COVID-19 and the need for disability conscious medical education, training, and practice

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Abstract. The COVID-19 era exposes what was already a crisis in the medical profession: structural racism, ageism, sexism, classism, and ableism resulting in healthcare disparities for Persons with Disabilities (PWD). Early research highlights these disparities, but we do not yet know the full impact of this pandemic on PWD. Over the last 20 years, many medical schools have attempted to develop disability competency trainings, but discrimination and inequities remain, resulting in a pervasive distrust of medicine by the disability community at large. In this commentary, we suggest that disability competency is insufficient because the healthcare disparities experienced by PWD are not simply a matter of individual biases, but structural and systemic factors requiring a culture shift in the healthcare professions. Recognizing that disability is a form of diversity that is experienced alongside other systemic disadvantages like social class, race, age, sex, gender identity, and geographic location, we explore the transformative potential of *disability conscious* medical education, training, and practice that draws on insights from intersectional disability justice activism. *Disability conscious* medicine is a novel approach, which improves upon competency programs by utilizing disability studies and the principles of disability justice to guide us in the critique of norms, traditions, and institutions to more fully promote the respect, beneficence, and justice that patients deserve.

Keywords: Disability, disability justice, medical training, diversity, COVID-19

1. Introduction

Michael Hickson died of COVID-19 on June 11, 2020 in St. David's South Austin Medical Center in Texas after the hospital decided that further treatment for his related pneumonia was futile. Of note, the hospital was not at capacity or short of resources to provide continued care for Hickson. His wife, Melissa Hickson, feels that disability and racial bias – Hickson was a 46-year-old Black man with quadriplegia and an anoxic brain injury – contributed to the hospital's decision to terminate treatment [1]. A conversation she recorded revealed a physician's assumptions about Hickson's quality of life:

> Physician: So as of right now, his quality of life – he doesn't have much of one.
> Melissa Hickson: What do you mean? Because he's paralyzed with a brain injury, he doesn't have quality of life?
> Physician: Correct.

When Melissa Hickson asked why her husband was being denied treatments that other patients received, the physician said, "his quality of life is different from theirs. They were walking, talking people" [2]. Facing civil rights complaints from ADAPT of Texas and the

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National Council for Independent Living, representatives of St. David's claim the decision was not made on the basis of disability [1]. However, even if the physician's motive was misinterpreted and no specific actions in the case are deemed illegal, the fact remains that the rhetoric and result were catastrophically tragic. In this case, we must consider not only the apparent biases of one doctor, but the totality of the underlying systemic inequities. Beyond the behaviors of individual physicians, the COVID-19 pandemic exposes what was already a crisis in the profession: structural racism, ageism, sexism, classism [3,4], and ableism[1] [6] – all of which contribute to healthcare disparities and disproportionate rates of death [7]. In this commentary, we argue that the medical profession at all levels of education, training, and practice should look to critical disability studies, and especially the wisdom of intersectional disability justice activists, to confront systemic injustice. Catastrophe calls for change.

In making this claim, we carry forward an ongoing conversation in the literature regarding disability studies, medical education, and the healthcare professions. Previous calls to action, including a 2009 commentary by Kirschner and Curry [8], as well as a recent article by Bowen et al., call for disability training in medical curricula to develop "competency," defined as "desired knowledge, skills, and behaviors required to successfully perform the health care role" [9]. While we agree that disability training would improve the competence of future physicians, we believe that more collective action is necessary to transform the practice and delivery of healthcare. Beyond competence, we argue for what we call disability *conscious* medicine[2] which takes into account the structural violence[3] in the culture of Westernized medicine. This consciousness begins with engagement with critical disability studies, a multidisciplinary academic field rooted in the history of civil rights activism by disabled people which explores the social, political, and cultural contexts of disability.

