



Report of the Disability Rights Commissioner¹ and Children's Commissioner² to the Prime Minister

Fetal Alcohol Spectrum Disorder: A Call to Action

¹ The Disability Rights Commissioner is responsible for protecting and promoting the rights of disabled New Zealanders which comprise 24% of New Zealand's population

² The Children's Commissioner represents 1.1 million people in Aotearoa New Zealand under the age of 18, who make up 23 % of the total population and advocates for their interests, ensure their rights are upheld, and help them have a say on issues that affect them.

Report to the Prime Minister on Fetal Alcohol Spectrum Disorder: A Call to Action

Introduction

1. The Disability Rights Commissioner³ and Children's Commissioner⁴ both have a statutory mandate to report to the Prime Minister on certain matters. This statutory mandate is not used often and invoked only where concern is of sufficient magnitude to warrant bringing to the attention of the Prime Minister.
2. The matter we wish to draw to your attention through this report is the lack of appropriate progress on providing greater support for those with Fetal Alcohol Spectrum Disorder (FASD) and their whānau and on implementing the cross-agency FASD Action Plan.
3. While feedback from some agencies on this Report indicates work occurring that may benefit those with FASD, some of it remains future-focused and appears to lack overall coherency. Work does not appear to be co-designed with those with FASD and their families, be tailored specifically for those with FASD, nor have the active cross agency governance required to make a strategic difference.
4. It is our view that New Zealand may be in breach of its international and domestic obligations and Tiriti commitments, a matter we both wish to raise through upcoming examinations of New Zealand's performance against the UN Convention on the Rights of the Child (CRC) and the UN Convention on the Rights of Persons with Disabilities (CRPD).
5. We would appreciate an opportunity to discuss this report with you at the earliest opportunity.

Executive Summary

6. In our view, those living with FASD in New Zealand may experience an egregious breach of their human rights under international and domestic laws through being excluded from obtaining sufficient support. This lack of support can have grievous ramifications for individual well-being, family cohesion, and too often, a trajectory towards the criminal justice system. Professor Ian Lambie⁵ argues that the high-profile case of Teina Pora, whose FASD led him to confess to a crime he did not commit, **is the tip of an iceberg**.
7. This lack of support extends to the resources available to the medical profession, service providers, educators and the Judiciary, leaving those with FASD and their family/whānau isolated and powerless to help. Most significantly FASD has been shown to increase death by suicide⁶. These issues have been hiding in plain sight in New Zealand for too long. We can do much better.
8. There has been a long history of advocacy for better protection of the rights of those living with FASD and their family/whānau. There is an estimated 1800 (a very conservative estimate) children born with FASD each year in New Zealand. While there has been some recent investment and focus

³ Section 5, 2 (k) of the Human Rights Act 1993 provides for the DRC to report to the Prime Minister on any matter affecting human rights, including the desirability of legislative, administrative, or other action to give better protection to human rights and to ensure better compliance with standards laid down in international instruments on human rights.

⁴ Section 12 (1)(k) of the Children's Commissioner Act 2003 provides for the Children's Commissioner to report, with or without request, to the Prime Minister on matters affecting the rights of children

⁵ Chief Science Advisor to the Justice Sector) in his 2020 Report on Brain and Behaviour Issues

⁶ O'Connor MJ, Portnoff LC, Lebsack-Coleman M and Dipple KM (2019) Suicide risk in adolescents with fetal alcohol spectrum disorders. *Birth Defects Res*, 111(12) 822-828

on the prevention of FASD, insufficient attention has been paid to the support required for people with FASD and their family/whānau.

