

## **Physician Assisted Suicide, Disability, and Paternalism**

Disability rights advocates condemn certain actual and contemplated “life or death” practices in our society on the grounds that they wrongly discriminate against disabled people. Among these are the selective abortion of fetuses that will develop conditions like Downs’ Syndrome, and genetic counseling intended to discourage couples at high risk of producing disabled offspring from reproducing. The focus of this paper will be on another practice condemned by some disability activists—physician-assisted suicide (PAS). We can distinguish three basic legalization of PAS options in order from least to most restrictive: i) all competent adults are eligible for suicide assistance; ii) competent adults who are terminally ill or “severely disabled” are eligible, while the healthy and able are not; and iii) only competent adults who terminally ill are eligible.<sup>1</sup> The Oregon Death with Dignity Act passed via referendum in 1994, and initiative I-1000, adopted by state of Washington voters in 2008, are examples of iii).<sup>2</sup> The objection of some disability rights advocates (hereafter, the DR objection) that PAS wrongly discriminates against disabled people is certainly directed at ii) and iii), and possibly i) as well. The disability rights group “Not Dead Yet” has argued that the Oregon law “is really about a deadly double standard for people with severe disabilities, including both conditions that are labeled terminal and those that are not.”<sup>3</sup> It and other DR groups filed an *amicus* brief in the case of *Oregon v. Gonzales* (2005) calling for the court to invalidate the Oregon law on the grounds that it violated the Equal Protection clause of the 14th Amendment and the Americans with Disabilities Act.<sup>4</sup> Ron Edmundson gave testimony as a representative of Not Dead Yet before the Hawaii state

legislature in opposition to a proposed PAS law similar to Oregon's, claiming that the real objective of those who support iii) is to pave the way for ii).<sup>5</sup>

There are two distinct but compatible variants of the DR objection. According to the first, even if legalized PAS benefited all the disabled people who chose it, and they chose it autonomously, the practice should still be forbidden because it harms disabled people as a class (including those who would never opt for it). This objection is analogous to an objection to legalizing prostitution that alleges that it would harm all women through its "message," symbolism, or social meaning (something like "it's okay to objectify women"). It is also similar in some respects to the most important objection to Jim Crow laws or a ban on interracial marriage, namely, that they harm all black people by helping to perpetuate their subordinate position in a system of racial caste. It assumes that disabled people, like racial minorities in the U.S., constitute a historically marginalized group that has suffered and continues to suffer systemic injustice. It claims that a PAS law like Oregon's reinforces a social stigma attached to disability, thereby harming all disabled people. It has that effect even if its supporters (unlike supporters of Jim Crow) have no malicious intent toward the group that the law stigmatizes.

According to the other variant of the objection, the persons for the sake of whom we should not allow PAS are the very ones who would opt for it if it were legal. It is analogous to an objection to legalizing prostitution that focuses on the plight of prostitutes—the physical and spiritual harms that they suffer, their exploitation and lack of freedom. It alleges that the majority of disabled people who would opt for PAS if it were legal would be making a choice that is neither free nor in their best interests, so the option should be denied them for the sake of both their autonomy and their welfare. Ron Amundson endorsed this "paternalistic" variant of the DR objection in the testimony referred to earlier. He said that Not Dead Yet:

... believes that the so-called free choice of assisted suicide is a forced choice, and it leads to the same kind of exploitation [as workers faced with the choice of accepting slave wages or starving]. The freedom it offers for a few people is paid for by the exploitation of many others. Terminally ill or disabled people sometimes do have suicidal feelings when they feel a lack of support, or a shame for their own condition, or when they feel that they are a burden on their families. The desire for death under those conditions is not a free choice, but a forced choice.<sup>6</sup>

Harriet McBryde-Johnson also supports the objection, claiming:

choice is illusory in a context of pervasive inequality. Choices are structured by oppression. We shouldn't offer assistance with suicide until we all have the assistance we need to get out of bed in the morning and live a good life. Common causes of suicidality -- dependence, institutional confinement, being a burden -- are entirely curable.<sup>7</sup>

In what follows I argue that we should reject the paternalistic DR objection to PAS laws of type iii). I claim that there are likely to be more violations of autonomy if we deny terminally ill people the option of PAS than if we don't. However, I concede to the critics of Oregon-type laws that they cannot be defended solely on the basis of a moral duty to respect autonomy. Their denial of PAS eligibility to everyone who is not terminally ill is best defended on the grounds that the majority of such people are better off alive than dead and the duty to protect their prudential good overrides the duty to respect their autonomy. In short, the best defense of such laws is a "hard" paternalist one. The charge that they reflect anti-disability prejudice itself reflects two errors: it overlooks the possibility of a hard paternalist defense of them, and it confuses terminal illness, which is at best one type of disability, with disability itself.

### Tainted Preferences and Dignity

Calling the second variant of the DR objection "paternalistic" does not imply disapproval of it. There are plenty of examples of paternalism whose justifiability few besides doctrinaire libertarians would dispute—seat belt laws, requiring hunters to wear

red and sailors to have a life vest on board, and so forth. An example of a paternalistic law that few judge problematic is a ban on usury. Such a law prevents those who are desperate for money but at high risk of defaulting on a loan from borrowing at exorbitant interest rates. The rationale behind it would seem to be the same as the one underlying the DR objection: to protect those who are weak, vulnerable, and easily exploited from making forced choices that are bad for them.

