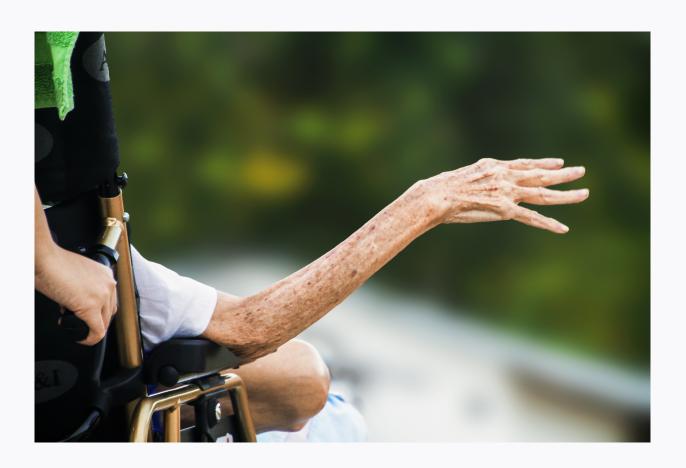


An Equal Opportunity to Live: Analysis of 'The Impact of the Terminally III Adults (End of Life) Bill II'

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Executive Summary

The Department of Health and Social Care, together with the Ministry of Justice, has produced an assessment of the impact of the Terminally III Adults (End of Life) Bill on people with protected characteristics as set out in the Equality Act 2010.

The equality IA claims to take 'a neutral stance on the substantive issue of assisted dying' but, instead of focusing on equal protection for the lives of people with protected characteristics, the equality IA promotes the idea of 'equal opportunity' for people to end their own lives. What is missing here is the importance of equality of access to suicide prevention.

Disabled people have highlighted the experience of having their lives devalued by others and even being told that they would be 'better off dead'. Providing people who face such prejudice with access to the means of ending their own life not only fails to mitigate this 'substantial disadvantage' but could lead to it having lethal consequences.

The equality IA notes but does not give sufficient weight to the prevalence of abuse of disabled people, of women and of elderly people. People with these characteristics are at much greater risk of ending their life under the Bill as a result of pressure or coercion by another. They are also at much greater risk of ending their lives as a result of social pressure or of barriers in accessing the means to live and thrive. The provisions of the Bill are a threat to the equal opportunity to live.

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Introduction

The Department of Health and Social Care has produced two impact assessments of the Terminally III Adults (End of Life) Bill (the Bill) and a related Memorandum. The first is principally concerned with financial costs and cost reductions of implementing the Bill ('financial IA'). [1] A second impact assessment, cosponsored by the Ministry of Justice, concerns the impact on equality law ('equality IA'). [2] Alongside these two, the Department Health and Social Care and the Ministry of justice have also issued a Memorandum on whether the Bill is compatible with the European Convention on Human Rights ('Memorandum'). [3] This is the second of three papers on the three documents. [4]

Equal opportunity and equal protection: Ending of life as a 'benefit'

The equality IA considers 'the impact of this bill on people who share each of the 9 protected characteristics as set out in section 4 of the Equality Act 2010, as well as additional dimensions'. [5]

The equality IA states several times that 'government has taken a neutral stance on this bill... and on the substantive issue of assisted dying'. [6] Nevertheless, it frames the equality impact assessment as though there were a consensus that providing people with the means to take their own life was, unequivocally and uncontroversially, a benefit and perhaps even a healthcare benefit. [7] The only disbenefits given

serious consideration are the risk of someone ending their own life who did not have decisionmaking capacity and the risk of someone being coerced by another person into ending their own life.

If capacity is present and coercion by another person is absent, and other eligibility requirements are fulfilled, access to lethal drugs to end one's own life is assumed to be a benefit. The equality assessment is thus framed primarily in question-begging terms as 'equal opportunity for accessing assisted dying' [8] with the caveat 'subject to the person having mental capacity'. [9]

This assumption is very different from the approach in the financial IA which sought to avoid assessing whether the intentional shortening of life was a benefit or disbenefit:

'Given that the intent of this Bill is to provide lawful assistance to terminally ill adults to end their life, and that this provision may be considered a benefit or disbenefit depending on individual views and circumstances, impacts have not been quantified in QALY terms'. [10]

What is missing from the analysis of either document is any consideration of suicide prevention and the right to protection of people who are in danger of taking their own life. [11] Suicide prevention strategies are based on the ethical conviction that 'every suicide is a tragedy' [12] and that suicide can be prevented. This includes suicide by people who are chronically or terminally ill. [13]

