

FASD in New Zealand: A Time to Act

Call to Action Consensus Statement September 2014

“This Call to Action is for urgent strengthened efforts to improve the lives of individuals with Fetal Alcohol Spectrum Disorder (FASD) and their families and prevent this brain-based disability. FASD demands shared responsibility with committed cross-government and cross-sector policy and service delivery working together in a coordinated, funded and effective strategic direction.”

This Consensus Statement is based on information shared at the Fetal Alcohol Spectrum Disorder (FASD) Symposium and the FASD Policy and Research Roundtable hosted by the University of Auckland’s Centre for Addiction Research and Alcohol Healthwatch on 5th and 9th September 2014¹. It identifies areas of priority to prevent FASD and to address the gaps in service delivery to those affected by FASD. It is underpinned by a commitment to the Treaty of Waitangi. It recognises New Zealand’s obligations under a range of United Nations charters.

FASD Prevention Policy and Practice

- Reduce the environmental influence of alcohol known to increase harm including reduction in availability, increase in price and restriction of promotional marketing.
- Strengthen consistency and effectiveness of non-stigmatising messages to not drink pre-conception, during pregnancy or when breastfeeding, including on the product and point of sale.
- Require screening and brief intervention with women of childbearing age by primary health and addiction services, and referral to specialist services for those at increased risk.
- Ensure FASD prevention is taught across the education curriculum and in specialist courses.

FASD Screening, Assessment and Diagnostic Training and Practice

- Direct health funding to support FASD training in integrated diagnosis and care planning with child health, mental health and other services across the lifespan.
- Provide for the establishment of a Centre of Excellence where expertise can guide and maintain consistency of evidence-based practice and continuing education across services.
- Together with FASD experts, develop guidelines and referral pathways for children and youth with FASD similar to that for Autism Spectrum Disorder.

¹ ***Disclaimer: This FASD Call to Action Consensus Statement has been developed in good faith and places no obligation on any individual attending on behalf of their organisation.***

- Screen children for FASD at point of entry into Children's Teams, Gateway or other child health programmes.
- Ensure children in care who are at very high risk of having FASD are screened and if positive, receive timely diagnosis, care and education adapted to their special needs.
- Provide for Specialist FASD Advisor in schools.
- Screen for FASD in youth justice, care and protection residences and alcohol and drug services and provide appropriate intervention pathways to reduce the risk of recidivism.

FASD Intervention Policy, Training and Practice

- Ensure that the parent/caregiver voice is included and heeded in regard to FASD specific policy around health, education and justice.
- Prevent discrimination by recognising FASD is a lifelong disability with significant unmet need that is not explained by poor parenting practice or other circumstances.
- Recognise the fiscal, emotional and time-consuming demands on those caring for a child or adult with FASD by ensuring their eligibility for financial and respite care support.
- Ensure those diagnosed with FASD are eligible for disability and education supports that are not predicated on IQ alone but equally consider deficits in executive and adaptive function.
- Fund and mandate experts to deliver integrated intervention training and support programmes in mental health, justice, addictions, education, police etc. that will assist individuals with FASD to reach and maintain their potential.

FASD Research

- Build a research network to guide and conduct FASD-related research.
- Fund a World Health Organisation national prevalence study which New Zealand has been invited to participate in to ascertain the scale of FASD.
- Conduct a Youth Justice FASD prevalence and intervention study.
- Develop a national database for the collection and analysis of FASD clinical data.
- Conduct a cost benefit analysis to determine the cost of FASD in New Zealand.
- Research the outcomes of FASD and the cost-benefit of intervention strategies.

Background to this FASD Call to Action

Fetal Alcohol Spectrum Disorder (FASD) is a range of physical, cognitive and behavioural impairments caused by alcohol exposure during fetal development. Alcohol is a teratogen that interferes with normal cell growth and function during development. Impairments may include facial and organ malformations but primarily FASD is about multiple brain deficits that substantially impair day-to-day functioning and communication across the lifespan. These pose major challenges for individuals with FASD, their families and the broad range of service providers they encounter, that are amenable to appropriately directed support.

Alcohol, being almost universally available is pervasive in New Zealand society, making FASD prevention particularly challenging. In the developed world FASD is recognised as the leading preventable cause of developmental disabilities, yet in New Zealand, no reliable data has so far been gathered, no comprehensive government plan of action has yet been established and babies continue to be born adversely affected by alcohol.

Based on overseas studies and drinking patterns, New Zealand could have 3,000 babies a year or more born with FASD. Better information is vital to develop effective policy and health and other sector responses to reduce the prevalence and societal impact of FASD.

Babies born with FASD don't outgrow the problems. On the contrary their difficulties grow as they grow. Individuals with FASD are more likely to experience adverse outcomes than the general population particularly in adolescence and adulthood. Referred to as secondary disabilities, these adverse outcomes include mental health problems, addictions, education failure, trouble with the law and becoming victims of crime.

Māori are disproportionately harmed by alcohol. The damage alcohol (waipiro) causes to unborn babies was recognised by Māori when it was first introduced in the 1800s. Recognising FASD and re-orienting existing services toward improved outcomes for the FASD-affected population will reduce the cost burden of secondary disabilities and increase prevention. The earlier in life that FASD is recognised and responded to appropriately, the greater the chance of successful living and protection of the next generation. Neglecting this has dire long term consequences, especially for our most vulnerable children.

Currently many individuals with FASD are behaving inappropriately in the community without appropriate support structure and are over-represented in the justice sector. This is a cost to society as well as an ineffective way to manage FASD disability. Caregivers are crumbling under the strain of preventing further harm from occurring by building the child's strengths and are doing so in isolation of effective supports or recognition. Many parents are simply blamed for the problem – as indeed often are their disabled children - when it is the teratogenic effects of alcohol and misunderstanding to blame. That must change.

FASD has complex lifelong implications that no one agency or family can address alone. FASD prevention and intervention is a societal responsibility requiring Government and cross-sector

commitment and collaboration that has the backing of Government funding. The cost of neglecting FASD is far too great.

Some of the action points identified in this FASD Call to Action represent work already begun by front-line professionals and families as demonstrated at the FASD Symposium and Roundtable. Much of this work has occurred in the absence of specific funding or structure. To ensure FASD planning and practice is well informed and funding is effectively directed, existing FASD experience and expertise must be recognised and more fully engaged in the process.

These matters form the substance of this Call to Action. They are consistent with the '*FASD Call to Action*' from the delegates attending the 2013 Australasian FASD Conference in Brisbane [http://www.phaa.net.au/AFASDC_2013.php], the recommendations made by the New Zealand Parliamentary Health Select Committee in their *Inquiry Into Improving Child Health Outcomes and Preventing Child Abuse* (2013), and subsequently agreed to by the Government and '*The International Charter on the Prevention of FASD*' [The Lancet Global Health, [Volume 2, Issue 3](#) - e135 - e137, March 2014].

The '*FASD in New Zealand: A Time To Act*' Symposium on 5 September and the '*FASD Policy and Research Roundtable*' on 9 September 2014 were hosted by the:



The symposium presentations and panel discussion can be viewed on www.fan.org.nz

For further information contact Christine Rogan Health Promotion Advisor and FASD Project Coordinator for Alcohol Healthwatch / Email: christine@ahw.org.nz / Tel: 09-5207037