

Taking Action on
Fetal Alcohol Spectrum
Disorder: 2016–2019
An action plan

Cover image

The cover image symbolises strength and growth. This beautiful photo was captured by Jakob Gyde – a young, passionate and talented photographer, who is living with FASD. We wish to thank Jakob and his family for allowing us to use this image. The Gyde family are part of FASD-CAN, the Care Action Network in Aotearoa. This organisation provides support for families living with FASD. More information about FASD-CAN can be found on their website www.fasd-can.org.nz.

Citation: FASD Working Group. 2016.
Taking Action on Fetal Alcohol Spectrum Disorder: 2016–2019: An action plan. Wellington: Ministry of Health.

Published in August 2016 by the Ministry of Health
PO Box 5013, Wellington 6140, New Zealand

ISBN: 978-0-947515-36-2 (print)
ISBN: 978-0-947515-37-9 (online)
HP 6450

This document is available at health.govt.nz



This work is licensed under the Creative Commons Attribution 4.0 International licence. In essence, you are free to: share, ie, copy and redistribute the material in any medium or format; adapt, ie, remix, transform and build upon the material. You must give appropriate credit, provide a link to the licence and indicate if changes were made.

Minister's foreword

This Action Plan is New Zealand's first attempt to take a strategic and coordinated national approach to fetal alcohol spectrum disorder (FASD). It reflects the Government's commitment under the National Drug Policy to collaborate across sectors and communities to reduce alcohol-related harm.

The earliest stage of our lives lays the foundation for our health and wellbeing. The effects of alcohol exposure during this period can be significant. Around 570 New Zealand children are born each year with FASD. That means that their bodies and brains have been permanently damaged by their exposure to alcohol while in the womb. Fetal alcohol spectrum disorder is an under-recognised and under-supported condition that can have a devastating effect on a person's life and on the lives of the people close to them. It is having a disproportionate effect on our most vulnerable children and families.

This damage is preventable. We all need to work together to support women and their families and whānau to have healthy, alcohol-free pregnancies. Prevention means shifting our drinking culture. It means ensuring that the same messages are coming from every direction. It means reducing stigma and other barriers to people accessing the help they need, and ensuring our interventions are culturally appropriate.

Our approach to FASD needs to be coordinated. The breadth of FASD's effects across a person's life means that agencies, professionals, communities and families need to be working together to achieve change. This Action Plan commits agencies to working more closely together to support collaboration at the community level. It provides a framework to link existing initiatives and programmes and ensure we are all working towards a common goal.

Tackling FASD requires good evidence. Currently, the extent of our knowledge, especially in the New Zealand context, is limited. This Action Plan will give us a better understanding of the scope of the problem, who is affected and where our investments are likely to have the biggest impact.

I would like to thank the people who shared their experience and insight with us during the consultation process. We received 150 submissions from around the country – most from affected families and frontline professionals. People overwhelmingly supported the development of a whole-of-government action plan on FASD. I was touched by the passion and dedication of the submitters.

I was also inspired by the work that is already under way. Thanks to some incredibly committed people around the country, there is a growing awareness of FASD and some excellent examples of how people and services can do things differently to prevent this disorder and improve outcomes for those affected. We want to use this Action Plan as a way to spread best practice across New Zealand.

Too often in the past, we have concentrated on people's impairments in addressing conditions like FASD. This Action Plan acknowledges that everyone has strengths and that working to the strengths of people with FASD, their caregivers and the wide range of relevant professionals is essential for reducing the impact of FASD.

I am proud to introduce this Action Plan as a first major step towards understanding and addressing FASD and its related effects in New Zealand, on individuals, their families and whānau and communities.

Hon Peter Dunne
Associate Minister of Health

Acknowledgments

We wish to acknowledge and thank everyone who shared their insight and experience with us during the development of this Action Plan. This includes those who submitted on the discussion document as well as everyone we talked to during consultation. A special thanks to Christine Rogan, the team in the Hawke's Bay, the clinical advisory group and the lovely ladies in Rotorua for being so generous with your time, experience and networks. We particularly wish to acknowledge the contribution of the families and whānau who are living with FASD. This Action Plan has been shaped by what you shared.

Agencies involved in the FASD Action Plan

Child Youth and Family

Children's Action Plan Directorate

Department of Corrections

Health Promotion Agency

Ministry of Education

Ministry of Health

Ministry of Justice

Ministry of Primary Industries

Ministry of Social Development

New Zealand Police

Contents

Minister's foreword	iii
Overview	1
What is the problem?	1
Our approach	2
Goals and priorities	4
Prevention	4
Early identification	5
Support	6
Evidence	7
Actions	8

Overview

Fetal alcohol spectrum disorder (FASD) is the umbrella term used to describe the range of effects that can occur when a fetus is exposed to alcohol during pregnancy.

In the broadest sense, this includes miscarriage, stillbirth, premature birth, physical abnormalities and an increased risk of negative health outcomes for the child and even his or her offspring. However, FASD more commonly refers to a constellation of physical and neurodevelopmental impairments experienced by people who were exposed to alcohol during pregnancy.

