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No Body Is Expendable: Medical Rationing and Disability Justice During the COVID-19 Pandemic

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The health threat posed by the novel coronavirus that caused the COVID-19 pandemic has particular implications for people with disabilities, including vulnerability to exposure and complications, and concerns about the role of ableism in access to treatment and medical rationing decisions. Shortages of necessary medical equipment to treat COVID-19 have prompted triage guidelines outlining the ways in which lifesaving equipment, such as mechanical ventilators and intensive care unit beds, may need to be rationed among affected individuals. In this article, we explore the realities of medical rationing, and various approaches to triage and prioritization. We discuss the psychology of ableism, perceptions about quality of life, social determinants of health, and how attitudes toward disability can affect rationing decisions and access to care. In addition to the grassroots advocacy and activism undertaken by the disability community, psychology is rich in its contributions to the role of attitudes, prejudice, and discriminatory behavior on the social fabric of society. We call on psychologists to advocate for social justice in pandemic preparedness, promote disability justice in health care settings, call for transparency and accountability in rationing approaches, and support policy changes for macro- and microallocation strategies to proactively reduce the need for rationing.



Public Significance Statement


This article explains barriers faced by disabled people in obtaining access to healthcare, including lifesaving treatment during the COVID-19 pandemic. Ableism can affect quality of life determinations and result in discriminatory behavior, unfairly costing disabled lives. Psychologists are positioned to advocate for social justice alongside the disability community by including disability in research, promoting meaningful inclusion in training and education, and leveraging roles in health care practice and leadership.

Keywords: disability justice, medical rationing, COVID-19 pandemic, ableism, advocacy

For people with disabilities, the novel coronavirus that caused the COVID-19 pandemic has life-limiting implica-

tions. Although not all disabilities put individuals at higher risk to become infected or to experience complications from

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COVID-19, a great many people with disabilities are particularly vulnerable during this pandemic. Disabled people living in institutional settings such as group homes, assisted living facilities, and nursing homes, are at significant risk of contracting the virus in such confined settings by daily contact with numerous rotating caregivers who themselves are exposed to multiple other patients. Those who live independently but rely on personal care assistants for activities of daily living also have greater difficulty protecting themselves through self-isolation.

The disability community has been especially affected by predictions of demand outpacing necessary medical equipment supply to treat COVID-19. Media reports from countries such as Italy, which was heavily impacted by the virus prior to the United States, demonstrate the devastating effect these shortages have had. As such, shortages occurred or threatened to occur in the United States, triage guidelines emerged outlining the ways in which lifesaving equipment, such as mechanical ventilators and intensive care unit beds, may need to be rationed among affected individuals. Disabled people fear that they could be de-prioritized for emergency medical intervention, and possibly passed over for testing due to being perceived as lower priority than non-disabled individuals (Lund & Ayers, 2020). On the face of it, rationing strategies that emphasize likelihood of survival and life expectancy may seem a reasonable approach to a desperate situation. However, this brings to the forefront complex ethical and social justice issues that disproportionately affect marginalized groups, including the disability community.

The arguments related to the ethics of health care rationing can become highly philosophical, and there is a long history of friction between the disability rights movement and the field of bioethics (Ouellette, 2011). For example, in 2003, the prominent disability activist and lawyer Harriet McBryde Johnson published an article in *New York Times Magazine* about her first-person account of professional encounters with renowned bioethicist Peter Singer (Johnson, 2003). Johnson challenged Singer's views that disabled newborns should not be provided life-saving treatment and that it is ethically permissible to euthanize them. Johnson passionately argued that the presence of disability does not predict poor quality of life and that such assumptions are based totally on prejudicial beliefs. Disabled bioethicist Joseph Stramondo (2016) wrote "the lived experience of disability produces variations in moral psychology that are at the heart of the moral conflict between the disability movement and mainstream bioethics" (p. 22). He described the conflict between mainstream bioethics and the disability rights movement fundamentally as the insider/outsider distinction identified by the social and rehabilitation psychologist, Tamara Dembo (1964; see also, Dunn, 2015). There is a discrepancy between self-reports of quality of life by individuals with disabilities and estimates from health care

providers known as the disability paradox (e.g., Ubel, Loewenstein, Schwarz, & Smith, 2005). Health inequities and inappropriate decisions about care can be the outcomes of these misestimates (Amundson, 2005; Kothari, 2004). As Dembo (1964) put it, "The role of the outsider is that of an observer, and the role of the insider is that of a participant . . . because the observer is an outsider, the impact of the situation affects him little" (p. 231).

