
Considering Quality of Life while Repudiating Disability Injustice: A Pathways Approach to Setting Priorities

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Introduction

This article proposes a novel strategy, one that draws on insights from antidiscrimination law, for addressing a persistent challenge in medical ethics and the philosophy of disability: whether health systems can consider quality of life without unjustly discriminating against individuals with disabilities. It argues that rather than uniformly considering or ignoring quality of life, health systems should take a more nuanced approach. Under its proposal, health systems should treat cases where disability leads to lower quality of life because of disability-focused exclusion or injustice differently from cases where lower quality of life results from laws of nature or appropriate trade-offs in the face of resource scarcity. Decisionmakers should ignore quality-of-life losses that result from injustice or exclusion when ignoring them would improve the prospects of individuals with disabilities; in contrast, they should consider quality-of-life losses that are unavoidable or stem from permissible trade-offs in response to resource scarcity. While health systems should not amplify existing injustice or exclusion of people with disabilities, they are not required to sacrifice the legitimate interests of others in need of medical care.

The most common quality of life metric, the quality-adjusted life-year (QALY), is calculated by multiplying the years of life a given intervention produces by the average quality of life the beneficiary enjoys during those years. So, for instance, a liver transplant that is

expected to extend life by twenty years at eighty percent of full health (represented as a quality of life of 0.8) produces $0.8 \times 20 = 16$ QALYs. Health systems that use QALYs to set priorities will therefore tend to assign less value to saving the life of someone with a preexisting disability: saving a liver transplant recipient for ten years will produce only 8 QALYs, whereas saving a completely healthy person for ten years will produce 10 QALYs. This consequence is frequently described as undesirably discriminatory.¹

In response to the concern that QALYs discriminate against individuals with preexisting disabilities, two strategies are most prominent. One is to argue that such discrimination is justified rather than invidious.² The other is to ignore quality-of-life considerations.³ Many bioethicists have noted that neither response appears fully satisfying: as Paul Menzel puts it, we can describe “the contradiction between conventional [cost-effectiveness analysis] and our convictions about relative equity of lifesaving as the ‘QALY Trap.’”⁴

This article sketches a third approach, which I call the Pathways Approach, to considering quality of life when setting health care priorities. The Pathways Approach differentiates (1) disability-associated disadvantages that result from private preferences, and (2) those that result from public policies that impose unjust deprivation on people with disabilities, from (3) disadvantages that are unavoidable or (4) could be avoided only by unjustly allocating limited resources. In the first part of the article, I explain how the Pathways Approach achieves this differentiation and why it is ethically attractive. In the second part of the article, I explore some implications of the Pathways Approach and contrast it with other attempts to escape the “QALY Trap.”

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The Pathways Approach is applicable not only to cases of absolute scarcity (such as deciding which of two patients to save) but also to other areas of health policy where cost-effectiveness is proposed as a design element, such as value-based health insurance or formulary construction.⁵ The approach could also potentially be applied outside of health contexts, so long as quality of life is the basis for setting priorities in those contexts. Similarly, while I focus on examples at the “macro” level of health policy (governmental policy), the Pathways Approach could in principle also be used at the “meso” (institutional) or even “micro” (clinical) levels, so long as the meso- and micro-level decisions

objectionable choices are not appropriate objects for legal regulation. For instance, a religious congregation that refuses to accept a prospective member with trimethylaminuria or a husband who divorces his wife when she develops alopecia might both be ethically criticized as callous. Yet the law should not punish their callousness.¹⁰

I will argue that even if privately imposed disadvantages are real — for instance, if individuals with trimethylaminuria experience disadvantages in dating or friendship — these disadvantages should be ignored for priority-setting purposes when considering them would set back the interests of people with

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are based on reliable information about how specific disabilities might be connected to disadvantage. Absent such information, the use of the Pathways Approach *ad hoc*, particularly at the clinical level, is vulnerable to bias,⁶ although it might still be preferable to the use of unmodified QALYs to make clinical decisions.

I. Considering Pathways to Disadvantage

A. Privately Imposed Disadvantage

Certain private choices are ethically acceptable even though, in aggregate, they impose disadvantages on individuals with specific disabilities. For instance, a person who uses only sign language may reasonably prefer to live with others who communicate in the same way, and the same is true for someone who only uses a non-signed language.⁷ Similarly, it can be ethically acceptable to decide whom to date or marry on the basis of personal and even arbitrary inclinations.⁸ An attraction to long, flowing hair can justify not dating someone with alopecia; a feeling of repulsion toward certain smells can justify not dating someone with trimethylaminuria. (This is so even though our private preferences arise in a context of stigma and bias, including bias against people with disabilities.) Yet ethically acceptable choices about rooming and dating can impose substantial disadvantages on individuals with certain disabilities.⁹ Additionally, some ethically

disabilities. This reasoning parallels that of *Palmore v. Sidoti*, a child custody case in which the Supreme Court considered whether and when governmental actors are permitted to take privately imposed disadvantages into account:

In common with most states, Florida law mandates that custody determinations be made in the best interests of the children involved. The goal of granting custody based on the best interests of the child is indisputably a substantial governmental interest ... It would ignore reality to suggest that racial and ethnic prejudices do not exist or that all manifestations of those prejudices have been eliminated. There is a risk that a child living with a stepparent of a different race may be subject to a variety of pressures and stresses not present if the child were living with parents of the same racial or ethnic origin. The question ... is whether the reality of private biases and the possible injury they might inflict are permissible considerations for removal of an infant child from the custody of its natural mother. We have little difficulty concluding that they are not. The Constitution cannot control such prejudices but neither can it tolerate them. Private biases may be outside the reach of the

law, but the law cannot, directly or indirectly, give them effect.¹¹

In *Palmore*, the Supreme Court recognized the real burdens that private biases produce but elected to ignore their effect on the child's interests, on the basis that considering such burdens would magnify the effect of private biases. The Supreme Court has recognized the allowability of crafting policy in response to private biases, however, when doing so would remediate rather than magnify the effects of bias.¹²

This article's proposed approach extends *Palmore's* reasoning to the context of setting health care priorities. Under the Pathways Approach, a government or commercial insurer would not be permitted to set priorities based on quality-of-life judgments that include the negative effects of private aversions or biases on individuals with specific disabilities, when considering such effects would further disadvantage those individuals. This is so even if considering the effects of private bias and aversion would help other disadvantaged groups or individuals with other disabilities. Notably, this approach would not differentiate ethically objectionable private aversions from ethically acceptable ones, since a decisionmaker may not place a stamp of approval on either class of aversion.

Some have criticized *Palmore* for its willingness to sacrifice the real-world interests of children targeted by private bias in order to avoid giving effect to those biases.¹³ The Pathways Approach, in contrast, would not sacrifice the real-world interests of individuals with specific disabilities — rather, it would advance their interests.

B. Unjustly Imposed Disadvantage

Many of the disadvantages that people with specific disabilities experience stem from illegal conduct such as employment discrimination. The same reasoning that proscribes exacerbating the effect of private biases or aversions would also proscribe priority-setting that disadvantages individuals with disabilities by exacerbating the effects of illegal discrimination or wrongful failure to accommodate.

The Pathways Approach, however, does not proscribe considering the quality-of-life effects of background injustices that do not target individuals with disabilities. Consider the following scenario: a limited education budget that results from a background injustice, namely inadequate taxation and excessive spending on less important objectives, puts the interests of special education students into conflict with the interests of general education students. The Pathways Approach would permit the consideration of the lower quality of life that special education students experi-

ence due to justifiable budgetary trade-offs. This is because the background injustice that necessitates these trade-offs — unlike the operation of private aversions or illegal discrimination — does not distinctively injure individuals with disabilities. Distinctive injury need not be solely focused on disability — it can also include identity-based injustice to individuals with an intersectional identity that includes disability, such as discrimination against women or people of color with disabilities. (Put another way, the Pathways Approach directs decisionmakers to set priorities based on quality of life outcomes in a society without *disability-focused* injustice, not quality of life outcomes in a *perfectly just* society. I will return to this issue in Part II.)

The Pathways Approach, however, does not preclude efforts to reduce background injustice. Advocates for priority-setting have been criticized in the past for regarding the paucity of resources devoted to health improvement as fixed, and for otherwise ignoring background injustice.¹⁴ While many of these criticisms overlook the explicit recognition by priority-setting advocates that current resource allocations are inadequate, or ignore the fact that setting priorities does not preclude efforts to increase resource availability,¹⁵ critics are correct to remind us that the background conditions that make specific priority-setting arrangements necessary are not inevitable. It is possible to recognize the fact that disabilities would often remain disadvantaging in our actual society even if we resolved trade-offs in the most ethically defensible ways, while working to achieve a society in which disabilities are less disadvantaging.

C. Unavoidable Disadvantages

The prior two sections have discussed categories of disability-associated disadvantage that health systems should not consider when doing so would further disadvantage individuals with disabilities. In this section and the next, I consider categories of disadvantage that health systems should consider, even when doing so would be worse for individuals with disabilities.