9. This report identifies key issues and sets out recommendations for your consideration. In brief, there is an urgent need for access to greater support, at a minimum to Disability Support Services funded by the Ministry of Health. In addition, there is a need for increased diagnostic capacity, training for professionals, a prevalence study, full implementation of the existing Action Plan, and an all of government focus and approach to joining up services and extending services the Action Plan identifies as imperative to reduce harm.
10. This paper is endorsed by and has contributions from FASD-CAN⁷, and Professor Ian Lambie, Chief Science Advisor for the Justice Sector. The report has also been shared with the Ministries of Health, Education, Police, Justice, Corrections, Women, Te Puni Kōkiri and Oranga Tamariki who were invited to make comment. It will also be shared with the Social Sector Science Advisors and Chief Science Advisor.
11. Towards the end of 2019 FASD-CAN invited families to contribute to a report on experiences over the life-span of those with FASD. The report is provided as **appendix one** to this paper. It is illustrative of the experiences in New Zealand faced by those living with FASD and their families/whānau.

Background -what has happened to date?

Key Developments to date

12. There is a long history of advocacy in New Zealand aimed at the prevention of and improving outcomes for those with FASD. This report does not traverse this history, but instead focuses on developments since 2016.
13. FASD-CAN is a charity which was established in 2013 and comprises parents, caregivers, extended whānau and professionals working alongside them. It is a non-profit incorporated society and receives no government funding.
14. An Action Plan “Taking Action on Fetal Alcohol Spectrum Disorder 2016–2019” was developed by the Government in consultation with FASD-CAN. The Plan is a cross-agency plan and stated on the Ministry of Health website that it **will be implemented over 3 years**. The goals of the cross-agency plan are on prevention and enabling **people with FASD and their family/whānau live the best possible lives**. The plan includes four priority areas (prevention, early identification, support and evidence).
15. The plan is a good plan and still has currency. The problem is that it has not been fully implemented and those areas that have been, have not been prioritised by families nor co-designed with those affected. Of particular concern is that little, if any, attention has been given to appropriately supporting people with FASD and their family/whānau.

⁷ A non-profit incorporated society made up of parents, caregivers, extended whānau and professionals to improve the lives of those living with FASD.

Many meetings and discussions have occurred

16. We have exercised our advocacy mandate tirelessly on this issue, in partnership with FASD-CAN and others. But little real progress has been made. There have been numerous meetings between officials, Ministers, FASD-CAN and other advocates (including ourselves) over the years. Some good relationships have been developed. Nothing in this report is intended as a reproach of individual agencies. Rather, our hope is that by raising the issues in this report, the Prime Minister and other Ministers will direct the necessary changes required across agencies to better support the FASD community.
17. While much of this report focuses on the challenges associated with FASD, because this validates the experience and facts, we wish to emphasise that individuals with FASD can thrive with the right support. We hope this report helps lead to all people with FASD having an equal opportunity to thrive in New Zealand.

Identification of the Issues

What is FASD?

18. FASD is a lifelong disability. Individuals with FASD will experience some degree of challenge 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. Every individual with FASD is unique and has areas of both strengths and challenges⁸.
19. While the “S” in FASD refers to ‘spectrum’, we wish to make it clear that FASD is not on a continuum with mild, moderate and severe cases, as is often thought. Only those prenatally exposed to alcohol with severe impairments reach the diagnostic criteria for FASD. Individuals with FASD show differing profiles of strength and impairment that can be considered to sit on a spectrum rather than a continuum. In fact, those with a very low IQ tend to have better outcomes than those of higher ability so cannot be considered to be more severely affected. All individuals diagnosed with FASD will be differently rather than more or less impacted⁹.
20. This section of the report identifies the multiple gaps in New Zealand’s response to FASD.

Lack of Prevalence data for New Zealand

21. The Ministry of Health suggests that around 1800 babies with FASD are born each year, but this is an estimate only, and is likely to be a significant under-estimate. Based on overseas studies and New Zealand’s drinking patterns, which is a pattern of rising hazardous drinking among women of child-bearing age, the 2-3% prevalence rate established in Canada¹⁰ is an appropriate guide for New Zealand, and even then, it may well be significantly “under counting” the New Zealand position. At a bare minimum, this would mean approximately 1800 new cases of FASD per year in New Zealand.
22. The World Health Statistics 2017 shows New Zealand’s consumption of alcohol per person at 10.1L and Canada’s consumption at 10L per capita. It should be noted that the 2016 global level of alcohol consumption was 6.4L per capita¹¹.