There is no single cause or motivation for people seeking to end their lives, nor does suicide affect only one sector of society. However, there are things that can be done to help, both at the individual level and at the social level. One element of suicide prevention is limiting the opportunities for people to end their lives or to access to the means of doing so. This is reflected in practical measures such as the removal of carbon monoxide from the gas supply [14], restrictions on the volume of non-prescription pain medication that can be sold in a single transaction [15], or physical barriers preventing access to places associated with suicide. [16]

There is a relationship between mental ill health and suicide, in that mental health problems can make people more vulnerable to suicide. The treatment of mental health problems can reduce suicidal feelings in some patients. However, not everyone who attempts suicide has a diagnosed mental illness and most people with a mental illness have never attempted suicide. It is not only mentally ill people who are vulnerable to suicide.

Equality concerns in light of suicide prevention

Outside the context of the Bill, equality concerns will and should focus not on equality of access to the means of ending one's own life but equality of access to the means of being prevented from ending one's own life. [17] Opportunities for ending one's own life are not benefits that should be maximised by equality of opportunity. They are dangers or vulnerabilities, that should be minimised or mitigated.

The equality IA states that the Bill 'would have impacts on eligible, terminally ill adults by giving them a choice to request, and be lawfully provided with, assistance to end their own lives'. [18] It does not acknowledge that an impact of the Bill would be that the lives of eligible patients would thereby be cut short by weeks or months

(or years in the case of misdiagnosis), and that within the terms of the Bill such decisions could have been made unwisely, or under the influence of social pressure or financial hardship, or under the influence of mental illness. The equality IA assumes that greater choice is a benefit without considering the adverse impact of that choice in relation to loss of life.

A clear example of this assumption is seen in the equality IA discussion of assisted suicide in Switzerland. The practice in Switzerland is not subject to specific statutory regulations, nor is it confined to people with a terminal illness. It is not delivered as part of healthcare services but by private organisations. [19] These organisations term the practice 'assisted suicide' [20] or 'accompanied suicide'. [21] Until 2009 the Swiss Government included these deaths in the national suicide figures [22], and while they are now counted separately they are officially designated 'assisted suicide'. [23]

The practice of travel to a third country for the purpose of obtaining assistance in suicide in a relatively unregulated environment is sometimes termed 'suicide tourism'. [24] It is a controversial activity even among those who are in favour of 'assisted dying' (that is, of assisted suicide or euthanasia) [25] and most jurisdictions where assisted dying is legal restrict it to citizens and/or residents. It is thus a mistake to characterise those who have sufficient income to travel abroad for assistance in suicide as enjoying a benefit that is not 'accessible to those from a lower socioeconomic background'. [26] Rather, those who have easier access to this form of suicide are thereby more vulnerable to suicide. That is not a benefit.

The equality IA notes that while the Bill (in Clause 2(3)) provides that a person is not to be considered terminally ill only because they are a disabled person or person with a mental disorder

(or both) [27], it will cover someone who possesses those characteristics if they also have a terminal illness. [28] This is an important admission.

The impact of the Bill on disabled persons and on people with a mental health condition thus needs to be considered. However, in the equality IA this equality concern is framed primarily in terms of disabled people facing 'barriers in accessing this voluntary assisted dying service' [29] and this represents a 'risk' of disabled people being 'put at a substantial disadvantage'. [30] This is construed as being similar to barriers to access in 'other healthcare service areas'. [31]

There is no recognition in the equality IA that the provisions of the Bill aim at ending the life of a patient and that providing lethal drugs for the purpose of ending life is not like 'other healthcare service areas'. The provisions of the Bill lead directly to loss of life-years (as recognised, at least to some extent, in the financial IA) [32] and engage with the patient's right to life (as recognised, at least to some extent, in the Memorandum). [33] The first equality concern in relation to the Bill should therefore be how it affects the right to life of protected groups, not least of people with a disability, older people, and people with mental health conditions.

The 'substantial disadvantage' that is faced daily by disabled people in this regard, and that has been highlighted by disabled people who are critical of the Bill, is the undervaluing of people's lives and the assumption that disabled people would be 'better off dead'. [34] It adds insult to injury to imagine that what is needed to redress this pervasive bias in society is greater access to the means of ending life, and the specific promotion of assisted suicide as an option for disabled people.

