Submission on:

Taking Action on Fetal Alcohol Spectrum Disorder (FASD)
A Discussion Document

Ministry of Health

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Women's Health Action (WHA)

Women's Health Action is a women's health promotion, information and consumer advisory service. We are a non-government organisation that works with health professionals, policy makers and other not for profit organisations to influence and inform government policy and service delivery for women. Women's Health Action is in its 32nd year of operation and remains on the forefront of women's health in Aotearoa New Zealand. We are highly regarded as leaders in the provision of quality, evidence-based consumer-focused information and advice.

We provide evidence-based analysis and advice to health providers, NGOs and DHBs, the Ministry of Health, and other public agencies on women's health (including screening), public health, and gender and consumer issues with a focus on reducing inequalities. We have a special focus on breastfeeding promotion and support, body image promotion, maternal and child health, and women's sexual and reproductive health and rights.

Please visit our website for more information: www.womens-health.org.nz

Thank you for the opportunity to provide feedback on this discussion document- 'Taking Action on Fetal Alcohol Spectrum Disorder FASD'. Please note that we have focused on answering the general questions and the questions relating to Outcome 1. which reflects our expertise as a women's health promotion organisation.

Please indicate which sector(s) your submission reflects
(you may tick more than one box in this section):

- ☐ Māori
- ☐ Pacific
- ☐ Asian
- ☒ Consumers/families/whānau
- ☐ Service provider
- ☒ Non-government organisation
- ☒ Public health organisation
- ☐ Primary health organisation
- ☐ District health board
- ☐ Professional association
- ☐ Justice sector
- ☐ Education sector
- ☐ Social sector
- ☐ Academic/research
- ☐ Local government
- ☐ Industry
- ☐ Other *(please specify)*:

Questions and Answers

1. From your experience and perspective, what would you like the Government to take into account when developing the Action Plan?

Women's Health Action (WHA) views alcohol use during pregnancy as an important women's and children's health issue and supports the development of an action plan to address fetal alcohol spectrum disorder (FASD) in the context of a wider commitment to women's and children's health.

Given that the focus of any actions to address/prevent FASD will inevitably focus on the health behaviours of both pregnant women, and women of reproductive age who could possibly be pregnant, we believe it is critical that the Plan be developed using a sex, gender and diversity analytical lens as articulated by the World Health Organisation[1]. Sex, gender and diversity-based analysis is the process by which a policy, program, initiative or service is examined for its differential impacts on diverse women and men (depending on the focus of said policy, program etc.). It provides information about how lived realities are differentiated by a person's sex and gender, along with other aspects of a person's identity and context including their ethnicity, socio-economic status, whether or not they experience a disability, their sexuality etc. This means that analysts, researchers, evaluators and decision makers are able to ensure that policies and initiatives are responsive to people's specific needs and circumstances and therefore have intended and equitable outcomes. In the case of an Action Plan on FASD, a sex, gender and diversity analytical lens will require an evaluation of women's lived realities and contexts, and will ensure that actions to address FASD address, rather than compound, gender-based and other inequalities experienced by women.

It is also our view that this plan presents a timely and important opportunity to progress a women-centered health promotion approach to reducing alcohol use by women during pregnancy. A women-centered framework would emphasise the range of issues and determinants affecting women's health and encourage the uptake of a respectful and gendered approach to women and alcohol use during pregnancy. This means an awareness of, and commitment to avoiding, a fetus-centered framework, that ignores pregnant women as worthy of health promotion and enhancement in their own right, and instead focuses solely on fetal or infant health. Additionally a women-centered approach implicitly and explicitly replaces victim blaming and punitive, shaming attitudes and practices aimed at pregnant women who use alcohol. A harm-reduction approach to women's alcohol use during pregnancy has been shown to be consistent with a women-centered health promotion framework in other jurisdictions, such as Canada. This approach recognises that while alcohol-free pregnancies may be the ideal, for some women a *reduction* in alcohol use is an improvement that can more realistically be achieved. Collateral improvements in nutrition, vitamin intake, personal safety, and food and housing

[1] World Health Organization. (2009). Strategy for integrating gender analysis and actions into the work of WHO. Retrieved from: http://apps.who.int/iris/handle/10665/44044

Gender analysis in health: a review of selected tools (2003) http://www.who.int/gender-equity rights/knowledge/9241590408/en/

security can also be part of the overall harm-reducing framework. When these kinds of measures are part of health promotion regarding alcohol use during pregnancy, overall health for women and their fetuses can be improved even when alcohol use continues[2].

Further, because of evidence confirming the relationship between FASD and vulnerability we believe it is essential to that the Plan be based on and informed by a social determinants of health framework[3]. The social determinants of health (SDH) as articulated by the World Health Organisation, are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life. These forces and systems include economic policies and systems, social norms, social policies and political systems. A SDH framework insists that health promotion activities look beyond solutions based on individual choice and behaviour to address the structural influences on peoples' health and lives. In the case of FASD, it will require understanding and addressing the causes of women's and children's vulnerability that increase their susceptibility to FASD.

