



Fetal Alcohol Spectrum Disorder in New Zealand:

Activating the Awareness and Intervention Continuum

Executive Summary

April 2007

This Alcohol Healthwatch briefing paper contains information on:

- Fetal Alcohol Spectrum Disorder (FASD)
- FASD in New Zealand
- NZ policy and action
- Moving forward on FASD prevention
- Improving the outcome for affected child and family
- Summary of recommendations
- Alcohol Healthwatch's position.

This paper is one of a set of 6 that includes:

- The Advertising of Alcohol – In Support of Increased Restrictions
- Reducing the Legal Blood Alcohol Concentration for Driving
- Alcohol Health and Safety Advisory Statements
- Alcohol Excise Tax – Changes to the New Zealand System
- The Sale of Liquor in New Zealand – Recommended Changes to the Act
- **Fetal Alcohol Spectrum Disorder in New Zealand: Activating the Awareness and Intervention Continuum**

These documents can be viewed in PDF on www.ahw.co.nz

“The future is not the result of choices among alternative paths offered by the present, but a place that is created. Created first in the mind and will, created next in activity. The future is not some place we are going to but one we are creating. The paths are not to be found, but made, and the activity of making them changes both maker and destination.”

(John Schaar – Professor Emeritus Political Philosophy, University of California, 2003)

“It’s Our Time – Go Tell the World”

(The message from young people affected by FASD to the 2nd International Conference on Fetal Alcohol Spectrum Disorder: Research Policy and Practice Around the World. Victoria, BC Canada, 2007 <http://www.interprofessional.ubc.ca/FASD.htm>)

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Executive Summary

This Alcohol Healthwatch¹ briefing paper outlines current knowledge of Fetal Alcohol Spectrum Disorder² caused by drinking alcohol during pregnancy and the situation in Aotearoa New Zealand regarding its prevention and treatment. The purpose of the paper is to inform and guide the development of effective policy and responses within the various relevant public sectors.

Section 1: An overview of Fetal Alcohol Spectrum Disorder

- Alcohol is a substance that is toxic or teratogenic to a fetus. A teratogen is an agent that during pregnancy can cause birth defects and developmental disorders. The developing central nervous system throughout pregnancy is particularly sensitive to alcohol.
- Fetal Alcohol Spectrum Disorder (FASD) can cause permanent and preventable disabilities. As such, FASD prevention and intervention are critical public health issues that require a high degree of planned action at a policy and service delivery level to reduce harm.
- Fetal Alcohol Spectrum Disorder is an umbrella term used to describe a range of adverse effects including Fetal Alcohol Syndrome (FAS), Partial FAS (PFAS), Alcohol-Related Disorders (ARND) or Alcohol Related Birth Defects (ARBD) (Chudley et al, 2005).
- The sensitivity of the developing central nervous system to the neuro-toxic effects of alcohol means there is no known safe level of exposure at any time during pregnancy. The adverse effects can vary depending on such things as the timing and duration of exposure, genetics and maternal health. Not all babies are affected to the same degree but generally speaking, the greater the exposure the higher the risk of damage.
- Fetal Alcohol Syndrome is recognised as the leading preventable cause of mental retardation in the developed world. Most affected individuals are within the borderline to average IQ range but will have adaptive functional deficits that may be unrelated to overall IQ.
- FASD is often described as a hidden or invisible disability. The disorders of FASD are more difficult to diagnose than full FAS and may be associated with other conditions such as Attention Deficit Hyperactivity Disorder, Autistic

¹ Alcohol Healthwatch is a non-government organisation that works to reduce alcohol-related harm through the principles of the Treaty of Waitangi and the Ottawa Charter for Health Promotion of the World Health Organisation.

² Fetal Alcohol Spectrum Disorder is an umbrella term used to describe a range of adverse effects including FAS, Partial FAS (PFAS), Alcohol-Related Neurodevelopmental Disorders (ARND) or Alcohol Related Birth Defects (ARBD) ,(Chudley et al, 2005). The use of the word 'fetal' or 'fetus' is not an Americanisation but is the Latin origin (Liggins Institute, 2005).

Spectrum Disorder or Conduct Disorder. Diagnosis generally requires a specialised, multidisciplinary assessment.

- FASD is associated with primary disabilities, those that are the direct result of the insult to the brain and other organs, and secondary disabilities which can result from cognitive and functional needs going unmet. Secondary disabilities include mental health disorders, educational failure, alcohol and drug problems, employment problems and trouble with the law.
- FASD is estimated to affect 1 in 100 live births. However, recent epidemiological studies of young school age children suggest the prevalence is much higher.

