

COST-EFFECTIVENESS AND DISABILITY DISCRIMINATION

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It is widely recognized that prioritizing health care resources by their relative cost-effectiveness can result in lower priority for the treatment of disabled persons than otherwise similar non-disabled persons. I distinguish six different ways in which this discrimination against the disabled can occur. I then spell out and evaluate the following moral objections to this discrimination, most of which capture an aspect of its unethical character: it implies that disabled persons' lives are of lesser value than those of non-disabled persons; it constitutes "double jeopardy" or violates Frances Kamm's non-linkage principle; it conflicts with equality of opportunity; it conflicts with fairness, which requires ignoring (some/most) differential impacts of treatment; it wrongly gives lower priority to disabled persons for equally effective treatment; it conflicts with giving all persons an equal chance to reach their full potential; and, it is in conflict with giving priority to the worse off.

INTRODUCTION

It is widely accepted that the prioritization of health-care resources should be guided by two ethical aims or norms. One is to use limited resources in the manner that maximizes the benefits to the population served by them. The cost-effectiveness (CE) of how alternative resource uses would serve this goal of maximizing aggregate benefits is typically determined by the analytic measure cost-effectiveness analysis (CEA). The cost-effectiveness

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ratio (CER) of a health intervention is determined by dividing the costs of that intervention, in monetary terms, by its health benefits, typically measured in quality adjusted life years (QALYs). The CER (the cost/QALY) of different health interventions, either for the same or different conditions, can then be compared for their relative cost in producing a unit of health benefit or QALY.¹ The second ethical aim or norm is to distribute those benefits equitably or fairly among the population served. It is also widely recognized that these two goals can conflict and so one must sometimes be balanced or traded off against the other. One specific form of that conflict is between cost-effectiveness and avoiding unjust discrimination against persons with disabilities. In several ways that I will explore shortly, treating persons with a disability can result in fewer benefits and/or greater costs than treating otherwise similar non-disabled patients. This paper explores the moral objection, or putative injustice, to persons with disabilities in prioritizing health interventions by their CE; the different versions of the objection that I will distinguish are not mutually exclusive and I believe several of them correctly identify respects in which health resource prioritization by CE wrongs persons with disabilities.

In the USA it was a confluence of two events that focused attention on this problem and initiated discussion of attempts to respond to it. In 1990 the landmark Americans with Disabilities Act (ADA) became federal law with the express purpose to “establish a clear and comprehensive prohibition of discrimination on the basis of disability.”² Since it prohibits discrimination on the basis of disability in both public and private services and programs, in health care “it applies to programs provided by the government, benefits provided by employers, and services provided by physicians.”³ Moreover, the ADA defined disability broadly to include any chronic medical condition, physical or mental “that substantially limits one or more of the major life activities of (an) individual”. Thus, typical chronic medical conditions that even with treatment significantly limit function, such as chronic obstructive pulmonary disease (COPD) and congestive heart failure (CHF), as well as functional limitations that are congenital or caused by injury, are covered by the ADA.

The other event that interacted with the ADA to focus on discrimination against persons with disabilities was the landmark effort by the state of Oregon to initiate an explicit process to prioritize and ration health services within its state Medicaid program. The Oregon Health Services Commission (OHSC) was charged with establishing a prioritized list of treatment/condition pairs, that is, types of treatment given to patients with a particular condition. If a particular treatment had substantially different

¹ Gold *et al.* (1996).

² Public Law 101–336, July 26, 1990, 104 Stat. 327, 42 USC 1201–1213, 47 USC 225 and 611.

³ Orentlicher (1994).

outcomes and benefits when given to patients with different conditions it could appear more than once on the list; for example, the initial list distinguished neonatal intensive care for infants below 500 g and for infants between 500 and 2500 g birthweight because of the much worse outcomes in the former group. The initial list of treatment/condition pairs was prioritized by what was essentially a cost-effectiveness standard, using Quality Adjusted Life Years (QALYs) as the measure of benefits of treatments. The list of treatment/condition pairs was then prioritized from those which produced the most to the least benefits for the resources they required.

Oregon's initial application to the Health Care Financing Administration (HCFA), the federal agency that administered Medicaid, for the waivers necessary to put its new programme into effect was rejected. HCFA held that Oregon's proposal would violate the ADA, using language and analysis prepared by the National Legal Center for the Medically Dependent and Disabled.⁴ Their analysis imagined the following scenario:

"Patient A and Patient B are both injured in an accident. Treatment A is recommended for Patient A, while Treatment B is recommended for Patient B. However, Treatment A will sustain Patient A's life, but will not restore the abilities A lost after the accident (such as an ability to walk), while Treatment B will sustain B's life *and* restore his ability to walk. If the basis for funding B but not A is a quality-of-life judgment that being able to walk is of greater benefit than not being able to walk, for example, then a decision to deny treatment to A would be discrimination based on A's resulting level of disability. In effect, B's life would be considered more valuable than A's life because B will regain an additional function while A would not. Under the second scenario, a distinction between two effective treatments would be based not on treatment effectiveness, because both treatments would sustain life, but on an inappropriate assessment of the underlying quality-of-life each patient will have after treatment. This scenario describes the Oregon plan."⁵ (The National Legal Center made no distinction between whether the disability was pre-existing or a result of treatment; I take up this issue later.)