⁸ Canadian Guidelines: FASD: A Guideline for Diagnosis Across the Lifespan 2015

⁹ Dr Valerie McGinn, Neuropsychologist, The FASD Centre, Aoteroa

¹⁰ Population-based Prevalence of Fetal Alcohol Spectrum Disorder in Canada: BMC Public Health (2019)

¹¹ World Health Statistics 2017: Monitoring Health for the SDGs

23. A study, published in the New Zealand Medical Journal (27 July 2018), found 23 per cent of women who took part in the Growing Up in New Zealand study continued to drink in their first trimester and 13 per cent continued drinking after the first three months.
24. To properly identify, plan and budget around the size of the population affected by FASD within the New Zealand context, research into its prevalence here is needed. We understand that the Ministry of Health did not participate in the World Health Organisation prevalence study.

The 2016-2019 FASD Action Plan: A good Plan with Little Action on Support

25. Some parts of the 2016-2019 FASD Action Plan have been implemented including things such as:
 - A national social marketing campaign aimed at building social support for drinking less and reducing hazardous drinking among young adults;
 - Key messages for consumers and health professionals developed to raise awareness of the harms of alcohol consumption during pregnancy;
 - Online resources developed for frontline professionals to improve their knowledge and strategies to address FASD and;
 - Pregnancy and parenting services established in three pilot locations for pregnant and postpartum women experiencing alcohol and drug (AOD) issues.
26. Some actions relating to training clinicians in the use of FASD diagnostic tools has also taken place, but progress has been hampered by resource constraints.
27. Oranga Tamariki report that it expects FASD to be the disability type most common amongst the population of tamariki they work with. Oranga Tamariki note they are undertaking research on disability and working to build competencies amongst frontline staff to better respond to the needs of those with FASD, including the recruitment of a Regional Disability Advisor with a speciality in FASD.
28. The FASD-CAN report at appendix one notes that **“Every person who provided a response said that the 2016-2019 FASD Action Plan had not contributed anything positive to them or their family”**. This is most unfortunate.
29. For a child with FASD to live well, their primary caregiver also needs to be supported to live well. Families describe that the stress of raising children with FASD can be seriously detrimental to the health and well-being of the parent-caregiver.

Lack of funding

30. The only new money we are aware of for implementing the Action Plan is \$7.6m over three years for some FASD related initiatives arising out of a successful bid by the Ministry of Health (in partnership with agencies such as Oranga Tamariki) to the Proceeds of Crime Fund.
31. The initiatives aim to improve diagnostic capability, reconfigure existing child development support, improve support to parent children with FASD and to undertake research on what an effective system wide approach to FASD would look like. Some work to co-design and program manage an approach to FASD is also underway.

32. While being appreciative of the efforts by the Ministry of Health to obtain this funding, applying to a contestable fund is not a sustainable way to manage what should be ordinary service delivery responsibilities.
33. Furthermore, neither families nor those with FASD were involved in any co-design of the initiatives for the Proceeds of Crimes funding. Feedback from FASD-CAN indicates little confidence that these initiatives are sufficiently focused on direct support to be of significant benefit to them.

Lack of Accountability

34. The Action Plan is intended to be cross-agency. There appears to have been little accountability across government for ensuring the Plan is delivered. We convened a meeting in December 2019 with the Ministries of Health and Education and Oranga Tamariki to raise concerns about governance of the Action Plan.
35. It was agreed at that meeting that the governance group required a re-set. We therefore look forward to the inclusion of representation from families and those living with FASD and the programme management approach outlined above to progress rapidly. Governance oversight must be reviewed and ensure that members comprise senior people with the appropriate mandate to strategically steer this Plan.

