

Taking Action on Fetal Alcohol Spectrum Disorder (FASD)

A discussion document

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Introduction

Purpose

The purpose of this discussion document is to enable the New Zealand public and any interested parties to contribute to the development of an Action Plan to address fetal alcohol spectrum disorder (FASD). The recommendations arising out of this discussion will be presented to the Government in mid-2016.

Process and timeline

The Government has committed to developing an Action Plan (the Plan) to address FASD and has asked the Ministry of Health to lead this work. Many agencies are involved in the development of the Plan.

The proposed timeline for completing the Plan is June 2016. The public discussion period for this document is until Friday 26 February 2016. After this the Ministry of Health will continue to consult with key people and organisations on the development of the Plan, but there will be no further opportunity for public submissions.

The need for an Action Plan

New Zealand does not currently have a comprehensive strategy to address FASD. Fetal alcohol spectrum disorder (FASD) is the umbrella term used to describe the range of effects that can occur in a person who has been exposed to alcohol in the womb.

If a woman consumes alcohol during her pregnancy it can result in significant harm to the fetus. Babies born after exposure to alcohol may have permanent damage to their brain and other critical organs, functions and structures. These effects can have a profound effect on a person's life, and increase the likelihood of negative outcomes for them, their family and wider society. These outcomes are preventable.

How you can help

We want your feedback on the high-level principles and outcomes we are proposing. We want to know if these set the right vision and direction for the Plan.

This document highlights what we think the current issues are and outlines what we believe are the best building blocks for a more joined-up and effective approach to preventing and responding to FASD. We're interested to hear whether you think we have got these right, and what you think the Government should be prioritising in the Plan.

We will be asking you questions to guide the discussion (you'll find these at the end of the document), but you can tell us about other ideas or concerns you may have as well.

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

Navigating this document

Part One focuses on what we know about FASD. This is the most technical part of the document and it draws on the available evidence to discuss things like drinking during pregnancy, the effects of alcohol on the fetus, and different types of fetal alcohol spectrum disorders (FASDs).

Part Two sets out what we know about the impact that FASD has on individuals and families. This is based on a combination of international evidence and our conversations with clinicians, frontline professionals, affected families and other experts.

Part Three outlines the high-level principles and outcomes we are proposing for the Action Plan. We want to know whether these set the right direction for the Plan and if anything is missing.

Part Four goes into more detail about the proposed outcomes and outlines a set of 'building blocks' for action under each outcome. We want to know if the building blocks we are proposing are the right ones and if there is anything else we should be focusing on.

Part One: What we know about FASD

Effects of alcohol on the fetus

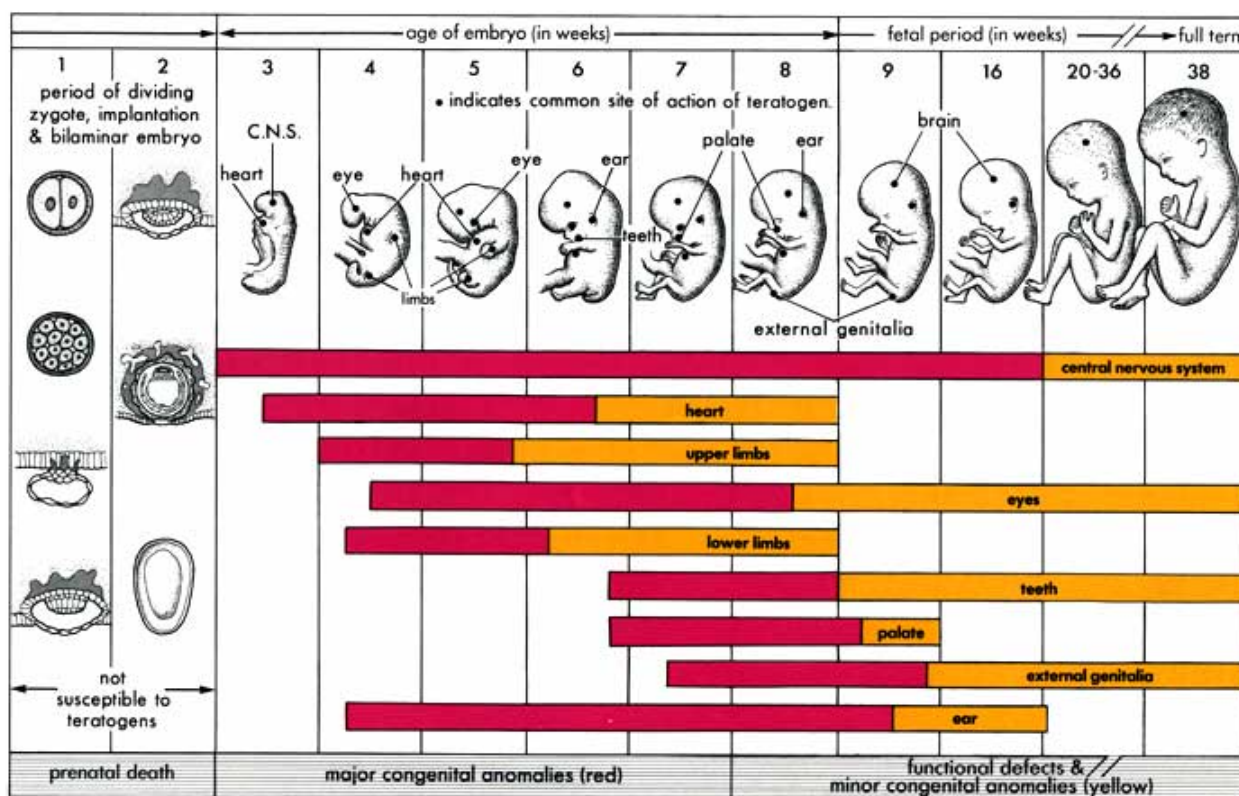
Of all of the substances of abuse, including cocaine, heroin and marijuana, alcohol produces by far the most serious neurobehavioural effects in the fetus.

(Stratton et al 1996: 35)

Alcohol is a *teratogen*: a toxic substance that can inhibit healthy development of the fetus. When alcohol is consumed during pregnancy it can easily cross from the mother to the baby via the placenta, exposing the developing baby to blood alcohol levels similar to those in the mother. Exposure to alcohol and its metabolites (the chemicals alcohol gets converted to) can damage cells and interrupt essential developmental processes.

Figure 1 shows the periods of development of the fetus that are most likely to be affected by alcohol. The red (or dark) bars indicate when alcohol exposure is likely to have the most severe impact, and the yellow (or light) bars indicate periods of continued sensitivity. What this shows is that the most vulnerable period for most organs is the first eight weeks of pregnancy. This is often before a woman knows she is pregnant. It also highlights that the developing brain is susceptible to the effects of alcohol right through pregnancy.