2.a. What is your community or organisation already doing to prevent or respond to FASD?

Women's Health Action has contributed to the evidence base surrounding women's alcohol use in New Zealand, including alcohol use by pregnant women. In 2012, in partnership with Alcohol Healthwatch, we undertook a research project which examined the dynamics of women's alcohol use in New Zealand through both an analysis of existing literature as well as focus groups with the providers of health and social services. We identified a clear intersection between gender-based violence and women's harmful alcohol use, along with other gendered dynamics that need to be understood and addressed in order to reduce women's harmful drinking. The research project culminated in a policy briefing paper that can be retrieved from our website[4].

We have also worked with the Health Promotion Agency, former ALAC, and the Advertising Standards Authority to address alcohol advertising, both alcohol advertisements targeted at women, and advertising targeted at men that employs derogatory and degrading messages about women. Our work in this area has resulted in the publication of an article in an international peer-reviewed journal[5].

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[2] Poole, N., & Greaves, L. (2013). Alcohol Use During Pregnancy in Canada: How Policy Moments Can Create Opportunities for Promoting Women's Health. *Can J Public Health*, *104*(2), e170-e172.

[3] Solar, O., & Irwin, A. (2007). A conceptual framework for action on the social determinants of health. Retrieved from http://www.who.int/social_determinants/publications/9789241500852/en/

[4] http://www.womens-health.org.nz/wp-content/uploads/2014/08/WomenAndAlcoholBriefingPolicy_web.pdf

[5] Towns, A. J., Parker, C., & Chase, P. (2012). Constructions of masculinity in alcohol advertising: Implications for the prevention of domestic violence. *Addiction Research & Theory*, *20*(5), 389-401.

Our goal in all of our health promotion and policy activities relating to women and alcohol, is to ensure health information and policy is sensitive to the specific drivers, and impacts of, harmful alcohol use in women's lives, and to ensure women are able to access the information, safety, support, and resources they need in order to archive health and wellness for themselves and their families.

2.b. What is the best way for the Action Plan to support this?

Our Policy Briefing Paper 'Women and Alcohol in Aotearoa New Zealand' concluded with a series of action points to inform the review of the National Drug Policy. We believe are number of these are relevant to the development of this Action Plan and to other policy areas relating to women's alcohol use.

Action Points:

- Include a specific focus on women and the use of gender-based analysis.
- Recognise the health and social cost of alcohol-related harm, and enable the necessary commitment and investment to achieve measurable and sustained reductions in alcohol-related harm within the next 5 years.
- Commit to evidence-based policy implementation, and support the development of a sector-led national alcohol harm reduction strategy and accompanying action plan.
- Recognise the link between alcohol harm and social inequities, and enable actions that measurably reduce inequities and mitigate the risks of contributing to further inequities.
- Explicitly provide for workforce development and planning to meet the needs and expectations of wāhine Māori.
- Include wide consultation with Māori to identify how to meet their aspirations for whanau ora.
- Include wide consultation with Pacific peoples to identify how policies and services can better meet their needs and expectations, and address inequities.

2.c. What does the Action Plan need to focus on, build on or take into account to ensure that it is responsive to Maori?

See the above action points listed in our response to question 2.b.

3. Do you support the Key Principles?

Yes.

4. What changes would you make to these principles? Why?

While we support the five key principles we strongly encourage the addition of a further principle: 'Reducing inequalities'. Within this principle we would like to see a recognition of the need to incorporate both sex, gender and diversity-based analysis and a social determinants of health framework, along with the principles of the Treaty of Waitangi, in the development of a FASD Action Plan. We believe actions to address FASD, if they are to be responsive and effective, must be informed both by women's lived realities, and the structural factors that contribute to women's vulnerability and to their alcohol use in pregnancy.

5. Do you support the proposed outcomes?

Partially.

6. What changes would you make to these outcomes? Why?

Because of the strong correlation between FASD and vulnerability, it is our view that the Action Plan needs to mandate actions and activities to address pregnant women's vulnerability. We urge the addition of an outcome relating to this or an amendment to 'Outcome 1', that refocuses it towards harm-reduction and women-centeredness. For example: Women are supported to reduce the harm caused by alcohol-use during pregnancy and to have safe and healthy pregnancies.

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

7. Do you support these building blocks?

No, we are of the view they require further development.

8. What changes would you make to these building blocks? Why?

We are of the view that the building blocks in their current form are inadequate for achieving increased support for women to reduce or avoid alcohol during pregnancy in that they: overly focus on individual behaviour change; do not attend to structural inequalities and vulnerabilities shaping women's lives and choices; are focused on abstinence rather than harm-reduction; and by over-reaching into women's reproductive years beyond pregnancy, risk undermining women's autonomy and rights.

