Taking Action on Fetal Alcohol Spectrum Disorder (FASD): A discussion document

Submission to the Ministry of Health

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Contact

MARILYN HEAD, BA, DIP TCHG, MSC, SENIOR POLICY ANALYST

DDI 04 494 6372 OR 0800 283 848 | E-MAIL **MARILYNH**@NZNO.ORG.NZ **|** www.nzno.org.nz

NEW ZEALAND NURSES ORGANISATION | PO BOX 2128 | WELLINGTON 6140

About the New Zealand Nurses Organisation

NZNO is the leading professional nursing association and union for nurses in Aotearoa New Zealand. NZNO represents over 47,000 nurses, midwives, students, kaimahi hauora and health workers on professional and employment related matters. NZNO is affiliated to the International Council of Nurses and the New Zealand Council of Trade Unions.

NZNO promotes and advocates for professional excellence in nursing by providing leadership, research and education to inspire and progress the profession of nursing. NZNO represents members on employment and industrial matters and negotiates collective employment agreements.

NZNO embraces te Tiriti o Waitangi and contributes to the improvement of the health status and outcomes of all peoples of Aotearoa New Zealand through influencing health, employment and social policy development enabling quality nursing care provision. NZNO's vision is *Freed to care, Proud to nurse*.

OVERVIEW

1. The New Zealand Nurses Organisation (NZNO) welcomes the opportunity to comment on your discussion document: *Taking Action on Fetal Alcohol Spectrum Disorder* ("the document").

2. NZNO has consulted its members and staff in the preparation of this submission, in particular members of the Neonatal Nurses College (NNC), College of Primary Health Care Nurses (CPHCN), College of Child and Youth Nurses (CCYN), Women's Section, Te Rūnanga o Aotearoa (te Rūnanga), and our professional nursing, policy and research advisers.

3. NZNO is a member of Alcohol Action New Zealand and was a founding signatory to the Public Statement on Alcohol by Doctors and Nurses[1] in response to the historic opportunity to change New Zealand's drinking culture presented by the Review of New Zealand's liquor laws by the New Zealand Law Commission in 2009.

4. Our position on addressing alcohol-related harm remains consistent with that statement, and with the recommendations in the Law Commission's Report (NZLC, 2009), namely, that comprehensive

[1] http://www.sfc.org.nz/pdfs/DoctorsandNursesStatement25-11-09_2_.pdf

regulation around the sale and promotion of liquor, as well as access to integrated health interventions are necessary.

5. While we welcome recognition of Fetal Alcohol Spectrum Disorder (FASD) as one of the many preventable and harmful consequences of alcohol consumption, NZNO is concerned about the policy pathway this document signals and the implications for resourcing that may ensue.

6. We support the collection of data and research to inform policy decisions we believe education and therapeutic responses to FASD need to be seen and delivered within the wider context of meaningful responses infant neurodevelopmental disorders, including prevention measures.

7. The specific targeting of FASD which is not unique, or indeed easily identifiable in terms of symptoms, causes, or harm, carries multiple risks in terms of messaging for young women which may cause unnecessary stress and further stigmatisation of the most vulnerable women.

8. The increasing incidence and severity of FASD (at least 600 children born each year with (May & Gossage 2001) that we are seeing now is clearly related to the deregulation of the sale (and promotion) of liquor which has not only allowed easier access to liquor, but encouraged more drinking at a younger age. We should not be surprised by the consequences, but considerable caution is needed to ensure that a focus on FASD does not lead to shifting blame and inciting fear among young women.

9. Pregnancy is primarily a woman's health issue and for women to be responsible for their actions they need to have control over their reproductive decisions, to be trusted to make the right decisions for themselves, and to not be economically penalised in employment or discriminated against. A suite of regulatory reform beginning with the abortion law reform and including fair recognition of women's reproductive labour in employment law (paid parental for at least 26 weeks, equal pay etc) is needed.

10. Similarly, regulatory controls on folate enrichment of flour, fluoridation food standards etc. is needed to support fetal and infant health.

11. Though the document notes the heightened risk of FASD with the two in five unplanned pregnancies (Morton et al, 2010) where women may not have reduced drinking in anticipation of pregnancy (Mallard et al 2013), it does not identify actions which could improve planned pregnancy, including ensuring universal access to affordable family planning services.

12. With regard to any issue concerning reproduction we note that higher fertility rates among Māori and Pacific peoples (who have less access to primary health care and family planning services) mean that they are disproportionately affected. Addressing equity failures first and foremost, ie meeting unmet health needs, would thus have a disproportionately beneficial effect. Removing funding inequalities to Māori and iwi providers will help reduce health disparities, as will progressing proportional representation in the health workforce.