Lack of current supports

36. One important source of funding **not** easily available to those with FASD is the Ministry of Health funded Disability Support Services (DSS). Individuals with FASD are not currently eligible for DSS by virtue of FASD alone unless they also have other recognised impairments such as an intellectual impairment (which only affects 20% of those with FASD). All individuals diagnosed with FASD have severe and permanent brain impairment across at least three brain domains among the 9-10 domains tested in order to be diagnosed.
37. The types of supports funded through DSS include things such as:
 - a. Child development services
 - b. Community Day Services
 - c. Respite Care
 - d. Community Residential Case Services
 - e. Funded Family Care
 - f. Hearing and Vision Services
 - g. Home and Community Support Services
 - h. Individualised Funding
 - i. Supported Living
38. At present, the primary provision of support to those with FASD is through mental health and addiction services. Some with FASD may be able to access the Child Disability Allowance or the Disability Allowance. Some support is also provided through the Ministry of Education Learning Support function (eg some teacher aide provision which supports a range of learning support needs and can be accessed based on need, rather than diagnosis).
39. A child with FASD may also be eligible for ORS funding which provides more specialist resource. Some children with FASD may be eligible for the Ministry of Education's Intensive Wrap-around Service which includes specialist assessments in some DHB areas. The Ministry of Education hopes

as part of its future roll out of its Learning Support Delivery Model that a broader range of services will be able to be accessed by a broader range of children. The Ministry has also contracted the Donald Beasley Institute to identify research on better supports for neuro-diverse students.

40. Families indicate that service provision across government is uneven and very difficult to access. Some liken it to a lottery that eludes most families who feel shunted from one service to another. This results in a cycle of repeated failure, frustration, exhaustion and despair.
41. Making a diagnosis of FASD requires a multidisciplinary team and involves a physical and neurodevelopmental assessment. As described earlier, FASD is a lifelong disability.
42. The requirement in the DSS eligibility criteria for the presence of an intellectual disability results in those with impaired intellectual and adaptive function being funded for DSS, while those with their executive brain function affected do not receive funded support. Given the impacts of both and the requirement for support, it is unclear why such a distinction is made. The distinction is utterly arbitrary in our view.
43. Furthermore, it is incongruous with a well-being and equity approach that people with some impairments are eligible for DSS (if deemed required), but people with FASD are not. There is simply no basis for such distinction.

Early Intervention is Key

44. Access to better supports would make a fundamental difference to the lives of people living with FASD and their families/whānau and could change the trajectory for many.
45. A key finding by Professor Ian Lambie (Chief Science Advisor to the Justice Sector) in his 2020 Report on Brain and Behaviour Issues was that: “Brain and Behaviour issues need evidence-based solutions rather than political ones, because currently resources are overwhelmingly directed to prisons, instead of cost-effective health, education and family support”.
46. Professor Lambie goes on in his report to explain that even where brain damage is permanent, its negative consequences and impacts do not have to be. “Our education system should be geared to provide evidence-based help for known conditions”. “Early intervention is vital from government systems to help families, health and education providers do better – and ultimately, to prevent the first steps onto a pathway into offending”.
47. Feedback from a variety of agencies endorses the need for research and prevalence data, much greater attention to people with FASD and acknowledges the gravity of impact for them including a lack of early intervention and support leading to care and protection and incarceration outcomes.
48. Given the benefits of early intervention it is unclear why New Zealand approaches resolving issues concerning FASD with such apathy when the wellbeing of people with FASD and their whānau could be improved and costs further down the track could be avoided.

No defensible reason for FASD exclusion

49. Set out below are various definitions we consider support the proposition that FASD is indeed a disability and should be funded as such.

