Disability bioethics and the commitment to equality

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Abstract
Robert Veatch’s The Foundations of Justice: Why the Retarded and the Rest of Us Have Claims to Equality (1986) delves into deep questions of justice through the case of a child with disabilities. I describe what is basically right about this vision, as well as what is problematic from the standpoint of contemporary disability bioethics. From there, I dive into the notion of vulnerability that is at play in his work. He describes disability as necessarily a condition of weakness, lesser-than existence, and neediness. When disability is viewed in this way as an inherently vulnerable state of being, the essential sociopolitical dimensions of disability receive inadequate attention, which, in turn, makes it impossible to identify injustices correctly. I connect these points to concrete challenges faced by disability communities during the COVID-19 pandemic, which have raised profound questions about the just use of scarce critical care resources. Any case drawn from the pandemic is a very different kind of case than that of the child in Veatch’s book, but a commonality is the question of who should get what limited resources when needs and urgency vary.

Keywords Disability bioethics · Justice · Equality · Vulnerability · Scarce resources · Pandemic

Introduction

Robert Veatch’s The Foundations of Justice: Why the Retarded and the Rest of Us Have Claims to Equality (1986) delves into deep questions of justice through the case of a child with disabilities [1]. Eddie Conrad, a boy with physical and cognitive impairments, needs more extensive speech therapy than is currently offered in his elementary school, and the funding for this therapy would mean cuts to other programs enjoyed by students in the school system. Veatch prompts the reader to consider: What would justify allotting limited resources to Eddie over other children? Veatch believes that examining this case will offer a better grasp on why any
person with a disability, vulnerability, or disadvantage has claims on others; further, since we are all limited in some way that could be relevant for our pursuits, equality claims will end up being established for all of us by looking at a case like Eddie’s.

Especially at the time of its writing, Veatch’s book is distinctive in taking on fundamental questions of moral and political philosophy by focusing on the needs and interests of persons with disabilities (PWDs). Health care is not central to his analysis, though questions of scarce resources, moral status, and disability are certainly relevant to bioethics. Despite its extensive discussion of issues related to disability, the field of bioethics has been criticized repeatedly for devaluing and marginalizing PWDs [2–5]. Decades after Veatch’s book, an area of research and scholarly activism called disability bioethics would emerge, which centralizes the perspectives of PWDs when unpacking complex notions like just health care. In this paper, I analyze Veatch’s arguments from the perspective of contemporary disability bioethics. He and I were engaged in discussions about disability ever since I was his student at Georgetown University, and we continued those conversations when revising the fourth edition of The Basics of Bioethics together [6]. The critical points I raise below regarding Foundations of Justice are all points, I believe, that Veatch would have received with humble and friendly openness.

I begin by providing an overview of Veatch’s vision as presented in Foundations of Justice. I describe what is basically right about this vision, as well as what is problematic from the standpoint of contemporary disability bioethics. From there, I dive into the notion of vulnerability that is at play in his work—a concept that is still relatively common in mainstream bioethics. He describes disability as necessarily a condition of weakness, lesser-than existence, and neediness. I argue that when disability is viewed in this way as an inherently vulnerable state of being, the essential sociopolitical dimensions of disability receive inadequate attention, which, in turn, makes it impossible to identify injustices correctly. I connect these points to concrete challenges faced by disability communities during the COVID-19 pandemic, which have raised profound questions about the just use of scarce critical care resources. Any case drawn from the pandemic is a very different kind of case than that of Eddie Conrad, but a commonality is the question of who should get what limited resources when needs and urgency vary.

Veatch’s vision for egalitarianism

In his book, Veatch asks: “Why does anyone in need, disadvantaged through physical or mental handicap, have a claim?” [1, p. 21]. He wants to establish equality claims and obligations of justice through a broad base of consensus (at least for readers in the US context), so he builds an argument that he believes Judeo-Christian and secular theorists alike could accept. There are clear challenges with this project, given that there is no monolithic secular or Judeo-Christian perspective.

