

## Physician Assisted Suicide and the Disabled

Disability rights advocates condemn certain actual and contemplated “life or death” practices in our society on the grounds that they wrongly discriminate against the disabled. Among these are the selective abortion and/or infanticide of severely disabled babies, and eugenics counseling intended to discourage couples at high risk of producing disabled offspring from reproducing. The focus of this paper will be on another such practice—physician-assisted suicide (PAS). We can distinguish three basic legalization options: i) all competent adults are eligible for suicide assistance; ii) only competent adults who are terminally ill or “severely disabled” are eligible; and iii) only competent adults who terminally ill are eligible (e.g. the Oregon Death with Dignity Act). The objection of disability rights advocates (hereafter, the DR objection) that PAS wrongly discriminates against the disabled 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.”<sup>1</sup> It and other DR groups submitted an *amicus* brief in the case of *Rodriguez v. Oregon* (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>2</sup> Though their legal challenge was rejected, their moral challenge remains: the law offends against the ideal of fair and equal treatment for different groups and encourages an elitist, “ableist” belief in the inferior status of the disabled.

Many discussions of PAS by authors sympathetic to Not Dead Yet’s position assume that autonomy and equality are the only values relevant to deciding the issue; quality of life is a value that should be excluded from the debate because judgments based on it invariably reflect ableist prejudice. I believe that such judgments can be perfectly consistent with egalitarianism and that a satisfactory treatment of the issue can

and should be sensitive to equality, autonomy, and quality of life. I shall argue that there are excellent reasons based on those values to oppose a PAS with either unlimited eligibility or eligibility for the non-terminally ill disabled, but not a PAS that's limited to the competent, terminally ill.

### Two DR Objections; DR vs. "Pro Life" Objections

There are two distinct but compatible variants of the DR objection. According to the "paternalistic" variant, 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. This objection 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. According to the other variant of the DR objection, even if legalized PAS would benefit everyone who chooses it, and they choose it autonomously, the practice should still be forbidden because it harms the class of disabled people as a whole. This objection is analogous to an objection to legalizing prostitution which alleges that doing so would harm all women by sending to sexist males a message that reinforces their sexism (that women are fungible objects whom it is permissible to treat as "mere means").

The second, nonpaternalistic form of the DR objection also shares important similarities 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. The DR objection assumes that disabled people, like racial minorities in the U.S., constitute a historically marginalized group that has suffered systematic injustice. A difference between the race and disability cases is that Jim Crow and anti-miscegenation laws were intended by their white supporters to reinforce white supremacy, whereas certainly limited and probably

even unlimited PAS laws are not intended by most of their supporters to target and oppress all disabled people. But supporters of the DR objections can (and should) reject this difference as irrelevant. What really matters are the foreseeable consequences of a practice, not the intentions or motivations of its supporters. The objection of the civil rights movement to Jim Crow was not that its supporters' racist motivation was sufficient to render it unjust but rather that it helped to buttress racial caste. Supporters of the DR objection should claim similarly that what makes legalized PAS wrong is the actual, foreseeable harm it would do to the disabled. If that harm is both substantial and clearly foreseeable yet supporters of PAS overlook or dismiss it, then the charge that they are motivated by ableist prejudice (perhaps unconsciously) becomes credible. But it would still be PAS's consequences rather the motivation of its supporters that make the practice wrong.

Ron Amundson endorsed the paternalistic version of the DR objection in testimony he gave to the Hawaii state legislature opposing a proposed PAS law similar to Oregon's. Speaking on behalf of Not Dead Yet, Amundson said that the group:

... 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>3</sup>

Adrienne Asch has defended the "prevention of harm to all disabled people" version of the DR objection to selective abortion that targets disability.<sup>4</sup> Asch says:

... prenatal diagnosis and selective abortion communicate that disability is so terrible it warrants not being alive.... Women will be forced to decide whether or not they want to carry their pregnancies to term knowing that children are predisposed to cancer, heart disease, diabetes, or depression. As a society, do we wish to send the message to all such people now living that there should be "no more of your kind" in the future? If we use the technological solution of prenatal diagnosis to eliminate such people, what will become of our attitudes and practices toward any of those odd people who were missed by the

technology and happened to be born? What will happen to our attitudes toward and services for the millions of people whose disabilities occur in childhood, adolescence, or later in life through accident, disease or anything that could not be detected prenatally? What attention will we continue to give to the enforcement of civil rights or to the barely begun environmental and institutional changes that seek to remove barriers for disabled people and to encourage their full social, economic, and political participation?<sup>5</sup>

Asch identifies two ways in which the practice she is attacking would harm disabled people: directly, via the hurtful message it conveys to them (“you don’t have lives worth living”), and indirectly, by weakening the willingness of the able to provide accommodations and support for the disabled. Supporters of the nonpaternalistic DR objection to legalized PAS make similar claims about that practice.