For the past decade, the field of disability studies has been strengthening its understanding of intersectional disability justice. Calling for intersectionality, Anna Mollow has written, "if race and disability are conceived of as discrete categories to be compared, contrasted, or arranged in order of priority, it becomes impossible to think through complex intersections of racism and ableism in the lives of disabled people of color" [11]. We cannot address topics like race, gender, class, and disability discretely, because humans occupy multiple identities simultaneously, and the experience of oppression should not be represented as something that can be measured or compared. Disability justice accounts for the wholeness of the person and relies upon solidarity across communities and different types of disability [12]. Going beyond topics of accommodation and inclusion, the disability justice model:

– creates conceptions of wellness not centered on norms;
– decenters whiteness, the patriarchy, and competitive standards of productivity;
– disrupts hierarchies of power, such as the doctor-patient relationship;
– reconceptualizes care in terms of collectives and communities rather than patients and providers;
– values interdependence rather than independence as a desirable health outcome; and
– provides models for achieving collective access.[4]

In the following sections of this commentary, we will expand upon: 1) traditional medical regard for disability, and the negative experiences and perceptions of the disability community up to and including the COVID-19 era, 2) the limited impact of previously implemented disability competence trainings to effect needed change, and 3) the transformative potential of disability conscious medical education, training, and practice that draws on insights from intersectional disability justice activism. We argue for a paradigm shift in how we identify and understand disability-related healthcare inequities, rather than a pivot to another set of practices to address them. In order to address the problem, we must first learn to understand it – by turning to persons with disability (PWD) and disability scholars to understand disability justice and intersectionality resulting in disability consciousness. This reckoning with systemic injustice will require the collective action of the whole profession.

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[1]Linton defines ableism as "the centering and domination of the nondisabled experience and point of view" and the idea that "people with disabilities as a group are inferior to nondisabled people" [5].

[2]Sharon N. Barnartt of Gallaudet University argued in 1996 that "disability consciousness," based on the concept of collective consciousness, was a more accurate term than "disability culture" to describe the coalition and coming together of the disability community. Whereas cultures, in Barnartt's view, maintain social order, collective consciousness involves critique of norms, traditions, and institutions, spurring collective action for social change [10].

[3]For more on "structural violence" see Farmer PE, Nizeye B, Stulac S, and Keshavjee S. (2006). Structural violence and clinical medicine. PLoS medicine, 3(10), e449. doi: 10.1371/journal.pmed.0030449.

[4]This list is adapted from the 10 Principles of Disability Justice as articulated by Sins Invalid [12].

2. Disability discrimination in medicine

The disability community at large has expressed a pervasive distrust of medicine [13] which begins with consideration of the problematic history and relationship between the medical profession and eugenics. In the late nineteenth and early twentieth centuries, the eugenics movement sought to improve qualities of the human population by preventing people with "defective" inheritable traits from reproducing through methods of segregation, sterilization, and even euthanasia [14]. The role of physicians in this history cannot be ignored. In the late 1910s, Chicago surgeon Harry J. Haiselden allowed at least six "defective" infants to die, and flagrantly publicized these acts as noble through journalism and film [15]. Similarly, as numerous states in the U.S. implemented eugenic laws and policies throughout the twentieth century, the medical community willfully participated in discriminatory acts of violence such as involuntary sterilization, forced institutionalization, and denial of treatment [14,16]. Notably, these practices targeted women more than men; Black, latinx, and indigenous people of color more than whites; and the poor more than the wealthy [17]. U.S. sterilization policies were later credited by Nazi Germany as having influenced their Euthanasia Program [14]. Eugenics is more than a historical footnote; beyond the involuntary sterilizations that continue to this day, eugenic assumptions about what constitutes a "quality" as opposed to a "defective" body persist in medicine. Satz argues that "the way in which healthcare currently is practiced and funded is a form of negative eugenics, that is, preventing people who function in certain ways from existing. This is because healthcare seeks to prevent, ameliorate, or eliminate disability, with the goal of normalizing individuals" [18, pp. 20–21]. Measures of health are so anchored to conceptions of the "normal" that it is difficult for providers to imagine wellness in any other way.

