



Briefing Paper 2007

Fetal Alcohol Spectrum Disorder in New Zealand:

Activating the Awareness and Intervention Continuum

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

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).

- 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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Preface

Alcohol Healthwatch is a non-government organisation that works to reduce alcohol-related harm, applying the principles of the Ottawa Charter for Health Promotion of the World Health Organisation together with those of the Treaty of Waitangi.

This Alcohol Healthwatch briefing paper outlines current knowledge and the situation in Aotearoa New Zealand regarding the prevention and treatment of Fetal Alcohol Spectrum Disorder³ caused by drinking alcohol during pregnancy. The purpose of the paper is to inform and guide the development of effective policy and responses within the various relevant sectors.

Each section includes recommended actions based on available evidence and the current situation from within New Zealand and other countries. The paper does not discuss in detail all the possible activity that is known to be relevant to effective FASD prevention and intervention, but rather places the emphasis on issues and strategies to do with health outcomes.

The paper is one of a series produced by Alcohol Healthwatch that collectively form the basis of an Action on Liquor campaign, a comprehensive approach to the reduction of alcohol related harm in New Zealand. Others in the series are:

- Changes to Excise Tax for Alcohol
- Health & Safety Advisory Statements for Alcohol
- The Advertising of Alcohol – In Support of Increased Restrictions
- Reduction of Legal Blood Alcohol Concentration for Driving
- The Sale of Liquor in New Zealand – Recommended Changes to the Act

These documents can be viewed on the Alcohol Healthwatch Website www.ahw.co.nz

³ 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).

Section 1: An Overview of Fetal Alcohol Spectrum Disorder

“FASDs are common, expensive, devastating and preventable” (Clarren, 2007).

Fetal Alcohol Spectrum Disorder (FASD) brings with it a complex mix of problems that need to be understood to be effectively addressed. This section unpacks some of the key aspects of FASD and related issues to increase that understanding and concludes with relevant recommendations.

Fetal Alcohol Syndrome and FASD

In the 1960s and 70s, scientific research confirmed what had been recognised periodically through the history of western culture, that alcohol is a teratogen, an agent that during pregnancy can cause birth defects and developmental disorders (Jones and Smith, 1973).

Fetal Alcohol Syndrome (FAS) is the most notable medical diagnosis of a range of associated disorders, collectively referred to as Fetal Alcohol Spectrum Disorder (FASD). The full syndrome is most often associated with moderate or heavy alcohol use throughout pregnancy and binge drinking (5 or more drinks together) particularly early in pregnancy.

FAS consists of measurable deficits in three categories:

- characteristic facial malformations
- brain and central nervous system disorders
- growth retardation

Other conditions associated with FAS may include:

- heart & kidney defects
- hearing and eyesight impairment
- skeletal defects
- immune system deficiencies

(Stratton et.al, 1996; US Dept Health and Human Services, 1997)

The facial characteristics unique to FAS occur around the third week of human embryonic development and include a flat elongated philtrum (the area above the top lip), a thin upper lip, small wide apart eyes and a small head circumference (Clarren S, 2000). The recognisable face of FAS becomes less distinctive over time. Conversely the associated neuro-behavioural disorders become more obvious and significant later in a child's development (Streissguth, 1997; Stratton et al., 1996).

Identifying if an individual is affected by FASD is multi-faceted and ideally requiring a multidisciplinary approach (Chudley et al, 2005). The range of disorders can be assessed using a 4 digit diagnostic code developed by the University of Washington to reflect the magnitude of expressions of the disorder (Astley & Clarren, 1999). This diagnostic guide has been expanded in Canada through broad-based consultation, to cover 7 categories to ensure a full range

of disorders are identified and the needs of both the child and the family can be appropriately met (Chudley et al, 2005).

Central nervous system disorders

All fetal organs can be adversely affected by alcohol. However the formation of the central nervous system is the most sensitive developmental process adversely affected by alcohol, at levels of exposure that are lower than the threshold of exposure required to impair growth and organ formation. For brain development, the dose-response relationship appears linear without threshold, down to the lowest measurable level of exposure (Sampson et al, 2000). Hence the best advice is to avoid alcohol during pregnancy due to this sensitivity.

Damage to the brain is physiological. It can reduce IQ (intelligence quotient) but not necessarily always result in mental retardation (Streissguth, 1997). Ten specific brain domains are identified as critical functional central nervous system diagnostic parameters for successful FASD identification and management. These are: achievement, adaptation, attention, cognition, executive functioning, language, memory, motor, sensory/soft neurological, and social communication (Lang 2006).

“The cognitive processes that most people use to regulate their conduct and to adapt to their social environments are located primarily in the anterior lobe of the brain. The effect of alcohol on the fetal brain is such that this region does not develop sufficiently to allow the fetal alcohol syndrome (FAS) individual to appropriately control his or her actions.”

(Yukon District Court, Regina v: J (T) (1999), cited in Williams, 2006)

An adult with Fetal Alcohol Spectrum Disorder may score within the average range on measured IQ - between 70 and 90 and have a high degree of expressive language, but have a level of comprehension similar to that of a child. This often leads to common misinterpretation of responses that requires a paradigm shift in thinking and approach by clinicians and educators. Rather than trying harder to change the behaviour of the person, a different response based on proven best practice models may bring about the desired behaviour change (Malbin 1993).

Information processing speed is slower in children prenatally exposed to alcohol (Burden et al, 2005). After controlling for prenatal drug exposure, postnatal environmental factors and child verbal IQ, one study showed that children in the alcohol-exposed group had decreased executive functioning at levels of exposure less than one drink a day (Noland et al, 2003).

Without support and understanding, people with FASD have difficulty negotiating a world that they do not understand and that does not understand them and the way they function. This can lead to other disorders developing and compounding a multitude of difficulties throughout their lives. For example youth with FASD are disproportionately represented in the criminal justice system. A recent study in Canada to assess and ascertain the prevalence of FASD in juvenile justice facilities found that 23 percent of youth fitted the FASD diagnostic criteria (Fast & Conry, 2004).

FASD at the molecular level

Just how alcohol causes a teratogenic effect on development is not yet fully understood at a molecular level. Alcohol may alter metabolic processes and the supply of nutrients resulting in permanent structural and functional changes in the developing central nervous and other systems (Ministry of Health, 2006; Fagerlund et al, 2006).

Some variability in outcome could be in part explained by genetic predisposition (Jacobsen and Jacobsen, 2007). Evidence to date suggests there may exist a protective effect from alcohol teratogenesis when a mother has at least one copy of the ADH1B*2 or ADH1B*3 allele which are associated with more rapid metabolism of alcohol. However, the Jacobsen studies suggest that increasing maternal age and a longer history of drinking increases the risk of FASD and conclude that adolescent and younger women should be strongly encouraged to delay the age they initiate drinking to protect the health of future offspring.

There are many unpredictable factors that determine the outcome of drinking alcohol during pregnancy. The most critical factor for development remains the direct toxic (teratogenic) effect on the baby in-utero, however the effect will depend on the amount and duration of alcohol in the bloodstream; the timing of exposure during gestation; the mother's age and state of health; whether first or subsequent pregnancy; and some genetic predispositions (Larkby and Day, 1997).

Genetics appear to play a part in susceptibility to FASD (May and Gossage, 2001). Twin studies reveal genetic variation in susceptibility despite having equal exposure to alcohol (Streissguth and Dehaene, 1993; Christoffel and Salafsky, 1975).

“For example, there is a family I know with 4 children born to an alcoholic mother who eventually died from her alcoholism: Child #1 had some problems in school, but is functioning well independently. Child #2 has ARND and a borderline IQ, looks normal but has lots of problems controlling impulses and has poor judgment. Child #3 has full FAS and a normal IQ, looks affected, has problems with impulse control and poor judgment, but because of the obvious look of FAS the system takes that child's disabilities more seriously. Child #4 was exposed but is not affected at all - bright, no behaviour or learning problems, good judgment, mature, responsible. So we cannot always assume that if a child is exposed that the child will be affected the same way.”

(Kellerman, 2005)

A small amount of research points to a genetic link between paternal drinking prior to conception and an increase in the risk of learning impairment and hyperactivity in children (Cicero, 1994).