It is striking that, in the view of the equality IA, the role of independent advocates in relation to people with learning difficulties is not primarily to protect them from subtle pressures to opt to end their lives, but is 'to provide support and advocacy on end of life care, including access to assisted dying'. [35] This makes it sound as if an independent advocate might see their role as encouraging a person with learning disabilities to consider taking their own life. Such an approach contrasts with the concern expressed by Dan Scorer of the learning disability charity Mencap:

'As I mentioned earlier, our concern is how those discussions around assisted dying are initiated. For many people with a learning disability who are terminally ill and in an incredibly vulnerable position, doctors are very important and influential figures. Having a doctor come to you and say, 'What do you think about assisted dying —is that something you might want to consider?' could move them towards or into potentially accepting a course of action that they had never considered before.' [36]

Capacity and coercion by another person

The equality IA highlights two safeguards included in the Bill 'to protect people who may be more vulnerable'. [37] These are the requirement for capacity and the exclusion of coercion by another person. The requirement of capacity is essential to the Bill as it is essential to any procedure requiring consent. If the person does not have capacity to make this decision then the ending of life is not truly voluntary and the action of supplying lethal drugs for this purpose is complicit in the non-voluntary ending of life. However, while capacity to make a decision, as set out in the Mental Capacity Act 2005, is a necessary condition, it is not sufficient to ensure that the decision is free from undue influence.

The inadequacy of mental capacity as the test for human freedom in the context of ending life is shown by the need for consideration of coercion as a distinct requirement. A decision could pass the minimum threshold of mental capacity and yet the decision might still be shaped in large part by a coercive relationship. Protection of the vulnerable thus requires that the Bill not only exclude those who lack mental capacity but also exclude those whose decision has been affected by pressure or coercion from another person.

The equality IA acknowledges that some protective categories, most notably people with disabilities, women, and older people are more likely to be victims of coercive behaviour or abuse:

Disabled people are also twice as likely (compared to non-disabled people) to be victims of domestic abuse which includes coercive behaviour'. [38]

Women are more likely to be victims of domestic abuse (1.6 million women compared to 712,000 men in the year ending March 2024), which can manifest as physical, emotional and sexual abuse, and can include coercive behaviour. [39]

Elderly people, who are in all other jurisdictions the main recipients of assisted dying, are often dependent on those who care for them, putting them at increased risk of elder abuse, although we have no data on this in the context of assisted dying. Pre-pandemic data (2018) from the Crime Survey for England and Wales estimates 210,000 adults between 60 and 74 years experienced domestic abuse. [40]

As domestic violence and coercive behaviour typically occur within the context of intimate relationships, it is arguable that this issue is relevant for the protected characteristic of marriage or civil partnership, but this possibility is not identified in the equality IA.

Acknowledging that coercion has an adverse impact on people with protected characteristics, the equality IA lists the various provisions of the Bill that seek to mitigate these. First and foremost in the Bill is the requirement for a declaration, by the person, that they have not been coerced or pressured by any other person into making the decision. [41] The co-ordinating doctor, an independent doctor and the review panel must then state that they are satisfied that the declaration 'was not coerced or pressured by any other person' [42], the patient must then make a second declaration with which again the coordinating doctor must be satisfied. [43] These processes are buttressed by mandatory training in detecting coercion or pressure [44], and by the creation of a new criminal offences of inducing a person to make a first or second declaration 'by dishonesty, coercion or pressure'. [45]

An obvious flaw in these safeguards is that someone may feel pressured into saying that they have not been pressured or they may not be aware that they have been pressured. Where patients are not fully aware then it is very challenging for this to be uncovered by doctors who would meet the patient on only few occasions, still less by a social worker, a lawyer or a psychiatrist who would meet the patient on only one occasion, or possibly not meet the patient at all.

The protection given by the new criminal offences within the Bill may be assessed by comparison with the 2015 law against controlling or coercive behaviour in the context of domestic abuse. [46] Estimates for the prevalence of this offence range from 572,000 to 774,000 but of these less that 25,000 were reported to the police in 2018/2019 and of reported cases only 6% were charged – which is lower than other forms of domestic abuse (such as stalking or assault). [47] The lower levels of reporting and charging (even in comparison to other forms of domestic abuse

which are themselves underreported) is in part due to a difficult of detecting and evidencing this behaviour. [48]

The prevalence of coercive behaviour is such that it will certainly be present in the population that is eligible for VAD services. The relevant question for an equality impact assessment is how effective the provisions in the Bill will be in preventing victims of coercive control from dying under the influence of that coercion. The experience of other sectors is that evidencing coercion and controlling behaviour is extremely challenging and that the great majority go unreported.