50. The Ministry of Health website refers to FASD as “physical, cognitive, behavioural and neurodevelopmental disabilities that can result from alcohol exposure during pregnancy. There is no typical FASD profile, however, common issues may include intellectual and developmental disabilities, attention deficits, poor social understanding, hyperactivity and learning disabilities.”
51. When FASD is assessed through the definitions set out below the basis on which this exclusion occurs is completely perplexing to individuals and families and seems utterly arbitrary.
52. The New Zealand Human Rights Act 1993 defines disability as “a physical, intellectual or psychological disability or impairment, loss of psychological, physiological, or anatomical structure or function, reliance on assistance or illness”
53. Article 1 of the Convention on the Rights of Persons with Disabilities references disability as, “those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”;
54. The eligibility criteria for Ministry of Health funded Disability Support Services references disability as:
 - physical, intellectual or sensory disability (or a combination of these) which:
 - is likely to continue for at least 6 months
 - limits their ability to function independently, to the extent that ongoing support is required.
55. The Ministry of Health will also fund DSS for people with:
 - some neurological conditions that result in permanent disabilities
 - some developmental disabilities in children and young people, such as autism
 - physical, intellectual or sensory disability that co-exists with a health condition and/or injury.
56. Ostensibly, FASD meets all these criteria. It is therefore untenable in our view that those with FASD alone are prevented from accessing DSS.
57. Being eligible for DSS does not mean that people with FASD will have all their needs met. Amending the eligibility criteria for those with FASD would not automatically result in the person having unlimited access to resources, therefore inferences to “opening the floodgates” in some meetings we have attended are exaggerated, not to mention this being an inadequate response to a potential breach of human rights.
58. Simply, changing the eligibility criteria would allow a person with a diagnosis of FASD (regardless of the presence of an intellectual disability) to access such funded supports once they are assessed as needing them. We acknowledge that work is needed on developing additional resources and supports for those with FASD (as discussed with officials), but this need not preclude people accessing existing supports now and should be considered in light of the cost benefit of early timely intervention.

A Human Rights and Te Tiriti o Waitangi Approach

59. We recommend a human rights and Te Tiriti o Waitangi approach be taken to protecting and promoting the rights of those living with FASD and their whānau.

60. Such an approach would ensure that human rights and Tiriti obligations including rangatiratanga, equality and non-discrimination, participation, partnership, empowerment and accountability are applied in responses to FASD. While there has been consultation in New Zealand with the community over aspects of FASD, a step-change is needed to allow people with FASD and their families/whānau to meaningfully participate in decisions affecting them.
61. When thinking about disabled people being able to enjoy rights on the same basis as others, it is important to understand the social model of disability. The social model recognises that a person is disabled by the barriers around them (structural, attitudinal, Policy, infrastructure etc), rather than their specific impairment. The social model encourages states to focus on reducing such barriers.

Te Tiriti o Waitangi

62. Te Tiriti o Waitangi requires partnership decision-making, proactive support from the government for rangatiratanga, alongside ensuring equity of outcomes for tangata whenua. In our view, successive governments have failed to adequately honour commitments to Māori impacted by FASD and their whānau.
63. The evidence shows that Māori experience disproportionate levels of alcohol related harm. Unfortunately, there is very little research which has looked at the experiences of whānau Māori who require support and care for alcohol related health problems, including FASD.
64. The Health Research Council awarded Hāpai te Hauora a Ngā Kanohi Kitea a grant to explore whānau Māori experiences with an FASD. We understand this work is in its early design stages and there has been some set-back due to COVID-19. However, we hope this research can assist New Zealand's understanding of the impact of FASD on Māori.
65. In the absence of existing data and research, we can point to some limited information about the potential level of alcohol related harm during pregnancy.
66. According to the New Zealand Health Survey 2017-18, Māori are 1.6 times more likely to be hazardous drinkers than Non-Māori 11. Women with unplanned pregnancies who regularly drink in a risky way will be at greater risk of causing harm to the foetus. The highest rates for drinking during pregnancy in New Zealand were for Māori women with 34 percent reporting drinking alcohol at some time during their most recent pregnancy 12.
67. Analysis of New Zealand Health Survey data over the past decade indicates that hazardous drinking by women has been steadily rising overall, and the percentage increase for Māori women shows the steepest rise.
68. A controlled study of children presenting to a DHB child health service for an FASD assessment, found Māori to be overrepresented 13. Importantly, as the authors point out, this finding must be considered in the context of colonized experienced across generations causing unresolved trauma arising from loss of land, language and culture. It must also be viewed in relation to alcohol availability in areas of high deprivation.

