

September 2024

**To Ministry of Health**

Please find attached our submission on the End-of-Life Choice Act Review 2024

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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/$file/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 10 – Right to life**
* **Article 16 – Freedom from exploitation, violence and abuse**
* **Article 21 – Freedom of expression and opinion, and access to information**
* **Article 25 – Health**
* **Article 26 – Habilitation and rehabilitation**

# The Submission

DPA welcomes this opportunity to feedback to the Ministry of Health on the review into the End-of-Life Choice Act 2019.

A disabled person’s life has inherent value equal to a non-disabled person’s life. However, belief in the inherent and equal value of disabled people’s lives is not held by some people. Both historically and in current times, disabled people have been and are subject to eugenic policies, forced sterilisation, forced detention, institutionalisation, and inequality before the law.[[2]](#footnote-3)

Over the past three years since the EOLC Act became law on November 6, 2021, 929 New Zealanders have chosen to end their lives through voluntary euthanasia/assisted dying.

The context in which assisted dying is offered to disabled people is also an important consideration when dealing with this issue from a disability perspective.

There are issues around power and control, in particular the imbalance of power which exists between disabled people and non-disabled people.

According to 2021 research by the New Zealand Family Violence Clearinghouse, this imbalance of power and control is expressed in the fact that disabled people are disproportionately at greater risk of violence, neglect and abuse in New Zealand.[[3]](#footnote-4)

The same findings around the high rates of violence and abuse faced by disabled people are also evident in the Whanaketia final reports of the Royal Commission of Inquiry into Abuse in Care released in 2024.[[4]](#footnote-5)

The high risks of disabled people facing violence, abuse and neglect is one of the key reasons behind our concerns around disabled people being coerced, bullied and manipulated into assisted dying if the criterion for eligibility is extended.

DPA recognises and acknowledges that there are widely divergent views held about the ethics of voluntary euthanasia amongst our membership, disabled people in general as well as within the wider community.

Of primary concern for DPA is that disabled people are not subject to undue pressure to opt for assisted dying due to withdrawal of disability support, homelessness, exclusion from society or undervaluing of disabled people lives, while, at the same time, ensuring that people who do choose it and meet the criteria for doing so will have their choices respected.

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| **Recommendation 1:**  a.) That the current assisted dying regime which provides the right to people with a terminal illness who have less than six months to live to choose it remains in place with no further expansion in the criteria.  b.) That upholding the right of disabled people to live a good life with the support required take precedence over expansion of the remit of the EOLC Act.  c.) Only when disabled people in Aotearoa New Zealand have meaningful equity, participation and inclusion in society should the criteria for assisted dying be expanded. |

Below we outline our specific reasons for doing so within the context of recent government policy decisions which have impacted upon disabled people and the larger human and disability rights contexts.

**Q.1: Access to assisted dying**

* Do you think changes are needed to the eligibility requirements for a person to receive assisted dying?
* Do you think that changes to areas other than eligibility are needed to support access to assisted dying?

# DPA opposes any expansion in the current eligibility criterion beyond terminal illness of less than six months duration.

The risks to expanding eligibility for disabled people are manifold. Currently many disabled people live on low incomes[[5]](#footnote-6) and struggle with discrimination daily in terms of accessing food, housing, health, education/training, employment, decent incomes, information and community inclusion.[[6]](#footnote-7)

DPA is deeply concerned that this review of the Act comes at a highly stressful time for the disabled community in New Zealand because of the wide-ranging cuts to the public sector and consequential cuts to support and services which are vital to the inclusion and wellbeing of many disabled people in our communities.

Recent restrictions to disability support services (DSS), [[7]](#footnote-8) the associated announcement around transitioning DSS to the Ministry of Social Development,[[8]](#footnote-9) coupled with changes to eligibility for emergency housing[[9]](#footnote-10) and new welfare policy settings in the form of the traffic light system through Work and Income New Zealand have all created significant anxiety for many disabled people across Aotearoa[[10]](#footnote-11).

Through our members surveys DPA has heard that the cumulative impacts of these and other measures on disabled people have negatively affected the physical and mental health and wellbeing of many in our disability community.

