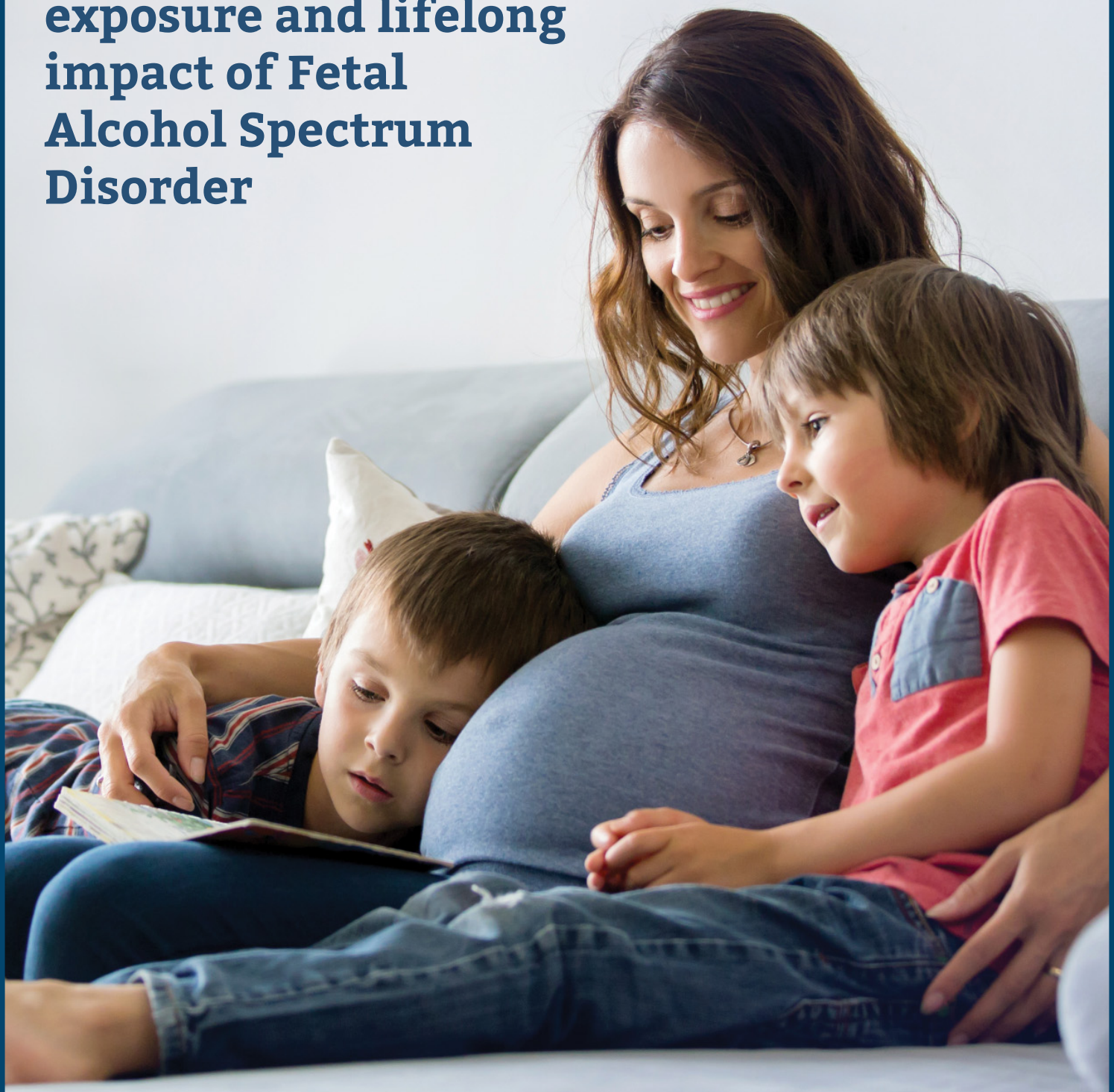
Alcohol Healthwatch
Whakatūpato Waipiro

Prenatal alcohol exposure and lifelong impact of Fetal Alcohol Spectrum Disorder



Introduction

Most adults in Aotearoa New Zealand drink alcohol/waipiro. In 2019/20, 81.5% of adults aged 15 years and over reported drinking in the past year, equating to 3,263,000 adults.[1] Past-year drinking was more common among men (84.6%) than women (78.5%). Of particular concern, recent trends have shown **significant increases in past-year drinking among women**, especially among Pacific and Asian women.[1]

Hazardous drinking also remains high, with one in four (26%) adult drinkers reporting hazardous drinking (a pattern of drinking that carries a risk of harming the drinker's physical or mental health or having harmful social effects on the drinker or others).[1]

Whilst adolescents have shown positive reductions over time in hazardous drinking[1], as well as reductions in monthly binge drinking (5+ drinks in an occasion)[2] and sexual activity[3] (but not contraceptive use), alcohol use continues to cause them high levels of harm.

