6 March 2018

To the Justice Select Committee

Please find attached DPA’s submission on the End of Life Choice Bill. We would like to thankfully acknowledge the contribution and input of Nelson Curry in preparing this submission.

DPA wish to appear before the Select Committee to speak to our submission.

Disabled Persons Assembly NZ Inc.

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**Introducing Disabled Persons Assembly NZ**

The Disabled Persons Assembly NZ (DPA) is a pan-disability disabled person’s organisation that works to realise an equitable society, where all disabled people (of all impairment types and including women, Māori, Pasifika, young people) are able to direct their own lives. DPA works to improve social indicators for disabled people and for disabled people be recognised as valued members of society. DPA and its members work with the wider disability community, other DPOs, government agencies, service providers, international disability organisations, and the public by:

* telling our stories and identifying systemic barriers
* developing and advocating for solutions
* celebrating innovation and good practice

**End of Life Choice Bill**

The Disabled Persons’ Assembly NZ (DPA) believe a disabled person’s life has as much value as a non-disabled person’s life. However, the equal value of disabled people’s lives is not a view held by everyone. Both historically and in current times, disabled people have been and are subject to: government-led eugenic policies, forced sterilisation, forced detention, institutionalisation, and inequality before the law and in policy and practice. For some members of the community fears about the potential danger of the proposed legislation to disabled people are rooted in living memory. DPA are concerned this Bill in its current state reinforces the stigmatisation of disabled people and their lives. There is a diversity of views on End of Life Choice (EoLC) Bill within the disability community.

Although we do not have a position on the wider issue of euthanasia, as an organisation we have responded to the Bill from a disability rights perspective, while holding the position of the equal value of disabled people’s lives as a central tenant of our work.

Introduced into the current inequitable social context, we believe that the EoLC Bill conflicts with this value. The Bill has the potential to inhibit or endanger the realisation of good and equal lives for disabled people.

Our key areas of concern within the Bill relate to:

* The scope of the Bill and eligibility of people to pursue physician-assisted dying;
* Issues of consent and coercion raised by the Bill;
* The inadequate number and type of safeguards within the process of approval for physician-assisted dying;
* Inadequate processes for ongoing monitoring and reporting on the practice of physician-assisted dying; and
* Likelihood of future liberalisation of eligibility criteria.

Disabled people’s social and well-being status is demonstrably worse than their non-disabled peers across: income, educational achievement, health and social participation indicators. Disabled people lack access to the financial and social resources of their peers, as well as to properly resourced government supports which enable them to live good lives. DPA are concerned that under this proposed legislation disabled people may pursue or be coerced into physician-assisted dying because their quality of life is affected by this lack of resources. DPA believe that the New Zealand government must address its own role in policy setting and practice and engage comprehensively with disabled people before legislating the eligibility of disabled people for physician-assisted dying.

In addition to recognising a need for more disability support for our community, we note that palliative care is an equally under-resourced area of health care. The proposed law is intended to be used when “the best that palliative care can offer” is no longer – in the eyes of the individual – considered enough to alleviate “suffering”. We do not consider that New Zealanders are currently being offered “the best” of either palliative care or disability support. A choice between continuing to live with inadequate care and/or support and ending one’s life is a choice uniquely shaped by difficult and inequitable circumstances for disabled people.

**The scope of the Bill and eligibility of people to pursue physician-assisted dying**

DPA are concerned about the eligibility for physician-assisted dying under the EoLC Bill. Specifically, clause 4 of the Bill is missing any definition of “grievous and irremediable medical conditions”, and what conditions it refers to. The above term is not medical, has no common use in everyday language, and has been incorrectly adopted into this Bill from other jurisdictions.

DPA do not believe a medical practitioner could reasonably or consistently reach a conclusion about the eligibility of people with non-terminal medical conditions. The wording of the EoLC Bill leaves open the possibility that people may qualify for physician-assisted dying merely on the grounds that they are disabled, including where the provision of better social, economic and disability-specific supports and opportunities would easily and vastly improve their quality of life.

DPA believe that the clinicians who would have responsibility for approving any patients for physician-assisted dying, do not, as a group, have appropriate knowledge or training around disability perspectives, supports or an understanding of disability rights. This means that clinicians may be unreasonably biased and make assumptions about the experience and value of disabled people’s lives when considering cases of physician-assisted dying.

**We strongly recommend the eligibility under clause 4 – “grievous and irremediable medical conditions” – be completely removed from the End of Life Choice Bill.**

**We further recommend that palliative care is significantly better resourced and the “best [it] can offer” is made widely available to terminally ill New Zealanders.**

**We recommend that all clinical education in New Zealand is broadened to include a disability rights perspective and the disability community are involved in the development of curriculum and educational resources.**

**We strongly recommend that, should this Bill progress further into law, clinicians involved in any aspect of physician-assisted dying processes have extensive training in disability rights and must consult with disability experts.**

**We strongly recommend that, should this Bill progress further into law, disabled people are consulted in depth at every point of review and their voices are taken into account as a group who are uniquely affected under this proposed legislation.**

**Possibility of future liberalisation of eligibility criteria under euthanasia legislation**

Internationally, there has been instances of liberalisation of eligibility criteria under euthanasia laws, such that people who would not have been eligible under original legislation have over time become eligible. For example, in Belgium, where euthanasia was initially legalised in 2002 for adults over 18, the law was modified in 2013 to include minors under 18.[[1]](#footnote-1)

Liberalisation of eligibility criteria could be extremely concerning, given the aforementioned issues for disabled people.

