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

HDC Act and Code Review

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PO Box 1791, Auckland, 1140

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Please find attached Parents of Vision Impaired (NZ) Inc's response to the HDC's *Act and Code Review consultation questions 2024*.

Ngā mihi,

Rebekah Graham

National Executive Officer
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About us: Parents of Vision Impaired

Parents of Vision Impaired (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. Our current membership is at just over 1300 parents, with over 900 email subscribers.

PVI offers 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.

Additionally, 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.

The Proposed Changes

The Health and Disability Commissioner (HDC) is required by law to review the Act and the Code regularly and recommend to the Minister of Health what changes should be made.

These reviews are an opportunity to make sure the Act and the Code remain fit for purpose in promoting and protecting the rights of all New Zealanders accessing health and disability services.

This consultation document covers five topics where we think the Act and the Code can be improved. These are:

- Supporting better and equitable complaint resolution;
- Making the Act and the Code more effective for, and responsive to, the needs of Māori;
- Making the Act and the Code work better for tāngata whaikaha | disabled people;
- Considering options for a right of appeal of HDC decisions; and
- Minor and technical improvements.

PVI's approach

Our submission takes a whole of life approach – disabled children are often excluded from having a say about outcomes that affect them.

In our submission, we draw on several key documents. These are listed below, along with the relevant components.

The 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 from public transport and with regards to housing, and including 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, govenments 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].** In particular, *Article 9: Accessibility* and *Article 19: Living independently and being included in the community*. These articles recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, including those related to *housing*.
- **United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP)**[2]**.** In particular, *Article 21*, which states that Indigenous peoples/persons with disabilities have the right to full and effective participation in all aspects of life. Realization of this right requires accessibility in terms of physical environments, transportation, information and communications, *housing*, and access to other facilities and services open or provided to the public, both in urban and in rural areas.
- **United Nations Convention on the Rights of the Child[3].** In particular, *Article 23*, which recognizes that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance, and facilitate the child's active participation in the community. This includes access to independent and dignifying forms of public transportation and *housing*.

NZ Disability Strategy (2016-2026). The New Zealand Disability Strategy[4] is the Government's primary vehicle for implementing the UNCRPD and includes the NZ Disability Action Plan[5].

Enabling Good Lives Principles[6]. The following principles are particularly relevant to our submission:

- **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.
- **Mainstream first:** Disabled people are supported to access mainstream services before specialist disability services.
- **Easy to use:** Disabled people have supports that are simple to use and flexible.

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[1] See https://www.odi.govt.nz/united-nations-convention-on-the-rights-of-persons-with-disabilities/read-the-convention/

[2] See https://www.un.org/development/desa/indigenouspeoples/declaration-on-the-rights-of-indigenous-peoples.html

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

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

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

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

Our submission

Topic 1: Supporting better and equitable complaint resolution

1.1 Did we cover the main issues about supporting better and equitable complaints resolution?

Yes

1.2 What do you think of our suggestions for supporting better and equitable complaint resolution, andd what impacts could they have?

We support the changes proposed.

In particular we support the acknowledgement that providers do not clearly advertise or communicate their feedback processes.

We support the explicit protections against retaliation.

We support the proposed changes to Right 10 to simplify and set clearer expectations for provider complaint processes, including promoting the right to complain.

We support the proposed changes to the Code to clarify the role of whānau in the consumer–provider relationship and to help providers to enable whānau participation appropriately:

- Changing the wording in Right 3 (Dignity and Independence) from 'independence' to 'autonomy' to recognise the interdependence people often have with whānau and support networks;
- Strengthening Right 8 (Support) to include the right to have whānau involved even where they cannot be present physically; and
- Clarifying Right 10 (Right to Complain) to explicitly allow for complaints to be made by support people on behalf of the consumer.

1.3 What other changes, both legislative and non-legislative, should we consider for supporting better and equitable complaint processes?

Providing 'feedback' opportunities for less 'formal' complaint mechanisms that still capture the needs for improvement but perhaps with less administrative cost?

Topic 2: Making the Act and Code more effective for, and responsive to, the needs of Māori

2.1 Did we cover the main issues about making the Act and the Code more effective for, and responsive to, the needs of, Māori?

Yes

2.2 What do you think about our suggestions for making the Act and the Code more effective for, and responsive to, the needs of Māori, and what impacts could they have?

This is a good start. We fully support all the recommend suggestions and agree that this will have positive impacts going forward.

We are highly supportive of the reference to the Treaty articles and commend the HDC for their thoughtfulness in this regard.

2.3 What other changes, both legislative and non-legislative, should we consider for making the Act and the Code more effective for, and responsive to, the needs of Māori?

We recommend that approaches incorporate these suggestions into business as usual for all persons, not just Maaori.

Topic 3: Making the Act and the Code work better for tāngata whaikaha | disabled people

3.1 Did we cover the main issues about making the Act and the Code work better for tāngata whaikaha | disabled people?

Yes

3.2 What do you think of our suggestions for making the Act and the Code work better for tāngata whaikaha | disabled people, and what impacts could they have?

We support the proposed changes.

3.3 What other changes should we consider (legislative and non-legislative) for making the Act and the Code work better for tāngata whaikaha | disabled people?

Include reference to UNCRoC and explicitly mention the rights of disabled children.

Topic 4 — Considering options for a right to appeal HDC decisions

4.1 Did we cover the main issues for considering options for a right of appeal of HDC decisions?

Yes

4.2 What do you think about our suggestions for considering options for a right of appeal of HDC decisions, and what impacts could they have?

We support the proposed changes

4.3 What other options for a right of appeal of HDC decisions, both legislative and non-legislative, should we consider?

If it were easier to make a complaint, feel supported and heard, and get an effective response/result, there would be less need to complain to the HDC. Currently there are either insufficient or ineffective other mechanisms to be heard.

The estimated level of complaints tells us that many people are unhappy with the way they are treated but have limited recourse to talk about this to someone who will take them seriously/be effective in getting results.

We recommend a process for aggregating complaints and following up with providers/services/areas of commonality to create meaningful change.

Topic 5 — Minor and technical improvements

5.1 What do you think about the issues and suggestions for minor and technical improvements, and what impacts could they have?

We support the proposed changes. We would support fines to increase to $100,000.

5.2 What other minor and technical improvements, both legislative and non-legislative, should we consider?

We support making it difficult for providers and researchers to undertake retrospective research at a population level where it is impossible to get informed consent for fear of breaching the Code.

There needs to be greater (not less!) ethical approaches taken to research. Better approaches to informed consent need to occur, not fewer. A way to address this issue is for the HDC to work with ethics committees to ensure clarity and ethical approaches across the whole of the country.

5.3 What are your main concerns about advancing technology and its impact on the rights of people accessing health and disability services?

We are concerned about AI – we do not think the use of AI is ethical or helpful in any way for disabled children or their families. We think AI should be banned in all instances related to health and disability. AI represents a significant threat to privacy and to data sovereignty, and is often inaccessible for disabled persons.

We do not see any need for AI in health and disability services. Services can be more than adequately provided by a person.

Health and disability services need to be provided by qualified human beings, not cheap bots.

We note that no disabled person has requested AI health services in place of a qualified human professional.

5.4 What changes, both legislative and non-legislative, should we consider to respond to advancing technology?

AI should be banned in health and disability services due to the inability of AI and related technologies to uphold human rights. HDC has already identified several risks; until technologies can adequately satisfy these stated risks they should not be used in health or disability services.