In this section, I argue that certain disabilities impose quality-of-life losses that are outside our power to prevent, and that it is legitimate to consider such unavoidable losses when setting priorities. In defending this claim, I depart from both the value-neutral model of disability that Elizabeth Barnes has recently defended and the well-known social model of disability. The social model asserts, in what Barnes calls its “strong” form, that while people with disabilities experience various disadvantages in current society, these disadvantages could all be ameliorated through social or policy change. As Barnes puts it, the social model holds that:

disability is the disadvantage produced by social prejudice against certain types of persons (persons with impairments). Were society not organized in a way that penalizes people with impairments, there would be no disabled people. Disability just is the negative net effects of having an impairment in a society that discriminates against those with impairments.¹⁶

Proponents of the “strong” version of the social model also claim that all of the bad effects of impairments stem from social prejudice.¹⁷ Barnes has offered a very compelling criticism of the social model, namely that some bodily or mental differences, such as chronic pain, produce disadvantages that social and policy changes cannot fully ameliorate.¹⁸ I disagree, however, with her value-neutral model’s assertion that we can never regard even these bodily differences as bad in themselves for their possessors.¹⁹ Rather, I contend that some bodily differences — those that make experience impossible; those that make the exercise of agency impossible; and those that impose severe pain — are unavoidably bad.

The paradigm case of a bodily difference that makes experience and agency impossible is death. A major reason why death is bad is that it deprives us of our capacity to have experiences or exercise agency.²⁰ These deprivations are bad under any attractive way of organizing the built environment or the social world. The badness of death supports the further claim that bodily or mental differences that share almost all of death’s bad features, such as persistent vegetative state and coma, are also bad.²¹ This claim is contrary to the value-neutral model — or, at the very least, shows that the value-neutral model only applies to a limited set of disabilities.²² (That death and unconsciousness are bad states to be in is fully compatible with the reasonableness of sometimes choosing or risking these states in order to avoid other outcomes. We see this in everyday cases: when you go on a road trip, you slightly raise your risk of ending up in an inherently bad state, death, even though staying in town isn’t an inherently bad state to be in.)

Does the claim that states like coma are unavoidably bad support the claim that bodily differences like blindness are unavoidably bad, because both people who are blind and people who are dead lack the capacity to have visual experiences? No. As Barnes describes, even while blindness closes off some possibilities, it can open up others.²³ Coma, anencephaly, and death, unlike blindness, do not open up alternative possibilities because they block the capacity to have experiences at all. Furthermore, Barnes’ case for her claim that specific disabilities cannot be inher-

ently bad relies centrally on the first-person testimony of individuals with those disabilities²⁴ and coma and death render such testimony unavailable.

Turn now to mental disabilities that remove the capacity for complex thought, interpersonal interaction, and/or long-term planning while still leaving open the possibility of having experiences. (Severe psychosis and advanced dementia might be examples.) We often cannot obtain first-person testimony from people with these disabilities, and even if we could, they might (as Barnes acknowledges) be unreliable reporters.²⁵ Profound mental disabilities close off many valuable possibilities while opening few or none. This differentiates profound mental disabilities from other mental disabilities that allow for complex thought, interpersonal interaction, and long-term planning, but that still may — like blindness — often be disadvantaging because of the arrangement of the social world.²⁶

I also contend that pain is unavoidably bad. Here I disagree with Barnes, who argues that pain is not unavoidably bad by appealing to the testimony of disability rights activist Nadina LaSpina, who has post-polio syndrome, has had both of her legs amputated below the knee, and is in chronic pain. Even if LaSpina’s testimony can be sufficient to support Barnes’ claim,²⁷ my reading of LaSpina’s testimony departs from Barnes’. Consider the following:

Pain is part of her disability, says LaSpina; it comes with the territory. She says she’s happy with herself “as a person with a disability — with whatever pain there is. That’s part of it.” It’s like being Italian, she goes on. “I’m proud of being Italian. There are things I’m ashamed of, like the existence of the Mafia — but these things do not stop me from embracing my Italian-ness. I love being a woman, but I hate going through menopause. But I wouldn’t want a sex-change operation just because of menopause. Certainly the pain ... of disability [is] not wonderful, yet that identity is who I am. And I am proud of it.”²⁸

Barnes interprets these statements as supporting the idea that LaSpina’s pain is good for her — that pain is a *necessary* feature of her disability. But it is more plausible to read LaSpina as believing that while pain happens to be part of her disability, and while she wouldn’t give up her disability in order to obtain pain relief, pain is not a *necessary* part of her disability. Analogously, LaSpina’s assertions she would not want to change sex to avoid menopause, or renounce her Italianness to avoid being associated with the Mafia, do not entail that she regards menopause or the Mafia as necessary or desirable parts of those identities; rather, her state-

ments would be consistent with endorsing efforts to disband the Mafia — which she describes as a shameful organization — while preserving Italian identity, or efforts to enable women who wish to do so to retain their gender identity while avoiding menopause. Similarly, LaSpina's disability pride need not require that she be averse to medical interventions that eliminated her pain while preserving her disability.

Some pains, of course, may be truly inextricable aspects of bodily differences or achievements that are good for a person. Barnes offers pain from athletic training as an example. But the possibility of inextricable pains provides no reason to think that LaSpina's pain, or pain in general, is inextricable from disability. A more plausible view is that LaSpina is experiencing, to use Barnes' terminology, both an "intrinsic bad" (being in chronic pain) and a "local good" (being disabled).²⁹ Even if her situation is good for her on balance, it would be better without the intrinsic bad. Similarly, even if there are locally good aspects of pain itself, as might be the case for a person who values suffering, they must be balanced against its intrinsic badness.