Figure 1: Alcohol exposure and its potential effects on development at different periods



Source: Adapted from Moore and Persaud (1993)

Drinking during pregnancy in New Zealand

Despite advice from the Ministry of Health¹ that women who are pregnant or are planning to get pregnant should not drink alcohol, the evidence suggests that about one in two pregnancies in New Zealand are alcohol exposed.² Around 10% of pregnancies will be exposed to alcohol at high risk levels (O’Keefe et al 2015).³ A single binge or more than seven standard drinks in a week is classed as high risk. These figures are likely to be an underestimate as they are based on self-report (Lange et al 2014).

Most of this exposure occurs in the first trimester, particularly before a pregnancy has been confirmed (Superu 2015b). Unplanned pregnancies are at heightened risk of alcohol exposure because they tend to be confirmed later and women may not reduce their drinking in anticipation of getting pregnant (Mallard et al 2013).

Drinking alcohol during pregnancy can compromise the health of both the mother and her unborn baby. It increases the risk of a number of pregnancy complications, including injuries, miscarriage, stillbirth, growth restriction and premature birth (British Medical Association Board of Science 2007). It also increases the likelihood of sudden infant death syndrome (Kesmodel et al 2002) and can cause permanent damage to the brain and body of the developing fetus. There is no known safe amount of alcohol in pregnancy.

FASD

Fetal exposure to alcohol can lead to permanent damage to the brain and other critical organs, functions and structures. Fetal alcohol spectrum disorder (FASD) is an umbrella term used to describe the range of different effects that can result from this exposure.

Some of these effects will include visible abnormalities: damage to the body, major organs and skeleton. However, some of the most serious damage will be ‘hidden’, in the brain. FASDs are often characterised by communication, behavioural and sensory issues and can exist alongside or be mistaken for other conditions. These issues will manifest themselves at different points along the developmental trajectory and may not be obvious until an important developmental milestone is delayed or not achieved. This may not be recognised as relating to alcohol exposure or any resulting brain damage.

There is no typical FASD profile (Gibbard 2013: 26). However, common issues may include: intellectual and developmental disabilities, attention deficits, poor social understanding, hyperactivity, learning disabilities, poor coordination and planning, poor muscle tone, working memory deficits, receptive language deficits, executive functioning deficits (eg, difficulty organising and planning), and the inability to learn from the consequences of behaviour (SAMHSA 2014a).

¹ This message is also supported by other health organisations, such as the Health Promotion Agency, the Royal Australian and New Zealand College of Obstetricians and Gynaecologists, the New Zealand College of Midwives, and a host of international organisations.

² This is the (rough) average of the findings of the three latest pieces of local research: 19% (Ministry of Health 2015a), drawing on a small cohort of pregnant women (565); 56% (O’Keefe et al 2015), using a larger cohort (2600), but the cohort only included first-time mothers and those who hadn’t had a miscarriage; and 71% (Superu 2015b), the largest cohort (6800), but the questions asked merged pre-pregnancy consumption and consumption before pregnancy awareness, meaning this may overestimate prevalence.

³ This is based on any episode of binge drinking (four or more standard drinks) at any stage in pregnancy. We don’t have sufficient data to say how many women would fall into this category based on number of drinks a week.

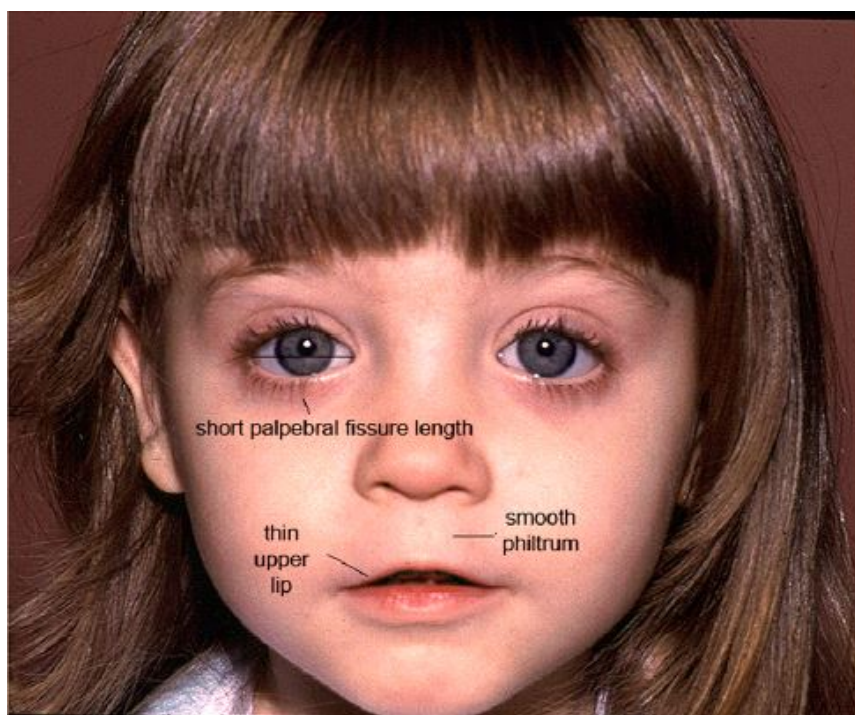
Fetal alcohol syndrome

The most recognisable form of FASD is fetal alcohol syndrome (FAS). FAS sits at the most severe end of the FASD continuum in that, overall, people with FAS have the most widespread and severe damage (Mattson et al 2011: 2). Individuals with FAS generally have reduced intelligence (Streissguth et al 2004: 3) and are more likely to meet the criteria for intellectual disability.

FAS is a clinically consistent⁴ diagnostic term. It describes the full expression of a characteristic pattern of abnormalities that can occur in an individual exposed to alcohol while in the womb. These include:

- permanent impairment of the central nervous system, which may manifest in issues with behaviour, learning, communication and adaptive functioning
- the presence of three facial anomalies (see Figure 2)
- growth restrictions – babies born with FAS are usually smaller than other babies and tend to remain smaller throughout their lives.

Figure 2: Child presenting with the three diagnostic facial features of FAS



© 2015, Susan Astley, PhD, University of Washington.

⁴ This means there is consensus about how to diagnose it.

The wider spectrum

Since FAS was first described it has become clear that a spectrum of effects is possible when alcohol is used during pregnancy. Fetal alcohol exposure can cause significant brain damage and result in severe neurocognitive impairment and behavioural issues without causing any facial characteristics (British Medical Association Board of Science 2007: 2; SAMHSA 2014: 1–41).

FASD is a non-diagnostic term that includes people with FAS, those who are diagnosed as having other FASDs, and people who are affected by fetal alcohol exposure but who may not have any diagnosis. This could be because they haven't been diagnosed, or because they don't quite meet the clinical criteria (eg, there is no record that they were exposed to alcohol in the womb).

