Inquiry into preventing child abuse and improving children's health

Submission to the Health Select Committee

From the Fetal Alcohol Network New Zealand (FANNZ)

Thank you for the opportunity to make a written submission on the important public health matter of preventing harm to the children of Aotearoa New Zealand.

This submission is made on behalf of the hundreds of individuals who make up the Fetal Alcohol Network New Zealand (see appendix 1 for further details). The primary focus of this submission is on alcohol exposure before birth, addressing its lifelong implications and its prevention.

We applaud the Health Select Committee for its focus on prevention in this inquiry. We would welcome the opportunity to make an oral submission.

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Introduction

The causes and solutions to addressing this country's continuing unacceptable level of inter-generational child abuse and neglect appear complex. What is not so complicated is the understanding that alcohol is a root cause and alcohol exposure before birth is a causal pathway. This was documented in New Zealand as far back as 1874 with these immortal words;

"….our babies are not born health because the parents drink to excess and the child suffers.[1]"

The knowledge and evidence backing up such historical observations, has been presented over and over again to decision-makers but the issue remains stubbornly marginalised[2]. There is evidence to show that New Zealand has a relatively high level of drinking during pregnancy but there is little to show that this is being taken seriously enough within the health sector. Few district health boards have this as a prevention priority. There is no research looking into the effects of alcohol exposure on New Zealand children or to ascertain a likely prevalence.

It is well recognised internationally that prenatal damage from alcohol does not dissipate in childhood but is lifelong[3]. A Swedish Labour Market study illustrates this point well. It looked at the adult outcome on individuals who were exposed in utero to alcohol at a time when

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[1] Petition of Haimona te Aotearangi to the House of Representatives, 1874.

[2] Alcohol Healthwatch (2007). Fetal Alcohol Spectrum Disorder: Activating the Awareness and Intervention Continuum.

[3] Streissguth et al (1996). *Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE).* Final Report. University of Washington School of Medicine Department of Psychiatry and Behavioural Sciences.

alcohol availability increased in one region of Sweden for a short period. The policy was reverse one year later due to the immediate increase in alcohol-related problems, but the legacy was clearly lifelong.

The researchers found, ***"….that around age 30 the cohort in utero during the experiment have substantially reduced educational attainments, lower earnings and higher welfare dependency rates compared to the surrounding cohorts."*** (Institute for Labour Market Policy Evaluation, 2008[4]).

New Zealand with its liberal approach to alcohol availability and promotion can expect a similar outcome - on an ongoing basis. Addressing this harm must be prioritised.

Responses to the Terms of Reference of this Inquiry.

1/ *To update knowledge of what factors influence best childhood outcomes from before conception to 3 years, and what are significant barriers.*

Based on our experience, the main issue with knowledge is that it is usually not acted upon – which points to the second part being the issue - barriers.

Barriers may present as political, structural, emotional, ethical or economic to name a few. Viewed in light of the fact we are talking about preventing future children being born brain damaged by alcohol or by abuse and neglect, there is no real justification for these barriers. Their removal will require a mind-shift:

> Political – Alcohol is political. The Government allows 24/7 sale, supply and promotion and seems willing to tolerate $5 billion burden of health and social harm with the responsibility for this being directed at the drinker and community. This can change with Governments taking a leadership role in harm reduction.
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> Structural – Systems are set up to work in the interests of the contract. There appears little flexibility to enable workers to work collaboratively across systems, to bridge gaps, to innovate and to accommodate new information or direction based on need.
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> Emotional – Evidence may be rational but emotion is often the driver. That is why so much of our policy is written in the aftermath of some regrettable tragedy – the 'Moral Panic' phenomenon. We should not have to wait for more tragedies and outcry to respond appropriately to the information before us.
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> Ethics – It is important that any and all interventions do no harm. Believing there is a sacred 'right' to drink, many people avoid the subject for fear of labelling, stigma, backlash and guilt that may accompany the issues. However rights and non-intervention are far from neutral. There is a balance to be struck but doing nothing causes more harm than good.

[4] Nilsson J Peter (2008). Does a pint a day affect your child's pay? The effect of prenatal alcohol exposure on adult outcomes. *Institute for Labour Market Policy Evaluation*, Working Paper 4.