My further suggestion is that just as health systems should consider the badness of death when setting priorities, they should also consider other unavoidably disadvantaging conditions like pain, coma, and severe psychosis. While there may be challenges in precisely measuring how disadvantaging these conditions are, there is no disagreement that they are disadvantages, nor is there anything we could do to prevent their being disadvantaging. Assigning lower priority to individuals with unavoidably disadvantaging conditions may be worse for them, but does not amplify a background injustice: rather, it recognizes a fact, independent of our choices, about what different patients stand to gain from treatment.

D. Unjust-to-Prevent Disadvantages

In this section, I argue that when the social changes required to eliminate or reduce certain quality-of-life losses that result from disability would unacceptably sacrifice the interests of others in society, we should regard these disadvantages as similar to unpreventable disadvantages for the purposes of social policy.

Social policies that aim to improve quality of life for individuals with specific disabilities often do so by reallocating limited public resources, changing social norms, or changing the built environment. Others' legitimate interests in public resources, norms, and spaces set ethical limits on such efforts. As an example, designing effective websites requires balancing the interests of people with different disabilities:

To simultaneously meet the needs of people with different disabilities, there are some navigation compromises. Linear navigation must be provided by default because it allows a person to traverse all elements along a single dimension, like moving down a list. This makes it easier to search non-visually for an element and to navigate with limited switch input. Another compromise is the level of navigation. People need to perceive all elements, so navigation should move to every element (both interactive and non-interactive) by default. This may be an inconvenience for people with physical disabilities (who may want to navigate only to interactive elements).³⁰

The allocation of limited resources for programs like public education or health care likewise involves trade-offs.³¹ Similarly, justice requires balancing the interests of people with disabilities against those of others, including individuals experiencing disadvantage that stems from sources other than disability. For instance, the interests of personal-assistance workers in more generous wage-and-hour protections can conflict with the interests of people with disabilities who use these workers' services.³² More generally, plausible accounts of justice recognize values other than the mitigation of disadvantage.³³ These other values also set limits on efforts to mitigate disadvantage caused by interaction between disability and the social world.

I further suggest that just as there is no ethical problem with incorporating unavoidable disadvantages into priority-setting, there is no ethical problem with considering disadvantages that are preventable — but would be unjust to prevent — when setting priorities. While we might wish that conflicts and trade-offs did not exist, an appropriate resolution to these conflicts must consider the interests of all potential beneficiaries.

II. Evaluating the Pathways Approach

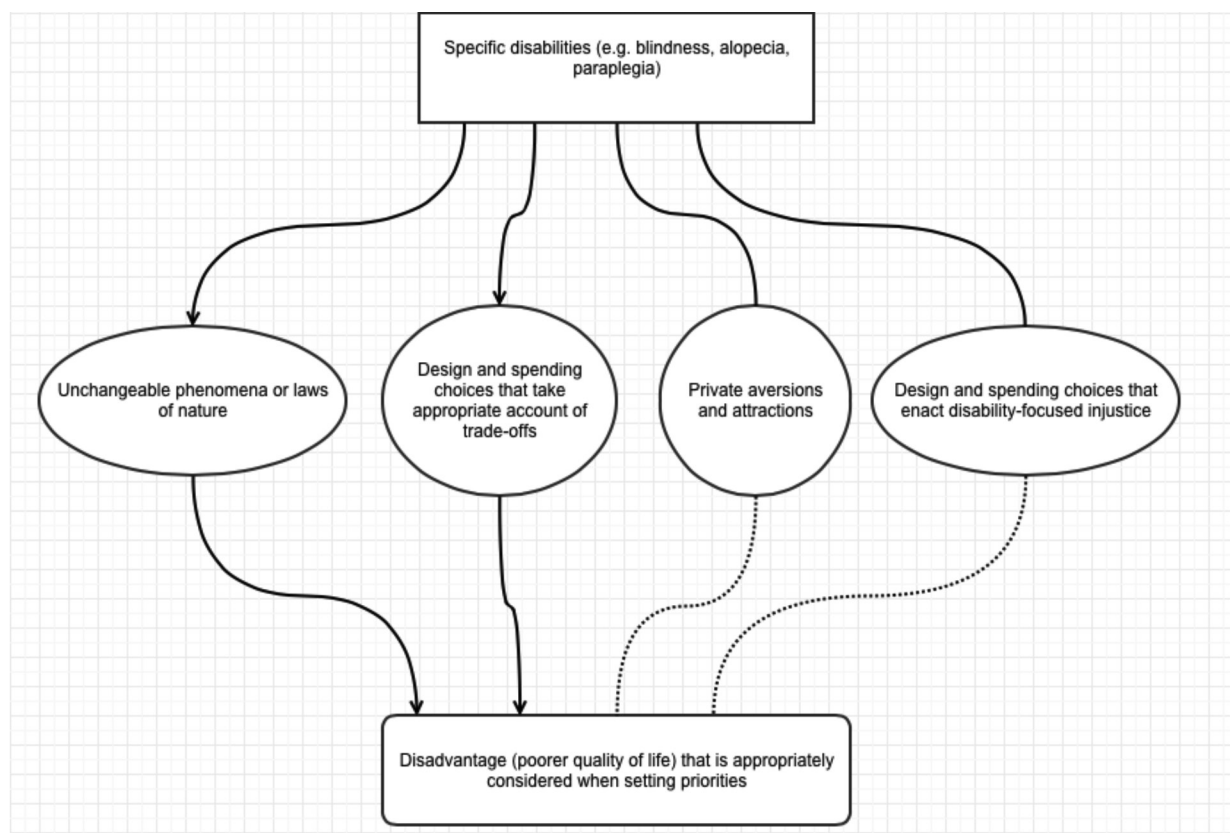
In this section, I turn from proposing the Pathways Approach to summarizing it and contrasting it with alternative attempts to solve the problems of traditional QALY approaches.

