PARENTS OF VISION IMPAIRED (NZ) INC
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Providing a community to support parents of children with vision impairments

18 August 2025

Committee Secretariat
Health Committee
Parliament Buildings
Wellington

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Tēnā koe,

Please find attached a submission from Parents of Vision Impaired NZ on the *Healthy Futures (Pae Ora) Amendment Bill*.

We would like to speak to this submission.

Ngā mihi,

Rebekah Graham

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ABOUT PARENTS OF VISION IMPAIRED NZ

Parents of Vision Impaired NZ (PVI) is a registered charity which supports parents who have blind, low vision, or vision-impaired children. There is no cost to enrol, and we provide a supportive community of parents who are overcoming challenges every day. We offer parents advice, information, and opportunities to meet other parents. We publish a quarterly newsletter (eVision) and have a members-only Facebook page for families and whānau to share information and to network. PVI also runs an annual conference and AGM which allows parents and whānau to get together face to face for a longer time to talk, listen and learn in a social setting. PVI takes an active part in the disability sector through making sure that the voice of visually impaired children and their parents is heard in consultations with government, schools, local councils, and other organisations.

OUR APPROACH TO THIS BILL

PVI takes a whole of life approach with the understanding that disabled children and whānau should have a say about outcomes that affect them. In doing so, we draw on key components of the following, and have highlighted the relevant aspects of each to this Bill:

New Zealand Bill of Rights Act (1990). This Act states that everyone has the right to be free from discrimination from government and state officials, including with regards to education and on the grounds of disability.

International conventions. Aotearoa New Zealand is a signatory to United Nations conventions that emphasise disabled peoples' right to accessible transport and housing. As such, governments are required to undertake all appropriate legislative, administrative, and other measures for the implementation of the rights recognized in the following conventions:

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)[1]:

- *Article 7 – Children with disabilities*: States must ensure that children with disabilities enjoy all human rights on an equal basis with others, with their best interests as a primary consideration.
- *Article 9 – Accessibility:* States must take appropriate measures to ensure that people with disabilities have equal access to the physical environment, transportation, information, and communication.
- *Article 19 – Living independently and being included in the community*: States must ensure that people with disabilities can live in the community with choices equal to others and have access to the support they need.
- *Article 25 – Health:* States must provide persons with disabilities with the same range, quality, and standard of free or affordable healthcare as provided to others, including disability-specific services.

United Nations Convention on the Rights of the Child (UNCRC)[2].

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[1] See https://www.whaikaha.govt.nz/about-us/the-uncrpd

[2] See https://www.ohchr.org/en/professionalinterest/pages/crc.aspx

- *Article 23 – Rights of Children with Disabilities.* Children with disabilities must enjoy full and decent lives in conditions that ensure dignity, promote self-reliance, and facilitate active participation in the community, including online.
- *Article 29 – Aims of Education*. Education should develop a child's personality, talents, mental and physical abilities, and support them to participate fully in a free society. Digital access plays a key role in that participation today.

NZ Disability Strategy (2016-2026). The New Zealand Disability Strategy[3] is the Government's primary vehicle for implementing the UNCRPD and includes the NZ Disability Action Plan[4]. Of interest to this submission is

Outcome 3: Health and Wellbeing (ensuring disabled people have the highest attainable standard of health), and

Outcome 5: Accessibility - *"We have access to all places, services and information with ease and dignity."*

Enabling Good Lives Principles[5]. The following principles are particularly relevant:

Self-determination: Disabled people are in control of their lives.

Ordinary life outcomes: Disabled people are supported to live an everyday life in everyday places; and are regarded as citizens with opportunities for learning, employment, having a home and family, and social participation - like others at similar stages of life.

Mana enhancing: The abilities and contributions of disabled people and their families are recognised and respected.

OUR SUBMISSION

We **strongly oppose** the *Healthy Futures (Pae Ora) Amendment Bill* because it undermines equity, weakens accountability, and risks worsening already stark health disparities for disabled children and their families, particularly tamariki Māori with vision impairment.

OUR CONCERNS

1. **Erosion of Te Tiriti o Waitangi commitments**
   The repeal of **Te Mauri o Rongo** and the weakening of iwi-Māori Partnership Boards directly breach Te Tiriti o Waitangi obligations. The Waitangi Tribunal's 2019 Hauora Report[6] emphasised the Crown's duties of *tino rangatiratanga* (self-determination), *ōritetanga* (equity), *whakamaru* (active protection), *kōwhiringa* (options), and *pātuitanga* (partnership). These principles were embedded in the Pae Ora Act 2022 for good reason.