¹² Ministry of Health. 2015. *Alcohol Use 2012/13:New Zealand Health Survey*. Wellington: Ministry of Health.

¹³ Crawford et al (2020). Cognitive and social/emotional influences on adaptive functioning in children with FASD: Clinical and cultural considerations. *Child Neuropsychology Journal*. <https://www.tandfonline.com/loi/ncny20>

69. Māori have long recognised the adverse impact that alcohol (waipiro) has on their people. In a petition to the House of Representatives in 1874, seeking redress for the destruction caused by the introduction of alcohol, this example was cited, “Our children are not born healthy because the parents drink to excess and the child suffers.¹⁴”
70. Since 1 July 2019, significant duties are imposed on the Chief Executive of Oranga Tamariki (new section 7AA) to provide a practical commitment to the Tiriti o Waitangi. This new provision will require a focussed effort by the Agency on the needs of Māori with FASD. The recent report of the Māori Inquiry into Oranga Tamariki stressed the need for whānau-centred, Kaupapa Māori aligned and mātauranga Māori informed approaches.¹⁵ In recommending a way forward, that report noted that:¹⁶
- The ultimate vision of what whānau want are comprehensive, wrap-around ‘by Māori, with Māori, for Māori’ services that are designed from the true lived experiences of whānau, and which offer long-term solutions for all tamariki and their whānau to flourish.*
71. The recently released Review of the Health and Disability System had a key theme of “*Developing more effective Tiriti based partnerships within health and disability and creating a system that works more effectively for Māori.*”
72. Te Puni Kōkiri note in its feedback on this report that it understands Māori face a higher risk of FASD and support the implementation of the 2016-19 FASD Action Plan as a matter of considerable importance and urgency.

International Obligations

73. A range of international human rights conventions and declarations New Zealand has signed up to are relevant to FASD:
- Universal Declaration of Human Rights (UDHR)
 - Convention on the Rights of Persons with Disabilities (CRPD)
 - Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)
 - International Covenant on Economic, Social and Cultural Rights (ICESCR)
 - Convention on the Rights of the Child (CRC)
 - UN Declaration on the Rights of Indigenous Persons
74. The UDHR (Article 1) provides that all human beings are born free and equal in dignity and rights. This promise is unfulfilled when the life that follows, in this case a person with FASD, is not sufficiently supported to enjoy the same rights as others.
75. When the State distinguishes between impairment types in relation to who can obtain necessary support, without reference to the impact of that impairment on the person’s life, the State is potentially discriminating against certain groups of people – in this case those living with FASD. This contravenes New Zealand’s obligations under Article 5 of the CRPD – which promotes equality and non-discrimination.

¹⁴ Petition of Haimona Te Aoterangi & 167 others to the New Zealand House of Representative 1874.

¹⁵ Whānau Ora Commissioning Agency, (2020), *Ko Te Wā Whakawhiti, It’s Time for Change: A Māori Inquiry into Oranga Tamariki – Report*. <https://whanauora.nz/maori-inquiry/>

¹⁶ Ibid., at 68.

