Feedback summary

To all who participated in this important hui, thank you.

This report is a summary of the discussions held on the day. It aims to assist with informing future developments of the FASD Action Plan: A Plan of Action 2016-2019. The views expressed in this report are of attendees at the hui and are not to be attributed to the University of Auckland and Alcohol Healthwatch, nor do they reflect the organisational views of the agencies to which the attendees belong. For further information contact christine@ahw.org.nz

FASD Action Plan Hui Overview

“The Plan will continue past 2019”

Implementation and current status of progress of activities outlined in the FASD Action Plan were shared by the Ministry of Health, the lead agency for the Plan. Representatives from the Cross-Ministry Governance Group, including the Ministry for Children Oranga Tamariki and the Health Promotion Agency (HPA), also contributed to the discussion regarding the Plan’s progress.

The Ministry of Health presented a spreadsheet illustrating the scope and status of progress (Appendix One).

A panel of speakers then shared examples of work being carried out as it relates to the Plan. Their topics broadly covered FASD prevention, responsiveness to Māori, assessment of FASD and intervention, and research.

Prior to the hui, the Commissioner for Children Judge Andrew Becroft requested that a position paper be tabled at the hui entitled “A Vision of No School Removals” (Appendix Two). Strong appreciation and support for this vision was expressed at the hui. It was reinforced by all that attended the hui that FASD is a serious and complex issue requiring a multidisciplinary, systems-based approach that is across and between communities, service providers, whānau and the Government.

It was confirmed by the Ministry of Health representatives that the Plan would continue beyond its 3-year duration. This news was well-received, as demonstrated by the overwhelming support from attendees that the Plan needed to continue. The Plan was perceived to provide hope to families and staff in the sector through its aspirational nature, multidisciplinary

---


3 Personal notes shared by participants are highlighted in this summary report.
approach, and signal that it provided regarding the Government’s concern about FASD and need to take action. However, expectations surrounding the implementation and progress of the Plan were considered by many attendees to be insufficient, leaving many areas unaddressed and requiring urgent action.

It was clear from the views and experiences shared, that the speed of implementation needed to increase considerably in order to reduce the harm to those born affected in this generation and the next. The areas of prevention activity led by the HPA appeared to show the greatest progress. The areas with least progress related to a change in the wider drinking culture, FASD assessment, and development of a consistent pathway of care for those affected.

For many of those living with FASD (individuals and families) progress to-date was perceived to be ‘extremely poor’.

It was noted by one of the Panel members that during the Mental Health Symposium in Wellington, Dr Ashley Bloomfield, the Director General of Health, spoke about implementation. He said, “In NZ, we are really good at articulating our vision and mission, but we are not good at implementation.” The issue of implementation was also perceived to apply to FASD.

While there was strong support for the FASD Action Plan to continue, several important factors were also deemed to be absent thus limiting its effectiveness and inclusiveness. There were calls for the following amendments moving forward:

i. To honour Te Tiriti of Waitangi;

ii. To enact evidence-based environmental change that most effectively reduces alcohol harm, i.e. increase alcohol prices/excise tax, reduce availability, restrict alcohol advertising/sponsorship; and

iii. Apply systems thinking and systemic implementation of the Plan across Ministries, particularly where evidence indicates systemic barriers exist.

What follows is a selection of specific areas or key themes for which participants were asked to provide feedback relating to perceived progress and ways forward.
1) Prevention

“We haven’t changed the drinking culture in NZ yet”

Progress to date: 2016-2019

The prevention of FASD is fundamental to the outcomes of the Plan. However, it is more complex than simply increasing awareness. The work to-date has generally fitted into 4 categories:

1. Developing and disseminating consistent and unambiguous messaging and awareness-raising activities;
2. Working with health professionals;
3. Focusing on the role of unplanned pregnancies (not unwanted pregnancies), and
4. Enabling a change in our drinking change, improving wider well-being and reducing alcohol-related harm.