As a challenge to the expendability argument, this article identifies and explores social justice concerns surrounding *ubiquitous ableism*, which we define as social prejudice and discrimination against disabled individuals in favor of non-disabled persons. Such sociocultural beliefs have the potential to affect medical rationing decisions, especially in extreme circumstances, like the current COVID-19 pandemic. Whether explicit or implicit, the message that some lives are more worthy than others can be transformed into policy and practice where disability is concerned. To elucidate and combat this problem, we explore the psychology of ableism and proactive responses to it and then social determinants of health that influence disability (e.g., education, employment). We then examine common perceptions of the quality of life of disabled persons and discuss the importance of health disparities in the disability community, recommending ways that psychologists can advocate for social justice both for and alongside the disability community. We begin by defining the scope of medical rationing and the questions it raises where the allocation of resources is concerned.

Medical Rationing

The concept of medical rationing calls into focus the relationship between the person and their somatosensory body, behavior and the reactions of observers. Collectively these concepts, particularly in response to this pandemic, highlight that disability is largely a social psychological phenomenon. Wright (1960, 1972, 1983) wrote about groundbreaking psychosocial approaches to disability, focusing a critical lens on the physical, social, and psychological environments where people with disabilities live. She believed these environments could either promote or hinder psychosocial adjustment. Wright's works examined the conceptualization of person versus environment attributions, impressions of and attitudes toward people with disabilities, self-esteem issues, and coping versus succumbing behaviors (Dunn & Elliott, 2005). Wright (1972) detailed the importance of 20 "value-laden beliefs and principles" that she believed should guide both quality rehabilitation and the promotion of the welfare and rights of individuals with disabilities (see also, Wright, 1983). Dunn and Elliott (2005) noted several important themes that reverberate throughout Wright's beliefs and principles which include (a) individuals are worthy of dignity, respect, and encouragement, no matter how severe their disability; (b) the social

and physical environment has profound consequences for coping and adjusting to a disability; (c) no matter the circumstance, all individuals possess unique, personal assets that can aid rehabilitation; (d) active involvement of clients as comanagers of rehabilitation has positive benefits for themselves and for practitioners; and (e) psychological issues are constants throughout the rehabilitation process (see also, Dunn, Ehde, & Wegener, 2016). Despite the fact these constructive views of disability permeate the education, training, and research in rehabilitation psychology, they have unfortunately not extended to other areas of health service psychology or interdisciplinary professional education, which subsequently impacts health care decision-making such as medical rationing.

Although the COVID-19 pandemic has brought the conversation about rationing to the forefront, the truth is that medical rationing happens all the time. Rationing occurs when resources are limited, and medical resources are indeed finite (Brody, 2012). There are many potentially beneficial treatments, but there is never certainty that any given treatment will work for a particular patient. Health care providers must weigh both the costs and benefits of any intervention to justify its expense.

Perhaps the clearest example of medical rationing comes from organ transplantation where specific criteria are used to determine which candidates receive organs. Other examples of rationing are rules that require less expensive first line interventions before a more expensive treatment. This occurs in single payer systems or government sponsored health care programs such as the Veterans Health Administration. These examples vary in the extent to which they affect mortality and may reduce both costs and medical waste. However, there is real concern that some rationing approaches unfairly discriminate against people with disabilities and chronic health conditions. For example, organ transplantation continues to be denied on the basis of disability alone (Chen et al., 2020), despite recent guidance from the American Academy of Pediatrics (Statter, Noritz & the Committee on Bioethics, Council on Children With Disabilities, 2020) and over a dozen state laws. The question becomes, what is a fair approach to allocating scarce resources?

Disability activist and founder of the Autistic Self Advocacy Network, Ari Ne'eman (2020), described how the Alabama triage guidelines published in response to the COVID-19 pandemic made "people with severe or profound intellectual disability unlikely candidates for ventilator support" (para. 4), whereas Tennessee's guidelines detailed people with spinal muscular atrophy and others who required assistance with activities of daily living among those ineligible for critical care in situations of scarcity. The University of Washington Medical Center's guidelines perhaps most explicitly ration care on the basis of disability discrimination with the prioritization of care to "the survival

of young otherwise healthy patients more heavily than older, chronically debilitated patients" (Carlson, 2020, p. 12). Although not intended for the purpose of making decisions on who receives care (Ho, 2007), many state guidelines for rationing scarce resources rely on Sequential Organ Failure Assessment (SOFA) scores, which estimate the functioning of major body systems, in part to decide who gets a ventilator in times of shortage. The higher the score, the more likely multiple bodily systems are already failing and the less likely an individual is to be allocated care (Ho, 2007). Problematically, SOFA scores are inaccurately elevated if an individual does not communicate verbally (Chanques et al., 2014). Some individuals with disabilities may not have communicated verbally prior to a deterioration in health from COVID-19 or medical trauma may limit their verbal communication. Some providers adjust with this consideration in mind, but many may not.

