

Dear members,

I'm writing to you in your capacity as members of the Health, Social Care and Sport Committee, currently taking evidence on the Assisted Dying for Terminally Ill Adults (Scotland) Bill. My name is Ben Colburn, and I am Professor of Political Philosophy at the University of Glasgow. One of my core areas of published research is the ethics of assisted dying, and in particular the implications of assisted dying laws for people with disabilities.

I have listened with interest to the recording of yesterday's session on long-term conditions and disability. I was impressed by the sincerity of the people who gave evidence. However, I am concerned that a number of claims were made which – though no doubt well-intentioned – are refuted by relevant evidence in this field. I think it is regrettable that the session did not involve wider representation, for example from disability advocates who support the proposed bill, and from Scotland's rich community of academics who have researched this topic and produced a substantial evidence base. I imagine those lacunae don't make your complex job easier.

I am writing now to offer two sources which I hope might be useful to you. The first is a peer-reviewed research paper which summarises all relevant published studies on the relationship between disability and assisted dying, and evaluates the degree to which they support or undermine disability-based arguments about whether assisted dying should be legalised or not. My key research findings are that:

1. People with disabilities are not generally opposed to assisted dying laws.
2. Assisted dying laws do not harm people with disabilities.
3. Assisted dying laws do not show disrespect for people with disabilities.
4. Assisted dying laws do not undermine healthcare for people with disabilities.

The attached paper details the substantial peer-reviewed evidence base for each of these findings. I am also attaching a short policy summary, based on that paper, which I co-authored with colleagues in the Philosophers Consortium on Assisted Dying in Scotland.

I hope this is useful to you. I, and my colleagues at the Consortium, would be delighted to assist you further, if there is anything we can do to help your deliberations. (E.g. we have further policy summaries and links to research papers on our website at <https://www.pcads.org/pcads-policy-papers/>, including international comparisons, and an analysis of the effects of assisted dying laws on palliative care provision.)

In any case I would be grateful if you would publish this as part of the committee's correspondence. I know that would reassure people who might otherwise be concerned about the one-sidedness of yesterday's hearing.

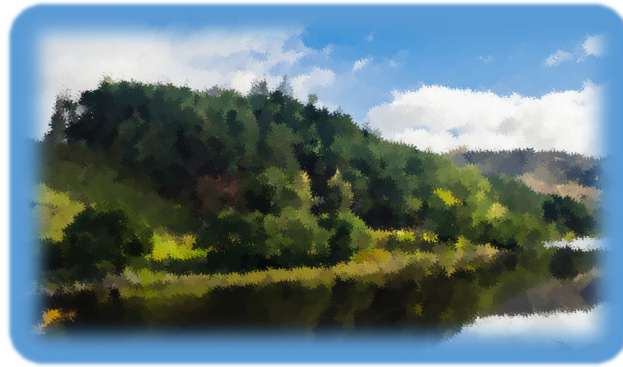
Thanks, indeed, for the very important work you are doing for the people of Scotland!

Yours sincerely,

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PCADS Policy Paper: Disability and Assisted Dying Laws

Some people oppose legalization because of fears about the effects that assisted dying laws might have on people with disabilities. This policy paper identifies several arguments of this nature, and summarises the relevant evidence and academic research. It concludes that **assisted dying laws should not be opposed on the basis of the views of people with disabilities, their welfare, respect, or concerns about healthcare provision.** In fact, respect for disabled people's autonomy is a further reason to legalize assisted dying.

This conclusion is supported by four key findings:

1. People with disabilities are not generally opposed to assisted dying laws.
2. Assisted dying laws do not harm people with disabilities.
3. Assisted dying laws do not show disrespect for people with disabilities.
4. Assisted dying laws do not undermine healthcare for people with disabilities.

I. People with disabilities are not generally opposed to assisted dying laws.

Some opponents of assisted dying claim that there is consensus amongst people with disabilities that assisted dying should be prohibited.

In reality, this picture of unanimity isn't borne out by the evidence. A recent survey of 140 disability rights organisations in the UK indicated that only 4% explicitly oppose assisted dying laws. A substantial majority either remain silent (84%) or explicitly endorse neutrality (4%) on assisted dying.¹ The position of Disability Rights UK is representative:

The issue of assisted dying divides Disabled people. It is a complex issue on which Disabled people hold different, passionately held views. Disability Rights UK respects those different views.²

People with disabilities themselves 'do not oppose assisted dying with one voice ... at a minimum the views of the wider community are more mixed than the views of their leaders', as prominent disability rights campaigner Professor Tom Shakespeare says.³ Polling suggests strong support for assisted dying laws amongst people with disabilities, at roughly the same level as in the general population.