Insofar as this is the rationale behind a ban on PAS, it is “soft” paternalism. As many writers distinguish them, paternalism is “soft” if it interferes with self-regarding choices that are substantially involuntary for the chooser’s own good, while it is “hard” if it interferes with fully voluntary choices for that reason.<sup>8</sup> J.S. Mill’s example of detaining a bridge crosser unaware that the bridge he wishes to cross is dangerous is an instance of soft paternalism. Nonculpable ignorance of crucial facts surrounding the circumstances of a choice or its consequences renders it substantially involuntary. An example of hard paternalism is forcing a life saving blood transfusion on a competent adult Jehovah’s Witness who refuses to authorize one because it is his conscientious belief that transfusions are sinful. In the case of soft paternalism the interference can be justified by appeal to the chooser’s own beliefs and values. In the case of hard paternalism the interference imposes on the chooser values and preferences that are other people’s on the grounds that his own are mistaken or misguided in some way. If respecting autonomy means letting people act on their self-regarding voluntary choices based on their own values even if those values are misguided, and if it is always wrong to violate the autonomy of another competent adult, then soft paternalism is permissible because it respects autonomy, while hard paternalism is wrong because it violates it.<sup>9</sup>

Amundson distinguished three different motivations that might lead a disabled person to choose suicide. The first compares the disabled person to the worker who is faced with the choice between working for a capitalist for subsistence wages and

starving. The quadriplegic who prefers suicide to its alternative makes a choice that is “forced” because the alternative—to continue to live in an ableist society that neglects his most basic needs—is not minimally acceptable (or so he believes). He may not be acceding to a threat, and hence may be not “coerced,” but he acts “under duress” or “involuntarily” because he, like the worker under capitalism as described by Marx, makes a choice under conditions that he reasonably thinks provide him with no minimally acceptable alternatives.<sup>10</sup>

The other two motivations for suicide that Amundson mentions are shame based on the belief that a life with disability cannot possibly be dignified, and the altruistic desire not to be a “burden” on others, especially loved ones. Amundson does not explain why a choice motivated in either of these ways is “forced,” and it is difficult to see why they would have to be. Arguably what really bothers those who press the paternalistic DR objection to PAS is not lack of freedom but lack of autonomy. Choices that are forced by an absence of acceptable alternatives are nonautonomous, but so are choices that are the product of psychological compulsion (literally irresistible urges) and even choices that are the result of fully voluntary weakness of will. Amundson supposes that a refusal to provide PAS to any disabled person who wants it because he believes that he lacks dignity and/or does not wish to be a burden on others does not violate his autonomy, because the preferences that prompt his request for suicide assistance are not genuinely autonomous.

Why think that they are not genuinely autonomous? One possibility is that they are not autonomous simply by virtue of resting on normative error, or false views about the basis of human dignity or what society owes them. If either a religious, sanctity of life ethic or a Kantian ethic is correct, then the belief that any life with disability lacks dignity is false. According to the sanctity of life view, all human beings have “full moral status,” have lives that are sacred and endowed with dignity, because they were created

by God in “his image.” The Kantian view is different, claiming that all “persons” have full moral status and a dignity that is “beyond all price” by virtue of possessing capacities for moral agency. According to both views, the person who chooses “death with dignity” because he thinks that it is undignified to lead a life in which he lacks full control over his bowels or is mobile only with the help of a wheelchair, holds a mistaken belief about the basis of human dignity.<sup>11</sup>

The problem with saying that preferences are nonautonomous if they rest on normative error is that it is fundamentally dishonest. Interference with choices that’s premised on this view really violates autonomy in the guise of respecting it. We should avoid the “monstrous impersonation” condemned by Isaiah Berlin of equating “true” autonomy not with the choices people make based on their actual values and preferences, but with the choices their “rational” selves would make if they had the correct values and suffered from no ideological delusions.<sup>12</sup> This is not to deny that an “authenticity” requirement of some sort belongs in a satisfactory account of “autonomous choice.” It’s to say that false and/or unreasonable normative commitments can be authentically held.

However, Amundson and McBryde-Johnson needn’t take the view that the preferences in question are “false” or “tainted” by virtue of their reflecting normative error. Instead, they can say that they are tainted by virtue of their origins in an oppressive social environment. According to this view it is not enough to be autonomous that one *currently* has acceptable alternatives to one’s preferred choice. (That’s necessary for one’s choice to be voluntary). It’s also necessary that one’s preferences were formed in a social environment that provided one acceptable alternatives (allowing for the satisfaction of *basic needs*) as those preferences were taking shape. For example, in the Afghanistan ruled by the Taliban, women who went out in public without the company of a male relative risked being beaten. Women

socialized in a patriarchal culture as oppressive as that may support its oppressive practices toward women (e.g. agreeing that if their daughters are raped they bring shame to their family), but their support should not count as autonomous given its origins in an oppressive social environment.<sup>13</sup> Amundson and McBryde-Johnson can say that the same holds for the beliefs about dignity and not being a burden on others held by disabled people who've been socialized in an ableist society that treats them unjustly from birth to death. Those beliefs reflect an ableist ideology that serves the interests of the able at the expense of people with disabilities. What makes them tainted, inauthentic, or nonautonomous is their origins in an oppressive society, not their falseness *per se*. The reason why the option of PAS provides only the illusion of freedom is that the preferences it allows disabled people to satisfy were molded under conditions of unfreedom.

### Two Bad Libertarian Replies to the DR Objection

The paternalistic DR objection alleges that the denial of PAS to severely disabled people is acceptable soft paternalism that does not violate autonomy because:

1. Interference with a competent adult's self-regarding choices violates his autonomy if and only if his choice is voluntary and reflects autonomously formed preferences and beliefs.
2. Severely disabled people who ask for PAS are motivated either by self-interest, or by the belief that a life with severe disability lacks dignity or imposes an undue burden on others to provide them with care or assistance.
3. If their request is motivated by self-interest, or the conviction that life in an ableist society that refuses to provide reasonable accommodations and support would be very poor, then it is not autonomous because it is involuntary.

4. If it is based on the belief that a life with disability is undignified or imposes an undue burden on others, then it expresses beliefs and preferences that are nonautonomous by virtue of their origins in an oppressive social environment.
5. Therefore, no matter what motivates the request for PAS by the severely disabled, its denial does not violate their autonomy.

I will claim shortly that this argument fails because its third premise is false, but before doing so I want to consider two objections to it pressed by libertarians.