What, if anything, is the difference between the DR objection to legalizing PAS and the objection of “pro-lifers”? That there is some perhaps superficial similarity in the positions of the disability and right to life movements on this issue is undeniable. Both assume that equality is the central value at stake in the debate, that proponents of legalization are elitists who support discrimination against the disabled. Both the DR movement and defenders of the sanctity of life ethic vilify Peter Singer, “mainstream bioethics,” the “personhood” criterion of who has full moral status, and “the quality of life ethic.”<sup>6</sup>

The pro-life movement’s objection to PAS is based on the “sanctity of life” principle. I take that principle to be an absolute deontological side-constraint that forbids the intentional killing (or the abetting or assisting thereof) of any *homo sapien* at any stage of its life (from conception to brain death), regardless of whether the human being to be killed is better off dead and he or she consents to or requests “a quick and painless death.” So stated there is nothing essentially “religious” about the principle. It becomes religious only when pro-lifers defend it *via* the argument that all human beings (not just those who are “persons” in the Kantian sense) have full moral status because they were

created in God's image, and to intentionally kill an innocent human is to infringe on God's dominion over life.

One difference between the objections of the two groups is that one relies on these religious ideas while the other does not. According to views like John Rawls' "political liberalism," the fact that the pro-life objection depends on religion is sufficient to discredit it, because public policy in a liberal democracy ought to be decided on "neutral" or "public" grounds that all reasonable citizens must acknowledge regardless of which "comprehensive philosophical doctrines" they happen to accept.<sup>7</sup> If we reject Rawls's view and hold that it is permissible for citizens to base their political convictions on their religious beliefs, then the fact that the pro-life objection is based on religion while the DR objections are based on "public" values may not be so significant. In any case there are other differences between them at least as important as this one. The most important one is that the DR objection says that we ought to oppose legalized PAS because it would *harm* disabled people, whereas the pro-life objection is that it would give to man a prerogative that is God's alone. The former opposes legalization on the basis of the "legal paternalism" and "harm to others" principles, whereas the latter opposes it on the basis of "pure legal moralism."<sup>8</sup> Of course many right to lifers do think that legalized PAS would lead to harm or rights violations of the weak and defenseless (e.g. poor and elderly people who might be pressured into "consenting" to their quick deaths). Many worry that legalizing PAS for the competent terminally ill will eventually lead via the slippery slope to legalizing active euthanasia for incompetents who are not terminally ill. But these concerns seem secondary. The heart of the pro-life objection to legalization is the sanctity of life principle, and that principle implies that it is wrong to abet the killing of innocent persons, even if doing so would not harm them or others.

Another difference between the objections is that the DR objection condemns legalized PAS only for present day, ableist societies. In a fully just society that has

overcome ableism and shows equal concern for everyone's most urgent needs, a PAS for all competent adults and possibly even a PAS limited to the terminally ill would not harm the disabled and thus would be unobjectionable. The objection of religious right-to-lifers assumes, to the contrary, that PAS of any kind would remain wrong even in a society in which the disabled are fully empowered and all traces of ableist ideology have vanished.

### The Paternalistic DR Objection; Soft and Hard Paternalism

Let's consider the paternalistic DR objection more closely. Calling it "paternalistic" does not imply an adverse judgment of it. After all, there are plenty of examples of paternalism whose justifiability few 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 beside libertarians 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 Amundson's objection to PAS: to protect those who are weak, vulnerable, and easily exploited from making choices that are contrary to their long term prudential good.

Amundson distinguished three different motivations that might lead a disabled person to choose suicide. One is a self interested calculation based on how low one's quality of life is likely to be in an ableist society that neglects the basic needs of the disabled. The other two are a shame based on the belief that a life with disability cannot possibly be a dignified one 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 the latter two ways is "forced," and it is difficult to see why they would have to be. I want

to suggest (on Amundson's behalf) that his focus on coercion is misplaced and that what really concerns him are choices deficient in *autonomy*. Choices that are coerced by an absence of acceptable alternatives ("external coercion") are certainly nonautonomous, but so are choices that are the product of psychological compulsion (literally irresistible urges, a kind of "inner coercion") and even choices that are the result of fully voluntary weakness of will. Amundson supposes that a refusal to provide PAS to the disabled who want it does not violate their autonomy because their requests for suicide assistance are not genuinely autonomous. The reason why they are nonautonomous is that they are based on motivations that reflect a false, ableist ideology and thus manifest a sort of "false consciousness." Any disabled person who recognizes ableism as an ideology that serves the interests of the able at the expense of the disabled (thereby achieving something like the Marxist's "class consciousness") would not feel ashamed of his condition or believe that he is a burden on his society.