Other FASDs include:

- *partial fetal alcohol syndrome (pFAS)*: where people almost fit the full FAS criteria but don't show all three of the facial features
- *alcohol-related neurodevelopmental disorder (ARND)*: where people don't have any of the facial features, but present with cognitive and behavioural issues relating to damage to their central nervous system
- *alcohol-related birth defects (ARBD)*: where people have defects of the skeletal system or major organs but not the behavioural or cognitive issues seen in people with FAS (this term is not used much anymore).

The diagnostic criteria for these disorders are not clinically consistent, and clinicians would have to prove that a person was exposed to alcohol in the womb to give them a diagnosis of any disorder except FAS.

Prevalence of FASD

There is no New Zealand data on the prevalence of FASD, but studies from the USA suggest that 1% of the population (May and Gossage 2001) is a solid, conservative estimate for New Zealand.⁵ This implies that about 46,000 people in New Zealand may have an FASD, with around 570 more born each year. Around 10% of these may have FAS.⁶

International research suggests that out of this 46,000:

- 38,180 have speech and language disorders
- 32,200 will develop a mental illness
- 21,160 have congenital heart defects
- 18,400 are diagnosed with attention deficit hyperactivity disorder
- 12,880 experience sensorineural hearing loss
- 8740 have an intellectual disability (Thanh and Jonsson 2009).

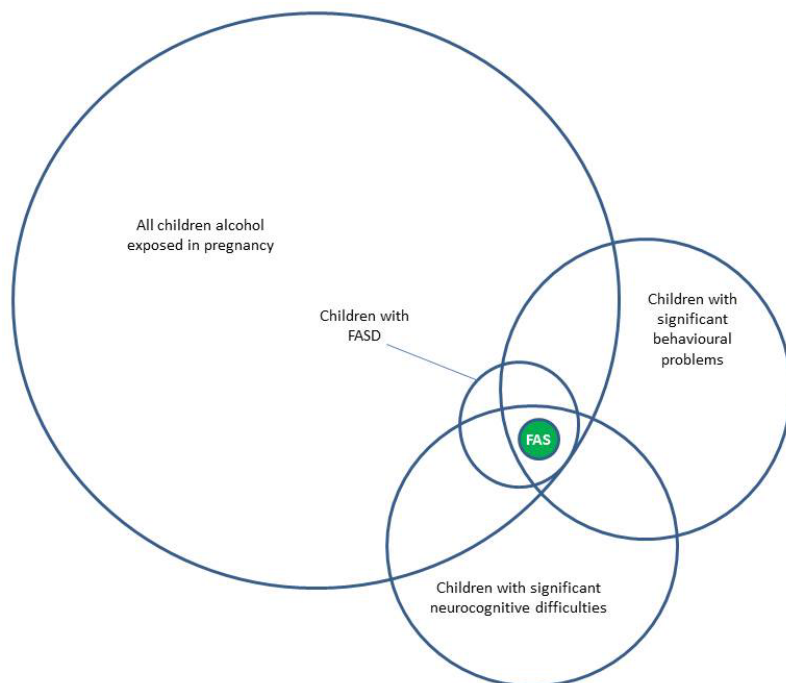
⁵ International research has produced a range of estimates of FASD prevalence. Some studies have estimated that prevalence rates in the USA and Western Europe could be between 2% and 5% of the general population (see May et al 2009), although others have produced much lower estimates (see Ospina and Dennett 2013 for a summary). Although the wide range of estimates makes it difficult to know with certainty what the prevalence is likely to be, a widely used figure is 1%. We have therefore also assumed a figure of 1% in line with overseas practice.

⁶ Again a range of estimates have been produced for FAS prevalence and the ratios of FAS to other FASDs. We've based our estimate of 10% on the findings of Astley (2010) which align well with what we are hearing from local clinicians. However we note that based on estimates from the Office of the US Surgeon General, 25% of those born with an FASD may have FAS (US Department of Health and Human Services 2005, cited in SAMHSA 2014a: 1–4).

As New Zealand has higher rates of drinking during pregnancy than the USA,⁷ we would reasonably expect the figure of 1% to underestimate the prevalence of FASD and related issues in New Zealand.

FASD, neurodevelopmental issues and mental health issues

Figure 3: Relationship between FAS, FASD, and other issues



Note: Please note that this diagram is designed to be illustrative only and is not drawn to scale.

It can be hard to differentiate FASD from other conditions. We know from both international experience and local clinicians that while people affected by FASD may not be diagnosed as such, they are likely to have other diagnoses. This may be because of misdiagnosis, or because the person has more than one disorder. The effects of fetal alcohol exposure can cause the same kind of issues that are associated with a wide range of other conditions (Liebson et al 2014), and people with FASD are at a heightened risk of developing mental health issues (Williams et al 2015).

People with FASD are likely to be diagnosed as having disorders that fall under the mental health umbrella. These include attachment disorder, oppositional defiant disorder and conduct disorder. They are also likely to be diagnosed with a neurodevelopmental disorder. These include autism spectrum disorder, intellectual disability and attention deficit hyperactivity disorder. Neurodevelopmental disorders result from the brain not developing in a typical way. These cannot be 'cured' – but they can be managed.

Treatment for any of these conditions should be based on the behaviours and challenges the person is presenting with and should start as soon as difficulties emerge. The best chance of making lasting changes is by starting early and having a consistent intervention across settings.

⁷ About 10% of American women report drinking during pregnancy, with around 3% drinking at high risk levels. See Tan et al 2015.

However, when a person has a neurodevelopmental issue, treatment needs to take into account the way their brain works if it is going to be successful. For example, some behaviour therapies aim to teach an individual to think differently in order to behave in less antisocial ways. These therapies will not work if the underlying brain damage stops the person from understanding cause and effect.

Although people affected by fetal alcohol exposure have high rates of mental health issues, FASDs are *neurodevelopmental* disorders. Not everyone affected by FASD will be able to be diagnosed, so improving outcomes for people with FASD means focusing on neurodevelopmental issues more broadly.

Part Two: The impact of FASD

FASD and vulnerability

Not every deficit identified in a child with prenatal alcohol exposure may be solely the result of that one exposure.

(Gibbard 2014: 27)

There is a complex inter-relationship between FASD and other vulnerabilities, and having an alcohol-affected child is likely to compound any issues the family is already experiencing. As is true with other health issues, there are wider determinants involved in the development of this disorder. Alcohol-exposed pregnancies do happen in all sectors of society (Superu 2015b), but FASDs tend to be concentrated in certain families and communities (Abel 1995).

Certain factors increase the risk that alcohol exposure will lead to an FASD. The timing, pattern and amount of alcohol consumption are key variables, and the risk increases as drinking does. However, two women can drink the same amount of alcohol during pregnancy but have different outcomes for their babies.

