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To Ministry of Health.

Please find below DPA’s submission on Manatū Hauora Health of Disabled People Strategy.

For any further inquiries, please contact:

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# Introducing Disabled Persons Assembly NZ

**We work on systemic change for the equity of disabled people**

Disabled Persons Assembly NZ (DPA) is a not-for-profit pan-impairment Disabled People’s Organisation run by and for disabled people.

**We recognise:**

* Māori as Tangata Whenua and [Te Tiriti o Waitangi](https://www.archives.govt.nz/discover-our-stories/the-treaty-of-waitangi) as the founding document of Aotearoa New Zealand;
* disabled people as experts on their own lives;
* the [Social Model of Disability](https://www.odi.govt.nz/guidance-and-resources/guidance-for-policy-makes/) as the guiding principle for interpreting disability and impairment;
* the [United Nations Convention on the Rights of Persons with Disabilities](https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html) as the basis for disabled people’s relationship with the State;
* the [New Zealand Disability Strategy](https://www.odi.govt.nz/nz-disability-strategy/) as Government agencies’ guide on disability issues; and
* the [Enabling Good Lives Principles](https://www.enablinggoodlives.co.nz/about-egl/egl-approach/principles/), [Whāia Te Ao Mārama: Māori Disability Action Plan](https://www.health.govt.nz/publication/whaia-te-ao-marama-2018-2022-maori-disability-action-plan), and [Faiva Ora: National Pasifika Disability Plan](https://www.moh.govt.nz/notebook/nbbooks.nsf/0/5E544A3A23BEAECDCC2580FE007F7518/%24file/faiva-ora-2016-2021-national-pasifika-disability-plan-feb17.pdf) as avenues to disabled people gaining greater choice and control over their lives and supports.

**We drive systemic change through:**

* **Leadership:** reflecting the collective voice of disabled people, locally, nationally and internationally.
* **Information and advice:** informing and advising on policies impacting on the lives of disabled people.
* **Advocacy:** supporting disabled people to have a voice, including a collective voice, in society.
* **Monitoring:** monitoring and giving feedback on existing laws, policies and practices about and relevant to disabled people.

## United Nations Convention on the Rights of Persons with Disabilities

DPA was influential in creating the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD),[[1]](#footnote-2) a foundational document for disabled people which New Zealand has signed and ratified, confirming that disabled people must have the same human rights as everyone else. All state bodies in New Zealand, including local and regional government, have a responsibility to uphold the principles and articles of this convention. There are a number of UNCRPD articles particularly relevant to this submission, including:

* **Article 3: General principles**

The principles of the current Convention shall be:

1. Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons;
2. Non-discrimination;
3. Full and effective participation and inclusion in society;
4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
5. Equality of opportunity;
6. Accessibility;
7. Equality between men and women;
8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.
* **Article 4.3: Engaging with disabled people and our organisations on issues that affect us**
* **Article 25: Health**
* **Article 26: Habilitation and rehabilitation**

## New Zealand Disability Strategy 2016-2026

Since ratifying the UNCRPD, the New Zealand Government has established a Disability Strategy[[2]](#footnote-3) to guide the work of government agencies on disability issues. The vision is that New Zealand be a non-disabling society, where disabled people have equal opportunity to achieve their goals and aspirations, and that all of New Zealand works together to make this happen. It identifies eight outcome areas contributing to achieving this vision. There are a number of Strategy outcomes particularly relevant to this submission, including:

* **Outcome 3 – Health and wellbeing**

# The Submission

Improving the health and wellbeing of disabled people is vital if we are to live a good life. DPA hopes that the adoption of a Manatū Hauora Health of Disabled People Strategy  will contribute to improving the health and wellbeing of disabled people by looking at the health and wellbeing of disabled people holistically; setting targets, expectations and duties on health care providers; and measuring outcomes.

Manatū Hauora Health of Disabled People Strategy  needs to clearly set out the differences between disability and health; health and disability are not the same and require different services, supports and reasonable accommodations.

## Principles

DPA believes that there are several principles which need to underpin Manatū Hauora Health of Disabled People Strategy. The principles need to include: equity, accessibility, mana enhancing, fairness and they must link to the principles of the UNCRPD and those of Enabling Good Lives (EGL). DPA understands that the then Capital and coast district Health Board did some work with disabled people to align the EGL Principles to ensure their relevance and appropriateness to health and health settings.

## Manatū Hauora health of disabled people strategy and intersectionality

The Manatū Hauora health of disabled people strategy needs to explicitly address the intersectionality of demographics currently underserved by the health service. Disabled people are part of every other demographic, so Manatū Hauora health of disabled people strategy needs to address the health of disabled women, Tāngata Whaikaha Māori, disabled Pasifika, disabled Rainbow people as part of addressing all demographics underserved by our health system.

## Improving Health Outcomes for Disabled People

The primary purpose of Manatū Hauora health of disabled people strategy is to improve health outcomes for disabled people.

People with a learning disability have some of the poorest health outcomes of any demographic, so there is an urgent need for measures that specifically target this group. This is highlighted by the huge gap in life expectancy for people with a learning disability, with data[[3]](#footnote-4)[1] from the Ministry of Health showing that women with a learning disability have a life expectancy nearly 23 years less than the average for all NZ women, while men with a learning disability over 18 years less than the average for all NZ men.