This Action Plan aims to create a more effective, equitable and collaborative approach to FASD. It is a cross-agency commitment designed to build on the work that is already under way by providing coordinated support to those on the frontline of this issue.

Rather than establishing FASD-specific services and systems, this Action Plan will support the current system to be much more responsive to the needs of individuals, families, whānau and communities.

This Action Plan sets out a high-level vision of what we want to achieve, and how we can achieve that vision at a practical level. It includes a set of priorities that will direct our actions and investment. Each priority includes indicators of success. These indicators will help us keep track of progress and let us know whether the things we are doing are helping us achieve our goal.

A package of actions supports these priorities. We chose these particular actions because they are likely to have the greatest impact in the immediate and short term. This includes building evidence-based knowledge and understanding and collecting the data required to set baselines, develop services and evaluate initiatives in the future. All ten actions are designed to work together, and each contributes to more than one priority.

This Action Plan is a living document. We will update it as new priorities and new evidence emerge. We have designed it to contribute to a number of cross-agency projects, including Investing in New Zealand's Children and their Families,¹ the Youth Crime Action Plan, the Special Education Update, the 'A Good Start in Life' project and the review of Child Development Services. The Action Plan will evolve as these projects develop.

We will undertake a full review of this Action Plan three years from now, in recognition of the fact that we will be learning as we go. This review will provide us with the opportunity to re-evaluate our priorities and investments and make the most of emerging evidence. It will also ensure that this important issue stays on the Government's agenda.

This Action Plan contains actions for government, but its actions have been shaped by, and attempt to support the work of, the people on the frontline. We will continue to engage with them and other stakeholders as we implement the Plan.

What is the problem?

The damage alcohol does to the developing body and brain is permanent. It shapes the life of the person affected, as well as those who care for them. Based on international evidence, FASD is likely to be New Zealand's leading preventable cause of non-genetic intellectual disability. If we do not provide an effective response to it, it will continue to contribute to outcomes we want to avoid for our young people. These include increased mortality, abuse and neglect, poor educational achievement, engagement with the criminal justice system, benefit dependence, and mental health and alcohol and drug (AOD) issues.

1. This project arose from the Modernising Child, Youth and Family review.

The evidence indicates that:

- at least one in two pregnancies are exposed to alcohol; one in ten are exposed at high-risk levels
- two in five pregnancies are unplanned, increasing the chance they will be exposed to alcohol
- pregnant women do not consistently receive timely maternity care or support for their AOD issues
- health professionals do not consistently provide information on the risks of drinking during pregnancy or routinely screen for alcohol issues
- most clinicians lack the capability to diagnose FASD
- families of people with FASD struggle to access appropriate support and report a lack of understanding from services, professionals and even other family members
- FASD affects about 50 percent of children and young people in Child, Youth and Family (CYF) care.

Our approach

This Action Plan ultimately aims to improve people's health and wellbeing. It supports the vision of the New Zealand Health Strategy:

All New Zealanders **live well, stay well, get well** in a system that is **people-powered**, provides services **closer to home**, is designed for **value and high performance**, and works as **one team** in a **smart system**.

This is a cross-agency Action Plan. It acknowledges changes taking place across the health and social sector, particularly an increasing focus on an integrated cross-agency approach to vulnerable children and their families. This Action Plan aligns with, and makes the most of, the opportunities provided by other government policies, projects and priorities.

Fetal alcohol spectrum disorder is preventable. This Action Plan takes a **social investment approach**

and recognises that the greatest return will come from **prioritising prevention**. It focuses efforts on population-based strategies that are likely to have the greatest overall impact, and reduce inequalities. It accepts that prevention does not have to be absolute to be successful and those who are more vulnerable require more resources.

Everyone has a role to play in reducing alcohol-exposed pregnancies and improving outcomes for affected individuals and families. This Action Plan focuses on fostering **collaboration to achieve a collective impact**. It takes a **whole-of-government approach**, providing central guidance to support professionals, non-government organisations (NGOs), communities, iwi, hapū, whānau and individuals to improve outcomes in their own spheres of influence. It aims to create partnerships and shared understanding between families and whānau, communities and professionals.

Supporting families and whānau to improve their own health and wellbeing is one of the best investments we can make. Our approach actively seeks to **address the stigma** felt by women with AOD issues and the individuals, families and whānau affected by FASD. It concentrates on **building on people's strengths** and natural supports, and on providing assistance that is accessible, culturally appropriate, responsive and coordinated. Although this Action Plan is weighted towards **early intervention**, it takes a **life-course approach**. We understand that the needs and strengths of people and their families and whānau will change over time; for example, babies born with FASD may become parents themselves.

This Action Plan acknowledges that some families and whānau need more help than others. Our approach incentivises **equity of access** and the delivery of **equitable outcomes**, as well as the collection of data that will allow us to monitor progress and measure outcomes across populations, regions and priority groups. As it implements this Plan, the Government will ensure that people who are more affected by the current system have the opportunity to provide meaningful input into system and service design, delivery and improvement.