The libertarian's first objection also targets the third premise. It assumes that freedom, coercion, and voluntariness are at bottom moral notions, so that a choice is involuntary only if others have limited one's options in a way that violated one's rights.<sup>14</sup> What's more, the libertarian insists that society's failure to provide accommodations and a support network to disabled people does not violate their rights. On the contrary, it would be a state that mandates such measures that violates the liberty and property rights of employers, hotel and restaurant owners, taxpayers, etc. Perhaps the quadriplegic woman who chooses suicide because the alternative is a very poor life in an ableist society is just like the worker without any capital, who must choose between working for a capitalist for subsistence wages and starving. But neither choice is involuntary, because neither person is the victim of any rights violations.

This objection to the argument is unconvincing. The desperate borrower acts under duress even if no one threatens to violate his rights if he doesn't accept the loan shark's offer, and convicted murderers remain in prison involuntarily even though their incarceration does not violate any of their rights. We should reject a "moralized" analysis of freedom, coercion, and voluntariness.<sup>15</sup> Moreover, even if we accepted such an analysis we should reject the libertarian's view that to require employers to provide reasonable accommodations for disabled employees violates their property rights. Property rights are not absolute, so civil rights laws do not violate them.

The libertarian's other objection to the argument is that even if a nonmoralized conception of voluntariness is correct, then while it may turn out that the choice of most quadriplegics to opt for PAS will qualify as involuntary, the choice of others, perhaps only a minority, won't. But a law that denies PAS eligibility to all disabled people would apply to those in the minority whose choice is fully autonomous. The objection is that that violates *their* right to self-determination. The fact that the good the law does for the majority outweighs the harm it does to this minority is simply irrelevant, according to the libertarian. One can't justify a violation of one individual's rights by pointing to the greater good that it makes possible for many others.

At least one defender of the paternalistic DR objection, Jerome Birkenbach, concedes that *some* disabled people who request a quick death through PAS are making a fully autonomous choice. Sue Rodriguez was a Canadian woman with ALS who fought for a legal right to an assisted suicide when her condition deteriorated to the point that she would be unable to take her own life without assistance. Birkenbach describes her (unsuccessful) attempt to win that right as "taking control over her own life." But he adds:

...even if Sue Rodriguez herself was neither vulnerable nor the victim of social attitudes about the low value of her life, her case is arguably exceptional. The weight of the evidence warrants caution about generalizing from her case. In any event, the law must be written for everyone, not just the exceptional person. It is a commonplace in political theory that an institutional constraint on autonomy may well be justified if, in general and in the long run, it protects people who are vulnerable, though on occasion it produces undesirable, even right-infringing, results for the exceptional few.<sup>16</sup>

Birkenbach seems to me to make an important and correct point here, though it is hardly an uncontroversial "commonplace." We should not suppose that in order for a law to be justifiable on soft paternalist grounds, it is necessary that absolutely every person whose liberty it restricts would consent to it if she were rational and well informed. If a large majority of those in class X who choose to do Y are making a nonautonomous choice

contrary to their own best interests, and they would if well-informed consent to restrictions on their freedom to do Y, then the state may forbid all in X to do Y for their own good, including the small minority whose choice is neither imprudent nor deficient in autonomy.

Implicit in this principle is the proviso that there is no feasible way for the state to distinguish the two groups, and its only options are to permit all in X the freedom to do Y or permit none. The principle so qualified still is not quite right, since it ignores the magnitude of harm that the different groups suffer. But we needn't worry about the precise formulation of the principle. Feinberg relies on it in his soft paternalist defense of Social Security. The law exists for the sake of the many who know that they would not save enough for their retirement unless the government forced them to. To the few who are prudent and disciplined enough to save on their own but are nevertheless also subject to mandatory withholding, Feinberg says that "the compulsion is for their sakes, not yours."<sup>17</sup> The principle in question—Birkenbach's "commonplace"—explains why Social Security is not unjust in spite of the fact that it violates the autonomy of the few and perhaps even leaves them worse off than they would be if allowed to put their contributions in a privately managed account instead. It follows from the principle that the second libertarian reply to the paternalistic DR objection should be rejected as well.

#### Another Objection to the DR Argument

Supporters of Oregon's limited eligibility law face a slippery slope challenge—Why only the terminally ill? Why not eligibility for all competent adults?—that we'll take up shortly. But those who oppose the Oregon law on the basis of the paternalistic DR objection face a similar challenge: why not also limit or abolish the right to reject unwanted medical care? As Mayo and Gunderson have noted, if the choice of PAS by a

terminally ill or severely disabled person is likely to be nonautonomous and for that reason should not be granted, the same will be true of a decision by the same person to refuse or discontinue medical treatment.<sup>18</sup> Not Dead Yet admits as much and is consistent: it opposes *both* the right to PAS and the right to reject unwanted medical care. The *amicus* brief that it co-authored with other DR groups in *Oregon v. Gonzales* mentions four widely publicized cases in which people with severe disabilities that were not life threatening sought to end their medical care. The courts ruled that their requests had to be honored, and the brief protests that such rulings reflect an anti-disability bias.

Because Not Dead Yet seems to oppose any right of disabled persons to reject medical treatment, Mayo and Gunderson charge the group with supporting an untenable “medical vitalism”—the view that physicians should try to keep patients alive for as long as possible, with or without their consent. That charge seems to me incorrect. I think that Not Dead Yet would agree with Birkenback that laws should be framed to deal with what is usual rather than what is exceptional. Its position is that few of the life or death decisions made by disabled people in our society will (or could) be autonomously made. A just law will recognize this and deny the option of choosing death to all disabled people. The moral duty to obey a just law, not the principle of medical vitalism, is what justifies thwarting the (rare) fully autonomous choice of a disabled person to refuse medical treatment or seek help to commit suicide.

Still, Mayo and Gunderson are right to object that Not Dead Yet’s reasons for opposing PAS would, if cogent, require that we also reject a right that is well entrenched in common sense moral thinking and that few would wish to eliminate, namely, the right not to seek treatment for one’s condition or to discontinue it at any time and for any reason.