These dilemmas pose the question, is rationing ableist? There are multiple principles of distributive justice that have been proposed to guide decisions about health care rationing. These include affording everyone an equal share, basing distribution according to need, following free market conditions, or attempting to maximize overall usefulness. There are competing priorities in this debate, including maximizing efficiency, or, in other words, doing the most good at the least expense; equity, or treating individuals equally; and justice for those most affected. Scheunemann and White (2011) described three different approaches to distributive justice: utilitarianism, egalitarianism, and prioritarianism.

An example of a utilitarian approach is the health economist method of Quality Adjusted Life Years, which uses a measure to adjust life years for quality and then maximizes distribution of resources to save the most quality adjusted life years. Then, formulations to calculate cost per quality adjusted life are estimated (Bickenbach, 2016). The biggest difficulty with this approach, which inherently privileges people who have good health, is the controversy surrounding how to quantify quality of life. This is particularly important for individuals with disabilities, whose lives are constantly devalued by outsiders. Disability Adjusted Life Years quantify less value to each year lived with disability than a nondisabled year of life (National Council on Disability, 2019) based on the beliefs of nondisabled outsiders. Egalitarian approaches emphasize that individuals have equal moral status and aim to provide equal opportunity to everyone. The basic example of this approach would be a lottery for priority access to resources. This random selection can occur quickly and is least susceptible to biases (Bickenbach, 2016). However, the downside of such an approach is that resources could end up being allocated to those unlikely to actually benefit from them. Another type of egalitarian approach would be first-come first-served; however, there is significant inequality in such an approach.

Individuals who are able to quickly secure medical care are typically those with the social and financial resources that ensure health care access in the first place. Many disabled people routinely experience economic discrimination because of a lack of educational opportunities and under- or unemployment. There are also significant costs to managing a disability, many of which are not covered by insurance (Mitra, Palmer, Kim, & Groce, 2017). Because of these factors, what may seem like an egalitarian approach is likely still made inequal due to discrimination.

Prioritarianism is focused on those who are the most affected by prioritizing individuals who have not had as much opportunity. For example, in this approach one might favor medical allocation toward younger patients over older patients to give all individuals equal opportunity to a full life span. Although the justification is not stated as intrinsic worth or social usefulness, this lifecycle principle does make inferences about the worth of lives of older individuals including those with chronic illnesses (although prognostic differences are not to be taken into consideration).

Rationing decisions do not affect patients and their families alone. The rule of rescue is the psychological impulse for humans to save those who are facing imminent death (Scheunemann & White, 2011). In this way, not providing resources to a particular individual, in other words allowing them to die, has an emotional toll on health care providers as well, now identified in the trauma literature as moral injury. Moral injury is identified by Shay (2014) as the soul wound inflicted by doing something that violates one's own ethics, ideals, or attachments. When choices about who lives and who dies are deflected onto front-line providers when there are not enough resources to treat everyone who needs it, they may experience moral injury (Brecher, 2008).

One area where bioethical scholars appear to agree is that rationing should be transparent. Explicit rationing according to Scheunemann and White (2011) is preferable to implicit rationing because the rationale for such implicit decisions are not publicly disclosed and are very likely to be unfair to one or more groups as a result of hidden biases influencing such decisions. Thus, although the above-mentioned rationing guidelines are alarming, their transparency has allowed advocates to critique them on the basis of equity. In the United States, many states do not adopt state-wide guidelines, which allow hospitals to develop their own guidelines. These guidelines are rarely shared or developed with representation from the disability community. Because societies may be unable to agree about common principles to guide rationing, it is easier to establish a fair process for priority setting as opposed to agreeing on principles (Daniels, Porteny, & Urritia, 2015). Key elements involved must include transparency about the grounds for decisions; allow appeals for rationales; and procedures for revising decisions as needed. Transparency is crucial because, as Daniels (2000) stated, "there must be no secrets where justice is

involved, for people should not be expected to accept decisions that affect their well-being unless they are aware of the grounds for those decisions" (p. 1317).

