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

Submission form

How to have your say

Please take the time to make a submission. The final pages of this consultation document explain how to make a submission and how to make sure it reaches the Ministry in time. There are also questions that might help you to write your submission. Your feedback is important: it will help shape the Fetal Alcohol Spectrum Disorder Action Plan.

All submissions are due with the Ministry by **5 pm** on **Friday, 26 February 2016**.

The Ministry of Health must have your submission by this date and time. Any submissions received after this time will not be included in the analysis of submissions. In making your submission, please include or cite relevant supporting evidence if you are able to do so.

There are two ways you can make a submission:

- fill out this submission form and email it to:
  FASD_Plan@moh.govt.nz

or

- mail your comments to:
  FASD Action Plan
  Ministry of Health
  PO Box 5013
  WELLINGTON 6145

The following questions are intended to help you to focus your submission. It will help us analyse the feedback we receive on the plan if you can use this format. You are welcome to answer some or all of the questions and you can tell us about other ideas or concerns you may have as well.

You do not have to answer all the questions or provide personal information if you do not want to.

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Organisation (if applicable): Nurse Practitioners New Zealand

Position (if applicable): Secretary

Are you submitting this as *(tick one box only in this section)*:

- ☐ an individual or individuals (not on behalf of an organisation)
- X☐ on behalf of a group or organisation(s)

If you are an individual or individuals, the Ministry of Health will remove your personal details from your submission and your name(s) will not be listed in the published summary of submissions, if you check the following box:

- ☐ I do not give permission for my personal details to be released.

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
- X☐ Professional association
- ☐ Justice sector
- ☐ Education sector
- ☐ Social sector
- ☐ Academic/research
- ☐ Local government
- ☐ Industry
- ☐ Other *(please specify)*:

Questions

General

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

NPNZ would like to highlight the point made on page 17 of the document "Taking action on Fetal alcohol spectrum disorder"- under the sub-title 'Empowering women to make active, planned choices about pregnancy' the document talks about improving access to effective contraception and increasing early confirmation of pregnancy.

Where we refer to Women we mean females of child bearing age as we wish to be mindful of those teenagers who may already engage in sexual relationships before the age of 18 i.e. Adulthood.

Within the current funding model for antenatal care in New Zealand Nurse Practitioners cannot charge for ante-natal care under the Section 88 Primary Maternity Services legislation, as they are not recognised as ante-natal care providers. Given the majority of Nurse practitioners are in Primary care and that they tend to be in areas that are rural and remote, or work with disadvantaged groups of society it would seem sensible to include them in the schedule of payments in Primary maternity services. As this would open up access to more New Zealanders and stimulate the desire of Primary care providers to employ Nurse Practitioners to undertake this role.

Thus improving access to effective contraception and increasing early confirmation of pregnancy which would help to reduce the number of alcohol-exposed pregnancies. We would also like to see an increased funding in long acting reversible contraceptives as the Jadelle implant does not suit everyone, and many pregnancies are unplanned- even within long-term relationships. Furthermore the removal of some special authority restrictions for some contraceptive medicines which currently present a barrier to Family planning Nurse Practitioners. Part of the ability to confirm early pregnancy would be access to Ultra Sound scans which currently NP's have difficulties accessing and again is a funding/radiology contract issue as NP's are not included in the definition of a provider under Section 88.

Although the focus of sexual and reproductive health strategies has tended to be on younger women (particularly teenagers), the evidence highlights that older women, who are in relationships are also an important target population around both birth control and around education for alcohol consumption. (Superu 2015b). Improving funding to Family planning or for Primary care NP's for more outreach clinics to allow 2-day clinics on a monthly basis would help provide improved access and birth control choices to New Zealand women.

"Any effective strategy will need to ensure that barriers to accessing reproductive and sexual health services (including cost, vulnerabilities and cultural norms) are accounted for."

We would also like to highlight on Page 18 of the document -
"Increasing access to support and specialist services for women at high risk of having an alcohol-exposed pregnancy.
Some women will need help to reduce their alcohol consumption when pregnant or planning pregnancy. Some will be dependent on alcohol, and stopping abruptly could put their health and that of their babies at risk. Not only do we want to ensure that women who need it can and do access treatment, but also that their unique treatment needs are routinely met.
Many alcohol-dependent women are vulnerable and have a range of other issues, so meeting their needs includes access to appropriate services and supports, and a more holistic, family-centred, wrap-around approach to care. This is likely to contribute to the prevention of future alcohol-exposed pregnancies". In addition a targeting of resources in those families or communities where prevalence is high in order to change attitudes to alcohol and the drinking culture.