As outlined in our response to Q.1, we assert that an effective Action Plan on FASD, and specifically activities aimed at addressing women's alcohol use during pregnancy, will need to incorporate both a sex, gender and diversity-based analytical lens, and a social-determinants of health framework. As we have discussed earlier, these are health policy development tools that have been developed and mandated by the World Health Organisation. They are highly relevant to policy development in the area of FASD because women will largely be the recipients of FASD prevention initiatives and because of evidence that shows the intersection of FASD and vulnerability. Applying a sex, gender and diversity-based lens, and social determinants framework requires asking, and answering, a series of questions with the intention of building knowledge about the nature and scope of women's alcohol use in pregnancy in order to inform policy and treatment responses. These include[6]:

1. How do factors such as poverty, exposure to violence, tobacco use and mental health problems interface with a women's substance use during pregnancy, and with biological processes affecting her overall health, including an increased risk of giving birth to a child with FASD?
2. What specific ethical considerations need to be attended to regarding women's alcohol use in pregnancy, so that surveillance and screening practices, for example, do not retraumatise women and/or prevent women from accessing pre- and postnatal care?

[6] Poole, N. (2011). Bringing a women's health perspective to FASD prevention. *Fetal Alcohol Spectrum Disorder: Management and Policy Perspectives of FASD*, 161-174.

3. How might messaging and support be tailored to address the needs of diverse women, beginning with diversity in level of risk, through various combinations of community awareness campaigns, individual messaging, supportive services, policies and community health promotion activities? What combination will be effective in preventing or reducing women's alcohol use problems, and specifically, alcohol use in pregnancy?
4. How does child welfare and related public policy affect women's choices, and how might policy be conceptualised as both women- and child-centered, rather than a dichotomy?

Following the learnings of successful FASD policy interventions in jurisdictions similar to New Zealand, such as Canada, we assert that there is a strong evidence base for a women-centered approach to FASD prevention[7]. The answers to the above questions in the Canadian context have helped move the focus of FASD prevention initiatives away from women's alcohol use alone to include evidence on the determinants of, and influences on, women's drinking and access to assistance leading to the development of a women-centered FASD response. As described by Poole (2011) this approach:

> brings the focus of public health support to the mother-child unit. Emphasis is placed on the woman's health from preconception through pregnancy and post-partum, supporting her interest in making positive changes, and her confidence in her ability to do so. As a first step, the negative and demeaning societal condemnations of substance use during pregnancy need to be acknowledged, so that service providers can assist women in dealing with the stigma they are likely to have experienced. Adopting a women-centered approach demands a paradigm shift – away from seeing mothers who use substances as unfit, uncaring and unworthy of support, and towards a positive perspective on women's capacity for change. FASD prevention demands that we see - and are hopeful about - women's strengths, that we support substance users by removing barriers to treatment and involving women in determining what they need to better care for themselves and their children.

Crucially, a women-centered approach requires that policy makers and service providers recognise diversity in risk levels and determinants of alcohol use and make a number of service options available. It is of critical importance that services be non-judgemental, in order to encourage women to access care and treatment.

We also urge the Ministry to consider the merits of a harm-reduction rather than abstinence orientation which are consistent with a women-centred approach to FASD policy[8]. In the context of drinking during pregnancy, a harm-reduction approach means that service providers are willing to discuss goals other than abstinence, despite the known risks of alcohol. This requires considering all aspects of harm that contribute to, or result from, women's alcohol use. Practitioners oriented toward harm-reduction seek to discuss, promote, and facilitate actions that reduce harm in many areas of a woman's life, not only her alcohol use. This requires recognising the interrelatedness of issues and being flexible enough to work from where women "are at", without judgement. Service providers must develop the skills and

[7] Ibid.

[8] Ibid.

awareness to be able to tolerate women's needs to go at a slower pace than may be optimal. Women who use alcohol should be central to defining the level, type, and pace of change they can make. Systemic changes needed to minimize harm and support at-risk women are often revealed in this process.

Finally we are perturbed by the following statements in Outcome 1. : 'Shifting New Zealand's culture to one of moderation, or not drinking if *pregnancy is a possibility*, requires sustained effort over time and a whole government and sector approach and commitment to achieve this' and 'Ultimately we want to create a social consensus about women not drinking when they are pregnant or *likely to become pregnant'.* We understand the desire to target FASD preventions towards the first trimester, and to women who may not know they are pregnant, given this crucial time in fetal development. However, we argue that such intentions need to be carefully tempered against women's human rights to reproductive autonomy and freedom. Respect for women's reproductive autonomy and freedom is central to women's welfare because childbearing takes place in women's bodies and because they are generally expected to take primary responsibility for child rearing, meaning that women carry a disproportionate burden to reproductive responsibility. We urge a consideration of, and respect for, women's reproductive human rights in the development of the FASD Action Plan. This should include placing limitations on the potential 'function creep' of FASD prevention initiatives beyond pregnancy.