Alcohol use has been linked to over 200 health conditions[4], and when consumed during pregnancy, can harm the developing baby and cause Fetal Alcohol Spectrum Disorder (FASD).

Everyone's right to health

Aotearoa New Zealand's vision, as outlined in the Child and Youth Wellbeing Strategy[5], is to make **"New Zealand the best place in the world for children and young people"**. For the Crown to uphold and honour its obligations to Te Tiriti o Waitangi, effective actions that address the longstanding health inequities between Māori and non-Māori are required. In addition, the right to health is also enshrined in commitments by Aotearoa New Zealand to international treaties[6,7] that recognise the "right of everyone to the enjoyment of the highest attainable standard of physical and mental health."[7]

The pro-drinking environment in Aotearoa New Zealand

To prevent the harms from alcohol, we need our communities to be safe and healthy places to live and raise children. But this vision is compromised when alcohol is readily available, sold at low prices, and heavily marketed.

- In Aotearoa New Zealand, the affordability of alcohol has been increasing. In 2017, **alcohol was more affordable than ever before**,[8] meaning that wages could buy a greater quantity of alcohol than they could in previous years.
- The higher the number of places that sell alcohol, the more alcohol harm in communities.[9] There **are disproportionately more places that sell alcohol in low income areas**.[10]
- Alcohol is also pervasively marketed across a range of media. Tamariki Māori and Pacific children have **respectively five and three times greater exposure** to marketing than New Zealand European children.[11]

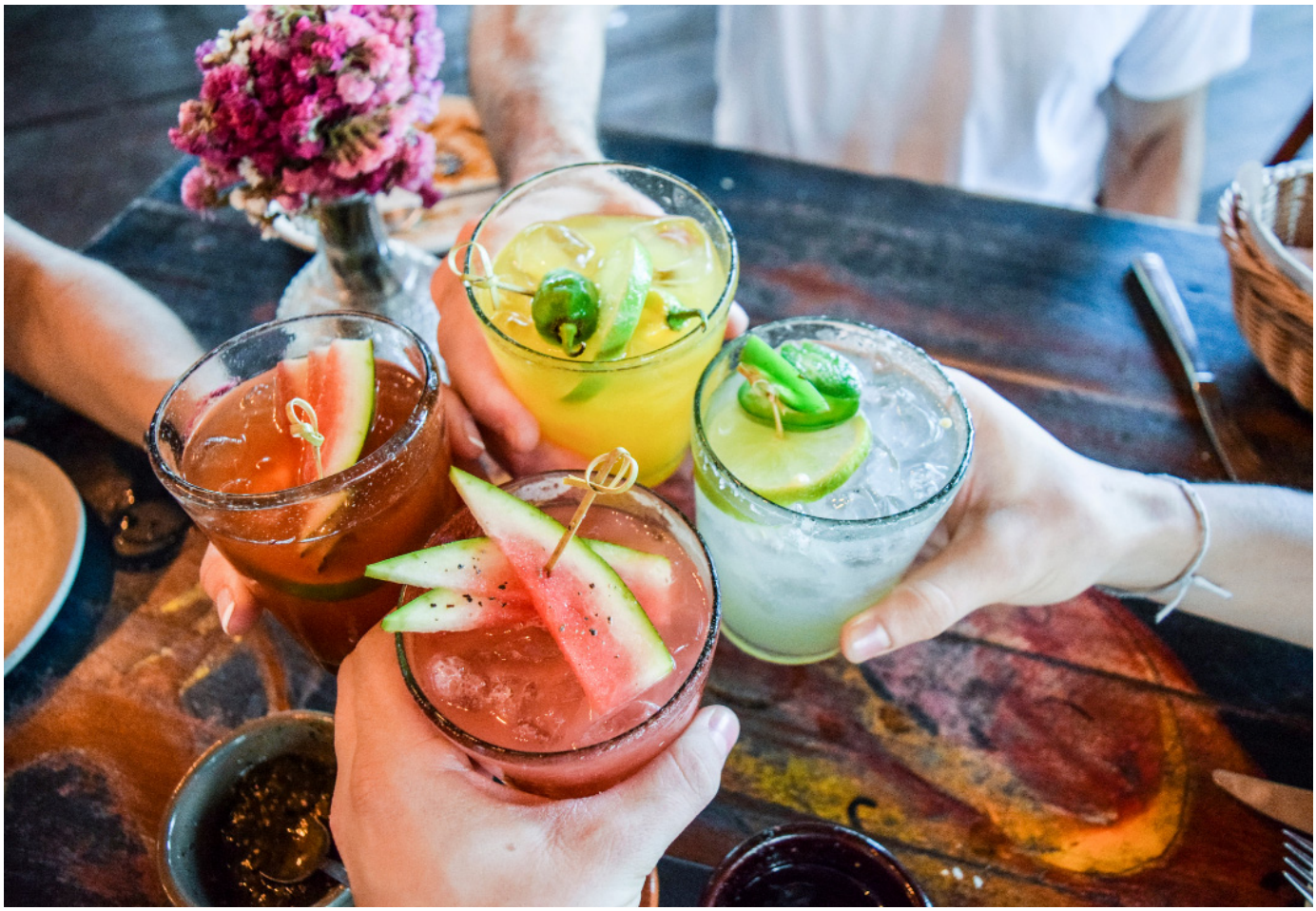
Unequal exposure to these alcohol risk environments drives inequities in alcohol use and harm (including FASD). Further, the legacy of colonisation, and the inequalities and cultural alienation arising from it, are described as key drivers behind unjust differences in alcohol use and harm between Māori and non-Maori.[12,13] For example, it is estimated that approximately 35% of the relationship between Māori ethnicity and increased hazardous drinking is explained by experience of racial discrimination.[14]

