“Assisted Dying & Disability”*

Christopher A. Riddle

The Department of Philosophy / Applied Ethics Institute
Utica College, NY
cariddle@utica.edu

DRAFT

Please do not cite, duplicate, or distribute without author’s permission.

INTRODUCTION

In 2011, Schüklenk et al. authored a report as members of the Royal Society of Canada Expert Panel on End-of-Life Decision-Making that arrived at at least two major conclusions. While there was an emphasis on the need for an increase in palliative care

---

*Acknowledgements: I would like to thank audiences at San Diego State University and Utica College. I am especially grateful for comments by Richard Arneson, Adam Cureton, and Randall Curren. Thank you to Joshua Turner for research assistance.
services, the major finding was that Canadians should have access to assistance in dying.¹

In my mind, this report is unrivaled in its scope, care, and precision. The findings of the report, while impressive, failed to engage with the experience of disability in a thorough manner. What follows is my attempt to explore the implications of such an endorsement for people with disabilities and to argue that assisted dying ought to be permissible.

In a very brief section of the report titled “Disability”, Schüklenk et al. state that

[t]here is a dearth of empirical literature describing end of life care, palliative care and attitudes towards assisted suicide and euthanasia concerning disabled populations in Canada. It is fair to say that there is no consensus among this group.²

Though I find myself somewhat sympathetic to this statement, I can only agree with it partially. While academic literature has a multitude of perspectives on this issue, the public attitude amongst mainstream disability rights scholars, activists, and more generally, people with disabilities, is relatively consistent in its conclusion: assisted dying should not be permitted.³ The main justifications focus on what its permissibility says about people with disabilities, and the harm that people with disabilities might be subjected to as a result of its legalization.

² Ibid., 11.
³ The Coalition of Provincial Organizations of the Handicap (COPOH) might appear to depart from what I claim is the dominant view with their support for Sue Rodriguez in Rodriguez v. British Columbia (Attorney General) 107 D.L.R. (4th) 342 (1993). That said, Bickenbach provides a reasonable justification for this in Jerome Bickenbach, “Disability and Life-Ending Decisions,” in Physician Assisted Suicide: Expanding the Debate, ed. Margaret P. Battin et al. (New York: Routledge, 1998), 125, when he states that “COPOH was in an awkward position. In its factum it argued that there is a real danger that ‘negative stereotypes and attitudes which exist about the lack of value and quality inherent in the life of a person with disability’ may be the primary cause of the suicidal wish”. In actuality he suggests, despite initial appearances, COPOH does not drastically depart from the views of Not Dead Yet.
Although originating in the U.S., the disability advocacy group Not Dead Yet is perhaps one of the loudest and most influential disability rights groups internationally. Their position is clear when they state that assisted dying is the “ultimate expression of society’s fear and revulsion regarding disability”\(^4\). More importantly, such groups tend to share the sentiment that

‘safeguards cannot be established to prevent abuses resulting in the wrongful death of numerous disabled persons, old and young.’ Indeed, the only true safeguard against abuse ‘is that assisted suicide remain illegal and socially condemned for all citizens equally’.\(^5\)

Other prominent activists and theorists echo this sentiment. Gregor Wolbring, for example, states

We believe that as long as disabled people are viewed as a suffering entity, as an object of charity, as a life not worth living, we cannot accept the broadening of our access to death. It is not without a reason that studies show that the support for euthanasia is greatest among the healthy and young and lowest among the elderly and frail and the ones with the least control over their lives.

We believe that the legalization of euthanasia will force people to be euthanized in a misbegotten effort to do the right thing: save their loved ones from financial ruin, remove family members from the care taker role, cease to be a burden on the state.\(^6\)

Carol Gill extends this concern when she suggests that this harm is not limited to what people with disabilities might inflict upon themselves. Instead, the negative attitudes towards people with disabilities are perpetuated to such an extent that harmful stereotypes become ingrained in healthcare professionals who, with no ill-intent, do tremendous harm

---

\(^5\) Ibid.
to the disabled. She suggests that physicians and health care professionals who know little about the lives of disabled people might do tremendous harm.\(^7\)

Margaret Somerville echoed this sentiment in the media by stating, “[m]any seriously harmful consequences from legalizing euthanasia could far outweigh any benefits it might have”\(^8\).

I set out to explore these critiques and to conclude that despite these criticisms, assisted dying ought to be permissible. I arrive at the conclusion that if we respect and value people with disabilities, we ought to permit assisted dying. I do so in the following manner. First, I examine recent changes in legislation that have occurred since the aforementioned report. I suggest that these changes are likely to only strengthen opposition to assisted dying from disability rights activists and people with disabilities. Second, I explore the opposition to assisted dying that focuses on risk and the vulnerability of people with disabilities. Here I suggest that this risk ought not to be of special concern. Third, I focus on respect for people with disabilities and in particular, respect for their autonomy and decision-making abilities. Ultimately, I conclude that upholding this respect requires the legalization of assisted dying, rather than the denial of access in a misguided effort to protect people with disabilities.