The notion of an "autonomous choice" requires more clarification than I can give it here, but it is a familiar one from many accounts of informed consent in biomedical ethics and many discussions of the core values of liberal political morality.<sup>9</sup> I assume that being fully voluntary isn't sufficient for a choice to be autonomous, and being fully rational and/or prudent isn't necessary. A choice (e.g. to continue smoking rather than try to quit) can be both fully autonomous yet contrary to one's long term interests. When confronted by friends/loved ones who cannot be dissuaded from making such choices, we may wonder if and when it is morally right forcibly to intervene. If acting on the choice would do them serious and irreparable harm, the principle of beneficence requires that we prevent them from acting, while the principle of respect for autonomy forbids forcible intervention. (Persuasion is okay, but deception, manipulation, and coercion are not). The two moral principles (considered as "prima facie" duties) conflict in these cases, raising the question of which takes priority. The answer to that question determines

whether “hard” paternalism is ever permissible. Hard paternalism restricts a competent adult’s liberty for her own good in ways that violate her autonomy—for example, forcing a blood transfusion on an unwilling, adult Jehovah’s Witness who’s at risk of dying without it. Soft paternalism restricts liberty for the person’s own good but without violating autonomy, because the person in question either previously consented to the coercion or would now consent, given her present values and preferences, if she were thinking clearly and were well-informed of relevant factual matters. A clear example of this is forcing someone who has accidentally poisoned himself to swallow the antidote, after efforts to persuade him that he will die without it have failed.

It is widely thought that the distinction between soft and hard paternalism is morally significant in a simple and direct way: soft paternalism is permissible while hard paternalism never is. Whether or not Amundson and other defenders of the paternalistic DR objection share this view is a question to which we’ll return later. I think they assume that in deciding whether to allow disabled people who choose suicide to proceed, we do not have to settle whether beneficence overrides autonomy or *vice versa*, because there is no conflict between the two principles in this case. The decision of most disabled people to opt for suicide, like the choice of those in desperate need to borrow at usurious interest rates, is both nonautonomous and extremely imprudent. The paternalism that justifies thwarting such choices is soft.

Libertarians will reject the paternalistic DR objection to PAS for at least two reasons. First, they deny that the choice of PAS is usually coerced. Coercion according to the standard libertarian view occurs only when one has been physically restrained or threatened with extreme evil by another agent who had no right to limit one’s options in those ways.<sup>10</sup> Since no one is putting a gun to the head of the quadriplegic/desperate borrower and demanding “either opt for PAS/accept the loan at a usurious rate or I’ll blow your brains out,” the choice to opt for PAS/accept the loan is not coerced. The

problem with this criticism of Amundson is that it depends upon an unduly narrow view of what coercion is.

The libertarian's other objection is that even if a wider conception of coercion is correct, then while it may turn out that the choice of most quadriplegics/desperate borrowers to opt for PAS/the usurious loan will qualify as coerced, the choice of others, perhaps only a minority, won't. But a blanket ban would apply to all disabled people/borrowers, including 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>11</sup>

If we accept Birkenbach's "commonplace" (as I think we should), then we must reject the second libertarian reply to the paternalistic DR objection. 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 is restricted by it would consent to the law (if they 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 minority in X whose choice is neither imprudent nor deficient in autonomy. The proviso to this principle is that there is no feasible way for the state to distinguish the minority from the majority, and its only options are to permit all in X the freedom to do Y or permit none.

### Problems with a Soft Paternalist Rationale for No PAS

The failure of the libertarian criticisms of the paternalistic DR objection does not mean that the objection succeeds. There are other problems with it. Anita Silvers worries about the negative side-effects for other disabled people of the paternalism that Amundson and Birkenbach defend. Preventing quadriplegics from opting for suicide “for their own good” would harm disabled people 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>12</sup>

Perhaps the biggest problem of all with the paternalistic DR objection as Amundson and Birkenbach present it lies with their assumption that if a choice is coerced (and thus, nonautonomous), then it follows that thwarting it will not violate the chooser’s autonomy. That assumption is incorrect: interference with a nonautonomous choice can still violate autonomy. Consider a WW II British spy who has been captured by the Gestapo and can either swallow a cyanide capsule or suffer torture followed by

execution. His decision to swallow the cyanide is nonautonomous (because coerced), but he certainly would not, if rational and well-informed, consent to anyone's preventing his suicide. Both the quadriplegic who opts for suicide over life in an ableist society that provides few accommodations and little support, and the terminally ill person who chooses a quick and painless death over a "natural" but protracted and anguish-filled one seem to me relevantly like the case of someone who urgently needs money and can borrow it only at usurious interest rates. All are coerced, none is autonomous. But that doesn't settle the question whether a denial of PAS to such persons is justifiable on soft paternalist grounds.

So would a ban on PAS violate autonomy, or can it be justified on soft paternalist grounds? Let's begin with unlimited eligibility PAS (i.e. no restriction to the terminally ill and/or severely disabled). The soft paternalist argument against this option might seem most promising, given that the majority of all people who attempt suicide seem to suffer from emotional disturbance or mental illness of some sort.<sup>13</sup> Wouldn't they if rational consent to others' denying them suicide assistance or even thwarting their own, unassisted efforts to end their lives? Probably most of them would, but there is surely also a minority who wouldn't consent, so the proviso to Birkenbach's "commonplace" requires that we (or the state) distinguish that minority from the majority if it's feasible to do so. And doing so might be feasible. We could require that applicants for PAS undergo psychiatric screening to ensure that they are in their right minds. Perhaps such a screening requirement would be costly to administer and not entirely effective, but perhaps we could offset those costs by charging PAS applicants a fee. If this is practicable, then soft paternalists shouldn't oppose unlimited eligibility. They should support it together with a screening requirement.