FASD and vulnerable mothers

The mother's health⁸ and wellbeing⁹ are key mediators of alcohol's effects on the fetus (SAMHSA 2014b: xxi), and babies born with FASD often have mothers who are vulnerable. International research is not without its limitations (Esper and Furtado 2014), but it does highlight that although the birth mothers of children with FASDs are diverse in ethnicity, education and economic background, they are likely to:

- be unemployed
- have lower educational levels
- come from families with substance abuse issues
- have mental health issues and problems with substance abuse and dependence
- have histories of trauma, including sexual abuse and exposure to violence
- have unmet health and maternal care needs
- have children in care (Astley et al 2000; Esper and Furtado 2014; Wodinski 2014; Astley 2010).

Both the international literature and the experience of local professionals suggest that some women will need significant support to stop drinking. In one study, 84% of the mothers of children with FASDs felt they had a problem with alcohol use but were reluctant to reduce their drinking because: it helped them cope (94%), they were in an abusive relationship (72%) or they were too depressed (79%) (Astley et al 2000).

⁸ As well as factors such as her metabolism and genetic make-up.

⁹ For example, her level of stress and use of other drugs.

All of these factors – particularly in combination – can contribute to a woman’s health and/or drinking pattern and therefore to the risk of an FASD developing. What the research highlights is that addressing these wider determinants will have an impact on FASD. It also shows that prevention efforts need to take a whole range of factors into account and must include wrap-around, multi-agency support for women at high risk of giving birth to children with FASDs.

Vulnerable children and FASD

Anyone born with an FASD is at heightened risk of poor outcomes over their lifetime. Their bodies will be less robust and resilient, and their brains won’t work the same way as other people’s. They are likely to have a harder time learning things, controlling themselves and navigating society. When that child is born into a family that is already vulnerable, the issues are likely to worsen.

For example, the kinds of behaviours children with FASDs tend to present with can increase the risk that these children will be exposed to abuse or neglect.¹⁰ They can be harder to parent than children with typically functioning brains, and even the most confident and well-resourced parents are likely to struggle. As well as frequently having problems with sleep (SAMHSA 2014: 1–27) and attachment (O’Connor et al 2002), these children can come across as deliberately disobedient, often repeating behaviours they have been told off for already.¹¹ This can pose difficulties for their parents and caregivers, some of whom will have experienced adverse life circumstances themselves and find parenting a child with a range of impairments difficult.

Research from the USA indicates that over 60% of children with FASDs aged 6 to 11 years have experienced physical abuse, sexual abuse or domestic violence, and have spent over a quarter of their lives to that point without their basic needs being met (Streissguth et al 2004).

It is well understood that growing up in an adverse environment can have an impact on the developing brain. All children are at risk when they experience abuse, domestic violence or neglect. However, when that child’s brain has already been damaged by alcohol, it is even more vulnerable to the effects of other factors, and the potential for negative outcomes increases (Andrew 2013: 7).

Both the international evidence and the experience of local professionals suggest that we need to be paying more attention to alcohol exposure and its neurodevelopmental implications if we want to be successful in reducing the number of vulnerable children in New Zealand.

Internationally, about 21% of children in foster care have FAS and between 30 and 50% have an FASD (Ospina and Dennett 2013). We expect children affected by FASD to be over-represented in Child, Youth and Family care and to come into frequent contact with Children’s Teams as they roll out around the country.

¹⁰ Astley (2010) found a two- to five-fold increase in the rate of physical and sexual abuse among alcohol-exposed children who had an FASD compared to alcohol-exposed children who didn’t have brain damage.

¹¹ This statement is based on our conversations with families, clinicians and other experts.

FASD across the life course

The features of FASD are complex and multifaceted; they originate from organic brain damage caused by alcohol, but they interact with genetic and other influences. Over the lifespan of the affected person, these features may be exacerbated or mitigated by environmental experiences.

(Gibbard 2014: 27)

It is hard to paint a picture of a typical life course for someone with an FASD because there isn't one. People affected by FASD can experience a variety of outcomes as they progress through life. This can be determined by a range of factors, including the nature and severity of the damage that has occurred, the safety and stability of the home environment, the community they are born into, and the level and appropriateness of care and support they receive.

The following table outlines the potential effects of fetal alcohol exposure, how they might manifest in people's lives, and the opportunities to prevent negative outcomes. It is not exhaustive, but it draws on research and interviews with families and clinicians.

Table 1: Potential expressions of FASD across the life course

Age	Common issues and experiences	Opportunities and protective factors
<i>Infants (age 0–2 years)</i>	If mothers are poly-drug users the baby may experience post-birth withdrawal symptoms. Babies with FASD are often irritable, have trouble feeding and sleeping, have weakened muscle tone and immune systems, and have difficulties with attachment that may be diagnosed as 'failure to thrive' (Kelly and Streissguth 2000; Olson et al 2007; Paley and O'Connor 2007; Coons 2013). ¹² They are likely to be smaller (British Medical Association Board of Science 2007) and may have birth defects, including abnormalities of the heart, eyes, kidneys and joints.	During infancy the fetal brain continues to develop, grow and change at a significant rate, which means that interventions early in life have a better chance of mitigating some of the effects of the damage alcohol has caused to the brain (Kodituwakku 2010).
<i>Early childhood (age 2–4 years)</i> <i>"He wasn't saying much and seemed not to progress from a certain point so I checked it out with Plunket and he had delayed speech. At kindy they put his behaviour down to that." (Parent)¹³</i>	The child may be highly active and talkative, although with some language delays. He or she is likely to be very friendly, with little fear of strangers or anything else (Coons 2013: 21). Sleeping and eating are likely to be issues, and there may also be attention and behaviour concerns (Kelly et al 2000). The child may experience significant developmental delays by the time they reach school (SAMHSA 2014a: 1–23).	Stimulating and supportive learning and home environments can help to mitigate these concerns. Specialist intervention may also be required to address specific issues, such as challenges with speech and language.

¹² See SAMHSA 2014a: 1–21 for a summary of the research.

¹³ These quotes comes from our conversations with parents.

