HOW TO CITE:
Mercer E. Gary and Joel Michael Reynolds, “Why Only Disability Justice Can Prepare Us for the Next Public Health Emergency,” in Disability Justice in Public Health Emergencies, eds. Joel Michael Reynolds and Mercer E. Gary, Routledge: New York; London, 2024.
doi: 10.4324/9781003502623-1

WHY ONLY DISABILITY JUSTICE CAN PREPARE US FOR THE NEXT PUBLIC HEALTH EMERGENCY

Mercer E. Gary and Joel Michael Reynolds

On January 30, 2020, the World Health Organization declared a *Public Health Emergency of International Concern* (PHEIC) over what would quickly become known as SARS-CoV-2 or COVID-19. This emergency status was officially ended in the United States in May 2023 amidst much dissent and debate. Although emergency conditions resulting from COVID-19 will likely wax and wane over the coming years, there is good reason to think that the incidence of severe global pandemics will increase over the next century, as will declarations of emergency (Curseu et al. 2009; The Lancet Planetary Health 2021). The declaration of an emergency calls for urgent action, but it just as urgently demands careful reflection. Official “emergency” status licenses unparalleled executive intervention, completely reorganizing the lives of those who live under its decree. Such official recognition, however, is heavily dependent on the social context in and from which the emergency arises. Highlighting *which* circumstances rise to the level of an official emergency clarifies our reigning assumptions about what threshold of active harm—and in relation to which groups of people—demands immediate intervention.

This volume articulates the contributions of critical disability scholarship for thinking about emergencies, especially in relation to research in bioethics and public health ethics. The essays collected here emerged from a symposium held virtually at Georgetown University in November 2021, driven by a sense of the urgent need for more critical disability perspectives in pandemic scholarship and response. Our central claim is not simply that existing public health emergency responses have failed and still fail to address the multifaceted needs of disabled people, but rather that the ethical and political insights of disability theory and advocacy provide key resources for equitable disaster planning for all. Anticipating arguments across the 11 chapters, we begin by reviewing the standards governing the declaration of a public health emergency as well as the practical and political implications of such a declaration. By examining these standards, we place in sharper relief the emergency conditions that lack official recognition. As the United States has now officially announced an “end” to this years-long public health emergency, we will also consider what the loss of this official status will mean for the provision of pandemic response resources.

DOI: 10.4324/9781003502623-1

The declaration of a public health emergency is an administrative rallying cry, one pitched to correspond to the severity of the present threat. Such threats are diverse, including infectious disease outbreaks, bioterrorist attacks, natural disasters, humanitarian crises, or other forms of disorder that pose an imminent threat to population health (see HHS, Sect. 319; WHO Emergencies Programme). Public health emergencies fall under the broader umbrella of disasters, which philosopher Naomi Zack has defined as "an event (or series of events) that harms or kills a significant number of people or otherwise severely impairs their daily lives in civil society" (Zack 2009, 6).[1] The World Health Organization's designation of a PHEIC emerged only in 2005, in the wake of the 2003 SARS-CoV epidemic. Since then, the WHO has declared six PHEICs, all of which were the result of disease outbreaks. Though not the only factors at play, virulence and spread carry considerable weight in such a declaration: fellow deadly coronavirus SARS-CoV saw 8,096 infections and 774 deaths at a rate of 9.6% while the 2012 MERS-CoV epidemic resulted in 2,553 infections and 876 deaths at a rate of 34.3% (Zhu et al. 2020). At the time of the January 2020 declaration, there were 7,818 confirmed cases and 2,977 deaths associated with COVID-19 across 19 countries and five WHO regions (WHO Novel Coronavirus Report). Unlike SARS-CoV and MERS-CoV, COVID-19's high viral shedding in the early stages of infection and proportion of asymptomatic or mildly symptomatic cases capable of transmitting the virus have made community spread particularly difficult to control (Wu et al. 2021).[2] These factors number among what Zack calls the "objective features" of a disaster.