What about PAS for the terminally ill only? Birkenbach cites "the findings of psychologist Carol Gill that the desire among 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>14</sup> But it does not follow from Gill’s findings that terminally ill people would consent to others’ denying them the option of PAS. The final stage of dying can be quick or prolonged, and whether or not terminally ill people lack adequate resources and treatment options, the overwhelming majority of them are likely to prefer quick to prolonged even when there is no difference in pain between the two. One of the things we fear about dying is something that the use of powerful narcotics usually exacerbates rather than prevents, namely, the gradual loss of mental functioning and ability to interact with others. We fear lapsing into a coma and then being kept alive in such a state through advanced medical technologies. Often there’s an element of altruism to this fear: we wish to spare our loved ones the anguish of watching us linger indefinitely in a pitiful, undignified state. Surely this reasonable fear is what prompted Sue Rodriguez to fight for a legal right to suicide assistance. For this reason it seems likely that the majority of terminally ill people in contemporary America would not consent on purely self-interested grounds to having the option of PAS denied to them, even if they were assured of satisfactory terminal care and adequate “pain management.”<sup>15</sup>

It has to be admitted, however, that a certain number of terminally ill people would, if it were legal, choose PAS before they are ready to die and while they still enjoy a satisfactory quality of life, because they’ve been pressured by others not to be “a burden.” Denying them the option of PAS would not violate their autonomy. Whether these cases represent only a minority of terminally ill people, as the Philosopher’s Brief claims and I agree, is doubted by Felicia Ackerman, who objects that the Brief “gives no good reason to believe this far-from-obvious claim.”<sup>16</sup> But surely if there is a “presumption” here, it is that restrictions of liberty will cause more violations of autonomy than no restrictions will. The “burden of proof” seems to me to fall 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, I conclude that their attempt to justify no PAS for the terminally ill on soft paternalist grounds fails.

What about the soft paternalist argument against PAS eligibility for the seriously disabled who are not terminally ill? Wouldn't those severely disabled people who desire to end their lives only because they are ashamed of their condition or wish not to be a burden to others consent to having their suicide choices thwarted or left unassisted by others, if their thinking weren't distorted by ableist prejudice? The answer to this question seems to me that they clearly would. But that does not give us a soft paternalist rationale for denying their suicide requests. While their belief that a life with disability cannot be dignified reflects deep normative error, it is still *their* belief and *their* error. If we thwart their choices we should be honest about what we are doing and admit that we are violating autonomy. 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>17</sup> Instead of pretending that the paternalism we are practicing is "soft," we should admit that it is "hard."

What of the seriously disabled person whose suicide decision is based on a self-interested calculation about how bad the remainder of his life is likely to be in a society where ableist prejudice is deeply entrenched? If the discrimination and injustice that he suffers are bad enough, then his situation may be comparable to that of the slave with no hope of emancipation, doomed to a life of abuse and suffering. A decision to commit suicide in such circumstances is coerced and nonautonomous, but like the decision of the British spy to swallow the cyanide, it may be prudent in the circumstances and one that he would approve of if he could step back and evaluate it from a hypothetical standpoint that is rational, well informed, and free of all coercive influences. The best

objection to the suicide decision of the seriously disabled person whose plight is this bad may not be paternalistic at all. It might be one that cites his moral duty to other disabled people to remain alive, become politically active, and fight for the cause of disability rights. The idea that such a duty exists fits well with the nonpaternalistic objection to PAS for the seriously disabled which we'll examine shortly.

### The Hard Paternalist Objection to Unlimited Eligibility

In addition to the soft paternalist objection to unlimited eligibility PAS which we have considered and rejected, there are several other possible objections to it, including the objection of pro-lifers based on sanctity of life, an objection based on the Kantian principle of humanity, and hard paternalism. I won't examine the Kantian objection here.<sup>18</sup> I wish to defend the hard paternalist objection. According to the hard paternalist, whether it is possible to implement an affordable and effective screening requirement for unlimited eligibility PAS is largely beside the point. Respect for autonomy is not the only or even the main reason to provide PAS eligibility to those who are terminally ill or to deny it to those who are not. We should deny PAS to many whose suicide decision would be fully autonomous because they are much better off alive than dead and our duty to prevent them from suffering grave harm overrides our duty to respect their autonomy. Correlatively, there should be PAS eligibility for the terminally ill not simply because there are likely to be fewer autonomy violations under that policy than if PAS is forbidden to everyone. Part of what justifies it is that most terminally ill people will reach a point where they are better off ending their lives than waiting for a "natural" death, making their suicide decisions both autonomous and prudent or rational.