Whatever political motives may have been involved, HCFA's initial rejection of the Oregon plan identified a deep conflict between the ADA and any prioritization of health-care services based on their cost-effectiveness. This conflict had not been well appreciated heretofore. The example of discrimination based on disability cited by Secretary Sullivan in his initial rejection of Oregon's waiver request was a specific scenario, but the problem can be generalized. In the next section I shall set out six ways in which priority setting using cost-effectiveness (most would apply as well to prioritizing by effectiveness alone, ignoring costs) can result in

⁴ Unpublished letter from Secretary of Health and Human Services Louis W. Sullivan to Governor Barbara Roberts of Oregon, August 3, 1992.

⁵ *Ibid.*

discrimination against persons with disabilities; here, I use discrimination in a value neutral sense, leaving open whether, when and why such discrimination may be unjust.

FORMS OF DISABILITY DISCRIMINATION FROM CEA

I and others have discussed these forms of discrimination before, so I will only summarize them briefly.⁶ First, when health interventions are life saving the QALYs produced will depend on the life expectancies of the patients who receive them. Since many, although of course not all, disabilities such as cystic fibrosis (CF) or AIDs cause patients to have shorter life expectancies, the years of life saved and QALYs produced by life saving interventions for such disabled patients will be fewer than for otherwise similar non-disabled patients. Note that this will be true even if the intervention is unrelated to the disability, for example an appendectomy performed on a person with CF or AIDs.

Second, since disabilities reduce an individual's health-related quality of life, life-saving interventions for a disabled patient, for example with COPD or impaired vision, will produce fewer QALYs than with an otherwise similar non-disabled patient, and again even if the intervention is unrelated to the individual's disability and is equally effective for the condition treated. The quality adjustment of the benefit of additional life years, even if the same number, reduces the overall benefit.

Third, when health interventions protect or improve health related quality of life, a pre-existing disability in effect often acts as a co-morbidity that makes treatment less effective in improving a patient's health-related quality of life. Patients with COPD or CHF, for example, have substantial limitations in mobility and ability to carry out a variety of activities requiring physical exertion; this would reduce the benefit they would otherwise receive from an intervention like a hip replacement, which is also intended to restore mobility and ability to carry out physical activities.

Fourth, the presence of a disability, or a more severe disability, can often make a treatment more complex or extended, and so more expensive, than it would otherwise be; for example, the typical costs of neonatal intensive care for extreme low birth weight newborns are much greater than for low birth weight newborns because their stays in neonatal ICUs are typically much longer. Cost-effectiveness gives higher priority, other things being equal, to less expensive treatments.

⁶ Brock (2000). That paper also drew in some places on an earlier effort to address some of these issues (Brock, 1995).

Fifth, the disability may not be pre-existing, but the result of treatment being less effective or itself causing a new functional limitation. To take an example mentioned earlier that arose regarding the initial Oregon proposal, neonatal intensive care for extreme low birth weight newborns (less than 500 g) typically leaves them with various substantial disabilities often caused by their treatment, whereas neonatal intensive care for low birth weight newborns (500 to 2500 g) is typically associated with much less or no resultant disability. Therefore, the QALYs produced by treating a typical low birth weight newborn will be substantially greater than those from treating an extreme low birth weight newborn.

Sixth, persons with severe disabilities may usually, though certainly not always, be less productive of economic benefits as a result of their disabilities. When this is so, there will be greater productivity gains from effectively treating non-disabled patients than from equally effectively treating similar patients who will still be left with an unrelated disability which lowers production gains from treating them. Although production gains of this sort are usually part of a full CEA, they are typically ignored in the health sector. Whether they should be is controversial; I have addressed this issue elsewhere and shall largely ignore this form of discrimination in this paper.⁷ I have illustrated these different ways in which prioritization of health interventions by their cost-effectiveness or by their relative benefits will discriminate against the disabled in order to make clear that the discrimination will be systematic and far reaching, not a minor and rare occurrence. However, often, perhaps even usually, health interventions will be equally cost effective and beneficial for persons with and without disabilities. In other cases the health-care needs of the disabled will receive higher priority when disabled persons' function can be effectively restored or ameliorated by treatment of their disability. So it would be a mistake to believe that persons with disabilities will always fare worse in prioritization of health resources, but the ways and frequency with which they will fare worse are extensive. (I set aside the important cases where persons are partially or fully responsible for having their disabilities. These cases raise the important more general issue, which I cannot pursue here, of whether and when persons' responsibility for their health needs should affect their claims for health care to meet those needs.)

Sometimes treatment of persons with disabilities will receive lower priority for reasons unrelated to their disabilities. But to emphasize what should be obvious, the cause of the disabled faring worse than the non-disabled in these six ways is not unrelated to their disabilities. On the contrary, it is precisely as a result of their disabilities that their treatment is less cost-effective and so has lower priority in each of these six cases; it

⁷ Brock (2003).

is the disability itself that reduces the benefit and/or increases the cost of treatment, and so makes it less cost-effective.

A DEFENCE OF CEA'S DISADVANTAGING PERSONS WITH DISABILITIES

Not every disadvantage is unjust, nor is being placed lower on a priority list always unjust discrimination. Any priority list will place some treatments and/or some patients lower than others. So the question is which, if any, of these different forms of disadvantage and lower priority are unjust (I do not address whether they are legally in violation of ADA or other laws)?