Age	Common issues and experiences	Opportunities and protective factors
<p><i>School (age 5–12 years)</i></p> <p><i>“He spent a lot of his time sitting outside the principal’s office or in the isolation room.”</i> (Parent)</p>	<p>Alcohol-exposed children cannot always keep up academically,¹⁴ and the gap between them and their peers tends to start widening (Coons 2013: 22).</p> <p>The child’s behaviour can be difficult to understand or manage due to a high level of impulsivity and a lack of planning ability (Matson et al 2011).</p> <p>Disrupted school experiences are likely, and this can exacerbate problems and lead to a decline in behaviour, conduct and engagement.</p>	<p>Specialist assessment and interventions (eg, medication and behaviour supports, including training for caregivers) and support from parents, teachers and other professionals can help to mitigate these issues and keep children engaged in education (SAMHSA 2014a).</p>
<p><i>High school and the transition to adulthood (age 13–20 years)</i></p> <p><i>“He got into trouble because he was hanging around his cousin and his friends and wanted to please them by doing things they wanted him to do.”¹⁵</i></p>	<p>Many of the symptoms associated with FASD can manifest themselves much more severely when children reach high school. This relates to a range of factors, including an increasing expectation for people to be independent and self-managing, the increasing complexity of the mental processes required (eg, abstract thought), greater disruptions to routine (eg, multiple teachers), and the difference between physical and mental development.</p> <p>Generally speaking, young people affected by FASD are at an increased risk of coming into contact with the criminal justice system (Streissguth et al 1996), attempting suicide (Huggins et al 2008) and having mental health and addiction problems.¹⁶</p>	<p>Living in a stable, nurturing home for more than 70% of one’s life, diagnosis before the age of six, not being exposed to physical or sexual abuse or domestic violence, and receiving disability services have been shown to decrease the likelihood of negative outcomes, including disrupted school experiences and trouble with the law (Streissguth et al 2004).</p> <p>Even later in life the right kind of supports or interventions can help to lessen the likelihood and impact of these issues (SAMHSA 2014b: 45–47).</p>
<p><i>Adulthood</i></p> <p><i>“He cannot get a job because he continues to lose his important documents. Whenever he has had a job, he would not follow the directions and so would lose it.”¹⁷</i></p>	<p>There is very little literature on the life experiences of and outcomes for adults with FASD. Adults with FASD may have ongoing difficulties with adaptive and daily living skills and often need help with money management, medical care, productive work and safe housing (Streissguth et al 1996).</p> <p>Many of the issues that emerge in adolescence continue into adulthood, including mental health issues, substance abuse issues, and contact with the criminal justice system (Coons 2013).</p> <p>Parents affected by FASD may need significant support but may be reluctant to seek it in case this results in the removal of their child (Rutman and Van Bibber 2010).</p>	<p>The transition to adulthood for individuals with FASD should be viewed as a transition to ‘interdependence’ rather than a transition to independence (Bennett 2009). That is because, even with the best support and the earliest intervention, many people with FASD will need support for all of their adult life, and some of that will need to be intensive.</p>

¹⁴ See Mattson et al 2011: 11 for a summary of the research.

¹⁵ Taken from Dubovsky 2013: 67.

¹⁶ See SAMHSA 2014a: 1–28 for a short summary of the research.

¹⁷ Taken from Dubovsky 2013: 67.

Part Three: The Action Plan

Why do we need a plan?

Fetal alcohol spectrum disorders and their consequences are preventable. If we can reduce the number of babies exposed to alcohol in the womb, we can reduce the number of people affected. Even after a disorder has developed, recognising and responding appropriately to a person with FASD can make a huge difference to that person's life and improve the outcomes for everyone.

An action plan is necessary because FASD is a complex and multifaceted issue, which requires a coordinated response across a variety of sectors. To be effective in addressing FASD, everyone needs to be on the same page, have a clear idea of how they can make a difference, and be supported to play their part.

At the moment there is a lack of good local evidence. We need to be collecting information to inform our efforts and investments, and we need to be evaluating the effectiveness of interventions. Although our approach can and should be informed by international experience and evidence-based approaches, we need to know how things work in the New Zealand context.

Data on the financial implications of FASD in New Zealand is lacking, but it is likely that FASD is costly to both the New Zealand government and to wider society. Estimates of the annual cost per person with FASD vary, but a very conservative estimate would be NZ\$15,000 (Sueb Wongpat et al 2009).¹⁸ Assuming 46,000 people have FASD, this suggests an annual cost to New Zealand of *at least* \$690 million.

Our proposed approach

We think it's important for the Plan to be developed with a clear vision of what we are trying to do and why we are trying to do it. In developing our proposed approach we want to know what people think is important. To start to test this we have had conversations with a wide range of interested parties, including affected parents, families and caregivers, relevant professionals, international and local experts, and representatives from a range of government agencies.

Lots of common themes came out of these conversations. We've distilled these into a series of key principles and high-level outcomes to drive the direction of the Plan. We now want to test them with a wider audience.

Key principles

We asked people which principles they thought should underpin the development of the Plan and the actions contained within it. We received a lot of different suggestions, and have condensed them into the following principles.

¹⁸ Suebwongpat et al (2009) estimated the annual cost per case in New Zealand to be \$16,333. This uses 2008 dollars and excludes significant sources of cost such as the justice sector. If these were included the number would be much higher.

1. Focus on empowering families and whānau

Families and whānau are our most important asset for preventing alcohol-exposed pregnancies and improving outcomes for people with FASD. A woman's family, partner and social networks are a strong influence on her drinking patterns. Families raising children and young people with FASD have the greatest influence on their outcomes. Even if it's just mum and baby, increasing the family's ability to improve their own health and wellbeing will provide the greatest return in this generation and the next.

To work out the best way to do this, the Plan has to be influenced by the perspectives and experiences of the families and whānau experiencing these issues. It also needs to take a life-course approach, recognising that people's needs and strengths will change over time and that babies born with FASD will probably grow up to be parents themselves.

2. Collaborate to achieve a collective impact

Everyone has a role to play in reducing alcohol-exposed pregnancies and improving outcomes for the affected individuals and families. A whole-of-government commitment is important, with central leadership supporting professionals, non-government organisations, communities, families and individuals to work more closely together to improve outcomes within their own spheres of influence. With everyone pulling in the same direction, we will have a much greater impact on this complex and multi-faceted issue.

3. Prevention is always possible

We need to take a public health approach to these issues. That means taking every opportunity to prevent issues emerging or worsening and to address the factors that drive hazardous alcohol consumption. FASD can be prevented completely if a woman doesn't drink during pregnancy. That's what we should ultimately be aiming for. However, a more severe disorder can still be mitigated if a pregnant woman is supported to stop or reduce her drinking.

Identifying a child with FASD early on is an opportunity to prevent secondary issues and improve outcomes. It can also act as a catalyst for preventing subsequent siblings from being alcohol exposed. With FASD we don't just get one chance at prevention, and this Plan needs to make the most of every opportunity we get. Putting resources in early is likely to have the biggest impact.

4. Build on strengths

We aren't starting from scratch with this Plan. It needs to build on what's already working. This includes existing initiatives here in New Zealand and work being done overseas – including efforts to increase the evidence base. The Plan also needs to recognise and build on people's strengths. This includes the strengths of individuals with FASD and the people who care for them. While the focus tends to be on impairment when we're talking about FASD, focusing on what people can do is important. The Plan also needs to build on the strengths of professionals and empower them within their own scope of practice.