Prevention initiatives that have commenced under the banner of the FASD Action Plan include:

- Rolling out of the Community Alcohol & Drug Service Pregnancy and Parental Service to three regions of New Zealand (Gisborne, Napier and Whakatane);
- Engagement with medical and midwifery Colleges to develop e-learning modules;
- The ‘Pre-Testie Bestie’ social media campaign to target a pre-pregnancy audience; and
- The Ministerial Forum on Food Regulation (Australian & New Zealand Government Ministers) requiring Food Standards Australia New Zealand (FSANZ) to design and mandate an alcohol and pregnancy warning label for all alcoholic beverages. This work is due for completion by the end of 2019.

Moving forward:

“Whatever we learn about alcohol and pregnancy and are doing, we have to share with one another”

a) For primary prevention (preventing exposure to alcohol in pregnancy)

- Enact the Law Commission recommendations to limit the supply/promotion of alcohol so that the FASD prevention messages for pre-conception and pregnancy have a supporting context.
- Stop licensing liquor outlets in lower socio-economic areas – especially near schools.
- Work with whānau to build and support protective factors - value our indigenous approach and knowledge and acknowledge the reality within communities. Hapū Wānanga and Whānau Ora are great approaches.
- Use non-judgemental language to promote the risk of alcohol and unplanned pregnancy.
- Use higher profile and more visible FASD messaging to counter misleading misinformation from other sources e.g. ‘alcohol never did me any harm’ or ‘light to moderate use is safe’.
- Include a levy on all alcohol products to provide on-going funding for the FASD Action Plan.
- Include Dads/males in prevention messages, as partner’s influence FASD prevalence.
- Reinforce the fact that FASD is brain damage.
Show the Oranga Tamariki, ‘Risking it All’ DVD in every school – integrate as part of health curriculum and/or sex education; equivalent to ‘Mates and Dates about respectful relationships.

Undertake activities that encourage young people to develop healthy relationships.

b) For secondary prevention (screening for current alcohol use in pregnancy)

- Increase Ministry of Health support for a strategic approach to alcohol and pregnancy screening e.g. through Screening Brief Intervention/Referral Treatment
- Continue working with health professionals - it is important to talk about alcohol in primary care settings - some health professionals still do not know what FASD is, some continue to believe it is only relates to those with facial anomalies, some continue to advise light to moderate drinking as safe, many say nothing at all.
- Address obstacles to engaging midwifery and general practices. Given they are private businesses, incentives and targets are likely to be required to ensure screening is undertaken. Audits of screening need to be carried out.

c) For tertiary prevention (preventing harms to persons and families affected by FASD)

- Work on developing diagnosis – we can’t prevent what is invisible.
- As the burden of alcohol and pregnancy falls heavily on Māori, pregnancy messaging and approaches to support need to be culturally responsive.
- Establish a Māori Committee for FASD.
- Lift marginalisation by eliminating stigma of FASD.
- Ensure support approaches are collaborative and community-based – it is important that the community voice is heard and heeded.
2) Assessment and Intervention

“We have a Plan…. Where are the strategies?”

Access to FASD assessments remains a key factor for preventing future harm and inequities.

The significant barriers that are encountered by families and others within the health system signals the need for change. It is important that identifying maternal risk has an early intervention referral pathway for both the mother and the child so that early intervention can be undertaken.

It is equally important that families concerned about a child, adolescent or adult have timely access to FASD-informed assessment and support. This can reduce the burden of unmet needs that give rise to the secondary conditions that are too often associated with having FASD. These are no more inevitable than FASD itself.

Progress to date: 2016-2019

- The existing New Zealand FASD clinical network has joined with Australia and is growing.
- Basic frontline workforce development training opportunities have increased. Subsequently, there has been an increase in interest in learning how to tailor practice to best serve the needs of this vulnerable population.
- There has been a positive shift toward more individual clinicians showing an interest in FASD diagnosis. However, best-practice multi-disciplinary teams within public health services have not increased and this is concerning.
- Establishment of the Oranga Tamariki Practice Centre – a freely available FASD-Informed Practice training, with video and information added to the website.
- Efforts to improve Gateway assessment capacity were perceived to have been unsuccessful.

Moving forward:

Feedback showcased continued, strong support for team diagnosis and an integrative collaborative approach to follow-up care post-diagnosis. There was a belief that an increase in resources was urgently needed in this area.