There are numerous teratogens that can cause various or specific birth defects and disorders. Alcohol is often used in conjunction with other substances increasing the likelihood of a range of developmental problems (Sampson et al, 2000). However, alcohol is singularly the most common, significant and pervasive teratogen known in western society (Stratton et al, 1996).

Prevalence of FASD

Overseas studies estimate that Fetal Alcohol Spectrum Disorder, which includes FAS, collectively affects 1 in 100 (1%) live births (May and Gossage, 2001).

Recent epidemiological studies have found the numbers of individuals affected to be much higher in some communities. In a study of grade 1 school pupils in a wine producing region of South Africa, the prevalence of Fetal Alcohol Syndrome was found to be 42/1000 and as high as 103/1000 in one school (May et al, 2000; Rendall-Mkosi, 2006). A similar study, carried out in a random sample of Italian primary schools to ascertain the prevalence and characteristics of FASD, found the rate of Fetal Alcohol Syndrome to be 3.7-7.4 per 1000, and an FASD rate of 20.3-40.5 per 1000, an overall average rate of 3.5% of all live births (May et al, 2006).

FASD is often described as a hidden or invisible disability. The disorders associated with FASD are more difficult to diagnose than full FAS and may be associated with other conditions such as Attention Deficit Hyperactivity Disorder, Autistic Spectrum Disorder and/or other mental health disorders. Diagnosis generally requires a specialised multidisciplinary assessment, to ascertain the degree of underlying organic brain damage.

Since FASD is not routinely screened in infancy and early childhood, many children with FASD remain undiagnosed which can lead to misclassifications and further harm. Children without the presenting features of the full syndrome are even less likely to be assessed. In addition FASD leads to both primary and secondary disorders or disabilities that require different types of intervention. Both disabilities are thought to be preventable.

Passive systems of surveillance such as birth defect registries appear to be inefficient at finding the spectrum of disabilities of FASD (Carmichael Olsen, 2006). The results of epidemiological studies that use active recruitment rather than relying on clinical or record-based systems, suggest that FASD is likely to be far more prevalent in the western world than previous studies have estimated (May et al, 2006).

Diagnosis using simple bio-markers at birth is an area that is under development and holds some promise for the benefits of early intervention. For example neonatal cranial ultrasound can inexpensively and effectively gather neuro-anatomical information to inform effective early intervention strategies that otherwise would not have been available for these infants (Bookstein et al, 2005; Grant et al, 2006).

Primary disabilities

Primary disabilities are the result of the direct insult to developing organs and central nervous system in the fetus leading to such things as developmental delay, hearing and eyesight problems, memory problems, epilepsy and/or physical birth defects and organ damage. Generally, any individual major anomalies would be picked up by WellChild services in New Zealand or when the child presents to a paediatric service with a specific problem, but these are not necessarily linked to any prenatal alcohol exposure.

“The only reason she [doctor] finally agreed to write a referral letter was because of my insistence and the fact that she had seen that programme on TV....”

(Symes, 2001).

In the absence of full presenting features of FAS, the link between various disorders and prenatal alcohol exposure is often not made at the clinical level because the clinician is not trained in FASD identification. Even when the full characteristics of FAS are present a diagnosis can be missed or avoided.

Secondary disabilities

Secondary disabilities are those that can develop over time due largely to a lack of appropriate and timely protective interventions (Streissguth, 1996).

“This group is at high risk of experiencing poor outcomes including poverty, homelessness, and involvement in the criminal justice system – all of which have negative impacts on the health – both general and economic – of our society.”

(Child and Youth Officer for British Columbia, 2006).

A longitudinal study of secondary disabilities in a population affected by FASD in the USA (Streissguth et al, 2006) showed that:

- 90% had diagnosed mental health problems
- 80% of adults were dependent for their daily needs
- 80% had employment problems
- 60% were expelled from or dropped out of school
- 60% had been in trouble with the law
- 50% had inappropriate sexual behaviour
- 50% had been confined for mental health reasons, alcohol and drug treatment or as a consequence of law violations
- 30% had alcohol and drug problems (prevented from being more significant due to family intervention and control)

Diagnosis and early intervention were shown to improve developmental outcomes of the primary disabilities and are critical factors in preventing secondary disabilities from developing (Streissguth et al, 1996; Motz et al, 2006). Emotional and behaviour problems are significantly associated with FASD in adulthood and appear to be independent of intellectual impairment (Spohr et al, 2007).

FASD prevention therefore requires appropriate timely responses integrated at multiple levels across multiple services.

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

There is currently no research in New Zealand to estimate the extent of FASD as a public health issue. This however, does not mean that the problems are not being experienced and that the impact is not being felt by many families, communities and service providers.

The occurrence of FASD is likely to be as significant as has been found in other developed countries that consume alcohol, and already a drain on limited revenue trying to deal with the long-term implications of unmet needs. Children affected by prenatal alcohol exposure are coming to the attention of services for example Child Youth and Family services and being recognised as needing special attention because of prenatal alcohol exposure (Appendix 1). The small amount of evidence that is currently available strongly points to New Zealand having a significant problem.

How much do women in New Zealand drink during pregnancy?

The number of individuals affected by FASD in New Zealand is unknown. Based on international estimates of 1 case per 100 live births, New Zealand could expect approximately 500 new cases of FASD each year, even though this is likely to be an underestimation of the true extent. By way of contrast approximately 50 babies a year are born affected by neural tube defects.

However, while there are no comprehensive prevalence studies, there is some evidence available on the drinking behaviour of New Zealand women during pregnancy as follows:

- A 1994 national study in New Zealand showed 41.6% of pregnant women consumed alcohol during pregnancy. Hazardous drinking was not confined to any one socioeconomic group (Counsell et al, 1994).
- A 1999 nutrition report on 500 pregnant women in New Zealand showed that 29% continued to drink alcohol after their pregnancy was confirmed. Of the 24% of women who regularly drank to intoxication before pregnancy recognition, 11% continued to do so throughout pregnancy (Watson and McDonald, 1999).
- A survey of midwives reported that 36% of pregnant adult clients and 82% of pregnant teenage clients drank during their pregnancy (Mathew et al, 2000).
- A 2002 study reported that a quarter of pregnant New Zealand women at 24 weeks report consuming alcohol in the previous 7 days (McLeod et al, 2002). The study found that women who were older, had previous pregnancies, had a tertiary education and higher income levels, were more likely to drink.
- In 2004, 82.4% of women drinkers reported having stopped alcohol intake during pregnancy. No significant differences were found between Maori and Non-Maori. (Ministry of Health, 2007a).

- A 2006 study of the awareness of the effect of alcohol use during pregnancy (Parackal et al, 2006) showed that more than 50% of women were of the opinion that if a pregnant woman wanted to drink, then some alcohol was safe in pregnancy. Nearly 20% of all women had binged at least on one occasion in pregnancy, most having done so before they realised they were pregnant.

In the absence of individual assessments, it is unclear whether drinking during pregnancy is actually decreasing or that fewer women are reporting it due to their awareness of the issue and possible stigma if admitting to drinking. Clearly if 50% of women believe that some alcohol during pregnancy is safe, then some will be more likely to drink themselves.

It is hoped that efforts to date, though limited, have resulted in a real reduction of drinking during pregnancy. However, of concern is the high prevalence of heavy drinking from an early age in New Zealand, particularly among young adolescent women (Ministry of Health, 2007a). This has implication far beyond the acute risk of harm to the individual drinker and the immediate risk that may also pose to a fetus should the drinker be pregnant at the time of consumption. There is now evidence that early initiation and a longer history of drinking are associated with the severity of teratogenic insult to the fetus when exposed to alcohol during pregnancy (Jacobsen and Jacobsen, 2007).

The status of alcohol and pregnancy advice in New Zealand

While we have a good indication of the extent and patterns of drinking by women of reproductive age from research gathered over the past 12 years, there is scant evidence as to the information and advice women are receiving from health service providers. There seems to be a mix of approaches with some health professionals conscientiously asking and advising patients about alcohol use during pregnancy while others advise that some alcohol during pregnancy is acceptable or ignore the subject completely.

A survey of medical practitioners conducted over 11 years ago showed that less than half of the doctors surveyed advised pregnant women to abstain from alcohol (Leversha and Mark 1995). The Mathew et al (2000) survey of midwives showed that while midwives are likely to advise pregnant women to avoid alcohol, they also indicated that their level of knowledge was limited and they would benefit from training in the subject.