5. Strive for sustained, systemic change

Some significant shifts are required for New Zealand to prevent and effectively respond to FASD. This issue challenges some of our social norms and assumptions and highlights how the design of current systems, structures and supports tends to assume typical neurodevelopment. While change won't happen overnight, the Plan needs to lay the foundation for, and create a momentum for, a different future.

Key outcomes

Based on the conversations we have had with people about what the Plan needs to do, we've developed the following outcomes.¹⁹

- **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.

¹⁹ We want people to be able to easily engage with these outcomes in this discussion document, so we have kept them descriptive. The Action Plan will contain measurable outcomes.

Part Four: What we can do differently

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

Key facts

- Around one in two pregnancies in New Zealand are alcohol exposed.²⁰
- About 10% of pregnancies are exposed at high risk levels (O’Keefe et al 2015; Ho 2009; Mallard et al 2013).
- Among women who had been pregnant in the last 12 months and who reported drinking alcohol during their most recent pregnancy, 78% also reported risky drinking²¹ in the past year (Ministry of Health 2015a).
- Two in five pregnancies are unplanned (Morton et al 2010).

Overview of the issues

New Zealand research shows that drinking during pregnancy is not restricted to women of any age group, ethnicity, education level or socioeconomic status (Superu 2015b). It also highlights that that even if they drink throughout their pregnancy, women make an effort to lower the risk to their babies.

Alcohol consumption during pregnancy happens under different circumstances. Some women will continue to drink when they are aware of their pregnancy. They tend to have higher rates of drinking before pregnancy and display a range of other risk factors (Superu 2015b; O’Keefe et al 2015; Ministry of Health 2015a). Others won’t know they are pregnant when they are drinking but will stop when they find out. Local evidence suggests that most women fall into the latter category (Ministry of Health 2015a; Superu 2015a).

However, confirmation of pregnancy may not happen until after the first trimester (Ministry of Health 2015b). By the time women find out they are pregnant, the fetus may have already been harmed by exposure to alcohol. Any damage is likely to be more severe if the mother has been drinking heavily or frequently during that time.

The international evidence stresses that a comprehensive multi-faceted approach is necessary for reducing alcohol-exposed pregnancies (eg, Barry et al 2009; British Medical Association Board of Science 2007). Any approach should address the diverse needs of all women of childbearing age and include actions targeting the whole population, those at increased risk and those with the highest risk of having a child with FASD (Barry et al 2009).

²⁰ See footnote 2 for more detail.

²¹ Defined as more than four standard drinks on one drinking occasion.

Any actions we take towards prevention will also build on work that is underway to support women to have alcohol-free pregnancies (eg, the Health Promotion Agency's alcohol and pregnancy work programme).

Building blocks for action

Shifting New Zealand's drinking culture

Drinking alcohol is normalised in New Zealand, and excessive drinking and intoxication are generally accepted. This environment is not conducive to supporting women to be alcohol free during pregnancy. To be effective, any strategy that aims to address FASD and prevent alcohol-exposed pregnancies must also address the current drinking culture.

Shifting New Zealand's culture to one of moderation, or not drinking if pregnancy is a possibility, requires sustained effort over time and a whole-of-government and sector approach and commitment to achieve this. It involves working together to support evidence-informed efforts that are likely to nudge the culture in the right direction.

Providing clear, unambiguous and consistent messages

Women are currently receiving mixed messages about the risks of drinking during pregnancy, including those they receive from health professionals (Wouldes 2009). Research shows that women tend to listen to the advice that conforms to their own drinking preferences (Research New Zealand 2014: 9).

If we want to reduce the number of alcohol-exposed pregnancies, then it is crucial that consistent messages come from every direction. This includes all health professionals and other key influencers, including friends and family members. It also includes the messaging coming from the alcohol industry (eg, in advertising and at point of sale). Ultimately we want to create a social consensus about women not drinking when they are pregnant or likely to become pregnant.

Empowering women to make active, planned choices about pregnancy

Improving access to effective contraception and increasing early confirmation of pregnancy is likely to help to reduce the number of alcohol-exposed pregnancies. Although the focus of sexual and reproductive health strategies has tended to be on younger women (particularly teenagers), the evidence highlights that older women are also an important target population (Superu 2015b).

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. It will also need to consider the wider family context and encourage men to play a more active, supportive role with regard to contraception and pregnancy. Men's involvement in preconception health tends to increase healthy preconception behaviour in their female partners (Czeizel et al 2013).

Supporting a consistent primary health care response

While most primary health care providers (such as general practitioners) will ask women about their alcohol consumption at least once during pregnancy, the evidence shows that: few are using validated screening tools, referrals to specialist services are not commonly provided, and there are barriers to having basic conversations and routinely collecting data (Wouldes 2009). Awareness raising and getting evidence-based tools into primary practice is likely to improve a

primary health care provider's ability to support women to have alcohol-free pregnancies, and to reduce consumption when abstinence is not achievable.

Given that the evidence shows that mothers who give birth to a child (or children) with FASDs are likely to have a history of poor antenatal care (Esper and Furtado 2014), a consistent response also needs to use proactive strategies to engage women who may not currently be accessing services.

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,²² 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.

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

Key facts

- Eleven percent of 0–4-year-old clients and 14% of 5–9-year-old clients wait for longer than eight weeks to be seen by specialist mental health services (Ministry of Health 2015c).
- Some children are not able to access Child Development or Early Intervention Services, and others could be waiting between 6 and 18 months.²³
- Of the children assessed as having an FASD by a multidisciplinary team in Hawke's Bay, 93% had one additional and 64% had two or more additional disorders (Health Promotion Agency 2015: 20).

Overview of the issues

If we can recognise the impacts of fetal alcohol exposure early, we have a much better chance of improving outcomes for those affected. This includes reducing the likelihood that initial impairments will lead to the development of other conditions and/or contribute to secondary issues, such as poor educational outcomes, mental health and addiction issues, benefit dependency and involvement with the criminal justice sector.

²² These can include mental health issues, unstable housing, unemployment, family violence, justice system involvement etc.

²³ This comes from conversations we have had with clinicians and Ministry of Health officials.

Early intervention increases the opportunity to take advantage of key developmental windows and increased brain plasticity in infancy and early childhood. Early identification of these issues in a child can also signal that their family is in need of extra care and support. Ultimately this can help to prevent subsequent siblings developing similar problems.

Although those affected will present with a range of issues, most of these will relate to the damage their brain sustained during pregnancy. Ideally we want these issues to be understood in relation to the specific impairments rather than as signs of a personality defect or poor parenting. That way the individual presenting with them (and those caring for them) can be treated accordingly, and the right interventions and supports can be put in place.

With a better understanding of what's going on in people's brains, parents and professionals can adapt their approach to suit people's needs and strengths. Without this understanding we're expecting people with brain damage, and the people caring for them, to change things that they can't.