All DHBs should have clear pathways and policies for assessing and managing at risk alcohol dependent pregnant women. The policy should emphasize collaboration and responsibilities across services and agencies (CADS, Adult Mental Health, Consultation liaison service - both psychiatry and alcohol and drug, ED, Maternity services as well as GPs, CYFS, mental health, police, NGOs etc). ACC and the sensitive claims process needs also to be part of the equation to manage previous trauma and prevent that from impacting on current and future whanau members.

In addition adequate resources are needed to ensure we can support safe alcohol and other drug withdrawal management, followed by appropriate (i.e. able to accommodate pregnant women and/or her children) residential rehabilitation services, or community services able to provide an intensive 'wrap-around' service. These services do not exist currently.

Further, child protection laws need to be strengthened to protect the unborn child and force drug and/or alcohol dependent pregnant mothers into treatment - MHAct and the new Substance use compulsory treatment Act are not sufficient to do this.

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

Nurse Practitioners work in a wide variety of settings across New Zealand and within many specialities including, Primary Care, youth work, Family planning and Mental health. We are fortunate to have a Nurse Practitioner in an Alcohol and other drugs service. This means they are working in areas that often are hard to reach in terms of health services, or in terms of engagement with health services.

Nurse Practitioners as part of their holistic approach to the care delivery, that they often lead, and the comprehensive assessment skills they possess are ideally placed to provide health education and advice on drinking in pregnancy.

As the report highlights the community's attitude about the consumption of alcohol probably needs to change. Members of our organisation work with the people who are affected by FASD and their mothers.

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

The best way for the action plan to support this is to look at how funding is allocated within Primary care and for ante-natal care in order to facilitate access for more New Zealanders to Nurse Practitioners especially in the lower socio-economic areas, rural/remote locations and those groups that may not readily engage with a GP.

Providing more opportunities for Nurse Practitioners within Family Planning and allowing them to work to the top of their scope of practice and provide delegated authority to Family planning RN's through the ability to issue standing orders would also increase the ability of individuals to prevent unplanned pregnancies.

One issue with continuity of care that could be reviewed is that the PHC nurses (including NPs) who provide 1st antenatal care are hampered & locked down by the Section 88 funding model to enable early and closer to home access to care, tests and scans which would go long way to identifying and preventing potential damage. For marginalised groups GPs may not be the health care provider and midwives not accessed in early pregnancy; and if 1st AN care was funded (first trimester only) for initial care by NPs & RNs, not just GPs & MWs to help create the fence at the top of the cliff , not just the ambulance at the end of pregnancy & a child with a lifetime of FASD.

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

As above

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?

X☐ Yes

☐ No

Please provide reasons and comments below.

Many pregnancies are unplanned, so improving access to contraception and to family planning advice is key, as is the ability to access early pregnancy confirmation/advice as the earlier a pregnancy is detected the earlier the mother can deal with their alcohol intake. Building on the public health campaigns of Family violence and smoking cessation a similar campaign around drinking in pregnancy is needed.

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

No changes

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?

X☐ Yes

☐ No

Please provide reasons and comments below.

In addition adequate resources are needed to ensure we can support safe alcohol and other drug withdrawal management, followed by appropriate (i.e. able to accommodate pregnant women and/or her children) residential rehabilitation services, or community services able to provide an intensive 'wrap-around' service. These services do not exist currently. Support around leaving violent relationships is also a key factor and having adequate refuge spaces and mental health\ social support going into those places to provide a safe stable environment. One thing we have to bear in mind is that alcohol and smoking are both coping strategies for stress, so in order for women to give these up in pregnancy we need to look at ways to facilitate a reduction in their stressors- whether this is through input from mental health services, Alcohol and Other drug teams or for support through social services to deal with the stressors of social deprivation, unemployment, family violence, previous trauma. We need to provide them with another coping strategy before we attempt to remove their current crutch from them. Whether this multidisciplinary/multi agency approach could be delivered from "Well women clinics" as a one-stop shop is an intriguing question. Co-ordination of care and of agencies would be key- this is a key strength of mental health services, but is a skill that could be learnt by other services.

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

No changes

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?

X☐ Yes

☐ No

Please provide reasons and comments below.

Increasing access to support and specialist services for women at high risk of having an alcohol-exposed pregnancy.

All DHBs should have clear pathways and policies for assessing and managing at risk alcohol dependent pregnant women. The policy should emphasize collaboration and responsibilities across services and agencies (CADS, Adult Mental Health, Consultation liaison service - both psychiatry and alcohol and drug, ED, Maternity services as well as GPs, CYFS, mental health, police, NGOs etc).

In addition adequate resources are needed to ensure we can support safe alcohol and other drug withdrawal management, followed by appropriate (i.e. able to accommodate pregnant women and/or her children) residential rehabilitation services, or community services able to provide an intensive 'wrap-around' service. These services do not exist currently.