If wellness is measured by proximity to an ableist norm, so too are medical conceptions of "quality of life." Numerous studies have demonstrated that healthcare providers consistently assume the quality of life experienced by PWD to be lower than what is self-reported [19]. In fact, the self-assessment by PWD of their quality of life is comparable to that of their non-disabled peers [20,21]. Disabled bioethicist Stramondo writes, "To me, there is little paradoxical about disabled people valuing their own life more than it is valued by non-disabled people making judgments based on stereotype and stigma" [22]. It is critical here to note that "quality of life" self-reported by PWD tends to be a holistic reflection on the totality of their experiences, whereas medical providers are more accustomed to "healthcare-related quality of life," which is a scholarly subset of outcomes in research. Due to this narrow understanding, the medical community often incorrectly equates disability with pain, suffering, limitations, and dependence [13]. However, disability and illness are not cognates. Even where there is overlap, healthcare providers are wrong to assume that lives which include pain and other challenges are of lower "quality" than nondisabled lives. While physical medicine and rehabilitation physicians for both children and adults alike are committed to the function and quality of life of patients, even physiatrists are not exempt from attitudes that promote ableism over health.

Within a system structured on norms, PWD face multiple barriers to care that translate to significant healthcare disparities [23]. A 2007 report by the Institute of Medicine titled "The Future of Disability in America" highlights this issue, demonstrating that PWD not only face physical barriers to receiving healthcare (e.g. inaccessibility of facilities and/or equipment), but also barriers related to the knowledge and attitudes of healthcare providers [24]. Several studies have demonstrated that both physicians and medical students report a lack of comfort in interviewing and examining PWD [25–29] often translating to poor outcomes and negative attitudes towards working with this patient population [25–27,29]. PWD themselves also report negative outcomes, including higher than average rates of difficulty finding the right type of care, denial of treatment, and generally negative personal interactions with medical providers [25,30,31].

The COVID-19 crisis in particular spotlights the consequences of disability discrimination in the medical community. While there are some resources for those with disabilities such as the COVID-19 specific webpage[5] of the American Association on Health and Disability, research and journalism have identified many concerning issues. Triage protocols in Italy, where the number of cases quickly overwhelmed the healthcare system, deprioritized people on the basis of age and the presence of comorbidities impacting likelihood of survival [32]. Similar situations emerged in the United States, exposing the entrenchment of disability discrimination throughout the healthcare system. In order to prioritize ventilators to patients "most likely to benefit,"

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[5]https://www.aahd.us/covid-19/.

one of the largest hospital systems in New York called for "compassionate extubation" of patients with "prior advanced health problems" after seven days [33,34]. Additional policies – Alabama's devaluation of people with intellectual disabilities, Tennessee's exclusion of people with spinal muscular atrophy, and the University of Washington's age- and health-based allocation guidelines – prompted a response from the American Association of People with Disabilities, who petitioned Congress to prohibit such rationing [32]. The U.S. Office of Civil Rights has worked to address these discriminatory triage practices [35]. However, we should expect the law to protect us in this way and work to prevent such injustices in the first place. Activist Ari Ne'eman writes about disabled peoples' perceptions of healthcare experiences in a time of pandemic:

> Disabled people who require ongoing ventilator care and other forms of expensive lifelong assistance are used to being asked by medical professionals if they would rather abandon life-sustaining treatment – often with the clear implication that "yes" is the right answer [32].

These attitudes perpetuate healthcare disparities as well as violate the core bioethical principles of autonomy, beneficence, nonmaleficence, and justice [16]. Problematically, PWD lack representation on hospital triage committees and within the larger medical community [34], prompting recent calls for a more disability-inclusive response to the pandemic [6,34].