This means that there needs to be specific measures in Manatū Hauora health of disabled people strategy to support improved health outcomes for those with an intellectual or learning disability without which there is a risk that this group of disabled people and their whānau will fall even further behind.

## UNCRPD Article 25

This Article affirms the right of disabled people to enjoy the highest standard of health without discrimination on the grounds of disability; and affords us the same range, quality and standards to free or affordable healthcare available to everyone.

Manatū Hauora Health of Disabled People Strategy  needs to ensure that it is meeting the rights set out in Article 25 as a minimum.

## Coverage

DPA believes that Manatū Hauora Health of Disabled People Strategy  must cover all areas of health as well as access to health services; this is very wide and needs to include issues such as parking at hospitals, training for staff, access to patient records and health information as well as public health initiatives, sexual health and reproduction services and funding.

## Access to Primary Healthcare

Initiatives to improve health literacy and access to primary health care for disabled people need to be resourced and prioritised. MoH have commissioned numerous reports highlighting this including:  [Ngā Kawekawe o Mate Korona](https://www.health.govt.nz/news-media/news-items/nga-kawekawe-o-mate-korona-impacts-covid-19-report) , and <https://www.health.govt.nz/publication/health-indicators-new-zealanders-intellectual-disability>

## Funding

Funding is a major issue for disabled people accessing health services. The Monitoring Report, My Experiences My Rights from the Donald Beasley Institute (DBI) expands on the issue of funding:[[4]](#footnote-5)

* The two-tiered support systems of MoH and ACC were perceived as generating two different health classes within the disability community;
* Inadequate funding under the MoH system was reported as negatively impacting the type, timeliness, quality, and length of treatment and services provided to Interviewees;
* A lack of funding for disability-specific services (for example, for Foetal Alcohol Spectrum Disorder);
* A lack of consistency, coordination and communication was experienced by Interviewees who received funding from either the MoH or ACC;
* Primary health care, allied health care, and mental health services were unaffordable for many Interviewees;
* Prescriptions, as well as transport and the cost of parking at health services were also reported as unaffordable.
* Some Interviewees were financially disadvantaged by the length of appointments they required. For example, being charged for double appointments because they had a greater number of complex issues to discuss with health professionals, or because they communicated using an alternative form of communication.

Manatū Hauora Health of Disabled People Strategy  needs to adequately deal with the funding issues listed above.

## Sexual and reproductive health

There are many barriers for disabled people needing to access sexual and reproductive health services. These barriers include: negative assumptions about disabled people’s fitness to be parents; the inaccessibility of fertility services; a lack of knowledge around gender affirming health care and disability.

Again, Manatū Hauora Health of Disabled People Strategy  needs to ensure full access to sexual and reproductive health services for disabled people to meet NZ’s obligations under the UNCRPD.

## Screening programmes

DPA is aware from our member’s feedback that health screening programmes are often inaccessible to many disabled people.

For example, the bowel cancer screening programme relies on people being able to read the pack sent in the mail, physically take the sample, and get to a post box to send it back. This entire process, or parts of it, are inaccessible to many disabled people meaning that they are unable to participate in the screening and they don’t have an early warning of bowel cancer.

Similarly, breast cancer screening and other women’s screening programmes are often inaccessible to disabled women, again meaning that they are not warned of potential life-threatening diseases.

Manatū Hauora Health of Disabled People Strategy must ensure equal access to screening programmes.

## Access to health information

Lack of access to health information for disabled people is an extremely broad issue. It ranges from being able to make appointments online, read patient notes, read appointment letters and health education material.

If health outcomes are to improve for disabled people, then Manatū Hauora Health of Disabled People Strategy  needs to address access to health information across the broad range of health information people need to be able to access.

## Mental Health Services for disabled People

Manatū Hauora Health of Disabled People Strategy needs to clearly state and measure disabled people’s access to and participation in mental health services.

## Framing

Manatū Hauora Health of Disabled People Strategy  needs to have outcomes posed in a positive state: where we want to get to. DPA is very keen to engage with Ministry of Health on framing-up outcomes in a positive way.

## Conclusion

DPA has put forward the key areas that we believe need to be included in Manatū Hauora Health of Disabled People Strategy. There are so many styles and ways of presenting such strategies that we can only guess how this one might look. We are eager therefore to assist the MoH with progressing Manatū Hauora Health of Disabled People Strategy to ensure that it brings about the desired improved health outcomes for disabled people.

1. United Nations. (2006). *United Nations Convention on the Rights of People with Disabilities.* Retrieved from: <https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf> [↑](#footnote-ref-2)
2. Office for Disability Issues. (2016). *New Zealand Disability Strategy.* Retrieved from: <https://www.odi.govt.nz/nz-disability-strategy/> [↑](#footnote-ref-3)
3. [1] Ministry of Health. Health Indicators for New Zealanders with Intellectual Disability <https://www.health.govt.nz/publication/health-indicators-new-zealanders-intellectual-disability> [↑](#footnote-ref-4)
4. https://www.donaldbeasley.org.nz/assets/projects/UNCRPD/Health-and-Wellbeing-Report/My-Experiences-My-Rights-A-Monitoring-Report-on-Disabled-People\_s-Experience-of-Health-and-Wellbeing-in-Aotearoa-New-Zealand-Long-Report.pdf [↑](#footnote-ref-5)