But disease factors alone do not an emergency make. Rather, it is the "exigency, calamitous harm, [and] unavoidability of harm through ordinary processes" in combination with disease factors that legitimate the declaration of a public health emergency (Haffajee et al. 2014). The transformation of a viral threat into a full-fledged emergency for the public is therefore dependent on the social and political conditions into which the virus enters: factors like patterns and modes of travel, frequency of large public gatherings, housing availability, and reliability of access to food, water, and electricity number among the circumstantial determinants of an emergency. Absent conditions for substantial community transmission, even the most infectious disease would fail to meet the threshold of calamitous harm. Likewise, where ordinary processes are robust enough to respond effectively to an imposing threat, harms become avoidable and escalation interrupted. It stands to reason, then, that an unequal distribution of resources before a crisis begins will place some institutions in better positions than others to maintain normal functioning.[3] In other words, the onset of an emergency will be felt most acutely when and where the chips are already down.

On the other hand, we seem to be *less* likely to call an event a disaster or emergency if it occurs within patently unequal background conditions. Zack explains this apparent paradox by way of a distinction between disaster and risk: following widely held intuitions, Zack takes disasters to mark a significant departure from one's normal life. Where significant threats of harm have extended for long periods of time and have become sedimented within a particular social milieu, what in an acute crisis would be called a disaster is more appropriately described as a *risk* that can nonetheless be incorporated into normal daily life (Zack 2009, 4–6). Here Zack juxtaposes the threat posed by automobile accidents—which resulted in 6 million deaths globally between 2002 and 2007—and avian flu—which led to 192 deaths during the same period. The risk of traffic fatalities, though considerably higher than the risk of death by avian flu, does not pose the same kind of disruption to society precisely because they are so much more common (Zack 5). The familiarity of institutional procedures and social norms for handling automobile accidents, combined with societal dependence on cars for transportation and societal normalization of the deaths such transportation hastens, highlight the extent to which the risks of driving are treated neither as a disaster nor an emergency but as normal and ordinary within contemporary life.

The conversion of disaster into risk is not necessarily negative, given the unavoidability of danger and the practical utility of developing habituated responses to it. But it's also clear that this conversion process operates unevenly, enabling dominant groups to downgrade the urgency of events lived as emergencies by marginalized populations. When borne primarily by the underclasses, circumstances that meet the objective criteria of a disaster may well be compatible with the maintenance of normal life for the privileged and thereby understood as failing disaster's subjective criteria. The developments of the past several years, as well as the arguments in this volume, underscore the contested nature of disasters and the frequency with which emergency conditions escape official recognition (see Valentine, Chapter 7 and Miller, Chapter 9).

This uneven recognition reflects public priorities for resource distribution, as official declarations of emergency issue urgent moral demands that open administrative doors enabling state, federal, and international intervention. The recognition that ordinary processes are no longer sufficient for the management of the crisis means that extraordinary funds can be accessed, regular policies bypassed, and more extensive executive actions taken. These opportunities turn the official label of a "public health emergency" into a powerful tool. Consider, for instance, former Massachusetts Governor Deval Patrick's 2014 declaration of the opioid crisis as a state-level public health emergency. The first such declaration concerning opioid addiction, it ushered in some of the broadest policies seen on the issue to date, including prescription monitoring and the banning of a particular painkiller (Wetter et al. 2018). While controversial at the time, Patrick's order prefigured similar actions to publicize and address widespread opioid addiction in other states and, in 2017, at the federal level.[4] The example of the opioid crisis underscores the real potential of an emergency declaration to incite administrative action and galvanize popular support. Under Section 319 of the Public Health Services Act, the Secretary of the U.S. Department of Health and Human Services has renewed COVID-19's status as a national public health emergency every 90 days from January 2020 until May of 2023. At that point, waning support for state intervention into lingering pandemic conditions in the winter and spring of 2023 led to the U.S. Government's decision to end the official public health emergency.