Section 2: FASD in New Zealand

- The number of individuals affected by FASD in New Zealand is largely unknown though anecdotal evidence suggests there are significant numbers of individuals affected with and without a diagnosis.
- The level of maternal drinking in New Zealand is relatively high. Surveys suggest that around 50% of women believe some alcohol in pregnancy is safe and 20-36% of women continue to consume alcohol during pregnancy. According to midwives the figure is closer to 80% for pregnant teenagers.
- Health advice on drinking during pregnancy continues to be inconsistent despite the official guideline for New Zealand being to avoid alcohol whilst pregnant, planning pregnancy and when breastfeeding.
- The cost of failing to prevent FASD is significant. New cases of FASD could conservatively be costing New Zealand \$3.5 million annually in extra medical, educational and social services. This does not include the cost of secondary disabilities that can develop if the individual is not receiving adequate and appropriate care according to need.

Section 3: FASD in New Zealand Policy

- FASD whether diagnosed or undiagnosed is already a cost burden to New Zealand, a burden that is compounded from a lack of adequate, timely and appropriate intervention. While FASD is being acknowledged in New Zealand and ad hoc efforts to reduce associated harm have been occurring for the last two decades, there is no consistent policy and FASD prevention and intervention attracts few specific financial resources.
- A lack of evidence of the prevalence and incidence of FASD in New Zealand has been cited as the reason why health policy and programmes have not been developed to prevent and/or treat FASD in this country. Without trained professionals to diagnose FASD, the prevalence cannot be accurately assessed; a catch 22 situation.

- FASD is recognised as a disability only if the person has an IQ below 70. No health, educational or social services systematically address FASD needs.
- Significant opportunities already exist to integrate knowledge and advice on FASD within existing services and for developing guidelines for diagnostic and other services.

Section 4: Moving forward on FASD prevention

- Prevention, surveillance, diagnosis and intervention are inseparable parts of the same continuum. FASD prevention therefore requires three levels of approach, primary, secondary and tertiary.
- To be ethical, awareness raising needs to ensure there is appropriate referral processes and informed support services for concerns that may be raised.
- Primary prevention includes universal public health awareness messages to the general population to avoid drinking alcohol during pregnancy such as health warning labels on containers and at point of sale and integration with existing public health programmes.
- Secondary prevention includes targeted and general screening of pregnant women to identify populations and individuals at increased risk.
- Tertiary prevention is more specifically related to individuals who are at high risk of drinking during pregnancy. Early appropriate intervention can prevent further harm in the current and subsequent pregnancies, find and identify children at risk of FASD and reduce 'trans-generational' FASD.

Section 5: FASD as a disability

- Identification and referral for multidisciplinary diagnosis early in development is a protective factor and is essential for accurate assessment of the developmental needs of infants and children thought to be affected.
- Early identification and intervention of children at risk is also a critical and pivotal preventive measure since it can reduce the negative flow-on effects of secondary disabilities that individuals with FASD are at high risk of developing and increase knowledge and awareness in community services.
- Significant benefits can be gained from the provision of developmental screening and follow-up diagnosis for the individual, for the family and for the community in general. However a lack of training for health professionals means that diagnosis of FASD will be unlikely or inaccurate and follow up service provision inadequate throughout life.
- Families seeking medical advice and intervention for a child exposed prenatally to alcohol, often encounter barriers to identifying FASD which can lead to further problems for the individual and their family. There are multiple reasons for this including not wishing to 'label' the problem, a belief that

nothing can be done to fix any damage, lack of training and confidence in diagnosing FASD or the belief that the family will be stigmatised rather than helped by this diagnosis.

- Diagnosis is a positive starting point. Ensuring the needs of individuals with FASD are appropriately managed will reduce the likelihood of secondary disabilities developing. However current disability and other policy does not take into account the range of functional deficits associated with organic brain disorders such as FASD and therefore denies services to the majority of affected families, increasing the risk of secondary disabilities.
- Developing policy specific to FASD combined with sector training in identifying FASD and its effects will improve understanding and collaboration between sectors, help to keep any duplication of inappropriate and ineffective services to a minimum and improve support and outcomes for affected families.

Alcohol Healthwatch's Position

- Fetal Alcohol Spectrum Disorder (FASD), the result of drinking alcohol during pregnancy is a critical, preventable public health issue. FASD causes distressing, permanent and preventable primary and secondary disabilities. FASD prevention and intervention are part of the same continuum that requires a higher degree of planned integrated action at a policy and service delivery level, than has been the case to date.
- There is proven cost-effective benefit from investing in FASD prevention and early intervention at the individual and at the population level. Any preliminary cost involved with establishing better systems will be more than offset by the preventive and protective factors associated with awareness, diagnosis and interventions and that help to prevent secondary disabilities and trans-generational FASD.
- There is now sufficient international evidence, effective models and strategic policy for New Zealand to develop its own specific policy guidelines and a cost-effective action plan. All that is required is a willingness to commit to FASD as a significant issue that is amenable to proactive prevention and intervention efforts. Reducing the harm of FASD must become a Government priority.