Some commentators have argued that none of these forms of discrimination from CEA are unjust. David Hadorn, for example, claims that this disadvantage to persons with disabilities is an inevitable and acceptable consequence of a rational priority setting process:

Banning consideration of quality of life and ability to function is ... counterproductive; moreover, it is inconsistent with the massive effort to facilitate and fund health outcomes research – the lion's share of which deals with quality of life and ability to function.⁸

However, the issue here is only the use of quality of life and ability to function in prioritization of resources between different patients or groups of patients; that is what disadvantages persons with disabilities. Health outcomes research will still be important for determining the relative benefits of alternative health interventions for the same patient or group of patients.

In early writings, Paul Menzel too defended this use of QALYs in priority setting, despite acknowledging that it can disadvantage the disabled, though in later work he at least partially retracted this view:⁹

Quality of life considerations as well as likelihood of medical success sometimes do get associated with disabilities (though not *only* with disabilities). Such considerations must not be seen as biased against persons with disabilities just because they catch disabilities in their net. They ought to be regarded as inconsistent with ADA only if we would reject them as legitimate considerations at all were they not sometimes to deny care to persons with disabilities. This is a tough distinction for many to accept, for it means that even with the ADA, particular disabled individuals will end up disadvantaged. It is, however, a distinction utterly essential to maintain if we are going to have any significant rationing at all ... Rationing that considers quality of life must be allowed to go forward even if at times it happens to disadvantage persons with disabilities. Indeed, it is questionable whether we could ever devise a system of priority setting that was not informed in some measure by assessments of quality of life.¹⁰

⁸ Hadorn (1992).

⁹ Menzel's later view is in Nord *et al.* (1999).

¹⁰ Menzel (1992).

Both Hadorn and Menzel assume that rationing of health resources is both necessary and desirable, and in this they are surely correct. But they also seem implicitly to assume that the rational basis for doing so is in terms of the relative health benefits of those interventions, given comparable costs, that is, in terms of their relative cost-effectiveness. And they are both also correct that quality of life considerations as well as preserving life must be considered in assessing those benefits. I acknowledged in the first paragraph of this paper that this should be *one* of the ethical aims that guide health resource prioritization. But I also noted that a second moral aim should be to distribute those resources fairly or equitably, and Hadorn and Menzel say little to establish that prioritization by CE does that. To assess that question, we will need to assess a series of moral objections to how health resource prioritization by CE disadvantages persons with disabilities. We shall see that most of these objections target some, but not all, of the six forms of discrimination distinguished above, and that they have differential moral force or plausibility. Each of the objections, to the extent it has some moral force, will in turn suggest ways to constrain or depart from CE in order to meet the moral objection to its use here. I want to emphasize at the outset that these different moral objections are not mutually exclusive. Part of the complexity of the issue I address in this paper is that it does not raise just one moral problem, nor in turn admit of one relatively simple solution.

MORAL OBJECTIONS TO CEA'S DISABILITY DISCRIMINATION

Each of the moral objections that I consider below is an attempt to characterize what is morally objectionable about at least some of the forms of discrimination against persons with disabilities from CEA. I emphasize that none of these objections or arguments should be understood to constitute all things considered or decisive ethical objections against this use of CEA. Even if some or all of the moral objections considered below do identify an unfairness or injustice in this use of CEA, it is a further question whether other moral considerations, in particular concern to maximize health benefits, can support that use and may in some circumstances override the unfairness or injustice all things considered.

CEA IMPLIES THAT DISABLED PERSONS' LIVES ARE OF LESSER VALUE THAN THOSE OF NON-DISABLED PERSONS

One objection to the use of CEA and quality of life considerations in priority setting has been that it appears to imply that the lives of disabled persons are worth less than the lives of non-disabled persons.¹¹ This is incompatible with the moral equality of all persons and with the common moral claim that all lives should count equally. The outcome of preserving the life of

¹¹ Parens and Asch (2000).

a disabled person under CEA is less good and so of lower priority than preserving the life of an otherwise similar non-disabled person, merely because the former's life is less good or valuable due to her disability. Specifically, the survival of the disabled person is a lesser good or of lesser value than the non-disabled person, as measured with the QALYs used by CEA, because of the disabled person's lower life expectancy and/or health-related quality of life. Saving two lives is commonly considered a better outcome than saving one, and most believe that if we have to choose, no injustice is done by saving the two. An intervention that preserves a person's life for a longer period and/or with a better quality of life than some alternative intervention will produce a better outcome, both for that person and simpliciter. This moral objection extends the apparently same line of reasoning to the case of disabled and non-disabled persons – preserving the disabled person's life is a less good outcome in terms of minimizing morbidity and mortality, the goals of health care. The shorter life of lesser quality that the disabled person will have is less good and of lesser value than the longer and better quality life that the non-disabled person will have.

Hadorn and the early Menzel would apparently deny this claim. The relevant moral standard, they argue, is maximizing health benefits with limited resources, and it is merely a contingent and unintended effect of the use of this rational and morally acceptable standard that it sometimes results in lower priority to treatment of persons with disabilities. This is no more unjust discrimination against the disabled, they might argue, than giving a scarce intensive care bed to the sickest patient is unjust discrimination against the less sick patient.

But the apparently morally problematic implication in the case of disabilities is not hard to find, and it is clearest in the case of life-saving treatment. Preserving the lives of persons with disabilities, who other things being equal have a lower health-related quality of life and/or life expectancy, produces fewer QALYs or benefits. The future life that the disabled person will have if treated is less good or of less value than the future life that the non-disabled person would have if treated instead. It is a less good or valuable outcome if the person with a disability survives than if the person without a disability survives because the person with a disability has a less good and so less valuable life – it will be shorter and/or of lesser quality. This seems to imply that the lives of persons with disabilities are worth less or have less value than the lives of persons without disabilities.