Government-commission reviews[12,15,16] have all recommended stronger regulation of alcohol prices, availability and marketing to create healthier environments for communities to thrive. Given our drinking culture is social and collective in nature, we all have a collective responsibility to enable and promote alcohol-free pregnancies.

Alcohol use during pregnancy

In Aotearoa New Zealand, alcohol use is common among women before pregnancy recognition. The Growing Up in New Zealand Study (a longitudinal cohort study of 7000 families of children born in 2010), found that **71% of women reported using alcohol prior to pregnancy or becoming aware of their pregnancy**.[17] Applying the current birth rate, this equates to ~40,000 conceptions per annum exposed to alcohol.

The study also found that **23% of women reported drinking during the first trimester, reducing to 13% after the first trimester**. The odds of drinking alcohol before pregnancy were significantly higher for younger women, European or Māori women, and women with an unplanned pregnancy. Alcohol use during the first trimester was higher among



women who were European or Māori, with no secondary school qualification, in their first pregnancy, and/or with an unplanned pregnancy. In the second and third trimesters, alcohol use was more likely for European or Māori women aged 30 years and over, and for women in their first pregnancy.[17]

Studies examining the influences of alcohol use in pregnancy have identified factors such as: social relationships and norms; stigma; trauma and other stressors; alcohol information and messaging; and access to trusted equitable care and essential resources.[18] A Master's thesis examining how Māori women manage decisions about alcohol use when pregnant identified a *Trading off* process that existed within a wider and complex social context. *Trading off* incorporated processes regarding: learning the rules about alcohol, getting messages about alcohol and pregnancy, changing alcohol use while making role transitions, and using alcohol in the processes of fitting in, releasing pressure, and carrying on as normal.[19]

Risks of alcohol use during pregnancy

The knowledge that alcohol use harms unborn babies is not new. On 18 August 1874, a petition by Haimona Te Aoterangi and 167 others was presented to the House of Representatives that showcased the harm from waipiro –

> *"…for some law to be passed by the Assembly and the Government affecting this evil thing, grog, which is destroying us, so that a stop may be put to drinking among the Māoris, for that is at the root of the evils under which we suffer…it impoverishes us: our children are not born healthy because the parents drink to excess, and the child suffers…"*

Drawing on decades of international and national FASD research, the Ministry of Health, Health Promotion Agency/Te Hiringa Hauora, Royal New Zealand College of General Practitioners, New Zealand College of Midwives and other health sector agencies currently recommend:[20]

Stop drinking alcohol if you could be pregnant, are pregnant or are trying to get pregnant

This recommendation (also included in New Zealand's low risk drinking advice[21]) is based on there being **no known safe level of alcohol use during pregnancy**. While heavy or frequent use of alcohol increases the risk of lifelong harm, no amount of prenatal alcohol exposure can be considered safe.