13. A universal approach is needed to ensure that all children have their physical, emotional, developmental, social and spiritual needs met, and are able to grow up in a supportive and nurturing environment.

14. NZNO supports a focus from planning for pregnancy to three years of age and other recommendations in the Health Committee report on the Inquiry into improving child health outcomes ((Health Committee, 2013).

15. People also need to be supported to have healthy lifestyles and pregnancies including having access to accurate, assimilable information, timely interventions and therapeutic services.

16. Increasing health literacy across our ethnically diverse and geographically dispersed populations requires a safe, comprehensive and integrated approach to health promotion and presented in multilingual and multimedia formats.

17. Empowering all New Zealanders to reach their health potential also requires a fundamental shift in focus and funding to service models that support health and well-being. Such models must include access to good health information and the promotion of health literacy and self-management at all levels of care; early intervention for addiction, mental and sexual health problems; immunisation; and screening and health promotion programmes.

18. Flexible funding streams to facilitate community-based initiatives, including nurse-led clinics, walk-in centres, and nurse partnerships with other health professionals, will address barriers to care, optimise the use of health workforce skills and reduce future health demand.

19. Health practitioners (need to be equipped with the tools to recognise, understand and respond to FASD and we support research and education specific to the condition.

20. Extending parental leave to 26 weeks, and ensuring culturally appropriate comprehensive social, education and health services for all mothers and children, including integrated midwifery and PHO services and free, accessible primary health care, will help parents ensure their children get the best start in life, reduce entrenched health disparities and maximise the value of health spending.

21. There are two areas which the document does not explore. The first is the critical area of the workforce capacity, which is related to resourcing and service structure. Assessment, diagnoses, medical treatment and behavioural management are clearly within the scope of health practitioners regulated under the Health Practitioners Competence Assurance Act 2003. However there are some aspects such as respite care, home support etc. which may be provided by kaiāwhina. Education, training and authority needs differ and the document needs to clarify where responsibility lies and where resources, if any, will be directed.

22. We caution that it is not possible to lay extra responsibility onto health practitioners without appropriate resourcing, as is currently happening with some aspects of the Children's Action Plan. Community and home services require considerable workforce resourcing, including clinical oversight. Identifying specific workforce requirements will be critical to ensuring robust safe services.

23. Secondly, the document does not explore protections potentially available to the unborn child. Several countries have child welfare laws to address prenatal drug exposure (treating the issue as a matter of civil rather than criminal law). Such laws vary considerably as this is a very complex area, but we believe it warrants some attention in a document focused on preventable prenatal harm from alcohol.

CONSULTATION QUESTIONS

General

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

The best opportunity for reducing incidence of FASD a is prevention of alcohol exposure at conception and before confirmation of pregnancy, so committing to taking appropriate regulatory action to reduce that risk is essential.

Investment needs to be made in public and professional education on FASD as part of an overall strategy of health promotion, health literacy, and self-management of chronic conditions and universal access to primary health care which must include preplanning for pregnancy and universal access to affordable family planning services.

We suggest the governed could:

- increase professional and societal awareness of that not all people/children (including those with FASD) will respond in typical/predictable ways to conventional behaviour management strategies; and.

- ensure access to therapeutic and behaviour management services which are able to deal with the wide range of presentations resulting from FASD and other cognitive and physical disabilities.

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

NZNO is a member of Alcohol Action and supports its 5 + recommendations to decrease access to and demand for alcohol by:

- Raising alcohol prices
- Raising the purchase age
- Reducing alcohol accessibility
- Reducing marketing and advertising; and
- Increasing drink-driving counter-measures.

We strongly recommend enacting legislation for the following priority areas to decrease the demand for alcohol, ie

- Phase out alcohol advertising
- Phase out alcohol sponsorship
- Institute a minimum unit price for alcohol
- Increase the tax on alcohol

NZNO members and staff disseminate information and education, attend conferences, and make submissions to government, local government and other agencies about health implication of alcohol.

Our members are receptive to education about FASD, supportive to families and individuals with FASD (where this is known) and encouraging of assessment to diagnose this and commence implementation planning.

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

There needs to be more capacity in existing agencies, particularly Plunket and FPNZ, and more flexible referral criteria for families to access prompt assessments and commencement of providing co-ordinated support – therapeutic, as well as respite. Access to mental health support for parents dealing with the “double-edged sword” of realising their role in the development of their child’s condition, as well as living with the outcomes, is also important. .