Goals

FASD is prevented and people with FASD and their family/whānau live the best possible lives

Principles

Prioritise prevention

Achieve equity of access and outcomes

Focus on supporting families and whānau

Take a whole-of-government approach

Destigmatisation

Collaborate to achieve a collective impact

Build on strengths

Invest in sustained, systemic change

Priorities

Prevention

Families and whānau understand the risks of drinking during pregnancy and are supported to have healthy, alcohol-free pregnancies.

•
Women with alcohol and drug issues are consistently receiving proactive, practical and non-judgemental support to improve their health and wellbeing and effectively reduce their risk of having a child with FASD.

Early identification

People with neurodevelopmental impairments are identified early and receive timely and effective assessments from FASD capable teams.

Support

People and their families, whānau and caregivers receive timely, joined up support tailored to their needs, strengths, age and stage.

Evidence

There is an improved New Zealand evidence base so we can make good decisions, effective investments and monitor outcomes and progress.

Action areas

- 1 Increase collaboration and coordination to better support the activities aimed at shifting New Zealand's drinking culture and targeting harmful alcohol consumption
- 2 Develop and disseminate clear, unambiguous and consistent messages to increase the whole community's awareness of the risks of drinking during pregnancy, including FASD
- 3 Support primary care to provide high-quality, responsive and equitable maternity care, including screening and brief intervention for alcohol
- 4 Increase access to equitable and culturally competent sexual and reproductive health care
- 5 Increase access to support and specialist services for women with alcohol and drug issues
- 6 Enhance the ability of frontline professionals to recognise and respond effectively and compassionately to people with FASD and other neurodevelopmental impairments
- 7 Improve the capability of clinicians to diagnose FASD
- 8 Improve cross-sector collaboration and capacity to provide effective assessments for people showing signs of significant neurodevelopmental impairment
- 9 Develop a coordinated, consistent, accessible and appropriately resourced pathway for supporting affected people and their families, whānau and caregivers
- 10 Conduct research into the incidence of FASD and other neurodevelopmental impairments in a New Zealand cohort

Goals and priorities

The overall goals of this Action Plan are 1) that FASD is prevented and 2) that people with FASD and their family/whānau live the best possible lives.

In order to achieve these goals, the Plan sets out four priorities: prevention, early identification, support and evidence. This section looks at the priorities in further detail; for each, it sets out 'what success looks like' (that is, our vision of what we wish to achieve) and 'indicators of success' (that is, our concrete goals for achievement by 1 July 2019).

Prevention

Current rates of alcohol consumption during pregnancy are higher than they should be, but research shows that women are already trying to reduce the risk to their unborn children from alcohol. We need to build on this effort by creating a more informed and supportive social context and an accessible and equitable continuum of care that is responsive to individual and family/whānau needs and circumstances. We need both universal and targeted prevention approaches. Abstinence is the ideal goal, but we must balance this with a harm reduction approach when appropriate.

What does success look like?

Families and whānau understand the risks of drinking during pregnancy and are supported to have healthy, alcohol-free pregnancies.

Women with AOD issues consistently receive proactive, practical and non-judgemental support to improve their health and wellbeing and effectively reduce their risk of having a child with FASD.

Indicators of success

By 1 July 2019:

- rates of drinking during pregnancy, particularly among Māori women, have decreased (baseline: New Zealand Health Survey 2012/13)

- the number of pregnant women who have been advised not to drink by a health professional has increased (baseline: New Zealand Health Survey 2012/13)
- screening and brief interventions for alcohol are routine in primary maternity care
- schools have the resources to teach specific content that explicitly addresses the negative impact of alcohol use during pregnancy
- information on alcohol and pregnancy and FASD is included in relevant resources distributed by all agencies.

'I met with a young woman this week who proudly told me she has given up drugs and now only drinks alcohol as she is pregnant.' – Social worker

'Alcohol does more harm to an ill-informed public, but education is insufficient on its own to address our drinking culture or address FASD.' – NGO

'FASD doesn't occur in isolation, it results from a complex relationship between biological, social, psychological, environmental and economic factors – preventing FASD is not just a matter of personal responsibility and choice.' – NGO

'We believe there is a problem of under reporting alcohol use during pregnancy due to the worry by women that they will be judged and concern that their children will be removed from their care.' – Maternal and infant mental health worker

Early identification

Early identification of FASD allows us to take advantage of key developmental windows and increase the chance of positive outcomes for children with FASD and their families, whānau and caregivers. Early identification also helps us direct resources towards the mothers and families/whānau most in need of support and gives us the greatest chance of preventing future pregnancies from being exposed to alcohol.

Improving people's ability to recognise and respond to signs of neurodevelopmental impairment, including FASD, is crucial. Tools and training should be available to a wide range of professionals, and there need to be clear pathways for referral.

There is evidence that multidisciplinary assessments are best practice for understanding people's needs and strengths. Improving capacity and coordination within and across sectors will make multidisciplinary assessments more accessible.

What does success look like?