1 While some prefer ‘person with disability,’ others prefer ‘disabled person.’ I use the former for the sake of consistency.
Still, Veatch believes three common premises underlie any sensible notion of justice: (1) humans are equal in their finitude; (2) resources of the world belong to the community; and (3) there is an individual and collective responsibility to use those resources to ensure equality, addressing disadvantage as necessary [1, pp. 66, 77, 152]. He is especially concerned with equality of well-being. As a matter of public policy, the kind of equality Veatch defends is equality of outcome, approximated through necessary levels of resource commitment [1, pp. 138–139]. What arises, then, is a robust form of egalitarianism. Because he views PWDs as “losers in the natural lottery,” just institutions and social arrangements would require “resources be channeled into in-kind medical and educational services” [1, p. 143]. He summarizes his position as follows: “Given the incalculable, irreplaceable losses the handicapped may have suffered, the extra resource commitment should, as much as is possible, exactly compensate for the handicap so that all have a chance for equality” [1, p. 152].

Veatch then considers how public institutions should determine the appropriate allocation of community resources to achieve this equality. He proposes using Ronald Dworkin’s “equal auction” test, which is a hypothetical calculus where people imagine they do not know their position in a society and need to allocate resources “to eliminate retardation if it is preventable and to compensate (in cash or services) for unpreventable retardation” [1, p. 156] (see [7]). He argues for extensive allocation for this purpose, only limiting resources when further expenditures would jeopardize others’ well-being to the same extent that PWDs have decreased well-being [1, p. 159]. He concludes that this test, given all the above considerations, means providing the speech therapy for Eddie Conrad as a requirement of justice. Ultimately, Veatch believes that a just system would prioritize those who are the worst off in terms of their well-being [1, p. 185]. And because everyone has deficiencies, which can vary and worsen, this compensatory conception of justice benefits all of us [1, p. 167].

The insights and problems with this vision

Especially given its 1986 publication date, the task taken on in *Foundations of Justice* to build solidarity on issues related to disability and disadvantage is exceptional. Veatch emphasizes, repeatedly, that we all have deficiencies when it comes to mental and physical abilities, beauty, and character traits. Indeed, he states this point clearly: “We all have handicaps that would entitle us to compensation if only the resources were adequate. Since all are in this situation, all are in one class. Everyone is handicapped; no one is part of the group we call ‘they,’ no one should be stigmatized” [1, p. 200]. Viewing disability as part of the human condition is an improvement over seeing it as Othering, as something set apart and not worth mentioning in a book on justice.

In his book, Veatch highlights how traditional theories of justice can fail to go far enough in establishing the grounds for full-throated equality claims for PWDs [1, pp. 80–86]. He wants to build a strong basis for correcting disadvantages for the worst off. His argument “begins with an affirmation that the retarded are fully...
members of the moral community, equal in moral worth to the rest of the community. They should, therefore, have equal opportunity for well-being in their lives” [1, p. 152]. At the level of broad brushstrokes, Veatch’s project has similarities to current conversations about equity. His emphasis on the interests, needs, and rights of PWDs is distinctive among texts in moral and political philosophy, as well as in bioethics. His vision includes a substantial restructuring of the distribution of resources in health care, education, and other spheres of life. Broadly speaking, this kind of restructuring is consistent with the aims of many disability activists over the years.2

Still, there are some fundamental problems with how Foundations of Justice arrives at this conclusion. One problem is obvious in the language: the words retarded and handicapped are now widely rejected as terms associated with the paternalistic, exclusionary, and eugenic treatment of PWDs. Retarded has risen to the level of a slur, denigrating the humanity of persons with intellectual and cognitive disabilities. The word was part of a national campaign called Spread the Word to End the Word, and in 2017 Rosa’s Law replaced the term “mental retardation” with “intellectual disability” in all federal documents in the United States [8, 9]. The subtitle of Foundations of Justice uses retarded as a substantive adjective (i.e., “the retarded”), which is another problematic linguistic move for referring to a diverse group of persons under a single, stigmatized categorical label. Such terms were commonly used and accepted in medicine and politics at the time Veatch wrote this text, but they now noticeably date the book.