The Government claims that the Bill 'would apply equally to all sexes and there is no strong evidence that it would have a substantial differential impact on any sex.' [49] However, on the contrary, there is very strong evidence that coercive and controlling behaviour is widespread, that it is underreported, that it is more challenging to identify and address than other forms of domestic abuse, and that it disproportionately affects women. Insofar as women are more commonly subject to coercive and controlling behaviour than men in other contexts then there is very strong reason to think that women would be in greater danger of ending lives under this Bill as a result of pressure or coercion by another person. [50]

Pressure from society

The equality IA alludes to the concern raised by the Equality of Human Rights Commission, that coercion can occur not only through the direct actions of another person but also because of structural pressures, for example, through inadequate health or social care, lack of financial resources or social attitudes that lead people to feel that they are a burden to others or that they do not have a real choice. [51] Such pressures may be felt more by those who are elderly and by

those with disabilities, who are both represented disproportionately among those who are eligible to be given the means of ending their lives.

The equality IA states that the safeguards of the Bill aim to 'mitigate the risk of undue influence on any person seeking assistance in accordance with the bill'. [52] However, the references to pressure or coercion in the Bill are only to pressure or coercion 'by any other person'. [53] There is nothing in the Bill that would prevent the provision of means to end life to someone who was under the influence of social pressure. Someone who seeks death under the Bill under pressure, for example, because of the lack of home care, or due to financial concerns, or the concern that they were a burden to others, could still satisfy the Bill's criteria of eligibility and of mental capacity. It is not simply that these social pressures might be hard to detect. Even if such pressures were overt and were known to the coordinating doctor, this would not prevent the person being eligible for access to assistance to end their own life.

The equality IA concludes that 'Although we are unable to quantify the extent of any impact, the bill may have a positive impact on those from lower socioeconomic backgrounds by making assisted dying available without incurring cost.' [54] This positive assessment fails to acknowledge that those from 'lower socioeconomic backgrounds' will frequently experience inequality in relation to access to healthcare, including access to palliative care and mental health services, and will frequently experience inequality in accessing other goods and services. [55] Such socioeconomic inequalities in access to health and social support exacerbated inequalities experienced by people who are also older, or who also live with disability, or who also experience mental health problems.

Where someone faces barriers in accessing the means to live and thrive, providing them with increased access to end life 'without incurring cost' will not be a benefit to them but a threat to their life. The provisions of the Bill are a threat to the equal opportunity to live.

Getting Help

If the issues discussed here affect you or someone close to you, you can call Samaritans on 116 123 (UK and ROI), visit their website https:// www.samaritans.org/ or contact them on jo@samaritans.org.

If you are reporting or writing about a case of death by suicide, whether assisted or nonassisted, please consult media guidelines https:// www.samaritans.org/about-samaritans/mediaguidelines/ on how to do so responsibly.

Endnotes

- [1] <u>Terminally III Adults (End of Life) Bill (as amended in the House of Commons Public Bill Committee): impact assessment</u> ('financial IA'), Department of Health and Social Care (DHSC) / Ministry of Justice (MoJ) (14 May 2025).
- [2] <u>Terminally Ill Adults (End of Life) Bill: equality impact assessment</u> ('equality IA'), DHSC / MoJ (14 May 2025).
- [3] <u>Terminally III Adults (End of Life) Bill: ECHR memorandum</u> ('Memorandum'), DHSC / MoJ (2 May 2025).
- [4] The other two being: Ending Life as Cutting Costs: Analysis of 'The Impact of the Terminally Ill Adults (End of Life) Bill I'; and A Human Right to Suicide Prevention: The Impact of the Terminally Ill Adults (End of Life) Bill III.
- [5] Equality IA, pp.1-2.
- [6] Ibid., page 20.
- [7] *Ibid.*, page 6.
- [8] Ibid., page 14.
- [9] *Ibid.*, page 19.
- [10] Op. cit., Financial IA, para. 92, emphasis added.
- [11] Jonathan Herring, <u>The Right to be Protected</u> <u>From Committing Suicide</u>, Oxford: Hart Publishing, 2022.
- [12] World Health Organization. <u>Preventing suicide: A global imperative</u>. Geneva: World Health Organization, 2014, p.2.