## Terminal Illness and Respect for Autonomy

This last objection to the paternalistic DR argument has merit, but it is of secondary importance. If the DR objection to the Oregon law is supposed to be a species of soft paternalism, then it has to be claimed that denying PAS to terminally ill people who want PAS either for self-interested reasons or reasons grounded in beliefs about “death with dignity” does not violate their autonomy. But such a claim is untenable.

Someone who chooses suicide when terminally ill and in great pain can be said to be making a choice that is “forced” by the fact that there are no acceptable alternatives to it. The same can be said of people with cancer and a bleak prognosis, who “volunteer” for clinical studies that test new cancer drugs. But from the fact that such choices are involuntary, it hardly follows that thwarting them is consistent with respect for autonomy. Whether interference with involuntary choices respects or violates autonomy depends on whether those making the choices would consent to the interference, on the basis of their own non-tainted autonomously formed values and preferences, if they were thinking clearly, were well-informed, and were not subject to any coercive influences.

Consider the following example. The Gestapo has captured a British spy, whom it will torture and then execute soon unless he swallows a capsule in his possession that will kill him instantly and painlessly. His choice to swallow the capsule is “forced” and involuntary; the alternative to not swallowing it is horrible. There is a priest in the same holding cell as the spy, concerned that the spy will go to hell if he commits the mortal sin of suicide. He can’t free the spy, but he can take the capsule away from him. Surely if

he does that for what he thinks is the spy's own long term good, he violates his autonomy and engages in hard paternalism (assuming that the spy does not share the priest's views about suicide and damnation). He prevents the spy from making an involuntary choice, a choice the spy would not make if the condition that renders his choice involuntary (his captivity by the Gestapo) were removed. But he violates the spy's autonomy because the spy would not freely consent to the interference on the basis of his own autonomously formed value convictions.

Hence, even though the choice of PAS by any terminally ill person is involuntary, that settles nothing. What we need to ask is whether people would consent to being denied the option of PAS if they are or were terminally ill. Surely many do or would want the option for a couple of reasons. First, they have the same prudential preference to avoid physical pain and mental anguish that motivates the spy's decision to swallow the capsule of poison. Second and probably more important, many fear the gradual loss of mental functioning and ability to interact with others that usually accompanies the progression of terminal illness. The loss of the higher human capacities is not something that powerful painkillers can prevent. If anything, they only exacerbate it. Many of us don't want to remain alive without our higher faculties because we hold views about dignity that may be inconsistent with the religious, sanctity of life view but are fully congruent with Kantian moral philosophy. According to Kantian view, someone who had but permanently loses those capacities *does* suffer a loss of dignity, and it is *right* to prefer a quick death to a prolonged one in order to avoid such indignity.<sup>19</sup> It may well have been this sort of belief about dignity (rather than the tainted and false one according to which it is undignified to depend on others for help to use the bathroom) that prompted Sue Rodriguez (who was terminally ill as well as paralyzed) to fight for a legal right to suicide assistance. Of course if what was said earlier is right, then the question of whether the Kantian view is correct is irrelevant. What matters is that those

who hold it did not form it under oppressive social conditions. Their choice of PAS when they are terminally ill may be forced, but the fact that they would not consent to having their forced choice thwarted by others, because they hold this view about dignity, means that denying them PAS violates their autonomy.

We can now see why the third premise in the DR argument as described above is false. The quadriplegic who for self-interested reasons opts for PAS over life in an ableist society that neglects his urgent needs certainly does make a forced, involuntary choice. But if the alternatives that he must choose between are comparable to the alternatives that the British spy faces, then he would not consent to others' thwarting his choice of suicide any more than the spy would. Thus, others' thwarting it violates his autonomy. This does not mean that it is wrong to deny him PAS eligibility, only that the denial can't be justified on soft paternalist grounds. We'll return to this case shortly.

### More Autonomy Violations of the Terminally Ill with a Ban on PAS or with the Oregon Law?

However large is the number of people who want and would autonomously choose the option of PAS if they are terminally ill, it has to be admitted that there are many other people who either do not want the option or would not autonomously choose it if they had it. As Ackerman notes, if the option is available then terminally ill people who don't choose it may be challenged, and many may prefer not to have to defend their decision to wait for a "natural" death.<sup>20</sup> Also, those committed to the sanctity of life principle might have self-regarding reasons for not wanting the option of PAS. They regard assisted suicide as immoral and might fear that if it were available they will backslide and choose it. Hence, they support a restriction on their own liberty to forestall the possibility of a weakness of will condemned by their own moral

conscience.<sup>21</sup> For both of these groups it simply is not true that “more choice is better than less.” Withholding from them the option of PAS does not violate their autonomy.

Additionally, there are people whose election of assisted suicide would be involuntary because they were “guilt tripped” into it by relatives eager to avoid the financial costs of their continued care. Other terminally ill people may choose PAS only because they are suffering from a depression that is treatable with the right medications. Birkenbach mentions “the findings of psychologist Carol Gill that the desire among [some?] terminal patients to die may be motivated by the realization that death is the only escape from an intolerable institutional setting, or inadequate medical or palliative care.”<sup>22</sup> The Oregon law’s waiting period helps to weed out PAS requests that fail to reflect the person’s own deepest values and preferences because of impetuosity or other temporary emotional impairments. The law requires physicians to refuse requests from patients who are not mentally competent, though it does not require that psychiatric experts screen all requests. Defenders of a right to PAS for the terminally ill ought to concede that even if a very stringent psychiatric screening requirement were in place, it is likely that some requests that are involuntary and/or nonautonomous would slip through the cracks and be granted.

The “commonplace” principle to which Birkenbach appealed requires us to weigh the effects of legalizing PAS on the groups just mentioned against the effects of not legalizing it on those who want the option of PAS because they hold Kantian views about “death with dignity” or prefer a quick to prolonged death for purely prudential reasons. The “Philosopher’s Brief” written by Ronald Dworkin and others that was submitted in *Washington v. Glucksberg* (1997) claimed that under a PAS law with proper safeguards, the number of those whose autonomy is violated when their nonautonomous request is wrongly granted will be far smaller than the number of those terminally ill people whose autonomy is violated under a ban on PAS.<sup>23</sup> I agree.