Further, child protection laws need to be strengthened to protect the unborn child and force drug and/or alcohol dependent pregnant mothers into treatment – MH Act and the new Substance use compulsory treatment Act are not sufficient to do this.

One issue with access to empowering women to make active planned choices of pregnancy is that the PHC nurses (including NPs) who provide 1st antenatal care are hampered & locked down by the Section 88 funding model to enable early and closer to home access to care, tests and scans which would go long way to identifying and preventing potential damage. For marginalised groups GPs may not be the health care provider and midwives not accessed in early pregnancy; and if 1st AN care was funded (first trimester only) for initial care by NPs & RNs, not just GPs & MWs to help create the fence at the top of the cliff , not just the ambulance at the end of pregnancy & a child with a lifetime of FASD.

In terms of consistency of Primary Health care response Nurse Practitioners are ideally placed to provide that consistency especially in the rural and remote areas.

Education for young people about the dangers of alcohol and the unborn fetus, i.e., education at school which influences the boys as well as the girls and educates the teachers for them to reinforce the issues, e.g. FASD should be included in ETOH safety in all year 9 checks in schools.

Advertising campaigns in the media and in alcohol outlets paid for by the alcohol industry, similar to the posters we see in Radiology departments advising people who are pregnant or think they are to advise the radiologist prior to an x-ray.

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

No changes

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

Reduce the advertising of alcohol

Increase the funding for health care providers, improving the ability of Nurse Practitioners to provide ante-natal care through changes in the funding model.

b. How would you prioritise these actions?

1. Shifting New Zealand's drinking culture
2. increasing access to support and specialist services for women at high risk of having an alcohol-exposed pregnancy
3. providing clear, unambiguous and consistent messages
4. empowering women to make active, planned choices about pregnancy

supporting a consistent primary health care response

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

Admissions to ED of people affected by alcohol.

A reduction in drink driving numbers

A decrease in the number of unplanned pregnancies

An increase in the number of early detected pregnancies

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

In the short term it would have to be less public consumption of alcohol, or community acceptance of alcohol consumption.

In the long term it would be the diagnosis of children with FASD.

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?

X☐ Yes

☐ No

Please provide reasons and comments below.

Providing support for early years education to help identify children who may have FASD, and support within the education environment to help minimise the neuro-cognitive deficits where possible. Providing training and appropriate screening tools for Health professionals to screen high-risk women, and also tools for screening potential FASD affected children. New Zealand teenagers should have a free comprehensive Health check with a focus on FASD for those that schools report as having behavioural and learning difficulties not attributable to another formal diagnosis, as integral part of the Ministry's guidance. These checks ideally provided by Nurse Practitioners and supported by prescribing Registered Nurses' (either prescribing under their own right and in their Nursing scope or under Nurse Practitioner/Gp standing order) in schools, GP practices and Youth OSS's, who would also be able to provide contraceptive advice, health promotion and contraception prescriptions.

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

No Changes

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

There is an inconsistency of funding of child development services by District Health Boards, so a budget or policy adjustment so that it was consistent throughout the country would improve access for children and their whanau. Improving the skills and capabilities of school nurses and broadening their role in Secondary schools in terms of Health education and promotion.

b. How would you prioritise these actions?

11. building family and community capacity to understand and identify FASD and other neurodevelopmental issues
12. increasing clinical capacity and capability
13. providing multidisciplinary assessment and the creation of an individualised profile
14. ensuring clear referral pathways
15. building evidence-based awareness and understanding among professionals

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

This is much more subjective; perhaps an increase in numbers of children reviewed by CDC's

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

Improvement in function of those affected with FASD, both short term and long term.

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?

X☐ Yes

☐ No

Please provide reasons and comments below.

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

No Changes

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

b. How would you prioritise these actions?

- improving community understanding
- support for parents, families and caregivers
- support to navigate the system.
- accessible care and support pathways universal approaches tailored to need
- multidisciplinary care planning and coordination
- universal approaches tailored to need

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

Number of women accessing these services
levels of engagement with these services
Ability of services to work together to provide wrap around services and co-ordinated response (seamlessness)

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

Number of women successfully reducing alcohol intake during pregnancy

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?

X☐ Yes

☐ No

Please provide reasons and comments below.

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

No changes

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

b. How would you prioritise these actions?

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

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

Can we change the attitude to alcohol consumption in NZ.

Reduced numbers of expectant mothers reporting alcohol consumption

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

A reduction in alcohol consumption

Final comments

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

With respect to maternal rights to have freedom of choice we shouldn't forget the foetus has no choice about their environment. Child protection laws need to be strengthened to protect the unborn child and force drug and/or alcohol dependent pregnant mothers into treatment - MHAct and the new Substance use compulsory treatment Act are not sufficient to do this.