

Submission to the Committee Inquiry on the Voluntary Assisted Dying Bill 2021

Shaun Bickley



Dear Committee members,

I am writing to express my **opposition** to the Voluntary Assisted Dying Bill 2021, from a **human rights and disability rights perspective**. In other countries with euthanasia laws, disabled people are pressured into euthanasia or even outright forced. In this submission, I will outline that this bill takes insufficient measures to protect disabled people in Queensland, and that the legislation has failed to include disabled people in a meaningful way.

About me

I am a developmentally disabled voter residing in the Maiwar electorate. I have over a decade of professional experience with disability rights advocacy internationally and have previously worked on health care advocacy in the United States, where euthanasia is legal. I have also presented on the history of eugenics and euthanasia to audiences in North America, Australia, and Europe.

Report incomplete and misleading

The Queensland Law Reform Commission's *A legal framework for voluntary assisted dying* covers an expansive 888 pages. It was therefore surprising to see the abuses of euthanasia omitted and the perspective of disabled people excluded from the report. You will not see, for instance, that:

- A 2015 study in the *New England Journal of Medicine* revealed that in the Belgian region of Flanders, doctors self-reported hastening the deaths of 1.7% of all people who received euthanasia in 2013 *without any request* from the patient for euthanasia. ¹
- Similarly, a 1991 compilation of studies published in the *Lancet* showed that between August to December of 1990, euthanasia was performed without request (before it was legal) on .8% to 1.6% of all deaths (not all euthanasia deaths) in the Netherlands within that time. ²

The report also fails to mention any high-profile incidents of coercion or forced euthanasia in any country. In presenting the stated legal protections of those countries and then omitting instances where they failed, the report misrepresents those legal protections as functional. For instance:

¹ Chambaere, K., Vander Stichele, R., Mortier, F., Cohen, J., & Deliens, L. (2015). Recent trends in euthanasia and other end-of-life practices in Belgium. *The New England Journal of Medicine*, 372(12), 1179-1181.

² Van Der Maas, P., Van Delden, J., Pijnenborg, L., Looman, C., & Central Bureau of Statistics, T. (1991). Euthanasia and other medical decisions concerning the end of life. *The Lancet*, 338(8768), 669-674.

- In the Netherlands, Dr. Marinou Arends [had an elderly woman held down and euthanised](#) after the woman refused euthanasia three times. Despite facing criminal prosecution, the Dutch Supreme Court cleared her of wrongdoing in April 2020.
- In the United States, [Kate Cheney was one of the first people euthanised under Oregon's Death with Dignity law](#), in 1999. She had early-onset dementia. Her daughter Erika took her to four different professionals who prescribed euthanasia. The fourth noted that “[Cheney’s] choices may have been influenced by her family and that her daughter Erika may [have been] coercive,” but authorised euthanasia anyway.
- Canada recently expanded Medical Assistance in Dying to disabled people without terminal illness, giving them a right to euthanasia but not palliative care. [Canada's Disability Inclusion Minister has noted it is already easier to get euthanasia than a wheelchair in some parts of the country](#). The bill was passed over the [opposition of disability advocates and organisations, physicians, bioethicists, and legal scholars](#).

By withholding this information, the Law Reform Commission decreases the likelihood that legislators will be able to properly craft safeguards to address these possibilities and presents a falsely rosy view of how these laws operate. Instead of a balanced legal guide, the report reads as a promotional pamphlet for euthanasia. It eschews even using the word euthanasia—despite that being the subject matter of the report’s material and widely utilised in the laws of other countries—in favour of the euphemism “voluntary assisted dying.” Such euphemisms obscure euthanasia’s historical connection to eugenics, and allows this issue to be cast purely as one of personal choice rather than the state-sanctioned eugenic removal of disabled people from society.

Moreover, the report cites the fact of their consultation with disabled people and communities without including our points and criticisms, falsely presenting the document as something crafted *with* disabled people instead of *over* disabled people.

Nothing about us without us

For most of the history of Western civilisation, decisions about disabled people have been made by non-disabled people, often without the inclusion of disabled people at all. Since the 1990s, disabled people globally have demanded to be included in policies about disabled people, encapsulated in the slogan “nothing about us without us.”

While not every person with disability has a terminal illness, every person with a terminal illness has a disability. By definition, the proposed euthanasia legislation exclusively affects disabled people; more, the people at risk of being coerced under the law are also disabled people.

Yet the people designing and advising on the law, and the people who would oversee its implementation, are overwhelming non-disabled people. Part 8 of the Draft bill outlines the Voluntary Assisted Dying Review Board. All of the identified

roles for Review Board members are medical or legal professionals; they might incidentally be disabled, but there is nothing in the law that requires them to be.

Medical professionals are not the arbiters of disabled people's human rights or lived experience. If a review board established for women's health included no women but instead gynaecologists, it would be rightly decried as ridiculous: simply being an expert on women's anatomy does not qualify someone to make determinations on women's human rights. A review board established for Aboriginal health should likewise contain Aboriginal people, or better yet be done in partnership with Aboriginal people. Why, then, it is acceptable for a board meant to, among other things, protect disabled people's human rights and prevent coercion not to include disabled people among its members?