- [13] D.A. Jones, 'Assisted dying and suicide prevention', Journal of Disability & Religion 22.3 (2018): 298-316.
- [14] M. Nordentoft, P. Qin, K. Helweg-Larsen and K. Juel, <u>'Restrictions in means for suicide: an effective tool in preventing suicide: the Danish experience'</u>. *Suicide and Life-Threatening Behavior*, 37.6 (2007): 688-697.
- [15] J.S. Lim *et al.* 'Association between means restriction of poison and method-specific suicide rates: a systematic review'. AMA Health Forum 2.10 (2010).pp. e213042-e213042).
- [16] R. Merli and A. Costanza, <u>'Effectiveness of physical barriers to prevent suicide by jumping from high-risk bridges: From an integrative review to a northern Italian province's paradigm'</u>. *Preventive medicine reports*, (20240 102745.
- [17] B.L. Mishara and D.N. Weisstub, <u>'Is Suicide Prevention an Absolute?'</u> Crisis. 2018 Sep;39(5):313-317. doi: 10.1027/0227-5910/a000568. PMID: 30354747; B.L. Mishara and D.N. Weisstub, *Practical Ethics in Suicide: Research, Policy and Clinical Decision-Making Paperback* Cambridge: Cambridge University Press, 2024.
- [18] Op. cit., Equality IA, p. 4.
- [19] Op. cit., Financial IA, para 7.4.
- [20] EXIT. FAQ: 'What Does Physician Assisted Suicide Mean?'.
- [21] Dignitas, 'Accompanied suicide'.
- [22] D.A. Jones, 'Euthanasia, Assisted Suicide, and Suicide Rates in Europe', Journal of Ethics in Mental Health, 11.5 (2022), p.7.
- [23] Federal Statistical Office. Cause of Death Statistics 2014: Assisted Suicide and Suicide in

<u>Switzerland</u>. Neuchatel: Federal Statistical Office. 2016.

- [24] D. Sperling. *Suicide Tourism*, Oxford: Oxford University Press, 2019.
- [25] On the ambiguity of the term 'assisted dying' see D.A. Jones, <u>Defining the Terms of the Debate:</u> <u>Euthanasia and Euphemism</u>, Oxford: The Anscombe Bioethics Centre 2021; D.A. Jones, 'How (not) to define 'assisted dying', Journal of Medical Ethics, published Online First: 29 January 2025, doi: 10.1136/jme-2024-110415; Jones DA, 'Assisted dying' is assisted suicide and / or <u>euthanasia'</u>, JME Forum, 31 January 2025.
- [26] Op. cit., Equality IA, p. 17.
- [27] *Ibid.*, p. 6.
- [28] Ibid., p. 6.
- [29] *Ibid.*, p. 6.
- [30] *Ibid.*, p. 7.
- [31] Ibid., p. 6.
- [32] Op. cit., Financial IA, para. 253.
- [33] Op. cit., Memorandum, p. 28.
- [34] See for example the documentary by Liz Carr, <u>'Better off dead'</u>.
- [35] Op. cit., Equality IA, p. 11.
- [36] Transcript of the <u>Public Bill Committee</u> <u>Debates</u> on the Bill, col. 273.
- [37] Op. cit., Equality IA, p. 7.
- [38] Ibid., p. 8.
- [39] *Ibid.*, p. 12.
- [40] Ibid., p. 14.

- [41] Terminally III Adults (End of Life) Bill (as amended in Public Bill Committee), clause 7(3).
- [42] *Ibid.*, clause 9(2), 10(2), 15(2).
- [43] *Ibid.*, clause 17(4).
- [44] *Ibid.*, clause 7(7).
- [45] *Ibid.*, clause 31.
- [46] Serious Crime Act 2015, Section 76, see Crown Prosecution Service: <u>'Controlling or Coercive Behaviour in an Intimate or Family Relationship'</u>.
- [47] Home Office, <u>Review of the controlling or coercive behaviour offence</u>, London: Home Office 2021.
- **[48]** C. Bishop and V. Bettinson. 'Evidencing domestic violence*, including behaviour that falls under the new offence of 'controlling or coercive behaviour'.' *The International Journal of Evidence & Proof* 22.1 (2018): 3-29.
- [49] Op. cit., Equality IA, p. 12.
- [50] F. Mackenzie, <u>Safeguarding women in assisted dying</u>, The Other Half, 2024.
- [51] Written evidence submitted by the Equality and Human Rights Commission (ADY0317) to the House of Commons Health and Social Care Committee on Assisted Dying / Assisted Suicide (January 2023).
- [52] Op. cit., Equality IA, p. 14.
- [53] *Op. cit.*, Terminally III Adults (End of Life) Bill (as amended in Public Bill Committee), clause 1(2), etc.
- [54] Op. cit., Equality IA, p. 17.

[55] R. Cookson, C. Propper, M. Asaria and R. Raine, 'Socio-economic inequalities in health care in England'. *Fiscal studies*, 37.3-4, (2016): 371-403.



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