

**Health Care Resource Prioritization and Discrimination
Against Persons With Disabilities¹
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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 The act includes separate titles prohibiting discrimination on the basis of disability in employment, public services, transportation, and public accommodations. 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 defines 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,” although the Supreme Court has ruled that to be covered by the ADA a person’s limitation must persist despite use of available corrective measures.⁴ Thus, typical chronic medical conditions that even with treatment significantly limit function, such as chronic obstructive pulmonary disease (COPD), congestive heart failure, and AIDS, as well as congenital or injury caused functional limitations are covered by the ADA.

Shortly before the ADA was passed, another landmark effort in health policy began, the development by the state of Oregon of an explicit process to prioritize and ration health services within its state Medicaid program. Medicaid is the joint federal/state program initially established in 1968 to fund health care services for the poor who otherwise lack and cannot afford health insurance. However, largely as a result of budget pressures created by rapidly rising health care costs during the decades of the 1970s and 80s, most states significantly tightened the eligibility requirements for their Medicaid programs. In particular, income eligibility requirements were either reduced or not adjusted for inflation so that by the time Oregon began its Medicaid changes a majority of Americans with incomes below the federal poverty level nevertheless earned too much to qualify for their state Medicaid programs. While the benefits’ package for persons who qualified for Medicaid remained relatively generous, many in need were not eligible to receive those services; in addition, low reimbursement rates often made it difficult for Medicaid recipients to secure services. In effect, the practice of the states had been to ration people, by limiting eligibility for the Medicaid program, rather than rationing services available to members of the program.

Oregon proposed two major changes in its Medicaid program—to expand income eligibility to 100% of the federal poverty level with further increases in the income limit to follow over time, and to prioritize and limit the health care services available under its Medicaid program.⁵ They proposed to ration services rather than people, arguing that with limited resources it was more rational and equitable to provide the most important services to all in need rather than a broader range of services to some, but none to others, in need. This change promised to increase the overall health benefits that the limited pool of resources available for Oregon’s Medicaid program would produce and to treat more equitably those Oregon citizens unable to afford health care or insurance by providing the same package of services to all. It was hard to argue that this would not be overall a change for the better for indigent Oregon citizens without access to health care.

A remarkable feature of the Oregon plan was its open and explicit acknowledgment that resources available for health care, like resources available for all other goods and services, were limited and so it was necessary to ration some potentially beneficial health care. One consequence of the traditional practice of pretending health care was an unlimited good was the irrational and inequitable status quo Oregon set out to change—no longer would it be denied that rationing health care already takes place nor that it should take place. But of course this only raised the question of how health care services should be prioritized and rationed – by what procedures and according to what standards? Broadly, Oregon sought to combine substantial public input with appropriate professional expertise in a process that would be open and accountable. The Oregon Health Services Commission (OHSC) was established to carry out several tasks. It was to hold a series of public meetings to attempt to determine relevant values of Oregon citizens on health care priorities. However, since the principles and values developed in the public meetings were quite general their impact on the process appears to have been limited.

The OHSC was also to develop a prioritized list of the services then provided under the state's Medicaid Program. Specifically, it was to establish 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 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 grams and for infants between 500 and 2500 grams birthweight because of the much worse outcomes in the former group, a case to which I shall return below. The initial list of treatment/condition pairs was prioritized by what was essentially a cost effectiveness standard, reflecting the very common, indeed to many health policy experts and others self-evident, principle that limited resources for health care should be used to maximize health benefits for the population served.

To measure the health benefits of different treatments the OHSC adapted the Quality of Well Being Scale (QWB) developed by Kaplan and Anderson.⁶ Oregon citizens were asked in telephone surveys how much particular kinds of impairment of health-related quality of life—described in terms of “physical or emotional symptoms and of different degrees of impairment in mobility, physical activity, and social activity”—would reduce quality of life measured on a scale from 0, equivalent to death, to 1, equivalent to full unimpaired quality of life; thus, each level of impaired function was assigned a specific value from 0 to 1. Health professionals were used to match patients with various medical conditions to appropriate levels of function on the QWB scale both before and after treatment, making possible a quantitative measure of the degree of improvement in health-related quality of life typically produced by each treatment/condition pair. By adding the typical duration of the gain in quality of life from treatment, the overall benefits--essentially in terms of Quality Adjusted Life Years (QALYs), a measure that combines the two main types of benefit from health interventions of extending life and improving quality of life—of each treatment/condition pair was calculated. Using state Medicaid data on the costs of different treatments the cost effectiveness of each treatment/condition pair was calculated. The list of treatment/condition pairs was then prioritized from those which produced the most to the least benefits for the resources they required.