Alcohol is a teratogen; an agent or substance known to alter the course of normal fetal development. Alcohol consumed by the mother is transferred freely to their baby via the placenta and umbilical cord, where it can interfere with how the rapidly-developing cells grow and migrate to form the whole body.[22] Depending on a range of factors, exposure to alcohol can cause major congenital abnormalities, as well as cognitive, emotional and functional deficits. Due to the brain and central nervous system being the first and the last system to develop throughout gestation, these areas are particularly sensitive to the neurotoxic effects of alcohol. In 2016, over 400 disease conditions were identified as associated with FASD.[23]

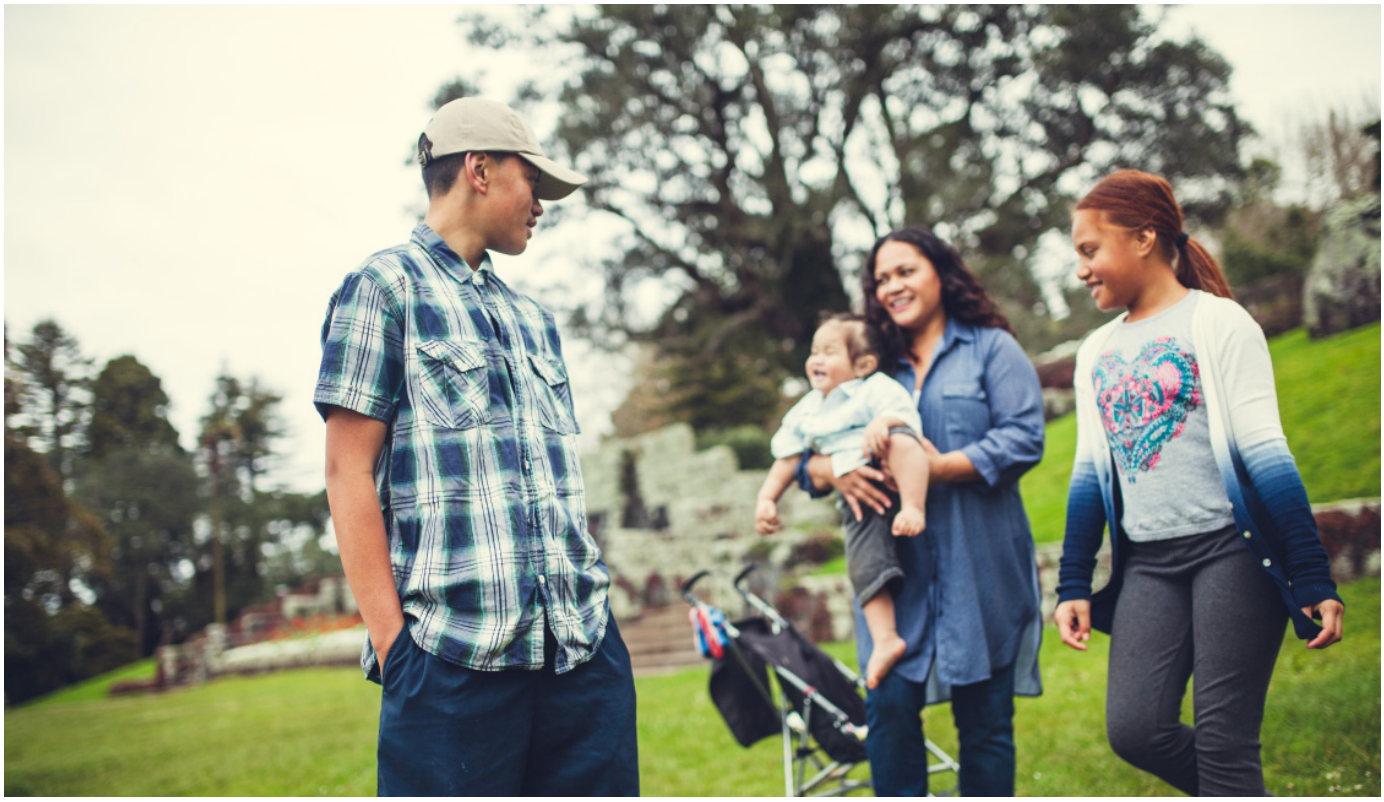
The extent to which permanent deficits in development occur **depends on the interplay between a number of factors**, including the timing and duration of exposure, the amount of alcohol used per occasion, maternal wellbeing, and genetics. This individual variance of effects of prenatal alcohol exposure makes the identification of children born affected by alcohol exposure more complex.