Psychology of Ableism

The field of psychology is rich and its contributions to the role of attitudes, prejudice, and discriminatory behavior on the social fabric of society is robust. Social psychology has demonstrated that negative attitudes are pervasive toward individuals with disabilities (Nario-Redmond, 2019), and other types of attitudes such as patronization can be equally harmful. Research from rehabilitation psychology has shown that disability itself is not an adequate predictor of an individual's quality-of-life, but rather only one factor in the complex biopsychosocial realities of human beings (Albrecht & Devlieger, 1999; Amundson, 2010; Post, 2014; Ubel et al., 2005). Increasingly, the concept of disability as a form of diversity (e.g., Dunn & Andrews, 2015) and recognition of the harmful effects of ableism has been recognized in the field of psychology. Although this phenomenon has lagged in the multicultural and diversity dialogue, significant work has been done to argue that the primary difficulties faced by disabled people are related to attitudinal and environmental problems (Nario-Redmond, 2019). These include significant health disparities, higher rates of poverty and social exclusion, and barriers in accessing health care services (Emerson et al., 2011; Iezzoni, 2011).

All psychologists have an ethical obligation to develop disability humility, which entails recognizing one's knowledge about disability will never be complete and people with disabilities are the authority and experts about their own lives (Reynolds, 2018). To provide medical care that is just in its treatment of people with disabilities, medical education must also include a focus on the development of disability humility. With knowledge of the potential life-limiting harm of societal biases, the field of psychology shoulders the burden to improve our own competence and humility while also encouraging and raising expectations that other disciplines do the same.

One of the main challenges disabled individuals face in daily life is the ubiquity of ableism. *Ableism* refers to the use of stereotypes, prejudicial attitudes, and discriminatory behavior with the intent to oppress or inhibit the rights and well-being of people with disabilities (e.g., Bogart & Dunn, 2019a, 2019b; Nario-Redmond, 2019). Sometimes ableism is obvious and direct, as when a nondisabled person taunts or bullies a disabled person in the workplace for being "slow." Other times it can be subtle and may even appear to be positive. Such cases of ableism occur when, for example, a disabled child makes a basket during a half-time basketball event, which encourages the assembled crowd to roar approval because such children are not expected to be

capable of doing much with a basketball. Such examples are also known as “inspiration porn” (Young, 2014). However, whether positive or negative, ableism represents a form of control that a nondisabled majority wields over a disabled minority to marginalize their experiences, expectations, and contributions. Ableism, then, often objectifies disabled persons for the benefit of nondisabled persons (Dunn, 2019).

In health care settings, ableism is pernicious and destructive because it promotes nondisabled persons as representing an ideal state of being. In contrast, disabled persons risk being seen as not fully human because their physical, emotional, or cognitive abilities fail to conform with perceived norms or standards; indeed, they may be “invisible” to others (e.g., Chouinard, 1997). Though belief in the efficacy of eugenics has long been debunked, the desire for perfection or appearing and being “normal” persists. In medical settings, many professionals view disabilities through the medical model (Olkin & Pledger, 2003), that is, as a deviation that needs to be fixed or repaired rather than accepted as another legitimate way of being. *Disability* is characterized as pathology or an abnormality that needs to be addressed by medical intervention or normalization, which is a euphemism for ableist assimilation.

According to social psychologists, ableism is often conveyed through attitudes, that is, global evaluations representing favorable, unfavorable, or mixed reactions toward other people, ideas, or things (e.g., Bem, 1970; Eagly & Chaiken, 1993; Katz, 1991). An individual’s attitudes are comprised of cognitions (beliefs), affect (emotions), and behavior (whether past, current, or future). What sort of attitudes do nondisabled people have regarding disabled people? Generally speaking, nondisabled people hold negative attitudes toward people with disabilities (e.g., Dunn, 2015; Livneh, 1982; Vilchinsky, Findler, & Werner, 2010). There are a variety of reasons for these negative attitudes, but in the main they occur because of the stigma and stereotypes tied to disabilities, the fact that most nondisabled people have limited or no meaningful contact with disabled others, and that knowledge of disability via education or the mass media is sparse (Dunn, 2015; see also Chan, Livneh, Pruett, Wang, & Zheng, 2009).