On the marae I am always hearing, 'No ears kid!... He's such a no ears kid!' And those are the kids that are the most likely to get [punished] because they'll have been told something a hundred times by a hundred people and they're still doing the same thing. People think it's deliberate. But you look at where those no ears kids come from and it's the whānau who drink the most.

(Aunty of a person with FAS)

Recognising the impacts of fetal alcohol exposure can be difficult, particularly when there are no visible signs of damage, such as physical disabilities or abnormal facial features. Not only do individuals with FASD present with different issues, but the same individual will present differently across the life course. For example, someone presenting with sensory regulation issues as an infant may display language difficulties as a toddler and problems with executive function as an adolescent. Others won't present with any obvious issues until they are older.

Our approach needs to focus on improving people's ability to recognise and respond to early signs of any neurodevelopmental issue, as well as the system's capacity to carry out more comprehensive assessments when a child has reached an age when these are possible.

Building blocks for action

Building family and community capacity to understand and identify FASD and other neurodevelopmental issues

Parents, caregivers, family members and members of the community have a key role in early identification and intervention. Those closest to the child are likely to be the first to notice emerging issues, and their concerns need to be taken seriously. The more they understand about FASD and other neurodevelopmental issues, the more they can be effective agents of change within their own families and communities. Any community education initiatives will need to be developed carefully to ensure they don't increase the level of stigmatisation experienced by people who are affected by these disorders and their families.

Building evidence-based awareness and understanding among professionals

Relevant professionals must be well informed if they are going to support families to improve the outcomes for people with FASD or other neurodevelopmental issues. While our primary focus needs to be on improving the knowledge of professionals coming into contact with children (eg, teachers), it is important to note that as people age, the list of professionals they are likely to be in contact with includes police officers, alcohol and drug treatment professionals, and employment support staff. Professionals need to know enough to be able to recognise when someone is presenting with an issue that could be related to a neurodevelopmental issue or fetal alcohol exposure – and know what to do next.

Ensuring clear referral pathways

Not only do professionals need to be able to understand and recognise these issues, but they also need to be able to confidently make referrals when they need help beyond their scope of practice. At the moment there are no clear referral pathways, and when people do try to seek help it can be difficult to find.

Providing multidisciplinary assessment and the creation of an individualised profile

Although there is no international consensus on how to diagnose the full FASD spectrum, there is consensus that a multidisciplinary assessment is required to fully understand the impact of alcohol on neurodevelopment. Although different approaches are proposed for assessment, these tend to focus on how a person's brain works, how well they function and their specific needs and strengths. An FASD diagnosis is something that should be considered at the end of this assessment, but ultimately the aim is to create an individualised profile that helps people to understand their strengths and needs, and provides guidance to their caregivers and professionals on how they will need to tailor their approaches to suit.

This kind of comprehensive assessment needs to be joined up: it requires input from educators, social workers and a range of health professionals.

Increasing clinical capacity and capability

Currently the teams doing these assessments may not have access to the professionals they need in order to conduct these assessments to the standard required. Clinicians need support to play their role in responding to FASD and other neurodevelopmental issues. They require specialist knowledge and skills to be as effective as possible. This includes information on how to assess, differentiate these disorders from other conditions, and identify what sort of clinical interventions (including medication) are likely to be effective.

Training existing clinicians and developing clinical guidelines can help, but we know that when referrals are made currently, they may not result in a child being seen by appropriate specialists, or seen in a timely manner. Increasing the capacity of child development services and mental health services is crucial to ensure the issues are identified and addressed as early as possible. We need to ensure the right team is available at the end of the referral pathway. This is likely to require substantial investment, including an increased number of (or different use of) specialists such as speech and language therapists and neurodevelopmental psychologists.

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

Key facts

Based on international data:

- about 10% of children in special education settings have either FAS or partial FAS (Ospina and Dennett 2013)
- between 10 and 20% of people in prisons and other correctional settings have an FASD (Ospina and Dennett 2013)
- around 80% of adults with an FASD will not be able to live independently without some level of support (Streissguth and Kanter 1997)²⁴
- children and adolescents with an FASD have a 95% lifetime likelihood to experience mental health issues (Williams and Smith 2015).

Overview of the issues

The impacts of alcohol exposure in the womb can last a lifetime. It is important that people with FASDs, and their family and carers, are appropriately supported at the right time for as long as they need that support. Government, communities and families all have a role to play, and if they can work together to support people affected by FASD, then lives and outcomes will improve.

Currently people with FASDs and their parents, families and caregivers are experiencing barriers and service gaps when they try to find appropriate services and supports. Universal services²⁵ may not exist, and those that do may not quite meet their needs because they tend to assume typical cognitive abilities and neurodevelopmental trajectories. Specialist services²⁶ and supports tend to have tightly defined criteria for eligibility and are often time limited or age restricted, which doesn't suit people with ongoing needs or issues usually seen in other age groups. As a result, it can be hard for people affected by FASD to access the appropriate support.

I can make a star chart for anything you want but that's not going to be any help when it comes to parenting a child with brain damage.

(Parent of a child with an FASD)

²⁴ In a 1996 study of adults with an FASD, the most common things people needed support with were managing money and making decisions (80%), followed by accessing social services (70%) and accessing medical care (66%). The majority also had trouble finding and keeping a job, shopping and having relationships.

²⁵ Services that are available to anyone, like early childhood education or visiting the doctor.

²⁶ Services that are only available to those that meet certain criteria or have specific needs, like disability support services.

What constitutes appropriate support will differ between families and individuals. Some people will present with more moderate issues. Others will be severely impaired or have significant behavioural issues. Needs may even become more significant with age, in response to either brain maturation or changing family or economic contexts. Throughout their life someone with an FASD and their parents/caregivers may need help regarding health issues, daily functioning, accessing services, behavioural problems, income support, educational difficulties, justice issues, accommodation and employment. However, it can be difficult for people to navigate a wide range of services – particularly if they are cognitively impaired – and at present there are no clear pathways for accessing support.

Not all support needs to be resource intensive. The experiences of families and caregivers highlight the fact that a little understanding (as long as it is evidence based) can go a long way in helping them feel less frustrated and isolated.

Building blocks for action

Improving community understanding

Understanding from their community can make a huge difference to affected individuals and their families. Support is more likely to come when issues are understood. When families are able to draw on local support they are better able to produce good outcomes for themselves. Community understanding can be particularly helpful in avoiding negative outcomes (eg, criminal justice sector involvement) and supporting young people transitioning into adulthood, and from school into employment.

Universal approaches tailored to need

Universal services and supports should be able to be tailored to meet the needs of people with FASD and other neurodevelopmental issues. With the right resources and support, professionals are better placed to improve outcomes within their own scope of practice. For example, teachers can adapt programmes and approaches to the needs and strengths of someone with an FASD or other neurodevelopmental issue.

