Summary of Chapter 6: Data, Research and Monitoring

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 6 about data, research and monitoring. Chapter 6 explains the role of data in the disability system and examines how well the Crown collects and uses information to understand the needs of taangata whaikaha Maaori, monitor performance of the disability system, and support evidence-based policy decisions.

Why is data important?

Disability statistics and information are important to Aotearoa New Zealand's health and disability system. The Crown needs accurate data to compare information between different groups over time. Data allows the Crown to design policy effectively and monitor outcomes. Reliable data are essential to address existing health disparities in Aotearoa New Zealand.

What data does the Crown collect on taangata whaikaha Maaori?

There are two main ways the Crown collects data, survey data and administrative data.

Surveys gather information by asking targeted questions. According to Statistics New Zealand, Maaori have a higher prevalence of disability than non-Maaori. The 2023 Household Disability Survey is the most recent and comprehensive survey on disability data. The survey showed that Maaori had the highest disability rate compared with other ethnicity groups. According to the survey, 184,000 Maaori were disabled. The age-adjusted prevalence rate among Maaori was 24 per cent, this is significantly higher than the national disability rate of 17 per cent.

Administrative data is information or records made when people use public services. We identified that administrative data also show disparities between Maaori and non-Maaori, for example, the overrepresentation of taangata whaikaha Maaori in prisons.

What are the limitations of the Crown's data collection practices?

The claimants argued that the Crown did not show how surveys will be improved to accurately measure health outcomes of taangata whaikaha Maaori and allow for

comparisons between taangata whaikaha Maaori and non-Maaori disabled people over time. The claimants also argued that the administrative data collected by the Crown was not thorough and did not include those who did not access support services,yet might still identify as taangata whaikaha Maaori.

The evidence showed that there are no uniform methods to collecting administrative data among Government agencies in relation to disability. We find the lack of a streamlined approach concerning, with the effects being that data that may be collected are not being shared, or adequately used to gain an accurate understanding of disability in Aotearoa New Zealand.

Is the Crown's definition of disability adequate?

Claimants argued that the Crown's definition of disability should reflect how taangata whaikaha Maaori choose to identify. The Crown highlighted the challenges of gathering disability data. It is a positive step that the Crown undertook to improve disability data in surveys and the use of the Washington Group Short Set of Questions on Disability. The latter is a set of questions developed by the Washington Group on Disability Statistics that measure the prevalence of functional difficulties at different levels of severity in relation to mobility, cognition, vision, hearing, language and communication, and daily living. However, while we acknowledge the Crown's efforts to improve disability data, the Crown's definition of disability remains inconsistent across its agencies and has not been developed in partnership with taangata whaikaha Maaori.

Is Crown research on taangata whaikaha Maaori sufficient?

Claimants also raised concerns about the lack of Crown disability research, particularly the lack of targeted funding. They said there is no ring-fenced funding for Maaori disability research. The Crown argued it is investing in research to understand a te ao Maaori perspective of disability. We acknowledge the challenges the Crown faces, however, these challenges are not impossible to overcome if the Crown provides funding and prioritises research into understanding te ao Maaori perspectives of disability.

Does the Crown have sufficient data monitoring mechanisms?

Monitoring mechanisms are processes that collect information, track outcomes and identify problems in the disability system. Claimants identified the absence of data for taangata whaikaha Maaori, and how this impacts health outcomes for taangata whaikaha Maaori and the Crown's ability to effectively monitor the disability system. The Crown pointed to steps it was taking to make improvements. However, the evidence showed insufficient information on the Crown's monitoring requirements. We did not receive evidence that the Crown collects sufficient data to gain a true understanding of experiences and needs of taangata whaikaha Maaori. The data gaps limit the Crown's ability to effectively report on and monitor service performance.

