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When Anti-Discrimination Discriminates

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An attempt to reduce disability discrimination can do more harm than the ostensible discrimination itself. Such is the case with Shavelson et al.'s (2023) argument for equal access to medical aid in dying (MAID). They argue that not providing equal access to people whose "diseases make unassisted self-administration impossible" violates disability rights. But what if MAID itself is discriminatory? This is a central argument put forward by many disability rights advocates and disability bioethicists.

While pro-MAID bioethicists make a distinction between dying and disability, their critics within disability rights emphasize that dying people are themselves disabled—and that they can experience ableism during the dying process (Braswell 2019, 25–46). Indeed, data from states such as Oregon, where a specifically US version of MAID has been legal since 1997, show that patients' reasons for seeking assisted dying often have more to do with anxieties about disability—such as dependence, attenuated autonomy, incontinence, or the fear of being a financial or emotional burden—than with their imminent mortality itself (Coleman 2010; Kelly 2018). Because disabilities of some sort accompany all extended dying, we must always consider a broad array of disability rights principles such as access, accommodations, and discrimination regarding assisted dying practice, policy, and ethics. MAID is thus itself a disability rights issue.

Considering MAID as an exercise of autonomy can obscure the fundamental understanding of MAID as killing a disabled person that is assisted, encouraged and—in some jurisdictions—carried out by their healthcare team. In contrast, long-accepted standards of care discourage suicide and encourage patients to value their lives. MAID, however, denies disabled people such suicide prevention under the principles of patient autonomy and consent. In view of this expanded scope of MAID's ethical implications, we argue that Shavelson et al.'s focus on the self-administration safeguard procedure in MAID is too narrow a

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disability discrimination analysis. A more capacious framework maintains that withholding suicide prevention interventions differentially violates the core bioethical principles of equality and justice. We expand Shavelson et al.'s disability discrimination argument about self-administration to the broader claim that withholding equal access to suicide prevention is what creates an "underclass" comprised of all disabled people in the dying stage of life.

We propose that the fundamental premises of MAID discriminate against all people with disabilities, and in effect, discriminate against all people because everyone will become disabled, legally and functionally, at some life point and unequivocally at the time they are dying. The Canadian MAID law and its application offer a case study of how appeals to the moral principles of autonomy and equal access can have the unintended harm of expanding what is intended for a bounded target population into a universally available treatment of medical killing.

Canada's current expansion began less than ten years ago, in 2016, with a seemingly modest legalization of MAID for the terminally ill. Nonetheless, the number of people killed by MAID grew from 2,838 in 2016 to 10,064 in 2021—an increase of 32.4 percent. This expansion has shaped attitudes toward the killing of not only disabled people but also other marginalized populations: 28% of Canadians now favor euthanasia for poverty and 28% for homelessness (Hopper 2023). These are all conditions whose deleterious effects could be alleviated by less harsh means than legalized killing. Such attitudes suggest that when MAID becomes a solution for complex medical conditions or social problems, killing becomes acceptable. Moreover, the ostensible efficiencies and economic benefits MAID seems to offer may incentivize the option to the point of coercion (Deneen 2020).

As with the current policy in the US, this practice appears as euphemisms such as "aid" or "assistance in dying" and rests on appeals that it remediates suffering and brings mercy. Such language reframes an act of killing as beneficence that merely hastens a natural dying process. Recent bioethical articles argue, in contrast, that this distinction is philosophically inconsistent and potentially supports unjust public policy even when limited to dying people (Friesen 2020; Reed 2020). The Canadian example shows that even such constrained use of the term "dying" rapidly leads to applying MAID to broader populations, such as the disabled, the mentally ill, or even the poor, who cannot be considered actively dying or to have a terminal diagnosis.

This policy has been legalized over the objections of every major Canadian disability rights group, as well as the United Nations (Coelho et al. 2022). The logic of invoking disability discrimination to extend medical killing to disabled people whose death is not imminent is untenable. If the justification of equal access prevailed to support the reasoning that since MAID was legal for dying people, how could it be denied for the disabled or mentally ill? Shavelson et al.'s paper presents the same underpinning reasoning. And in Canada, this is a troublingly simplistic application of disability discrimination.

Any policy that results in unequivocal, irreversible patient death that uncritically invokes patient autonomy and the related logic of free choice for its justification risks carrying out harm in the service of benefit, violating the most fundamental principle of bioethics. Arguments based on autonomy, like that of Shavelson et al., minimize the discriminatory function of all assisted suicide, aid in dying, end of life options, death with dignity, euthanasia, and medical killing laws and practices. The well documented limitations of consent in healthcare treatment and decision-making clarify the epistemological limitations of making decisions in the present about future situations (Garland-Thomson 2020; Drought and Koenig 2002). The conservative inclination of bioethics toward avoiding harm over achieving benefit well serves people with disabilities, who are both a vulnerable and underserved population (Garland-Thomson and Iezzoni 2021).