Economics – Health and or social justice is usually viewed as a cost when in reality the cost is not 'health and justice' but the 'absence' of these. Prevention, that results in the absence of something is difficult to measure and therefore far less likely to receive funding ahead of the rest of Vote:Health. This imbalance is uneconomic in the long-term.

No barrier is insurmountable when there is resolve to change the status quo. It comes down to the choice between barriers being used to deflect and obfuscate or their removal from the pathway to harm reduction.

In an ideal world, there would be no babies born affected by FASD. However in our current alco-genic environment and for all of the barriers mentioned above, there will always be children damaged by alcohol and it is wrong and unjust to single out the mothers for blame.

These are the children of a society that embraces and encourages drinking, tolerates intoxication and one in which we all share some responsibility. It is the responsibility of those who can make a change to do so. We may not be able to prevent all from being born affected by alcohol but we most certainly can reduce their numbers and treat justly those affected.

A child, adolescent or adult, whose genetic potential has been severely compromised by alcohol before birth is not able to change so readily. They will struggle to understand and manage their learning and behaviour and most people do not understand the degree of their disability. Without knowledge and appropriate support, these individuals become the parents who are readily judged as failures in our society – through no fault of their own.

It will take courage and commitment to change the mindset and reorient services to better meet this primary and secondary harm. Other Governments have recognised and are taking steps to systematically address the problem and New Zealand must also.

Remedy:

- Act on existing knowledge.

- Consult with experts – including affected families – and work together on a cross ministry approach to addressing FASD prevention and intervention.

2/ ***Practical improvements targeted at the preconceptional services so that children 'at risk' of adverse health outcomes are identified early, monitored appropriately, and followed through to achieve best outcomes.***

Drinking by women of childbearing age is now being recognized as significant and therefore much of the harm may be occurring before the pregnancy is consciously recognized. Reducing the risk to the health of young women and their children in such a pro-drinking environment requires effective measures known to reduce harm overall. The more robust control of availability - increasing price, stopping advertising, replacing alcohol sponsorship, requiring bottles to carry health warnings, no supply before age 20 years – are the opposite of what has happened over the past 2 decades.

The message that alcohol is a risk to the health of the child needs to be consistently and sustainably delivered by health professionals whenever contraception, pregnancy and/or child health is discussed. We know from surveys that women are not regularly receiving that information and when they do it may be incomplete, inaccurate or misleading. At least 50% of women believe some alcohol during pregnancy is acceptable and safe[5]. The internet or friends and relatives will add to the confusion. This needs a concerted effort to ensure consistent accurate information is being provided at every opportunity.

Add to that the myths and misinformation; the belief that you have to be an alcoholic to have affected children; the 'drank like a fish and nothing wrong with the kids' stories; the relentless pro-drinking bombardment of young minds; brand identity loyalty; sugar flavoured pink and purple designer drinks; cheap high alcohol content products available 24/7; the pressure to drink to be social – the list goes on and on.

Not only is the information available for women passive, inconsistent and ad hoc, it is unlikely to be discussed pre-conceptionally. In a strongly alco-genic environment, where there is nothing reminding women of the risks, little can be expected to change. The level of maternal alcohol consumption may be shocking to some but it is not surprising.

With minimal Government input to identify and address the problem, we should not be surprised this country's rate of consumption during pregnancy remains so high and can expect that many of our babies will be damaged by alcohol exposure.

Remedy:

- Support alcohol reform as documented by the Law Commission Review and strongly supported by communities across New Zealand. Evidence shows this would reduce harmful consumption overall and send a strong message that alcohol needs to be treated with far more caution and that the Government is serious about addressing the harm it is causing.

- Health professionals need guidance training and encouragement to discuss alcohol as part of general health consultations and those relating to contraception and reproduction in particular. Alcohol Healthwatch together with the University of Otago, has produced an online guide to assist clinicians to engage women about alcohol and pregnancy more effectively and competently[6].

- Back the work to require alcohol products to carry a highly visible pregnancy warning and back this up with point of sale information and a social media campaign.

- Ensure health and social wellbeing curriculum – from primary school through to tertiary education – incorporates the subject of FASD, its cause and effect.