A. Quality of Life in a "Realistic Utopia"

The Pathways Approach — like a traditional QALY approach — allows health systems to consider individuals' expected future quality of life. But rather than considering their expected future quality of life in the *actual* world, it considers what their expected future quality of life would be in a *moderately idealized* world where individuals with disabilities are not subject to

Figure 1

Differentiating Routes to Disadvantage



In Figure 1, dashed lines represent pathways that ought not be considered when assessing disadvantage for purposes of priority setting. Solid lines represent pathways that may be considered.

discrimination, although scientific and resource limits still exist (Figure 1). So, to return to the liver transplant example discussed at the outset, the priority a paraplegic individual would receive for scarce organs would depend on the pathway by which her disability is predicted to lead to poorer quality of life in the world as it is.

Unlike traditional QALY approaches, the Pathways Approach recognizes that many disadvantages that people with disabilities experience are contingent on the arrangement of the social world. But it improves on the “social model” of disability by incorporating considerations of distributive justice into priority-setting decisions. In doing so, it responds to important criticisms of the social model of disability that David Weisbach and Adam Samaha have recently offered. Weisbach criticizes the social model for failing to consider trade-offs between the interests of people with specific disabilities and the interests of others:

Accommodations can be costly ... We need to understand what resources should be used to provide these accommodations. The issue is essentially distributive. To provide accommodations, we have to take from some to give to others. Sometimes we will be justified in doing so, but sometimes we will not be, and we must distinguish these cases. The tools of discrimination, however, are not up to this task. The social model ignores the brute fact of scarcity and, therefore, is unable to address distributional questions.³⁴

By allowing priority-setting processes to recognize that scarcity sets limits on our ability to optimize social arrangements for individuals with disabilities, the Pathways Approach addresses Weisbach’s concern. Similarly, the Pathways Approach agrees with Samaha’s observation that while the social model “suggests causes of disadvantage, ... what we do about it is a matter of contested norms,” and that “opposition to

social restructuring as a remedy for disability need not be the product of ignorance, insensitivity, false consciousness, or political immorality,” but “might be an understandable reaction within a coherent normative framework.”³⁵ Under the Pathways Approach, determining which disadvantages should be considered for purposes of priority-setting will depend on choices about the correct normative framework.

While the Pathways Approach bases priority-setting judgments on quality of life outcomes in an idealized world, it need not settle the question of what the idealized world would look like. Rather, the Pathways Approach is modular: members of any given society, or adherents of any given political doctrine, can employ the approach’s core insight by considering which social institutions should exist, and what the claims of people with specific disabilities to scarce resources, or to comparative priority for assistance, would be in those institutions.³⁶ This modularity, of course, is consistent

life that result from background injustice, rather than directing priority-setting actors to altogether ignore the effects of unjust bias.

A more radical variation of the Pathways Approach would adopt a line of reasoning due to G.A. Cohen. Even though I find this variation radically implausible, understanding it helps to illustrate the structure of the Pathways Approach. Cohen argues that arbitrary disadvantage is always unjust, irrespective of whether it is avoidable or whether avoiding it would be worse for everyone, and that the idealization employed when assessing whether a given policy is just should therefore ignore the feasibility of implementing that policy.³⁸ A Cohen-inspired version of the Pathways Approach might therefore set priorities in a way that ignores even differences in quality of life caused by unavoidable disadvantage — for instance, it would give a person in an irreversible coma the same chance of receiving a scarce organ as anyone else.