More problematic still is evidence that health care providers (e.g., nurses, doctors, psychologists) who work with disabled persons harbor negative attitudes toward them. Such attitudes are not necessarily explicit; that is, consciously held or verbally expressed. Instead, they are implicit biases—automatic, unconscious reactions that members of a medical team can possess and subtly impart to their clients. One study found that the staff in a facility serving people who had multiple disabilities implicitly associated infantilizing attitudes and childlike characteristics with disability (Robey, Beckley, & Kirschner, 2006). Similar research finds that biased attitudes toward people with disabilities held by health care workers are unfortunately

routine (Benham, 1988; Brodwin & Orange, 2002; Reeve, 2000). Other studies demonstrate that care providers of disabled individuals are often more pessimistic and upset about their charges’ prognoses than the affected individuals themselves (Bodenhamer, Achterberg-Lawlis, Kevorkian, Belanus, & Cofer, 1983; Cushman & Dijkers, 1990; Dijkers & Cushman, 1990; Ernst, 1987). Another study found that nurses, nursing assistants or students, and physicians exaggerated the extent to which postsurgical or cancer patients were experiencing negative affective states (i.e., depression, anxiety, hostility) compared to the patients’ actual self-reports and assessments (Mason & Muhlenkamp, 1976; see also, Adcock, Goldberg, Patterson, & Brown, 2000).

Biased attitudes also create significant disparities in preventative care provided to people with disabilities (Hughes, 2006). Based on assumptions that individuals with disabilities are not sexually active, women with disabilities are less likely to receive appropriate preventative screening in gynecological care (Abells, Kirkham, & Ornstein, 2016). Diagnostic overshadowing can leave people with disabilities to struggle with undiagnosed and untreated conditions, including psychological diagnoses, that were inaccurately attributed to their more visible or primary disability (Iezzoni, 2011). Disability bias both reduces and restricts access to health care.

Social Determinants of Health

The social determinants of health have a direct influence on the health status of all individuals, including individuals with disabilities (Emerson et al., 2011). McGinnis, Williams-Russo, and Knickman (2002) estimated that medical care was responsible for only 10–15% of preventable mortality in the United States. Therefore, it became apparent that where and how people live must also be addressed. As half of all deaths in the United States involve behavioral causes, evidence has shown that health-related behaviors are strongly shaped by social factors, including income, education, and employment (McGinnis & Foege, 1993). People’s lifestyles and the conditions in which they live and work strongly influence their health and longevity. Recognition of how social and economic factors impact health not only impacts the way a society makes policy but challenges the values and principles of how systems are created and how progress is measured.

As this pandemic challenges both the strength and elasticity of every social system involved in health and wellness, it is important to examine the underpinnings of existing health disparities and the values and beliefs of existing systems that created inequities for individuals with disabilities. Healthy People 2020 (Centers for Disease Control and Prevention [CDC], 2018), the U.S. government’s prevention agenda for building a healthier nation, organized the social determinants of health around five key domains: (a) Eco-

conomic Stability, (b) Education, (c) Health and Health Care, (d) Neighborhood and Built Environment, and (e) Social and Community Context. Within each of these domains, individuals with disabilities, compared to individuals without disabilities, are more likely to experience challenges across the spectrum of social participation, from finding a job to being included in regular educational classrooms to receiving basic preventive health care and access to and using technology (Iezzoni, 2011).

As social determinants of health decrease, morbidity and mortality rates across the population increases. Frier, Barnett, Devine, and Barker (2018) demonstrated that, following the acquisition of disability, there is a decline in social determinants of health, which negatively impacts quality of life for individuals with a disability and those closest to them. Relationships between many social factors, such as socioeconomic status, and many health outcomes occur not only through direct relationships but also involve more complex pathways involving biopsychosocial processes (Anderson & Armstead, 1995). The effects of declining social determinants of health can reduce an individual's ability to participate in rehabilitation processes, which can impact their long-term adjustment and access to education, vocational education, work, leisure, and other activities. As individuals with acquired disabilities may not be aware of their rights or accommodation availability without rehabilitation, they may become restricted to their domestic environment in a state of isolation from the broader disability community. Despite the Supreme Court decision (*Olmstead v. L.C.*, 1999) decades ago, most homes and community spaces remain segregated and not fully accessible to individuals with disabilities, limiting options for sufficient social and emotional support for people with disabilities. Social inclusion of individuals with disabilities is an essential requirement for health promotion and quality of life (Cobigo & Stuart, 2010; Hall, 2009; Hughes, 2006; Schlock, 2004).