“Is funding the hole in the Plan?”

a) Early Intervention

- Need to ring-fence FASD funding, as a lack of funding affects more than just the individual affected.
- Increase the capacity of Child Development Services to diagnose and support those with neurodisability.
- Address and remove obstacles for services to collaborate effectively within competitive funding/contracting silos.
- Support multi-disciplinary diagnostic processes within every region. There exist many potential diagnostic teams that have the capability and motivation but lack the capacity to fulfil the need for assessment in their regions.
Aim for national consistency of co-ordinated Multidisciplinary Assessment services that are perceived to be ‘good enough’ to meet the needs of the affected person(s).

The prevalence of language disorders among those affected by FASD necessitates the inclusion of Speech Language assessment as part of any diagnosis.

Consider an ‘opt out’ FASD register/database (like the Cerebral Palsy register) for multidisciplinary teams providing diagnosis.

Support established teams with a post-diagnosis co-ordinator – this person is not just a navigator but someone who can help problem-solve and provide some intervention for families. Training for families could be considered moving forward.

Increase training across the health professional workforce, especially at management level. Training the diagnostic team as well as referral services is not the current problem; the barrier often relates to management higher up in the system.

Align the New Zealand diagnostic guideline with the Australia guideline, ensuring cultural responsiveness is embedded throughout.

Increase management, leadership and family support

A co-ordination role to help co-ordinate assessment and follow-up would be valuable.

Families affected by FASD are an incredibly dedicated but very stressed group of people, they need home-based support.

b) Support

"First priority – entitlement for those with FASD to have their disability recognised and needs funded"

- Recognise FASD as a permanent disability, rightfully entitled to receive disability assessment and support. This will ensure children and young people who receive a diagnosis have a clear pathway for support under the umbrella of disability services.
- Funding for FASD disability should be needs-based not diagnosis-based – aligning with the principles of ‘well-being’.
- Improve utilisation of the Whānau Ora approach, because it meets the individual/whanau where they are, not where the system requires them to be.
- Improve early intervention services, as it enables those with FASD to lead successful lives. Services can provide much-needed support to people with FASD and their families, and can increase the ethical value for clinicians making the diagnosis.
- Move the conversation from the ‘problem’ to discussing practice and solutions. Many people are becoming aware of FASD (teachers, mental health workers, etc.) and now require the knowledge to change their practice.
- Honour the experiences of whānau living with FASD by ensuring representation at the FASD Plan Governance level.
- Place the person at the centre of support services. Utilise storytelling to provide a local context as well as personal accounts.
- Focus should centre on the Plan’s positive statement “Supporting family and whānau to improve their own health and wellbeing is one of the best investment we can make”. Although it is stated in the Plan, the focus needs to be strengthened and realised.
- Require support for the entire family, because they are the people who are doing the work of preventing harm, mostly unaided.
- Investigate the level and appropriateness of FASD support available from national helplines/Telehealth services – Plunket, AOD, lifeline, victim support, etc.
- Require education for those with FASD to tie to ORRS funding.
- Recognise that longevity of services is the key; FASD is for life.
3) Evidence for FASD

“We don’t know the scale of this problem”

Progress to date: 2016-2019

A range of data and evidence is being collected, although it appears to lack co-ordination. The following progress was noted by participants:

- The 2010 Growing up in New Zealand (GUiNZ) longitudinal study has collected maternal drinking behaviour and has the ability to examine associations with child development outcomes.
- Specific funding for FASD research and screening/assessment protocols is being investigated. This work is ongoing.
- A stocktake of services engaging with FASD and information about pathways to respond to children coming into care has been conducted.
- The Pregnancy and Parental Service programme to support women with children and complex needs, set up in three pilot locations, has been evaluated. Communication with Australian researchers has taken place.
- In the education space, the ALERT programme in schools has been shown to improve self-regulation of behaviour for those with neurodevelopmental impairments. Under the FASD Action Plan, a cross-Ministry decision has been made to support a pilot programme in two primary schools and youth justice facilities. This will be evaluated.
- Most FASD research in Aotearoa remains characterised as unfunded, small scale and student-led. It is clear that there remains an enormous gap in research sufficient to understand the scale and type of problem as evidenced by research carried out in other countries. FASD prevalence in the general population, or within particular settings (e.g. Justice) remains unknown.