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

The Plan should identify how the expertise of those who have experience (e.g. the aunty quoted on page 19) can be utilised in planning how to engage Maori in a wide range of contexts (not as a homogenous group but as a diverse community of people) in strategies to reduce the incidence of FASD and support whānau and those with FASD.

Utilising and properly resourcing Māori and iwi services (and ensuring pay equity) and supporting the development of the Māori health workforce would also be useful.

Part Three: The Action Plan

Key principles

- *Focus on empowering families/whānau.*
- *Collaborate to achieve a collective impact.*
- *Prevention is always possible.*
- *Build on strengths.*
- *Strive for sustained, systemic change*.

(Pages 11−12)

3. Do you support these principles?

It is difficult to disagree with any of the above (which are themes rather than principles) – empowerment is certainly a key to healthy making healthy life decision yet there is an issue with a focus on family/whānau on a matter that primarily affects women. The primary focus should be on women and the primary principle should be to affirm women's rights to reproductive and sexual health as expressed by various articles of the UN Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW).

Notwithstanding the implications of epigenetic research indicating the paternal influence on the health of a child, the mother's use of alcohol is the key factor in FASD. A focus on whānau and family without acknowledgement of women's central role (not just that she is 'influenced by') is not empowering, particularly when there are legislative barriers to women controlling their reproduction. Similarly, the extent to which a family/whānau is empowered to act responsibly with alcohol, when it has no control over where or to whom it is advertised, and available in the local community is moot.

We suggest that FASD must be considered as part of collaborative whole of government approach to alcohol, to supporting vulnerable families and

children and those with chronic care needs, and to equity. Making a difference in alcohol consumption patterns may take a long time and involve many different strategies. Reducing preventable ill health in infants also requires a collaborative response.

Collaboration between primary health, public health in schools and child developmental services is in the best interest of the child, as is access to assessment and treatment. The sooner FASD and other neurodevelopmental issues are identified and a collective plan of care devised the better. Ideally such issues need to be identified before school in order to put the support network in place to avoid further cognitive delay.

NZNO agrees that prevention is always possible (and preferable) and strongly supports a public health approach. However, we are somewhat concerned with the emphasis on identifying children with FASD outside a comprehensive programme for identifying and treating children with special needs, for obvious reasons. We suggest that this approach is focused on comprehensive primary health care ie access to good health information and the promotion of health literacy and self-management at all levels of care; early intervention for addiction, mental and sexual health problems; immunisation; and screening and health promotion programmes.

We also agree with building on what is already working and again recommend utilising comprehensive women and child focused services such as Plunket, Family Planning, Whanau ora, Pasifika as well as those services directed specifically at women, youth, and addiction and mental health.

While NZNO would welcome a focus on sustained systemic change, unless the intention is to underpin it with the regulatory change needed to support attitudinal and behavioural change to the use of alcohol, we do not support this principle. This is because without the regulatory support needed to change the current environment, women are at risk of being targeted to effect behavioural change, of being demonised, and of their families stigmatised.

Proposed outcomes

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

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

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

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

(Page 13)

5. Do you support these outcomes?

In general yes

Outcome 1. We support the focus on women. This needs to be approached from the perspective of improving alcohol consumption patterns across society. While it is practical to identify having 'alcohol-free pregnancies' as a goal to avoid risk to the unborn baby, for women the way it is expressed heightens what they are giving up/missing out on and can turn pregnancy into an experience of loss. Thought needs to be given to the role that alcohol currently plays in how all people relax, celebrate, socialise – and how people might be able to achieve similar objectives with their same social groups yet in other ways.

Moreover, there is a considerable risk with unplanned pregnancies that information expressed in uncompromising terms and setting unrealistic expectations will increase unnecessary distress and guilt, and may even lead to women considering an abortion. The British Pregnancy Advisory Service warns that the "the risk of physical or neurological damage to babies from isolated episodes of binge drinking by their mothers in early pregnancy is minimal" (Henderson, Kesmodel, & Gray, 2007).

In the current context we suggest it may be useful to provide additional recommendations to the blanket "no alcohol" advice in the Ministry of Health's guide to alcohol during or while preparing for pregnancy. The NICE guidance, for example is to avoid drinking alcohol in the first three months of pregnancy as it may increase the risk of miscarriage and if drinking during the remainder of the pregnancy keep to 1-2 units (a glass of wine) per week.