**LEGISLATION**

\(^7\) Carol J. Gill, “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, no. 1 (2010): 35.

In February of 2015, the Supreme Court of Canada ruled in *Carter v. Canada*, that it was impermissible to deny competent adults the right to seek assistance in dying.\(^9\)

The decision, more specifically, stated the following:

> We conclude that the prohibition on physician-assisted dying is void insofar as it deprives a competent adult of such assistance where (1) the person affected clearly consents to the termination of life; and (2) the person has a grievous and irremediable medical condition (including illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition.\(^10\)

Of special importance here is not only the fact that the Supreme Court suggested that it was wrong to deny anyone the right to seek assistance dying, but that the decision approximated legislation in other progressive jurisdictions around the world.

A closer look at other laws might help clarify precisely what is at stake here. In the Netherlands, the Dutch Act of 2002 specifies, amongst other things, that a physician will not be prosecuted if they are found to have acted with due care. Part of what it means to have acted in such a manner is to “be satisfied that the patient’s suffering was unbearable, and that there was no prospect for improvement”\(^11\).

Section 3.1 of the Belgian Act states that the patient must be “in a medically hopeless condition of continuous unbearable physical and mental suffering that cannot be alleviated and that is resulting from a serious and incurable disorder caused by illness or accident”\(^12\).

A final example can be given from Luxembourg. Sections 2.1.2 and 2.1.3 of the Luxembourg Act state that

---

\(^10\) Ibid.
\(^12\) Ibid., 58.
[t]he request should be made voluntarily and carefully, it should be repeated and should not result from external pressure. The patient’s medical situation must be hopeless and the patient must report constant and unbearable mental or physical suffering with no prospect of improvement.\textsuperscript{13}

If we contrast these examples with legislation from the United States, fundamental differences become obvious. In Oregon for example, the person must be a capable adult with a terminal illness (less than 6 months to live).\textsuperscript{14} Similarly, the Death with Dignity Act in Washington State requires that the individual “has been determined by the attending physician and consulting physician to be suffering from a terminal disease, and who has expressed his or her wish to die”\textsuperscript{15}. Finally, recent legislation in Vermont suggests that a patient must have a “‘[t]erminal condition’ [which] means an incurable and irreversible disease which would, within reasonable medical judgment, result in death within six months”\textsuperscript{16}.

The most important difference between these two groups of legislation is the shift in Canada and European countries away from the terminal, towards the incurable. In \textit{Carter v. Canada}, terminal illness was rejected as a necessary condition for granting the request of assisted suicide. Legislation in the Netherlands, Belgium, and Luxembourg are similar in nature. However, of those States in the U.S. that permit assisted dying, the overwhelmingly dominant view is that terminal illness is a requirement.

This shift is especially important for disability rights activists, because no longer do people have to be facing imminent death to seek assistance dying. Instead, individuals

\textsuperscript{13} Ibid.
\textsuperscript{14} ORS 127.800-897
\textsuperscript{15} RCW 70.245.020 s.1.
\textsuperscript{16} Act 39 (18 V.S.A. Chapter 113).
can judge their lives to be so dominated by suffering so as to warrant ending their lives, sometimes drastically prematurely.

Legislation in Luxembourg distinguishes between kinds of suffering and suggests that the suffering need not be physical in nature, but can be solely psychological. This is to suggest that if one has become disabled and wishes to end their own life because of how little value they perceive their life possessing (even though they experience no physical pain or shortened life expectancy), they can do so.

If disability rights activists were concerned that people with disabilities suffering from a terminal illness might hasten the death experience because of social pressure, surely this shift becomes even more problematic as the scope of those who can be pressured into seeking assistance ending their own life has expanded greatly. All individuals with disabilities, not just those with terminal illnesses, are now subject to the pressures disability rights activists claim to be present. Bickenbach believes that “it is more likely than not that for a person with disability the decision to kill oneself, or seek assistance to do so, is a coerced, manipulated, or forced decision”\(^\text{17}\).

RISK & VULNERABILITY

To be clear, while I think many of the concerns regarding people with disabilities being subjected to risk are correct, I think the implications are perhaps overstated. Wolbring has stated that “every safeguard put forward at the beginning of the debate [i] that euthanasia is for a terminal condition; ii) that the purpose of euthanasia is

\(^{17}\) Bickenbach, “Disability and Life-Ending Decisions”, 127.
to abolish physical pain; iii) that euthanasia is only for people who can provide informed consent; iv) and that euthanasia is about self-determination] has already been broken beyond repair\textsuperscript{18}, and my position need not deny that safeguards have been ill-conceived or continually violated.