9.a. What actions would support these building blocks?

As above.

9.b. How would you prioritise these actions?

As above.

10.a. What would we want to measure to make sure we were achieving this outcome?

Women's experiences and perceptions of interventions and service provision.

10.b. What would be the best indicator of change in the short term? In the long term?

High engagement in services, women's positive views on interventions and services.

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

We support these building blocks and agree that early identification and assessment may help improve outcomes for children with FASD and their families. However, we urge some consideration be given in the further development of Outcome 2 to the potential for judgemental, stigmatising, discriminatory and punitive attitudes and practices within, and outside of the health system, towards women and their families if there is to be a significant increase in FASD diagnosis and intervention. There is ample social and health science evidence across a range of pregnancy-related health outcomes including alcohol-exposed pregnancies, that well intended health interventions can inadvertently result in stigma,

discrimination, blame and guilt which can undermine, rather than promote, women's and children's health[9] [10]. For example, by leading families to avoid health care, affecting welfare entitlements or leading to criminalisation and child welfare involvement, and by compounding feelings of hopelessness, trauma and dispossession. Having a child diagnosed with FASD risks being stigmatising and potentially criminalising for women, especially for women who are already vulnerable and are easily alienated from health service engagement. There needs to be careful consideration given in the development of the Action Plan to how these potential implications will be ameliorated.

We therefore urge the Ministry of Health to consider, and address, the potential for increased stigma, discrimination and punitive consequences towards women and their families if there is to be increased efforts to identify and treat children whose neurodevelopment issues are related to FASD. Further, we urge consideration of how FASD-related neurodevelopmental issues will be distinguished from non-FASD-related neurodevelopmental issues in early interventions. Not all women whose children are experiencing neurodevelopmental issues will have consumed alcohol during pregnancy and women must not feel subjected to scrutiny, suspicion or blame for their pregnancy behaviours if they seek help for a young child with neurodevelopment issues.

15-18.b. Outcome 3: People and their families, whanau and caregivers receive timely, joined-up support tailored to their needs and strengths

Again we support these building blocks in principle and agree that people with FASD may benefit from joined up support tailored to their needs and strengths. However, in order to fulfil this potential we urge the Ministry of Health to consider, and address, ethical considerations such as the potential for stigma and discrimination, and punitive consequences for those families labelled with an FASD diagnosis.

19-22.b Outcome 4: There is an improved evidence base so we can make good decisions and effective investments

We share the Ministry's concern that there is a lack of New Zealand specific evidence to inform policy in regards to FASD and support this being a priority area in the Action Plan. We advocate strongly for investment in research to include gender-based analysis of the impact of FASD prevention activities and of women's views and perceptions of, and barriers to achieving, alcohol-free or reduced pregnancies.

We also hold concerns about forming policy related to women's light to moderate alcohol use during pregnancy given the 'significant body of conflicting research – particularly on the effects of light to

[9] Salmon, A. (2011). Aboriginal mothering, FASD prevention and the contestations of neoliberal citizenship. *Critical Public Health*, *21*(2), 165-178.

[10] Bell, K., McNaughton, D., & Salmon, A. (2009). Medicine, morality and mothering: public health discourses on foetal alcohol exposure, smoking around children and childhood over-nutrition. *Critical Public Health*, *19*(2), 155-170.

moderate drinking during pregnancy'. It is our view this this conflicting evidence about the effects of light to moderate drinking undermines Outcome 1 with its emphasis on alcohol-free pregnancies, and "pre-pregnancies". We believe that if the Ministry is to promote alcohol-free pregnancies (and "pre-pregnancies") for all women, including those who would drink lightly to moderately, that this *must* be supported by evidence and international consensus and if not that women should be provided with information about the potential risks, and or unknowns of light and moderate alcohol use during pregnancy and supported to make informed choices about their alcohol use.

23. Is there anything else you want to tell us? If, so feel free to make any further comments?

Given our expertise in the field of sex, gender and diversity-based analysis, women-centered health promotion frameworks, and issues relating to sexual and reproductive health and rights, Women's Health Action would welcome the opportunity to work with the Ministry of Health in the development of an Action Plan to address fetal alcohol spectrum disorder (FASD). As we have outlined in our comments above, we believe these perspectives will be critical for ensuring the success of actions to promote alcohol free pregnancies and the engagement of families in early intervention services for children with FASD and to ensuring a reduction in inequalities for New Zealand women, children and whanau. We look forward to further engagement with the Ministry of Health on this issue.