Studies looking at how alcohol affects genes and subsequent fetal development indicate that alcohol use prior to conception by either or both parent may increase the risk of harm to the fetus.[24] Alcohol use in combination with other substance use, such as tobacco, can also increase the risk of adverse outcomes.[25]

While not all prenatal alcohol exposures will necessarily result in clinically significant deficits in development, the Growing up in New Zealand Study found that consumption of ≤3 standard drinks per week during pregnancy, and importantly, during very early pregnancy when the pregnancy might not be known, was associated with less regulated, focused and interactive infant behaviour.[26]

What is Fetal Alcohol Spectrum Disorder?

FASD is a diagnostic term used to describe impacts on the brain and body of individuals prenatally exposed to alcohol. **FASD is a lifelong disability**. Individuals with FASD will experience some challenges in their daily living, and need support with motor skills, physical health, learning, memory, attention, communication, emotional regulation, and social skills to reach their full potential. Each individual with FASD is unique and has areas of both strengths and difficulties which are important to recognise and support.[27]



A small percentage of children with FASD will show physical signs of prenatal alcohol exposure that a trained doctor could identify, alongside the associated developmental problems the child may present with. This is more likely to be recognised where prenatal alcohol exposure is known to be part of the child's prenatal history. More usually, children with FASD do not receive a diagnosis until their functional difficulties have become significantly out of step with normal development for their age, and problematic. To receive a diagnosis of FASD the individual has a serious disability (eg. three or more developmental domains where their functioning is below the 3rd percentile compared to the general population). **There is no 'mild form' of FASD**.

Generally speaking, **FASD is an 'invisible disability' in our communities**. While signs may have been there throughout the pre-school years, it is often not until middle-childhood that a medical assessment is sought. However, the likelihood of receiving a diagnosis of FASD early on in development is low.[28] Often families will have received a string of other co-morbid diagnoses, often from multiple clinicians, such as Attention Deficit Hyperactivity Disorder, Dyslexia or Reactive Attachment Disorder before receiving a more comprehensive medical and psychological assessment relating to the effects of prenatal alcohol exposure. In many cases, prenatal alcohol exposure (as an underlying cause of presenting problems) is overlooked or dismissed due to lack of knowledge, experience and/or resources to investigate further. Each differential diagnosis made is costly and may not lead to effective, supportive strategies required for a child with multiple brain impairments. Unfortunately, by the time the child receives an FASD diagnosis, their difficulties may have escalated to include mental health problems, school suspension, and in some cases, trouble with the law – and caregiver burnout. These difficulties are not inevitable, but are due largely to the delay in recognition of the complexity of brain impairments and provision of effective strategies to reduce the symptoms.

To that end, FASD is a disorder that has two necessary avenues of prevention:

1. preventing prenatal alcohol exposure through effective population-based and targeted policies and programmes to reduce alcohol use; and
2. preventing the secondary harms to persons born with FASD, through timely and appropriate recognition and evidence-based responses.

FASD is a lifelong disability, but the associated harm affecting individuals with FASD and their whānau does not have to be.