76. The CRPD describes in detail the measures required to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. These measures include training for health and other professionals, early intervention and access to appropriate community care and support services across education, health, community services, employment and criminal justice sectors for the communities, families and individuals.
77. The necessary supports and services (including but not limited to health, community, education and employment services) should be accessible to all people with impairments resulting from FASD.
78. Importantly, the CRPD notes that to prevent concealment, abandonment, neglect and segregation of children with disabilities (which includes children with FASD), state parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families (article 23(3)).^[14]
79. The CRPD also states that a child with disabilities should enjoy a full and decent life, in conditions which promote self-reliance and facilitate the child's active participation in the community. This includes the right of the disabled child to special care and assistance designed to promote the fullest possible social integration and individual development (article 23).
80. This is also supported by the Convention on the Rights of the Child (CRC), which states are obliged to ensure adequate prenatal and postnatal health care for mothers (article 24(d)).
81. The matters in this paper will be drawn to the attention of the UN next year as part of New Zealand's examination of compliance with the CRC and the CRPD. In 2016 New Zealand acceded to the Optional Protocol to the UN Convention on the Rights of Persons with Disabilities. The Optional Protocol provides that State Parties can take a claim to the UN of violation of the CRPD after domestic remedies have been exhausted. We hope that with the Prime Minister's direction, the issues in this paper could be resolved domestically.
82. It is also important to note that when applying international conventions to NZ legislation, the courts tend to interpret domestic legislation consistently with international obligations (eg *DP v R*, CoA 2016). It would be open to a court to interpret the domestic Ministry of Health Rules on Disability Support Services consistently with the CRPD.

Domestic Laws

83. In our view, New Zealand is also potentially in breach of its domestic obligations. The NZ Bill of Rights Act 1990 (BORA) and the Human Rights Act 1993 (HRA) are the two main legislative frameworks which are critical to the enjoyment of disabled peoples' human rights and fundamental freedoms.
84. Section 19 of the BORA prohibits discrimination against persons on the grounds specified in section 21 of the HRA. Disability is one of the prohibited grounds of discrimination under the HRA (s 21(1) (h)). Section 92 of the HRA allows the Human Rights Review Tribunal to grant a declaration of inconsistency if section 19 of the BORA has been breached.
85. As set out in paragraphs 38-45 of this report, FASD meets the various definitions of disability. We consider the lack of equitable provision of services to those with FASD discriminates on the basis of

the nature of the impairment and therefore potentially puts decisions by successive governments in breach of s19 of the BORA and s21 of the HRA.

What is the situation in other countries?

Canada

86. Noting it is often difficult to make direct international comparisons to levels of support (as influenced by tax and social security frameworks in place), two countries New Zealand is often compared to are Canada and Australia.
87. Some states in Canada have models New Zealand could aspire to. In parts of Canada FASD is recognised as a disability and provides access to FASD specialised supports (delivered through a range of research networks, public health and other government providers) such as:
 - physicians and paediatricians
 - speech and language therapists
 - occupational therapists
 - psychologists and psychiatrists
 - physiotherapists
 - social workers
 - educators
 - training for parents and caregivers
 - guidance for a range of front-line workers
 - peer and community support programs, including a much greater level of community living options available than in NZ)
 - online portals
 - transitional programs for young people moving to the next life-stage
88. Canada also has an FASD inter-disciplinary research network leading, producing and sustaining national collaborative research in prevention, diagnosis and intervention practice.
89. Canada also developed guidelines for FASD diagnosis which have been adopted world-wide, including in New Zealand.

Australia

90. On 9 September 2019, the Australian Senate referred an inquiry to a select committee into effective approaches to prevention and diagnosis of FASD and strategies for optimising life outcomes for people with FASD. The Committee was due to report back by 15 June 2020 however this appears to be delayed due to COVID-19.
91. This is the second such Inquiry of magnitude in Australia, with the first being in 2012¹⁷. The 2012 Inquiry led to significant investment in the development and implementation of an FASD Action Plan. The focus of the current Inquiry is on how successful Australia has been in implementing its Action Plan including gaps in ensuring a nationally co-ordinated response and adequacy of funding.
92. There may be some useful approaches arising out of this Inquiry for New Zealand to consider. It is important to reflect on is the seriousness with which the Australian Senate is taking FASD. We

¹⁷ FASD: The Hidden Harm 2012

would like to see urgent and serious consideration given to providing better support for people with FASD and their family/whānau.