   The repeal of Te Mauri o Rongo and weakening of iwi-Māori Partnership Boards strips away critical safeguards for Māori health. For parents of blind and low vision children,

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[3] Office for Disability Issues. *New Zealand Disability Strategy*. Accessed from: https://www.odi.govt.nz/nz-disability-strategy/

[4] See https://www.odi.govt.nz/disability-action-plan-2/

[5] See https://www.enablinggoodlives.co.nz/about-egl/egl-approach/principles/

[6] Waitangi Tribunal. (2019). *Hauora: Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry (WAI 2575).*

this is deeply concerning: Māori are already overrepresented in disability statistics and experience poorer health outcomes.

Strong Treaty-based partnerships are essential to ensuring services meet local needs and respond appropriately to disabled tamariki Māori and their whānau[7]. Meaningful iwi partnerships are not symbolic; they it ensures that services are designed and delivered in ways that are culturally safe, locally responsive, and inclusive of disability needs. Removing decision-making roles for iwi will worsen inequities for Māori disabled children, who already face higher rates of unmet health needs[8].

2. **Loss of workforce values and cultural competence**
   Te Mauri o Rongo set out values and behaviours expected across the sector. Its removal signals that respect, equity, and cultural competence are optional. Parents already encounter barriers in – from GPs who dismiss our concerns, to hospital staff who provide inaccessible information. Tangible improvements occur when health systems are culturally responsive[9].

   The **NZ Disability Strategy (2016–2026)[10]** and the **UN Convention on the Rights of Persons with Disabilities (Articles 9, 25)** both require that services are accessible, equitable, and delivered in ways that respect disabled people's dignity. Repealing Te Mauri o Rongo undermines these obligations and leaves families like ours more vulnerable to poor practice.

   Te Mauri o Rongo provided sector-wide expectations around culturally safe, respectful, and inclusive care. Its removal sends the message that values and principles no longer matter. For vision impaired families, this risks an erosion of accessible, person-centred care. We already struggle with clinicians who lack understanding of blindness and low vision; further devaluing cultural competence and shared values will compound inequities.

3. **The return to health targets results in poorer outcomes**
   Findings from the National Government's previous health targets (2008–2017) showed clear evidence that having health targets distorts priorities, encourages gaming of data,

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[7] Ingham, T. R., Jones, B., Perry, M., King, P. T., Baker, G., Hickey, H., Pouwhare, R., & Nikora, L. W. (2022). *The Multidimensional Impacts of Inequities for Tāngata Whaikaha Māori (Indigenous Māori with Lived Experience of Disability) in Aotearoa, New Zealand*. International Journal of Environmental Research and Public Health 2022, Vol. 19, Page 13558, 19(20), 13558. https://doi.org/10.3390/IJERPH192013558

[8] Ministry of Health. (2019*). Whaia Te Ao Mārama 2018–2022: The Māori Disability Action Plan*.

[9] Cormack, D., Stanley, J., & Harris, R. (2018). *Multiple forms of discrimination and relationships with health and wellbeing: Findings from national cross-sectional surveys in Aotearoa/New Zealand*. International Journal for Equity in Health, 17(1). https://doi.org/10.1186/S12939-018-0735-Y

[10] Office for Disability Issues, & Statistics New Zealand. (2010). *Disability and Māori in New Zealand in 2006: Results from the New Zealand Disability Survey*. http://archive.stats.govt.nz/browse_for_stats/health/disabilities/disability-and-maori.aspx

and sidelines complex patients[11] [12]. Disabled children too often fall into the “too complex” category and risk being deprioritised under target-driven systems.

Health equity requires flexible, needs-based approaches, not blunt targets that incentivise exclusion. The **World Health Organization** has repeatedly warned that target-driven health systems risk worsening inequities unless paired with adequate resources and equity monitoring[13].

Evidence shows that rigid health targets under previous governments led to data manipulation, staff burnout, and the sidelining of complex patients. Disabled children and their families often fall into the “too hard” basket under such systems[14]. We fear this Bill will again incentivise services to deprioritise people with lifelong, complex needs in favour of quick wins to meet targets.

4. **Politicisation of health governance reduces independence and accountability**
By reducing board size and increasing Ministerial control, the Bill centralises power and erodes the independence of Te Whatu Ora. Parents already struggle to be heard within health systems; making governance more partisan reduces avenues for accountability and advocacy.

The **Code of Health and Disability Services Consumers’ Rights (1996)** affirms our right to services of an appropriate standard and to be treated with respect. Weakening governance independence risks undermining these protections in practice.

By consolidating power in the hands of the Minister and reducing independent governance, the Bill politicises healthcare delivery. This diminishes accountability and makes it harder for families like ours to advocate effectively for change. Disabled people and their families need stronger accountability mechanisms, not weaker ones.