I believe this moral objection to CEA is indecisive at best – in a sense it tells us only what we already knew. The defender of CEA (as with the defender of utilitarianism) will insist that both persons count equally in our moral calculus and decision, and there is simply a greater health benefit obtained if we prioritize the non-disabled person. What we need to

determine is if this is an adequate account of the moral equality, or equal moral worth, of persons. We need to turn to other versions of the moral objection that CEA unjustly discriminates against persons with disabilities to make that determination.

PRIORITIZATION BY CE IS “DOUBLE JEOPARDY” OR VIOLATES KAMM’S NON-LINKAGE PRINCIPLE

Why else might this disadvantage that persons with disabilities will suffer in prioritizing health-care resources by cost-effectiveness or relative benefit standards be thought unjust? When having a disability is a morally undeserved disadvantage, it would only compound that undeserved disadvantage to use it as the basis for giving disabled individuals lower priority for health-care treatment than otherwise similar non-disabled individuals.¹² John Harris criticizes this as “double jeopardy.”¹³ Frances Kamm expresses this idea as the “non-linkage principle” – “the fact that some undeserved bad thing has happened to you [should] not make it more likely that another bad thing will happen”.¹⁴ I would reformulate this principle a bit more precisely as: we should not use a person’s undeserved or unjustified disadvantages as the grounds or basis for choosing to impose a further disadvantage on them. Social policies under our control should not compound further an already existing undeserved or unjustified disadvantage. (Of course, this line of argument will not apply in cases where persons are partially or fully responsible for having their disabilities. I set aside here these cases where responsibility may make the disadvantage not undeserved or unjustified.)

While my concern here is morality, not the law, it is worth noting that the law also recognizes this point. For example, the ADA in the USA requires employers to make reasonable accommodations to enable persons with disabilities to hold employment positions. But it does not require always ignoring disabilities in distributing scarce goods like desirable jobs in order to avoid violating the non-linkage principle. Schools are not required to hire people with epilepsy as school bus drivers because their disability, though undeserved, creates too substantial and unnecessary a risk to the students’ safety. Likewise, if one important goal of the provision of health care, simplistically put, is promoting health, then if their disabilities greatly reduce a person’s capacity to benefit from that care, giving them lower priority for care need not always necessarily be,

¹² The very large “luck egalitarianism” literature addresses when disadvantages are undeserved. See, for example: Arneson (2007), Cohen (1989), Dworkin (1981), Fleurbaey (1995), Hurley (2003); Roemer (1998).

¹³ Harris (1987); the double jeopardy charge is also discussed by McKie *et al.* 1998.

¹⁴ Kamm (2004).

all things considered, morally wrong. Here too, not violating the non-linkage principle could sometimes require too great a cost or sacrifice in furthering the goal of health promotion.

A further difficulty with the non-linkage principle's core idea of not using a morally undeserved disadvantage to serve as grounds for disadvantaging that person still further with regard to some other good or benefit is that we seem not to accept the principle in this very general form. For example, undeserved differences between persons in intelligence, caused at least in part by undeserved genetic differences between them, result in a wide range of disadvantages in other socially controlled and distributed benefits such as admission to high quality universities and professional schools, access to desirable jobs, and future incomes. The social institutions that result in these violations of the non-linkage principle are typically not morally criticized for doing so – that differences in intelligence influence such outcomes is not considered always an injustice that requires some competing moral consideration to ever be morally justified.

I think what we see here is that the non-linkage principle does seem to articulate a forceful moral objection to the way CEA disadvantages persons with disabilities in the competition for scarce health resources. But what the precise form, scope, and limits of that principle should be is not clear, and leads us into difficult and unsettled issues in moral and political philosophy. Unfortunately, this means that to what extent the non-linkage principle correctly characterizes the injustice in CEA's treatment of persons with disabilities remains unclear.

PRIORITIZATION BY CEA CONFLICTS WITH EQUALITY OF OPPORTUNITY

A different line of moral objection to CEA's treatment of disabled persons in health resource prioritization appeals to the widely accepted moral and political principle of equality of opportunity. In the most well-developed theory of justice in health care, Norman Daniels has argued that the importance of health care for justice is its role in countering the diminishment of opportunity caused by disease and disability.¹⁵ Disabilities, understood as conditions that substantially limit one or more major life activity of persons, will by definition reduce individuals' opportunity from that which otherwise similar non-disabled persons enjoy, and thereby deny them equality of opportunity with non-disabled individuals. It is important that equality of opportunity is typically understood to require measures that may not be cost-effective in comparison with other uses of resources not designed to promote equality of opportunity, although this again is not to say that cost-effectiveness

¹⁵ Daniels (1985, 2008).

would never be relevant in choosing between different opportunity-enhancing interventions for persons disadvantaged by disability. For example, ramps to permit persons confined to wheelchairs access to public buildings do not have to pass a cost-effectiveness test to merit funding; it would not defeat the moral case for them to show that the funds could be better used to improve the stairs used by many more non-disabled persons. Equality of opportunity has a moral priority that can at least sometimes override or trump maximizing overall benefits in the health sector or elsewhere, although this is not to say, of course, that it requires unlimited measures and resources. If equality of opportunity justifies special, non-cost-effective, measures to improve the opportunities of persons with disabilities, then it certainly seems in conflict with that perspective to use those persons' disabilities in health-care resource prioritization as grounds to further worsen, rather than improve, their opportunities.

