Summary of Chapter 15: Fetal Alcohol Spectrum Disorder (FASD)

About the Hauwhaikaha report

The Waitangi Tribunal is a permanent commission of inquiry. It makes recommendations on claims brought by Maaori relating to legislation, policies, actions or omissions of the government (Crown) that are alleged to breach the promises made in te Tiriti o Waitangi/the Treaty of Waitangi.

The Health Services and Outcomes Inquiry (Wai 2575) (health inquiry) concerns claims relating to health services and outcomes that are important to Aotearoa New Zealand. In December 2017, the health inquiry was organised into three stages. This inquiry is the first part of the second stage and concerns claims relating to the State disability system.

The Hauwhaikaha report summarises what we heard during the disability inquiry and outlines our findings and recommendations.

Summaries of each chapter of the Hauwhaikaha report

People who want to read the full report, can find it here: www.waitangitribunal.govt.nz/en/publications/tribunal-reports/by-wai-number/wai2575hauwhaikaha or www.bit.ly/Hauwhaikaha

We have also produced summaries of each chapter of the report, for those who do not want to read the whole report.

This document is a summary of chapter 15 about issues related to Fetal Alcohol Spectrum Disorder (FASD).

What is FASD?

FASD is a neurodevelopmental disorder that affects the development and function of the brain, and can lead to lifelong physical, behavioural, learning, social function and intellectual challenges. FASD is caused due to exposure to alcohol before birth, though not all pregnancies that are exposed to alcohol result in FASD. FASD manifests in a spectrum of signs and symptoms and the impacts of FASD vary for every person, requiring a range of support.

The Alcohol Healthcare claim

The Alcohol Healthcare claim was presented in the first hearing of the disability inquiry in March 2022. Eight witnesses provided evidence, which included both extensive personal experiences of the effects of FASD and evidence by specialists in FASD. During the inquiry, we recognised the Crown's acknowledgment of several issues in relation to the impacts of FASD on Maaori, and suggested the claimants and Crown enter mediation to explore how to accomplish some of their mutual aspirations.

Through the mediation process, the Crown and claimants agreed on specific actions to improve how FASD is addressed for Maaori. In June 2023, the parties held a FASD hui at Parliament. During the hui, a FASD Maaori advisory group was announced and named: Te Kaahui Taurikura. The role of Te Kaahui Taurikura Roopuu is to determine priority areas of work that focus on the impacts of FASD on Maaori.

The claimants described the mediation process as a useful template for future engagement between the Crown and Kaupapa Maaori organisations. However, they noted that while the mediation process was useful in achieving some of the claim's goals, some issues remain outstanding. Claimants further noted that despite these positive steps, Maaori continue to experience prejudice, and significant further work

and systemic change are required to address the full extent of prejudice against Maaori in relation to FASD.

Is Crown prevention and diagnosis of FASD adequate for Maaori?

Diagnosing FASD can be difficult if maternal alcohol use is not known or undisclosed, as fetal alcohol exposure cannot be confirmed. Additionally, FASD is not usually obvious until developmental milestones are delayed or not achieved.

The claimants submitted that the Crown has failed to provide adequate and sustainable funding for FASD diagnosis, which has resulted in ongoing prejudice to those affected by FASD. Experts noted FASD services require additional funding to train and build capacities for accessible and culturally safe FASD assessments. Moreover, without funding for adequate diagnosis, claimant witnesses have stated that individuals may be misdiagnosed and whaanau marginalised from society.

The Crown acknowledged that there are limited publicly available specialists for whaanau to obtain a diagnosis. The Crown stated that adequate information and advice for parents and carers of people with FASD is an identified gap that is often filled by non-government organisations.

In April 2024, the Aotearoa New Zealand Clinical Diagnostic Guidelines for FASD (FASD guidelines) were released. The FASD guidelines are for clinicians and professionals who undertake FASD assessment and diagnosis in a health context. In May 2024, Te Whatu Ora commissioned workforce training on the FASD guidelines to 30 health professionals working in Child Development Services (CDS) under Whaikaha – Ministry of Disabled People.

We are concerned that despite the updates from the Crown regarding funding increases in FASD support, more long-term funding is needed for prevention and diagnostic services. The evidence showed that we lack culturally informed resources, co-designed with Maaori, to prevent FASD. Moreover, claimants and witnesses shared their experiences with inadequate diagnostic services that resulted in misdiagnosis.

Are Maaori with FASD eligible for Disability Support Services (DSS)?

Individuals with a sole diagnosis of FASD are currently not eligible for Disability Support Services (DSS) funded by the Crown. For many years, people have advocated for improved support and services for those with FASD, their families and whaanau, including extending eligibility for DSS to include those with a sole diagnosis of FASD.

The Report of the Disability Rights Commissioner and Children's Commissioner to the Prime Minister: Fetal Alcohol Spectrum Disorder: A Call-to-Action 2020, clearly stated that the Disability Rights Commissioner considered there is no defensible reason for FASD to be excluded from DSS. The report noted that FASD symptoms meet the criteria for DSS and the exclusion seems to be arbitrary.

In August 2022, New Zealand was examined by the United Nations Committee on the Rights of Persons with Disabilities on its progress regarding its commitments to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The UN Committee recommended that New Zealand amend DSS eligibility to include FASD. In June 2023, the UN Committee observations were accepted by the Crown with modification, noting that 'Cabinet and funding decisions will be needed to implement them'.