People with neurodevelopmental impairments are identified early and receive timely and effective assessments from FASD-capable teams.

Indicators of success

By 1 July 2019:

- a minimum assessment for FASD has been developed, tested, endorsed and implemented
- a clinical pathway for FASD has been developed, tested, endorsed and implemented in all DHBs
- FASD diagnostic guidelines are embedded in clinical competencies
- professionals working with children and young people are able to identify the potential signs of FASD, and know where to refer someone for assessment
- there is an agreed 'home' for FASD assessments across the life course, and sufficient capacity to carry them out.

'Bolstering a diagnostically agnostic service for child neurodevelopmental services would benefit more children. It might also reduce stigma and encourage early engagement. Even with a clear history of high-risk antenatal alcohol exposure, the individual outcome is multifactorial.'

– DHB

'There needs to be a shift in community awareness of neurodevelopmental disabilities and in culture (both from the community and the health/education/welfare community) from assuming that someone is 'probably fine' to 'the question has been raised; we had better check it out'.'

– DHB

'Children with difficulties of the degree often posed by FASD deserve assistance. There is a danger that significantly impaired children will not receive such supports if they do not have a diagnosis of FASD, even though FASD is a diagnosis made on the balance of probabilities rather than certainty. It is also possible that valuable resources will be spent in clarifying whether or not children have FASD rather than clarifying what actual difficulties they are facing and strengths they have, and helping them appropriately.'

– Professional organisation

'Whānau need to be involved in the assessment process in a way that empowers them and is comfortable and manageable for them.'

– Psychologists at a Youth Forensic Service

'Courts need to recognise people who have this disorder and give them the right support.'

– NGO (Disabled Persons' Organisation)

'Professionals encountering people with neurodevelopmental disorders, including FASD, must also have access to information relevant to their profession and practice.'

– Professional organisation

Support

Fetal alcohol exposure affects everybody differently. We need to ensure that services and supports are responsive to need rather than diagnosis and flexible enough to adapt to changing age, stage and circumstance. We also need to help family members to understand FASD and to look after their own health and wellbeing.

Not all support needs to be resource-intensive. A little understanding (as long as it is evidence-informed) can go a long way. Support should build on a person or family's natural resources and strengths and focus on developing and reinforcing essential skills and strategies. To be as effective as they can be, interventions need to be consistent across settings. Coordination between agencies and sectors and partnerships between individuals, families and whānau and professionals are essential.

What does success look like?

People and their families, whānau and caregivers receive timely, joined-up support tailored to their needs, strengths, age and stage.

Indicators of success

By 1 July 2019:

- teachers report increased understanding of what FASD is and how they can support affected children and young people to achieve at school
- youth justice professionals can adapt their approach to people with FASD and other neurodevelopmental impairments
- a pathway of support is in place for people with FASD across agencies
- people with neurodevelopmental impairments have improved access to child development services in the health and education sectors
- a survey of families, whānau and caregivers shows improved support and family functioning.

'It is easy to believe all these children will fail; then they will. We need pathways of evidence-based and aspirational approaches to support these children and adults succeeding.'

– Father of a daughter with FASD

'I'm a normal person, but I just have these hurdles that other people don't have. What I find difficult, others might find easy. I think way differently to other people. I don't really understand when you tell me things, but if you show me, then I'll get it.'

– Young man with FASD

'I know firsthand how devastating the effects of FASD are and it needs a thorough and therapeutic response towards all involved – pregnant women, people with FASD and the families/caregivers, educators and community surrounding them.'

– Foster parent of a child with FASD

'Those affected come in through many doors, not just health. The FASD Action Plan needs to facilitate and support an intersectoral response, bringing diverse sectors together with a common purpose, common goals and systemic enablers.'

– NGO

'His behaviour is very difficult and the carers had no training on how to deal with him. Most didn't last long. Teacher aides and support people need proper training so they can understand what they are dealing with.'

– Grandmother of a young man with FASD

'The Government needs to make sure children and adults with FASD get a better deal than I did. Make sure they have more support at home and at school and the right services for them.'

– Person with FASD

Evidence

There are significant gaps in the international knowledge base in terms of FASD, and very little New Zealand-specific data exists. We need to base our policy and service development on robust data. Baselines are also necessary for monitoring progress and the outcomes of this Plan.

We need to routinely collect and analyse key data, including on alcohol consumption during pregnancy, whether a pregnancy is planned or not and diagnoses of FASD. If we standardise our approach to data collection, we can ensure that the data effectively supports evaluation and monitoring.

We need to engage in and encourage research and evaluation to ensure that New Zealand's approach is effective. We need to implement and monitor evidence-based interventions to improve outcomes and ensure value for money.

What does success look like?

An improved New Zealand evidence base allows us to make good decisions and effective investments, and monitor outcomes and progress.

Indicators of success

By 1 July 2019:

- the Ministry of Health receives regular data on the use of alcohol during pregnancy and can break down this data by age, ethnicity and region
- there is a standardised cross-agency data protocol for recording and reporting FASD diagnoses
- New Zealand has a baseline for the incidence of FASD.