Felicia Ackerman has objected that the Brief “gives no good reason to believe this far-from-obvious claim.”<sup>24</sup> The reply to Ackerman is that if there is a general presumption about such matters, it is that restricting liberty will cause more violations of autonomy than not restricting it will. Given that (rebuttable) presumption, the burden of proof falls on Birkenbach and Ackerman to show that the ban they favor would prevent more violations of autonomy than it would cause. Since they do not discharge that burden, their attempt to defend no PAS for the terminally ill on soft paternalist grounds should be judged a failure.

### Why Not PAS Eligibility for All Competent Adults?

In its legal brief Not Dead Yet objected that if the Oregon law were really about autonomy and empowering individuals, then it wouldn't limit eligibility for PAS to the terminally ill. That limit, it insisted, was proof of ableist prejudice. Not Dead Yet was assuming that the only possible justification for the Oregon law is the principle of respect for autonomy. Birkenbach seems to share that assumption (as well as the assumption that terminal illness is a kind of disability). He says:

Respecting autonomy does not mean respecting the right of people to arrive at correct decisions that are in their self-interest and consistent with their welfare; it means respecting their right to make whatever decision they wish. To its credit, Not Dead Yet realizes this, and makes the point [in its legal brief] ... that if the court ... finds a constitutional right to assisted suicide, then it should apply that right to ‘every citizen, regardless of their health status.’ Though a rhetorical flourish, the submission is not without a point. It is telling that in all of the hundreds of pages in these three court decisions, there is never any suggestion that the right to physician-assisted suicide should extend to people who do not have a severe disability. Implicit in the judgments themselves, in other words, is precisely the prevailing prejudicial social attitude that having a disability is a sensible reason for committing suicide.<sup>25</sup>

Birkenbach and Not Dead Yet see ableist prejudice behind the Oregon law because they ignore the possibility that the justification for its limit lies in beneficence or a concern for

the prudential good of those denied eligibility. They're right to note that the principle requiring respect for autonomy cannot justify a denial of PAS to anyone who is neither terminally ill nor seriously disabled but still decides autonomously to end his life. Their mistake is to think that that's important. The justification for denying eligibility to those who are not terminally ill but want assistance to end their lives is that most of them will be better off if society thwarts their wishes. We should deny PAS to them not out of respect for their autonomy but in spite of the fact that we're violating it.

Consider someone who wishes to kill himself because he has been unfaithful to his wife. After calm and careful deliberation he has decided that he deserves to die as punishment for his infidelity. A society that provided PAS to people like this self-punishing suicide would be one in which self-determination has (in the words of Daniel Callahan) "run amok."<sup>26</sup> Of course to say this is to endorse hard paternalism. But I suggest that defenders of the Oregon law must embrace a "moderate" hard paternalism according to which the duty of beneficence sometimes (not always) overrides the duty to respect autonomy.

Birkenbach and Not Dead Yet may overlook the possibility of a hard paternalist justification for the limits on eligibility built into Oregon's law because they assume that the duty to respect autonomy has to be absolute. They disagree with the libertarian as regards both the conditions under which choices should count as autonomous and the truth of Birkenbach's "commonplace." But they agree with the libertarian that respect for autonomy always trumps beneficence whenever the two values clash, and thus, that hard paternalism is always wrong. DR advocates who take this view about autonomy are likely to regard empowering people with disabilities as important only as a means to increasing their autonomy. (An alternative view is that it is valuable mainly as a means to improving their welfare or quality of life). Much of "disability studies," especially those quarters of it that lean heavily on Michel Foucault's ideas about "power," seems

committed to the primacy of the value of autonomy.<sup>27</sup> This belief in the primacy of autonomy is one thing that distinguishes the DR critique of limited PAS from that of social conservatives who appeal to sanctity of life. Birkenbach and Not Dead Yet suppose that in a fully just society that has overcome ableism and shows equal concern for everyone's most urgent needs, a PAS of the sort favored by the libertarian (where all competent adults are eligible) and possibly even a PAS limited to the terminally ill would be unobjectionable, because in such a society any choice of suicide by a disabled person would be fully autonomous. The "pro life" objection assumes, to the contrary, that PAS of any kind would remain wrong even in a society in which people with disabilities are fully empowered.

### Ackerman's Objection

Felicia Ackerman finds a defense of the Oregon law that appeals to the value of beneficence unconvincing. Doesn't such a defense assume that *only* terminally ill people have a quality of life so low as to make plausible the judgment that they are better off dead? And isn't such an assumption untenable?<sup>28</sup> As Ackerman notes, some people who are not terminally ill but suffer from severe physical disabilities like quadriplegia or severe mental disabilities like extreme bi-polar disorder may, because of the absence of an adequate social network to support their needs, have a quality of life just as low as the late stage cancer patient. Indeed, Ackerman argues, the class of persons who should be eligible for PAS, according to a principle of beneficence sensitive to quality of life, should include some who are not sick or disabled at all but have a low quality of life for other reasons. She mentions in this connection "a young, healthy, and able bodied person who is serving a life sentence without possibility of parole or who is desperately poor, unskilled, and stupid, and able to earn a living only by working at

drudge work that he detests.”<sup>29</sup> Since the principle of beneficence really requires extending PAS eligibility to these persons as well, the desire to limit PAS to the terminally ill cannot stem from beneficence. Ackerman echoes Not Dead Yet’s claim that such a desire betrays an elitist “double standard.”

Though her examples of the young convict serving a life sentence and the unskilled and stupid person fail to convince (perhaps they are not seriously meant to), certainly there are others besides competent adults in the late stages of terminal illness who are not better off alive than dead. These include human beings incapable of sentience or consciousness (e.g. anencephalic babies and those in a permanent vegetative state), those with advanced cases of Alzheimer’s disease (some of whom when competent expressed a preference for a quick death to being cared for and kept alive with advanced Alzheimer’s), and those in the late stages of terminal illness who are severely retarded. But since people in each of these groups are not capable of deciding to take their own lives, the question of extending PAS eligibility to them is moot. They raise the different question of whether “nonvoluntary” (neither voluntary and involuntary) euthanasia ought to be legalized.