Hard paternalism comes in different strengths. The extreme hard paternalist holds that *whenever* beneficence and respect for autonomy conflict, beneficence *always*

trumps. This view implies, quite implausibly, that we should force the life saving blood transfusion on the Jehovah's Witness who refuses to consent to it. The moderate hard paternalist admits that there are cases like this one in which autonomy trumps beneficence but holds that there are other types of cases in which beneficence overrides autonomy. An example might be someone who wishes to kill himself (call him "Jeff") because he has been unfaithful to his wife. After calm and careful deliberation Jeff has decided that he deserves to die as punishment for his infidelity. The moderate hard paternalist agrees with Daniel Callahan that a society that provides PAS to people like Jeff is one in which self-determination has "run amok."<sup>19</sup> Of course the hard paternalist who says this will have to identify relevant differences between the two types of cases. I believe that that can be done but won't pursue the matter here.

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 a subgroup of the disabled, the terminally ill. That limit, it insisted, was proof of ableist prejudice. Not Dead Yet was assuming that the justification for the Oregon law has to rely exclusively on 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:

Why should the right to physician-assisted suicide depend on whether one is physically able to perform the act? What does it matter that one is in pain, or in a terminal state, or has any medical condition whatsoever? We learn from John Stuart Mill that the value and importance of self-determination is not contingent on what is decided or done. 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, as a final submission, that if the court ignores all of its preceding arguments and 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>20</sup>

Birkenbach and Not Dead Yet see ableist prejudice behind the Oregon law because they ignore the possibility that the justification for its limits is hard paternalism. They're right to note that the autonomy principle 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. According to the hard paternalist, the justification for denying eligibility to those who are not terminally ill is that for most who fall in that category and wish to end their lives, beneficence trumps respect for their autonomy. We should deny PAS to people like Jeff not out of respect for their autonomy but in spite of that fact that we're violating it.

I suspect that Birkenbach, Not Dead Yet, and other DR advocates overlook the possibility of a hard paternalist justification for 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 genuine autonomy exists 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. DR advocates who take this view about autonomy are likely to regard empowerment for the disabled as important only because it allows them to make fully autonomous choices. (An alternative view is that it is valuable mainly as a means to increased well being). Much of "disability studies," especially those quarters of it that lean heavily on Michel Foucault's views about "power," seems committed to the primacy of the value of autonomy.<sup>21</sup>

To highlight the differences between this DR approach and the moderate hard paternalism that I wish to defend, consider the case of Jim, who can no longer play competitive rugby, his life's passion, because a traffic accident has left him paraplegic.

He is convinced that his life is no longer worth living and wants to end it. We stipulate that his suicide decision is fully autonomous, that his values and preferences are not infected by ableist prejudice, that they were formed in a society in which the disabled are fully integrated and empowered. I believe that under these conditions Amundson, McBryde-Johnson, Birkenbach, and Ackerman would all have to say that Jim has a moral right to receive suicide assistance from anyone willing to provide it. By contrast, the moderate hard paternalist says that we should block his decision if it is likely that he will adapt to his condition and eventually come to enjoy his life.<sup>22</sup>

### Objections to the Hard Paternalist Argument

The hard paternalist claims that people like Jeff and Jim are *better off alive* and that this gives us a very strong reason to thwart their suicide decisions. By contrast, the majority of those who are terminally ill and wish to end their lives judge correctly that they are or soon will be *better off dead*. An objection to the argument is that any judgment to the effect that someone is better off dead is unavoidably “elitist.”

The objection fails, because it confuses prudential value and moral status judgments. A prudential value judgment takes the form of “so and so is better off in condition X than in condition Y,” while moral status judgments have the form “people in condition X are equal to/count more than people in condition Y.” Hedonism and perfectionism are theories of prudential value, while liberal egalitarianism, racism, and the “speciesism” of the sanctity of life principle are some possible views about moral status. “X is better off alive while Y is better off dead” is a prudential value judgment, and the elitist moral status judgment “Y is superior to/has a higher moral status than X” does *not* follow from it.<sup>23</sup>

John Harris has claimed that to be disabled is to be in a harmed condition, which means that other things being equal, one is better off without the disability than with it. He claims that “disability studies” is guilty of the fallacy of supposing that from the prudential value judgment, “people are (other things being equal) better off able than disabled,” an elitist moral status judgment, “able people are superior to (entitled to more rights and privileges than) disabled people,” follows.<sup>24</sup> Allen Buchanan also claims to find this inference in the writings of many DR advocates.<sup>25</sup> Clearly the inference is fallacious. If we can encourage children to go to college because it would be good for them without thereby implying that people with no college education are less worthy than those with a college degree, then surely it is *possible* to “devalue” disabilities and try to prevent them without thereby implying that people with disabilities are less worthy.<sup>26</sup> Whether Harris and Buchanan are correct to claim that this logical error is commonplace in disability studies, I do not know, but I would point out that it is possible to believe that certain PAS practices both reduce the number of disabled people and promote an elitist view about their moral status without believing that they do the latter *by virtue of* doing the former. I’ll return to this point in the next section.