¹ Box, G. & Chambaere, K. (2021) [Views of disability rights organisations on assisted dying legislation in England, Wales and Scotland: an analysis of position statements](#). *Journal of Medical Ethics* 47 (2021): 264.

² Disability Rights UK (2015). Rights and justice. <https://www.disabilityrightsuk.org/rights-and-justice>, accessed 24 September 2023.

³ Shakespeare, T. (2016) [Just what is the disability perspective on disability?](#) *Hastings Center Report* 46: 31-32.

It is therefore wrong to oppose assisted dying laws on the grounds that people with disabilities oppose them. The majority of people with disabilities do not, and those opposing legislation on the grounds that they speak for the disabled community should be met with scepticism.

2. Assisted dying laws do not harm people with disabilities.

Opposition to assisted dying laws often focuses on the ideas that such laws are especially harmful to people with disabilities, that safeguards inevitably fail, and that there will be a 'slippery slope' from apparently rigorous protections to loose and harmful practices.⁴

Again, these fears aren't borne out by the evidence. Systematic reviews have examined the uptake of assisted dying amongst vulnerable people, including people with disabilities in countries where assisted dying has long been legal. One found that 'there is no clear evidence of a slippery slope' of higher or increasing uptake in vulnerable groups.⁵ Another concluded that the hypothesis that people with disabilities are disproportionately impacted 'does not seem to be borne out', and that

In no jurisdiction was there evidence that vulnerable patients have been receiving euthanasia or physician-assisted suicide at rates higher than in the general population... data do not indicate widespread abuses of these practices.⁶

This conclusion is reinforced if we look directly at individual studies. One study of Oregon and the Netherlands found no evidence of heightened risk for people with disabilities and non-terminal conditions, and 'no current factual support for so-called slippery-slope concerns'.⁷ Another from Belgium found no disproportionate impact on people with disabilities, nor an especial increase in requests made or granted to people with disabilities.⁸ In total, ten studies have explored this question, looking at data from all jurisdictions where assisted dying is legal. None have found evidence of harm, disproportionate impact, or a slippery slope.

3. Assisted dying laws do not show disrespect for people with disabilities.

Another concern sometimes expressed is that assisted dying laws are disrespectful, by communicating that disabled lives are less worth living and reinforcing negative stereotypes about people with disabilities.⁹ Relatedly, it is sometimes worried that assisted dying laws lead to people with disabilities being manipulated or pressured into choosing to die.¹⁰

⁴ e.g. Bickenbach, J. (1998) '[Disability and life-ending decisions](#)'. In M. P. Battin et al. eds. *Physician assisted suicide: Expanding the debate* (Routledge): pp. 123-132; Gill, C.J. (2010) '[No, we don't think our doctors are out to get us: Responding to the straw man distortions of disability rights arguments against assisted suicide](#)' *Disability and Health Journal* 3: 31-38.

⁵ Rietjens, J.A.C. et al. (2012) '[Medical end-of-life decisions: does its use differ in vulnerable patient groups? A systematic review and meta-analysis](#)'. *Social Science and Medicine* 74: 1282-1287.

⁶ Emanuel, E.J. et al. (2016) '[Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada, and Europe](#)', *JAMA* 316:79-90.

⁷ Battin, M.P. et al. (2007). '[Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in "vulnerable" groups](#)', *Journal of Medical Ethics* 33: 591-597.

⁸ Dierickx, S. et al. (2015) '[Comparison of the expression and granting of requests for euthanasia in Belgium in 2007 v 2013](#)'. *JAMA Internal Medicine* 175: 1703-6.

⁹ E.g. Krahn, G.L (2010) '[Reflections on the debate on disability and aid in dying](#)', *Disability and Health Journal* 3,51-55; Campbell, J. (2019). '[Disabled people like me fear legal assisted suicide: It suggests that some lives are less worth living](#)' *BMJ Opinion* blog.

¹⁰ E.g. Hendry, M. et al. (2012) '[Why do we want the right to die? A systematic review of the international literature on the views of patients, carers and the public on assisted dying](#)' *Palliative Medicine* 27: 13-26.

This line of thought is mistaken about the core of the argument *for* assisted dying laws. The idea is not that some lives are less worth living, but that each individual must decide what makes their life worth living, whether it remains so in their own eyes, and what to do about it.¹¹ This principle of equal respect for individual autonomy is what Baroness Hale evoked when she said

It is not for society to tell people what to value about their own lives ... If we are serious about protecting autonomy we have to accept that autonomous individuals have different views about what makes their lives worth living.¹²

Moreover, this line of argument against assisted dying itself shows disrespect for people with disabilities. As Christopher Riddle puts it:

Denying people with disabilities the right to exercise autonomy over their own life and death says powerfully damaging things about the disabled, their abilities, and their need to be protected.¹³