Calls for disability inclusion have extended beyond triage protocols to issues of data and surveillance, in response to what Reed et al. call the "disability data gap" [36]. Emerging data on COVID-19 continues to suggest that age and multiple chronic conditions are associated with an increased morbidity and mortality [37]. However, only a small subset of this data has focused on specific risks and impacts faced by PWD. For example, researchers have highlighted that people with spinal cord injuries may require closer supervision due to unique screening challenges and differences in symptom manifestation [38,39]. Other data suggests that people with intellectual and developmental disabilities experience more severe outcomes from COVID-19, likely related to higher rates of comorbid conditions as well as increased vulnerability to the physical, mental, and social effects of a pandemic [40,41]. However, more data is needed to better understand the risk that COVID-19 poses for PWD. Beyond the virus itself, research should consider the social and economic factors impacting PWD during the pandemic. In the same way

that demands were made early on in the pandemic to publish COVID-19 data by age, race, and sex [42], disability data needs to be collected and published to better highlight and understand these healthcare disparities.

3. Shortcomings of disability competence

According to the Centers for Disease Control and Prevention, 26% of U.S. adults reported having a disability[6] in 2016 [44]. By the numbers, all medical providers will care for PWD and many will experience, or be personally affected by, disability. For these reasons, there have been numerous calls for increased training to improve disability "competence." Improved disability competence would help prevent the kinds of biased assumptions we observed in Michael Hickson's story, not only about quality of life, but also about the value of disabled lives. But the health and healthcare disparities exposed by COVID-19 go deeper than bias: they point to structural, systemic, and social inequities that cannot be reduced to a lack of competence. In this section we outline competency efforts and discuss their shortcomings.

3.1. Disability competence in education and training

Although the Association of American Medical Colleges and other professional organizations recognize the need for medical education to include training related to disabilities [45], such programs remain limited. In a 2015 survey of curriculum deans at 75 medical schools, only 52% reported having a "disability awareness program" [46]. When generalizing this data to all American medical schools, the authors suggest that potentially no more than 23% have disability-focused training [46]. Among these schools, varying degrees of disability-related training have been implemented, including hands-on experiences with standardized patients, simulation exercises, panel discussions with patients with disabilities, and didactic approaches to highlight disability-related issues [46–49]. Of note, no standardized curriculum has been widely adopted.

Of disability curricula that have been proposed [8,46–53], several follow the Bloom's taxonomy framework used widely throughout healthcare education, propos-

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[6]The CDC defines disability as "any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions)" [43].

ing instruction based on three educational outcomes: knowledge, skills, and attitudes [49,51–53]. "Knowledge" and "skills" related to disability are largely addressed in cultural competence training, often alongside but discrete from issues related to race, gender, and class [49]. These topics include easily-assessed knowledge and skills that encourage effective communication and examination practices for patients with disabilities, but rarely explore more general skills directed towards a population that has historically been disadvantaged by medicine and society as a whole [52,53]. While many of these interventions have been well-received by faculty and students [46,47], true changes in "attitudes" are difficult to assess. Given their limited focus, these disability curricula seem to achieve tolerance at best and do not address, or even acknowledge, activism for disability rights and justice as valuable to future physicians [54].

Similarly, the concept of disability as a form of diversity and an aspect of identity has not fully permeated medical education and training [55,56]. The American Academy of Graduate Medical Education (ACGME) only appointed its first Chief Diversity and Inclusion Officer recently in 2019 [57]. However, it remains unclear whether disability diversity is fully appreciated by the ACGME as the culture of residency training interferes with resident physicians' abilities to prioritize and engage in opportunities that grow their disability consciousness. Efforts to improve patient safety (e.g. duty hours regulations) have not fully eliminated barriers to quality care [58]. Instead, resident physicians are part of an "assembly line" culture that reduces patients down to a product on the line. This is dehumanizing to both patients and physicians, and especially threatens the safety and experiences of patients that already face discrimination and disparities within the healthcare system.