No doubt there are views about prudential value that reflect elitist prejudice. These include the perfectionism of Aristotle and Nietzsche, according to which only a small minority of especially gifted persons is capable of achieving a genuinely flourishing life. But even a perfectionist account of the good can avoid elitism by recognizing that the lives of average grade school teachers, woodworkers, janitors, etc. can be just as worthwhile as those of the very greatest philosophers and artists. All it need do is include on its list of objectively valuable goods things that can be pursued and achieved by many different people in many different ways.<sup>27</sup> Friendship, love, knowledge (theoretical and practical), and play are such goods. A plausible perfectionism will recognize that conditions like quadriplegia, blindness, and deafness do not debar one

from realizing any of them and leading a flourishing life. There is no reason why its quality of life judgments should reflect a “medical” model of disability (according to which the most important disadvantages of disability are intrinsic to or inseparable from impairment) as opposed to a “social” model (according to which they are due to society’s response to the impaired condition).<sup>28</sup>

Felicia Ackerman advances what may seem the most serious objection to a hard paternalist argument for limiting PAS eligibility to the competent terminally ill. Doesn’t such an argument 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>29</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 because the remainder of their lives is likely to be utterly miserable, should, according to a principle of beneficence sensitive to quality of life, include some who are not sick or disabled at all. 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>30</sup> Since the principle of beneficence really supports PAS eligibility for anyone with a very low quality of life, those who want to limit PAS to the terminally ill cannot really be motivated by a commitment to beneficence. Their support for that limit instead betrays an elitist “double standard.”

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 a PAS limited to the terminally ill to be justified. Two points can be made here.

First, laws need to draw bright, easily identifiable lines. A law that makes only the terminally ill eligible for PAS draws such a line, whereas a law that extends eligibility to everyone 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. Second, it seems perverse to accuse those who support (on the basis of beneficence) PAS for the terminally ill only of being motivated by an elitist “double standard” because they *oppose* PAS eligibility for the severely disabled who are not terminally ill. The overwhelming majority of severely disabled people would have a satisfactory quality of life if only society provided them a decent support network. By contrast, the majority of those who are terminally ill eventually reach a point where they are better off with a quick and painless death no matter how supportive society is of their needs. Ackerman seems to think that this difference between the two groups is irrelevant, because “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.”<sup>31</sup> The reply to this is that allowing suicide assistance to the severely disabled because the injustice of inadequate social support has not been corrected would probably make it more difficult to correct it. A society that gives quadriplegics the option of assisted suicide is less likely to see the need to provide them with improved support. This is precisely the point of the nonpaternalistic version of the DR objection, to which I now turn.

## The Nonpaternalistic DR Objection

There are two ways in which any of the three PAS options might harm all disabled people. The first, indirect way is by promoting the belief that the decision of a disabled person to end his life is natural and rational. It might support or lend legitimacy to the “medical” model of disability according to which blindness, deafness, paralysis, etc. necessarily reduce quality of life greatly, regardless of how society responds to people with those conditions. Widespread acceptance of the “medical” model harms disabled people by implying that it is fruitless and wasteful to attempt to improve their quality of life through laws that require all public buildings to be wheelchair accessible, all employers to provide reasonable accommodations for disabled workers, and so on. If it lends credence to the medical model, a practice of PAS will harm disabled people by encouraging the able majority to withhold various forms of social support from them. The second way in which PAS might be thought to harm the disabled is through the message it communicates directly to them—“you people are better off dead.” In doing that it contributes to a public culture that denies disabled people what John Rawls called “the social bases of self-respect.”

The “social meaning” of a practice is not determined by the motivations of its supporters or whether the practice is in fact justifiable, by logic or by the correct moral theory (whatever it is). It is determined instead by contingent cultural and historical facts that vary from society to society. It is possible to imagine a society in which *de jure* racial segregation does not have a social meaning that harms the racial minority living in it. “Separate but equal” is not a contradiction and might actually serve legitimate, nonracist goals in a society very different from ours, that is, one that is not (still) trying to overcome the legacy of slavery and the KKK. Ours is a society with a long history of ignoring the justice demands of the disabled, of assuming that support for the disabled is

a matter of “charity” for church groups and other private entities. That history will affect the social meaning of many practices that involve the disabled.

To which of the three legalization options is the nonpaternalistic DR objection a good and decisive objection? I think we ought to agree that it is decisive against a PAS for terminally ill and disabled people only. That PAS option looks too much like a law that allows only black women, not white women, to have abortions. Though white women would have a grievance insofar as they are denied an important reproductive liberty, the social meaning of this law would be “there are more than enough of your kind,” and that would harm all black people both directly, by inflicting insult and psychological harm on them, and indirectly, by encouraging racist attitudes and behaviors in white people. It seems to me clear that a PAS under which disabled people who are not terminally ill are eligible but people like Jeff (the retributive suicide) are ineligible would harm disabled people directly by communicating the message that they are better off dead. It would also indirectly harm them by reinforcing widespread acceptance of the “medical” model of disability.