Even more than with the non-linkage principle, however, both the correct form, scope, and limits of a principle of equality of opportunity within a broader moral and political theory, as well as how it should apply to health care, are unclear and controversial. Just to cite one example, and oversimplifying greatly, on Daniels' interpretation, equality of opportunity requires the provision of health care necessary to prevent or restore persons' loss of normal function from disease or injury. The goal is to provide all persons with the range of opportunities normal in their society for persons similarly endowed and motivated. On this interpretation, which my co-authors and I elsewhere called the "social structural" account, equality of opportunity is not violated when differences not the result of disease or injury and within the normal range in natural endowments, such as intelligence, result in inequalities in expectations and opportunities.¹⁶ (Of course, again, other moral considerations may justifiably limit how much we must do, all things considered, to satisfy equality of opportunity.) On an alternative interpretation, which we called the "brute luck" account, equality of opportunity is violated when some persons are worse off than others through no fault of their own. The effect of undeserved natural disadvantages, such as genetically based lower intelligence, violates the brute luck account of equality of opportunity but not the social structural account. These two accounts will in turn differ about whether resource prioritization by CEA violates equality of opportunity only when it disadvantages persons with disabilities from disease or injury, or when it also disadvantages persons simply at the lower ends of the ranges of natural endowments but not suffering from disease or disability. This is hardly the only unsettled and controversial issue in how to interpret equality of opportunity in the context of resource prioritization, but it is a fundamental one. Equality of opportunity may ultimately turn out to be

¹⁶ Buchanan *et al.* (2000).

the correct basis for the moral criticism of CEA's implications for persons with disabilities, but that cannot be established until we resolve many unsettled issues about equality of opportunity more generally.

PRIORITIZATION BY CEA CONFLICTS WITH FAIRNESS, WHICH REQUIRES IGNORING (SOME/MOST) DIFFERENTIAL IMPACTS OF TREATMENT

CEA disadvantages persons with disabilities in health resource prioritization when their disabilities result in fewer benefits and/or higher costs from treatment. Yet to ignore differences in benefits and/or costs in prioritization would appear to be irrational and in conflict with the first aim of health-care prioritization cited at the outset of maximally improving population health. I shall suggest that fairness provides a moral reason to ignore at least some such differences, although again this reason will not always be all things considered morally decisive.¹⁷ (Ignoring such differences would still be compatible with attending to differential benefits and costs of alternative treatments in selecting treatments for the same patient or group of patients; then there is no distributive conflict between different individuals and issues of fairness do not arise.)

How does prioritizing health resources by CEA conflict with fairness? I will illustrate the conflict with an example, which for simplification assumes an unrealistic certainty about health outcomes. Suppose we have two treatments: treatment A would produce an expected survival of 10 years at .95 HRQL for the patients who need it, whereas treatment B would produce an expected survival of 9 years at .90 HRQL for the patients who need it; without treatment, all the patients will die now. We have enough resources to fund only one of the treatments, and cost-effectiveness tells us to fund A. But the patients who need B to survive could object that these differences in life expectancy and HRQL are too small to justify saving the patients who need A and letting those who need B die. Although the B patients would receive slightly fewer QALYs, that is, a slightly smaller health benefit, they should still receive a fair chance to get the treatment they need. The small differences in life years and their quality are insufficient to justify the very great difference in how the different patients are treated – some live and the others die. This objection is most pressing if the prioritization literally determines who lives and who dies, as for example in some organ transplantation, but I believe it extends much more broadly.

Fairness is about the mediation of competing claims of different individuals, in this case the claims of each group to get the treatment

¹⁷ John Harris argues for an extreme version of this position in "Quality, Value and Justice", and in "Double Jeopardy and the Veil of Ignorance – a reply".

they need. Suppose we understand the A's claims as stronger than the B's because they would get a slightly larger benefit from treatment, or suffer a slightly smaller loss without treatment. Nevertheless, as John Broome has argued, fairness is not then met by simply satisfying the stronger claim when we cannot satisfy both.¹⁸ If claims grounded in fairness were conceived in this way, then fairness would not serve as a moral consideration independent of, and potentially in conflict with, maximizing benefits or the good. But I believe it would be a mistake to reduce fairness to goodness in this way. There are different ways of interpreting the claims of fairness that I cannot pursue here, but one, following Broome, is that fairness requires that claims be satisfied proportional to their strength when we cannot fully satisfy them all. In my example above, the two groups of patients have an almost equal claim to have their health needs met, but both groups' claims cannot be satisfied. Fairness then requires the next best, that they have an equal, or nearly equal, chance to have their claims satisfied. On this interpretation, fairness and goodness are distinct moral considerations that are sometimes in conflict and so must then be balanced or traded off. If we give great, though not absolute, weight to fairness when it conflicts in this way with goodness then we will ignore most of the differences in benefits from treating patients with and without disabilities that cause prioritization by CE to disadvantage disabled persons. I say "most" because of two limitations to this fairness argument. (Besides the limitations about to be noted, there is controversy whether saving the greater number is consistent or in conflict with fairness, but so far as I can see that issue does not affect the issue of disability discrimination.)