A survey of midwives in 2000, showed that the majority of midwives advised abstinence but 79% were keen for training in effective communication about alcohol and pregnancy (Mathew et al, 2001).

It appears that medical advice continues to be mixed. In a recent series on obstetric practice in NZ Doctor Magazine (19 April & 3 May, 2006), an obstetric specialist advised general practitioners to counsel clients planning pregnancy to cease smoking and drug taking but to only “moderate” their alcohol intake pre-pregnancy. The author also stated that there was debate about the amount of alcohol that was safe to drink during pregnancy. This advice is inconsistent with official advice which is that there is no known safe level of drinking during pregnancy and no safe time and therefore women who are pregnant, planning pregnancy or breastfeeding should avoid alcohol (Ministry of Health, 2006).

Health professionals specialising in women's and maternal health services are an obvious and important source of information. However, the Parackal et al (2006) survey ascertained sources of information for women of reproductive age and found that respondents were more likely to have received their advice from television, newspapers or magazines than from health professionals.

The current practice and knowledge-base of the workforce within other health services engaging with women of reproductive age is not known increasing concern and likelihood that women will receive no professional advice or, when they do, may receive inconsistent or inaccurate advice. This situation presents an important missed opportunity to improve knowledge and practice that prevents FASD and address concerns regarding any children born affected.

The price being paid for Fetal Alcohol Spectrum Disorder

From neurobiological evidence it is clear that early brain development is a critical determinant of health and wellbeing for all individuals throughout their life. If early brain development is adversely affected during the prenatal and postnatal period, this can lead to a range of significant health and social problems that are of concern and cost to society as a whole (Brainwave Trust, 2006).

“Too often it is the 'effect', the end result, which gets the attention and not the 'cause'. The 'cause' factors can start at conception, be accelerated at birth, and be almost finished by the time a child starts school.”

(Brainwave Trust, 2004)

Alcohol is of particular concern in this regard because it is the most commonly used recreational drug, a pervasive teratogen and the leading preventable cause of impaired early brain development before birth (Stratton et al, 1996).

The irreversible damage to neuronal development associated with FASD adversely impacts all further development with lifelong consequences for the individual, their family/whanau and society. FASD is therefore a significant contributor to the burden of disease, to the burden of social costs and to health inequalities.

New Zealand postgraduate studies have gathered a small amount of qualitative data from affected families indicating that living with FASD causes multiple long-term health and social problems, distress, disablement and disadvantage (Symes, 2001; Salmon 2006). For example the Symes (2004) doctoral study interviewed New Zealand caregivers raising children with FASD and found:

- 58% reported mental health problems such as serious depression, suicide attempts, panic attacks and attention deficit disorders
- 93% had problems with repeated lying
- 75% problems with theft
- 76% with property damage
- 26% with lighting fires

- 70% with violence
- 96% with anger problems
- 56% with sexuality problems
- 50% needed regular supervision in adulthood

The findings mirror those in international published papers (Streissguth et al, 1996; Spohr et al, 2007).

These experiences point out the importance of a knowledgeable, evidence-based approach to this disability in delivering government funded services. Significant gaps in knowledge among the health, disability, education, justice and social services will inevitably lead to inappropriate intervention that will amplify existing problems rather than resolve them and lead to further inappropriate and unnecessarily duplication of costly services.

“We have had three assessments of one sort or another in a 12 month period. The assessments are to see what sort of assistance you need and [the agent] then contact the required agency for you – who come round – and yes – do a further assessment! My concern is that we will continue with a series of ‘assessments’- with little to follow. Cynically, I am coming round to the thought that, as long as assessments are carried out, then the various organizations are doing OK –fulfilling their agreed outputs etc.” (Correspondence with caregiver of adult with full FAS).

Where the workforce had taken the opportunity to inform themselves on the subject, for example, case workers at the Permanent Placement Unit of the Child Youth and Family Service, families report that their experience and outcome as far more positive and effective (Symes, 2004).

There is currently no funded research that informs the follow-up of the primary or secondary outcome for children exposed to alcohol before birth and so nothing specific has been implemented to address the multiple needs of affected families. For instance a search of the Ministry of Education website reveals 12 documents relating to ADHD (Attention Deficit Hyperactivity Disorder), 11 relating to ASD (Autistic Spectrum Disorder) but none relating to Fetal Alcohol Syndrome or FASD, despite all these disorders requiring special educational services.

FASD costs

The financial implications of FAS and FASD have never been assessed in New Zealand but anecdotal evidence and financial estimates from overseas suggests it is likely to be already costing the country a great deal of money.

International estimates vary. The USA estimates the life-time health-care costs for one individual with Fetal Alcohol Syndrome at 1.4 million (Lupton et al, 2004).

In Canada, using an estimated life-time care cost of \$1 million per person, the calculation for FAS alone costs Canadian taxpayers an extra \$4 billion every year across all systems (Clarren, 2007). This estimate is based on the annual

Canadian birth rate and an FAS prevalence rate of 1 per 1000 live births (4,000 babies born with FAS) ⁴. This figure is cumulative as it is additional to the cost of those already born with FASD.

"It would be my belief that that is very conservative in all ways. The rates of FAS and FASD are undoubtedly far higher than 1/1000 and the cost per person over a lifetime is not clearly known but might be much higher as well in both outgoing costs to the person and decreased income and taxes paid." (Personal correspondence with Professor Clarren, 8/04/07).

A recent econometric study from Canada conservatively estimates that supporting an individual with FASD from age 12 months to adulthood (up to age 21) is approximately \$14,342 (Canadian) per person per annum. This amounts to an annual national figure of \$344 million (Stade et al, 2006). An FASD rate of 3/1000 live births was used to calculate the national annual figure. The calculations included direct and indirect medical, educational and social service costs as reported by families raising affected children, but excluded any neonatal intensive care costs and ongoing adult care costs. The seriousness of this is being recognised in Canada. One Provincial Government for instance, Manitoba, has just announced additional funding of \$7.5million for programmes and services to address FASD prevention efforts and improved family support (13/04/07 <http://news.gov.mb.ca/news>).

Using a prevalence rate of 3/1000 live births, New Zealand could expect 173 children to be born significantly affected each year (based on the 2006 New Zealand birth rate of 57,740). Applying the above cost estimates, these cases would conservatively be costing New Zealand taxpayers an extra \$3.46 million per annum (using a conversion rate of \$17075 (NZ) per person with FASD per annum).

By way of comparison, a comprehensive multi-disciplinary diagnostic assessment of an individual is estimated to cost about \$3,000 (Clarren, 2007). At that rate, to provide these 173 New Zealand children with an accurate diagnosis so that services can be appropriately targeted and secondary disabilities reduced would cost \$519,000 nationally per annum once the diagnostic process was in place.

If lifetime care costs for FAS and FASD were calculated together with a higher estimated prevalence rate (which is quite likely given the current drinking culture in New Zealand), then it can be assumed that FASD is costing New Zealand an enormous amount of avoidable revenue expenditure, not unlike that now recognised in Canada and the United States.

There is however, no national data available to indicate the likely FASD incidence and cost burden to New Zealand services and families. Nonetheless, anecdotal evidence suggests that individuals with FASD are continuing to come to the attention of health, educational and social service professionals and are being referred to other services for ongoing assistance, most of which are not

⁴ Note by way of comparison that May et al (2006) found an FAS rate of 3.7-7.4 per 1000 and an FASD rate of 20-40 per 1000 in 5-6 year old pupils in Italian schools.

equipped to respond adequately or appropriately (Symes, 2004; Salmon, 2007; also see Appendix 1).

Without appropriate knowledge and skill for services and families to manage the needs of people with FASD appropriately, the unmet need of individuals will inevitably result in increased cost and duplication of ineffective services across lifetimes and generations. The cost of diagnosis, early intervention and ongoing support by appropriately trained personnel within services would likely be much less than the cost of not identifying and treating FASD affected individuals appropriately and would be far less traumatic and dysfunctional for families.

Recommended Actions

Section 2: FASD in New Zealand.

4. Acknowledge 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: New Zealand Policy and action on FASD

The development of policy and systematic programmes for addressing FASD matters is critical. This has been recognised in countries such as the United States and Canada where systematic research and many field-initiated projects are underway (Carmichael Olson, 2006).