Full Summary of Recommended Actions

Section 1: Fetal Alcohol Spectrum Disorder.

1. Acknowledge FASD as a significant public health problem associated with alcohol that can lead to unnecessary distressing and avoidable disabilities.
2. Acknowledge FASD as a diagnosable disability that is amenable to positive, appropriately delivered cost-effective interventions.
3. Recognise that FASD requires a higher level of clinical knowledge, skill and research investment in New Zealand.

Section 2: FASD in New Zealand.

4. Acknowledge that existing evidence of the level of drinking during pregnancy in New Zealand is a problem that requires urgent comprehensive nationwide action.
5. Develop culturally appropriate non-judgemental prevention programmes for groups that research show to be at high risk of drinking during pregnancy, such as teenagers and also link these to other prevention and treatment programmes.
6. Research the primary health care sector to ascertain the type and level of advice that women of reproductive age are being provided.
7. Provide the primary health care sector with a comprehensive education programme to ensure they are knowledgeable and resourced to provide consistent and appropriate advice as per the Ministry of Health Guidelines.
8. Accept that conservative international estimates of FASD prevalence and the financial burden will be similar for New Zealand and likely to be an underestimation given our binge drinking culture and increased consumption by women of reproductive age.
9. Acknowledge that FASD is already costing New Zealand and undertake an econometric study of the likely cost as well as a cost effectiveness analysis of establishing, integrating and maintaining systematic FASD prevention and early intervention services.

Section 3: FASD in New Zealand Policy.

10. Prioritise and resource FASD action across relevant ministries and services and adopt as a starting point the Strategic Plan of the National FASD Advisory Group.
11. In consultation with an expert group, develop integrated policy with targeted funded objectives in the National Alcohol Strategy.

12. Develop specific FASD guidelines for relevant sectors based on available best practice models.

13. Engage fully with existing FASD community and family advocates to ensure planning and service provision is well informed and appropriately responsive.

14. Direct funding toward maintaining and strengthening existing FASD community-based advocacy and support organisations while developing comprehensive scheduled services to meet stated objectives.

Section 4: Moving forward on FASD prevention.

Ethical prevention

15. Ensure that prevention efforts are being carried out in an ethical manner, and that adequate and appropriate multi-dimensional treatment and community services are available for referrals.

Primary Prevention

16. Develop and fund a comprehensive, evidence-based prevention awareness campaign and ongoing programmes to reduce the likelihood of an unplanned pregnancy from being exposed to alcohol before pregnancy recognition.

17. Develop and actively disseminate alcohol and pregnancy information to the general population, for example through an advisory label on alcohol containers and tailor culturally appropriate supporting messages for specific groups such as teenagers, Maori, Pacific, new migrants and older mothers.

18. Ensure that all public health and primary healthcare professionals incorporate the Ministry of Health nutrition guideline advice on alcohol with clients when discussing nutrition, sexual health, contraception, conception and/or pregnancy with clients prior to and during pregnancy and breastfeeding.

Screening

19. Ensure all women of reproductive age, regardless of age, ethnicity, socio-economic status or pregnancy status are screened for alcohol use, using where appropriate brief intervention screening tools accompanied by appropriate advice and referral to an alcohol and drug service where needed.

Secondary Prevention

20. Require that all lead maternity carers screen pregnant clients for alcohol and other drug use during the first antenatal visit of every pregnancy and ensure all carers are well trained to carry out this screening process.

21. Ensure alcohol and drug services are equipped to understand and assess the risk of harm to mother and child from early pregnancy onwards and enabled to respond appropriately.

Tertiary Prevention

22. Incorporate an integrated Maternal-Child Service Model into existing DHB services based on evaluated and successful programmes.

23. Recognise that not all women who abuse alcohol during pregnancy will fit diagnostic criteria for alcohol use disorder but that they may require intervention to reduce the risk of FASD in current and subsequent pregnancies.

Section 5: FASD as a disability.

24. Prioritise a nationwide skills training programme for the health sector and allied workforce, particularly in regard to concerns that may arise following awareness campaigns.

25. Develop national guidelines for the support and treatment of FASD based on international best practice models and informed community consultation, rather than such things as an arbitrary IQ threshold.

26. Introduce an FASD training programme for all other relevant sectors to increase the understanding of appropriate responses to address the needs of affected children, adolescents and adults with FASD.

27. Ensure the eligibility for government funded services includes criteria that reflect the functional and behavioural deficits of developmental disorders like FASD to reduce the risk of secondary disability and family burnout.

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