For reasons that are not central to my purposes in this paper, the initial list was rejected by the OHSC. Taking account of differences in costs of treatments, as any cost effectiveness analysis (CEA) does, allows a treatment that produces a small benefit, but is relatively inexpensive and so can be given to many people, to receive a higher priority than a treatment that produces a very large benefit, but is much more expensive and so can be provided to only a few patients for the same overall costs; the example that received the most attention was that capping a tooth for exposed pulp was ranked just above an appendectomy for acute appendicitis, a life threatening condition, because an appendectomy was estimated to be 150 times as expensive as capping a tooth. Some commentators argued that the values of the adapted QWB scale that Oregon employed failed to give sufficient weight to saving life in comparison with improving quality of life, or that it ignored the so-called “rule of rescue” and that a revised scale would better reflect the high relative importance people give to saving life as opposed to improving quality of life.⁷ Others argued that the counterintuitive ranking arose because ordinary people’s rankings of the relative importance of different health services is a one-to-one ranking; in the example above, one tooth capping compared with one appendectomy.⁸ In any event, Oregon fundamentally revised its methodology from a cost effectiveness standard to what was essentially a relative benefit standard, with cost differences employed only as a tie breaker between treatment/condition pairs producing roughly the same benefit, and revised its priority list accordingly.⁹ The OHSC also made many “by hand” adjustments in the ranking to correct what looked to be “mistakes.”

Since Medicaid is a joint federal/state program with a variety of federal requirements, Oregon had to apply to the Health Care Financing Administration (HCFA), the federal agency that administers the Medicaid program, for waivers of a number of regulations in order to put its new program into effect. Although a publicly run health plan that would explicitly and openly ration care was obviously ethically and politically controversial, HCFA’s initial rejection of Oregon’s waiver request surprised most observers who had been following Oregon’s effort. Then Secretary of the U.S. Department of Health and Human Services Louis Sullivan denied the waiver request on the grounds that Oregon’s proposal would violate the ADA, using language and analysis prepared by the National Legal Center for the Medically Dependent and Disabled.¹⁰ That analysis imagined the following scenario:

A person is injured and two alternative treatments are recommended. Both treatments cost the same and are equal in every other respect—except that after Treatment A the person will live, but after Treatment B the patient will not only live but will also regain the use of his legs as a result. The State only has enough money to fund one treatment and it chooses to fund Treatment B because it provides the greatest improvement in the person’s function for the same amount of money.¹¹

The National Legal Center granted that this would not be discriminatory, but then posed a different 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.¹²

Some considered Secretary Sullivan's rejection of the Oregon plan as inconsistent with the ADA to be a smokescreen to avoid accepting a highly controversial rationing plan soon before the 1992 Presidential election, but whatever political motives may have been involved I believe the Secretary and the National Legal Center did identify a deep conflict between the ADA and any prioritization of health care services based on either their cost-effectiveness or their effectiveness or relative benefit without regard to cost. Yet any prioritization that ignores differences in the benefits produced by different services would appear to be irrational and deeply problematic. This conflict had not been well appreciated before Secretary Sullivan's decision in part because there had been so few public and explicit efforts to prioritize and ration health care before Oregon, and there have been none since in the United States with the systematic character of Oregon's effort. However, although few are today willing to prioritize and ration services as openly and explicitly as was Oregon, with the dominant force in health policy now to control health care costs, health plans, insurers and providers inevitably must and regularly are making decisions about what care to provide or cover and what to deny. Probably the dominant public concern about the growth of managed care is that it will deny patients needed and beneficial care. And there is no reason to believe that these provision and coverage decisions do not take into account, even if not systematically, the costs and benefits of different services. So while there are no comparable open conflicts like that between the Oregon plan and the ADA today, the issues raised by that conflict have hardly disappeared. It is those issues that I will explore in the rest of this paper. Before doing so, however, I want to note that Oregon revised its prioritization process and list to meet the Secretary's objections and the revised plan was subsequently approved. I shall consider those revisions below when I explore alternative strategies for avoiding the conflict between the ADA and rational priority setting.