Here is one limitation in this fairness argument. Suppose we could extend the lives of the As with treatment for 10 years at .90 HRQL, as above, but we could only extend the lives of the Bs for an hour, or even a day, if we treated them instead. One limitation of the fairness objection is that it must be possible to save the B's lives for a "significant period of time" if fairness generates a claim to receive a fair chance to get the treatment they need when in competition with the As. A significant period of time is obviously vague, but it is meant to signal that there must be some minimal threshold that B's need and claim for treatment must pass to require a fair competition against the A's, or for the A's claim not simply to override that of the Bs. An alternative interpretation of the fairness objection is that even here the Bs have some claim of fairness to get the treatment they need and want in order to survive, if only for an hour or a day, but the enormous difference in potential benefits to the two groups warrants very different chances for each, for example proportional to that difference in benefits. Giving each group an equal chance in this case would give no weight to

¹⁸ Broome (1991, 1999).

the competing moral consideration of goodness or benefits. There is not space here to pursue further the details of how this claim of fairness should be interpreted in the context of health resource prioritization, nor how it should be balanced against maximizing health benefits or goodness.¹⁹ Likewise, the same sorts of issues arise with regard to differences in patients' HRQL – there too fairness may justify ignoring many or most of the differences in outcomes that give rise to CEA's disadvantaging of persons with disabilities.

PRIORITIZATION BY CEA CAN WRONGLY GIVE LOWER PRIORITY TO DISABLED PERSONS FOR EQUALLY EFFECTIVE TREATMENT

If two patients have the same medical need for the same treatment, and the treatment is expected to be equally effective in each, then a plausible case can be made that their equal need for treatment generates an equal claim for treatment, and so they should have equal priority for treatment. If one of the patients receives lower priority than the other for the treatment because she is disabled, that would appear to be irrelevant and unjust discrimination against her because of her disability. So in the example of a life-sustaining treatment such as intensive care for severe allergic reactions threatening two patients' airways, barring special circumstances it would be reasonable to expect that the treatment should be equally effective in protecting their airways and preserving their lives, independent of whether one but not the other also suffers from a disability unrelated to and not affecting her present medical need and its treatment. If treating this allergic reaction in the disabled patient will produce fewer QALYs than in the non-disabled patient because the disabled patient has a shorter life expectancy and/or lower HRQL from her pre-existing disability, for example, severe coronary disease or blindness, that does not make the treatment of her allergic reaction any the less effective. The fewer QALYs result from her pre-existing disability that reduces her life expectancy or HRQL, but these pre-existing disabilities are unrelated to and have no effect on her need for treatment of her allergic reaction, nor the effectiveness of the intensive care in doing so; the intensive care treatment of the allergic reactions is equally effective in both cases.

This argument relies on a particular account of treatment effectiveness, however, which might be contested. If we have two alternative treatments for patients with a particular life-threatening condition, and one extends their lives for five years and the other for ten years, the second treatment could plausibly be understood to be the more effective treatment. Likewise,

¹⁹ It is worth noting that fairness may require additional weightings of lives saved based on the age of the persons saved if we accept age weighting of the sort required by a "fair innings" argument.

one might think that if the same life-extending treatment would extend the lives of one group of disabled patients for only five years because of their unrelated disability, and the lives of another group of non disabled patients for ten years, the treatment was more effective in extending life when applied to the second group of patients. On this understanding of effectiveness, the aim of the treatments in both pairs of cases is to extend life, and the latter case in each pair is seen as more effective because it extends life longer. But specific medical treatments are developed for specific medical conditions and their effectiveness is determined by how well they correct that condition; for example, the effectiveness of intensive care intubation to protect the airway in the case of severe allergic reactions is determined by how well it protects the airway. Understanding effectiveness in this second sense simply in terms of extending life has highly counter-intuitive and, I believe, unacceptable implications; for example, if two prisoners are intubated for severe allergic reactions and their airways are equally well-protected, we would not understand the treatment of the second prisoner as less effective because he is executed and dies a week later, while the second continues to serve his prison term. Consequently, I think the treatment specific understanding of "effectiveness" in the previous paragraph is the more plausible understanding.

Even on the first understanding of effectiveness, however, giving equal priority to equally effective treatments will not avoid the third and perhaps also fifth forms of discrimination against the disabled that I noted earlier. The third concerned treatments whose purpose is to improve or protect specific aspects of patients' health-related quality of life, but are less effective because a pre-existing disability acts as a co-morbid or complicating factor making the treatment less successful. This form of discrimination against disabled persons cannot be avoided by looking only at whether treatments are equally effective, since what the pre-existing disability does is precisely to make the treatment less effective. The fifth form of discrimination is where a particular treatment is less effective in some kinds of patients than in another kind, leaving the first kind disabled, but not due to any background conditions of pre-existing disability. This case seems simply to be a difference in treatment effectiveness, with disability entering the picture for some patients but not others only as a result of the treatment.

The first two forms of disability discrimination that I distinguished earlier, and which will be avoided by looking only to treatment effectiveness, are I believe clearly the most ethically worrisome; they give lower priority for equally effective treatments to disabled persons, on the basis of disabilities that are unrelated to those treatments. The third form of discrimination seems less morally problematic because it is based on an arguably relevant and defensible difference in treatment

effectiveness, although that difference in effectiveness is caused by a pre-existing disability. The fifth form of lower priority for disabled persons is simply to patients for whom treatment will be less effective, with that lesser effectiveness leaving a resultant disability; unless attending to treatment effectiveness is ruled out on other moral grounds, this may be a morally unobjectionable form of disability discrimination.