Some people with disabilities themselves voice the objection that it is disrespectful to deny them assisted dying in the name of ‘protection’. Participants in one study ‘often expressed concern that disabled people may be especially vulnerable to being denied end-of-life choices because of the way they are devalued in society’, and that ‘people with disabilities may be denied choice because they are assumed incompetent to make their own decision’.¹⁴

One challenge concerns cases where an individual’s cognitive functioning is severely impeded. It is important to draw a sharp line between those who have decision-making capacity, and those who do not and so cannot give informed consent. Most jurisdictions do not permit assisted dying for those who lack decision-making capacity. It is crucial to note that whether someone has decision-making capacity is independent of whether they have a disability, including an intellectual disability. This means that a blanket prohibition is the wrong way to respond to the challenge of impeded cognitive functioning. That strategy relies on pejorative stereotypes and ignores ways that appropriate support can facilitate autonomous decision-making for people with intellectual disabilities.

So, there is strong reason to think that assisted dying laws do not show disrespect to people with disabilities. In fact, the opposite is true.

4. Assisted dying laws do not undermine healthcare for people with disabilities.

Some people have worried that assisted dying laws will undermine other aspects of the healthcare system, for example by undercutting support for e.g. palliative care,¹⁵ or undermining trust between doctors and patients.¹⁶

¹¹ Colburn, B. (2020) [Autonomy, voluntariness, and assisted dying](#). *Journal of Medical Ethics* 46: 316-319.

¹² quoted in Delamothe, T. (2009) [Assisted dying: what’s disability got to do with it?](#) *BMJ* 339:b3446.

¹³ Riddle, C.A. (2017) [Assisted Dying & Disability](#). *Bioethics* 31: 484-9.

¹⁴ Fadem et al (2003) [Attitudes of People with Disabilities towards Physician-Assisted Suicide Legislation: Broadening the Dialogue](#). *Journal of Health Politics, Policy and Law* 28: 977-1001

¹⁵ Teno J. & Lynn J. (1991) [‘Voluntary active euthanasia: The individual case and public policy’](#), *Journal of American Geriatric Society* 39: 827–830; Miller R. (1992) [‘Hospice care as an alternative to euthanasia’](#) *Law, Medicine & Health Care* 20: 127–132.

¹⁶ E.g. reports in Silvers A. (1997) ‘Protecting the innocents: People with disabilities and physician-assisted dying’ *Western Journal of Medicine* 166: 407–409.

In fact, assisted dying laws tend to go hand in hand with greater support for palliative care, financially and otherwise.¹⁷ And it is reassuring that in jurisdictions where assisted dying is legal, we see very high levels of trust in doctors, and the best communication between doctors and their patients concerning end-of-life decisions.¹⁸ In the UK, polling suggests that few patients would come to distrust their doctors if assisted dying were legalized.¹⁹

Conclusions

People sometimes oppose assisted dying laws because of understandable concerns about their possible effects on people with disabilities. However, those concerns aren't borne out in the evidence. In fact proper respect for people with disabilities requires recognising their autonomy in this key domain, and not withholding it in the name of 'protection'. So, this policy paper has two key recommendations:

- 1. Assisted dying laws should not be opposed on the basis of the views of people with disabilities, their welfare, respect, or concerns about healthcare provision;**
- 2. Respect for people with disabilities speaks in favour of assisted dying laws where we can determine that decision-making capacity is present.²⁰**

Ben Colburn, Michael Cholbi, Michael Gill, Joseph Millum, and Glen Pettigrove
Philosophers' Consortium on Assisted Dying in Scotland, October 2023

¹⁷ Cholbi M. (2018) '[Palliation and Medically Assisted Dying: A Case Study in the Use of Slippery Slope Arguments in Public Policy](#)', in D. Boonin ed. *Palgrave Handbook of Philosophy and Public Policy* (Palgrave Macmillan): pp. 691-702; Smets T et al (2010) '[Legal euthanasia in Belgium: Characteristics of all reported euthanasia cases](#)' *Medical Care* 48: 187–192.

¹⁸ Van der Heide A. et al. (2003) '[End-of life decision-making in six European countries: descriptive study](#)' *The Lancet* 362: 345–350; Dobscha SK et al (2004) '[Oregon physicians' responses to requests for assisted suicide: A qualitative study](#)' *Journal of Palliative Medicine* 7: 451–461.

¹⁹ Graber MA et al. (1996) '[Patients' views about physician participation in assisted suicide and euthanasia](#)' *Journal of General Internal Medicine* 11: 71–76.

²⁰ This briefing is an updated version of '[Policy Briefing: Disability and Assisted Dying Laws](#)', *Policy Scotland* 2021. It is based on B. Colburn '[Disability-based arguments against assisted dying laws](#)', *Bioethics* 36 (2022): 680-686, where you can find references to further evidence.