When official emergency status is reached, the actions taken in its name will similarly reflect the priorities of those with administrative power. Certain commonly practiced emergency measures will disproportionately harm disabled people absent adequate proactive intervention. As has been emphasized by disabled activists in the wake of recent natural disasters like hurricanes and wildfires, responses as ostensibly simple as evacuation orders overlook the underlying resources needed to quickly leave one's place of residence, resources that many disabled people, and especially many poor disabled people, lack (Alexander 2015; Weibgen 2014; Nishida 2022). This volume therefore seeks to expose similar complications in the context of epidemic and pandemic disease: crisis standards of care, resource allocation policies, and triage practices number among the many aspects of pandemic planning that, absent specific consideration of the varied needs of disabled communities, will incur deadly consequences for disabled people. Disability advocates across activist, academic, medical, and public policy circles moved quickly in the early phases of the pandemic to articulate these dangers, leading to some significant changes in initial policies.[5] The first triage guidelines to come out of the Alabama Department of Public Health in March 2020, for instance, explicitly excluded certain people with intellectual and developmental disabilities from receiving ventilators should demand for those machines outstrip supply (ALDOPH). Groups including the Alabama Disabilities Advocacy Program and The Arc of the United States filed complaints against these initial guidelines, which were then revised in early April 2020 (see also Ne'eman et al. 2021). *Disability Justice in Public Health Emergencies* builds on the existing efforts of disabled people and disability advocates to articulate emergency planning priorities and response measures that (i) take into account the large body of qualitative and quantitative research on disabled people's health, needs, and experiences, (ii) recognize disabled life as valuable, and (iii) both acknowledge disabled communities as bearers of significant insights and also act upon said insights.

The resources identified in this volume are applicable well beyond officially recognized public health emergencies, whose very determination we and our contributors call into question. As several chapters will note, the conditions of resource scarcity, financial and occupational instability, social precarity, and increased mortality that partially characterize the calamitous harm of public health emergencies have preceded the pandemic for many disabled people (see Savin, Chapter 6 and Valentine, Chapter 7). The levels of poverty experienced by disabled people—more than twice as common than among non-disabled peers, both in the United States and globally—give some indication of this proximity to the crisis explored in the chapters to come (UN Disability and Development; National Council on Disability).[6] Though lacking the recognition, additional funds, and swift administrative actions attending official public health emergencies, many disabled communities have been living under emergency conditions for some time; indeed, the widespread precarity of disabled people is exacerbated by this lack of public support. Emergency conditions will persist for disabled people beyond the official "end" of the pandemic emergency, even as remaining public COVID-19 related funds dry up alongside political and social will for protecting the vulnerable. For a national pandemic response that has already been criticized as leaving responsibilities for risk management to individuals, these diminishing public funds will usher in new levels of privatization.

That the ongoing pandemic puts disabled people, already more likely to live on the edge of emergency due to ableist institutional and social practices, at additional risk for harm demands special consideration. When considered within pandemic planning, an emphasis on the vulnerabilities of disabled people tends to overshadow the active and constructive role that disabled communities play in constructing a more *just future for all*. The next section therefore turns to the framework of disability justice as not only a moral and political imperative, but as a set of strategies and priorities for emergency management.

Disability Justice

Historically, bioethics as a field has had a contentious relationship with critical disability scholarship; we acknowledge this and intend the volume as a critical intervention promoting the work of disability justice within a field that, still today, is too often hostile to it. As the work of disability bioethicists as well as disability theorists working outside of bioethics has frequently underscored, bioethics is held back by its continued privileging of—if not wholesale reliance on—biomedical understandings of disability (Scully 2008, Tremain 2008, Reynolds and Wieseler 2022). Despite decades of critique, the assumption that disability is nothing more than a problem with an individual body or mind requiring the expertise and intervention of medical providers remains widespread in ways that the essays in this volume detail and criticize. Even where disability issues are nominally included within mainstream bioethics and public health ethics, a focus on systemic ableism, a bold vision of justice, and the voices of disabled communities and activists are too often lacking. This collection therefore contributes to ongoing efforts to strengthen and complicate understandings of disability within healthcare ethics, as well as the practical project of addressing the harms experienced by disabled people during public health crises.