'It is imperative that we know how FASD is impacting children and families beyond the anecdotal and to accurately establish a likely prevalence.'

– NGO

'Research into FASD in New Zealand, notably the prevalence and outcomes, needs to be prioritised to inform evidence-based policy.'

– Professional organisation

Without comprehensive data, it will be challenging to implement the Action Plan: the magnitude of the problems cannot be assessed, and neither can the social or economic cost be quantified. It is also unlikely that the government will invest in developing services for FASD if the complexity of the problem is not known and if the mitigation strategies are supported by limited substantive evidence.'

– Professional organisation

Actions

There are many things we could be doing differently to achieve our goals. It is important to concentrate on those actions that are likely to have the biggest impact. The first iteration of this Action Plan focuses on getting the building blocks in place, to enable New Zealand's existing system to be more responsive, inclusive and supportive. We need to ensure that people have easy access to evidence-based information; that professionals have the knowledge, skills, resources and mandate to make a difference and that the infrastructure supports us all to learn as we go.

This section outlines the specific actions the Government will take over the next three years to achieve the goals outlined above and the rationale for their inclusion here. Some of these actions will begin immediately. Immediate actions are concentrated in the 'prevention' priority area as they

build on existing structures and initiatives. Actions aimed at improving assessment and support will take longer to carry out as they require more substantial changes, greater collaboration between agencies, workforce development and, potentially, additional funding.

1

Increase collaboration and coordination to better support activities aimed at shifting New Zealand's drinking culture and targeting harmful alcohol consumption

New Zealand research shows that women who drink more heavily or frequently before pregnancy are more likely to drink during pregnancy, to drink more during pregnancy and to continue drinking later into pregnancy.

Women's drinking does not happen in isolation. It is shaped by their social, environmental and cultural context. In New Zealand, this context includes the normalisation of alcohol consumption within our culture, particularly at social events. This works against our ability to support women and their families and whānau to be alcohol-free during pregnancy.

Shifting New Zealand's drinking culture to one of moderation requires sustained effort over time and a whole-of-government approach and commitment.

It involves working together to support evidence-informed initiatives that are likely to nudge the culture in the right direction.

The Government's commitment to reducing harmful drinking and creating a more supportive social context is reflected in policies such as the Sale and Supply of Alcohol Act 2012 and the National Drug Policy (2015). One of the Government's key strategies is to focus on supporting communities to identify and address local priorities relating to problematic drinking and alcohol-related harm.

This action focuses on increasing collaboration between agencies to ensure that their work complements each other's and supports collaboration and collective impact at a local level.

Activities

Establish an interagency group to develop, implement and monitor a collaborative approach aimed at shifting New Zealand's drinking culture

Extend existing culture change campaigns, eg, the 'Say Yeah/Nah' campaign

Support the Healthy Families communities to focus on alcohol harm reduction

Review the Ministry of Health's public health contracts and service specifications to ensure health promotion activities have a focus on preventing FASD and align with cross-agency priorities

Investigate options for increasing alcohol and drug prevention activity in schools

Encourage youth offending teams to consider the effects of alcohol on offending in their communities and incorporate strategies to reduce harmful use as part of their action plans

2

Develop and disseminate clear, unambiguous and consistent messages to increase the whole community's awareness of the risks of drinking during pregnancy, including FASD

Women currently receive mixed messages about the risks of drinking during pregnancy. They are likely to listen to advice that conforms to their own drinking preferences.

We need to focus on increasing community awareness and ensuring that the same messages are coming from every direction. This includes all health professionals (see also Action 3) and other key influencers such as friends, partners and whānau. The alcohol industry, including retailers, also has an important role to play.

The Ministry of Health and the Health Promotion Agency will be the key agencies responsible for developing accessible, evidence-based resources on alcohol and pregnancy. Other agencies will use their networks to disseminate these messages as widely as possible.

The Government will work in partnership with the alcohol industry to ensure that consumers receive clear, unambiguous and consistent messages about the risks of drinking in pregnancy through all channels.

Pregnancy warning labels on alcohol are covered by a trans-Tasman agreement that the Australian and

New Zealand governments are currently reviewing. While this review is under way, the Government will expect industry to continue to increase the number of alcohol products that have messaging such as the pictogram on the right. Government will work alongside industry to ensure that consumers understand that this symbol means **'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.'**



The Government will look for opportunities at point of sale and through health promotion and education initiatives to clarify and promote the message to 'stop drinking alcohol if you could be pregnant, are pregnant or are trying to get pregnant'. It will also look to the alcohol industry to support evaluation of the impact and effectiveness of this approach.

In developing these messages, we will be mindful of the stigma faced by women with AOD issues. We want to raise awareness and decrease acceptance of drinking during pregnancy, but we also want to ensure that women feel safe asking for help without fear of judgement or persecution.