The National Legal Center's example of discrimination based on disability that was cited by Secretary Sullivan in his initial rejection of Oregon's waiver request was a specific scenario, but I want to generalize the different forms of discrimination against persons with disabilities that either a cost effectiveness or relative benefit standard will produce. For convenience in exposition I will use QALYs as the measure of benefit of health interventions, but I believe the same issues arise with other benefit measures; QALYs might be calculated using the QWB, as in Oregon, or any of a number of other health-related quality of life measures.¹³ In what ways does priority setting conflict with ADA? 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

will be fewer with such disabled patients than with 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 by definition under the ADA substantially limit one or more major life activities, they will reduce an individual's health-related quality of life. For this reason as well, life-saving interventions will produce fewer QALYs with a disabled patient, for example with COPD or impaired vision, than with an otherwise similar non-disabled patient, and again even if the intervention is unrelated to the individual's disability. Third, benefit measures like QALYs will often discriminate against persons with disabilities with health interventions that protect or improve the quality of life. When a pre-existing disability in effect acts as a co-morbidity it can make a treatment less effective in improving a patient's health-related quality of life. Patients with COPD or advanced CF, 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 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 grams) typically leaves them with various substantial disabilities, whereas neonatal intensive care for low birth weight newborns (500 to 2500 grams) is typically associated with much less or no resultant disability; extreme low birth weight newborns typically have greater long term disabilities even with, and in part caused by, treatment. 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. This last example also illustrates a fifth way in which disabled individuals will be discriminated against when the standard for prioritization is cost-effectiveness, not just relative benefit. 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 be with no or a less severe disability; for example, the typical costs of neonatal intensive care for extreme low birth weight newborns are much greater than for low birth weight newborns. Since cost-effectiveness prioritizes on the basis of relative cost, as well as relative benefit, it will give higher priority to the less expensive treatment.

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, probably usually, health interventions will be equally cost effective and beneficial for persons with and without disabilities since the interventions will treat other conditions and not be affected by the presence of a disability. In other cases the health care needs of the disabled will receive higher priority when disabled persons' function can be effectively restored or ameliorated either by treatment of their disability, or by treatment which reduces their disability in the course of treating a different condition. 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. And, importantly, the cause of the disabled faring worse than the non disabled is not unrelated to their disabilities.

Instead, it is precisely as a result of their disability that cost-effectiveness or relative benefit standards give treatment of people with disabilities lower priority in each of the five forms of discrimination I have illustrated above; it is the disability itself that reduces the benefit and/or increases the cost of treatment, and so places persons with disabilities lower down on the priority list for treatment. Not every disadvantage, however, is unjust, nor is being placed lower on a priority list always unjust discrimination. Is this disadvantage and lower priority unjust (I do not address whether it is legally in violation of ADA)?

The answer to this question is controversial. Some commentators have argued that it is not unjust, that this disadvantaging of persons with disabilities is an inevitable and acceptable consequence of a rational priority setting process. For example, David Hadorn writes:

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.¹⁴

However, we are concerned with the use of quality of life and ability to function specifically for the purpose of prioritizing between, of selecting among, different persons or groups in allocating scarce health care resources. Even if we rejected such use there, outcomes research would still be important to determine which among alternative health interventions would most benefit a given patient or group of patients; this would be the first of the two kinds of funding decisions distinguished by the National Legal Center, which they granted would not be discrimination based on disability.

Paul Menzel too has defended this use of quality of life considerations in priority setting, despite acknowledging that it can disadvantage the disabled:

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.¹⁵

. One argument why use of quality of life considerations in priority setting is unjust to the disabled is that it appears to imply that the lives of disabled persons are worth less than the lives of non disabled persons, thereby violating the equal moral concern and respect that all persons are due. Hadorn and 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 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 morally problematic implication in the case of disabilities is not difficult to find, and it is clearest in the case of life-saving treatment. We use QALYs to measure the value of health benefits; because persons with disabilities have a lower quality of life, we produce less valuable benefits in QALYs by saving their lives than by saving the lives of persons without disabilities. 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. 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, worth less because of their disabilities, and so to be incompatible with their equal moral worth as persons.