Although the essays in this volume will offer their own framings of disability justice, we here review several different lineages of the concept along with their central commitments. Motivated in part by the persistent failures of the disability rights movement to address the concerns of disabled people of color as well as queer disabled people in the United States, the art-activist collective Sins Invalid developed *disability justice* as an alternative political and theoretical framework (Berne et al. 2018). Without dismissing their legislative gains, which include the protection of disabled people from certain forms of discrimination through Section 504 of the 1973 Rehabilitation Act, the 1975 Individuals with Disabilities Education Act, and the 1990 Americans with Disabilities Act, the disability justice movement highlights the inadequacies of a legislative and specifically anti-discrimination approach to bringing about justice for disabled people.[7] As a political movement grounded in expanding the liberal policies of the U.S. government, the disability rights movement seeks inclusion into the existing body politic without fundamentally altering the terms around which it coheres (see Lajoie 2022). Such a framework seeks to extend political rights—to healthcare, education, employment, and access to public space—but fails to address barriers to equal citizenship that persist even in the face of nominal inclusion or, even more minimally, non-exclusion.

The shortcomings of a disability rights framework become apparent when considering the needs of disabled people who lie outside its purview. For instance, within the education sector, funding for special education programs, as with funding for public education more generally, varies widely depending on the property values of the district to which one is tied (see Conlin & Jalilevand 2015). These economic disparities are demonstrably racialized, resulting in substantial under-resourcing of educational programs for Black and Latinx disabled youth (Marisco 2022). Moreover, the obstacles to access most easily addressed by the ADA represent only a small fraction of the barriers confronted by people with disabilities. In some cases, ramps can be built and sign language interpretation provided, to take just two examples, with minimal alteration of existing public services. The "reasonable accommodation" clause of the ADA, however, denies the necessity of more thoroughgoing transformations that would be required for people with intellectual and developmental disabilities to meaningfully participate in public life (Lajoie 2022; Carlson 2009). Indeed, advocating for inclusion within institutions that have proven so resistant to the concerns of disabled constituents is itself at times a source of objection.

Disability justice theorizing from performance groups like Sins Invalid to, more recently, activist-scholars such as Alice Wong (2020, 2022) and Leah Lakshmi Piepzna-Samarasinha (2018, 2022) has significantly pushed forward conversations concerning how to make the world more just and accessible for all, whether under emergency conditions or not. The guiding principles of this strand of disability justice theorizing reflect a central commitment to solidarity across marginalized identities, disabilities, and movements lacking in the mainstream disability rights movement (Berne et al. 2018). Dating back to the Combahee River Collective, the adoption of an intersectional analysis understands forms of oppression as altering, rather than merely adding to, one another. An intersectional analysis of racism and ableism thus demands a comprehensive, contextual examination of the ways that racism transforms the expression of ableism, as is evident, for example, when racist assumptions about proclivities for violence and disruptiveness impact the identification of behavioral disorders among Black children (Farkas & Morgan 2018). Even further, the intersectionality of disability justice requires seeing disability as extending beyond the cases prioritized by disability rights. An understanding of racialized disablement, as Desiree Valentine's chapter in this volume argues, is key to addressing the production of disability through systemic racism (see Bell 2012; Reynolds 2022; Schalk 2022). Take, for instance, the predominantly Black region of Louisiana where 25% of the country's petrochemicals are produced, nicknamed "Cancer Alley" after the scores of cases that arose among residents who had been exposed to hazardous substances. Recourse through the ADA has yet to be successful in halting the construction of future plants, indicating that a traditional disability rights framework is insufficient to address issues of racialized disablement (Wilson 2022; see also Jampel 2018). As Akemi Nishida notes, an intersectional lens is essential to the study of public health emergencies, since "the COVID pandemic is like a storm that intensifies and speeds up historically developed logics of oppression" (2022, 182). See April Dworetz's arguments in Chapter 4 of this volume for a related analysis of how race and racism, along with other social determinants of health, risk being reproduced by triage protocols.