The cause and effect of alcohol on the fetus was first identified in New Zealand in the 1970s. However, relative to other countries, there has been very little in the way of policy development relating to FASD as a public health and disability issue that has implications for multiple sectors and services. Attempts to get policy action at a Governmental level to address FASD to date has not resulted in any substantial or ongoing strategic planning, funding or action under the National Drug Policy (NDP) to date (Inter-agency Committee on Drugs 2000).

This section sets out recent activity at a policy and community level in New Zealand and makes recommendations for strategic action. It is not intended to be a complete dossier of activity but enough to illustrate the current situation relating to prevention and intervention activities in New Zealand.

Current Government policy on alcohol and pregnancy

Alcohol and pregnancy as a public health issue has been identified in some national health priorities. Priority three of the National Drug Policy 1998-2003, is “*the reduction in the prevalence of drinking among pregnant women and women planning pregnancy*”.

The National Drug Policy 2007-2012 (NDP) recognises that alcohol-related harm includes “*birth defects, including Fetal Alcohol syndrome and other permanent disabilities*” (Ministry of Health 2007b). A new National Alcohol Strategy based on the National Drug Policy is yet to be developed.

The existing National Alcohol Strategy 2000-2003 identifies as an outcome, “*Reduction in the prevalence of drinking among pregnant women and women planning pregnancy*”. However it goes on to state, “*Indicators/targets cannot be identified until baseline data are generated*”.

The NDP will guide the IACD to develop the National alcohol strategy. Plans are to include:

- Specifying the type of activities to be undertaken
- Contain specific outcome indicators and targets
- Identify ways to resource the activities
- Nominate which government agency will take the lead in each area

Developing new action plans under the NDP will include a systematic review of evidence, involvement of topic experts and consultation with stakeholders and include a stronger intersectoral focus encompassing both social and economic harms.

In addition, the Ministry of Health *Guide to Developing Public Health Programmes* which identifies *Informative Inputs* as the important first stage of the *Logic Model* in the development of a public health programme (Ministry of Health, 2006, page 5) and *The Public Health Workforce Development Plan* provide further avenues to propose that FASD is addressed as a public health issue.

There is recognition in the NDP that drug abuse underlies many social issues and concerns as they relate to five identified sub-themes:

- Strong families
- Healthy confident kids
- Better health for all
- Strong and safe communities
- Positive aging

While it is possible that FASD has implications for all of these sub-themes, it remains unknown whether the next National Alcohol Strategy will specifically call for targeted funding to be directed to any proposed FASD prevention and intervention objectives.

Ministry of Health

In 2006, the Ministry of Health strengthened their advice to avoid alcohol during pregnancy, when planning pregnancy and while breastfeeding. This is in line with other countries such as Germany, France, Canada and the United States where 30 years of research has been carried out. However, a search of the Ministry of Health website reveals very little indication of any other activity related to FAS or FASD.

The subject of drinking alcohol during pregnancy is mentioned in some health-related documents in addition to those discussed above including:

- The Alcohol and Drug Toolkit for District Health Boards (2001).
- The Food and Nutrition Guidelines for Healthy Pregnant and Breastfeeding Women (2006).
- A Ministry of Health pamphlet (4160), Alcohol and Pregnancy: When you drink so does your baby.

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 (Associate Minister of Health letter to the Fetal Alcohol Support Trust and others, 2005).

The Ministry of Health has a leadership role on the cross-ministry officials group known as the Interagency Committee on Drugs (IACD) and a Health Minister chairs the Ministerial Committee on Drug Policy (MCDP) which meets twice yearly. At a Government level there has been no documents produced that discuss the impact or implications of FASD for the New Zealand health and social welfare systems or the surveillance and research that may be needed, apart from a small briefing paper to the MCDP prepared by a Ministry of Health Official seven years ago (IACD, 2000) .

In response to questions from the Health Select Committee, the Ministry of Health advised that in 2004 its annual investment to promote responsible drinking to prevent FASD in New Zealand was between \$112,000 and \$160,000 (Government Response to the Health Select Committee, 2005).

In 2004 the Ministry of Health also contributed \$40,000 toward a joint alcohol and pregnancy research project with the Alcohol Advisory Council of New Zealand (ALAC). This investment followed a 2003 recommendation from the Health Select Committee to research the prevalence of FASD. However, as the current lack of clinical services for FASD precluded the gathering of accurate or meaningful incidence or prevalence data, the research grant was transferred to data collection regarding the drinking behaviour and knowledge of pregnant women resulting in the Parackal et al (2006) study.

Also in 2003, in response to a public petition to Parliament submitted three years earlier, the Government instructed the Ministry of Health and the Alcohol Advisory Council to submit an application to the Food Standards Australia New Zealand (FSANZ) to require a health advisory label on alcohol beverage containers advising of the risks of consuming alcohol when planning to become pregnant and during pregnancy⁵. This application has appeared on the FSANZ work plan and a decision on the future of the application will be made by FSANZ officials on its future direction in 2007. The application must gain the approval of both Australian and New Zealand officials to progress.

In addition, the Ministry of Health notes potential areas of development on prevention measures. In a letter responding to the Parliamentary Health Select Committee (May 2006) the Deputy Director of Public Health of the Ministry of Health noted that when the service specification component of the Maternity Notice (Section of the New Zealand Public Health and Disability Act 2000) is next reviewed, the Government will “*consider the option of*” amending the Notice to explicitly require maternity carers to address issues related to drinking alcohol during pregnancy. Currently the items covered in the Maternity Care Plan of the Notice include such things as: (g) smoking cessation options; (h) screening for infectious diseases; (i) assessment of risk of family violence but nothing relating to alcohol⁶.

The Ministry also advises that it is “*considering the potential of*” a WellChild register and advise that any planning for such a register will incorporate FASD information in their discussions.

Disability Services

FASD is not considered a disability, according to the Chief Advisor of the Ministry of Health Disability Services Directorate (Mundell, 2006)⁷. However, people with FASD will qualify for support if they meet the threshold for

⁵ For further discussion of health advisory labelling, read the Alcohol Healthwatch Briefing Paper: Health & Safety Advisory Statements for Alcohol.

⁶ A submission from Alcohol Healthwatch has been made to the maternity review calling for this action to take place.

⁷ Of note in this regard is a recent landmark ruling by the British Columbia Court of Appeal in an FASD case, which has overturned Canadian policy that cuts off disability benefits to an intellectually disabled adult with an IQ higher than 70 (CBS News, 20 December 2006).

intellectual disability, that being an IQ of 70 or less as well as significant deficits in adaptive behaviour. The definition of disability used for eligibility to Government funded Disability Support Services was approved by Cabinet in 1993, and covers intellectual, physical or sensory disabilities that last for 6 months or longer, and are of such severity so as to require assistance.

The Disability Services Directorate is aware of FASD and intends to develop a sub-code for a new data base for Needs Assessment and Service Coordination agencies (NASCs) (Mundell, 2006). Whether the threshold for eligibility will alter remains unknown.

The gaps in disability services, was a recurring theme raised by disability caregivers at the Disability Services Directorate (DSD) Consumer Forums held in Auckland in 2006 including:

- Uncertainty as to which agency or government department was responsible for providing services when there were dual health and disability
- Lack of integration between DSD services and Special Education Services
- Concern about eligibility for allowances, invalids benefits and funding of day to day services
- Inconsistent practices between Needs Assessment and Service Coordination Services (NASC)
- Lack of support for caregivers and families with disabled children
- Families having to constantly defend their needs

The summary of 'other issues' noted that there was *"little recognition of children with Fetal Alcohol Syndrome as having a disability."* (Ministry of Health Disability Services Directorate, 2006).

Mental Health Directorate

There is currently no indication that FASD is considered systematically as a specific policy issue within the Mental Health Directorate and associated services. However, the Auckland Region Community Alcohol and Drug Services, contracted by the Waitemata District Health Board under the Mental Health and Addiction Action Plan, provides a Pregnancy and Parental Service programme for women who are pregnant or with young children and who have alcohol and other drug problems and are poorly connected to other health and social services. The service has been operating for approximately five years.

Other mental health services such as Child and Adolescent Mental Health Services may address FASD issues on an ad-hoc basis depending on the interest and knowledge of individual practitioners within these services. Recently the Ministry organised a brief educational presentation on FASD in Wellington for the Child and Adolescent Mental Health workforce.

