs at almost all social events, and drinking alcohol is not just accepted but expected.

While only women drinking alcohol can lead directly to foetal alcohol spectrum disorder, in Australia men and women often drink alcohol together. Therefore interventions to reduce overall consumption of alcohol are needed. We recognise that NT has the highest level of alcohol consumption of any jurisdiction in Australia. All strategies to overcome the health disadvantage associated with this level of consumption are part of the mission of Public Health Association of Australia NT Branch. FASD is a part of this disadvantage but is important in that the costs of much alcohol consumption are borne by people who are not the users.

A key intervention to reduce alcohol consumption is to increase the price of alcoholic drinks. A floor price and volumetric taxation are effective ways to do this. Reducing the availability of alcohol through numbers of outlets, hours or days of opening and alcohol-free events are additional effective ways to reduce alcohol consumption; these will be a saving overall on our finances; they do not cost money and political fall-out can be managed appropriately. There has been vigorous lobbying in NT towards introduction of a floor price on alcohol below which it is illegal to sell any drink containing alcohol. We believe that recognition of the economic benefits to all Australians from this will lead to its introduction. Volumetric tax is an alternative mechanism to ensure that alcohol is fairly priced in relation to its true cost and benefit to the community.

Comprehensive public education about the effects of alcohol on unborn children will lead to public support for the implementation of these measures.

Engagement of men as boys, husbands, uncles, friends and members of society is required to manage FASD. Men must support women, and the entire community must take action in discussions about alcohol, and in the care of children. Children affected by FASD affect men and are cared for by men as well as women. A family and community approach is required.

2. Intervention

Increased awareness of foetal alcohol spectrum disorders among the general community and health professionals will lead to an acceptance that it is appropriate to conduct some form of screening of all children.

Research is underway to determine how this screening can best be done. Routine questioning of all pregnant women about their alcohol consumption from the date of conception may be all that is required for the majority of women and children.

Early diagnosis will enable best treatment of affected children, and interventions to prevent women from delivering a subsequent affected child. Education associated with screening will also enhance community awareness of FASD, and contribute to changing community standards about women drinking alcohol.

Quality data on prevalence of FASD are not available, but it is likely that these conditions are prevalent in the most isolated Aboriginal communities in Australia. Access to screening, diagnosis and treatment must be assured in these communities, and prioritised for prevention activities. This is an investment, likely to reduce future expenditure, and future economic benefits of a healthy community should be counted against costs.

Concern about stigma of FASD must be addressed. Here too, appropriate community education must be developed to enhance knowledge and change behaviour without contributing to stigma and avoidance of services by women and children.

Options to control the behaviour of pregnant women who are unable or unwilling to cease heavy drinking should be considered in some few instances, particularly where a woman already has a child affected by FASD. These must be the least coercive and invasive methods possible. However foetuses may be damaged by alcohol well before even the woman herself knows that she is pregnant, let alone interventions instituted. Therefore interventions in women who are obviously pregnant will have limited effectiveness in preventing FASD.

3. Management

One critical element of management is to prevent the birth of further children affected by their mother's drinking. This includes ensuring that contraceptive needs for girls affected by FASD are addressed urgently as they reach sexual maturity; accessible antenatal care; and ensuring that non-drinking is an acceptable option.

Management of FASD is lifelong, making this condition a heavy burden to the affected person, care givers and community. Although there is inadequate Australian data on the cost of a case, prevention and best practice management will be costly, justifying intensive prevention efforts.

The role and benefit of screening has not been established. Work on whether, how and which infants to screen for FASD is underway, and PHAA supports development and use of evidence-based guidelines to improve outcomes.

Early intervention is likely to be beneficial. A number of programs have been demonstrated to improve the outcomes for children affected by a range of disadvantaged backgrounds including alcohol exposure. Targeted family support, home visiting and educational day care programs are all likely to be beneficial. Since FASD is a lifelong condition early intervention may be cost-effective if it can reduce the incidence and severity of poor outcomes.

However we also believe that services should be available according to need, not diagnosis, and anyone with the disability associated with FASD should be entitled to appropriate services irrespective of whether there is proof of fetal exposure to alcohol. High levels of professional expertise and diagnostic skills are required for some diagnoses. Therefore systems that provide services based on demonstrated need rather than demonstrated diagnoses are progressive and support the well-being of remote and rural people and the most disadvantaged.

PHAA recognises the needs to determine population prevalence of conditions such as FASD for the establishment and monitoring of programs. However this may be achievable in selected populations, leaving other groups to access services based purely on need and irrespective of diagnoses.

Likewise we support free and public education to meet the needs of all children, rather than individual payments and programs.

Many cases of FASD are identified in foster care, and in juvenile detention, and the lives of these young people may be greatly improved through early detection and effective rather than punitive management.

A number of programs functioning in Central Australia are of particular importance for their potential to prevent, intervene early and effectively manage FASD. These include advocacy work on the introduction of an alcohol floor price; Australian Nurse Family Partnership Program; Educational Day Care and Targeted Family Support Programs. These are under evaluation and review, but results suggest improved outcomes in extremely difficult circumstances. Appropriate development and implementation of programs such as these more widely is likely to benefit individuals and communities at risk from FASD.

We believe that police, legal and corrections services are also extensively involved with people affected by FASD. However they are unable to effectively support these people in the absence of awareness of the condition, with provision of a diagnosis, in addition to education, skills, strategies and programs to ensure that affected people are protected from harm and from causing harm. Rehabilitation can be achieved but systematic approaches have been hampered by a lack of research.

4. Conclusion

1. Community-wide strategies to reduce alcohol consumption are required
2. Prevention based on access to contraception, and facilitation of non-drinking is required
3. Pre-natal and early childhood programs to enhance development of all disadvantaged children
4. High level interagency strategies are required to ensure appropriate management of people with FASD in the police, legal and justice systems

Thank you for considering the views of our organisation

Dr Rosalie Schultz
NT Branch President
Public Health Association of Australia
PO Box 1321
Tennant Creek NT 0861