

Taking Action on Fetal Alcohol Spectrum Disorder

Analysis of submissions

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Profile of submissions

The Ministry of Health received 150 submissions on the discussion document *Taking Action on Fetal Alcohol Spectrum Disorder*, which presents an Action Plan for addressing fetal alcohol spectrum disorder (FASD) in New Zealand. Approximately half (76) were from individuals; the remaining 74 were from groups or organisations.

Looking at submitters in terms of sectors of origin, the largest group of submitters (43) identified as consumers/families/whānau, and the second-largest group (36) identified as service providers. (Note that submitters were allowed to identify with more than one sector.) Some submissions did not indicate identification with any sectors.

Table 1: Sector groups, by submitter numbers

Sector	Total number
Consumer/family/whānau	43
Service provider	36
Non-government organisation	28
District health board	28
Education sector	19
Other	17
Professional association	14
Māori	12
Academic/research	11
Social sector	10
Did not identify	9
Public health organisation	7
Pacific	6
Industry	5
Primary health organisation	4
Justice sector	3
Asian	2
Local government	1

The submitters who identified as 'Other' included those from industry training organisations, the disability sector, addiction networks, private providers and iwi entities.

Key themes

Submissions were overwhelmingly (96 percent) in favour of the Action Plan, the principles and the outcomes outlined in the discussion document. However, a few submissions called for some key changes. The remainder of this document summarises the submissions.

Principles

- Over 90 percent of the submitters supported the principles in the discussion document; especially the focus on families and whānau.
- Approximately 50 submitters called for equity to be added to the principles, and over 60 submitters mentioned the need for a strong equity focus in other parts of their submission. This call for the addition of equity came from all sectors but especially from Māori, families/whānau, service providers and the justice and education sectors. Submitters who called for equity to be added to the principles described inequity in two different ways: ethnic inequity and service inequity.
- The majority of submitters called for a principle based on the reduction of stigma towards women, individuals with FASD and their families/whānau.
- Eighty-six percent of submitters supported the idea of a whole-of-government approach and wanted this to be added as a principle of the Plan. Some submitters called for more detail on what the whole-of-government approach would look like in practice, including accountabilities for the relevant government departments for achieving the collective impact outlined in the plan.
- Over 20 submitters drew attention to the need for a stronger evidence base to inform policy and wanted evidence to be added as a principle alongside the principle of building on strengths. Some called for practice-based evidence to inform immediate interventions while New Zealand-specific evidence is researched.
- Most submitters (mostly from families and service providers) supported principles 3, 4 and 5: prevention is always possible, build on strengths and strive for sustained, systematic change. They provided personal stories of facing barriers while navigating through the fragmented current service system. Some queried how the Action Plan aimed to create systematic change and wanted to know more practical details.

Outcomes

Note: The wording of these outcomes have been amended in the final Action Plan. This was done to reflect the feedback received during the consultation process.

Outcome 1: Women are supported to have alcohol-free pregnancies

Note: 'Outcomes' here are labelled 'Priorities' in the final Action Plan.

The majority of submitters supported this outcome. Only two did not support the building blocks that underpin the outcome.

Over 70 percent of submitters queried the role of men and families/whānau in this outcome (and in the Action Plan overall). They called for the word 'women' to be taken out and 'families/whānau' to be added to the title of the outcome, to ensure that the Action Plan did not take a gendered approach or blame women for FASD, and placed a greater emphasis on encouraging partners and families/whānau to be alcohol-free to support alcohol-free pregnancies.

Building blocks for action

- *Shifting New Zealand's drinking culture:* Most submitters strongly supported this building block. 80 percent of submitters called for greater government regulation of the sale and supply of liquor, in line with the Law Commission's 2010 report *Alcohol in Our Lives: Curbing the Harm*.
- *Providing clear, unambiguous and consistent messages:* Approximately 85 percent of submitters supported this building block. Submitters mainly called for a public health campaign to increase awareness and for health professionals to provide consistent messages on the harm caused by alcohol when it is consumed during pregnancy. The alcohol industry supported providing consistent messages that '*Stop drinking alcohol if you could be pregnant, are pregnant or are trying to get pregnant. There is no known safe level of alcohol consumption during pregnancy*' through alcohol warning labels and integrated campaigns run by the Health Promotion Agency.
- *Empowering women to make active, planned choices about pregnancy:* There was general support for this building block. More than 30 percent supported improving access to contraception such as long-acting reversible contraceptives and increasing messages on alcohol harm in sexual and reproductive health classes or schools.

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- *Supporting a consistent primary health care response:* There was strong support for this building block, which entails support for primary health care professionals (eg, general practitioners and other lead maternity carers) to be trained to screen pregnant women for alcohol consumption (using appropriate language to avoid stigmatising women) and to refer them to appropriate specialist services when necessary. A number of submitters called for alcohol exposure to be recorded in mothers' medical records and transferred to the children's medical record after birth.
 - *Increasing access to support and specialist services for women at high risk of having an alcohol-exposed pregnancy:* Submitters were very supportive of this building block and expressed encouragement for policy makers to target this group of women (alongside a universal approach). Submitters drew attention to the need for policy makers to take into account that FASD is an intergenerational issue, that is, many women who drink during pregnancy may themselves have FASD, other neurodevelopmental issues or other co-morbidities, such as mental health conditions, requiring support and specialist services.

Outcome 2: People with neurodevelopmental issues are identified early and receive timely assessments from FASD-capable teams

There was general support for this outcome. Seven submitters did not answer the question, and one partially agreed with the building blocks for action. Most submitters favoured early intervention only if there is a pathway created for specialist care and follow-up support.

