Submission on the Healthy Futures (Pae Ora) Amendment Bill

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1. Summary and recommendations

IHC opposes the repeal of the health sector principles in the *Pae Ora (Healthy Futures) Act 2022*. Removing these principles would further entrench the systemic health inequities faced by people with intellectual disability (PWID), particularly Māori with an intellectual disability, who are among the most disadvantaged population groups in New Zealand.

The health system does not currently deliver equitable care to the intellectually disabled population. Repealing the principles would remove critical guidance and accountability for addressing these long-standing failures. Any amendment to the Act should strengthen, not weaken, the sector's commitment to equity.

- Do not repeal the health sector principles. Instead, retain them as binding guidance for Health New Zealand, the Ministry, and all health entities.
- Strengthen the principles to explicitly name intellectually disabled people and require disaggregated monitoring of their health outcomes.
- Name intellectually disabled people (including Māori with intellectual disability) as a priority population in all relevant parts of the Act.
- Maintain and enhance obligations to engage with disabled people and their whānau in service design and delivery, with a focus on equity, cultural safety, and lived experience.

2. About IHC

IHC advocates for the rights, inclusion, and welfare of all people with intellectual disabilities and supports them to live satisfying lives in the community.

IHC was founded in 1949 by a group of parents who wanted equal treatment from the education, health, and social service systems for their children with intellectual disability. Today IHC is still striving for these same outcomes and is committed to advocating for the rights, welfare, and inclusion of all people with an intellectual disability throughout their lives.

We believe that people with an intellectual disability have the right to be to be part of a family, to be treated with respect and dignity, to have a say in their own lives, to live, learn, work and enjoy life as part of the community, and to have support that meets their goals and aspirations.

IHC is New Zealand's largest provider of services to people with intellectual disabilities and their families. IHC supports 1500 families with children who have an intellectual disability, provides support and training for 4000 adults in workplaces and helps more than 3500 people with disabilities to live in IHC houses and flats. We also provide specialist services such as behaviour support and training.

IHC advocates for the rights of all people in New Zealand with an intellectual disability an estimated population of 47,000.

3. The health system currently fails people with an intellectual disability

PWID experience some of the worst health outcomes in New Zealand. Despite being a known high-needs population, they are rarely recognised as a priority group in health strategy or practice in New Zealand.

Life expectancy for intellectually disabled people is up to 18 years shorter than for the general population. Māori men with an intellectual disability have an average life expectancy of just 62 years, compared to 74 years for other Māori men.

Other stark disparities include:

- PWID are over 3.5 times more likely to be hospitalised for preventable conditions.
- PWID are almost 3 times more likely to have visited an emergency department in the past year.
- They are up to 16 times more likely to be treated psychotic disorders.
- For intellectually disabled people aged 45–54, secondary health costs are over seven times higher than those in the general population, a result of crisis-driven care and system failure.

These outcomes point to a health system that is not designed for, or responsive to, intellectually disabled people. Many avoidable deaths and poor outcomes could be prevented with basic, low-cost, preventative care, including comprehensive annual health checks. Yet, there are no mechanisms in the current system to require this kind of equitable service design, or to hold Health NZ accountable for the needs of this population.

4. Māori with an intellectual disability face compounding inequity

The inequities faced by PWID are compounded for Māori with intellectual disability. They have worse health outcomes than both the general population and other Māori across nearly every health indicator:

- Almost 3 times more likely to have a mood disorder than other Māori.
- Over 3 times more likely to have dementia than other Māori.
- 1.63 times more likely to have coronary heart disease.
- Emergency department and hospitalisation rates are significantly higher than for other Māori.

Despite these alarming statistics, Māori with an intellectual disability are not named in health equity strategies, not monitored as a priority group, and rarely engaged in service design.

The current health sector principles, particularly clauses 1(a), (b), and (d), offer one of the few legislative mechanisms to ensure Māori and disabled people are actively included in the planning, delivery, and accountability of health services. Repealing these principles removes the legal imperative to engage with and provide for Māori with intellectual disability - people who are routinely excluded from decision-making and face some of the highest barriers to accessing care.

5. Repealing the principles is inconsistent with Te Tiriti o Waitangi and international obligations

The health sector principles are essential for operationalising Te Tiriti o Waitangi in the health system, particularly:

- Equity (1)(a)
- Māori decision-making authority (1)(c)
- Culturally safe, kaupapa Māori service design (1)(d)

They are also consistent with the UN Convention on the Rights of Persons with Disabilities (CRPD), which New Zealand has ratified. The CRPD requires States to:

- Ensure equal access to health services for disabled people (Article 25)
- Provide health services *as close as possible* to people's communities
- Require participation of disabled people in all matters affecting them (Article 4.3)

6. Why repealing the principles will make this worse

For people with an intellectual disability, especially Māori with an intellectual disability, the health sector principles are not an abstract list of ideals, they are one of the few legislative safeguards that could be used to ensure their needs are considered in planning, delivery, and evaluation.

Without these principles, there is less legislative requirement to address equity for this population, to provide culturally safe services, to involve people with lived experience, or to collaborate on prevention and early intervention. The current health targets do not address the key drivers of poor outcomes for PWID, such as lack of accessible health information, inadequate training for clinicians, and absence of preventative screening and health checks.

The health system has consistently failed to take PWID into account in its major reforms and priorities. Removing the principles makes the prospect of change even more remote. It risks cementing a model that measures success only in generic wait times and service volumes, while ignoring populations whose needs fall outside those metrics. For PWID, this would mean continued invisibility in policy, in data, and in practice - and a continuation of the unacceptable inequities they face today.

7. Conclusion

The repeal of the health sector principles would disproportionately harm intellectually disabled people, particularly Māori with an intellectual disability - a population that already experiences systemic neglect. Without strong guiding principles, there is no mechanism to ensure that health entities take action to close these extreme health gaps.

The current principles should not be seen as an impediment to timely and effective care; they are the very tools that ensure care is equitable, inclusive, and fit for purpose.

We urge the Committee to retain and strengthen these principles in the interests of a fair, humane, and accountable health system.

We wish you well with this important work.

8. References

All statistics in this submission taken from:
Beltran-Castillon, L., & McLeod, K. (2023). *From Data to Dignity: Health and Wellbeing Indicators for New Zealanders with Intellectual Disability*. IHC https://cdn.prod.website-files.com/628455c1cd53af649dec6493/6584cc68cbd28550e09d0397_Full_IDI%20report_final_web.pdf.