Foundations of Justice also fails to challenge eugenic perceptions of disability. Veatch considers “implications for the gene pool” as a potential objection to his compensatory conception of justice [1, pp. 165–166]. He imagines an interlocutor might be concerned that this massive shift in resource distribution would mean that more PWDs could survive and reproduce, which would perpetuate the affected genes. Veatch responds to this objection by pointing out that (1) not all disabilities are genetic; (2) severe genetic impairments are still rare; (3) people with serious conditions may decide against reproducing, regardless of how well supported they are; and (4) any change to the gene pool would be so slow that it could be counteracted with genetic technologies in the future [1, pp. 165–166]. Yet the text does not call this interlocutor’s challenge what it is—eugenics. Veatch’s responses to the eugenicist do not address the problem of eugenics head-on; instead, they attempt to allay the eugenicist’s concerns by pointing out how unlikely it is that the gene pool would be negatively affected if resources were more justly distributed. On the one hand, Veatch’s approach to this challenge has the strategy of even trying to convince the eugenicist that radical restructuring of public goods and services for PWDs is required as a matter of justice. On the other hand, Foundations of Justice is part of an unfortunately long line of works in moral and political philosophy that do not adequately dismantle eugenic arguments—even when doing so would clearly lie within the scope of the text.

2 Disability activism is not homogenous in its priorities or methods. Any descriptions about disability activism that I make are meant to be nuanced and not overbroad.
This brings me to an underlying concern with Veatch’s argument. Licia Carlson cites *Foundations of Justice* specifically with this comment:

To what extent does the assumption that persons with intellectual disabilities cannot lead meaningful lives underlie our philosophical discussions? The normative assumption that having a condition like mental retardation is ‘objectively bad’ can be found in even the most committed work on justice for persons with intellectual disabilities (Veatch 1986). [10, pp. 320].

Throughout, Veatch explicitly or implicitly associates disability with a form of weakness, neediness, or lesser-than existence [1, pp. 34, 140, 155, 168, 173, 192]. For example, while arguing against the stigmatization of disability, he says: “It is impossible to refer to a ‘good’ handicap…. To label a condition as a handicap is to say simultaneously that it is a condition we would rather not have” [1, p. 191]. He qualifies some disabilities as “severe,” though he appears to view all disabilities as inherently bad conditions. It is not clear how he delineates severe versus non-severe, but it is not based on the first-person testimony of persons with these conditions. He comments: “This does not mean that people with these conditions cannot lead good, productive, and enjoyable lives. It is just that no one in his right mind would actually prefer these conditions. We can, without stretching our use of the language, refer to these conditions as objectively disvalued” [1, p. 193]. Veatch thus acknowledges that PWDs can live good lives, but he suggests any successes would be despite the natural drawback of disability. Veatch’s vision for justice, then, is based on the presumption that PWDs have conditions that are objectively bad, a result of “losing” the natural lottery, so society has an obligation to allocate resources to make up for these inherent disadvantages.

This way of framing disability still pervades much of bioethics, public health reasoning, medical education, and clinical scholarship more broadly. Since this erroneous view of disability is not specific to Veatch’s work in 1986, the rest of this paper will expand on this concern. I situate my critique within the area of scholarship and practice known as disability bioethics. I then analyze different notions of vulnerability that have emerged in more recent scholarship and connect these considerations with the demands for just treatment of PWDs during the COVID-19 pandemic.

**Disability bioethics: a necessary shift in orientation**

There is an important distinction between bioethical work that discusses disability and disability bioethics. Disability can be discussed from a distanced and medicalized perspective, where persons with disabilities are an object of inquiry. The viewpoint of a non-disabled clinician, researcher, geneticist, philosopher, or parent may be exclusively represented. Scholars or practitioners can mention disability repeatedly in their work without ever acknowledging the disability rights movement or disability studies. The result is the continued Othering of PWDs and an overly narrow view of what it means to live with a disability, even by well-intentioned scholars and practitioners. This approach to projects related to disability also means that PWDs are marginalized in the very work that is directly about them and their lives and the
lives of future PWDs. The disability rights movement’s slogan “nothing about us without us” targets this kind of exclusion.