Given all these detrimental changes arising from the current government’s policy settings, DPA is deeply concerned that any extension to EOLC may well see disabled people opting to end their lives through assisted dying simply because they cannot access the support they need to be included in their community. We are hearing that some disabled people may feel that they must end their lives this way due to implicit societal messaging that we are a ‘burden’ both to the state and our communities.

This messaging around disabled people being a burden to society has a long history which stems back to the discredited eugenic theories of the nineteenth century and even earlier. In the modern-day context, the increasing emphasis by successive governments on assessing the productive capacity of disabled people, especially in welfare policy through medically assessing the capacity of disabled people to work while disregarding the widespread discrimination against us in the labour market, has seen the right to access adequate income support eroded.

Reductions in income support and disability support entitlements in some of the countries with which New Zealand regularly compares itself with have led to catastrophic outcomes for disabled people.

In the United Kingdom, the former Conservative Government initiated an austerity policy from 2010 onwards which saw drastically reduced eligibility for disability supports, benefit payments, transport and housing introduced,[[11]](#footnote-12) leading to a dramatically increased rate of suicide (3 to 4 times higher) among disabled people there.[[12]](#footnote-13) In Canada, which has a more liberal assisted dying regime than New Zealand’s in the form of the Medical Assistance In Dying (MAID) scheme, there have been increasingly numerous reported instances of disabled people accessing euthanasia due to lack of medical care, disability supports or due to facing an inadequate standard of living.[[13]](#footnote-14)

**Q.2: Safeguards**

* Do you think the Act provides sufficient safeguards to ensure that people only receive assisted dying if:
* they are eligible (referenced in clauses 5, 13, 14, 15, 16, and 17 of the Act)
* they actively seek and consent to it (referenced in clauses 11, 12, 18, 23, 33, and 34 of the Act)
* they are competent to consent to it (referenced in clauses 5, 6, and 15 of the Act)
* this consent is provided without pressure from others (referenced in clauses 11 and 24 of the Act).
* Do you think any changes are needed to safeguards provided through the Act?

**DPA’s major concern is that the limited safeguards that currently exist in the EOLC Act against abuse could be eroded.**

We state this as even amongst disabled people who are supportive in principle of assisted dying being made more available, there is a growing sense of unease about what further changes could be made following the conclusion of this review in the current fiscal and political climate.

Some of these changes could include the ability for medical specialists/practitioners to initiate discussions about euthanasia - which is currently forbidden – being legalised.

Under Canada’s MAID scheme[[14]](#footnote-15), the fact that there is no prohibition on medical professionals raising euthanasia as an option led a disabled Canadian man to pursue legal action against health authorities who suggested that he take up assisted dying after they initially refused to pay for supports that would have enabled him to live at home. [[15]](#footnote-16)

Even in New Zealand, the Health and Disability Commissioner investigated the case in 2023 of a health professional who allegedly counselled a suicidal man around opting for assisted dying, something that is currently illegal on the basis that assisted dying does not rightly cover people already experiencing mental distress.[[16]](#footnote-17)

We are also concerned about the implications of the clause preventing disabled people with permanent, non-terminal impairments and health conditions from opting for euthanasia being removed from the legislation.

**For these reasons, DPA wants to see at all existing safeguards within the legislation retained.**

DPA also seeks an additional further safeguard be added - to require a cooling off period of seven days once approval has been given before proceeding with the euthanasia. This would bring NZ more in line with other comparable countries. A cooling off period would apply to everyone who successfully applies for assisted dying in that they would not be able to proceed with it until after a minimum of seven days have elapsed from time of approval.[[17]](#footnote-18)

DPA acknowledges that people who are successful can reverse their decision at any time and not proceed, but requiring a cooling off period would ensure that anyone who successfully applies would have one last opportunity to reflect on their decision as there is no coming back from death.

As we have highlighted above, the possibility that assisted dying could be extended to cover people with more conditions and the prohibition against health professionals initiating conversations around it being lifted concerns us very deeply, especially against the background where significant sections of New Zealand society still struggle with the concept of disability equity and human rights.

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| **Recommendation 2:** that the EOLC Act be amended to incorporate a ‘cooling off period’ applying for the first seven days after approval for assisted dying is given. |

**Q.3: Process to receive assisted dying**

* Do you think any changes are needed to the process to apply for and receive assisted dying?