Examining this Cohen-inspired view helps us to understand how the Pathways Approach, in the form I propose it, represents a middle ground between the uncompromising utilitarianism of traditional QALY approaches and the uncompromising egalitarianism of quality-insensitive approaches. To build on Rousseau’s famous remark, the Pathways Approach takes people as they are (by responding to unavoidable disadvantage) and laws as they should be (by considering whether disadvantage results from disability-focused injustice). In contrast, QALY approaches take both laws and people as they are, rather than as they should be: what we should do is entirely determined by what makes people’s lives go well. And quality-insensitive approaches take both people and laws as they should be: what we should do can be entirely divorced from what makes people’s lives go well.

B. Comparing the Pathways Approach to Alternatives
Tyler John, Joseph Millum, and David Wasserman have recently argued for incorporating past quality of life into QALY-based approaches, and observe that doing so will often counterbalance the disadvantages QALY approaches impose on individuals with preexisting disabilities: as they put it, “Under our proposal, people with ... disabilities that reduce their quality of life will have their priority for life-saving health care resources lowered in virtue of the lower benefits that saving their lives provides, but raised in virtue of their being made worse off by the reduction in their quality of life.”³⁹ As John et al. concede, their approach becomes equivalent to the QALY approach

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with the approach providing more plausible answers in conjunction with some normative frameworks than with others.

Aspects of the Pathways Approach also resemble interpretations of the “undue hardship” and “reasonable accommodation” provisions of Americans with Disabilities Act and Rehabilitation Act. However, while undue hardship analysis and the Pathways Approach agree that private prejudices cannot be the basis for denying an accommodation, undue hardship analysis focuses narrowly on costs and benefits to a specific employer, whereas the Pathways Approach is able to consider costs and benefits to society more broadly.³⁷

Variations of the view I have proposed are also possible: one such variation might require that priority-setting judgements be based on quality of life in a society lacking not only disability-focused injustice but also background injustice of any kind. A variation going in the opposite direction might permit the use of priority-setting judgments that consider how ethically acceptable private discrimination affects individuals with disabilities. Still other variations might merely assign lower weight to limitations on quality of

whenever individuals' preexisting disabilities are not longstanding.⁴⁰

John et al., however, implicitly identify a weakness in the QALY approach, one on which I also focus: the right public policy for purposes of priority-setting is not necessarily the policy that maximizes overall well-being. John et al. instead propose what they call *moderate prioritarianism* — giving special but not overriding weight to the well-being of the worst-off individuals. But moderate prioritarianism merely replaces the welfare-maximization of the traditional QALY approach with a function that assigns greater weight to the welfare of the least advantaged. Another recent proposal, “justice-enhanced” cost-effectiveness analysis, similarly retains the welfare consequentialism at the heart of the traditional QALY approach while giving greater weight to avoiding the clustering of disadvantage.⁴¹ While the Pathways Approach gives some weight to differences in well-being, just as moderate prioritarianism and justice-enhanced cost-effectiveness analysis do, it differs from these approaches because it does not simply balance well-being against other values. Rather, it serves as a filter that counts only some sources of well-being and disadvantage while intentionally not counting others.

Because it does not assign a specific weight to well-being or to other values, the Pathways Approach could be combined with the approaches suggested by John et al. or by advocates of justice-enhanced cost-effectiveness analysis — their approaches could be used to determine how to *weight* the sources of well-being that count, while the Pathways Approach could be used to determine *which* sources of well-being count. For instance, incorporating the priority to the worst-off that John et al. employ could strengthen the Pathways Approach against the charge that, even if it prevents the exacerbation of injustice, it allows the exacerbation of unavoidable or justified disadvantage.

More recently, Lucio Esposito and Nicole Hassoun have proposed what they call an “Ethically Adjusted Life Year” (EALY), which regards a life-year saved as a higher priority than a year of disability relieved.⁴² Esposito and Hassoun's approach, however, avoids discriminating against people with preexisting disabilities only by imputing a quality of life to people who are dead.⁴³ It also entails the dubious conclusion that extending the life of a person with a disability for a given number of years, no matter how severe the disability is, is always preferable to reversing the disability for the same or a lesser number of years.⁴⁴ The Pathways Approach avoids these unattractive commitments while also limiting discrimination against individuals with preexisting disabilities.

C. Operationalizing the Pathways Approach

The Pathways Approach directs us to consider not only *how* individuals' lives are going, but *why* they are going well or badly. This emphasis on the causes of disadvantage means that the Pathways Approach rejects the QALY approach's reliance on population-wide surveys (which do not look at the justifications offered by survey respondents), and agrees with Barnes and others that the testimony of people who are currently experiencing, or have experienced, disabilities is crucial. But the Pathways Approach does not rely solely on the phenomenology of disability experience; it also includes the considered judgments of others.⁴⁵ In particular, it will include the perspectives of experts who have examined the social pathways that correlate disability with disadvantage, and of stakeholders who can testify to the justice or injustice of proposed changes in resource allocation.