In response to these shortcomings, some scholarship has gone beyond the call for disability competence training and proposed deeper engagement with critical disability studies. Scholars have articulated the value of this field for integration into medical education [59,60] as well as occupational therapy [61,62] and the rehabilitation sciences [63]. For Couser, disability studies enable medical professionals to consider disability from an inside as opposed to an outside perspective, thereby reckoning with the harms as well as the benefits of medical treatment [60]. Campbell critiques medicine's tendency to view disability as a personal medical tragedy, discounting the socio-environmental factors that shape disability [59]. Based on a global appraisal of disability

modules within medical education, Campbell describes "a fragmented system of implementation, poor communication among medical schools and conceptual confusion as to the meaning and goals of disability education for medical students"; moreover, "interventions are usually horizontally incorporated into the curriculum, limited in scope and short in duration" [58, p. 225]. We join Campbell in her call for a more comprehensive, vertically-integrated curriculum, building on the promise of the UN Convention on the Rights of People with Disabilities [64]. Indeed the gravity of the moment calls for broader actions. An appropriately urgent response is one that is not left to the next generation of healthcare providers but instead calls upon all levels of education, training, and practice. Further, by emphasizing the connection between disability experiences and other structural forces influencing health disparities, like racism, we call for a response that attends to the intersectionality of these issues and addresses the injustices together rather than separately.

3.2. Disability competence in research and practice

While our demand for a broad, multi-level culture shift may seem unattainable, other culture shifts in medicine have occurred in the recent past in response to systemic problems. For instance, the rise of patient-centered research and care[7] sought to improve patient autonomy and the patient-doctor relationship, and increase inclusion of patient perspectives in research. Arguably, if patient-centered care were sufficient, a story like Michael Hickson's should not have occurred. The problems exposed by the COVID-19 crisis are about more than patient autonomy and interpersonal interactions, and instead expose the need to re-examine the foundational assumptions of medicine and its centering on white, patriarchal, and capitalist structures and norms.

In practice, patient-centered care and disability competence have failed to disrupt the normalizing tenden-

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[7]While there are many definitions of patient-centered care, the core tenant is that the "individual's specific health needs and desired health outcomes are the driving force behind all health care decisions and quality measurements" [65].

cies of medicine with regard to disability-specific concerns such as cochlear implants, prenatal diagnosis and abortion, genomic editing, and end-of-life decisionmaking. On one hand, cochlear implants at an early age can improve verbal language acquisition and other benefits to childhood development [66,67]. On the other hand, some deaf parents report worrying that their children may potentially not identify with their culture if they are no longer deaf [66,67]. This worry is not unfounded as some scholars suggest that cochlear implants could eventually threaten the structure of the Deaf community [68,69]. Disability communities also resist research and funding that focuses on diagnosing autism, Down syndrome, and other conditions prenatally, resulting in termination of pregnancies on the basis of disability [70,71]. Although these medical ethics debates are beyond the scope of this article, it is clear that society is not prepared to assess the ethical implications of making "designer babies" with human germline genomic editing (HGGE) [72]. Who will decide which people, with which conditions and disabilities, maintain their "right to life?" [71]. If disability is diversity, then HGGE may seek to eradicate that diversity, which would have consequences for all of humanity, not just specific disability communities. Finally, many disabled scholars and advocates have identified another concern with the process of offering "Do Not Resuscitate" orders and hospice care, as well as medical assistance in dying (MAID) and physician-assisted suicide [73,74]. While compassionate care is important, what physicians perceive as mercy can actually be violence to those who wish to receive life-saving or – extending treatments, as in the case of Michael Hickson.

Beyond these concerns of the disability community, the shortcomings of patient-centered care and disability competence are that these models do not seek to alter the exclusive cultural, economic, and financial structures underlying the practice of medicine. Disability competence interventions in education, practice, and research to date have failed to enact the change that is needed. Future changes to medical education and clinical practice policies can only be successful if we first truly recognize the divide between disabled communities and medicine and then seek innovative solutions to bridge it. In the next section we will describe how a culture shift toward disability consciousness confronts the broader injustices of the for-profit healthcare industry.