No systematic data has been collected on FASD and mental health in New Zealand.

Other Ministries

FASD and its implications do not appear to be highlighted as a policy consideration relating to education, social development, justice or corrections in New Zealand, despite there being ample international evidence that FASD has a significant impact on these government services.

Alcohol Advisory Council of New Zealand

The Alcohol Advisory Council of New Zealand referred to earlier on page 25, is a government agency with a sole focus on alcohol. As such ALAC has a direct, long term interest in the issues relating to alcohol use during pregnancy. This involvement includes funding a working party and a discussion document in 1994 (Curtis, 1994) and a seeding grant to establish a national organisation in 1998. The organisation currently makes available:

- A video on alcohol and pregnancy called “Drinking for Two”.
- A pamphlet in English, Maori and Pacific languages called “Drinking and Your Baby”.
- Alcohol and pregnancy information on the ALAC website.

In 1998 ALAC agreed to provide an annual grant to support the coordination of work carried out by the newly established Fetal Alcohol NZ Trust (FANZ) and funded a national FAS conference. FANZ was the only national organisation to specialise in FASD. In 2003, the trustees of FANZ agreed to cease operations and that ALAC would coordinate national action with a national advisory group to guide the continuation of work on FASD issues. A multi-sector advisory group has met several times since 2004 to address FASD issues in the national interest. Included in the organised activities has been a visit to New Zealand by a multidisciplinary diagnostic team from Canada, (funded by ALAC) and the drafting of a strategic plan to replace the now defunct FANZ strategic plan.

The overall goal of the strategic plan is “Abstinence in pregnancy by 2020” and consists of four major goals:

- Preventing the incidence of FASD
- Identifying those affected by FASD
- Treating those affected by FASD in appropriate settings with appropriate interventions and
- Promoting multisectoral/multidisciplinary cooperation
- Information sharing

At the 2006 meeting of the advisory group, it was agreed that the strategic plan together with a briefing paper, should be put before the Inter-Agency Committee on Drugs (IACD) a cross-ministry officials group, for their consideration (see above). At the time of publication of this paper, the decisions and outcomes of that presentation are not known.

The ALAC Statement of Intent for 2006-2007, does not include any reference to alcohol and pregnancy, FASD or the national FASD advisory group (ALAC, 2006).

Alcohol Healthwatch

Alcohol Healthwatch is a small non-government organisation that, through its contract with the Ministry of Health, has had a long term commitment to FASD prevention and intervention. The aim is to ensure that FASD is a well recognised and resourced strategic public health priority and that services and community involvement is well informed, active and supported at all levels.

Over the past 15 years this action has included:

- In 1992, developing a pamphlet called “Alcohol and Pregnancy: When you drink so does your baby”. This resource was adopted by the Public Health Commission and subsequently the Ministry of Health.
- Developing and distributing (1994), a manual for health professionals.
- Providing (1994) the infrastructure and management for the Fetal Alcohol NZ Trust (FANZ) coordinated work programme which included training workshops, seminars and a national conference, resource development, policy advice and a public petition to require health warning labels. FANZ ceased operating shortly after the contract with Alcohol Healthwatch ended.
- Coordinating the 9th September FASD Awareness Day activities each year since 09/09/99, in collaboration with international organisations and advocates.
- Continuing since 2002 to develop and provide resources and advice including lectures on FASD for tertiary institutions.
- Establishing in 2004 the Auckland Region Fetal Alcohol Network (ARFAN) in collaboration with community organisations such as Pacificare Trust. ARFAN continues to provide a forum for information, advice and support on FASD matters.
- Participating in the ALAC national FASD advisory group.

Alcohol Healthwatch is currently working to develop and expand FASD prevention/intervention measures.

Fetal Alcohol Support Trust

Set up in 1998 in Hamilton and led by FASD family advocate Shirley Winikerei, the Fetal Alcohol Support Trust (FAST) has worked to support and advocate for the needs of families affected by FASD across New Zealand and to improve the knowledge and responsiveness of service providers. Relying entirely on charitable community funding, FAST has provided a life-line for many families in crisis, has provided resources to raise awareness of FASD and the best strategies for managing the associated disorders.

FAST provides an important link for families and other community advocates and groups such as the Fetal Alcohol Advocacy Southland. However due to a combination of a lack of volunteers, an inability to maintain sustainable community funding, and no government funding - FAST is struggling to maintain this work, despite strong advocacy across New Zealand.

Recommended Actions

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

“A comprehensive FAS prevention program should provide multiple and overlapping levels of reinforcement, incentives and controls.”

(Stratton et al, 1996)

Prevention, surveillance, diagnosis and intervention are inseparable parts of the same continuum (Clarren, 2007). Harm prevention is recognised as requiring a broad-based approach to alter behaviour within a variety of settings (Casswell and Gilmore, 1989). The Institute of Medicine (Stratton et al, 1996) sets out a comprehensive prevention/intervention approach for FASD consisting of:

- Universal prevention – primary prevention measures targeted to the general population
- Selective prevention – secondary prevention measures targeted to sub-groups in the population
- Indicated prevention – tertiary prevention measures targeted to high risk individuals.

These and their implications are discussed below.

The ethics of public awareness

Alcohol is a substance that causes birth defects. Yet alcohol beverages are highly promoted produce that are freely available to the general population, with limited regulation of access and no mandated health warning messages. As such there is an onus on the authorities that control the sale and supply of alcohol, to strongly and pro-actively influence public awareness of the consequences of drinking during pregnancy and to adequately and appropriately support those who may be adversely affected by the consumption of the product.

From an ethical and human rights standpoint prevention measures need to be carried out with the social consequence, rather than economic imperatives in mind, particularly when it comes to the needs and rights of children (Henteleff, 2007). However, it is also important when raising awareness of an issue as sensitive and preventable as FASD, to reduce any stigma and guilt and to ensure adequate follow-up support is on hand. No one sets out to deliberately harm their child by drinking alcohol and neither do they get to that situation entirely on their own.

Raising awareness needs to be done in the full knowledge that it may bring with it a certain level of anxiety about past drinking behaviour and in some cases may result in the realisation that a known person or loved-one may be affected by FASD.

Raising awareness raises expectations that services and support are available. It is therefore important to ensure, when raising awareness, that services and community support are available and knowledgeable enough to respond appropriately.

Primary Prevention

“The relevant nutrition to pregnancy begins before a woman conceives”.
(Ministry of Health, 2005).

Nutrition and wellbeing prior to pregnancy is a time that is all too easily neglected by busy women in a fast-paced modern society, yet this is inextricably linked to pregnancy outcomes and the future healthy development of every individual. There is a growing body of evidence that suggests that many adult diseases have their roots in poor nutrition prior to as well as during pregnancy (Barker, 2003).

The fetus is very vulnerable to the teratogenic effects of alcohol or deficiencies in vital nutrients such as folate which can be depleted by alcohol consumption early in pregnancy. This critical time of development is usually before a woman recognises her pregnancy and seeks advice from a lead maternity carer. Greater emphasis needs to be placed on preconception care to focus public attention toward the all important nutritional requirements and drug avoidance before pregnancy is detected. This together with the provision of advice to women at the time their pregnancy is confirmed (which is often not until several weeks after conception), will ensure the greatest number of opportunities to reduce risk are taken.

There is also a need to ensure that health messages about drinking during pregnancy are continuously delivered through various media and settings. The Government and ALAC resources on abstinence during pregnancy are available free to the health sector and the general public but they do not form a part of any comprehensive, active distribution or national awareness programme for the public. Being ‘available on request’ is too passive. Information needs to form part of a planned, proactive and sustained communication strategy. A comprehensive approach needs to include and will be reinforced by the inclusion of health advisory statements on alcohol containers and at all point of sale outlets⁸.

Secondary Prevention

Secondary prevention aims to target evidence-based prevention programmes to reach specific subgroups in society. For instance public health nurses in a variety of settings are well placed to recognise and address adolescent pregnancies that may be at risk from alcohol and other drugs and also to identify that a child’s behaviour at school may be related to their health history (Caley, 2006). This can lead to an important opportunity to provide positive prevention intervention with the mother to ensure subsequent pregnancies are alcohol and drug free.