Support for parents, families and caregivers

Whatever our approach, it is crucial that we support families to provide a stable home environment and to look after their own health and wellbeing. Children and young people with an FASD need routine, structure and constant supervision, and parenting them can be a full-time, full-on job. Parenting support networks and programmes can support parents by sharing effective strategies and tools for parenting someone with cognitive impairments. Access to behaviour supports, respite care, after-school care and holiday programmes can provide parents with a much-needed break, support wider family wellbeing (including that of siblings) and prevent burnout.

I cry most days. I cry for the life we thought we would have and never will have now. I cry for the life my daughter should have and never will have. I cry for the parents we should be to our son and never will be as our daughter absorbs all of our energy.

(Mother of a child with an FASD)

Multidisciplinary care planning and coordination

Best practice is for the results of the multidisciplinary assessment (the individualised profile) to form the basis of a multi-agency care plan. This ensures the right supports and interventions are put in place and that people working with the individual and their family can tailor their approaches accordingly. This care plan needs to involve all relevant agencies, be culturally appropriate, and acknowledge that needs may change over time while also ensuring that special attention is given to vulnerable stages of the life course (eg, transition periods).

Accessible care and support pathways

Specialist services and supports do need to be prioritised, but it is important that they are prioritised on the basis of need. People with an FASD will present with a range of issues, and they and their families could benefit from a range of different services and supports (eg, respite care, behaviour supports and medication). In order to better match their needs with appropriate support we need to ensure the eligibility criteria we currently use to prioritise services are aligned to what we know about the brain, and what can happen when it doesn't develop properly. This includes flexibility around the length of time supports are available and age restrictions for access.

Support to navigate the system

Individuals and families affected by FASD often have difficulty navigating the system and knowing how supports can be accessed. This is particularly likely for vulnerable families and those with neurological impairments. Experience has shown that people benefit from having someone to help them navigate the system, especially those with complex needs and people who are cognitively impaired.

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

Overview of the issues

There is still much we don't know about fetal alcohol exposure and the disorders that result. There are significant gaps in the international knowledge base, particularly in relation to effective interventions for people with an FASD. There is also a significant body of conflicting research – particularly on the effects of light to moderate drinking during pregnancy. Because there is currently no clinical consensus on how to diagnose the full fetal alcohol spectrum, much of the international evidence focuses on FAS rather than FASD more broadly.

New Zealand's own evidence base is next to non-existent. While we can and should draw on the international experience and evidence base, the lack of good local data means that policy makers are largely 'flying blind' with regard to FASD. There is a need for robust New Zealand data to underpin policy responses and interventions. Better data could shed light on a number of issues, such as:

- the **prevalence** of FASD in the population, as well as the prevalence of different subtypes
- the **outcomes** experienced by people with FASDs, such as the proportion who are in employment, receiving specialist health services, parenting children, in the correctional system, or engaged in education
- the **costs** of FASD to the New Zealand government and society

- the **incidence** of FASD and its various subtypes (ie, the number of babies born each year with FASD)
- **inequities** surrounding FASD (eg, whether it is disproportionately concentrated in certain areas of the country, in certain ethnic groups or socioeconomic strata, or whether secondary disabilities disproportionately occur in certain areas/populations)
- **risk factors** that make someone more susceptible to giving birth to a baby with FASD
- **protective factors** that reduce the likelihood of someone with an FASD developing secondary issues.

Building blocks for action

Routinely collect and analyse key data

One of the simplest ways for us to build our evidence base is by making sure we routinely collect and analyse the data we already have access to. That data becomes even more robust and useful if we can standardise the way it is collected.

For example, we currently have a range of professionals asking women about their alcohol consumption during pregnancy. But we don't get them to ask the same questions or pool that data centrally. If we had that data we could start to paint a much clearer picture of the issue and could make better decisions about addressing it. We could also track our progress much more easily. The routine capture of alcohol exposure data and the transfer of this information to the child's health record would improve care, and support the accurate identification and assessment of issues.

Other data we could be more routinely collecting includes:

- referrals related to fetal alcohol exposure
- any diagnosis of FAS or other FASD.

Evaluate the effectiveness of interventions

Internationally there is a lack of good evidence on what works to improve outcomes for people with an FASD. Although there are a few international interventions backed by a limited evidence base, there is no blueprint for New Zealand to work from. That gives us a lot of room for innovation, but it makes evaluating what we do really important. We want to know if what we are doing is improving outcomes, if it works as well for everyone, and if it gets us the best results for the money. This is important for our own decision-making and helps us to add to the international evidence base.

Encourage research

Robust research is needed to direct action and investment, cut through some of the complexity and help New Zealand fill some really big holes in its knowledge base. Not only should we support the continuation of the research that is already being undertaken (such as that carried out by the Health Promotion Agency), but we also need to encourage new enquiry.

For example, one of the key gaps in our evidence base is around prevalence: we don't know for sure just how many New Zealanders are affected by FASD. While we can work with estimates, actually having some robust data would help us to better design, deliver and target services and supports.

Other areas where New Zealand would benefit from research include:

- risk and protective factors
- the effectiveness of therapeutic interventions
- outcomes for people with an FASD.

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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.

This submission was completed by: *(name)* _____

Address: *(street/box number)* _____

(town/city) _____

Email: _____

Organisation (if applicable): _____

Position (if applicable): _____

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

- an individual or individuals (not on behalf of an organisation)
 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):

- | | |
|--|--|
| <input type="checkbox"/> Māori | <input type="checkbox"/> Professional association |
| <input type="checkbox"/> Pacific | <input type="checkbox"/> Justice sector |
| <input type="checkbox"/> Asian | <input type="checkbox"/> Education sector |
| <input type="checkbox"/> Consumers/families/whānau | <input type="checkbox"/> Social sector |
| <input type="checkbox"/> Service provider | <input type="checkbox"/> Academic/research |
| <input type="checkbox"/> Non-government organisation | <input type="checkbox"/> Local government |
| <input type="checkbox"/> Public health organisation | <input type="checkbox"/> Industry |
| <input type="checkbox"/> Primary health organisation | |
| <input type="checkbox"/> District health board | <input type="checkbox"/> Other <i>(please specify)</i> : |

Questions

General

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

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

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

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

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?

Yes

No

Please provide reasons and comments below.

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

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?

Yes

No

Please provide reasons and comments below.

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

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?

Yes

No

Please provide reasons and comments below.

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

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

b. How would you prioritise these actions?

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

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

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?

Yes

No

Please provide reasons and comments below.

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

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

b. How would you prioritise these actions?

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

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

Yes

No

Please provide reasons and comments below.

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

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

b. How would you prioritise these actions?

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

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

No

Please provide reasons and comments below.

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

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

b. How would you prioritise these actions?

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

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

Final comments

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