The disability justice movement's commitment to solidarity is further evidenced by its organizing across movements and disabilities. In addition to the centering of multiply marginalized queer, trans, Black, and Indigenous disabled people, disability justice finds the needs of all disabled people implicated in struggles for environmental sustainability, decarceration, demilitarization, and decolonization (see Ben-Moshe 2020, Erevelles 2016, Meekosha 2011, Puar 2017). The centrality of neoliberal policies of austerity to both the creation and denigration of disability demands that disability justice attend to the economic underpinnings of ableism (Lewis 2023). As demonstrated by Ally Peabody Smith's chapter, disability justice further refuses the marginalization of certain disabilities, especially those deemed most "severe" and "profound," and instead recognizes the incalculable value of all disabled people that frustrates mainstream cost-benefit analyses. Guided by an appreciation of the interdependence between disabled and non-disabled people alike, disability justice strives for collective access and collective liberation for all.

Activist-scholar understandings of disability justice are essential to this volume given both their ambitious visions of social transformation and their concretization in disability-centered emergency management practices on the ground. Leah Lakshmi Piepzna-Samarasinha (2022) and Akemi Nishida (2022) have detailed the efforts of disability justice organizing networks to better protect disabled communities during disasters including, but also preceding, COVID-19. Central to both Piepzna-Samarasinha's and Nishida's arguments are the histories of disabled community care networks made necessary by persistent and systemic failures of public institutions and private organizations to include (let alone prioritize) the needs of disabled people. On top of the costly care and inaccessible clinical environments, deeply rooted assumptions about disability held by providers and integrated into systems protocol make possible institutionalization, loss of parental rights, worsening of medical conditions, and even death real threats (Ben-Moshe 2020). In response to these dangers, and against the isolation experienced by many disabled people as a result of ableism, disabled communities have come together to care for one another's medical, material, and socio-emotional needs. Supporting this longstanding practice and line of scholarship, Sarah Clark Miller's chapter in this volume draws on Piepzna-Samarasinha's concept of *crip doulaship* as a method for supporting COVID long-haulers. But the insights gained from experiences of disability and ableism can also inform emergency management for all: in the midst of disaster and with limited resources, disabled communities "taught all of North America how to make air purifiers out of box fans and a twenty-dollar furnace filter from Lowe's and how to use masks for smoke and then viruses and what the different kinds were" (Piepzna-Samarasinha 2022, 19). Such practical insights demonstrate the kind of creative and accessible interventions borne of disabled experience and activism that are ultimately beneficial to society at large.

Further strands of theorizing justice in ways that center disabled people and communities can be found in feminist theory, philosophy of disability, and critical disability studies. The pioneering scholarship of other authors taken up in this volume, including Eva Feder Kittay, Nirmala Erevelles, Marta Russell, and Jackie Leach Scully, has consistently challenged liberal models of justice. They have been vocal in questioning whether the kinds of social transformation needed to dismantle systemic ableism and promote the multi-faceted flourishing of disabled people can occur within existing institutions. This volume contends that the works of Kittay, Erevelles, Russell, and Scully, among others, contain key resources for thinking critically about what justice demands. These thinkers are not members of the contemporary disability justice movement that grew out of Bay Area organizing, their theories should not be assumed to agree on all points. Indeed, the authors just cited disagree with one another on important points of political strategy and theoretical emphasis. Nonetheless, we consider these disagreements productive for furthering the conversations on what disability justice looks like and how we can get closer to it.