The reply to Ackerman is that it doesn’t have to be the case that every single terminally ill person has a lower quality of life than everyone who isn’t terminally ill in order for beneficence to support a PAS limited to the competent, terminally ill. Laws need to draw bright, easily identifiable lines. A law that makes only competent terminally ill persons eligible for PAS draws such a line, whereas a law that extends eligibility to every competent person whose quality of life is extremely low and unlikely to improve does not. The second law would require that whoever administers it be empowered to make quality of life judgments about individuals on a case by case basis, and that would create both an administrative nightmare and the potential for horrible abuses. No one

should want a system in which government officials get to decide when people are disabled enough or “unskilled and stupid” enough that they qualify for PAS.

We should deny PAS eligibility to the severely disabled who are not terminally ill, even if their request for suicide assistance is autonomous, for a couple of reasons. The first is that the majority of such persons are better off alive (even in an ableist society that treats them unjustly) than dead. Of course this is a “generalization” and as such admits of exceptions, but arguments for and against legal policies necessarily deal in generalizations. The second reason for not extending them PAS eligibility is that doing so would make it harder to correct the injustices that beset people with disabilities. It would encourage the able to believe that severely disabled people are better off dead no matter how responsive society is to their needs, making them less willing to support the laws and social policies needed to improve the plight of disabled people.

An objection to this argument is that if we deny PAS to those disabled people whom we concede are autonomous in their request for PAS and who sadly might indeed be better off dead, and if we do this because providing them PAS would hinder continued progress in the fight for disabled rights, then we are using them as “mere means” to promote the good and autonomy of others. This is an objection that libertarians rather than supporters of the DR position are more likely to press.<sup>30</sup> The principle discussed earlier in connection with Birkenbach’s “commonplace” seems to me to provide the basis of a good reply to it.

Anita Silvers worries that denying disabled people the option of PAS “for their own good” would harm them as a class by promoting the notion that they are unable to look out for their own best interests. Silvers says:

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. Doing so emphasizes their supposed fragility, which becomes a reason to deny that they are capable, and therefore deserving, of full social participation.<sup>31</sup>

Silvers seems to me to identify a reason why the criterion for PAS eligibility should not be *all competent adults except those with severe disabilities*. That legalization option is different from i)-iii), and as far as I know nobody supports it. It would single out disabled people in a way that can only be perceived as expressing an animus toward them.

### Terminal Illness, Disability, and the Good Life

I have claimed that the number of autonomy violations would be greater under a ban on PAS than under a PAS law like Oregon's. The "commonplace" principle cited by Birkenbach supports rather than opposes PAS eligibility for all and only terminally ill competent adults. I turn now to what seems to me the most serious error of those who press the DR objection to the Oregon law. That is their confusion of "terminal illness" with "disability."

I do not mean to deny that terminal illness is a kind of disability. The concepts of "disease," "disability," "normal species functioning," and so on, are elastic enough to permit us to think of terminal illness as a kind of disability. I only insist on what seems the obvious point that if it is kind of disability, it is only *one* kind and not the whole genus. The Oregon law extends eligibility for PAS only to the terminally ill and *denies* it to all *other* disabled persons. When Birkenbach allies himself with Not Dead Yet's legal brief attacking the Oregon law—when he says that "implicit [in support for the law] ... is precisely the prevailing prejudicial social attitude that having a disability is a sensible reason for committing suicide"—he is conflating one type of disability with disability *tout court*.

No doubt many able people do believe that it is better to be dead than severely disabled. Indeed, the perfectionism of Aristotle and Nietzsche goes much further,

claiming that only a small minority of especially gifted persons is capable of leading a genuinely flourishing life. But perfectionist theories are not required to take a narrow and elitist view of the human good. A plausible form of perfectionism will include on its list of objectively valuable goods things that can be pursued and achieved by many different people in many different ways.<sup>32</sup> Friendship, love, knowledge, and play are such goods. A plausible account of prudential value will recognize that conditions like quadriplegia, blindness, and deafness do not debar one from realizing any of them and leading a flourishing life. It will thus reject the “medical” model of disability according to which the most important disadvantages of disability are intrinsic to or inseparable from impairment. It will agree with the “social” model according to which the main disadvantages are due to society’s response to the impaired condition.<sup>33</sup> But since the Oregon law extends PAS eligibility only to those who are disabled by virtue of being terminally ill, not to those who are disabled by virtue of quadriplegia, blindness, deafness, etc., at most it can reflect and reinforce belief in a medical model of terminal illness, not a medical model of all disability. The Oregon law is fully consistent with the view that the overwhelming majority of severely disabled people who are not terminally ill would have a satisfactory quality of life if society provided them with a decent support network.

The political alliance between pro-lifers and groups like “Not Dead Yet” is powerful enough to block the enactment of PAS laws like Oregon’s in more than a few states. One of the unfortunate fruits of this alliance is inflation in the rhetoric used to impugn the laws and their supporters. Religious, sanctity of life opponents and some DR advocates unite in charging both with elitism, eugenics, a “systematic devaluation of the lives of the terminally ill,” and even Nazism.<sup>34</sup> While such attacks pack a powerful rhetorical punch, they are a polemical ploy of dubious intellectual and moral merit.

Danny Scoccia

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<sup>1</sup> Felicia Ackerman divides up the options differently. Her option #2 is that PAS should be “legally available just to the terminally ill, or possibly just to the terminally ill and to the severely and permanently disabled.” [“Assisted Suicide, Terminal Illness, Severe Disability, and the Double Standard” in *Physician-Assisted Suicide: Expanding the Debate*, ed. by M. Pabst Battin, Margaret Rhodes, and Anita Silvers (New York: Routledge, 1988), pp. 149-61, p. 149]. Note that this conflates my ii) and iii). Ackerman claims to be agnostic about whether PAS for all competent adults should be legalized and to be opposed only to any form of limited eligibility PAS.