**We strongly recommend that, should this Bill progress further into law, disabled people are consulted in depth at every point of review and their voices are taken into account as a group who are uniquely affected under this proposed legislation.**

**Issues of consent and coercion**

DPA are concerned about legal consent and the coercion of disabled people that could arise under the proposed legislation.

Issues of legal consent are already a highly problematic under New Zealand’s legislative framework. Disabled people do not have equality before the law in other respects, nor do they have equitable access information, communication or to supported decision-making resources.

Disabled people are already more likely than their non-disabled peers to experience abuse and violence. Disabled people and their whānau have also repeatedly spoken of the lack disability supports and strain that the lack of supports puts of disabled people and the people around them. This lack of support has even been used in court as a defence for people charged with the killing of their disabled family members.

DPA believe that the possibility of coercion from people who support their disabled members, is of very real concern.

**We strongly recommend that adequate and resourced support of disabled people and their family members in the community, including adequate provision of social, economic and disability-specific supports and opportunities, access to information, communication and supported decision-making, should be implemented ahead of considering legislating for physician-assisted dying.**

**We strongly recommend that, should this Bill progress further into law, disabled people are consulted in depth at every point of review and their voices are taken into account as a group who are uniquely affected under this proposed legislation.**

**Safeguards**

DPA are concerned about the robustness of safeguards, processes and practices that could sit underneath physician-assisted dying legislation. In particular we are concerned that there is inadequate provision for clear information, communication and supported decision-making to disabled individuals around physician-assisted dying.

DPA are concerned about how the proposed EoLC legislation intersects with current mental health as well as general health and disability legislation, policy and practice in New Zealand, including issues around:

* Compulsory treatment of people who are experiencing an “...abnormal state of mind… (whether of a continuous or an intermittent nature), characterised by... disorders of mood... of such a degree that it… poses a serious danger to the health or safety of that person...” as they relate to the Mental Health (Compulsory Assessment and Treatment) Act, section 2; and
* People’s rights under the Health and Disability Commissioner (Code of Health and Disability Services Consumers’ Rights) Regulations 1996, schedule (2).

DPA also note the inconsistency with section 63 of the Crimes Act 1961, which prohibits a person from consenting to the infliction on death upon himself or herself.

**We strongly recommend that, should this Bill progress further into law, disabled people are consulted in depth at every point of review and their voices are taken into account as a group who are uniquely affected under this proposed legislation.**

**Inadequate processes for reporting and monitoring**

DPA believe that the EoLC Bill, if it was to progress further into law, is significantly lacking in reporting and monitoring processes.

At minimum, to provide transparency, and as a matter of good practice and public interest, clause 21(5) would have to be amended to require the Ministry of Health to publicly report on essential aggregated qualitative and quantitative information about how physician-assisted dying was being put into practice.

To best monitor how legislation would be implemented, amendments to clause 22 would need to ensure that regulations, processes and practices of the registrar, review committee and implementation by relevant health boards and organisations were included in the review of the operation of the Act.

**We strongly recommend that, should this Bill progress further into law, disabled people are consulted in depth at every point of review and their voices are taken into account as a group who are uniquely affected under this proposed legislation.**

**We strongly recommend that, should this Bill progress further into law, processes be put into place where both the disability community and government are each able to monitor uptake and impact of assisted dying in the community.**

**DPA’s recommendations**

**We recommend the eligibility under clause 4 – “grievous and irremediable medical conditions” – be completely removed from the End of Life Choice Bill.**

**We recommend that all clinical education in New Zealand is broadened to include a disability rights perspective and the disability community are involved in the development curriculum and educational resources.**

**We strongly recommend that, should this Bill progress further into law, clinicians involved in any aspect of physician-assisted dying processes have extensive training in disability rights and must consult with disability experts.**

**We strongly recommend that adequate and resourced support of disabled people and their family members in the community, including adequate provision of social, economic and disability-specific supports and opportunities, access to information, communication and supported decision-making, should be implemented ahead of considering legislating for physician-assisted dying.**

**We strongly recommend that, should this Bill progress further into law, disabled people are consulted in depth at every point of review and their voices are taken into account as a group who are uniquely affected under this proposed legislation.**

**We strongly recommend that, should this Bill progress further into law, processes be put into place where both the disability community and government are each able to monitor uptake and impact of assisted dying in the community.**

DPA supports the End of Life Choice Bill submission from the New Zealand Human Rights Commission

1. Belgian Senate votes to extend euthanasia to children – http://www.bbc.com/news/world-europe-25364745 [↑](#footnote-ref-1)