Disability bioethics is a methodological approach to identifying, analyzing, and resolving issues in health care and the biomedical sciences that privileges first-person testimony of PWDs. In *Disability Bioethics*, Jackie Leach Scully explains:

Disability ethics, like feminist ethics, is a form of ethical analysis consciously and conscientiously attentive to the experience of being/having a ‘different’ embodiment. … And doing this means working from people’s experience of disability to see if and how it colors their perceptions, interpretations, and judgments of what is going on in moral issues, especially in moral issues that have direct relevance to disability and where differences in the experience of disability might be expected to have weight. [11, p. 11]

As its starting point for inquiry, disability bioethics focuses on the sociohistorical features of disability within a particular context and relies on the lived experiences of PWDs. There is an epistemic gap between those who have experienced disability and those who have not; moreover, no disability is a homogenous identity or experience for persons with that disability. The lens of disability bioethics aids the critical analysis of diagnostic categories, basic assumptions behind treatment and testing, funding priorities for research and medical care, and public health strategies.

A core tenet of disability bioethics is that disability is not merely a medical category, and having a disability need not mean having a deficient quality of life. Rosemarie Garland-Thomson’s “Disability Bioethics: From Theory to Practice” argues that the aim of disability bioethics “is to strengthen the cultural, political, institutional, and material environment in which people with disabilities can most effectively flourish. … Disability bioethics frames disability as valued social diversity and supports the civil and human rights-based understanding of disability” [12, p. 330]. At the time Veatch wrote *Foundations of Justice*, the idea that disability could be a form of valued social diversity was perhaps not well circulated or widely accepted among bioethicists, though this kind of challenge is vital for a project like Veatch’s.

Veatch is concerned about securing, to the greatest extent possible given realities and constraints of other ethical principles, equal well-being among all persons. From his standpoint in 1986, PWDs are “losers” in the natural lottery because disability puts a person at an immediate and constant disadvantage when it comes to achieving well-being. But, from the standpoint of disability bioethics, this view of well-being and disability is fundamentally flawed. In *Bioethics and Disability*, Alicia Ouellette urges bioethicists to pay attention to the work of disability activists and scholars when making claims about well-being: “If the evidence is that the story of disability need not be the story of tragedy, and that biased and disproven assumptions about life with disability are at play in medical decision making, then it is the business of bioethics to work with disability experts to figure that out and to work to eliminate that bias” [13, p. 69].

Those without a disability tend to undervalue life with disability [14–19]. Moreover, impairments and physiological differences can be associated with gifts, community, and enriched experiences. Contrary to Veatch’s suggestion, it is not the case that all rational people, other things being equal, would take a “magic pill”
to rid themselves of their impairment [20]. Many perceived features of disability that are deemed to be undesirable—such as losses to independence, self-sufficiency, and control over one’s life—are either a) common facets of human existence, or b) do not necessarily pose problematic limitations to individuals with disabilities as is commonly believed [2–4]. As put by Elizabeth Barnes, disability can be a form of human difference that is not “bad-difference” but instead “mere-difference,” so that we “needn’t deny that disabled people miss out on some intrinsically good abilities or experiences—it’s just that they have access to other, different good things” [21, p. 58]. These arguments are developed throughout disability studies, philosophy of disability, and disability bioethics.3

Rethinking vulnerability and disability

The key question, then, is why PWDs may experience diminished well-being. Veatch recognizes how resources can make a difference for the flourishing potential of PWDs, but he still describes disability as a form of inherent vulnerability, an inevitable risk to well-being. He argues that community resources should be diverted to help PWDs overcome the disadvantages of their body.

The social, economic, and political dimensions of disability are at the forefront of disability bioethics when it comes to determining the requirements of justice. Problems in living are significantly (or perhaps exclusively in some cases) due to disabling environments, not the impairment or physiological difference itself. The argument from disability bioethics is that community resources should be restructured to overcome the disadvantages of exclusionary policies, laws, and features of the built environment. This would mean, at minimum, ensuring access to basic goods and services, accommodating disabled ways of being in the world, and eliminating inequities that threaten the moral and political standing of PWDs. Scully, drawing on conceptual work from Mackenzie, Rogers, and Dodds, argues that most vulnerabilities associated with disability are contingent and not inherent: “Vulnerabilities to these harms are neither natural nor inevitable consequences of the impairment; they occur because of the unequal ways that existing material, cultural, and social resources are distributed and so are either produced or exacerbated by social institutions” [23, p. 208]. Part of the point here is to move away from viewing disability as a permanently pitiable state in need of charity, which is what Veatch’s argument runs the risk of perpetuating.