⁸ For more information on this topic read the Alcohol Healthwatch briefing paper entitled Alcohol Health and Safety Advisory Statements for Alcohol in New Zealand at www.ahw.co.nz

Screening

In general, the amount a woman drinks before she is pregnant can be an indicator of whether she will continue to drink during pregnancy. Simple screening questionnaires such as the T-ACE or TWEAK (see Appendix 2) in a primary care setting has been shown to be an effective tool for identifying women who may be at risk of drinking alcohol during pregnancy (Russell et al, 1994; Chang et al. 1999). Chang and colleagues looked at whether a short, structured discussion with a nurse or doctor about drinking could cut rates of prenatal alcohol use among 304 pregnant women. All of the women had been screened with the T-ACE questionnaire, which helps identify women who are at particular risk of drinking during pregnancy. Chang et al (2005) found that the intervention was most effective when a woman's partner was involved.

Universal and targeted screening will be effective in reducing the risk of harm to the developing child and will provide an effective early intervention opportunity to reduce the risk of alcohol use disorder in women. In addition, universal screening will reduce the risk of missed opportunities that can arise from ad-hoc judgement calls on who is likely to be at risk and reduce stereotyping and stigma, ensuring that all women are considered and treated equally.

Tertiary Prevention

“Pregnant women’s use of alcohol cannot be separated from other issues in their lives, such as violence, trauma history, isolation and socioeconomic status”

(Motz et al, 2006).

Intervention to prevent pregnant women at high risk of drinking alcohol during pregnancy giving birth to a child with FASD requires a multi-level and specialised approach. Though FASD can be found across the socioeconomic scale, studies of the mothers of children diagnosed with the full Fetal Alcohol Syndrome show they often have complex needs that require a multi-layered approach to reduce harm to them and their children.

Studies carried out in the United States show that mothers of children with full FAS are more likely to:

- Live at the poverty level
- Have 3 or more children
- Start drinking at an early age
- Come from an alcohol abusing family background
- Have experienced serious abuse themselves
- Have post traumatic stress disorder
- Have depressive disorders
- Live with partners who do not want them to quit drinking
- May have fetal alcohol related conditions themselves (Clarren 2000).

Screening for high risk women needs to take into account the fact that FASD may be “trans-generational” ie. FASD may be occurring over several generations (Streissguth & O’Malley, 2000).

Early intervention for high risk women and children

The evaluation of 10 years of the Toronto-based service “Breaking the Cycle” has identified that 92% of the mothers enrolled in the programme experienced triggering events that led them to engage in substance abuse (Mutz et al, 2006). Early engagement of pregnant women using substances in the first two trimesters resulted in positive outcomes for mothers and children.

The programme uses an integrated Maternal-Child Service Model to reduce harm based on several integrating theoretical frameworks such as harm reduction, relational theory, attachment theory and development theory. Important principles, such as ‘children first, strengthening families, equity and accessibility and community partnership, underpin the service. The programme also engages strongly with knowledge exchange and sector development and training.

Comprehensive early intervention programmes with pregnant women at high risk of alcohol abuse provide an opportunity to reduce the risk for both the mother and the child. FASD may be an unexamined cause of addiction relapse for a number of reasons (Mitchell, 2007). Women who have children with unidentified FASD are at high risk of relapse due to the behaviour of their children and the belief that they are poor parents. They may relapse because they have used during pregnancy and have experiences of guilt and shame or they may have FASD themselves putting them at high risk of use or relapse.

The closest New Zealand has come to an integrated service for substance abusing mothers is the Pregnancy and Parental Service of Community Alcohol and Drugs Services (CADS) in Auckland, however it does not have an integrated child assessment service. This model could be expanded to include child assessment and support programmes for families and be extended to other centres based on evaluation and meaningful dialogue with consumers and other service providers.

However, many women who continue to use alcohol during pregnancy may not fit the criteria for alcohol use disorder or come to the attention of services designed for identified risk groups. Nevertheless, New Zealand has a strong culture of heavy alcohol use where alcohol abuse is considered to be normal social drinking which can result in significant developmental problems for their child. Therefore a child-centred approach is an equally important prevention measure to identify other women at increased risk but not meeting criteria for or seeking treatment of problem drinking.

Recommended actions

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: Improving the outcome for the affected child and family

“The Ministry is working towards a New Zealand where people with impairments can say they live in ‘A society that highly values our lives and continually enhances our full participation’” (Ministry of Social Development, 2006).

Early developmental screening and intervention

Identification and referral for multidisciplinary diagnosis early in development is essential for accurate assessment of the developmental needs of infants and children thought to be affected by prenatal alcohol exposure. Not only is early identification and appropriate intervention important for the child’s development, it can reduce the negative flow-on effects of secondary disabilities of FASD (Streissguth et al, 1996).

It provides an opportunity to change the knowledge and behaviour of pregnant women to prevent subsequent pregnancies being affected, not only for the individual but within families and the community in which they live. Because FASD can be trans-generational it is a critical and pivotal prevention measure.

Although putting in place a process for multidisciplinary diagnosis entails some time and disruption of service adaptation and initial investment Significant benefits can be gained as follows:

For the community and services, the accurate diagnosis of FASD:

- Shifts the reality of FASD into the public domain increasing the opportunity to raise awareness to reduce drinking during pregnancy
- Increases ability to clarify misdiagnosis and co-occurring diagnosis
- Changes perceptions of individual having a disability rather than being ‘bad’
- Targets funding more appropriately
- Directs and guides more appropriate successful intervention and support
- Provides for more efficient linkages between services
- Increases the community understanding of and responsiveness to FASD
- Creates prevalence data by way of an accurately assessed clinical population

For the mother and family/whanau, the accurate diagnosis of FASD:

- Increases awareness and knowledge of alcohol as a key cause of problems
- Prevents subsequent alcohol exposed pregnancies

- Provides an opportunity to treat alcohol abuse
- Shifts the focus from the blame and guilt of 'poor parenting' to successful strategies
- Provides for coping mechanism that adjust to a disability
- Reduces the 'revolving door' of inappropriate and less effective therapies
- Develop ability to focus on strengths of individual
- Reduces inappropriate and often dangerous assumptions

For the child and family/whanau the accurate diagnosis of FASD:

- Provides an explanation and understanding of the reason for the child's behaviour problems
- Provides an opportunity to learn to compensate for dysfunction and be proactive rather than reactive
- Changes perceptions of self
- Facilitates learning how to avoid risk and conflict
- Highlights the recognition of the child's strengths
- Identifies other treatable conditions such as seizures, cardiac and visual problems
- Enables schooling and other services to be tailored to meet the child's learning needs and abilities

(Adapted from Opie, 2007; Dubovsky and Knight, 2007)

Barriers to effective intervention

"For these children, there has been a curious lack of enthusiasm for targeted activities directed at the prevention of secondary disabilities"
(Stratton et al, 1996).

Families seeking medical advice and intervention for a child exposed prenatally to alcohol often encounter a reluctant health profession (Symes, 2001; Russell, 2005). Some of the reasons behind the lack of FASD service development to better address the needs of affected individuals are multiple and may include any of the following:

- o That FASD is not considered a primary mental health diagnosis under the DSM IV (Child and Youth Officer, British Columbia, 2006).
- o FASD is included in very few medical textbooks and tertiary training.
- o Many medical and other professionals are not comfortable dealing with substance use or addiction problems.
- o There is reluctance to distinguish FASD out of fear of stigmatising or causing anxiety and guilt in the mother, child and family/whanau.

- There may be a misguided belief that there is little point in raising the subject since the damage is done.
- There is a lack of knowledge about the benefits of early identification for the individual and their family/whanau over a lifetime.
- There is a lack of the necessary skills to recognise and refer possible FASD clients for a medical assessment.
- There is a lack of trained multidisciplinary teams to carry out a full and accurate physical and psychological assessment of a child/adult.
- In New Zealand FASD is not considered a disability that fits the criteria for ongoing community and educational special needs services.
- There is a reluctance to diagnose FASD because of its ineligibility for many of the special educational, disability or support services for which a child/adult with FASD may need over a life-time.
- A belief that the Government would be doing something more about drinking during pregnancy if it was a serious issue.

“Was this [doctor’s] reluctance a misunderstanding of the condition and its ramification or was it indeed sensitivity and compassion toward the person who had caused the condition? Either way it was harmful and did not help in any way.”

(Russell, 2005).