Activities

Produce two key resources on alcohol and pregnancy – one for consumers and one for professionals – and use them to update existing government resources and make it easy for others to build similar messages into their own resources

Extend the public education campaign on alcohol and pregnancy

Provide guidance on alcohol and pregnancy for schools as they develop and implement their own curriculum

Formally review the success of the coverage, consistency and effectiveness of the voluntary alcohol warning label initiative in both Australia and New Zealand

Work in partnership with the alcohol industry to ensure that consumers receive clear, unambiguous and consistent messages about the risks of drinking in pregnancy through all channels

3

Support primary care to provide high-quality, responsive and equitable maternity care, including screening and brief intervention for alcohol

Timely, high-quality maternity care improves outcomes for mothers and babies. It is essential that everyone can access such care, and that those providing it have the capacity and capability to respond to individual need and circumstance.

Supporting primary care professionals to be more confident and effective agents of FASD prevention requires two things.

The first is to increase the ability of primary care professionals to proactively engage with and respond to women who have more complex health and social needs. This is particularly important given the Government's focus on vulnerable children. The Ministry of Health is reviewing the way it contracts and funds primary maternity services, to increase flexibility and equity of access and outcomes – particularly for Māori and Pacific women.

The second is to support primary care professionals to take a more consistent approach to talking to women about their alcohol use before and during pregnancy, and providing brief interventions as required. While most primary care providers ask women about their alcohol consumption at least once during pregnancy, few are using validated screening tools or routinely providing referrals to specialist services, and there are barriers to initiating the necessary conversations and routinely collecting data.

We can support women to have alcohol-free pregnancies by raising awareness among primary care providers, training primary care professionals and getting evidence-based tools into primary practice. If we do this in conjunction with a funding review, we will have the opportunity to build data collection and reporting requirements into service contracts.

Activities

Work with professional colleges to update clinical guidelines on alcohol and pregnancy and embed evidence-based interventions and messages into core workforce competencies

Review the current funding arrangements for primary maternity care to improve equity and flexibility and make alcohol screening, intervention and data collection routine

Develop and promote an e-learning module that covers alcohol and pregnancy risks and the basics of FASD, which can be tailored for different professions and attract professional development credits

Improve the consistency of alcohol and pregnancy advice in existing clinical support tools

Increase the uptake into practice of tools that embed alcohol screening early in all pregnancies

4

Increase access to equitable and culturally competent sexual and reproductive health care

Improving access to effective contraception and quality preconception advice and support is likely to help to reduce rates of FASD. Although the focus of sexual and reproductive health strategies has tended to be on younger women (particularly teenagers), the evidence shows that older women are also an important target population.

Design, delivery and funding of services need to account for barriers to accessing reproductive and sexual health services, including cost, vulnerabilities and cultural norms. We need to give consideration to individuals' wider family and cultural context, and we need to encourage men to play a more active,

supportive role in contraception and pregnancy. Men's involvement in preconception health tends to increase healthy preconception behaviour in female partners.

The Government is working on a Sexual and Reproductive Health Action Plan (SRHAP) for 2016–2026 in partnership with the sexual and reproductive health sector, professional bodies and district health boards (DHBs). Among other things, the SRHAP aims to increase people's access to confidential, safe, accessible, affordable and timely contraception, and to ensure that high-priority groups can access a range of culturally appropriate reproduction services.

Activity

Implement the Sexual and Reproductive Health Action Plan for 2016–2026

5

Increase access to support and specialist services for women with alcohol and drug issues

Some women need help to cease or reduce their alcohol consumption when they are pregnant or planning pregnancy. We must ensure that women who need treatment can and do access it but also that we can meet their unique treatment needs. The New Zealand Health Strategy includes a commitment to increasing support for pregnant and postpartum women experiencing AOD issues.

Some current initiatives are already supporting a more coordinated and intensive service response to pregnant women with AOD issues and address some of the barriers they face in accessing help. An example is the *Supporting Parents, Healthy Children* guidelines, which help mental health and addiction services to support parents with mental illness or addiction and their children. District health boards will implement these guidelines across the mental health and addiction sectors over the next five years. The Ministry of Health expects that, in this way, DHBs will help us achieve the systematic change we need. The

guidelines provide clear direction on improving coordination of care and providing focused support to pregnant and postpartum women.

The Ministry of Health will monitor the implementation of the guidelines and will continue to work with the sector to enhance its responsiveness to the diverse needs of pregnant women. This includes ensuring that pregnant women who are identified as having AOD issues have a clear pathway into effective and accessible treatment services.

The Government has committed funding to increase service provision for women with significant AOD issues and high and complex needs. Such women have the highest risk of having a child with FASD but face significant barriers to accessing and remaining engaged in more traditional services. The Ministry of Health will work with key stakeholders to identify regions that would most benefit from increased service capacity and will roll out and evaluate an intensive case-management service in those areas.