Note that one can endorse the nonpaternalistic DR objection to a PAS practice without conflating prudential value judgments and moral status judgments. The objection is not that *any* practice that would reduce the number of disabled people in the world would harm those who are living by saying to them, “you shouldn’t exist.” Counseling pregnant women to have adequate amounts of folic acid in their diet reduces the number of disabled people but doesn’t have an iniquitous social meaning. Since the majority of DR activists would surely admit this, they surely believe that it is *possible* for society to prevent disability because of its prudential disvalue without implying that disabled people have an inferior moral status. Whether or not either unlimited eligibility PAS or PAS limited to the terminally ill has the same iniquitous social meaning as a PAS limited to the terminally ill or the seriously disabled is question of empirical sociology.

The majority of DR activists may well believe that both do have such a meaning, and in believing that they may well be mistaken. But that's a different mistake from the logical blunder that Harris and Buchanan attribute to them.

I doubt that the other two PAS options (unlimited eligibility and the terminally ill only) have an iniquitous social meaning under current circumstances, and I see no hope for Not Dead Yet's view that unlimited eligibility might be innocuous while eligibility for the terminally ill only is iniquitous. If the quadriplegic who is not terminally ill is not eligible for suicide assistance under Oregon's Death With Dignity Act, how can able people possibly see it as endorsing the medical model of disability? How can that quadriplegic or other disabled people possibly interpret that law as implying that the disabled are second class citizen? In fact, according to Andrew I. Batavia and Hugh Gregory Gallagher, the founders of a DR group ("Autonomy, Inc.") that supports Oregon's PAS law, the majority of them do not. "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."<sup>32</sup>

Amundson claims that PAS just for the terminally ill poses a threat to the disabled even if it does not have the same iniquitous social meaning as PAS for the terminally ill or severely disabled. Amundson thinks there is the danger of sliding down a slippery slope: adopting PAS laws like Oregon's increases the chances that we will eventually legalize PAS for the seriously disabled too. Indeed, PAS for the severely disabled is the hidden agenda of supporters of PAS for the terminally ill only, such as the Hemlock Society. Amundson says:

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.<sup>33</sup>

But like many empirical slippery slope arguments, this one is not very plausible. If Humphrey or the Hemlock Society were a powerful lobby and public opinion shaper, then Amundson's fear might be justified. Since they are not, the fact that they hope or expect that PAS for the terminally ill only will eventually lead to PAS for the disabled too is not very strong evidence that it in fact will.

### Conclusion

In this paper I have argued:

- i) The soft paternalist DR objection to either a PAS for the terminally ill only or a PAS for the terminally ill or the severely disabled living in an ableist society fails. There is no good paternalistic objection to either practice.
- ii) There is a good paternalistic objection to unlimited PAS based on moderate hard paternalism.
- iii) There is nothing "elitist" about the judgment that a terminally ill person in the final stages of her illness may be "better off dead."
- iv) The nonpaternalistic version of the DR objection is the reason why we should oppose PAS for the terminally ill or the severely disabled. But when directed at PAS for the terminally ill only, that objection fails.

If the arguments were sound, then opponents of PAS laws like Oregon's should abandon the rhetoric of "elitism," "genocide," and so on. Associating such laws (and a defense of them that appeals to beneficence or quality of life considerations) with Nazism, eugenics, or a "systematic devaluation of the lives of the terminally ill" packs a powerful rhetorical punch, but it is a polemical ploy of dubious intellectual and moral merit.<sup>34</sup>

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<sup>1</sup> [www.notdeadyet.org](http://www.notdeadyet.org)

<sup>2</sup> The brief can be viewed at <http://www.notdeadyet.org/brief.html>.

<sup>3</sup> The full text of Amundson's testimony is available from his web-site at <http://www.uhh.hawaii.edu/~ronald/OpEd-suicide2.html>. Harriet McBryde-Johnson is another writer who supports the paternalistic DR objection. In "Unspeakable Conversations," (*New York Times Magazine*, Feb. 16 2003), McBryde-Johnson says, "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>4</sup> Asch judges such abortion permissible only if the disability would cause "protracted physical pain or death in infancy or early childhood." See Adrienne Asch, "Real Moral Dilemmas," *Christianity and Crisis* v. 46, no.10 237-240; reprinted as "Can Aborting 'Imperfect' Children Be Immoral?" in J. Arras and B. Steinbock (eds.) *Ethical Issues in Modern Medicine* (Mayfield Publishing, 1999), 5<sup>th</sup> ed., pp. 384-88.

<sup>5</sup> Asch, *ibid.*

<sup>6</sup> For an overview of some objections to mainstream bioethics from a DR perspective, see Ron Amundson and Shari Tresky, "On the Bioethical Challenge to Disability Rights," *Journal of Medicine and Philosophy* 32 (2007) 541-61. For criticism of mainstream bioethics from the perspective of a religious right to life ethic, see Wesley J. Smith, *Culture of Death: The Assault on Medical Ethics in America* (San Francisco, CA: Encounter Books, 2000), as well as his post "Personhood Theory: Why Contemporary Mainstream Bioethics is Dangerous" at <http://www.wesleyjsmith.com>.

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<sup>7</sup> John Rawls, *Political Liberalism* (Columbia University Press, 1993).