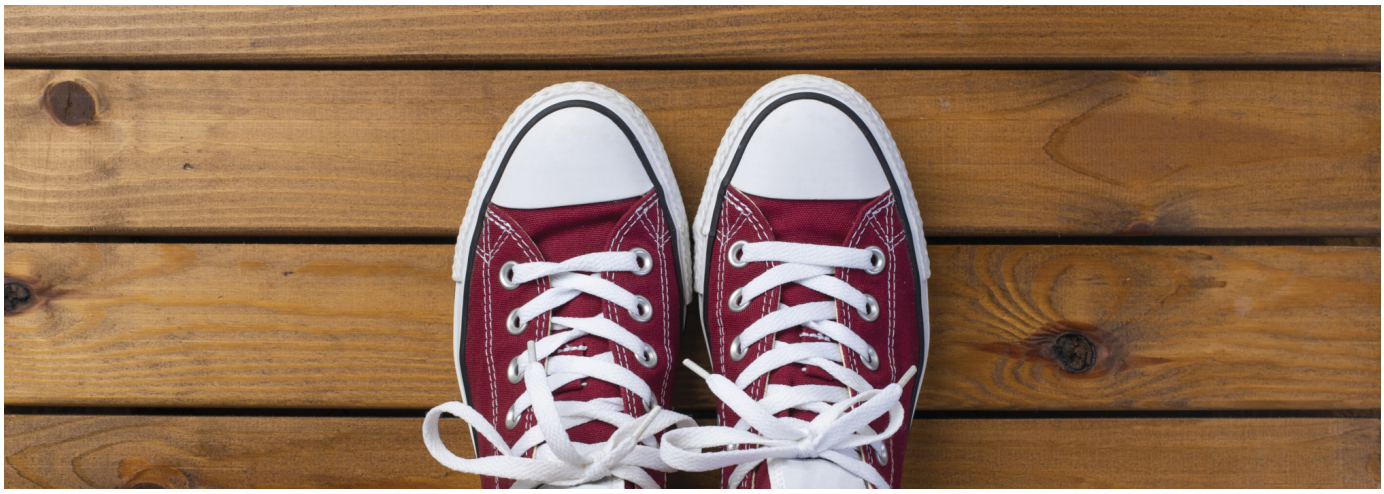
How many New Zealanders have FASD?

To date, no studies have been carried out to determine the prevalence of FASD in the population. Therefore, estimates can only be ascertained via comparisons with similar countries where such prevalence studies have taken place, eg. Canada.[29,30]

Extrapolating from these studies, the **incidence of FASD in Aotearoa New Zealand is estimated to be 3% of live births**. This represents a total of **1,800 babies born each year with FASD**.[31]

It is also estimated that:

- around half of the children and young people in Oranga Tamariki care are affected by FASD;[32]
- approximately 10-20% of people in prisons and other correctional settings have an FASD;[33]
- 80% of adults with an FASD will not be able to live independently without some level of sustained support;[34]
- children and adolescents with an FASD have a 95% lifetime likelihood to experience mental health issues;[35,36]
- individuals with FASD have a much higher risk of suicidal behaviour than the general population;[37] and
- (using recent Canadian clinical data), 48% of children diagnosed with FASD have significant and permanent impairment in six or more brain domains (with three domains being the minimum requirement for a confirmed diagnosis).[30] This proportion of impairment is likely comparable for children assessed for FASD in Aotearoa New Zealand.



The social and economic impact of FASD

Beyond the substantial and lifelong health and social impacts of FASD to individuals and whānau, the economic costs are considerable. The estimated annual cost of lost productivity alone from FASD-related morbidity and mortality in Aotearoa New Zealand in 2013, using a conservative 1% prevalence of FASD in the population, was estimated to be between $49 million and $200 million.[38] In 2018, it was estimated that the annual cost of new FASD cases in Aotearoa New Zealand was $171 million (excluding costs of existing cases and applying a 3% prevalence), or $95,978 per new case.[31]

FASD awareness and community action

September is World Fetal Alcohol Spectrum Disorder (FASD) Awareness Month. In Aotearoa New Zealand, this is marked specifically on the 9th of September – being the **9th day of the 9th month** – to symbolise the nine months of pregnancy in which to have a healthy baby, and to reflect on those already living with FASD. Everyone is invited to participate and wear red shoes to mark the month and day. More information can be found at **www.actionpoint.org.nz/fasd**.

In 2013, a group of volunteer parents and professionals formed FASD-CAN (Care Action Network) with the aim of connecting and increasing support for those living with FASD in Aotearoa New Zealand.

In 2016, the New Zealand Government supported the development of a cross-ministry FASD Action Plan (2016-2019)[32] that sets out a framework to reduce the harm from prenatal alcohol exposure. So whilst FASD remains a largely hidden disability, fields of interest and endeavour have continued to expand across sectors in Aotearoa New Zealand. This includes a claim to the Waitangi Tribunal's Health Services and Outcomes Kaupapa Inquiry (WAI#2624) regarding the Crown's failure to actively prevent FASD and its secondary harms among Māori.

Warning labels on alcohol products

From 31 July 2023, every alcohol product sold in Australia and Aotearoa New Zealand will be required to display a pregnancy health warning on the container as well as packaging. This label has been mandated by Ministers in both countries to reduce the prevalence and/or severity of FASD through:

- Increasing awareness of the risks of alcohol use while pregnant;
- Encouraging behaviour change; and
- Developing supportive social norms for alcohol-free pregnancies.