Activities

Increase support for pregnant and postpartum women experiencing AOD issues

Work with AOD workforce centres to monitor the implementation of the *Supporting Parents, Healthy Children* guidelines and ensure that women of childbearing age coming into contact with AOD services are routinely asked about the possibility of pregnancy and connected with maternity and sexual and reproductive health services

Implement and evaluate an intensive wraparound service for pregnant women with AOD issues and complex needs in three areas

6

Enhance the ability of frontline professionals to recognise and respond effectively and compassionately to people with FASD and other neurodevelopmental impairments

Professionals who work directly with people affected by FASD have expressed a need for more accessible information, education and tools to support them to recognise and respond effectively to people with FASD. There is a general desire for training to be cross-agency, to ensure that all frontline professionals have the same knowledge, use the same language and give the same advice about FASD.

Initially, a generic set of training modules will be developed. These will cover the basics, such as understanding FASD, alcohol and pregnancy and how to recognise and work with people with neurodevelopmental impairments. The training modules will be made widely available, and agencies will look for opportunities to embed them into existing workforce development programmes and resources (eg, Children's Teams training and the new vulnerable children's practice framework).

The Ministry of Health will also test how well existing service tools, such as PEDS, and the Well Child / Tamariki Ora (WCTO) programme are able to identify children who have FASD or other neurodevelopmental impairments.

Not all children with FASD will be detected before they start school, even with robust and effective

systems in place. Teachers are ideally placed to pick up on issues resulting from FASD as they become more obvious and have a key role in supporting children with FASD and their families. We need to make sure that teachers have a basic understanding of FASD, and that they have access to practical, evidence-based strategies for teaching people with FASD and managing complex behaviour when it is the result of neurodevelopmental impairment. In addition, teachers need to know where to go for more help and to access support and assessment. The Ministry of Education is developing a comprehensive resource to educate teachers about FASD and about what they can do to support affected children and young people to stay engaged in education.

People with FASD and other neurodevelopmental impairments are likely to be overrepresented in our youth justice system. Given this overrepresentation, and the consequences of these issues not being recognised for what they are in this setting, specific guidance is required for professionals working in the youth justice sector. This aligns with the Youth Crime Action Plan's goal of ensuring that the underlying causes of youth offending are understood and addressed.

Activities

Conduct a stocktake and gap analysis of current frontline and allied health workforce competencies for preventing, identifying and responding to FASD

Develop generic modules (eg, a module on working with people with neurodevelopmental impairments and alcohol and pregnancy) for use in training and resources for a range of professionals

Test the ability of the B4 School Check / WCTO screens to identify children with FASD and other neurodevelopmental impairments

Develop a resource for teachers, to improve their knowledge and practice regarding FASD

Develop guidance for people working in the youth justice system, to increase their awareness of and ability to respond effectively to people with FASD and other neurodevelopmental impairments

Liaise with Australian researchers around the development and testing of a screen for FASD in youth justice settings

7

Improve the capability of clinicians to diagnose FASD

Fetal alcohol spectrum disorder is often described as an ‘invisible’ disability, because the damage resulting from antenatal alcohol exposure is often ‘hidden’ in the brain. While some people present with visible signs of alcohol exposure, others present with a range of neurodevelopmental impairments that can be difficult to attribute to a specific cause. Sometimes the issues people present with are common to a number of disorders as well as FASD; some people will meet the criteria for multiple diagnoses.

A diagnosis of FASD is not always easy to achieve, but it can be beneficial. During consultation, families explained how it has made a huge difference to them to know what was actually happening with their child – even if it was a difficult diagnosis to accept. An FASD diagnosis can alert professionals and family members that the birth mother, the family and (potentially) other siblings are in need of support. Ultimately, a diagnosis of FASD is about understanding an individual’s unique pattern of strengths and impairments, which in turn can facilitate communication between health professionals, educators, families, whānau and carers on effective interventions and appropriate support.

In September 2015, the Ministry of Health surveyed a wide range of clinicians about their confidence in diagnosing FASD. The survey found that those clinicians who felt extremely confident about this diagnosis were definitely in the minority. This is not surprising, given that there is no international consensus on how to diagnose the full spectrum. The survey found that clinicians were using a range of different guidelines to support their diagnoses. This is not ideal; New Zealand needs a standard approach, to improve the consistency of diagnostic practice and allow us to collect and monitor comparable data over time.

The Ministry of Health has created a clinical reference group made up of local and international clinicians representing a range of sectors. The Ministry will work with these clinicians, and with professional colleges, to develop and test tools to support a diagnosis of FASD, including standardised diagnostic guidelines and protocols for data collection. Once we have developed these tools, we will investigate the most user-friendly and cost-effective ways to upskill existing clinicians and embed the tools into routine practice.

Activities

Conduct a stocktake and gap analysis of current clinical workforce competencies for formally assessing, diagnosing and managing FASD

Develop and test a clinical pathway for FASD / suspected FASD, including protocols for collecting standardised data

Develop and test a minimum assessment protocol for FASD

Test the accuracy and usability of facial screening software for FASD in a New Zealand cohort

Work with professional colleges to support the implementation of consistent diagnostic guidelines for FASD in New Zealand, and embed them into core training

8

Improve cross-sector collaboration and capacity to provide effective assessments for people showing signs of significant neurodevelopmental impairment

To fully understand the impact of alcohol on an individual's neurodevelopment, a multidisciplinary assessment is necessary. Such assessment tends to focus on a range of factors, including how a person's brain works, the range of life skills they have, signs of physical abnormalities and specific needs and strengths. A clinician may consider a FASD diagnosis as a result of this assessment. The ultimate aim of assessment is to create an individualised profile that helps people to understand their strengths and needs and provides guidance to their caregivers and relevant professionals.