Moving forward:

- Ensure research is conducted in partnership with Māori (as a Treaty requirement and due to the inequitable distribution of alcohol harm)
- Create a research hub for FASD
- Fund a prevalence study that has multi-agency and cross-government support
- Require targeted interventions to be evaluated, particularly for equity
- Undertake research that capture’s the children’s voice/adult’s voice of those who have FASD.
- Require the voices of families and their experiences to be heard throughout research
- Build more robust evidence to inform future actions.
- Undertake a cost burden/intervention benefit analysis to direct policy and planning of services.
- Collaborate and learn lessons from other sectors, e.g. Tobacco Control, that have advanced the research and policy agenda.

The final feedback of the day was from a wise young man (aged 10 years) with FASD who attended the hui with his mother.

‘if you don’t want people to drink alcohol, just don’t make alcohol’…

to which an adult responded

‘Alcohol is too easy to make – but we can stop the marketing!’
Appendix One: Update of progress on FASD Plan (supplied by the Ministry of Health)

<table>
<thead>
<tr>
<th>Purpose</th>
<th>Inter-related work</th>
<th>Key Stakeholders</th>
</tr>
</thead>
<tbody>
<tr>
<td>FASD is present in people with FASD and their family/whānau</td>
<td>NZ Health Review, Mental Health &amp; Addiction Review, WorkSafe</td>
<td>Ministry of Education - schools, Health Promotion Agency, Ministry of Primary Industries, Ministry of Justice, Department of Corrections - prisons, Ministry for Primary Industries</td>
</tr>
<tr>
<td>Across agencies plan (strategic) to get the building blocks in place</td>
<td>CHINAC Youth Health Indicators Strategy, Orange Tamaki Action Plan, Ministry of Social Development</td>
<td>Health Promotion Agency, Ministry of Social Development, Ministry for Social Development</td>
</tr>
<tr>
<td>Focus on prevention</td>
<td>Disability Support System Transformation</td>
<td>Ministry of Health - schools, Ministry of Social Development, Ministry of Health - schools</td>
</tr>
<tr>
<td>Action for Children</td>
<td>MOE Learning Support Action Plan, Disability Action Plan</td>
<td>Ministry for Primary Industries</td>
</tr>
<tr>
<td>Unilateral action and collaboration</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Priorities**

<table>
<thead>
<tr>
<th>Ten Action Areas</th>
<th>Progress to June 2019</th>
<th>Completed Activities</th>
<th>Actions not undertaken</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevention</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Increase awareness and collaboration to support activities to shift NOD’s risk-taking culture and targeting harmful substances</td>
<td>HPA extended existing culture change “say yes/no” campaign, Healthy Families, AOD prevention in schools</td>
<td>Workshops, training on CDS, expanding the SOS criteria to include FASD</td>
<td></td>
</tr>
<tr>
<td>Develop and disseminate clear, inclusive, and consistent messages to increase the whole of community awareness of the risk of drinking during pregnancy</td>
<td>Public and alcohol and pregnancy campaign, key messages resources for schools, healthy families, MOE, NDS, WHO, voluntary alcohol warning label initiative</td>
<td>Workshops, training on CDS, expanding the SOS criteria to include FASD</td>
<td></td>
</tr>
<tr>
<td>Support primary care to provide health, responsive, and equitable maternity care, including screening and SI</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support access to equitable, culturally appropriate, and competent reproductive health care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Early Identification</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Increase access to support and specialist services for women with AOD issues</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support women with AOD issues to improve their health and wellbeing and effectively reduce their risk of having a child with FASD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improve the ability of midwives to respond effectively to women with FASD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Evidence</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conduct research into the incidence of FASD other</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neurodevelopmental impairments in a NZ cohort</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**What success looks like**

**PREVENTION** — families and whānau understand the risks of drinking during pregnancy and are supported to have healthy, alcohol-free pregnancies. Women with AOD issues consistently receive proactive, practical, and non-judgmental support to improve their health and wellbeing and effectively reduce their risk of having a child with FASD.