DPA believes that it is essential that the EOLC process be completely differentiated from the process around end-of-life directives.

Recently, DPA made a submission to the Law Commission’s review on adult decision making. We recommended the need for protections to be afforded to people making end of life directives which determines how a person wishes to be treated both when and after they die.

There are clear pitfalls when people make requests for assisted dying as part of an end-of-life directive as for example, in Denmark and the Netherlands, people can state that they want euthanasia but may get to the point where they have the condition they did not want and then change their mind about assisted dying.

In the Netherlands, there was an internationally well reported case exactly along these lines where a doctor was prosecuted for not following correct procedure in the case of an older woman who requested assisted dying as her preferred means of death but failed to check (as legally required) that the woman had not changed her mind before doing so. This was the case as the woman, who lived with Alzheimer’s Disease, had also requested that she solely determine as to when the time was right for this to be done. [[18]](#footnote-19)

Before the woman was scheduled to be taken into dementia care, her doctor determined that the assisted death procedure be performed in line with her previously stated wishes and at least the first legal requirement of having her request legally and independently verified by two separate doctors was met. On the day the woman’s doctor appointed for the procedure, a sedative was placed in the woman’s coffee, she lost consciousness, only to fully awaken and protest that she had changed her mind while her daughter held her down so that the lethal injection could be administered.

We must not allow a similar situation to occur in New Zealand where people are forced into being euthanised based on an advanced directive.

This is why DPA wants to see all requests for assisted dying be kept separate from an end-of-life directive and instead follow the already established legal procedures for assisted dying.

DPA reiterates the importance of ensuring that if disabled people and their whanau request or decline medical treatment, that their choices be respected and implemented.

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| **Recommendation 3:** that assisted dying is not able to be legally chosen by people making end of life directives and has to be separately applied for through the legal processes established by the current EOLC Act. |

**Q.4: Oversight of assisted dying**

* Do you think changes are required to the roles and responsibilities of the entities established under the Act to oversee assisted dying (the SCENZ Group (clause 25), the End of Life Review Committee (clause 26), and the Registrar (assisted dying) (clause 27))?

DPA sees that there is no reason to change the roles and responsibilities of the entities established under the Act.

However, DPA recommends that all persons and bodies involved in the EOLC system mandatorily undertake disability responsiveness and awareness training as part of their work.

The requirement to complete disability responsiveness and awareness training would extend from members of the SCENZ Group, EOLC Review Committee and the Registrar through to front line health professionals registered to administer assisted dying services to people who request them.

Doing so would ensure that all personnel involved in the assisted dying process are aware of the sensitivity that the issue raises for the disability community and the need to administer the process in a way which respects the rights, dignity and autonomy of disabled people.

There is also a need to ensure that any person or organisation delivering disability responsiveness training provides a disability rights perspective versus a euthanasia perspective when doing so.

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| **Recommendation 4:** that all personnel involved in the assisted dying system be required to complete disability responsiveness and awareness education. |

**Q.5: Alignment with the wider health system**

* Do you think the assisted dying process aligns with other parts of the health system?

There is a clear need for proper government funding and support for palliative care options which enable terminally ill people and people with serious health conditions the choice to receive effective pain management alongside compassionate and high-quality care which enables a person to die a natural, dignified, pain-free, death and/or to live a better-quality life while managing serious illness.

People should not be faced with assisted dying as their only choice when faced by terminal illness when there are practical, workable solutions available, and which should be as equally well funded and resourced as the assisted dying service is.

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| **Recommendation 5:** that government properly fund and resource palliative care options for people with terminal illness and serious health conditions. |

**Q.5: Other feedback**

DPA recommends that this review investigate the Victorian assisted dying legislation as being a better model for New Zealand to follow given that it affords more robust safeguards to protect the interests of disabled people and people with health conditions.

We also reiterate our earlier recommendation that disabled people and disability organisations, including disabled person’s organisations, are involved in all facets of decision making around the assisted dying review.