<sup>2</sup> The laws are substantially identical. They permit but do not require physicians to provide terminally ill patients (a prognosis of death from natural causes within six months, verified by two physicians) with lethal medications. Patients must take the medications themselves; physicians may not administer them. Only state residents are eligible. Both physicians must attest to patient’s mental competence. There is a waiting period of roughly two weeks between the time of the patient’s formal, written request and the time of its being granted.

<sup>3</sup> [www.notdeadyet.org](http://www.notdeadyet.org). Of course Not Dead Yet does not speak for all disabled people or perhaps even most. According to Andrew I. Batavia and Hugh Gregory Gallagher, the founders of a DR group (“Autonomy, Inc.”) that supports Oregon’s PAS law, “Three consecutive Harris surveys have found that over 60 percent of people with disabilities support the right to assisted dying for competent terminally ill individuals.” That group’s web site is at [www.autonomynow.org](http://www.autonomynow.org).

<sup>4</sup> The brief can be viewed at <http://www.notdeadyet.org/brief.html>. The issue on which the case turned was whether the U.S. Attorney General has the power to decide

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that assisting a suicide is not a “legitimate medical purpose” within the meaning of the Controlled Substances Act. Kennedy’s majority opinion and Scalia’s dissent address this issue only and not the arguments of the DR brief.

<sup>5</sup> Amundson said: “Derek Humphrey, the granddaddy of the movement, made the following prediction in his famous suicide manual *Final Exit*: ‘What can those of us who sympathize with a justified suicide by a handicapped person do to help? When we have statutes on the books permitting lawful physician aid-in-dying for the terminally ill, I believe that along with this reform there will come a more tolerant attitude to the other exceptional cases.’ Humphrey is eager to grease the skids of this slippery slope. We feel threatened for good reason.” The full text of Amundson’s testimony is available from his web-site at <http://www.uhh.hawaii.edu/~ronald/OpEd-suicide2.html>.

<sup>6</sup> Ibid.

<sup>7</sup> “Unspeakable Conversations,” *New York Times Magazine*, Feb. 16 2003.

<sup>8</sup> See Joel Feinberg, *Harm to Self* (Oxford University Press, 1989), p. 12.

<sup>9</sup> Feinberg (ibid.) provides an influential defense of the view that hard paternalism is always wrong. Other defenses of it may be found in John Hodson, “The Principle of Paternalism” *American Philosophical Quarterly* v. 14 (1977) 61-69 and Donald VanDeVeer, *Paternalistic Intervention: The Moral Bounds of Beneficence* (Princeton Univ. Press, 1986). The majority of bioethicists seem to accept it, with Tom Beauchamp and James Childress, *Principles of Biomedical Ethics* being a notable exception.

<sup>10</sup> I rely here on Feinberg’s account of voluntariness in chapters 20 thru 23 of *Harm to Self*. Incorrectly believing that there is no acceptable alternative (e.g. the armed robber’s gun is not loaded, or his threat to shoot unless I surrender my wallet was only a bluff) should be distinguished from incorrectly believing that some alternative is unacceptable (e.g. the robber admits to having a squirt gun, threatens to squirt me

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unless I hand over my wallet, and I have a strong aversion to getting wet). In the first case my choice is forced, in the second it is not (unless the aversion is so strong and irrational as to constitute a form of psychological compulsion).

<sup>11</sup> Some DR advocates see the “death with dignity” argument for legalizing PAS as resting on such false views about dignity. Marilyn Golden, in “Why Assisted Suicide Must Not Be Legalized,” insists that “needing help is not undignified, and death is not better than dependency. Have we gotten to the point that we will abet suicides because people need help using the toilet?” [at <http://www.notdeadyet.org/docs/notlegal.html>]. Ackerman (p. 151) wonders whether proponents of the death with dignity argument have ever heard of Depends diapers.

<sup>12</sup> Isaiah Berlin, “Two Concepts of Liberty,” in *Four Essays on Liberty* (Oxford University Press, 1969), p. 134.

<sup>13</sup> The idea that the satisfaction/frustration of preferences is a good/bad thing only if they are autonomously formed is part of many accounts of autonomy. See Gerald Dworkin’s essay “The Nature of Autonomy” in his *The Theory and Practice of Autonomy* (Cambridge Univ. Press, 1988); Lawrence Haworth, “Autonomy and Utility,” *Ethics* v. 95 (Oct. 1984) 5-19; and Jon Elster, “Sour Grapes—Utilitarianism and the Genesis of Wants” in A. Sen and B. Williams (eds.), *Utilitarianism and Beyond* (Cambridge Univ. Press, 1982).

<sup>14</sup> See the analysis of coercion provided by Robert Nozick in *Anarchy, State, and Utopia* (Basic Books: 1974), p. 262. F.A. Hayek and Eric Mack offer similar analyses.

<sup>15</sup> For a critique of the libertarian’s moralized analyses of coercion, freedom, and voluntariness, see Serena Olsaretti, “Freedom, Force, and Choice: Against the Rights-Based Definition of Voluntariness,” *The Journal of Political Philosophy* v. 6 no. 1 (1998) 53-78.

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<sup>16</sup> Jerome E. Birkenbach, "Disability and Life-Ending Decisions," in Margaret P. Battin, Rosamond Rhodes, and Anita Silvers (eds.), *Physician Assisted Suicide: Expanding the Debate* (Routledge, 1998), p. 126.

<sup>17</sup> See *Harm to Self*, p. 18.

<sup>18</sup> David J. Mayo and Martin Gunderson, "Vitalism Revitalized: Vulnerable Populations, Prejudice, and Physician-Assisted Death," *Hastings Center Report* v.32 no.4 (July-August 2002): 14-21.