[5] Parackal et al (2006). Report on Awareness of the Effects of Alcohol Use During Pregnancy Among New Zealand Women of Childbearing Age. *Submitted to the Alcohol Advisory Council & Ministry of Health.*

[6] Pregnancy and Alcohol Cessation Toolkit: An online resource for Health Professionals. www.akoaotearoa.ac.nz/projects/pact

3. What practical improvements can be made to antenatal maternity services so that children 'at risk' of adverse health outcomes are identified early, monitored appropriately, and followed through to achieve best outcomes.

It is important that mothers are well equipped and supported to make the healthy choice, the easy choice. Messages therefore need to be reaching a wider audience than just the mothers.

It is very important that Lead Maternity Carers enquire and document any prenatal exposure to alcohol or other drugs during pregnancy, particularly what occurred before pregnancy recognition. This is vital information when assessing a child that may be having difficulties and at risk of having FASD. Prenatal alcohol exposure for instance is a critical element necessary for making a definitive diagnosis of FASD.

It is also vital to ensure that any efforts to raise public awareness of the risk to the fetus from alcohol, is backed up by a system that is equipped to respond appropriately.

Alcohol and other drug services as well as child and adolescent focused health services need to be able to support those who seek help once awareness is raised. This not only supports the mother and existing child but the knowledge may prevent further children from being born affected.

There are evaluated models from overseas that have proven highly effective such a P-Cap the Parent Child Assistance Program from Washington State[7]. The goals of the P-CAP program are to (1) assist mothers in obtaining treatment, maintaining recovery, and resolving the complex problems associated with their substance abuse; (2) guarantee that the children are in a safe environment and receiving appropriate health care; (3) effectively link families with community resources; and (4) demonstrate successful strategies for working with this population to prevent the risk of future drug- and alcohol-affected children.

Auckland's Community Alcohol and Drugs Services (CADS) supports a similar programme for women – the Pregnancy and Parental Service – but this is currently not extended to incorporate the integrated care of the child to the same extent as P-Cap and there is no publically funded paediatric service in Auckland region able to fully assess a child for FASD. Nevertheless this is a model that could be expanded.

Remedy:

Fully document maternal alcohol and/or other drug use exposure so that this is accessible for future assessments of the child's learning and behavioural development.

Ensure appropriate services are available for referrals when a serious risk is identified for mother or child.

Extend Pregnancy and Parental Services across Auckland and other regions' substance abuse services. Enhance these so the child can equally benefit from being accommodated in a safe environment and linked to the family which will reduce the risk to this child and future children.

[7] http://depts.washington.edu/chdd/ucedd/ctu_5/parentchildprog_5.html

4. What practical improvements can be made to post-natal services (including the interface between lead maternity caregiver, Plunket and primary care) to ensure best outcomes for children.

As stated above, the prenatal history of risk is as important as the post natal environment into which the child is born. In New Zealand, Alcohol-related Neurodevelopmental Disorder (ARND) is very poorly understood and seldom recognized by child health services but is the most prevalent diagnosis on the spectrum. Where ARND diagnosis does occur, the affected person and their family experience ongoing marginalisation through ineligibility or misunderstanding of the disability. This needs to change.

FANNZ, through the support of Alcohol Healthwatch and recent success with accessing small one-off grants is doing its best to educate service providers across all sectors, but for the most part, the systems within which they must operate are not enabling their knowledge to effect changes in practice. There are often glimpses of recognition at the policy level but nothing that represents a comprehensive approach has yet been achieved. This is surprising given that FASD is recognized in the literature as the leading preventable cause of birth defects and brain-based disability in the western world[8]

A lack of FASD prevalence data in New Zealand is sometime offered up as a reason why investment in this area is not prioritised. It goes something like this: No prevalence data = no funding = no action = no cases identified = no prevalence = no funding and so on. While this catch-22 may appear convenient and cost saving, it is compounding and perpetuating the problem, causing distress for affected families and addig to the existing burden of cost on society.

While the policy vacuum described above continues, it has the effect of minimising and marginalising the issue everywhere. Ignored by the policy-makers, means it will be ignored by health and social services (ie. not included in contract schedules), then overlooked by many health professionals who in turn believe it is of lesser importance.