Furthermore, Scully points out that a common error is to ascribe global vulnerability; she says that there is a “tendency on the part of the nondisabled to extrapolate a genuine vulnerability in one area of a disabled person’s life (e.g., physical weakness, economic precariousness) to a globally increased vulnerability stretching over an entirety of that person’s life” [23, p. 209]. Veatch appreciates this concern in one sense, which is why he spends an entire chapter arguing against stigmatizing

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3 At the time of writing this, the first Disability Bioethics Reader, edited by Joel Michael Reynolds and Christine Wieseler, is forthcoming with Routledge [22].
disability as something that will require constant community provisions. He misses the thrust of the concern, though, since he still describes disability as an objectively disvalued, undesirable, weak, needy, lesser-than way of being. Scully elaborates: “Vulnerability is strongly associated with qualities such as immaturity, weakness, helplessness, passivity, victimhood, and humiliation. … Against a backdrop of such strong negative associations, the more vulnerable a disabled person is believed to be, the less likely it is that others will treat the choices she makes or opinions she holds as worthy of respect” [23, p. 210]. PWDs can be construed as infantilized objects of care, in need of paternalistic protection, when they receive a blanket label of vulnerability.

This attitude toward PWDs may be a reason why laws or policy decisions that directly or indirectly affect disability communities are rarely based on collaboration with those communities. The disability rights movement’s slogan “Nothing about us without us” remains as relevant and critical today as it was from the birth of the movement. This has been evident most recently during the COVID-19 pandemic, where PWDs were especially susceptible to infection, hospitalization, and death, and yet crisis planning almost entirely excluded perspectives from disability communities at local and national levels.

### Scarce resources and equal regard during the COVID-19 pandemic

Back in 2010, the Institute of Medicine emphasized the importance of fairness, equitable processes, and community engagement when facing a public health disaster where scarce resources are at stake. Equitable processes include transparency, consistency, proportionality, and accountability to those affected by public health planning, including crisis standards of care [24, pp. 70–71]. Despite this guidance (and others like it) for years before the COVID-19 pandemic, public health agencies, researchers, and health care systems did not generally engage their community regarding these issues. As a result, education and communication about possible crisis plans were nonexistent (or nearly so) before the crucible of the pandemic. The groups who are most at risk during a pandemic—such as the elderly, people living in congregate care, prisoners, and PWDs—are often marginalized in public health discussions anyway, which makes successful engagement during a crisis especially difficult and unlikely.

Throughout the COVID-19 pandemic, numerous concerns arose regarding disability bias, disregard, and discrimination in how public agencies and health care systems handled challenges. For example, care workers in home- and community-based services were not initially protected as essential workers at the federal level, and they were not initially prioritized with personal protective equipment allotments. Ombudspersons were often unable to monitor facilities after increased safety protocols were enacted. Visitor restrictions in hospitals left many PWDs without necessary bedside caregivers and support, which created a particularly unsafe situation for patients with cognitive, intellectual, or neurological disabilities. Public health messaging and news conferences were often inaccessible across platforms. These kinds
of decisions, among others, contributed to a multitude of vulnerabilities for PWDs in the course of the pandemic [25].

Questions about equal treatment have been central to debates about the design of triage protocols. Triage protocols are enacted when demand for health care resources outstrips what is actually available during a public health disaster. Staff, supplies, and stuff are all scarce resources that may have to be allocated differently than they normally would be, even potentially reallocated according to certain criteria [26]. Disagreements have emerged regarding how the equality of persons should be taken into account in triage. For example, Ezekiel Emanuel et al. state: “Priority for limited resources should aim both at saving the most lives and at maximizing improvements in individuals’ post-treatment length of life. Saving more lives and more years of life is a consensus value across expert reports” [27, p. 2052]. The principle of saving the most lives may seem intuitively obvious during a pandemic, and it may seem egalitarian by focusing on maximizing life for anyone who is in need of care.