The Pathways Approach also represents a potential middle path for the application of disability discrimination law to health insurance. Rather than either prohibiting the use of all health insurance designs that disfavor individuals with specific disabilities (which could interfere with, for instance, value-based insurance) or permitting all such designs, the Pathways Approach would permit the use of designs that take quality of life into account only when doing so does not amplify existing discrimination.

I do not propose an exhaustive roadmap for operationalizing the Pathways Approach here, but I will make some brief suggestions. Two ways of operationalizing the Pathways Approach might be the use of extended cost-effectiveness analysis and the use of a social welfare function. An extended cost-effectiveness analysis could allow a given intervention to be evaluated along multiple axes: for instance, both in terms of whether it promotes well-being and in terms of whether it avoids distributive injustice or avoids giving effect to private biases.⁴⁶ The usefulness of an extended cost-effectiveness analysis might depend on whether the duty to avoid giving effect to private biases is categorically prior to the goal of promoting well-being, or whether the two goals can instead be balanced against one another. If the goals can be balanced against one another, a social welfare function could be another way of representing both of them for decisionmakers.⁴⁷

As an illustration, a simple version of extended cost-effectiveness analysis can be applied to the example discussed in the Introduction. If half of the quality of life loss after a liver transplant is attributable to bias or unjust policies, the Pathways Approach would convert the gain from adding 10 years to the transplant recipient's life from 8 QALYs to 9 Pathways-QALYs

(“P-QALYs”), where a P-QALY adds back the quality of life loss attributable to bias and injustice over a given year to the QALY value for that year. The difference between the QALY and P-QALY impact of a given condition can range from very large (if lost quality of life stems entirely from bias and unjust policy) to nonexistent (if lost quality of life stems entirely from unavoidable disadvantage).

Conclusion

When we set priorities, we should not act as if we were in a perfect world where disabilities impose no disadvantages. Nor should we act as if all the disadvantages that disabilities impose can be reduced to a single number and used to set priorities without regard to the connection between disadvantage and social injustice. Rather, we should pay more attention to the pathways by which disability engenders disadvantage. The Pathways Approach proposed in this article offers us a new way out of the “QALY Trap,” one that better reconciles the importance of quality of life with the importance of fairness toward individuals with disabilities.