Even birth mothers, who have had their often long-held suspicions about their child’s difficulties being related to their prenatal exposure to alcohol, can meet with resistance to a diagnosis of FASD for fear of causing stigma and guilt. However, they usually find the experience of diagnosis a positive starting point for them and their child (Symes, 2004; Russell, 2005). They are more likely to feel regretful rather than guilty wishing they had known the facts much earlier.

It is important that health professionals are trained not only to identify and diagnose FASD but to be confident in the knowledge that the benefit of this outweighs any perceived or real barriers to health and wellbeing they think this diagnosis may have on the child, mother or family. It is inappropriate to withhold information that may be important to them. Also, as stated above, early diagnosis and intervention are important for the informed delivery of follow-up services, reducing the risk of secondary disabilities developing and subsequent pregnancies being similarly affected.

The differential diagnosis between conditions such as FASD and other conditions such as hyperactivity, impulsivity, attention deficit, behavioural problems or poor academic performance is a specialised field and correct diagnosis is important in providing the best fit with educational, treatment and community support programmes (Malbin, 1993). As pointed out by Diane Malbin, treating FAS with Non-FAS Methods, provides a poor fit for the individual.

Eligibility of FASD for disability and other services

“I was told that she does not fit the criteria for services and I desperately need some help” (Communication with a Wellington mother of a 9 year old recently diagnosed with fetal alcohol syndrome 29/11/06).

This experience appears to be very common among families living with FASD, whether caring for affected children or adults (Symes, 2001; Salmon, 2007).

While there has been a great deal of positive work and shifts in attitude to ensure the inclusion of people living with disabilities in New Zealand society, a significant gap appears to remain regarding support services for many disabilities with a neurodevelopmental origin (Ministry of Health Disability Services Directorate, 2006). These appear to largely fall outside prescribed eligibility criteria set by government policy. Consequently, families are being left to manage children and adults with significant behavioural, emotional and functional deficits without adequate support or respite care, putting a strain on them, their families and increasing the risk of secondary disabilities developing.

“Those with FASD are the most misunderstood and since FASD is the most prevalent birth defect, [in North America] students with FASD, in all likelihood, outnumber other students with special needs. Educational success for students with FASD sets the stage for a positive and socially connected adulthood. A lot of resources are being used ineffectively.”

(Cunningham, 2007)

Very often a child or adult with FASD will appear to be relatively high functioning but clearly evidence shows that this is misleading. As pointed out in section one, while FASD is a leading cause of preventable mental retardation, the IQ for the majority of individuals with FASD is in the borderline to normal range - outside the threshold for service eligibility and misunderstood by various services. Any cognitive assessment will not provide a complete or accurate basis on which to assess the extent of their disabilities. Studies show that adaptive skill levels are always lower than cognitive ability levels (Russell, 2007).

“The individual tends to appear to be ‘normal’ have average or above average intelligence, has strong skills with verbal expression and can say that he/she knows what he needs... yet cannot follow through. The individual is often misjudged and criticised as non-compliant, uncooperative, resistant, manipulative and unmotivated.”

(Dubovsky and Knight, 2007).

The social expectations of a person who ‘looks’ relatively normal will always be higher than for someone who ‘looks’ disabled, adding further stress to an already difficult situation. Evidence suggests that secondary disabilities are more prevalent among individuals who do not have full FAS, though their functional impairment may not be dissimilar (Streissguth, et al, 2000). The poor prognosis for individuals without the full syndrome may be explained by the lack of ‘visibility’ of associated brain disorder.

The ability of an individual with FASD to function independently is related to brain pathologies affecting many specific domains of neurological functions of a psychiatric nature, not just those relating to cognition and intelligence (Mela, 2006).

“I guess what comes out of all of this for me is the lack of understanding from the agencies /professionals of the peculiarities of FAS – and how heartbreaking it is for all concerned. When you try to explain how she functions and the need for clear boundaries they imply obliquely, that you are a control freak.”

(Personal Correspondence with NZ caregiver of adult with full FAS).

The consequences of not recognising FASD as a specific disability in an individual can be severe (Dubovsky and Knight, 2007).

Effectiveness of improving FASD eligibility

The evidence that early appropriate intervention and ongoing support into adulthood is cost-effective and beneficial to the family and the affected individual has been established. However services that meet the needs of New Zealand individuals and families living with FASD remain minimal or non-existent. While this had been the case in other countries such as the USA and Canada, their responsiveness has improved dramatically over the last decade (Health Canada, 2006; Mela, 2006).

The current diagnostic, referral and eligibility situation in New Zealand appears to be denying families critical and appropriate intervention, diminishing their opportunity to realise their potential and leaving them vulnerable and at much greater risk of experiencing multiple and ultimately destructive problems throughout life. FASD is associated with many tragic and avoidable outcomes (Kellerman, 2006).

“Reading these stories just makes me want to cry. Once again, I am made aware how blessed our whole family is that [name] is so impaired. Isn't that a sad state – that a family celebrates having a more severely impaired child because they know he will always qualify for extra services and support.”

(Correspondence from a mother of a child with full FAS, 20/12/2006).

Secondary disabilities are largely avoidable through a better informed early intervention process, and through stable support processes. Their provision will reduce rather than increase the current burden of FASD in New Zealand.

Developing integrated policy to address existing FASD

Policy to address existing FASD is lacking in New Zealand. Consequently a skilled and knowledgeable workforce within relevant services has never been prioritised. Policy needs to be comprehensive, inclusive and integrated.

Several qualified overseas FASD experts who have visited New Zealand to present on FASD have expressed a willingness to help with developing a comprehensive response. This includes teaching multidisciplinary FASD diagnosis protocols so New Zealand can establish its own skill-based teams or centres. This training would be based on the best practice diagnostic guidelines available, such as those recently published by the Canadian Medical Association (Chudley et al., 2005).

Those in the wider health sector, teachers, social and community workers, and those in the justice system also need educating in the presenting characteristics of FASD and the importance of appropriate early intervention and/or referral options.

Ensuring individuals with FASD are appropriately supported will reduce the likelihood of secondary disabilities occurring and add value to multiple sectors. Training to increase understanding will ensure that care services that are needed can be planned long-term, be consistent and collaborative and help keep the duplication of inappropriate and ineffective services, to a minimum.

Can New Zealand afford to meet the needs of people with FASD?

As discussed in section 2 (page 21) the cost of training and integrating personnel within existing systems is likely to be insignificant alongside the cost of not treating FASD affected individuals appropriately and preventing further generations from being similarly affected.

There is no need for New Zealand to reinvent the wheel. Multimedia online training packages for health practitioners and international diagnostic expertise are available as and when requested. Training for other services can also be accurate and comprehensive based on best practice models that have been developed and refined over many years. The resources are plentiful.

The following selection of guidelines and strategies from Canada and the USA provide examples of national and regional initiatives that could be adapted and applied to address FASD in New Zealand across a range of Government services.

- Breaking the Cycle: Measures of Progress 1995-2005 (Mothercraft & Hospital for Sick Children, 2006).
- Canadian Northwest FASD Research Network
<http://www.fasdnetwork.ca/default.cfm>
- Enhancing Fetal Alcohol Syndrome (FAS)-related Interventions at the Prenatal and Early Childhood Stages in Canada (Canadian Centre on Substance Abuse, 2001).
- FAS Implications for Correctional Services (Correctional Services of Canada, 1998).
- FASD training study: Final Report (First Nations Child & Family Caring Society of Canada, 2006).
- FASD: Canadian Guidelines for Diagnosis, (Chudley et al, 2005).