5. **Impact on disabled children and their families**
Blind and low vision children often require multidisciplinary care – paediatrics, ophthalmology, genetic testing, occupational therapy, early intervention, and community-based supports. These services are already fragmented and necessitate a high level of systems navigation and literacy to access. Without a framework that embeds equity, values, and partnership, our children will be continue to be increasingly marginalised.

Disabled people already report significantly higher rates of unmet healthcare needs[15]. Families raising vision impaired children face additional barriers such as inaccessible

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[11] Gauld, R. (2011). *Are targets useful? An examination of health targets in New Zealand.* Health Policy, 103(2–3), 123–130.

[12] Tenbensel, T., et al. (2017). *Target-setting and performance in health care: A longitudinal analysis of the New Zealand health targets policy, 2009–2015.* Health Policy, 121(12), 1293–1301

[13] World Health Organization. (2008). *Primary health care: Now more than ever.* World Health Report

[14] Jones, B., King, P. T., Baker, G., Nikora, L. W., Hickey, H., Perry, M., Pouwhare, R., & Ingham, T. R. (2024). *Karanga rua, karanga maha: Māori with lived experience of disability self-determining their own identities*. Kōtuitui: New Zealand Journal of Social Sciences Online, 19(1), 45–64. https://doi.org/10.1080/1177083X.2023.2224422

[15] Stats NZ. (2021). *Wellbeing of Disabled People: Findings from the 2021 General Social Survey*.

information, lack of disability awareness among clinicians, and regional variation in services. This Bill compounds rather than addresses those inequities.

Healthcare systems that prioritise cost-cutting and short-term results fail disabled children and their families. Access to paediatric specialists, vision rehabilitation, mental health services, and accessible information already requires a high level of system navigation. Weakening Treaty protections, cultural competence, and health system independence will worsen this access and leave our children behind.

FINDINGS OF THE WAITANGI TRIBUNAL CLAIM 2109

Above we made a general comment about Te Tiriti obligations. We wish to give additional space in our submission to the findings from Wai Claim 2109 regarding blindness, deafblindness, low vision and visual impairments, as these are directly relevant to our community.

Wai Claim 2109 is a claim by Maaka Tauranga Tibble for himself and on behalf of all Kapo Maori (Maori blind, vision impaired and deaf blind persons) and their whanau and Kapo Maori Aotearoa/New Zealand Incorporated (Wai 2109)[16].

The Waitangi Tribunal's *Wai 2575 Health Services and Outcomes Inquiry* heard significant evidence from Māori disability claimants, including Kāpō Māori (Wai 2109). The findings are deeply relevant to current health reforms and highlight systemic inequities. The proposed changes to Pae Ora will undermine the gains being made in this area.

1. **Inadequate Crown engagement with Māori providers**
   The procurement and delivery of home support services have consistently favoured large, non-Māori, for-profit providers. This system has systematically excluded Māori providers, limiting whānau choice and reducing access to culturally responsive care[17].

   "The Crown talks about building relationships with Māori providers, but that's just propaganda. The reality is that contracts go to big non-Māori organisations, and Māori services are shut out."

2. **Discriminatory and culturally unsafe structures of care**
   Evidence showed that around 76% of disabled Māori are forced to receive home support from non-Māori for-profit organisations (who typically deliver culturally unsafe and substandard care), while only 15% access services from Māori providers, despite the latter demonstrating aroha, whanaungatanga, and more effective outcomes[18].

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[16] Tibble, M. T. (2019). Waitangi Tribunal Claim Wai 2575, #3.2.218. https://www.health.govt.nz/system/files/2024-05/wai-2109-kapo-maori-amended-particularised-statement-of-claim.pdf and Waitangi Tribunal. (2023). *Hauora: report on stage one of the Health Services and Outcomes Kaupapa Inquiry*. Wai 2575. Legislation Direct. https://forms.justice.govt.nz/search/Documents/WT/wt_DOC_195476216/Hauora%202023%20W.pdf

[17] Scoop (2024). *76% of Disabled Māori Forced into Non-Māori Care: Crown's Bias Exposed at Waitangi Tribunal*. Retrieved from: https://www.scoop.co.nz/stories/GE2412/S00013/76-of-disabled-maori-forced-into-non-maori-care-crowns-bias-exposed-at-waitangi-tribunal.htm

[18] Scoop (2024). *76% of Disabled Māori Forced into Non-Māori Care*. Retrieved from: https://www.scoop.co.nz/stories/GE2412/S00013/76-of-disabled-maori-forced-into-non-maori-care-crowns-bias-exposed-at-waitangi-tribunal.htm

“Disabled Māori are forced to accept care from people who do not understand us, our whānau, or our tikanga. We are left with providers who see disability only through a medical lens and not through te ao Māori.”