4. Opportunities for disability consciousness

We use the term "disability consciousness" in the way Sharon Barnartt proposed in 1996:

While a culture functions to maintain the social order, a collective consciousness impels the actions which comprise social movements. Disability consciousness impels the social movement actions which are occurring within the disability community at this time. The distinction has implications for the process of policymaking, as well as for its content [10, p. 2].

The development of a collective consciousness begins with recognizing "attributes for the problem which make it a societal rather than an individual problem," and "invok[ing] the necessity for collective action" [10, p. 5]. Disability conscious medical education, training, and practice requires not only an appreciation of humanities-based critical disability studies theory, but also the importance of an experiential intersection of disability with race, ethnicity, gender, sexuality, and class, best illustrated by disability justice activists of multiple marginalized identities.[8]

Therefore, raising disability consciousness begins with centering diverse disability voices. Wells et al. have argued that "from an educational point of view, recognition of the disabled person's own expertise and the idea of partnership is only fully realized when the disabled person is introduced as the teacher" [52, p. 788]. The power dynamic between patient and physician can only be addressed if the medical community accepts the disability voice and its authority on these issues. During residency and practice, physicians must be encouraged to seek out opportunities to include the perspectives of PWD whenever possible, drawing from patient perspectives, disabled activists and self-advocates in the community, along with larger voices in the disability studies literature. This will promote a sense of "disability humility" [13], enabling medical professionals to cede their own power. By actively and continuously listening to disabled voices, they may begin to imagine wellness and a "quality" life in a more expansive sense, discarding narrow norms.

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[8]For further reading on intersectionality and disability justice, we direct the reader to the following resources:

– The Disability Visibility Project Website: https://disabilityvisibility project.com/
– The Sins Invalid Website: https://www.sinsinvalid.org/
– Wong, A. (ed), (2018). Resistance and Hope: Essays by Disabled People, Disability Visibility Project
– Wong, A. (ed) (2020). Disability Visibility: First-Person Stories from the Twenty-First Century, Penguin
– Piepzna-Samarasinha, L. L. (2018). Care Work: Dreaming Disability Justice, Arsenal Pulp Press.

Once liberated from restrictive ideals of normality, medical professionals may learn to imagine *interdependence* rather than independence as a desirable health outcome and lifestyle. As disability justice activist Stacey Milbern Park explains, "We know no person is an island, we need one another to live. No one does their own dental work or cuts their own hair. We all need support. Hierarchy of what support is okay to need and what isn't is just ableism" [75]. Recognizing the inherent interdependence of all human beings facilitates a conceptualization of care and assistance as the ongoing work of a community rather than commodities that are produced and consumed. Care work is a broad spectrum of which medical care is only a part. Beyond physicians and surgeons, a medical caregiving team also includes nurses and nursing aides, physical and occupational therapists, technicians, environmental service workers, home health workers, personal needs attendants, childcare and elder care providers, and other domestic workers. Although workers in all of these categories are essential, they are not accorded equitable respect and remuneration. As our population ages, the Bureau of Labor Statistics classifies home health aides and personal care aides among the fastest growing occupations, yet median wages for these jobs are just $25,280 a year [76]. These wages reflect racial, ethnic, and gender pay gaps: 89% of the home care workforce are women, and disproportionately women of color [77]. Undervaluing this essential labor has consequences for those with disabilities: shortages of domestic care workers force PWD and the elderly to enter nursing homes and other congregate living situations [78], which are actually more costly to the healthcare system [79] and pose an increased risk of exposure to communicable diseases like COVID-19 [80].

The disability justice model conceives of care not as a transaction but as an organic process and way of life, in which PWD are both givers and receivers of care. Leah Lakshmi Piepzna-Samarasinha writes about care collectives that "work from a model of *solidarity not charity* – of showing up for each other in mutual aid and respect" [80, p. 41]. This model holds space for the human connection that the care relationship can yield, a connection which is too often absent from the clinical encounter. Care work is a rich opportunity for intercultural discourse and exchange across communities. Founded on solidarity, care networks repudiate the power dynamics and profiteering of the present healthcare system, in which the majority of profits go to people who have no contact with patients – top insurance and pharmaceutical company CEOs make be-

tween $44,000 and $225,000 *per day* [82] – while families go into debt [83], family members (mostly women) give up their careers to provide care to children and elders [84,85], and care workers bring in near-poverty wages [86].