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? One line of reasoning, setting aside cases where persons are responsible for causing their disabilities, is that 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 than otherwise similar non disabled individuals for health care treatment, especially when the treatment is unrelated to the disability. 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.”¹⁶ A different line of reasoning appeals to a moral principle of equality of opportunity. Equality of opportunity has a deep place in American moral and political culture, although its precise meaning and requirements are contested. 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.¹⁷ If disabilities are conditions that substantially limit one or more major life activities of persons, as ADA understands them, then disabilities by definition will reduce individuals’ opportunity from that which otherwise similar non disabled persons enjoy, thereby denying them equality of opportunity with non disabled individuals. Any of these three lines of argument would need much spelling out to fully establish that the disadvantages disabled persons suffer in prioritization of health care resources is indeed unjust, but I shall not pursue those details here.

At the core of these moral objections to practices that discriminate against the disabled is using or allowing an undeserved disadvantage--the disability that limits a person’s function--as grounds to disadvantage that person further with regard to some other good or benefit. In the case of health care resource prioritization it is using or allowing people’s undeserved disabilities as the ground for denying them care they would otherwise be eligible for, or for giving them a lower priority for care than they would otherwise have. But it is important not to assume that every case of discrimination in this sense is necessarily, all things considered, unjust. The ADA requires employers, for example, 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. Airlines are not required to hire people with severely impaired vision as airline pilots. Their disability prevents them from performing this job at an acceptable level and the good of the safety of others takes precedence over allowing

them an equal chance to become pilots. So if ignoring or accommodating a person's disability would require too great a cost in the good we seek to produce in a particular activity, here transporting people safely, then denying the person with a disability the benefit sought, here the job of airline pilot, is not, all things considered, unjust. Likewise, if the good of health care, simplistically put, is health, then using disability as a ground for denying persons care, or for giving persons lower priority for care, may not necessarily be, all things considered, unjust if not doing so would produce too great a cost or sacrifice in furthering the goal of health care.

I want now to explore some different standards than cost-effectiveness and relative benefit for health care resource prioritization that might avoid disadvantaging persons with disabilities in unjust ways. How did Oregon revise its ranking standard to avoid the apparent conflict with ADA and secure waivers from HCFA to implement its new Medicaid plan? In part by combining some treatment/condition pairs that had been held to be discriminatory when distinguished; for example, neonatal intensive care for newborns below 500 grams and between 500 and 2500 grams were combined into a single treatment/condition pair, thereby avoiding the apparent discrimination against extreme low birth weight newborns by grouping them with low birth-weight newborns who have much better treatment outcomes. More generally, they abandoned explicit evaluation of outcomes in terms of length and quality of life and now assessed them by "the probability (percent of the time) that within five years the average person with a particular condition receiving a specified treatment would (1) die, (2) have significant residual effects (symptoms) because of or in spite of treatment or (3) become asymptomatic".¹⁸ This largely avoids the first two forms of discrimination I noted above with life-sustaining treatment by ignoring the expected length of survival beyond five years and by not adjusting those surviving life years for differences in quality of life. However, the new second and third criteria still would apparently give lower priority to treatments for patients left with residual disabilities than to treatments that leave patients asymptomatic. This still gives weight to differences in outcomes in terms of patient quality of life and so is still open to the charge of discriminating on the basis of residual disability. On the other hand, since the prioritization standard essentially looks to whether, or the extent to which, a treatment works (as measured by 5 year survival and the continued presence or absence of symptoms which the treatment causes or for which it is intended), it does not discriminate based on differences in life expectancy and quality of life caused by a disability that is unrelated to treatment. Oregon's new criteria substantially, but apparently not completely, avoid the forms of discrimination against the disabled that I noted earlier. However, we need the reasons why particular criteria are or are not morally acceptable, a principled account of when and why disadvantaging of the disabled is and is not unjust. We need to look further.