Disability Justice in Public Health Emergencies seeks to put the insights of all of these thinkers in conversation. We understand each of the chapters in this volume to further the project of disability justice in its wider historical emergence, including through sober examination of the tensions between different ways of conceiving it and pursuing it. This volume deploys the concept of 'disability justice' in its most capacious theoretical sense and, at the same time, in the specific practical sense of building a world that is more just for disabled people and, thereby, more just for all people.

The volume's predominant here-and-now actionable focus is on intervening in the emergency procedures of institutional medicine and public health, which, admittedly, departs significantly from the community basis of much DJ organizing. As Guidry-Grimes and Savin note in Chapter 1, the kinds of interventions necessary in the immediate response to a public health emergency often cannot themselves advance the kind of transformative institutional change demanded by projects of disability justice. The essays in this volume go further than established disability rights critiques to advance the issues centered by disability justice. For example, Lajoie's arguments in Chapter 13 show clearly that medical and public health institutions have proven themselves to be untrustworthy to many disabled and otherwise marginalized people. This volume insists that healthcare institutions can *and must* do better. Working through the tensions between disability justice theorizing, bioethics, and institutional healthcare is a necessary component of such a project.

Overview of Contributions

The essays in this volume enumerate, analyze, and offer tools for addressing collective emergencies through the framework of disability justice. Language use, definitions, and political frameworks surrounding disability are all hotly contested. Given the lack of consensus, both locally and globally, over identity-first terms ("I'm a disabled person") and person-first terms ("I'm a person with a disability"), we have not directed contributors to adhere to a particular formulation, and we ourselves purposely alternate between them. Similarly, we have left the authors to articulate definitions of disability and disability justice that best aligns with their work, for we recognize that the demands of context may make a particular definition, model, or framing more suitable than another. We all, however, share the position that neither biomedicine, nor public health hold a monopoly on the definition of disability; individual, social, political, and historical context contributes as much, if not more, to any plausible definition of disability.

Part I, "*Crisis in the Clinic*," tackles triage processes and crisis standards of care, which emerged as key points of needed intervention for disabled people in the early days of the pandemic. Despite their shared focus on these clinical and administrative practices, the authors in this section each treat different areas of emphasis, collectively composing a fuller and more nuanced approach to accounting for disability in crisis procedures. Katie Savin and Laura Guidry-Grimes present disability justice and disability rights as distinct frameworks with varying recommendations for addressing ableism as reflected in existing triage protocols for public health emergencies. Although a rights-based approach has considerable relevance for revising formal protocols, these actions will not themselves achieve the goal of disability justice. Disability justice—as a radical and intersectional approach demanding a transformation of the background conditions of injustice shaping institutional policies—requires more thoroughgoing change.

Joseph Stramondo critiques Crisis Standards of Care (CSC) protocols, arguing against using quality of life judgments and intensity/duration of treatment metrics and pushing instead for a world in which bioethicists prioritize changing the upstream conditions that shape the downstream effects of systemic injustices. In a similar spirit, April Dworetz argues that a lack of attention to social determinants of health has led to the creation of CSC that perpetuate discrimination on the basis of race and disability specifically. Revised policies influenced by the work of advocates during the early stages of the COVID-19 pandemic have begun to diminish this bias by rejecting categorical exclusions of certain kinds of patients from eligibility, omitting or modifying SOFA scores, and avoiding third-party judgments of an individual's quality of life, among other measures. Continued progress on the revision of CSC, Dworetz contends, will require ongoing input from disability advocates and researchers, substantive involvement of multiply marginalized disabled communities in decision-making, and critical engagement with the most recent population- and individual-level research on disability.

Part II, "*Multiply Marginalized*" highlights specific aspects of systemic ableism and disabled experience that have resulted in increased harm under crisis conditions. Drawing on in-depth interviews with disabled adults in California's San Francisco Bay Area, Katie Savin develops a model of disability as constrained by the workings of the Social Security Administration. Restrictions on the savings and workforce participation of individuals receiving Social Security Disability Income actively place and keep many disabled people in poverty, which further influences the development of individuals' sense of self and strategies for survival. Savin shows the multiple ways in which the COVID-19 pandemic—and even administrative responses intended to relieve some of its negative effects on the most vulnerable members of society—functioned to worsen the living conditions of many disabled people. At the same time, certain pandemic relief programs did result in important gains: Savin argues that efforts like CalFresh's increased benefit generosity can serve as models for extending welfare programs beyond the duration of the current pandemic.