These structural inequities are too often taken for granted as part of an unchangeable reality or features of the culture that are beyond a physician's concern. While medical training often includes educational units on social determinants of health such as social class and race, these units could be improved with a more purposefully intersectional approach, including overlapping experiences of disability, race, ethnicity, gender, sexuality, and more. For example, the Center for Economic and Policy Research reports that nearly two-thirds of those experiencing longer-term poverty have a disability and nearly one-third of people with a disability live in poverty, whereas the rate of poverty for non-disabled people is just over 1:10 [87]. Addressing social determinants of health recognizes that medical impairments do not exist in a vacuum and that medical knowledge is both medical and social in nature. The World Health Organization's International Classification of Functioning, Disability, and Health (ICF) [88] is a step in the right direction towards understanding this complexity. However, the ICF paradigm has yet to influence usual billing and reimbursement models in medicine. Students should be taught to recognize specific impairments and their functional implications, but also consider larger social contexts: societal barriers, economic burdens, and social institutions in place, including the for-profit structure of the U.S. healthcare system.

Embracing disability as both a part of diversity and a demographic marker will allow us to advance the art and science of medical care and research. In addition, we should encourage more PWD to enter the practice of medicine, thereby offering professional and personal representation in the practice [89,90]. Diversity in medical schools and in positions of leadership is one step toward decentering whiteness and the patriarchy within medicine. However, diversity on its own will not lead to automatic change. It must be accompanied by efforts to build *collective access*, which entails not only physical accessibility and accommodations, but also a broader culture shift that embraces difference rather than expecting assimilation. This culture shift would involve, among other things, rethinking the competitive pedagogies and demanding working conditions that lead to burnout [91].

Building "collective access" refers not only to the accessibility of the healthcare professions, but also the

accessibility of healthcare services to the public – the whole public. Collective access entails financial and geographic accessibility [92]. Our understanding of health disparities will always be incomplete if we fail to seriously consider the role of prohibitive costs in preventing disadvantaged populations from receiving, and sometimes even seeking, the care they need [93]. Nirmala Erevelles remarks in *Disability and Difference in Global Contexts* that the insurance industry in America is essentially a gatekeeping mechanism with the power to determine which lives are worth saving, decisions that are often based on perceptions of an individual's contributions to society in the form of wealth, status, and labor capacity. "Put simply," she writes, "access to health care in the United States is predicated upon one's capacity to contribute to its profitability" [93, pp. 14–15]. These forms of institutionalized and legal discrimination are intersectional, and operate along axes of race, ethnicity, class, gender and gender identity, sexuality, and of course, disability status and chronic health conditions. Geographic distribution of resources is also critical, as evidenced by veterans' difficulties accessing healthcare due to distance [95], the limited availability of psychiatric and other mental health care in rural areas [96], and the severe under-resourcing of the Indian Health Service [97]. Any "Social Determinants of Health" curriculum without self-reflective consideration of how the healthcare system *itself* contributes to health disparities is therefore incomplete.