Tribunal Findings

The Crown acknowledged that the monitoring of disability was not previously prioritised, which explains the lack of data on taangata whaikaha Maaori. The Crown's collection of data does not adequately inform the Crown of how the disability system is performing in relation to taangata whaikaha Maaori health outcomes. Taangata whaikaha Maaori health is not regularly measured and reported on. Additionally, the Crown does not consistently use a definition and model of disability when collecting information about taangata whaikaha Maaori that allows for a te ao Maaori view of disability.

The Crown said that it is taking steps to improve the way it collects taangata whaikaha Maaori data, which will be more responsive to the needs of taangata whaikaha Maaori. However, we found that the Crown's actions to address the identified challenges are insufficient to correct the current lack of data. We acknowledge the challenges the Crown faces in collecting accurate data, however, these challenges are not impossible to overcome.

The Crown has a responsibility to actively protect taangata whaikaha Maaori health and wellbeing by providing disability services that try to close the gaps in health outcomes with non-Maaori. The Tiriti/Treaty principle of active protection means where there are persistent disparities in health status between Maaori and non-Maaori, the Crown must take appropriate measures to minimise the disparities over time. The principle of active protection requires the Crown to act, to the greatest

extent possible, to achieve equitable health outcomes for Maaori. Throughout this inquiry we heard evidence of inequitable outcomes for taangata whaikaha Maaori. To adequately address those inequitable outcomes, the Crown has a duty to inform itself by collecting relevant data. In this context, the Crown has a Tiriti/Treaty-based responsibility to collect culturally relevant data on taangata whaikaha Maaori to make informed policy decisions, monitor progress and eliminate health inequities.

Te Tiriti/the Treaty principle of partnership requires the Crown to empower Maaori to design and provide health services for Maaori. The Crown's obligation to consult and partner with Maaori in policy development and implementation is especially relevant where Maaori expressly seek it, and where disparities in outcomes exist. The Crown has a Tiriti/Treaty-based responsibility to partner with taangata whaikaha Maaori to collect information and design and monitor services. We agreed with claimants that partnership between taangata whaikaha Maaori and the Crown has been inadequate.

The principles of equity and active protection require the Crown to be well-informed of Maaori health outcomes. The Crown must maintain adequate data collection practices to keep itself informed of the needs of taangata whaikaha Maaori and deliver services. Furthermore, it should keep itself informed of any factors that may contribute to inequitable health outcomes for taangata whaikaha Maaori. However, the Crown has failed to fund and support adequate research about taangata whaikaha Maaori, which is a breach of the principles of active protection, partnership and equity.

While the Crown has acknowledged the importance of collecting and reporting data for taangata whaikaha Maaori, the ongoing absence of comprehensive and reliable data on taangata whaikaha Maaori and their whaanau reflects a lack of prioritisation and investment. The Crown's collection of taangata whaikaha Maaori data does not inform the Crown of how the disability system is performing in relation to taangata whaikaha Maaori health outcomes, as acknowledged by the Crown. The Crown has long been aware of the significant gaps and quality issues in its data, yet has not taken meaningful steps to resolve them, which is a breach of the principles of active protection, partnership and equity.

Inadequate data collection on taangata whaikaha Maaori has limited the performance reporting and monitoring of Crown organisations. This has meant that much of the Crown's work in the health and disability sector has not been routinely scrutinised. The Crown is lacking the tools to effectively use data to address inequitable outcomes for taangata whaikaha Maaori. The Crown is unable to monitor access needs of taangata whaikaha Maaori which limits the Crown's ability to effectively design, budget, plan and monitor services for taangata whaikaha Maaori, which is a breach of the principles of active protection, partnership and equity.

To uphold its Tiriti/Treaty obligations and prevent service providers from being prejudiced, the Crown must urgently address these data gaps. The knowledge and insights needed to understand the experiences of taangata whaikaha Maaori are accessible, but require investment in robust, kaupapa Maaori-led research, which can in turn inform government policy. Crucially, this must include the voices of taangata whaikaha Maaori, their whaanau and kaupapa Maaori service providers, so health and disability services are responsive to their needs.