For individual alcohol containers of 200ml or less, only the warning pictogram is required. For products >200ml (as well as for packages of alcohol products), both the pictogram and warning text are required, as shown beside.

This label will add to the other evidence-based actions and activities that are in place to support healthy pregnancies. It is another important step to building strong and consistent messaging about alcohol-free pregnancies being the safest option.

References

1 Ministry of Health. Annual Update of Key Results 2019/20: New Zealand Health Survey. 2020 **https://www.health.govt.nz/publication/annual-update-key-results-2019-20-new-zealand-health-survey** (accessed Nov 19, 2020).

2 Fleming T, Ball J, Peiris-John R, *et al*. Youth19 Rangatahi Smart Survey, Initial Findings: Substance Use. New Zealand: Youth19 Research Group, The University of Auckland and Victoria University of Wellington, 2020 **https://www.youth19.ac.nz/publications** (accessed Feb 19, 2021).

3 Clark, T, Lambert, M, Fenaughty, J, *et al*. Youth19 Rangatahi Smart Survey, Initial Findings: Sexual and reproductive health of New Zealand secondary school students. The Youth19 Research Group: The University of Auckland and Victoria University of Wellington, 2020.

4 Rehm J, Gmel GE, Gmel G, *et al*. The relationship between different dimensions of alcohol use and the burden of disease – an update: Alcohol and disease. *Addiction* 2017; 112: 968–1001.

5 New Zealand Government. Child and Youth Wellbeing Strategy. Wellington: Author, 2019 **https://childyouthwellbeing.govt.nz/sites/default/files/2019-08/child-youth-wellbeing-strategy-2019.pdf**

6 United Nations Human Rights. Convention on the Rights of the Child. United Nations, Treaty Series 1577, no. 3. UN General Assembly, 1989 **https://www.ohchr.org/en/professionalinterest/pages/crc.aspx**

7 United Nations Human Rights. International Covenant on Economic, Social and Cultural Rights. UN General Assembly, 1966 **https://www.ohchr.org/en/professionalinterest/pages/cescr.aspx**

8 Health Promotion Agency. Trends in affordability of alcohol in New Zealand. Wellington, New Zealand: Author, 2018 **https://www.hpa.org.nz/research-library/research-publications/trends-in-affordability-of-alcohol-in-new-zealand** (accessed Nov 2, 2020).

9 Cameron MP, Cochrane B, Livingston M. The relationship between alcohol outlets and harm: a spatial panel analysis for New Zealand, 2007-2014. 2017 **http://www.hpa.org.nz/sites/default/files/HPA%20Outlets%20Report%20January%202017.pdf** (accessed April 17, 2018).

10 Ministry of Health. Alcohol use 2012/13: New Zealand Health Survey. Wellington, New Zealand: Author, 2015.

11 Chambers T, Stanley J, Pearson AL, *et al*. Quantifying Children's Non-Supermarket Exposure to Alcohol Marketing via Product Packaging Using Wearable Cameras. *Journal of studies on alcohol and drugs* 2019; 80: 158–66.

12 New Zealand Law Commission. Alcohol in our Lives: Curbing the Harm: A report on the review of the regulatory framework for the sale and supply of liquor. Wellington, NZ: Author, 2010 **https://www.lawcom.govt.nz/sites/default/files/projectAvailableFormats/NZLC%20R114.pdf**

13 Muriwai E, Huckle T, Romeo J. Māori attitudes and behaviours towards alcohol. Wellington, NZ: Health Promotion Agency, 2018.

14 Winter T, Riordan BC, Surace A, Scarf D. Association between experience of racial discrimination and hazardous alcohol use among Māori in Aotearoa New Zealand. *Addiction* 2019; 114: 2241–6.

15 Ministerial Forum on Alcohol Advertising and Sponsorship. Ministerial Forum on Alcohol Advertising and Sponsorship: Recommendations on alcohol advertising and sponsorship. 2014.

16 Mental Health and Addiction Inquiry. He ara oranga: Report of the Government Inquiry into mental health and addiction. Wellington, New Zealand: Author, 2018 **https://mentalhealth.inquiry.govt.nz/assets/Summary-reports/He-Ara-Oranga.pdf**

17 Rossen F, Newcombe D, Parag V, *et al*. Alcohol consumption in New Zealand women before and during pregnancy: findings from the Growing Up in New Zealand Study. *The New Zealand medical journal* 2018; 131: 24–34.