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References

1. T.M. John, J. Millum, and D. Wasserman, “How to Allocate Scarce Health Resources Without Discriminating Against People with Disabilities,” *Economics and Philosophy* 33, no. 2 (2017): 161-184.
2. N. Beckstead and T. Ord, “Bubbles Under the Wallpaper: Healthcare Rationing and Discrimination,” in *Bioethics: An Anthology*, ed. H. Kühse, U. Schüklenk, and P. Singer (West Sussex, UK: Wiley-Blackwell, 2016): 406.
3. S. Kerstein, “Dignity, Disability, and Lifespan,” *Journal of Applied Philosophy* 34, no. 5 (2017): 635; G. Persad, A. Wertheimer, and E.J. Emanuel, “Standing by Our Principles: Meaningful Guidance, Moral Foundations, and Multi-Principle Methodology in Medical Scarcity,” *American Journal of Bioethics* 10, no. 4 (2010): 46-47.
4. P. Menzel, “How Should what Economists Call ‘Social Values’ Be Measured?” *The Journal of Ethics* 3, no. 3 (1999): 250-263.
5. M.E. Chernen, A.B. Rosen, and A.M. Fendrick, “Value-Based Insurance Design,” *Health Affairs* 26, no. 2 (2007): w195-w203; S.D. Sullivan et al., “Design, Implementation, and First-Year Outcomes of a Value-Based Drug Formulary,” *Journal of Managed Care & Specialty Pharmacy* 21, no. 4 (2015): 269-275.
6. A.B. Symons, D. McGuigan, and E.A. Akl, “A Curriculum to Teach Medical Students to Care for People with Disabilities: Development and Initial Implementation,” *BMC Medical Education* 9, no. 1 (2009): 78.
7. *Fair Housing Council of San Fernando Valley v. Roommate.com, LLC*, 2012. 666 F.3d 1216, 1221 (9th Cir.).
8. E.F. Emens, “Intimate Discrimination: The State’s Role in the Accidents of Sex and Love,” *Harvard Law Review* 122, no. 1307 (2009): 1340, 1356, 1374-1377; L. Halldenius, “Dissecting ‘Discrimination,’” *Cambridge Quarterly of Healthcare Ethics* 14, no. 4 (2005): 456.
9. P. Dua, M.F. Heiland, A.C. Kracen, and T.L. Deshields, “Cancer Related Hair Loss: A Selective Review of the Alopecia Research Literature,” *Psycho-Oncology* 26, no. 4 (2017): 438; A. Lateef and S. Marshall-Lucette, “Living with Trimethylaminuria (TMAU) from an Adult Viewpoint,” *Practice Nursing* 28, no. 8 (2017): 344-351; See Emens, *supra* note 8.
10. See Emens, *supra* note 8.
11. *Palmore v. Sidoti*, 1984. 466 U.S. 429, 433-34; M.A. Stein, “Mommy has a Blue Wheelchair: Recognizing the Parental Rights of Individuals with Disabilities,” *Brooklyn Law Review* 60, no. 3 (1994): 1097.
12. *Adarand Constructors, Inc. v. Peña*, 1995. 515 U.S. 200, 237.
13. D.A. Strauss, “Discriminatory Intent and the Taming of Brown,” *University of Chicago Law Review* 56, no. 3 (1989): 982-983.
14. T. Schrecker, “Denaturalizing Scarcity: A Strategy of Enquiry for Public-Health Ethics,” *Bulletin of the World Health Organization* 86 (2008): 600, 603.
15. G.C. Persad and E.J. Emanuel, “Dilemmas in Access to Medicines: A Humanitarian Perspective — Authors’ Reply,” *The Lancet* 389, no. 10073 (2017): 1008.
16. E. Barnes, *The Minority Body* (New York, NY: Oxford University Press, 2016).
17. See Barnes, *supra* note 16, 27.
18. See Barnes, *supra* note 16.
19. See Barnes, *supra* note 16, 102.
20. C.T. Solberg and E. Gamlund, “The Badness of Death and Priorities in Health,” *BMC Medical Ethics* 17, no. 1 (2016): 21.
21. K. Lippert-Rasmussen, “Two Puzzles for Deontologists: Life-Prolonging Killings and the Moral Symmetry Between Killing and Causing a Person to be Unconscious,” *The Journal of Ethics* 5, no. 4 (2001): 385.
22. See Barnes, *supra* note 16, 4.
23. See Barnes, *supra* note 16, 95-96.
24. See Barnes, *supra* note 16, 102.
25. See Barnes, *supra* note 16, 3.
26. See Barnes, *supra* note 16.
27. S.M. Campbell and J.A. Stramondo, “Review of *The Minority Body*, by Elizabeth Barnes,” *Notre Dame Philosophical Reviews*, November 2016, available at <<https://ndpr.nd.edu/news/the-minority-body-a-theory-of-disability/>> (last visited April 5, 2019).
28. See Barnes, *supra* note 16, 115.
29. S.M. Campbell and J.A. Stramondo, “The Complicated Relationship of Disability and Well-Being,” *Kennedy Institute of Ethics Journal* 27, no. 2 (2017): 157.
30. J.B. Jordan and G.C. Vanderheiden, “Modality-Independent Interaction Framework for Cross-Disability Accessibility,” in *Cross-Cultural Design: Methods, Practice, and Case Studies*, ed. P.L. Patrick Rau (Beijing, China: Tsinghua University, 2013): 218-222.
31. *Olmstead v. L.C.* 1999. 527 U.S. 581, 597.
32. S.R. Bagenstos, “Disability Rights and Labor: Is This Conflict Really Necessary?” *Indiana Law Journal* 92, no. 277 (2016): 285-287.
33. See John et al., *supra* note 1, 17.
34. D.A. Weisbach, “Toward a New Approach to Disability Law,” *University of Chicago Legal Forum* 1, no. 47 (2009): 68-69.
35. A.M. Samaha, “What Good is the Social Model of Disability?” *University of Chicago Law Review* 74, no. 4 (2007): 1275-1306.
36. See Samaha, *supra* note 35.
37. E.F. Emens, “Integrating Accommodation,” *University of Pennsylvania Law Review* 156 (2008): 839, 842.

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38. G.A. Cohen, *Rescuing Justice and Equality* (Cambridge, UK: Harvard University Press, 2008): 154-155, 165-166.
39. See John et al., *supra* note 1, 18.
40. See John et al., *supra* note 1, 21.
41. A. Zwerling, D. Dowdy, A. Von Delft, H. Taylor, and M.W. Merritt, "Incorporating Social Justice and Stigma in Cost-Effectiveness Analysis: Drug-Resistant Tuberculosis Treatment," *International Journal of Tuberculosis and Lung Disease* 21, no. 1 (2017): S71.
42. L. Esposito and N. Hassoun, "Measuring Health Burden Without Discriminating Against the Disabled," *Journal of Public Health* 39, no. 3 (2016): 635-636.
43. See Esposito et al., *supra* note 42.
44. See Esposito et al., *supra* note 42.
45. See Menzel, *supra* note 4.
46. S. Verguet, R. Laxminarayan, and D.T. Jamison, "Universal Public Finance of Tuberculosis Treatment in India: An Extended Cost-Effectiveness Analysis," *Health Economics* 24, no. 3 (2015): 318.
47. H.F. Chang, "A Liberal Theory of Social Welfare: Fairness, Utility, and the Pareto Principle," *Yale Law Journal* 110, no. 2 (2000): 215.
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