<sup>19</sup> This is entirely consistent with what Kant says about suicide in the *Groundwork*, because the case he considers there involves someone who wishes to end his life because its remainder promises more pain than pleasure, not because he is on the verge of losing his personhood capacities. For the Kantian argument against an unqualified "right to die," see J. David Velleman, "A Right to Self-Termination?" *Ethics* v. 109 no. 3 (April 1999) 606-28. For the Kantian argument for the permissibility of suicide when loss of personhood looms, see Thomas Hill Jr, "Self Regarding Suicide: A Modified Kantian View" [chapter 6 of his *Autonomy and Self-Respect* (Cambridge Univ. Press, 1991)]. Velleman endorses Hill's argument, going so far as to claim that "dignity can *require* (emphasis added) not only the preservation of what possesses it but also the destruction of what is losing it, if the loss would be irretrievable" (p. 617).

On my view, the principle that demands respect for others' autonomy will clash with the principle that requires respect for their dignity in cases where their choices reflect false but autonomously formed views about dignity. Velleman denies that such a clash is possible ["respect for a person's autonomy just is an appreciation of a value in him that amounts to a dignity" (p. 612)], but his view invites Berlin's "monstrous impersonation" charge. The "honest" Kantian admits that the two principles can clash and says that when they do the principle of respect for dignity trumps.

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<sup>20</sup> Ackerman, p. 154.

<sup>21</sup> I'm not claiming that this is a significant part of the motivation that leads supporters of a religious, sanctity of life ethic to oppose PAS laws like Oregon's. Perhaps it is not. Surely many are confident that they would never backslide and oppose the law because they believe that PAS is a heinous sin that society should prevent *others* from committing. Note that even if it were the sole motivation for their support of the law, that would not make it an instance of "self paternalism," like Ulysses having himself tied to his ship's mast. Paternalism of any kind, soft or hard, "self" or other, has to be motivated by a concern to protect or advance the prudential good of the subject, not prevent moral weakness of will.

<sup>22</sup> Birkenbach, p. 128.

<sup>23</sup> See Ronald Dworkin, Thomas Nagel, Robert Nozick, John Rawls, Thomas Scanlon, and Judith J. Thomson, "Assisted Suicide: The Philosopher's Brief," *New York Review of Books*, March 27 1997, pp. 41–47. The Brief claims that the number of autonomy violations caused by a ban on PAS "would undoubtedly be vastly greater" (p. 46). The issue in this case was whether terminally ill people have a constitutional right to PAS; the Court ruled that they do not.

<sup>24</sup> Ackerman, p. 155.

<sup>25</sup> Birkenbach, p. 130.

<sup>26</sup> See Daniel Callahan, "When Self Determination Runs Amok," *Hastings Center Report* v. 22, no. 2 (March-April, 1992), pp. 52-55. Callahan's main objection to unlimited PAS isn't entirely clear; it may rest on a religious, sanctity of life ethic. Ackerman objects that if the defense of PAS rests on an absolutism about the inviolability of autonomy, then we must extend eligibility to "people who believe their menstruation, or their irremediable stuttering, clumsiness, or foolishness deprives them

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of human dignity,” as well as to black Americans who believe that their skin color does likewise (p. 151). Note, however, that insofar as the beliefs and preferences of these people were formed under oppressive social conditions, the account of respect for autonomy described earlier does not imply that it is wrong to refuse PAS requests based on them.

<sup>27</sup> This aspect of disability studies is prominent in Shelley Lynn Tremain, *Foucault and the Government of Disabilities* (University of Michigan Press, 2005). For a journalistic piece critical of the Foucaultian orientation of academic disability studies, see Norah Vincent, “Enabling Disabled Scholarship” (at [www.salon.com](http://www.salon.com) originally published August 18, 1999).

<sup>28</sup> Ackerman, p. 152.

<sup>29</sup> Ackerman, p. 153.

<sup>30</sup> Surprisingly, Ackerman seems to endorse it when she says, “if unbearable misery arises from a social injustice that is not being corrected, it is hard to see how justice is served by forcing the victims to live with it, rather than correcting the injustice or by allowing the victims suicide assistance if the injustice is not corrected.” (p. 153)

<sup>31</sup> Anita Silvers, “Protecting the Innocents from Physician-assisted Suicide: Disability Discrimination and the Duty to Protect Otherwise Vulnerable Groups,” in Battin, Rhodes, and Silvers, p. 132

<sup>32</sup> See Richard J. Arneson, “Perfectionism and Politics,” *Ethics* 111, no. 1 (October 2000) 37-63, esp. p. 42. Martha Nussbaum defends a liberal, nonelitist version of perfectionism (a “thick, vague theory of the good”) in her “Aristotelian Social Democracy” [in *Liberalism and the Good* (ed. by R. Bruce Douglas, Gerald Mara, and Henry S. Richardson (New York: Routledge, 1990) pp. 203-52].

<sup>33</sup> The distinction between the “medical” vs. “social” models of disability is central

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to the disability rights movement. For an excellent explanation of it, see Ron Amundson, “Disability, Ideology, and Quality of Life: a Bias in Biomedical Ethics,” in D. Wasserman, J. Birkenbach, and R. Wachbroit, *Quality of Life and Human Difference* (Cambridge University Press, 2005), pp. 101-124. As I understand the distinction, the social model is fully compatible with the claim that other things being equal, one is better off without a disability than with one. That claim—made by John Harris, Allen Buchanan, Peter Singer, and other “mainstream bioethicists”—is criticized by some in disability studies as an expression of ableist prejudice and ideology. I don’t believe that that controversy is directly relevant to the issue of this paper.

<sup>34</sup> The quoted phrase is from Ackerman, p. 154. A “pro life” document that uses the language of “elitism” to impugn defenses of euthanasia for the permanently comatose is the 1992 letter of the U.S. Bishops’ Pro-Life Committee entitled “Nutrition and Hydration: Moral and Pastoral Reflections,” reprinted in B. Steinbock, J. Arras, and A.L. London (eds.), *Ethical Issues in Modern Medicine*, 6<sup>th</sup> ed. (New York: McGraw-Hill, 2003), pp. 341-48.