A radical position that would avoid all the forms of discrimination I distinguished above would be to abandon all appeal to assessments of the impact of treatments on quality or length of life (or to differences in their costs) when prioritizing resources for different persons, so as to avoid differences in these impacts that result from or in disabilities in some patients. This would still be compatible with attending to differential impacts of alternative treatments on length and quality of life in selecting treatments for the same patient or group of patients. However, this position would prevent us from taking any account of the differences in benefits between treatments in prioritizing. If the

aim of health care is, again simply put, to promote health, then to completely ignore the different impacts on health of different health interventions would be irrational. Even if taking account of the different impacts of different treatments was shown to be always unfair to those who needed the treatments providing lesser benefits, the opportunity costs in lost health benefits from ignoring all differences in benefits would be sufficiently great to at least sometimes override the unfairness. But taking account of differences in benefits has not been shown to be always unfair.

To explore a different response to this problem of discrimination, consider first prioritizing life-sustaining treatments.. Suppose two patients, one of whom is blind but who are otherwise similar, each need a lifesaving organ transplant and there is only one available organ. Should the disability and lower health-related quality of life of the blind patient, which will result in fewer QALYs produced if she receives the transplant, give her lower priority for the transplant? Many would say it should not, and so presumably does the ADA. Why? Frances Kamm has argued that from the subjective point of view of each patient his or her own survival is far more important than another's survival, even if the quality of life of the blind patient is not as good as the non disabled patient's, her survival would still be more important to her.¹⁹ From this deontological perspective, morality must take some account of the subjective point of view of individual persons, not just how matters look from an impersonal objective point of view. If from the subjective standpoint of each individual the benefit of surviving is not substantially different because one is blind, then each should be given an equal, or at least some significant, chance to live and the difference in their quality of life ignored. Each stands to get, as Kamm puts it, "the major part of what both stand to get," their life.²⁰ Moreover, each stands to lose everything, her life, and each equally needs the transplant for life. Since one individual would prefer an outcome where she survives in full health to one where she survives blind, we can grant that in this respect the former is a better outcome. But this difference in outcomes when two different patients each need life-saving treatment is insufficient to justify the very great difference in how they would be treated--one lives and one dies--if we select the patient who will be returned to full health with treatment.

Each of the ways that I have put above the reason for ignoring this difference in the quality of life of patients when life-saving is at stake does not imply that all such differences should be ignored, nor that the position is fully subjective in the sense that if each cares more about her own survival than the other's, that is sufficient to require ignoring the difference in outcomes. Kamm calls her position "subjective" to indicate that it combines the subjective point of view with an objective impersonal point of view which considers degree of benefit without regard to whether one gets it oneself. Each might not get the major part of what each stands to get if the difference in quality of life were very great, and if it was very great it might be sufficient to justify our saving one and letting the other die. A fully subjective view would have unacceptable implications. To take an extreme example, polls of the public have shown that around 10% of people would want treatment to sustain their lives even if they were in a persistent vegetative state (PVS), and to some or most of these 10% it could well be more important to them that they survive even if they were to be in PVS than that another survive in full health. A fully subjective view might then imply that if such a person came to be in PVS he should receive an equal chance for a scarce life-saving treatment with a person who could be

returned to full health. But few would accept this position; this difference in outcomes is sufficiently great to justify letting the PVS patient die and saving the other.

Roughly the same line of argument can be applied to differences in life expectancy between patients needing life-saving treatment and in turn the differences in expected QALYs treating them would produce. That Patient A would be expected to survive 10 years with treatment and Patient B 20 years is insufficient to justify the very great difference of saving B and letting A die, and we would expect that it would be more important to each from their subjective point of view that he or she survive. On the other hand, if the difference in expected survival was that A would live for 2 days and B for 20 years, this difference is sufficient to justify how we would treat each if we save B and let A die. In this case, it might not be more important to A that she be saved instead of B, but even if it were, as Kamm argues, this sacrifice of the loss of 2 days of life is sufficiently small that A should be morally expected to accept it in order for B to gain 20 years of life.²¹

None of the above reasoning is precise about when a difference in outcomes between patients, or between types of treatments, is sufficiently great that it can be used to decide who lives and who dies in cases of life-saving. Nor have I argued here whether significant but not sufficiently great differences in outcome should be ignored and patients given equal chances to obtain the treatment they need to survive, or whether some scheme of proportional chances should be used in which the patient who would get the worse outcome would get some but a lesser chance to survive.²² If in the case of life-saving treatment some but not all differences in outcome of quality or length of life should not be used to prioritize patients or treatments, then some but not all disadvantage based on disability in resource prioritization is unjust. I have not distinguished when a pre-existing disability results in a difference in outcomes of life-saving treatments from when the difference is caused by the treatment; some would hold that intuitively the former are more plausibly cases of unjust discrimination based on disability, but the basis for this view is not clear.

