June 2024

**To Justice Select Committee**

Please find attached DPA’s submission on Privacy Amendment Bill 2023

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 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:**

**Rangatiratanga / Leadership**: reflecting the collective voice of disabled people, locally, nationally and internationally.

**Pārongo me te tohutohu / Information and advice**: informing and advising on policies impacting on the lives of disabled people.

**Kōkiri / Advocacy**: supporting disabled people to have a voice, including a collective voice, in society.

**Aroturuki / 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.

The following UNCRPD articles are particularly relevant to this submission:

* **Article 3 – General Principles**
* **Article 13 – Access to justice**
* **Article 21 – Freedom of expression and opinion, and access to information**
* **Article 22 – Respect for privacy**

## 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.

The following outcomes are particularly relevant to this submission:

* **Outcome 7 – Choice and Control**

# The Submission

DPA welcomes the opportunity to engage with the Justice Select Committee on the Privacy Amendment Bill.

**DPA supports the Bill being passed.**

DPA notes that the legislation will improve transparency for individuals around when their information is shared using the new information privacy principle 3A (IPP 3A).

From a disability perspective, it will also give further impetus to New Zealand’s adherence to Article 22 of the UN Convention on the Rights of Persons with Disabilities around the need to respect the privacy of disabled people:

*1. No person with disabilities, regardless of place of residence or living arrangements, shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence or other types of communication or to unlawful attacks on his or her honour and reputation. Persons with disabilities have the right to the protection of the law against such interference or attacks.*

*2. States Parties shall protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others.*[[3]](#footnote-4)

For disabled people, this is an important protection given that information about, for example, the nature of a person’s impairment, living arrangements, and other information can often be shared with multiple agencies.

Currently, individuals sign privacy/information sharing consents which effectively give government agencies, private companies and non-government organisations the ability to share relevant information with other entities.

However, many people do not realise the extent to which their information is informally shared and with whom, particularly when this is across multiple organisations/agencies. Enabling greater proactive disclosure by organisations every time that information about individuals is shared will ensure that people, including disabled people, have a better idea as to whom their information is shared with and for what purpose.

According to the European Digital Rights Network, data privacy in the digital age is an important consideration for disabled people due to the discrimination and exclusion faced by our community. This is the case as any potential leakage or misuse of data by organisations can have adverse consequences including direct or indirect discrimination against disabled people.[[4]](#footnote-5)

DPA knows of one instance where a disabled person recently found out that their health information had been shared between providers without their knowledge. This is why the legislation is positive as it will enable both disabled people and non-disabled people to know how their data is being shared and to request any shared information to see how it is being used, for what purpose and as to whether it needs correcting. It will also give individuals the right to request that any further information sharing is halted.

DPA also notes that the legislation has several technical amendments, and we have no issue with these.

We have no recommendations to make in respect of this Bill.

1. <https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-articles> [↑](#footnote-ref-2)
2. <https://www.odi.govt.nz/nz-disability-strategy> [↑](#footnote-ref-3)
3. <https://social.desa.un.org/issues/disability/crpd/article-22-respect-for-privacy> [↑](#footnote-ref-4)
4. <https://edri.org/our-work/why-privacy-is-particularly-crucial-for-people-with-disabilities/> [↑](#footnote-ref-5)