It is preventing prevention. Under such circumstances, FASD is rendered virtually invisible and therefore almost impossible to prevent. Women of childbearning age will as a result, continue to drink during pregnancy under the illusion that there is little they need worry about.

Government is a beneficiary of the sale of alcohol through excise tax to the tune of around $800million each year. However, far too little of this is directed toward the workforce able to address alcohol-related harm, that would prevent more babies being born affected and support those born affected more effectively. The public is supportive of a tax increase for alcohol and there is unlikely to be much opposition to this being used for the most vulnerable people adversely impacted by it.

[8] Carpenter B (2011). Pedagogically Bereft! Improving learning outcomes for children with fetal alcohol spectrum disorders. *British Journal of Special Education*. DOI: 10.1111/j.1467-8578.2011.00495

Blaming the individual, failing to investigate and identify the harm done to children and leaving families and communities to carry the load alone is unacceptable. As discussed above, children who do not receive appropriate care due to the lack of understanding by those who care for them – and this includes services – end up in serious difficulties including being in trouble with our laws. Studies from Canada and the USA show that individuals with FASD are significantly over-represented in the Justice system and the numbers could be as high as 23% of the youth offending population.[9]

"The alcohol affected child grows to adulthood with a greatly increased risk of offending and becoming a victim of crime"[10].

New Zealand's Youth Court Judges are very concerned about this likelihood and together with experts in the field are trying to take steps to ascertain the scope of the problem. There is no justice in unnecessarily criminalising disability when there are more humane, effective and less costly alternatives to be found rather than incarceration.

It is equally unjust, and abrogating the State's responsibility to not act in the best interest of children. In that regard we commend the Young People's Reference Group of the Office of the Commissioner for Children whose submission to the Ministry of Social Development's Green Paper for Vulnerable Children put that firmly on the Government Agenda[11]. They could have chosen any topic but recognised and responded pro-actively to the hidden and marginalised issue of second-hand effects of alcohol on children and young people, including prenatally.

These young people recognise the obligation to protect children from the second hand effects of alcohol:

"Many of the second-hand effects of alcohol undermine the rights stated in UNCROC. When people around children abuse alcohol, children are affected physically, mentally and emotionally. The Government has an obligation to uphold the rights of children by protecting them from the second-hand effects of alcohol." (P.4)

These young people identify the gaps in research and education:

"It is apparent that the second-hand effects of alcohol (especially on children and young people) are not currently identified. As stated in the first section of the submission, this means the wide majority of New Zealanders are neither aware of the effects nor how they link in with other issues in New Zealand. It is obvious that the second-hand effects of alcohol need to be communicated." (P. 6)

These young people recognise that Governments are not shouldering responsibility:

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[9] Fast D, Conry J, Loock C. 1999. Identifying fetal alcohol syndrome among youth in the criminal justice system. *Journal of Developmental and Behavioural Pediatrics* 20(5): 370–2.

[10] Youth Court Judge Stephen O'Driscoll, NZ Law Journal, May 2011

[11] Submission on the Green Paper for Vulnerable Children By members of the Young People's Reference Group of the Office of the Children's Commissioner (2012). http://www.occ.org.nz/__data/assets/pdf_file/0006/9375/FINAL_Green_Paper_YPRGsubmission27_02_2012.pdf

"Currently the government has not effectively condemned the reality of the effects of second hand drinking. Whether it is in Parliament, in caucus, as part of the policies of a party or even by individual MPs, we seldom here the words "the effects of secondhand drinking", or any term similar, openly stated as damaging, or more importantly, linked in with any other issues New Zealand faces (i.e. poverty or domestic violence)".(P.7)

Remedy:

- Government leadership guided by expertise to effect change that will protect children born with FASD or who are vulnerable post-natally.

- Improve health, education and justice responsiveness to alcohol-related harm. The damage may be lifelong.

5. What, if any improvements can be made to the 'well child' services (especially hard to reach children.

There is no more vulnerable child in society than the child whose brain and genetic potential has been permanently compromised by prenatal alcohol exposure and whose function and behaviour is not recognised, misunderstood and mistreated. It is unreasonable to wait until the child and family are at crisis point before taking action.