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| **Recommendation 6:** that the Victorian assisted dying legislation is investigated as a better model for strengthening New Zealand’s EOLC Act. |

**Impacts on Tāngata Whaikaha Māori and ethnic communities**

It is important to note that not all cultures follow an individualised approach to life, with some taking a multigenerational approach and this includes many Māori who would never think about euthanising a loved member of their whānau.

This is reflected in the most recent New Zealand assisted dying statistics which show that lower percentages of Māori, Pacific and Asian peoples opt for this compared to Europeans who do so by a significant percentage. [[19]](#footnote-20)

This means that voluntary euthanasia remains a largely European concept that remains largely foreign to people from other non-European nations. It is essential that the views of Māori, Pacific and other ethnic communities are accorded due weight in terms of this review.

There is a fear that if assisted dying becomes being applied more widely that Tāngata Whaikaha disabled Māori will feel more pressure to go through assisted dying, something that will be concerning to many whānau throughout Aotearoa.

1. <https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-articles> [↑](#footnote-ref-2)
2. <https://nathaniel.org.nz/euthanasia/health-select-committee/15-bioethical-issues/bioethics-and-health-care/352-eugenics-in-new-zealand-synopsis-only> [↑](#footnote-ref-3)
3. <https://nzfvc.org.nz/news/new-research-shows-disabled-people-experience-higher-rates-violence> [↑](#footnote-ref-4)
4. <https://www.abuseincare.org.nz/reports/whanaketia> [↑](#footnote-ref-5)
5. In 2018, approximately 54% of all beneficiaries receiving benefits were disabled people. Kia Piki Ake Welfare Expert Advisory Group. (2019). Welfare system: statistics. Retrieved from <https://www.weag.govt.nz/background/welfare-system-statistics/#:~:text=Recipients%20with%20a%20health%20condition,Working%20For%20Families%20tax%20credits>). [↑](#footnote-ref-6)
6. <https://www.stats.govt.nz/reports/measuring-inequality-for-disabled-new-zealanders-2018> [↑](#footnote-ref-7)
7. <https://www.whaikaha.govt.nz/news/news/whaikaha-purchasing-rules-and-equipment-and-modification-services-ems-update> [↑](#footnote-ref-8)
8. <https://www.msd.govt.nz/about-msd-and-our-work/newsroom/media-releases/2024/transition-of-disability-support-services-to-msd.html#:~:text=15%20August%202024.,to%20MSD%20in%20coming%20weeks>. [↑](#footnote-ref-9)
9. <https://www.rnz.co.nz/news/political/524658/ministry-of-social-development-to-introduce-new-rules-for-cutting-emergency-housing-numbers> [↑](#footnote-ref-10)
10. <https://www.workandincome.govt.nz/on-a-benefit/obligations/traffic-lights.html#:~:text=The%20traffic%20light%20system%20lets,to%20contact%20us%20straight%20away>. [↑](#footnote-ref-11)
11. <https://citizen-network.org/library/disability-benefits-and-suicide.html> [↑](#footnote-ref-12)
12. <https://www.disabilityrightsuk.org/news/disabled-people-far-more-likely-die-suicide-non-disabled-people> [↑](#footnote-ref-13)
13. <https://jacobin.com/2024/05/canada-euthanasia-poor-disabled-health-care?ref=disabilitydebrief.org> [↑](#footnote-ref-14)
14. <https://www.justice.gc.ca/eng/cj-jp/ad-am/bk-di.html> [↑](#footnote-ref-15)
15. <https://www.ctvnews.ca/health/chronically-ill-man-releases-audio-of-hospital-staff-offering-assisted-death-1.4038841> [↑](#footnote-ref-16)
16. <https://www.nzherald.co.nz/nz/new-zealand-health-worker-under-investigation-for-raising-assisted-dying-with-a-suicidal-patient/TGZK3JCR5VBUNOAVGWDSBPOST4/> [↑](#footnote-ref-17)
17. <http://euthanasiadebate.org.nz/nz-end-of-life-choice-act-requires-no-cooling-off-period-unlike-usa-canada-australia/> [↑](#footnote-ref-18)
18. <https://www.bbc.com/news/world-europe-49660525> [↑](#footnote-ref-19)
19. <https://www.health.govt.nz/system/files/2023-07/registrar-assisted-dying-annual-report-2023-july23.pdf> [↑](#footnote-ref-20)