<sup>8</sup> “Pure legal moralism” is the principle that the prevention of “inherent immorality” (i.e. wrong actions that neither set back the agent’s own vital interests nor wrongfully cause harm to others) can justify restrictions on liberty. See Joel Feinberg, *Harmless Wrongdoing* (New York: Oxford University Press, 1990) chapter one for an explanation of pure legal moralism, and Feinberg’s *Harm to Others* (New York: Oxford University Press, 1987) for discussion of the harm principle.

<sup>9</sup> For a discussion of autonomous choice and informed consent, see Tom Beauchamp, *Principles of Biomedical Ethics* 6<sup>th</sup> ed (Oxford University Press, 2008), chapter 4. For a defense of a liberal perfectionism based on the core value of autonomy, see Steven Wall, *Liberalism, Perfectionism, and Restraint* (Cambridge University Press, 1997).

<sup>10</sup> See the analysis of coercion provided by Robert Nozick in *Anarchy, State, Utopia* (Basic Books: 1974), p. 262. F.A. Hayek and Eric Mack give similar analyses.

<sup>11</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>12</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>13</sup> Feinberg, however, denies that most suicide attempts are nonvoluntary. See his discussion in *Harm to Self*, p. 127.

<sup>14</sup> Birkenbach, p. 128.

<sup>15</sup> I concede that many Americans committed to the sanctity of life principle might not want the option of PAS available to them. They regard the option as immoral and

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may fear that if it were available they might backslide and choose it. But supporting a restriction on someone's liberty to prevent him from acting contrary to his moral conscience is not the same thing as supporting it "for his own (prudential) good." This reason in support of a ban on PAS is not based on paternalism (soft or hard) at all. I also question whether we ought to attach much moral weight to it if we think that the moral principles from which people are being prevented from backsliding are false.

<sup>16</sup> Ackerman, p. 155. The Philosophers' Brief authored by Dworkin, et. al. claims that the number of autonomy violations caused by a ban on PAS "would undoubtedly be vastly greater" (p. 46).

<sup>17</sup> Isaiah Berlin, "Two Concepts of Liberty," in *Four Essays on Liberty* (Oxford University Press, 1969), p. 134. 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.

<sup>18</sup> I won't be considering the Kantian argument against an unlimited PAS and for a PAS that's limited to the terminally ill. Thomas Hill Jr. defended a Kantian argument for the permissibility of suicide by those on the verge of losing their personhood capacities in "Self Regarding Suicide: A Modified Kantian View," chapter 6 of his *Autonomy and Self-Respect* (Cambridge University Press, 1991). J. David Velleman defends the Kantian position in "A Right to Self-Termination?," *Ethics* v. 109 no. 3. For discussion of how the Kantian argument differs from hard paternalism, and for some criticism of Velleman, see Danny Scoccia, "In Defense of Hard Paternalism" *Law and Philosophy* (2008) 27: 351-81(April 1999): 606–28.

<sup>19</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, but it certainly isn't hard paternalism.

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<sup>20</sup> Birkenbach, p. 130.

<sup>21</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>22</sup> "But if there's good reason to think that Jim will eventually come to enjoy a life without rugby, then a hypothetical well-informed Jim who is cognizant of that reason would consent to our thwarting his suicide, in which case denying him suicide assistance won't violate his autonomy." Reply: there's no guarantee that a well-informed Jim would consent to our interfering with his suicide decision. On the basis of his present values he might thoroughly disapprove of a future self that accepts a life without rugby. He might judge such a self to be guilty of corruption or "selling out."

<sup>23</sup> Suppose X is you or me, while Y is someone who is trapped in a fire, has no hope of being rescued, and faces a certain and excruciatingly painful death. Y is better off if he commits suicide than if he is burned alive, and you or I would be too if we were in his shoes. There is nothing remotely "elitist" about such judgments.

<sup>24</sup> John Harris, "One principle and three fallacies of disability studies," *Journal of Medical Ethics*, v. 27, no. 6 (Dec 2001): 383-88. Jeff McMahan has argued that if disability were not a harmful condition, then there would be no objection to causing people to be disabled. See his "Causing Disabled People to Exist and Causing People to be Disabled," *Ethics* 116 (October 2005): 77-99.

<sup>25</sup> Allen Buchanan, "Choosing who will be disabled: genetic intervention and the morality of inclusion," *Social Philosophy and Policy* 13 (1996), pp. 18-46.

<sup>26</sup> Buchanan, p. 33.

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<sup>27</sup> See Arneson, "Perfectionism and Politics," *ibid*, p. 42. Martha Nussbaum defends a liberal, nonelitist version of perfectionism (a "thick, vague theory of the good"). See 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>28</sup> The "medical" vs. "social" models of disability distinction is central 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.

<sup>29</sup> Ackerman, p. 152.

<sup>30</sup> Ackerman, p. 153.

<sup>31</sup> Ackerman, p. 153.

<sup>32</sup> See that group's web site at [www.autonomynow.org](http://www.autonomynow.org).

<sup>33</sup> See his testimony to the Hawaii State Legislature (citation in note #3 above).

<sup>34</sup> The quoted phrase is from Ackerman, p. 154.