Returning to Gill’s earlier claim, certainly the harm done to people with disabilities by physicians in the name of ‘helping’ otherwise burdened people, could be reduced, if not altogether, than substantially. That said, this harm is certainly not an inherent feature of medicine or assisted dying. In other words, there is nothing associated with making assisted dying permissible that makes harm to people with disabilities necessary.

We can reaffirm Wolbring’s concern about a broken system, while endorsing a reform of the conditions required to permit assisted suicide or euthanasia.

To deny there is a potential for abuse or harm would be foolish. That said, we do routinely engage in activities with a potential for harm. The examples we can employ need not be fanciful or straightforwardly risky. Take for example, the relatively benign act of visiting an emergency department. A recent study of Canadian emergency departments has found that among elderly residents of long term care facilities, visits to the emergency department are associated with an increased risk of acquiring a new respiratory or gastrointestinal infection. In fact, those who sought emergency medical treatment were more than twice as likely to obtain a new infection than those who opted

---

\textsuperscript{18} Wolbring.
not to visit the hospital. In this study, the incidence of new infection dropped from 8.3% to 3.4%.19

More generally, there is also potential for harm when being admitted into a hospital. Another Canadian study has found that 7.5% of patients admitted into acute care hospitals in the year 2000 experienced more than 1 adverse effect (unintended injury or complication resulting in death, disability, or a prolonged hospital stay).20 36.9% of the individuals experiencing adverse effects were judged to have experienced a “highly preventable” adverse effect. This means that of the 2.5 million annual hospital admissions in Canada, approximately 185 000 are due to adverse effects of treatment while already at the hospital, and that almost 70 000 of these instances are preventable.21

Another example can highlight the intended point further. Driving a car leads to a greater potential for harm than most other modes of transportation. Nonetheless, many of us opt to drive, despite the potential for harm, because there is a perceived benefit that outweighs this potential for harm.

21 Ibid.
Road traffic crashes rank as the 9th leading cause of death and account for 2.2% of all deaths globally. Furthermore, road traffic injuries are predicted to become the fifth leading cause of death (3.6% of all deaths globally) by 2030.22

In fact, traffic accidents are the leading cause of death globally for all 15-29 year olds with nearly 400,000 people under 25 dying on the world's roads each year, and on average, over 1,000 a day.23

In the U.S. alone, over 40,000 people die each year in traffic-related accidents and another 3.3 million are involved non-fatal road-traffic injuries.24

Nonetheless, we opt to drive instead of using alternative modes of transportation because despite the risk, we deem the benefits to outweigh that risk.

Similarly, in the two previous examples, we opt to go to the emergency department, or to get admitted into the hospital because the perceived benefits of doing so outweigh the potential for harm.

In the unfortunate event that we do find harm befalling us in any of the three abovementioned examples, we do not conclude that we should abandon those activities altogether. If one acquires a new infection after a visit to the emergency department, one does not view emergency departments as lacking worth. If one suffers from an adverse effect associated with medical treatment, one does not conclude that modern medicine should be abolished. Finally, if one is in a car accident and suffers harm, one does not think we should abandon cars or similar transportation devices altogether.

23 Ibid., 3.
24 Ibid., 217.
Similarly, simply because assisted dying has a potential for harm should not lead one to directly conclude that it as a practice should be abandoned altogether. Pointing to particular cases where perceived harm was done (a strategy often employed by disability theorists and advocates) does little more to suggest that assisted dying should be avoided, than pointing to a particular scenario that resulted in an adverse effect of medicine to conclude that all modern medical treatment should be prohibited.

In the unfortunate event of a new infection occurring, an adverse effect being suffered, or an accident happening on the road, we do one, or both, of the following things. First, we critically engage with the system surrounding that phenomenon. We ask probing questions into the design of the system to see if we can reduce instances of harm. We question the triage system in emergency departments, and ask if those with communicable infections ought to be prioritized, or treated differently than those who do not have such illnesses. We question surgical practices to ensure the physicians are following only the safest methods available. Finally, we examine traffic regulations and ensure they are working for, rather than against, us.

Secondly, we explore the actions of the individual(s) that have been harmed. We ask if it was imprudent for an individual with an autoimmune disorder to visit the emergency department during cold and flu season. We ask if a failure to disclose an aspect of one’s medical history contributed to an adverse medical effect. We ask if a driver in an accident was distracted or disobeying laws designed to promote safety.

Similarly, we can take action to drastically minimize the potential for harm to people with disabilities and other at-risk groups. If the system is as broken as Wolbring concludes, then we should adjust the regulations surrounding access to these medical
interventions. Furthermore, we as individuals should take action to explicitly express our desires to ensure there is as small of a grey area as possible.