93. The Australian equivalent of the New Zealand FASD-CAN receives government funding, unlike New Zealand which relies on volunteers. Given the lack of access to wider FASD specialised supports, this places a heavy workload and burden of responsibility on a small number of individuals.

A note on other impairment types

94. The Disability Rights Commissioner is approached by other groups raising similar frustration about the eligibility criteria for DSS for their impairment types (for example those living with Attention Deficit Hyperactivity Disorder, Fetal Anticonvulsant Syndrome, Myalgic Encephalomyelitis as well as a range of rare disorders).
95. When viewed through a social model of disability and through the definitions of disability above, there is also no basis to distinguish deny access to support for impairment types such as the above.
96. We consider it critical to design a more simplified and streamlined process to challenge or change eligibility criteria. This would prevent the need for prolonged and complex battles by each and every group fulfilling the definitions of disability but excluded from support services.
97. This report focuses on FASD because of the significant benefits of early intervention, numbers of those affected as well as broad societal and inter-generational impacts. FASD could initiate a staged approach to changing the system to make it easier for people more widely to access appropriate supports.
98. It is telling that in the final report of the Health and Disability System Review (2020), it is noted that *Disabled people **have not been well served by the existing health and disability system**. Their health outcomes are worse and the way the disability support system operates is complex and confusing. The Review found that there is wide unexplained variability in the way assessment processes work around the country, and this should be addressed. The Review proposes that disability support becomes an integral part of Tier 1 service planning, funding and provision. Home-based support, in particular, should be assessed by need rather than having eligibility determined by diagnosis. Needs assessment processes need to be more streamlined and less repetitive.*
99. Addressing the issues in this report would be a positive step towards greater equity for those currently missing out and for simplifying the system.

Conclusion and Recommendations

100. We consider successive governments have fallen short in their obligations to Te Tiriti o Waitangi, international human rights commitments and domestic laws in relation to supporting those with FASD and their families/whānau.
101. We consider New Zealand may be in breach of its international human rights obligations (eg the right to an adequate standard of health as well as the other human rights referred to in paragraphs 52-63 of this report) to those living with FASD and their family/whānau.

102. We also consider the Government is potentially in breach of its domestic obligations under the Bill of Rights Act 1990 and Human Rights Act 1993 through discriminatory treatment of those living with FASD.
103. In our view there is no logical basis to limit access to Disability Support Services for individuals with FASD to those with an intellectual impairment only. The effect of doing so results in most people living with FASD not being able to access support and given an opportunity to thrive.
104. There is much to be done in New Zealand to better respond to FASD. The FASD Action Plan provided a hopeful start but has failed to deliver to families and those with FASD. This report seeks to bring these matters to the attention of the Prime Minister and requests direction be given to:
 - a. A discussion between Ministers, FASD-CAN, the Disability Rights Commissioner and Children's Commissioner on the best mechanism to advance the issues in this paper, including a potential Select Committee Inquiry or other type of Inquiry;

Requests immediate direction to the following:

- b. Seeking a Cabinet decision to amend the current eligibility criteria to provide for those with a diagnosis of FASD (regardless of the presence of an intellectual disability) be able to access DSS if they are assessed as needing those services;
- c. Ensuring there is a commitment to implementing the 2016-2019 FASD Action Plan, in particular the actions relating to supports. These should be implemented in partnership with those affected. New timeframes should be established with appropriate governance put in place to support successful outcomes;
- d. Establishing a Ministerial roundtable of relevant Ministers to bring sufficient awareness and action to these issues and address the apparent gap in a cross-agency focus to the FASD Action Plan;
- e. Conducting an FASD Prevalence study in New Zealand to better understand the population and appropriate targeting of resources.
- f. In developing Policy advice, consideration should be given to making it easier for people with other impairments to access appropriate supports.

Appendix One: FASD-CAN Report: *The reality of FASD in Aotearoa*

Refer Attached report.