Any proposed review board must include disabled people. Moreover, no disabled person should be expected to represent all disabled communities. The review board should include multiple disabled people representing diversity of race, indigeneity, gender and gender identity, class, sexual orientation and expression, nationality, language, geographic location, and type of disability, all of which impact how an individual disabled person experiences medical care. This would likely expand the review board beyond 5 to 9 members, however, it would make for a more equitable and competent review board able to parse disability issues and better connect with our communities.

On coercion

As mentioned previously, Kate Cheney was one of the first people euthanised under Oregon's law in 1999. Her daughter Erika initiated the request and was refused three times; even the practitioner who granted the request noted she was coercive.

In 2008 in Oregon, a woman named Tami Sawyer moved in with a man named Thomas Middleton. [Within a month he was abruptly euthanised with her as the sole heir; within two days of his death she sold his estate for \\$200,000.](#)

The proposed Queensland euthanasia law ameliorates some of these concerns by requiring the person to make the request themselves. This does not prohibit the possibility of coercion, however.

- What mechanisms prevent the next Erika Cheney or Tami Sawyer from doctor-shopping on behalf of a vulnerable person?
- A refused request must be logged, but will other doctors have access to this information?
- What stops a family member from informally contacting multiple medical professionals in order to find one more ideologically aligned, and more interested in the family's wishes than the individuals?
- If a non-family member does not disclose being an heir, what mechanisms exist to alert the review board or any other authority of fraud or abuse?

It is not just family members who practice coercion. In Canada, [hospital staff have repeatedly pressured Roger Foley to accept euthanasia as treatment, going so far as to tell him how much money he's costing the hospital to stay alive.](#)

[Dr. Corinna Iampen was immediately offered euthanasia as she recovered from a spinal cord injury.](#) At the time, euthanasia was not yet legal for people who were not terminally ill.

These are things that were not supposed to happen, but they have. Like Canada, health care costs are defrayed by the state; the government also pays for the supports of NDIS participants. Disabled people are expensive. There's no way around that. Many medical and legal professionals see us as the sum of our medical conditions (as evidenced by the fact that this bill posits medical and legal professionals as the experts on disability and disabled people), and as such some of them will perceive us as taking money and resources that would be better spent on others. So long as we live in a society with ableism where disabled people are seen as less worthy of care, these pressures on disabled people will continue regardless of the law.

Equity Concerns

Beyond coercive pressure from individuals, the system exerts pressure on disabled people too. There are *significant* barriers to accessing the Disability Support Pension, such as residential requirements and steeper disability requirements than for other systems. Even the NDIS requires significant documentation from medical professionals, requiring out of pocket costs, and many disabled people can't keep up with the work requirements under Centrelink because they are disabled.

In creating a low-barrier form of euthanasia, this legislation forces disabled people who don't have the monetary or cognitive resources to keep fighting for disability supports to simply choose the path of least resistance and allow the state to euthanise them. This is already happening in Canada, where the country's Disability Inclusion Minister has noted [it's easier for many people to get euthanasia than to get a wheelchair.](#)

In Belgium, a man named Nathan Verhelst was granted euthanasia in 2013 after medical complications from gender transition surgery and rejection from his family. In the United States, Linda Fleming was the first person euthanised in Washington state, in 2009. She was divorced, bankrupt, and unable to find work.

This system creates two tiers of health care, wherein non-disabled people with depression get treatment while disabled people with depression get euthanasia. It also encourages people from marginalised communities; people experiencing hardship, poverty, rejection, and depression; people who don't want to be burdens to their family; vulnerable people; and many others to accept euthanasia because other options to improve their lives aren't available or aren't convenient to the state. It's certainly much easier to allow individual people to access euthanasia than it is to combat transphobia, racism, and ableism, or to make sure that vulnerable people's needs are understood and met.

Can we expect more Aboriginal and Torres Strait Islander people to access euthanasia? More people in poverty? More immigrants and refugees? After all, they need 10 years residency before they will even be considered for the Disability

Support Pension. It is the people marginalised at the most points of intersection who will suffer the most from this legislation.

Conclusion

For these reasons, I urge the committee **not to pass Voluntary Assisted Dying legislation** at this time. While the legal research on this issue has been lengthy, it has not been comprehensive or neutral and has omitted perspectives from disabled communities which are not important to its authors.

There needs to be **acknowledgment of the risks this legislation places on disabled people**, and you should work in partnership with disabled communities to address these issues. Even a law that works as intended 98.4% of the time is an unacceptable sacrifice when you or your loved ones are part of that 1.6% that can expect to be euthanised without request.

It is my contention that you should not give disabled people a moving walkway to euthanasia while maintaining barriers to disabled people's continued life and existence in the community. However, if you choose to move forward, it should be with the inclusion of disabled people in the drafting of the bill, in discussion of safeguards, and on any review committees that might be formed. Nothing about us without us.

I am available for further questions.

Sincerely,

Shaun Bickley
Disability Advocate