To point to examples in the history of assisted dying where people with disabilities have been perceived to be harmed and to suggest this is reason enough to stop assisted suicide or voluntary euthanasia, is to throw the baby out with the bathwater. To deny there is a potential for harm would be disingenuous. While the potential for harm is great, the potential for harm reduction is greater. There is nothing in expressing the concerns that have been made by disability rights advocates that suggests an all-out ban of these practices. Instead, the experiences relayed by people with disabilities and the words of caution expressed are valuable in assessing the system to reduce or eliminate the possibilities of harm, but not to eliminate or prevent the system itself.

RESPECT & AUTONOMY

The third part of my case relates to how people with disabilities are perceived and respected. Perhaps obviously, we should respect people with disabilities. People with disabilities do not have inherently less valuable lives and we ought not to regard them or their interests as being of any less importance than people without disabilities.

I argue that contrary to those who suggest that permitting assisted dying devalues the lives of people with disabilities, respect, both generally, as well as for the autonomy of the disabled, requires that we allow everyone to seek assistance dying.

In direct conflict with Bickenbach, Wayne Sumner suggests that “compassion for patient suffering and respect for patient autonomy provide powerful pro tanto reasons for
legalizing assisted death”\textsuperscript{25}. Sumner intentionally expands the scope of his comments to include everyone, not just people with disabilities.

In fact, Nelson argues that the very manner in which the debate has been conducted results in perpetuating demeaning attitudes towards people with disabilities. To endorse a blanket ban on assisted death is to ignore the fact that people with disabilities are individuals, capable of making important decisions on their own.\textsuperscript{26} People with disabilities have interests to not only be “free of pain and suffering […], but to be] treated as unique individuals and not as some anonymous ‘disabled person’ lacking a character of personal history”\textsuperscript{27}.

Disability rights activists suggest that dominant social attitudes influence people with disabilities in potential harmful ways. That said, this harm is of concern to both parties of the debate. 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.

Anita Silvers has made the point forcefully that “characterizing people with disabilities as incompetent, easily coerced, and inclined to end their lives places them in the roles to which they have been confined by disability discrimination”\textsuperscript{28}. Sumner punctuates this point when he insists that “many people in the disability community find this stereotyping to be itself demeaning and patronizing, complaining that it feeds rather


\textsuperscript{27} Ibid.

than starves social prejudices”⁹. Even Bickenbach, despite previous comments, highlights Not Dead Yet’s “paternalistic over-emphasis of the vulnerability of persons with disabilities”⁰.

That said, to highlight autonomy as the only issue of importance here would be a mistake. An affront to autonomy, while important, can be supplemented with a more general concern of respect for individuals and avoidance of suffering. Sumner extends his critique of Bickenbach when he states, “what is at stake for those who are denied the option of assisted death is much more than the infringement of their autonomy: additionally, they will experience serious, sometimes intolerable, suffering and in many cases will die horrible deaths”¹¹. By denying individuals with disabilities the right to seek assistance dying, we are perpetuating harmful attitudes towards the disabled while simultaneously creating a doubly disadvantaged group: not only do people with disabilities suffer from social injustices or harms associated with impairment, but they are forced to endure tremendous pain at the end of life from a misguided effort to provide protection. Simply put, a “refusal to grant the request [to seek assistance dying] would seem to be an unjustifiable form of paternalism. It has to be ultimately up to the individual to decide when his or her condition is causing unbearable suffering”¹². Denying people with disabilities the right to seek assistance dying denies basic autonomy rights and further marginalizes and segregates people with disabilities from other populations. If we care to promote the well-being of people with disabilities, I argue that the most effective way is to enact policy change while refusing the dominant view that

---

²⁹ Sumner, “Death, Disability, and Self-Determination”.
³¹ Sumner, “Death, Disability, and Self-Determination”.
³² Ibid.
people with disabilities are pitiable individuals, lacking the critical thinking skills required to assess the value of their own lives when weighed against suffering at the end of life.

CONCLUDING REMARKS

In what preceded, I endeavored to advance at least two claims that relate to disability and assisted dying. First, that by granting people with disabilities the right to assisted death, we do not hereby subject the disabled to the tremendous risk of being killed or devalued in any sort of manner that is of special concern. Second, in order to truly respect individuals with disabilities, we should uphold basic autonomy rights for the disabled to live and die as they wish.

Opposing views advanced by disability rights activists are often overstated and potentially rely upon a cynical view of the potential for protection through policy reform.

In short, all individuals capable of offering reasoned and informed consent, including people with disabilities that fall within that category, should be granted the right to assistance in dying.