Saving the most lives makes sense according to classic utilitarian reasoning, which is supposed to uphold the moral equality of all persons. Veatch argues against utilitarian conceptions of equal treatment. Veatch says that utilitarians “miss … the radical difference between treating people as equals in the sense of counting their benefits and harms and treating them as equals in the sense of striving to meet their needs even if it means decreasing the total amount of good in a society” [1, p. 100]. Many disability activists and scholars similarly objected to utilitarian conceptions of equality and justice during the COVID-19 pandemic. Ari Ne’eman, co-founder of the Autistic Self Advocacy Network, has argued: “By permitting clinicians to discriminate against those who require more resources, perhaps more lives would be saved. But the ranks of the survivors would look very different, biased toward those who lacked disabilities before the pandemic. Equity would have been sacrificed in the name of efficiency” [28]. As Katie Savin and I discuss elsewhere, equity and equal regard for the disability community means that PWDs have the same chance of receiving maximum health care as their nondisabled peers. Many people with disabilities, long having lived the harsh sociopolitical realities of inhabiting bodies with physiological differences, perceive the medical criteria used for triage as the usual grounds for discrimination [29]. Of note, multiple disability rights groups around the country filed formal complaints with the Office for Civil Rights (OCR) under the US Department of Health and Human Services; their complaints pointed out disability discrimination contained in triage protocols, which prompted numerous revisions at the state level [30].

Disability activists and scholars did not present one agreed-on approach to triage, but they urged health care systems to avoid a brute utilitarian calculation that would disregard their moral equality in crisis scenarios. The principle of saving the most lives would mean minimizing scarce critical care resources for any given person, but this approach does not take into consideration the ways in which PWDs may require additional resources due to their medical conditions and the discriminatory background conditions that lead to excess morbidity and mortality of PWDs generally. It

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4 Eventually, amidst the ramping up of complaints, Ne’eman became an official consultant for OCR during the pandemic—a relatively rare move by a governmental body.
would be unjust to refuse additional resources for a PWD in an intensive care unit (ICU) during the pandemic on the basis that resources are being “wasted.” As put by Joseph Stramondo: “Harking back all the way to the American eugenics movement, there is a long, grim history of confusing inefficiency with wastefulness when it comes to the fair treatment of disabled people. One could even conceptualize the entire disability rights movement as an attempt to draw this distinction” [31]. Some key recommendations from disability activists and scholars include removing any quality-of-life assessment in triage criteria, not having disability status as an exclusion criterion for scarce resources, and disallowing personal ventilator reallocation in a crisis [25, 30, 32].

Veatch’s argument to allocate scarce resources for Eddie Conrad has some affinities to these arguments. Veatch similarly emphasizes that giving additional resources to Eddie would not be a waste, that the benefit to this boy would be worth the expenditures even if it meant fewer benefits to others. It is possible that Veatch would not have entirely agreed with the disability critique of triage, since he argues in Foundations of Justice that additional resource allocations should be limited when doing so would jeopardize others’ well-being to the same degree. If nondisabled persons in an ICU would experience the same harms as disabled persons if denied scarce critical care resources, then Veatch might not object to trying to maximize life overall. At the same time, I do believe that Veatch would have supported recommendations to remove disability bias from triage criteria and decision-making processes. I regret that I did not ask him more questions along these lines in the last year before his death.

Concluding thoughts

Foundations of Justice is a distinctive text in moral and political philosophy and bioethics for centralizing and normalizing the interests of PWDs. Veatch came to a conclusion that is still considered radical today—at least to those outside the disability rights community. His extended plea to restructure community resources for the worst off is laudable, though there are some critical problems with how he comes to this conclusion. The field of disability bioethics has shifted the gestalt so as to build a tradition that centers the perspectives of PWDs. A core tenet of disability bioethics is that impairments and physiological differences are not necessarily conditions of suffering, weakness, or neediness. These insights and general shift in orientation should inform future work on justice, and “nothing about us without us” should be ensconced in all theorizing and practical work that affect PWDs.

Veatch is internationally known as an ardent defender of individual autonomy; his arguments over the decades to protect diverse values and ways of being in the world mean that clinicians (and others in power) should be profoundly humble when declaring what is “good” for another person. I know that Bob was keenly interested in the intersection of disability studies and bioethics, and I wish we could have explored more of these topics together.
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