- FASD: Community Discussions: Summary Report (Saskatchewan, 2002).
- FASD: Planning for Students with FASD: A guide for educators (Saskatchewan Learning, 2004).
- FASD: Strategies not Solutions. (Edmonton and Area Child and Youth with FASD Subcommittee, funded by Health Canada and the Alberta A&D Abuse Commission, 2004).
- FASD Ontario Justice Committee (members of the FASD Stakeholders of Ontario) funded by the Public Health Agency of Canada, <http://fasdjustice.on.ca/>
- Fetal Alcohol Syndrome (FAS) “Pregnant? No alcohol!” Campaign (Health Canada, 2003).
- Fetal Alcohol Syndrome: A resource for professionals (Saskatchewan Institute on Prevention of Handicaps (2000).
- Fetal Alcohol Syndrome and Women’s Health: Setting a Research Agenda. <http://www.bccewh.bc.ca/Pages/pubspdflist4b.htm#fas>
- Health Canada, Best Practice Guidelines, (2001).
- Health Canada, Best Practices: Fetal Alcohol Syndrome/Fetal Alcohol Effects and the Effects of Other Substance Use During Pregnancy (2000).
- Information and feedback sessions Health Canada FAS/FAE initiative announced in the February 1999, Budget.
- Interagency Coordinating Committee on Fetal Alcohol Syndrome (ICCFAS). <http://www.niaaa.nih.gov/AboutNIAAA/INteragency/>
- Mother and Child Reunion: Preventing Fetal Alcohol Syndrome by Promoting Women’s Health. <http://www.bccewh.bc.ca/Pages/policyseries.htm#fas>
- SAMHSA Database. The Substance Abuse and Mental Health Services of the United States Department of Health and Human Services, has a FASD Center of Excellence that has information on thousands of FASD resources. <http://www.fascenter.samhsa.gov/>

This is far from an exhaustive list of what is available but provides a sample of policy, projects, strategies and models that has been developed through the integrated collaboration of health, social, justice and educational professionals, researchers, community and family advocates, birth mothers and individuals affected by FASD.

For Aotearoa New Zealand, the development of ‘best practice’ approaches and models need only to draw on these or similar resources and incorporate an approach that is culturally responsive to the people.

Recommended action

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 include criteria that reflects the functional and behavioural deficits of developmental disorders, like FASD to reduce the risk of secondary disability and family burnout.

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Appendix 1.

Each of these children has been placed in the care of Child Youth and Family Services and has a probable history of alcohol and/or other drugs exposure prior to birth. As the advertisements mention, this is an important factor that needs to be taken into account by future caregivers alongside other adverse events that can adversely impact the child's health and development into adulthood.

North Shore Times Advertiser August

BRIGITTE

Brigitte is 5 months old. Her mother is European. Brigitte may have been exposed to alcohol and/or substances in utero. Her mother has a mental health condition. Brigitte is currently under the care of a range of health professionals in order to monitor her development/progress.

Brigitte needs permanent parents who have the time and commitment to provide for her needs. PERMANENCY will be secured under the Care of Children Act. Applicants must live in the Auckland Region as links with the biological parent will need to be maintained.

If interested, please contact
Child Youth and Family,
Telephone 914 1157
(office hours)



**PERMANENT
PLACEMENT
UNIT**

North Shore Times Advertiser May '07

CHARLOTTE

Charlotte is 9 months old and is of European and possibly Maori descent. Charlotte was exposed to drugs and alcohol in utero and as a result has some developmental delays. She is starting to make pleasing progress in all areas of development.


Charlotte will need ongoing input from the Child Development services to support her in reaching her full potential.

Charlotte needs a permanent home with a caring and committed family who can offer her security and stability.

She will need to be an only child or considerably younger than any other children in the family. Applicants should live in the Auckland region as links with her biological family will need to be maintained.

Permanency will be secured by orders under the Care of Children Act.

If interested, please contact
Child, Youth & Family,
Telephone 914 1157
(office hours)



**PERMANENT
PLACEMENT
UNIT**

September 2006

RANGI

Rangi is a happy, affectionate, strong minded and determined 31/2 year old Maori boy. He is a sociable, lively child who likes outdoor activities and enjoys the company of other children. Rangi has a good sense of humour.

Rangi needs a permanent family with parents who are able to set clear, consistent boundaries and firm routines and provide him with a nurturing, stable and secure environment.

Rangi's background is one of trauma. There is a possibility he was exposed to alcohol in utero. Rangi is currently under a team of health and educational professionals in order to monitor his development and progress.

Rangi needs to be the only child in the family or the youngest by at least 4-5 years.

Prospective applicants must live in the Auckland Region and contact with siblings will need to be maintained. Permanency will be secured by orders under the Care of Children Act.

If interested, please contact: Child, Youth and Family, phone: 914 1157 (during business hours).



**PERMANENT
PLACEMENT
UNIT**

MAX

Max is a 3 and a half year old boy of Samoan origin. Max is a happy child with an appealing personality and a wicked sense of humour. He is affectionate and responds well to adults and older children. He enjoys going to kindergarten, playing in the sand, going to the beach and listening to music.

Max was born with a bowel disorder and spent the first 15 months in hospital. He is a child with special dietary needs and that will be with him throughout his life. His new caregivers would need an informed understanding of diet in order to cater for him. Max may have been affected by alcohol while in utero. He may also need speech therapy.

Max needs to be the youngest in the family by at least 2 years.

Prospective applicants must live in the Auckland Region and contact with siblings and family will need to be maintained. Permanency will be secured by orders under the Care of Children Act.

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**PERMANENT
PLACEMENT
UNIT**

NORTH SHORE TIMES 29/12/07

Appendix 2.

Screening Instruments.

The purpose of screening is to identify health problems or risks in time for intervention to prevent serious consequences such as FAS (Stratton et al, 1996). There are many variations of screening instruments that have been used to ascertain risky drinking behaviour, such as the CAGE Test, the T-ACE Test, the AUDIT, MAST, SMAST and the TWEAK Test (Change, 2001).

Assessment of the effectiveness of these screening tools for brief intervention has been undertaken (Chang et al,2001; Aertgeerts & Buntinx, 2001; Bradley et al, 1998). These assessments indicate that the T-ACE Test and the TWEAK Tests appears to be the most sensitive for establishing risk drinking in women.

T-ACE
T Tolerance: How many drinks does it take to make you feel high?
A Have people Annoyed you by criticizing your drinking?
C Have you ever felt you ought to Cut down on your drinking?
E Eye opener: Have you ever had a drink first thing in the morning to steady your nerves or get rid of a hangover?
SOURCE: Sokol et al. 1989.

The T-ACE is used to screen for pregnancy risk drinking, defined here as the consumption of 1 ounce or more of alcohol per day while pregnant. Scores are calculated as follows: a reply of More than two drinks to question T is considered a positive response and scores 2 points, and an affirmative answer to question A, C, or E scores 1 point, respectively. A total score of 2 or more points on the T-ACE indicates a positive outcome for pregnancy risk drinking. The T-ACE was the first validated sensitive screen for risk drinking (defined as alcohol consumption of 1 ounce or more per day) developed for use in obstetric-gynecologic practices (Sokol et al. 1989) . An obstetrician developed the T-ACE after observing that asking patients about their tolerance to the intoxicating effects of alcohol did not trigger denial. The "socially correct" answer is not known (patients do not feel stigmatized to answer honestly), and tolerance reflects a pattern of drinking.

The four T-ACE questions (see T ACE textbox) take less than 1 minute to ask. The T-ACE is positive with a score of 2 or more points. One point is given for each affirmative answer to the A, C, or E questions. Two points are given when a pregnant woman reports that more than two drinks are necessary for her to feel "high" or experience the intoxicating effects of alcohol.

The TWEAK Test

Do you drink alcoholic beverages? If you do, please take our "TWEAK Test."

T	<p>Tolerance: How many drinks does it take to make you feel high? (Record number of drinks)</p> <p>Score 2 points if she reports 3 or more drinks to feel the effects of alcohol. Score:_____</p>	<p>No. of drinks</p> <p>_____</p>
W	<p>Worry: Have close friends or relatives worried or complained about your drinking in the past year?</p> <p>Score 2 points for a positive "yes". Score:_____</p>	<p>___ Yes</p> <p>___ No</p>
E	<p>Eye-Opener: Do you sometimes have a drink in the morning when you first get up?</p> <p>Score 1 point for a positive "yes". Score:_____</p>	<p>___ Yes</p> <p>___ No</p>
A	<p>Amnesia (Blackouts): Has a friend or family member ever told you about things you said or did while you were drinking that you could not remember?</p> <p>Score 1 point for a positive "yes". Score:_____</p>	<p>___ Yes</p> <p>___ No</p>
K(C)	<p>Cut Down: Do you sometimes feel the need to cut down on your drinking?</p> <p>Score 1 point for a positive "yes". Score:_____</p>	<p>___ Yes</p> <p>___ No</p>
	<p>Total Score = _____</p> <p>A total score of 2 or more points indicates a likely drinking problem.</p>	