3. **Separation from whānau and cultural disconnection**
   Claimants, including tāngata kāpō Māori, described historical and ongoing experiences of being separated from whānau and iwi. Colonially imposed systems of care reinforced medicalised notions of disability and denied disabled Māori access to te ao Māori, fragmenting cultural identity and belonging.[19]

   “Colonisation has meant that disabled Māori were separated from their whānau, excluded from marae, and told they did not belong. We were denied te reo and tikanga, and that pain carries through generations.”

4. **Lack of meaningful participation and systemic bias**
   Submissions criticised the Crown’s tokenistic notion of “relationship-building,” which was described as propaganda masking systemic exclusion. Claimants called for Māori providers and disabled Māori communities to have genuine roles in decision-making and equitable access to funding.[20]

   “We are invisible in the system. Our voices are not heard, our data is not collected properly, and decisions are made without us. That is not tino rangatiratanga.”

5. **Disproportionate barriers and data invisibility**
   Disability prevalence is significantly higher among Māori (approximately 32%) than the national average (24%), yet data collection on Māori disability remains fragmented and inadequate. This invisibility has hindered effective policy and service design.[21]

   “When Māori providers care for us, they show aroha and respect. They understand that disability is part of who we are as Māori, not something to be ashamed of. But too often, those providers are underfunded while the big non-Māori agencies take the contracts.”[2]

WHAT WE ASK

1. **Retain Te Mauri o Rongo in legislation** as a vital values framework for a culturally competent, compassionate health system.
2. **Strengthen, not weaken, iwi-Māori Partnership Boards** so that service design reflects the needs of local communities, including disabled Māori.
3. **Avoid reverting to rigid, punitive health targets** that marginalise complex cases. Instead, resource services properly and measure outcomes that reflect equity and wellbeing.

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[19] Abuse in Care Royal Commission (2022). *Panui – November 7.* Retrieved from: https://www.abuseincare.org.nz/our-progress/library/v/522/panui-november-7

[20] Scoop (2024). *76% of Disabled Māori Forced into Non-Māori Care: Crown’s Bias Exposed at Waitangi Tribunal.* Retrieved from: https://www.scoop.co.nz/stories/GE2412/S00013/76-of-disabled-maori-forced-into-non-maori-care-crowns-bias-exposed-at-waitangi-tribunal.htm

[21] The Spinoff (2022). *A Landmark Week for the Māori Disability Community at the Waitangi Tribunal.* Retrieved from: https://thespinoff.co.nz/society/16-03-2022/a-landmark-week-for-the-maori-disability-community-at-the-waitangi-tribunal

4. **Ensure disability voices**, including parent voices, are embedded in governance and decision-making structures, with formal mechanisms for accountability.
5. **Guarantee that all health workers**, including overseas-trained staff, receive mandatory training in cultural competence and disability awareness, including the rights of disabled people under Te Tiriti o Waitangi and the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

FINAL COMMENTS

This Bill risks taking our health system backwards. It undermines Te Tiriti, strips away accountability, and privileges political targets over community need. For families raising vision impaired children, the consequences are clear: less access, less equity, and less culturally safe care.

We cannot reiterate enough that what works for Māori whānau works for disabled children and their families too.

We urge the Committee to reject the regressive elements of this Bill and instead strengthen the Pae Ora framework to ensure that all tamariki – including those who are blind, deafblind, or have low vision – can live healthy, thriving lives.

FURTHER READING

Disability and Critical Health Psychology: Applications for Work and Everyday Life (Graham & McGuigan, 2025), featured in *Critical Health Psychology: Foundations, Approaches and Applications* – an open-access textbook exploring equity-focused and applied psychological perspectives. Read more here

Working Together to Support Self-Determination for Tāngata Kāpō Māori: An Exemplar (Masters-Awatere, Graham & Cowan, 2024), published in the *International Journal of Environmental Research and Public Health*. Read more here

Rumbold, A., Brown, S., Riggs, E., Ingham, T. R., Jones, B., Perry, M., von Randow, M., Milne, B., King, P. T., Nikora, L. W., Sporle, A., Ao, T. M., Study Group, arama, & Hauora Eru, R. P. (2023). Measuring Māori Health, Wellbeing, and Disability in Aotearoa Using a Web-Based Survey Methodology. *International Journal of Environmental Research and Public Health 2023, Vol. 20, Page 6797*, *20*(18), 6797. https://doi.org/10.3390/IJERPH20186797

Stace, H., & Sullivan, M. (2020). *A brief history of disability in Aotearoa New Zealand*. https://www.disabilitysupport.govt.nz/assets/History-of-Disability-in-Aotearoa-NZ-final1.pdf