Assessment for FASD needs to be comprehensive. It requires input from educators, social workers and a range of professionals. It should also include information from family, whānau and caregivers, as well as the individual being assessed. An accurate diagnosis of FASD is only one aspect of a comprehensive assessment.

Given the broad range of presentations associated with FASD, and the need for equity, assessments should be available across the board to any child or

young person showing signs of significant neurodevelopmental impairment, including persistent behavioural problems, regardless of the setting they present in.

The Ministries of Health and Education and CYF will work together with key stakeholders to ensure effective, equitable assessment for people affected by FASD. Drawing on the expertise of the clinical reference group (see Action 7) and the results of the research outlined in Action 10, these agencies will establish how to make the best use of existing resources and where we need to fill gaps in capacity to support assessments.

We will also develop common practice principles to guide these assessments and subsequent support plans, including expectations around their timing. We will develop a clear process for initiating and prioritising assessments. This process is likely to be shaped by the priorities of the Government's vulnerable children work streams, including Investing in New Zealand's Children and Their Families.²

Activities

Undertake policy and co-design work on the make-up and mandate of an appropriate multidisciplinary assessment team for FASD, the resourcing it will require and its ideal location/s

Place a greater emphasis on neurodevelopmental need in the review of Child Development Services

2. This project arose from the Modernising Child, Youth and Family review.

9

Develop a coordinated, consistent, accessible and appropriately resourced pathway for supporting affected people and their families, whānau and caregivers

Services need to cater for the wide range of needs of people with FASD. We need to ensure that we can adapt universally available services for someone whose brain works differently, and we need to make specialist support services, like supported living or respite care, more accessible.

Three significant projects likely to make a difference to people with FASD and their families are already under way. First, the Ministry of Education is currently redesigning its special education system to reduce fragmentation and inflexibility and remove barriers to access. Second, the Ministries of Health, Social Development and Education, as well as the Police, are working on an initiative designed to improve services and support available to children and young people with conduct problems. Third, as part of the 'A Good Start in Life' project, the Ministries of Health, Social Development and Education are working with NGOs to investigate options for more effectively integrating early intervention and support services for children with a disability. While not specifically aimed at people with FASD, all these projects are now taking FASD into account.

A planned stocktake on FASD interventions will support this work. It will examine what the evidence suggests is best practice for supporting affected people and their families, whānau and caregivers and

compare it with what is available now. The Ministry of Education has already started this process within its own sector. Other agencies will follow suit.

Drawing on the information provided by the stocktake and the research outlined in Action 10, agencies will work together to conduct a social investment analysis of the options for providing support that are likely to make the biggest difference to outcomes.

A cross-agency team will work across sectors and with affected individuals, families, service providers, clinicians and care coordinators to work out how best to resource and roll out a coordinated multiagency pathway of care for people affected by FASD across the life course. The pathway will focus on ensuring seamless transitions between child, youth and adult services.

Not everyone with FASD will be able to be diagnosed. While we will apply an FASD lens to identify and fill gaps in services and supports, in order to ensure equity, we need to make sure that access to support is based on need, not solely diagnosis. This means focusing on neurodevelopmental impairment more broadly, while ensuring that government-funded resources are directed towards those who need the most support.

Activities

Undertake a stocktake and gap analysis of FASD interventions, services and supports

Undertake social investment analysis and co-design work to develop pathways and target investment for multiagency support for people affected by FASD across the life course

Apply a neurodisabilities lens to the Cross-agency Conduct Problems project

Focus on neurodevelopmental need within the Special Education Update

Build on the A Good Start in Life project

10

Conduct research into the incidence of FASD and other neurodevelopmental impairments in a New Zealand cohort

One of the biggest gaps in our current knowledge base is the number of New Zealanders affected by FASD. To address this, the Government has invested in a three-year research project looking at the incidence of FASD in a representative cohort of eight-year-olds. The Ministry of Health is leading this project, with support from Superu and a clinical reference group including representatives from other agencies (see Action 7).

As well as improving New Zealand's understanding of the local incidence and experience of FASD, this research will test screening and assessment protocols, clinical pathways and basic support packages. Information from this study will inform many of the other actions in this plan, particularly those aimed at improving clinical capacity and support for affected individuals and families.

Activities

Work with the clinical reference group to develop research, screening and assessment protocols

Carry out screening and assessment with the Growing Up in New Zealand cohort

Develop and test a basic support package

Analyse information from the study to investigate:

- the relationship between alcohol use and neurodevelopmental outcomes
- the association between FASD and other neurodevelopmental outcomes in early childhood
- the relationship between other antenatal exposures (eg, smoking, nutrition) and neurodevelopmental outcomes