18 Lyall V, Wolfson L, Reid N, *et al*. "The problem is that we hear a bit of everything…": A qualitative systematic review of factors associated with alcohol use, reduction, and abstinence in pregnancy. *International journal of environmental research and public health* 2021; 18: 3445.

19 Stuart K. Trading off: A grounded theory on how Māori women negotiate drinking alcohol during pregnancy. Wellington, NZ: Massey University, 2009.

20 Health Promotion Agency. Evidence summary: alcohol and pregnancy. Wellington, NZ: Health Promotion Agency, 2019.

21 Health Promotion Agency. Low-risk alcohol drinking advice. n.d. **http://alcohol.org.nz/help-advice/advice-on-alcohol/low-risk-alcohol-drinking-advice**

22 Guerri C, Pascual M. Effects of alcohol on embryo/fetal development. In: Reproductive and developmental toxicology. Elsevier, 2017: 431–45.

23 Popova S, Lange S, Shield K, *et al*. Comorbidity of fetal alcohol spectrum disorder: a systematic review and meta-analysis. *The Lancet* 2016; 387: 978–87.

24 Zhou Q, Song L, Chen J, *et al*. Association of Preconception Paternal Alcohol Consumption With Increased Fetal Birth Defect Risk. *JAMA pediatrics* 2021; 175: 742–3.

25 Grewal J, Carmichael SL, Ma C, Lammer EJ, Shaw GM. Maternal periconceptional smoking and alcohol consumption and risk for select congenital anomalies. *Birth Defects Research Part A: Clinical and Molecular Teratology* 2008; 82: 519–26.

26 Schoeps A, Peterson ER, Mia Y, *et al*. Prenatal alcohol consumption and infant and child behavior: Evidence from the Growing Up in New Zealand Cohort. *Early human development* 2018; 123: 22–9.

27 Harding K, Flannigan K, McFarlane AA. Policy Action Paper: Towards a standard definition of Fetal Alcohol Spectrum Disorder in Canada. Canada: Canada Fetal Alcohol Spectrum Disorder Research Network, 2019.

28 Gibbs A, Sherwood K. Putting fetal alcohol spectrum disorder (FASD) on the map in New Zealand: A review of health, social, political, justice and cultural developments. *Psychiatry, Psychology and Law* 2017; 24: 825–42.

29 Ospina M, Dennett L. Systematic review on the prevalence of fetal alcohol spectrum disorders. *IHE Institute of Health Economics, Alberta, Canada* 2013.

30 Canada FASD Research Network. The National FASD Database-2019 Annual Report. Canada FASD Research Network. 2020 **https://canfasd.ca/wp-content/uploads/publications/National-Database-Annual-Report-2019.pdf** (accessed Nov 19, 2020).

31 Joint Food Regulation System. Decision Regulation Impact Statement: Pregnancy warning labels on packaged alcoholic beverages. 2018 **https://foodregulation.gov.au/internet/fr/publishing.nsf/Content/pregnancy-warnings-alcohol-labels** (accessed Nov 19, 2020).

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

33 Popova S, Lange S, Bekmuradov D, Mihic A, Rehm J. Fetal alcohol spectrum disorder prevalence estimates in correctional systems: a systematic literature review. *Canadian Journal of Public Health* 2011; 102: 336–40.

34 Streissguth AP, Barr HM, Kogan J, Bookstein FL. Understanding the occurrence of secondary disabilities in clients with fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE). Seattle: WA: University of Washington, Fetal Alcohol and Drug Unit, 1996.

35 Temple VK, Cook JL, Unsworth K, Rajani H, Mela M. Mental health and affect regulation impairment in fetal alcohol spectrum disorder (FASD): results from the Canadian national FASD database. *Alcohol and Alcoholism* 2019; 54: 545–50.

36 Williams JF, Smith VC, & Committee on Substance Abuse. Fetal alcohol spectrum disorders. *Pediatrics* 2015; 136(5): e1395-e1406.

37 Thanh NX, Jonsson E. Life expectancy of people with fetal alcohol syndrome. *Journal of Population Therapeutics and Clinical Pharmacology* 2016; 23.

38 Easton B, Burd L, Rehm J, Popova S. Productivity losses associated with Fetal Alcohol Spectrum Disorder in New Zealand. *NZ Med J* 2016; 129: 72–83.

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