Outcome 2 Note our comments regarding an undue focus on identification of FASD which is not straightforward; we believe that identification is primarily useful for statistical purposes to guide policy decisions around reducing FASD, professional education and service provision. While early identification of FASD will facilitate the development of a timely collective plan of care (ideally it should be identified before school in order to put the support network in place to avoid further cognitive delay), this must be part of an assessment /care plan for the whole range neurodevelopmental issues.

We strongly recommend focusing attention on providing the services families need to cope with and improve outcomes for those with such issues. In this respect we again stress the need for the government to act on well-established preventative measures for neural tube defects (NTDs) such as folate enrichment of flour, as advised by Chief Science Adviser, Sir Peter Gluckman. It is unconscionable that approximately 20 infants per year are born with NTDs like spina bifida and face a lifetime of disability, suffering, and multiple interventions which could have been prevented as they have been for many years in countries such as Australia, Canada, and the UK.

We support **Outcomes 3 and 4** and suggest that there is a clearer link between research, information and education. People need to be supported with information, professionals need evidence and education, and policy needs to be informed by evidence.

Education needs to be clear and founded in research. The NNNC notes that there are mixed messages in the media: eg can a pregnant women safely drink on occasion, in moderation or not at all? We would also like to see the collection and analysis of local data to support the education process. Statistics need to be relevant and specific to Aotearoa New Zealand's population and drinking culture.

Identifying at risk teenagers and adults within the population is another means of preventing FASD. Identifying vulnerable girls and women - those who have experienced violence or abuse, with mental health issues and/or a history of addiction, for example - and putting in community support services would not only reduce the incidence of FASD but also of other health problems.

GP's and midwives are usually the first health service accessed by pregnant women. Again education is paramount especially for those who present early in pregnancy, but also the knowledge of where to direct women for support for addiction.

Note that of the three actions recommended in the Ministry of Health's current guidelines for health professionals on Alcohol and Pregnancy ie

- ask women who are planning a pregnancy or are pregnant if they are drinking alcohol;

- provide brief advice about not drinking alcohol when planning a pregnancy or when pregnant and explain why; and

- assist women who are having difficulty stopping, or whose drinking is problematic, and refer them to a specialist addiction treatment service. (NZNO emphasis)

the third is the most problematic because there are insufficient services (and especially specialist services for women) to refer women to. We suggest that ensuring the availability of alcohol and other drug addiction counselling and residential rehabilitation services are essential preventative strategies to reduce the impact of FASD.

Once the infant has been delivered, FASD is difficult to detect unless the case is severe and the distinct facial features were present. Early detection of neurodevelopmental issues is important not only for the prevention of FASD in future pregnancies but also to access developmental programmes in a timely fashion.

Educating Plunket nurses, GP's and public health nurses in early detection for example when milestones are delayed is one means of early

identification. While there are acknowledged difficulties in raising the subject of alcohol in pregnancy as a reason for intellectual impairment in a child these can be addressed with education and support. In the past health employees were uncomfortable asking about smoking and more recently violence in the home; however with education and training it has become the norm. With increased public awareness and discussion around FASD, alcohol related questions would become easier to pose.

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

In addition to the above, NZNO suggests that shifting society's perceptions of alcohol should be separate outcome rather than a 'building block' to supporting women to have alcohol free pregnancies. The two are certainly related in that shifting to more moderate consumption patterns will mean that women have less adjustment to make at pre-conception and this support alcohol free pregnancy. However they are not the same.

The priority outcome is, rightly, focused on women, but the wider societal issues around alcohol require a differ approach. Conflating the two may exacerbate the risk of women carrying the full responsibility and opprobrium for FASD in a drinking environment over which they have little control, and where their autonomy and choices over their own sexual and reproductive health are limited. Women must be able to make independent choices for themselves on the basis of accessible evidence-based information, and not be coerced into actions based on fear, guilt or public opinion.

Part Four: What we can do differently?

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

Building blocks for action:

- *shifting New Zealand's drinking culture*
- *providing clear, unambiguous and consistent messages*
- *empowering women to make active, planned choices about pregnancy*
- *supporting a consistent primary health care response*
- *increasing access to support and specialist services for women at high risk of having an alcohol-exposed pregnancy.*

(Pages 14−16)

7. Do you support these building blocks?

In general yes, but as mentioned, we suggest "Shifting Aotearoa New Zealand's drinking culture" needs to be a separate outcome, rather than a building block. We also suggest that all these actions require a competent

and supported workforce and recommend that the workforce (clinical, research, health promotion) is considered as an essential building block to achieving these outcomes.

Note our previous comments re messaging. Messages need to be evidence based, and contextually appropriate.