Changes to social determinants of health resulting from the acquisition of disability, particularly reduction of earned income and increased expenses related to disability onset, impacts all aspects of life for the individual and those closest to them (Frier et al., 2018). Following the acquisition of disability, reduced income had subsequent negative effects on housing, transportation, social interactions, and personal relationships. These inequities in social determinants of health ultimately result in the overrepresentation of minority and oppressed groups among those most impacted by a crisis requiring health care services.

Comprehensive, quality health care services permit the promotion and maintenance of health, the prevention and management of disease, and reduction of unnecessary disability and premature death. Equitable access to care across populations is achieved through three primary components: timeliness of care, geographic availability, and point of

system entry, usually through insurance coverage which also includes access to necessary prescription drugs (Gulliford & Morgan, 2013). Yet, for disabled people, barriers to health services, such as the high cost of care, inadequate or no insurance coverage, the lack of availability of services and the lack of culturally competent care, place individuals with disabilities at higher risk for health complications than individuals without disabilities. For example, in 2009, 47.2% of adults with disabilities aged 18 years and over experienced delays in receiving primary and periodic preventive care due to barriers to care (CDC, 2010) as compared to unmet need or delayed care for 18% of U.S. adults who experienced affordability barriers and 21% who experienced nonfinancial barriers (Kullgren, McLaughlin, Mitra, & Armstrong, 2012). In 2011, 76.8% of adults with disabilities aged 18 years and over experienced physical or program barriers that limited or prevented them from using available local health and wellness programs (CDC, 2012). It is well established that individuals with disabilities encounter barriers to participate in society because of a disproportionate number of accessibility concerns (Wong, Alschuler, Mroz, Hreha, & Molton, 2019). Beyond architectural barriers, transportation is a common and often insurmountable barrier to access care or community integration (Bezyak et al., 2019). Barriers based in stigma, bias, and negative perception of disability are also related to the exacerbation of a wide range of disparities, including high unemployment rates and societal disengagement (Emerson et al., 2011; de Vries McClintock et al., 2016).

Access to health care impacts one's overall physical, mental, and social health status and quality of life. Given the detrimental effects of ableism and the barriers faced by disabled persons in the social determinants of health, it is easy for society to judge (or misjudge) the quality of life of someone living with disability as poor.

Quality of Life

Quality of Life (QOL) is a broad and multifaceted construct without a consistently agreed upon definition, but is usually measured through personal ratings of satisfaction in various life domains reflecting societal norms for well-being and expectations for a good life (Post, 2014). Although specific measures focused on health-related QOL (HRQOL) and subjective well-being have been developed, the impact of health status or disability on overall QOL is likely indirect and may not be a primary factor in QOL. Despite the focus in measurement of QOL on the perspective of the individual involved (insider), judgments of QOL and HRQOL made in a medical setting are often made by an observer (outsider) further complicating measurement and increasing subjectivity.

The discrepancy between insider and outsider views of disability QOL has been termed the "disability paradox"

(Albrecht & Devlieger, 1999; Ubel et al., 2005). Nondisabled (outsider) expectations that disabled individuals have a lower QOL is referred to as the “standard view” of disability, but self-reports of disabled people usually reflect favorable views of their own lives (Albrecht & Devlieger, 1999; see also Amundson, 2010; Ubel et al., 2005). Although QOL assessments are meant to reflect the individual’s experience, the negative views of disability are prevalent and QOL judgments by outsiders often call into question the disabled individual’s self-reported personal experience. One reason for the discrepancy is that the outsider focuses on the disability with an overemphasis on the negatives that are prominent in their own views of disability and without being able to see the individual in a broader context, including positive assets and experiences. This is explained as a focusing illusion when judgments are made based on certain aspects of the situation over others (Schkade & Khaneman, 1998). In addition, these judgments do not recognize disability as an aspect of identity or value disability culture and diversity experiences.

Consistent with the work of Wright (1960, 1972, 1983), psychological science has been clear: A disabled person’s ability to achieve their goals depends less on the nature of disability and individual coping skills than on personal, familial, and systemic interactions with schools, employers, health care providers and communities (American Psychological Association, 2012). This understanding of the social and environmental components of disability functioning underscores the need for biopsychosocial models of disability, such as the World Health Organization International Classification of Functioning, Disability and Health model, which recognizes the interaction between the biological, psychological, social, and environmental factors (World Health Organization, 2008). However, the influence of our communities, physical environments, and societal views on disability are not recognized in assumptions or measurements of QOL.