The third and fourth forms of discrimination against the disabled concerned treatment whose purpose is to improve or protect patients' health-related quality of life, and which is less effective either because a pre-existing disability acts as a co-morbid or complicating factor in treatment or because some non disabling difference between patients leaves one but not the other with a disability after treatment. Notice that these forms of discrimination cannot be avoided by the proposal some have made to look only at whether treatments are effective, not to any background conditions of disability, since it is precisely a difference in treatment effectiveness that generates these two forms of discrimination. We may be able to use roughly the same strategy here as sketched above regarding life-saving treatment, with a significant qualification. If we again want to take some account of the subjective point of view of individual patients, for each of whom their getting needed treatment will be most important despite a disability-related difference in treatment effectiveness and benefit, then we cannot simply prioritize by the degree of benefit different patients would receive from treatments.. Small differences in benefits will not be sufficient to justify treating or funding the cost of treating some, but not treating or funding the cost of treating others. The small difference in benefit would in this context be what Kamm has called an irrelevant utility or good, though I think characterizing it as an insufficient good or benefit more clearly directs attention at what it

is insufficient or irrelevant for, namely justifying treating the patient(s) who would receive the greater benefit. The qualification is that since the difference in outcome between patients treated or not treated in the case of life-saving treatment is typically much greater—one lives and one dies-- than in the case of treatment that protects or improves quality of life—both live, but only one gets an improvement in quality of life from treatment--with quality of life treatments smaller differences in outcomes of treatments can often justify treating the patient who will benefit more. Here again with quality of life treatments, some but not all disadvantaging of persons with disabilities because their disability will result in their benefiting less from treatment will be unjust.

A different way of thinking about the treatment of persons with disabilities in resource prioritization is as one species of the more general problem of what priority the worst-off should receive. Disability discrimination will not fully fit into a priority to the worst-off framework because, as Kamm points out, sometimes having a disability would not make one worse off than another. Kamm's example is the case of two persons with a life-threatening illness, one of whom has just become disabled and so would have a worse quality of life in the future if saved; neither has had a worse health-related quality of life until now (Kamm's backward looking conception of need), and each will die equally soon without treatment (Kamm's forward looking sense of urgency). Neither is worse-off measured either by her sense of need or urgency, yet it would be wrong not to treat the disabled person because his future quality of life would be lower; that would be an insufficient or irrelevant good.

There is no reason, however, to believe that disability discrimination always raises the same moral concern and usually our moral concern for the disabled may be for how their disability makes them worse off than others. If disabilities are understood as limitations in one or more major life activities, as the ADA does, then their moral significance may be that this disadvantage, other things being equal, makes persons with disabilities worse off than persons without them and that it is more important morally to help the worst off. The question raised by persons with disabilities for health care resource prioritization then will what priority should be given to the worst-off. This is a large, complex, and unresolved issue that I cannot pursue here, but I can at least distinguish three different components of the broader issue.

The first component—who are the worst-off for purposes of health care resource prioritization--has special importance for how a priority to the worst-off framework applies to resources for the disabled. Two aspects of this component are important here: Should the worst-off be understood as the sickest, or as those with the worst level of overall well being of which health is only one component? Should the worst-off be understood as those worst-off at a point in time, or over their lifetimes? If the sickest is the proper focus, then to the extent that where one falls on a health-related quality of life scale roughly corresponds to how disabled one is, those who are worst-off will roughly correspond to the most disabled. On the other hand, if the concern for the worst-off should be for those whose overall level of well being is worst, then some with significant disabilities may nevertheless have a higher level of overall well-being than others without any disability, and so receive less not more priority. Moreover, even if the proper perspective is how sick people are, whether that means now, over their lifetimes, or possibly some combination of both, will often determine which individuals or groups are the worst-off or most disabled.