Empowering women to make planned choices about pregnancy, including planned pregnancy requires the elimination of discrimination against women. There is a significant imbalance of power between men and women which needs to be considered in relation to reproductive rights. Gender disparities in employment, income, leadership etc. are ubiquitous and translate readily into disparities in power and control. They are fundamentally related to the unequal value accorded to productive, as opposed to reproductive, labour in our society, though equal participation in employment is expected.

The physical and health implications of parenthood for women and men are also hugely disparate, as is the reproductive period. While the family context and men's involvement in contraception and pregnancy should be considered, women's decisions over reproduction must take precedence. Empowering women requires women's autonomy to be respected and upheld in law and in practice. We refer you to the recommendations made in our recent submission to the Ministry for women on the draft Eighth Periodic Report of the New Zealand government to the UN CEDAW (2016)[2].

We support a primary health care approach ie a health rather than medical focus and note that in general practice and in public health the majority of PHC (ie immunisation, heart & diabetes checks, tobacco cessation, breast and cervical screening) is delivered and recorded by nurses. We suggest there is significantly greater scope for more utilisation of nurses and nurse-led services in reaching vulnerable girls and women (in schools, rural areas, disadvantaged communities) to collect data, educate and address issues with alcohol and pregnancy alongside general practice.

We strongly support increasing access to support and specialist services for women at high risk of having an alcohol-exposed pregnancy, including access to counselling and residential addiction rehabilitation facilities.

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

As above

[2] See NZNO's website www.nzno.org.nz/get_involved/submissions: http://www.nzno.org.nz/Portals/0/Files/Documents/Activities/Submissions/2_2016_01%20CEDAW_NZNO.pdf

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

Everyone has a role to play in supporting women to have 'alcohol-free pregnancies' and it is very important that messages and actions are not targeted exclusively at women. Promotion of drinking alcohol-free alternatives by others in support of women at social occasions; consideration of other ways to mark celebrations, for example

Empowering women to making healthy choices requires sensitivity and recognition of all the factors identified as contributing to vulnerability and satisfactorily addressing them

b. How would you prioritise these actions?

These actions are important but secondary to the regulatory measures needed to underpin healthier actions around alcohol. As we have found with tobacco cessation, education is important but has less influence over action than factors such as price and access. While these actions are useful, they are unlikely to stem the tide of FASD resulting from easy access to alcohol at a younger age. We note the difficulties and disparities in local government's willingness and ability to control liquor outlets which continue to be concentrated in poorer communities and which undermine community autonomy.

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

Reduced or no alcohol consumption in pregnancy.

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

Short term indicators may be awareness of the harmful effects of alcohol in pregnancy, but the only meaningful long term outcome is reduced or no alcohol consumption in pregnancy across all population groups.

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

Building blocks for action:

- *building family and community capacity to understand and identify FASD and other neurodevelopmental issues*
- *building evidence-based awareness and understanding among professionals*
- *ensuring clear referral pathways*

- *providing multidisciplinary assessment and the creation of an individualised profile*

- *increasing clinical capacity and capability.*

(Pages 16−18)

11. Do you support these building blocks?

In general yes – most are intrinsic to the education, training and practice of all regulated practitioners and the delivery of health services. It is not clear what is meant by the 'creation of an individualised profile'.

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

We suggest the first building block does not fit with this suite of actions which are primarily focused on multi and interdisciplinary professional training and practice.

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

Funding

b. How would you prioritise these actions?

With the exception of the first they are interrelated and would need to be developed as a specific care pathways for FASD and other neurodevelopmental disorders.

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

We assume there would be clinical indicators for the incidence and severity of FASD.

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

Clinicians were confident of the referral pathway ie that there were appropriate services and expertise to assist people eg drug and addiction services for pregnant women, behavioural and respite services for families etc.

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

Building blocks for action:

- *improving community understanding*

- *universal approaches tailored to need*

- *support for parents, families and caregivers*
- *multidisciplinary care planning and coordination*
- *accessible care and support pathways*
- *support to navigate the system.*

(Pages 18−21)

15. Do you support these building blocks?

Yes although we query 'support to navigate the system'. If services are joined up the pathways should be clear.

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

Evidence that people were accessing services in a timely manner and that they were satisfied with the support received.

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

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

Building blocks for action:

- *routinely collect and analyse key data*
- *evaluate the effectiveness of interventions*
- *encourage research.*

(Pages 21−22)

19. Do you support these building blocks?

Yes

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

None

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

Funding

b. How would you prioritise these actions?

They are interrelated and should be delivered concurrently, though it is difficult to routinely collect data

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

That interventions were effective.

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

Marilyn Head

Senior Policy Analyst

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