Access barriers that disproportionately impact marginalized communities are an indictment of the healthcare system as a whole, and public attention has elevated this issue within the political arena, as evidenced by the growing calls for a universal, single-payer system. The Medicare for All movement is motivated by a basic belief that healthcare is a human right. The American Medical Association (AMA), an organization representing a small fraction of physicians in the US and yet wielding significant political power, actively opposed efforts to organize a single-payer system for a century [98,99]. The AMA's history is also notable for maintaining a racial divide, with many local chapters denying membership to Black physicians during the Jim Crow era [99,100]. Tellingly, the alternative organization founded by Black physicians in response to this exclusion, the National Medical Association [99, p. 27], vocally supported single-payer activism in the 1960s while the AMA continued to stand against it [98,99, p. 74, pp. 36–38]. However, medical professionals can organize to build power and alter these circumstances. In the summer of 2019, a coalition of protestors comprising medical students, nurses, doctors, and other healthcare workers, alongside disability activists and members of the Jane Addams Senior Caucus, staged a rally and a die-in at the AMA's annual convention in Chicago demanding Medicare for All. Shortly thereafter, the AMA severed ties with the Partnership for America's Healthcare Future, an industry-backed lobbying group against single-payer proposals [98]. While the AMA remains opposed to Medicare for All, a coalition of physicians with the broader care collective and the disability community can be a force for change: collective action for collective access.

The disparities exacerbated by COVID-19 represent a moral imperative for significant change. A single-payer system providing universal healthcare would address systemic inequities by eliminating barriers to care based on employment, insurance, prohibitive costs and inequitable reimbursement rates for Medicaid which currently preclude many providers and care agencies from treating recipients. Additionally, it would provide long-term supports and services for elderly and disabled people that make age-in-place and community living the default, rather than institutional settings [101]. A single-payer system would eliminate premiums and out-of-pocket medical expenses reduce administrative costs and simplify the bureaucratic process and increase the amount of healthcare jobs. Systems change like this also has the potential to improve working conditions and increase the amount of time caregivers can spend with patients. In families and other care webs, if someone needs to take time away from work to care for a loved one, they will not have to sacrifice their own health insurance to do so. Of course, switching to a single-payer system would represent the beginning of a march toward health justice, not the end. The movement has not been without flaws: for years, Medicare for All proponents neglected the perspectives of the disability community, and earlier proposals failed to include essentials like long-term supports and services. Representative Pramila Jayapal's 2019 House bill changed that [102]. Now, PWD like activist Ady Barkan have moved into the limelight [103]. A singlepayer system on its own will not erase stigmas and traumas, nor resolve geographic and cultural barriers to care. Clearly a change of direction is called for. Currently, despite a professed commitment to patient-centered care, the system is market-centered. The inequities described in this article will soon pale in comparison to a situation in which millions of Americans will lose their health insurance along with their jobs, during a global pandemic.

Policies eliminating private insurance and prohibitive healthcare costs, and regulating the pharmaceutical industry would increase access and reduce disparities, but many of the problems we have elucidated are beyond policy. Access is a floor, not a ceiling. We are calling for a deeper culture shift that cannot be distilled into a simple set of actionable steps. Instead, we ask physicians to examine their own humanity, cultivate humility, and enter into coalitions with patients, PWD, and all levels of care workers. For almost two decades, disability competence steps, strategies, and directives have been implemented with little to no input from these stakeholders resulting in a clearly insufficient response. Disability competence solutions target only small-scale interactions between doctors and patients, but the bigger problems are structural, resulting from the organization of power. To change the system, we have to recognize our own power. With a coalition of disabled communities and scholars to help us strive toward disability justice in medicine, we can ultimately move towards disability consciousness.

5. Conclusion

It is not only possible, but imperative, to offer medical care that improves quality of life while dignifying and respecting the impact of disability on a person's life. The medical community must address structural violence impacting disabled, racialized, and other marginalized populations now more than ever. Healthcare providers are called to care for all individuals with compassion, empathy, and respect, regardless of their differences. Therefore, we must recognize the hypocrisy in professing to embrace those with disabilities while ignoring the ostracizing effects of centering our profession on curing the abnormal. Medical education, training, and practice should move beyond the goal of curing pathologies, a model that makes people feel broken and causes emotional and physical harm. Incorporating disability justice and intersectionality throughout medical education, training, and practice will promote the art of enabling as well as healing that should be inherent in the practice of medicine.

Conflict of interest

Authors AD and MQ have no conflicts of interest to report. Author CL has received an honorarium as a speaker for Catalyst Medical Education.

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