An alarming theme found in most bioethics literature and legal decisions in bioethics cases is that impairment reduces the quality and value to others and to the self of the life lived (Asch, 2001). Such bioethics decisions operate under the assumption that disability is inherently negative and significantly and unambiguously reduces a person’s QOL (Ouellette, 2011). Such an assumption calls into question the possibility that an individual with a disability can have a highly satisfying and meaningful life. Unfortunately, this understanding of disability is deeply ingrained in our culture (Stramondo, 2016).

The negative attitudes and evaluation of disability is especially pervasive in health care. Disability is typically considered a burden or hardship that reduces a person’s QOL, especially when it comes to decisions about providing, withholding, or withdrawing treatment (Reynolds, 2018). Sunil Kothari, a physician, accuses his fellow clini-

cians of “systematic misperceptions” regarding disability. He documents a series of studies showing that health care professionals tend to drastically underestimate the QOL of people with disabilities (Kothari, 2004). This is likely exacerbated by the massive underrepresentation of disabled people as health care professionals. The majority opinion among the general population, bioethicists, and health care professionals is that disabled people have a significantly lower QOL merely by virtue of their impairment as opposed to social factors. Amundson (2005) critiqued bioethicists who take this approach, maintaining that their judgments about disability are shaped by social stigma and ignorance rather than objectivity. He asked, when the topic is the QOL of disabled people, “Why should the opinions of nondisabled people be epistemologically privileged over those of disabled people?” (p. 112). As already noted, nondisabled people estimate that the QOL of disabled people is significantly lower than disabled people themselves report (Amundson, 2005; Silvers, 2005). Ableist assumptions often remain unexamined and research suggests that the narrative that disabled people are inherently worse off than nondisabled people is false.

Silvers (2005) maintained that bioethicists must set aside their assumption that impairments are inherently bad and the idea that reducing incidence of disability is “unquestionably good” (p. 475). Amundson (2005) remarked, “When our ‘objective’ judgments happen to match our own social prejudices, that coincidence alone should make us wary of our own objectivity” (p. 113).

Disability discrimination concerns are therefore raised when treatment decisions are being recommended based solely on COVID-19 rationing guidelines considering only one’s medical diagnosis and need of assistance for daily activities. The very real risk is that a medical diagnosis, which indicates very little about the individual’s QOL, may have more of an impact on their care than individual circumstances. The risk is further increased when disability is used in health related QOL assessments as a proxy for health. The result is that the medical diagnosis is more of a threat and factor in life or death decisions than COVID-19 complications and current medical status. Research on the prediction of QOL with disability demonstrates that predictions of poor QOL are not supported (Reynolds, 2018) and is extremely alarming that rationing guidelines regarding lifesaving care and treatment options could be based on predictions for QOL when predictions of future states are known to be inaccurate.

Given the concerns with the use of QOL and biases impacting views of disability and QOL assessment, the role of QOL in rationing decisions is problematic. As noted, Persad (2019) questioned whether health systems can consider quality of life without unjustly discriminating against individuals with disabilities. As discussed earlier, a year of

life lived with disability or Disability-Adjusted Life-Year is quantified as less valuable than a nondisabled year of life.

What Is the Disability Community Doing?

Threats posed by the COVID-19 pandemic toward the disability community have resulted in a surge of grassroots advocacy and expressions of group solidarity and support. The disability community has rallied together in response to threats of medical rationing during the COVID-19 pandemic. A group of activists called The Disability Underground Network quickly formed a public Facebook group, called Amplifying Voices—National Disability COVID-19, which serves to coordinate a rapid response to support members of the disability community facing discrimination or risk of being denied medical care. The NoBody Is Disposable Coalition was formed by individuals perceiving that they are targeted by triage plans during the COVID-19 pandemic to demand policies that avoid triage and avoid discrimination in triage. The coalition argues that comorbidities, especially those that have a disproportionate impact on people based on race, gender, size/body mass index, or disability, should never form the basis of rationing. Disability Justice Culture Club cofounder Stacey Milbern described her work as, “what it takes to flatten the curve is collective action and collective commitment. Interdependence is going to be what saves us, and COVID-19 is the extreme example of this” (Green, 2020, para. 9). Tragically, Milbern died from medical complications during the current pandemic but her work on collective justice continues.

Disability activists sounded the alarm that many rationing protocols violate the oaths taken by medical providers, and several laws including the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, and the Affordable Care Act (Bagenstos, 2020). Published rationing guidelines in relation to the current pandemic have resulted in multiple federal complaints of disability discrimination. Several of these guidelines were rescinded following a memo from the Office of Civil Rights (2020) on March 28, that confirmed they did indeed violate federal disability antidiscrimination laws, as a result of disability advocacy on the legal front. Disability advocates are now leveraging this memo to ask for changes at local and state levels, which are often where rationing protocols are developed and applied.