The second component of the issue of priority to the worst-off is why, for what moral reason, the worst-off should receive some priority, in health care resource prioritization. There are a number of different possible answers—for example, in order to reduce inequality, in order to increase equality of opportunity, because reducing greater deprivation has greater moral importance, because getting treatment will be subjectively most important to the sickest, or because the sickest have the greatest health needs. Some of these reasons would most plausibly apply to those whose overall well-being is worst, others to the sickest.

The third component of the issue of priority to the worst-off in health care resource prioritization is how much priority they should receive, which will be determined in part by why they should get priority. Even assuming a compelling moral reason for such priority, it would be implausible to give the worst-off absolute priority. Doing so would raise what has been called the “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 to produce much greater benefits for others less badly off. Here again, priority to the worst-off or disabled must be balanced against other moral considerations, including treatment effectiveness or benefits.

I cannot pursue here any of these three components of the priority to the worst-off issue, but progress on them may be necessary for us to make progress on the issue of what priority the disabled should receive. One reason for thinking the priority to the worst-off may be the right framework for much 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 or relative benefit standards in order to meet specific moral claims of the disabled. First, 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 disabilities are undeserved disadvantages, compensation is required in order to remove or reduce the 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 and to explore some, but by no means all, possible standards for prioritization that may avoid unjust discrimination against persons with disabilities. 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 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 to be done.

¹ This paper draws in places on, and extends the analysis of, my “Justice and the ADA: Does Prioritizing and Rationing Health Care Discriminate Against the Disabled?” Social Theory and Practice (1995) 159-185.

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

³ David Orentlicher, “Rationing and the Americans with Disabilities Act,” Journal of the American Medical Association 271 (1994) 308-14.

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⁵ I draw on Michael J. Garland, “Justice, Politics, and Community: Expanding Access and Rationing Health Services in Oregon,” Law, Medicine, and Health Care, 20 (1992) p. 70.

⁶ Robert Kaplan and John Anderson, “A General Health Policy Model; Update and Applications,” Health Services Research, vol. 23 (1988), pp. 203-35.

⁷ David Hadorn, “Setting Health Care Priorities in Oregon: Cost-Effectiveness Meets the Rule of Rescue,” Journal of the American Medical Association, vol. 265 (1991), pp. 2218-25.

⁸ David Eddy, “Oregon’s Methods: Did Cost-effectiveness Analysis Fail?” Journal of the American Medical Association, vol. 266 (1991), pp 2135-41.

⁹ Hadorn, op.cit.

¹⁰ Unpublished letter from Secretary of Health and Human Services Louis W. Sullivan to Governor Barbara Roberts of Oregon, August 3, 1992.

¹¹ Unpublished letter from Thomas J. Marzen and Daniel Avila, National Legal Center for the Medically Dependent and Disabled, Inc., to Representative Christopher H. Smith, U.S. House of Representatives, December 5, 1991.

¹² Ibid.

¹³ See Dan W. Brock, “Quality of Life Measures in Health Care and Medical Ethics,” in The Quality of Life, ed. A. Sen and M. Nussbaum (Oxford: Oxford University Press, 1993).

¹⁴ David Hadorn, "The Problem of Discrimination in Health Care Priority Setting," Journal of the American Medical Association 268 (1992), 1454-59.

¹⁵ Paul T. Menzel, "Oregon's Denial: Disabilities and Quality of Life," Hastings Center Report, vol. 22, no.6 (1992), pp. 21-25.

¹⁶ Frances Kamm, "Deciding Whom to Help, the Principle of Irrelevant Good and health-Adjusted Life Years," unpublished.

¹⁷ Norman Daniels, Just Health Care, (Cambridge: Cambridge University Press, 1985)..

¹⁸ New York Times, March 20, 1993, p. 8.

¹⁹ Kamm, op.cit. See also her Morality/Mortality Volume 1: Death and Who to Save From It, (Oxford: Oxford University Press, 1993).

²⁰ As Kamm notes, this might be interpreted as "the biggest part quantitatively of what either can get" or "the meaningful minimum that it is crucial that someone have."

²¹ Kamm, "Deciding Whom to Help..." op. cit. and Morality/Mentality op. cit.

²² Dan W. Brock, "Ethical Issues in Recipient Selection for Organ Transplantation," in Organ Substitution Technology: Ethical, Legal, and Public Policy Issues, ed. Debra Mathieu (Boulder, CO: Westview Press, 1988), p. 94.