**EFFECTIVE INTERVENTION** — People with neurodevelopmental impairments are identified early and receive timely and effective interventions. Data FASD-capable teams.

**SUPPORT** — People and their families, whānau and caregivers receive timely, proactive support tailored to their needs, strengths, age, and stage.

**EVIDENCE** — Improved New Zealand evidence base allows us to make good decisions and effective investments, and monitor outcomes and progress.
Appendix Two

A vision of No School Removals

Prepared for:

FASD Action Plan 2016-2019 hui:
What’s in the forecast?
Thursday 18 April, 8.30am – 12.30pm

Comments from the Office of the Children’s Commissioner

Children with FASD often suffer in their education from non-enrolment, limited attendance, or school removals for disciplinary (health and safety) reasons. This is a common occurrence for many children with a variety of neurodisabilities, neurodiversity, behavioural learning delays etc.

If we were to have a vision of No School Removals, we would need progress in several areas: some from the start of schooling, and others at the stage when young people are excluded.

We’ve identified several key advocacy levers the OCC will need to prioritise and then work on to progress towards this vision.

Our first comment is that two key principles should overarch all the ideas, suggestions and areas for advocacy below. The government needs to hold fast to these:

1. Keep policy child-centred
2. Ensure children’s voices are heard in all matters that affect them.

Advocacy areas:

Reduce causes of neurodisability and behavioural learning delays
- Reduce poverty
- Reduce stress for pregnant women and young parents - housing, income, childcare
- Reduce unplanned pregnancies or educate about family planning (as a means to improving the in-utero environment during fetal development)
- Reduce alcohol abuse (in general: culture shift across society, minimum alcohol pricing, advertising, location and number of licences …)

School removals (suspensions, exclusions, expulsions)
- Review school removal processes to ensure they are independent, fair and child-centred, e.g. create an independent tribunal, locally and nationally to hear exclusion / expulsion cases
- In the meantime, run a “PILOT REVIEW PANEL”. Develop and promote a mechanism for appealing exclusion decisions in a subset of schools (e.g. a region, only secondary…)
- Enforce requirement for re-enrolments of under-16s, and expand over-16s targets for monitoring by MoE
- Review policy on long suspensions
- Ensure conditions placed on returns to school are fair and relational (involve school changes too) and can be fulfilled by young person, not their adults
- Move towards restorative justice approaches to behaviour and discipline in schools
- Review educational programmes provided during removal period (e.g. activity centres)
- Improve quality of counselling and support for excluded students e.g. team established to ensure learning continues (preferably in a school)

**Better supports in school**

- Ensure Early Learning Centres are high quality
- “Primary carer” teachers for each child in Early Learning Centres
- Improve quality of transition to school
- Training for principals and board members about rights; what children and young people say in their school; potential uses of resources; behaviour management etc (e.g. through NZSTA training modules)
- Improve support for children with neurodisabilities & their families (e.g. Disability and Learning Support Action Plan)
- Ensure advocacy for children – e.g. individual children / young people can choose an adult to advocate on their behalf in school decisions about them
- Ensure physical environments are suitable for all learners
- Ensure Initial Teacher Education (training) includes enough focus on disability (including neurodisability), mental health, and culturally responsive teaching
- Ensure schools/ Early Learning Centres are adequately resourced for inclusion
- Ensure teachers have on-going professional development on responding supportively to challenging behaviours; learning strategies for diverse learners; and relationship management

**Learning and health supports for children (including reduce mental health difficulties)**

- Improve support for behaviour skills development e.g. include behaviour and relationship disorders in mental health service specifications; integrate MoE* and MoH* early intervention services;
- Review definition of disability and include FASD [influence Government response on mental health inquiry report]
- Improve maternal and infant mental health services, eg services to help with attachment
- Improve support for language development, e.g. parents as first teachers / early learning
- Promote social and emotional learning and reduce bullying, e.g. school programmes like ‘positive behaviour for learning’
- Adequate youth health services especially mental health, eg Youth One Stop Shops
- Reduce alcohol and other drug abuse by children and young people
- Multi-agency wrap around support for families from Early Learning Centres/schools including link to Whānau Ora

* MoE = Ministry of Education
* MoH = Ministry of Health