The Crown highlighted that although government-funded DSS for adults is not currently available for those with a sole diagnosis of FASD, Child Development Services (CDS) are available for children, from birth to 16 years of age, with developmental delay, intellectual, physical, or sensory disability, or autism. CDS provide expert assessment, including FASD diagnosis and early intervention support for children with disabilities and their whaanau. The Crown stated that it is not currently known how many children with fetal alcohol exposure are seen by CDS, due to the lack of comprehensive data. However, those with the highest needs are much more likely to access CDS. Access to CDS does not require formal eligibility criteria to be met, children with suspected FASD can access CDS if they require support services to meet developmental milestones.

During the inquiry, the Crown noted it was undertaking a review of eligibility for DSS. However, notwithstanding the extensive evidence, including the Disability

Commissioner's proposals for change, the UNCRPD's recommendations, and Whaikaha's subsequent review of eligibility, Maaori with a sole diagnosis of FASD are still not eligible for DSS.

Are the prevalence and incidence rates of Maaori with FASD in Aotearoa New Zealand known?

The Crown acknowledged that prevalence rates of FASD in New Zealand have not been accurately documented. The lack of data on the prevalence and incidence rates of FASD is influenced by challenges with diagnosis and compounded by the lack of comprehensive data gathering processes.

While FASD prevalence and incidence rates in Aotearoa New Zealand have not been accurately documented, claimants and witnesses argued that the limited research and practitioner experiences show Maaori are significantly over-represented in those with FASD.

Both the Crown and claimants highlighted overseas and domestic research that estimated prevalence rates of FASD. They said that in Aotearoa New Zealand, it is estimated that half the children who come into state care have FASD, mostly undiagnosed and untreated, and that sixty percent of tamariki (children) in state care are Maaori. Experts also noted that Maaori women reported a significantly higher rate of drinking during pregnancy as compared to other ethnicity groups.

While it is generally accepted that Maaori are disproportionately affected by alcohol related harm, including FASD, the evidence has highlighted apparent gaps on the prevalence of Maaori with FASD. Therefore, the true extent of the inequity remains unknown. These gaps have implications for the Crown's ability to understand the needs of those impacted by FASD, so as to inform policy.

Has the Crown adequately provided for Maaori to partner in its current response to FASD?

The claimants stated that notwithstanding an overall lack of FASD research in Aotearoa New Zealand, it is generally accepted that Maaori are disproportionately affected by alcohol related harm, including FASD. However, the response from the Crown has lacked Maaori input. They noted that Maaori with FASD require strong cultural connectedness and support. Claimants stated that Maaori deserve Maaori

models for prevention, assessment and diagnosis, Maaori models of care and Maaori targeted resources for understanding FASD within te ao Maaori. Engaging Maaori communities in open conversation about FASD is important, considering the stigma associated with prenatal alcohol exposure and FASD.

The Crown provided evidence on actions the Ministry of Health is taking to collaborate with Maaori to improve FASD responses for Maaori, including the mediation process it engaged in with the claimants. We commend both the Crown and the claimants for undertaking the mediation process in good faith. However, the Maaori-Crown relationship in the FASD context is still in an early stage of development. To bring visibility to the interests of Maaori with FASD, we reiterate the need to appropriately and adequately support taangata whaikaha Maaori groups, including Te Kaahui Taurikura Roopuu, to be able to engage in the development of FASD-related policy affecting Maaori.

Tribunal findings

The Crown is required by the principle of active protection to ensure that culturally appropriate health services are accessible. We consider current services and FASD workforce capacity are not yet at a level that would be widely judged adequate or sustainably guaranteed. We therefore agree with the claimants that more long-term funding is needed for prevention and diagnostic services, FASD education and workforce development, and community-led supports, including culturally-appropriate services for Maaori. The lack of accessible services to those individuals with FASD constitutes a breach of the principle of active protection.

The principle of equity requires that taangata whaikaha Maaori have fair and equitable access to services. We did not receive evidence of any reason for the exclusion of FASD from DSS access and we see no evidence for this distinction. We therefore consider that a breach of active protection and equity has occurred in relation to taangata whaikaha Maaori access to DSS.

The principle of equity also requires the Crown to inform itself of inequity and positively and protectively address it. While it is generally accepted that Maaori are disproportionately affected by alcohol related harm, including FASD, the evidence has highlighted apparent gaps in the data on the prevalence of Maaori with FASD.

Therefore, the true extent of the inequity remains unknown, representing a further breach of the principle of equity.

The relationship between Maaori and the Crown is characterised by the duty of good faith. Each Tiriti/Treaty partner must be conditioned by the other's needs and the duties of mutual respect. This in turn involves the obligation to consult. As noted in chapter 9 on partnership mechanisms, in the context of this inquiry, the Crown has a heightened Tiriti/Treaty duty to protect taangata whaikaha Maaori health and wellbeing and reduce adverse health disparities with non-Maaori through the development and implementation of disability policy. The Crown has historically failed to partner with taangata whaikaha Maaori in the design of FASD supports. As we stated in chapter 9 on partnership, it is unacceptable that the Crown duty to partner with Maaori should depend so starkly on the goodwill of Government officials. The Crown has not adequately provided for Maaori to partner with the Crown in its current response to FASD, which is in breach of the principle of partnership.