Recommendations for Advocacy and Social Justice

Where advocacy and justice issues are concerned, Scheunemann and White (2011) differentiated between macroallocation and microallocation. *Macroallocation* is the division of investment at a public or societal level, for example how much funding is allocated to public health or health care. *Microallocation* involves individual decisions

at the patient and family level. Macroallocation clearly has an influence on microallocation in that inadequate funding for public health care systems will result in fewer resources available to individuals who require treatment. It makes little sense to overfocus on microallocation when adequate macroallocation has the potential to minimize the microallocation required.

As hospital systems and individual providers grapple with decisions on how to plan, they maintain responsibility for other ethical decision-making, including the duty to plan. Leaving allocation decisions to exhausted, overtaxed, front-line providers is yet another injustice. Although difficult, these decisions are best made proactively, transparently, and with diverse input from stakeholders. Underrepresentation of people with disabilities in all levels of health care systems decision-making, from ethics committees to hospital leadership who make decisions on how many supplies to stockpile, is cited as another reason that plans to ration during this pandemic have been negatively biased in regard to disability (Bagenstos, 2020; Lund & Ayers, 2020). Psychologists in particular are likely to be members of hospital ethics committees and in health care leadership roles and are in a unique position to advocate for meaningful inclusion and elimination of ableism.

Until recently, people with disabilities have not been included in public health surveys, data analyses, and health reports, making it difficult to know the state of their health status and where existing disparities lie. For example, disability and social determinants of health are not currently included in the Center for Medicare Services risk adjustments, which could vary across disability populations and potentially impact readmissions risks and contribute to higher readmission penalties for safety-net hospitals (Meddings et al., 2017). Most recently, failure to collect data on people with disabilities and COVID-19 has resulted from the CDC’s optional allowance to use the “short form” in reporting cases, which doesn’t include demographics related to disability (CDC, 2020). Better disability health data would better inform policy and program development regarding critical issues of health disparities and health equity. Psychologist researchers are at the forefront of much data collection and should work to ensure disability is present and appropriately measured, emphasizing the importance of the lives of disabled people.

Several excellent recommendations have been made to identify a framework for fairly rationing ventilators and crucial care during the COVID-19 pandemic, (Emanuel et al., 2020; White & Lo, 2020). To lessen implicit bias by front-line health care providers, decisions about rationing of supplies or care should be made by committees composed of interdisciplinary perspectives, which include representation from the disability advocacy community. Categorical exclusions for care are not necessary because least restrictive, more individualized assessments of health status and

likelihood to respond to care are advised (White & Lo, 2020). When necessary, adjustment to standardized assessments should be considered based on the fact that results may be invalid due to the presence of preexisting disability. It is up to psychologists to educate our medical and community colleagues on the impact of ableism and make the case for culturally appropriate assessments that do not penalize people based on disability status.

In differentiating between equality (everyone is treated equally), equity (individual needs are met), and justice (the removal of systemic barriers and illumination of the cause of the initial inequity), we need to ensure our “objective” measures and guidelines are truly reflective of shared values and not simply mechanisms of biases. As medical, ethical, social justice, and disability communities coalesce to respond to this pandemic, there is opportunity to learn from mistakes and to prepare adequately for future threats. Adequate and involved representation from the disability community is crucial for decision making for pandemic preparedness. At a broader level, the inequities in our health care system must be ameliorated. Medical providers should receive education about disability not simply as a medical status but also as a social and political experience and learn to become aware of and question their conscious as well as unconscious biases and assumptions about disabled quality of life. Psychologists are positioned to facilitate this education by centering the voices of disabled people, identifying ableist practices, and advocating for disability justice. In our own field, and beyond the specialization of rehabilitation psychology, we must fully embrace disability as diversity, and work to recruit and retain disabled psychology trainees and disabled psychologists.

In particular, psychologists know that those who are affected by multiple marginalized identities—for example, disabled people who are elderly, poor, persons of color, and members of lesbian, gay, bisexual, transgender, and queer communities are the most vulnerable to facing discrimination in health care and the most disadvantaged in terms of social determinants of health. Psychologists can make a difference and help to save the lives of those at the intersections of multiple diverse identities. By being proactive, especially in policy and practice, we can reduce the need for rationing and strive for justice for all in our health care system.

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