This could be avoided through better information sharing of the child's pre- and post natal history and having services equipped with the skill to assess for FASD appropriately at every age and stage of child development. This is now starting to happen where our own initiative to train the first clinical teams in child assessment for FASD is occurring.

Without such services, those born with a Fetal Alcohol Spectrum Disorder are at extreme risk of developing serious mental health problems, experiencing school disruptions, being in trouble with the law, being unemployed and having alcohol and other drug problems. The child with FASD today becomes the parent of tomorrow.

A loving stable environment is vital for everyone's development, but this alone is insufficient to compensate or reverse prenatal damage from alcohol which has damaged the underlying structure and function of the brain.

Remedy:

- Support and bolster experts in FASD to build and maintain the quality and integrity of FASD multidisciplinary assessment and community education. This is a complex and sensitive area of health and research that needs special professional care.

- New Zealand needs a FASD Centre of Excellence that can deliver and guide the necessary training in prevention, assessment and intervention effectively and appropriately.

6. What practical improvements or interventions can be made to achieve optimal outcomes for children from the 6 week post-natal periods to 3 years of life, with particular reference to health services but not excluding education, social, housing, justice and other determinants of health?

To often the children at risk such as those caught by the second-hand effects of alcohol don't just fall through the cracks, they are sometimes pushed there.

Without protective factors, these children are at risk of re-victimisation through constant misunderstanding of the disabilities that punish rather than help. They are loving beautiful children but they can be difficult to parent and teach.

Too often it is the parent that is blamed for the behaviour, when the reality is everyone, child included is trying their best to do things right but failing societal expectations. This can lead to a breakdown in relationships and structure with child ending up in a series of placements that equally misunderstand and so the cycle of re-victimisation continues.

It take time and a willingness to accept this is 'real' problem and one amenable to a shift in approach to strategies that work best. Other countries are far advanced in this regard and so New Zealand does not need to reinvent the wheel.

One programme that has proved to be extremely helpful when a child is identified as having an FASD is to appoint the family a 'Keyworker'. This person acts as the 'go to' person for the family and is the link between them and the services that are there to assist to keep children safe and secure. This has proven very effective in British Columbia Canada and is one way to reduce the duplication and waste of time and resource from too many services intervening with each family[12].

Remedy:

- Support the training of our frontline health and social services workers to recognise children with possible FASD and ensure there is appropriate assessment service for referral.
- Appoint a keyworker to families identified as having a child with FASD, to ensure needs are appropriately met and the situation has stabilised.

Conclusion

If any of this work sounds too complex and expensive, it is nothing compared to the millions of dollars currently being wasted because harms like FASD are being neglected. As recognised back in 1874, and backed up by more recent evidence, this is a causal pathway to health inequalities and these are amenable to effective and relatively straightforward and inexpensive interventions. All that is needed is a willingness to engage appropriately and with purpose.

[12] Hume et al (2008). Keyworker and parent support program: Time 1 Summaritive Evaluation Report: Executive Summary. Minstry of Children and Family Development, British Columbia, Canada.

Preventing just one child from being brain damaged for life is priceless. However there is often heard the inevitable cry that New Zealand cannot afford to do this work, that addressing FASD means someone else loses out in a 'Rob Peter to pay Paul' situation.

Consider what the Young People's Reference Group have shared. They are calling for leadership on this issue. The work can be easily funded out of the $800 million liquor excise tax that currently ends up in the consolidated fund, for who knows what.

Children with FASD are already here and they deserve better than what society has delivered for them so far. If we stay with the status quo, their numbers will only grow. They need our help now and addressing their needs will help to prevent brothers and sisters from being similarly affected.

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Appendix 1

The Fetal Alcohol Network New Zealand (FANNZ) is formed through the shared interest, concern and expertise of individuals and agencies. In addition to families living with FASD, FANNZ has people who work in public health, maternal health, child health, addictions & mental health, disability, education, special education, social services, community services, youth justice & corrections services, and policy. The diverse fields reflect the far-reaching implications of FASD.

The network and activities is coordinated by Alcohol Healthwatch www.ahw.org.nz and has a website www.fan.org.nz. The coordination has been made possible thanks to funding from the Ministry of Health.

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