This is particularly true as the ostensible benefits of MAID—the reduction, even elimination of suffering—could be achieved through nonviolent means. Just as killing poor people is not an ethical solution to the problems of poverty, so too the suffering caused by ableism does not justify the solution of MAID. But the "unbearable suffering" that MAID applicants experience might be remediated by other means. For example, the degradation of disabled people in US nursing homes—worsened by the COVID-19 pandemic and that industry's capture by private equity—might reasonably lead people to contemplate ending their lives rather than living in this unsatisfactory situation. Providing MAID to these people does not address the root problem; instead, it intensifies the very discrimination, often carried out in the nursing home itself, that leads disabled people to want to end their lives (Gill 2010.) Similarly, the suffering of intellectually disabled people in the Netherlands who wish to end their lives due to loneliness could be alleviated by creating more humane environments (Tuffrey-Wijne et al.

2023; McCrary 2021). But because MAID has normalized killing as a solution to suffering, other options seem less tenable, available, or economically feasible, potentially attenuating the will to make them a reality. These risks are great enough when the killing is carried out by the person receiving the treatment. Empowering the healthcare team to kill, as Shavelson et al. propose, has much greater risks. In Belgium, where active killing has been legal since 2002, laws and regulations meant to protect patients from abuse "often fail to operate as such" (Raus, Vanderhaegen, and Sterckx 2021).

Many disability activists and organizations in the US recognize this danger (Shapiro 2023). A recent lawsuit arguing that California's End of Life Options Act discriminates against people with disabilities suggests that concerns raised by the Canadian, Belgian, and Dutch examples are just as valid in the US. The National Council on Disability published a comprehensive report in 2019 on the dangers of assisted suicide (NCD DREDF report). A strong argument about the discriminatory nature of MAID that complements the disability critique comes from Supreme Court Justice Neil Gorsuch's book *The Future of Assisted Suicide and Euthanasia* (Gorsuch 2009). O. Carter Snead's 2020 account of public bioethics, *What It Means to Be Human*, traces the legal history of euthanasia (Snead 2020). Taken together, the bioethical, moral, advocacy, and legal critiques of MAID mentioned here provide a path forward toward a bioethics, medical practice, and legal approach that achieves the goal of equal treatment for all.

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Aid in Dying Unaided?

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Why would we prohibit people with disabilities from receiving the assistance needed to achieve similar goals as people without disabilities? On its face, this would seem to be a discriminatory approach, one we should reject unless we have very good reasons to justify it. Public protection and personal safety might both be argued e.g. when requiring armed police or surgeons to possess certain physical independence—or prohibiting driving when people lack the mental capacity to judge risk.

But what of the situation critiqued by Shavelson et al. (2023)? They take issue with aid-in-dying laws, ones that allow people with a terminal illness to opt for a lethal prescription, but then prohibit them from physical assistance to administer it. Shavelson et al. decry this as disability discrimination—when people with a terminal illness and the mental capacity ("capacity") to choose aid-in-dying lack physical capability ("capability") to enact their choice unassisted. Describing them as a legally-created underclass (defined by the capacity to choose, without the capability to enact), Shavelson et al. seek reform of aid-in-dying laws to allow physical assistance where necessary. They anticipate further rounds of judicial clarification to hammer out if and when physical assistance should be allowed.

Of course, the downsides to this approach may be significant. For example, we can expect lengthy legal disputes. Amidst the upheavals of terminal illness, people with disabilities may have to resort to engaging lawyers. Despite stern limits on time, energy, and resource, this group may have to press the case in courts—that their informed choices are unfairly frustrated by prohibitions against assistance. Opposing lawyers may argue, for instance, that such prohibitions are required to protect society, including from practices that could be damagingly regarded as euthanizing vulnerable and disabled fellow citizens. Court battles around this topic look set to be as expensive as they are dispiriting, the more so given the terminal conditions facing litigants on at least one side of the argument.

Here, I offer a different way forward, not by arguing fair reasons to justify discrimination, but rather by taking a neurorehabilitative approach to circumvent the formation of the underclass described. A key step in this is the proper application of assistive technology (AT) to slim the space claimed between capacity and capability. The World Health Organization describes AT as follows:

> *Assistive technology is an umbrella term for assistive products and their related systems and services …. [which] can enhance performance in all key functional domains such as cognition, communication, hearing, mobility, self-care and vision. They may be physical products … or they may be digital and come in the form of software and apps that support communication, time management, monitoring, etc.* (WHO and UNICEF 2022).

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