PRIORITIZATION BY CEA CONFLICTS WITH GIVING ALL PERSONS AN EQUAL CHANCE TO REACH THEIR FULL POTENTIAL

The moral idea of equality at work in this objection to health resource prioritization by CE is that all persons should have an equal chance to realize their full potential, and no one should be disadvantaged because their potential may be less than that of others.²⁰ Applying this idea to the case of disabilities, having a lower potential in either health-related quality of life or life expectancy from a disability should not disadvantage persons in the prioritization of health resources. How should we interpret this idea? In the first two examples of discrimination cited earlier, which result from disabled persons' shorter life expectancy and lower health-related quality of life, if a treatment enables them to reach that lower potential it should have the same priority as treatments that enable non-disabled patients to reach their higher potential. How should we understand cases in which both the disabled and non-disabled patients might reach only part of their full potential from treatment? A seemingly natural interpretation would be to give equal weight or priority to an equal proportional gain by each towards their full potential. Suppose two patients A and B with a serious disease p are at .50 on a health-related quality of life scale where 0 is death and 1 is full health, but A's full potential with treatment is only .75 because of an unrelated disability, while B's is 1.0. If a treatment would move each to their full potential, .75 and 1.0 respectively, they should have equal priority for the treatment, although B's treatment produces twice the health gain as A's –.50 versus .25. Likewise, if their respective potentials remain .75 and 1.0, and A's treatment would move her up to .60, while B's would move her up to .70, their proportional gains towards their full potential are the same and they should have the same priority for treatment. However, if A's treatment would move her to .65, whereas B's would still move her to .70, then A's gain proportionate to her full potential is greater than B's and so A should have priority, despite getting a smaller health gain than B.

The third and fifth cases of discrimination from CEA that I cited earlier were where a pre-existing disability makes treatment aimed at improving health-related quality of life less effective, or a treatment is simply less

²⁰ Nord (1999).

effective and leaves one patient with residual disability after treatment. In the third case, the person disabled before treatment has a lesser potential gain from treatment because of his disability, while in the fifth case it could be argued that the person who ends up disabled after treatment turns out to have had a lesser potential gain. If all should have an equal chance to realize their full potential, then the lesser health gain of each of the disabled persons should not give them lower priority for treatment. Finally, this idea of each deserving an equal chance to realize their full potential could also rule out giving lower priority to the person whose disability makes his treatment more expensive. If the moral idea that each person deserves an equal chance to realize his or her full potential can be successfully defended, then it may correctly capture at least in part what disabled persons are owed and why health resource prioritization by cost-effectiveness can be unjust to them.

One possible objection to this approach is that it fails to adequately compensate disabled persons for their lesser functional potential. Consider the example of disabled A at .5 with a full potential of .75 and non disabled B at .75 with a full potential of 1.0. Suppose that treatment would move A only to .70 whereas treatment would still move B to 1.0. Now B would receive priority over A despite the fact that B's initial condition was better than A's, indeed better than where A would have ended up if she had received priority for treatment. This example illustrates that this approach can support increasing the initial undeserved inequality between A and B, can fail to support moves in the direction of equalizing opportunity, and can be in conflict with giving independent weight to severity or the worse off (this latter idea will be discussed in the next section). Any of these three implications could plausibly be argued to constitute injustices to persons with disabilities.

In a different respect, this proposal seems to give too much priority to the disabled in other cases where it is subject to the so-called "bottomless pit" problem. Consider extremely cognitively disabled individuals at .2 in health-related quality of life who have almost no potential for improvement; they could only be raised to .22, a condition they would value as better than death (e.g. as expressed in an advance directive), but at very great cost in health resources. Giving all persons an equal chance to reach their full potential implies that this very high-cost/small-benefit intervention should have equal priority with saving one or more other patients whose lives will be lost without treatment that would return them to full health. Defenders of the equal potential proposal could respond that justice or fairness to the disabled sometimes must be balanced against other moral considerations, here the amount of benefits to others that would be lost. But it is morally problematic whether this much priority to the disabled is required by justice or fairness, even before we turn to balancing it against this other moral consideration.

PRIORITIZATION BY CEA IS IN CONFLICT WITH GIVING PRIORITY TO THE WORSE OFF

In recent work in egalitarianism and distributive justice, many theorists have been led, usually by the so-called “levelling down” objection, to support some form of Prioritarianism. As characterized by Parfit, this is the view that benefiting people matters more morally the worse off those people are. Prioritarianism gives no independent moral weight to equality in outcomes, but instead gives special weight to improving the absolute position of the worse off.²¹ It is quite obviously in conflict with prioritizing by CEA which maximizes benefits without regard to who gets them.

What are the implications of Prioritarianism for the prioritization of health resources for persons with disabilities? That will depend in part on the metric that the prioritarian theory adopts. In a general prioritarian theory of justice, it is plausible that the appropriate metric is overall well-being; using this metric, having a disability need not make one worse off than another without a disability. In overall well-being, disabled persons are sometimes better off than non-disabled persons because other aspects of their well-being more than compensate for their worse health. Defenders of the overall well-being metric may welcome this implication, denying that persons’ disabilities should give them any priority when other aspects of their well-being more than compensate for the disadvantages from their disabilities. Alternatively, if the prioritarian metric for prioritizing health resources is health, not overall well-being, the implications will be different. I have argued elsewhere that there is some case for treating the distribution of health resources as a “separate sphere”, and so using the metric of health, but I shall not pursue that issue here.²² As I note below, however, even on a separate spheres’ interpretation of Prioritarianism that looks only to individuals’ health and not other elements of their well-being, disabled persons need not always have worse health.