Building blocks for action

- *Building family and community capacity to understand and identify FASD and other neurodevelopmental issues:* There was strong support for this building block. Submitters called for training across all sectors and communities to support early identification of FASD and clear referral pathways for support. Submitters also mentioned a need for other pathways for identification (eg, pre-school checks) to be included in the Action Plan.
- *Building evidence-based awareness and understanding among professionals:* There was wide-ranging support for this outcome, especially from families/whānau who had struggled to receive recognition of their child's condition from professionals. However, some submitters noted the need to develop a spectrum of methods to identify people with FASD throughout their lives, not just in the context of interactions with government agencies (eg, adoption agencies and Child, Youth and Family, CYF).
- *Ensuring clear referral pathways:* Over 70 percent of submitters mentioned the need for clear referral pathways. Many submitters also highlighted the high risk of a diagnosis where pathways for support are lacking. Some suggested that the wording of this building block needs to be changed to ensure it is client focused, and promotes pathways that are accessible and supported. Around 15 submitters supported training for professionals to refer to appropriate services.
- *Providing multidisciplinary assessment and the creation of an individualised profile:* Over 80 percent of submitters supported multidisciplinary assessments. Responses variously called for a multidisciplinary assessment team specifically for FASD and one capable of assessing other neurodevelopmental issues. Many submitters called for a set of diagnostic criteria for FASD based on the Canadian guidelines to be tailored for New Zealand. A few submitters called for a goal that diagnosis not be the only pathway for support and care and for a focus on support and care based on the needs of the individual.
- *Increasing clinical capacity and capability:* Around 50 submitters explicitly supported this building block. Many expressed concern about how an increase in clinical capacity and capability would be achieved, given funding limitations.

Outcome 3: People and their families, whānau and caregivers receive timely, joined-up support tailored to their needs and strengths

The majority of submitters agreed with this outcome and its building blocks for action. Eight did not answer, and two partially agreed with the building blocks.

Over 70 percent of submitters called for FASD to be recognised as a disability to ensure that people with FASD and their families, whānau and caregivers are able to access adequate funding and support services through Disability Support Services.

Building blocks for action

- *Improving community understanding:* Over two-thirds of submitters mentioned the need for greater community understanding of FASD, but many were concerned that improving understanding could lead to stigmatisation of families/whānau and individuals. They called for the Action Plan to mitigate this risk of stigmatisation.
- *Universal approaches tailored to need:* There was general support for this building block. Many submitters (especially Māori and Pacific submitters) wanted the Action Plan to ensure that approaches are tailored to socioeconomic status, and are culturally sensitive/responsive to the needs of their communities. Some family/whānau submitters and some from the disability sector called for the approach to be co-designed by individuals with FASD to ensure it meets their needs.
- *Support for parents, families and caregivers:* Most submitters supported this building block. Some mentioned the need for support services to be accessible and co-designed by parents, families/whānau and caregivers. Many families/whānau with a child with FASD described physical, emotional and financial exhaustion and a lack of support for them to alleviate stress arising from caring for a person with FASD.
- *Multidisciplinary care planning and coordination:* Most submitters supported this building block. Some submitters who discussed it in greater detail wanted the Action Plan to take a life-course and multi-agency approach to care planning and coordination, in acknowledgement of the fact that FASD is a lifelong condition. Several submitters mentioned a need for services to recognise developmental age rather than chronological age in regard to diagnosis, care planning and coordination.
- *Accessible care and support pathways:* Over 85 percent of submitters emphasised the importance of this building block. The majority of submitters called for care and support pathways to be flexible, holistic, wraparound and accessible at any stage of life and tailored to an individual's needs.
- *Support to navigate the system:* The majority of submitters mentioned this building block. Around half of submitters called for appointing an appropriate key worker or navigator to support families and individuals with FASD through the system. A small percentage of submitters noted that current fragmentation of services leads to barriers to access and called for this to be addressed.

Outcome 4: There is an improved evidence base so we can make good decisions and effective investments

Overall, there was strong support for this outcome, especially in terms of the collection of data on FASD prevalence in New Zealand. Many submitters supported the goal of evidence-based policy and interventions, but almost all submitters called for immediate action based on practice-based interventions and international evidence while New Zealand-specific evidence is being gathered.

Eighty-three percent of submitters supported the building blocks for this outcome. Eight did not answer the question, and only one indicated that they did not support the building blocks.

Building blocks for action

- *Routinely collect and analyse key data:* Submitters generally supported this building block. Several submitters, including some from professional associations, workforce development organisations and the health care sector, highlighted the need for the Action Plan to recognise the demand this building block will place on an already stretched workforce. Many questioned how the Action Plan aims to address infrastructure and resourcing gaps in order to enable this building block. Approximately 30 percent of submitters called for a national database to be set up for recording FASD-related data (including prevalence), which all agencies could access and provide input into.
- *Evaluate the effectiveness of interventions:* Almost all submissions mentioned evaluation of interventions. Many wanted evaluations to be built into all interventions and actions in the Action Plan.
- *Encourage research:* Nearly all submitters that mentioned research supported this building block. Around 20 submitters suggested that New Zealand should join the World Health Organization's FASD prevalence study. Many also called for a FASD Centre of Excellence to be set up to lead research and evaluations of FASD interventions in New Zealand. Over three-quarters of submitters wanted greater funding for research. Around 10 submitters called for all government agencies to publish data on people with FASD, including in terms of educational achievement and the justice system. Other suggestions included setting up research networks, conducting more population-based research and conducting research into the prevalence of FASD among children and young people in the justice system and in social sector care (eg, children in foster or CYF care). Submitters also wanted to ensure that families/whānau be part of research methodology.