Suppose we assume a separate sphere’s version of Prioritarianism, in which the metric is health. To the extent that where one falls on a health-related quality of life scale roughly corresponds to how disabled one is, then those who are most disabled seem to roughly correspond to the worse-off. But even on this separate spheres’ interpretation of Prioritarianism, important issues remain about who are the worse off. For example, are the worse-off those with worse health at a point in time, for example, at the time the resource allocation is made, or those with worse health over their lifetimes? Persons with long term or chronic disabilities may often be less sick now than others, but nevertheless suffer worse long-term or lifetime health. Notions of equality, and likewise concern for the worst off, within

²¹ Parfit (1991).

²² “Separate Spheres and Indirect Benefits,” *Op. cit.*

a general theory of justice should, I believe, apply at the most basic level to people's whole lives, not just to a particular time slice within those lives. Even within a separate spheres' perspective, it seems that Prioritarians should use lifetime rather than point in time health to determine who are worse off, and this will then give weight to the length of time that disabilities have been experienced.²³

A second fundamental issue for prioritarians is how much priority the worse off, assume those with worse lifetime health, should receive. Prioritarianism as characterized by Parfit is a weighted beneficence view, but this requires specifying a weighting – that benefiting persons matters more morally the worse off those people are is indeterminate on *how much more* it matters morally. The weighting can vary across a very broad spectrum from infinitely more (leximin), to infinitesimally more (e.g. utilitarianism, with priority to the worst off only when the total is the same). Perhaps the weighting might be determined in part by the moral reasons why the worse off are given priority, that is by the underlying moral basis of the prioritarian theory, which I cannot explore here. No plausible prioritarian position applied to health-care resource prioritization would give the worse-off absolute priority. Doing so would raise the so-called "bottomless pit" problem – for persons with very serious disabilities whom we can only make slightly better off, but at enormous cost in resource use, assigning their needs absolute priority would excessively drain off resources for very little gain that could be used instead to produce much greater benefits for others less badly off. Here again, priority to the worse-off or disabled must be balanced against other moral considerations, including treatment effectiveness or benefits. Many philosophers, I among them, would like to have a principled answer to how to weight concern for the worse off against other concerns such as maximizing aggregate health benefits. However, no such principled answer has been produced, it is not clear that a principled answer is possible or even what it would be, and so we may be forced to resort to intuitive balancing.

Progress on these two aspects of Prioritarianism – its metric and the weight given to the worse off – may be necessary for us to make progress on the issue of what priority the disabled should receive. One reason for thinking that priority to the worse-off may be the right framework for at least part of our moral concern for persons with disabilities is that it fits well with two natural intuitive ideas that are quite common in thinking about what we owe persons with disabilities generally. In each case, these ideas explicitly involve the rejection of benefit maximization as embodied in cost-effectiveness as the sole prioritization standard in order

²³ There is an extensive and excellent discussion of the time slice versus whole life positions, with a defense of the whole life view, in Mathew D. Adler, "Well-Being, Inequality and Time: The Time-Slice Problem and Its Policy Implications," unpublished.

to meet specific moral claims of the disabled. First, and as already noted, in the service of equality of opportunity, access to job opportunities and public facilities through special transportation, access ramps, and so forth, must be provided to persons with disabilities even when those resources could be used elsewhere to provide greater benefits to others who are not disabled. Second, it is very common to think that because (or when) disabilities are undeserved disadvantages, compensation is required in order to remove or reduce the undeserved disadvantage; moral claims for compensation in general are grounded in desert, not in whether meeting them is the use of resources that will produce the most benefits.

CONCLUSION

It was the confluence of the passage of the Americans with Disabilities Act and the effort by the state of Oregon to prioritize and ration health care in its Medicaid program that focused the problem of discrimination against persons with disabilities in health-care resource prioritization. I have sought here to lay out that problem by exploring some different versions of the moral objection that prioritizing health resources by CEA unjustly discriminates against persons with disabilities. Why not say which one of these versions of the moral objection correctly addresses the problem of health-resource prioritization and disabilities? Because, in my view, our moral concern for how the disabled fare in resource prioritization, and in particular that they do not suffer unjust discrimination there, may, and I believe does, have multiple sources. In some cases, for example, that concern may be that they receive an equal chance to reach their full potential, and in others it may be that their disability makes them among the worse off. These different ideas are not mutually exclusive; for example, we might want to combine in some fashion the equal chance to realize one's potential with the distinct idea of priority to the worst off. And, of course, if at least some of the other moral objections that I have explored to how health resource prioritization by CEA unjustly disadvantages persons with disabilities also contain part of the truth, as I believe they do, then a comprehensive view that captures all of these moral concerns will have to be more complex still. I have not been able to explore these more complex possibilities here, but I believe they constitute the next stage of the work that needs to be done. I have only been able to scratch the surface of the issues, in part because the problem of health-care resource prioritization for the disabled raises deep, complex and unresolved issues of health-care resource prioritization, and of moral and political philosophy, more generally. The issues of health-care equity and justice, as they affect both the disabled and others, have only begun to be seriously explored and there is much work still to be done.

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