Further interrogating the emergency conditions that preceded the pandemic for multiply marginalized communities, Desirée Valentine takes up the chronic injustices that undergird the racialized production of disability, or, as she puts it, *racialized disablement*. Valentine shows that a declaration of emergency depends on an assumed backdrop of normality where resources are not scarce, institutions function adequately to meet the needs of their constituents, and vulnerability to harm and suffering is not expected. These conditions are simply not met for many people. A simple distinction between normal life and emergency conditions, therefore, elides the ongoing racialized disablement enforced through state policy. Valentine argues that attending to the conjuncture of disability and racism is necessary to the response of emergency conditions both during and beyond the COVID pandemic. Savin and Valentine, respectively, attend to the economic and racialized discrimination that form part and parcel of the ableism experienced by multiply marginalized disabled people. Attending to these co-constitutive axes of oppression is central to the focus of disability justice and essential for effective interventions in crisis management, as well as crisis prevention.

Both the experience and recognition of disability, Nicholas Evans argues, are complicated by the condition of long COVID. On the one hand, given the life-altering changes to physical and cognitive functioning introduced by the syndrome and the forms of exclusion from public life that have followed, there are substantial reasons supporting an understanding of long COVID as a disability. On the other, individual reluctance to embrace a disabled identity, combined with the often invisible and sometimes transient nature of the condition, distance long COVID from some popular understandings of disability. Although long COVID research has received significant investments in a short period of time, scientific, governmental, and popular attention to the condition is likely to remain dependent on the fluctuating recognition of COVID itself as an ongoing threat. Evans argues that reconciling these tensions will require, above all, recognizing the harms of viral pandemics as extending beyond the point of initial infection.

Among the potential harms incurred from rendering disabled people as an afterthought in emergency planning is the shattering of communication strategies necessary for people with profound intellectual disabilities (PID). Though often assumed to be incapable of communication and marginalized even within disability advocacy communities, Ally Peabody Smith shows that non-speaking people may well be able to contribute to the direction of their own care. Smith argues that, because the participation of people with PID in the care process depends on the presence of speaking others with whom they have developed successful, non-verbal modes of communication, reasons of justice demand that emergency protocols make room for the inclusion of these care partners in clinical settings. Disorders of consciousness and intellectual disabilities continue to be marginalized in both bioethics and disability studies, in part because they require greater nuance from those utilizing a social model of disability as their basic framework (see Carlson 2016). Both Chapters 4 and 8 deal with categories of disability and specific diagnoses in ways that may attract criticism over the medicalization of disability. But taking a hybrid approach to understanding disability requires that we acknowledge the relevance of biomedicine and the possible utility of clinical categories, even as we refuse to let these dominate the conversation. Both chapters provide essential guidance for providers in cases where negative assumptions about the value of disabled lives are strongest.

Perry Zurn's chapter turns to the recent spread of the "pandemic" as a metaphor for widespread and deadly social ills including anti-Black racism, colonialism, and economic inequality. Although the rhetoric has clear appeal and investigation of the confluence of the aforementioned crises is urgently needed, Zurn argues that the over-extended language of "pandemics" hurts more than it helps. Among other effects, such language naturalizes social inequities while setting the collective goal as one of cure, not care. Zurn cautions against both moves insofar as they contribute to damaging discourses of pathologization that critical disability scholarship seeks to remediate. Instead, Zurn finds resources in disability justice's commitments to coalition, care, and transformative justice as touchstones for framing emergency response.

Although the entire volume is forward-looking in its articulation of sorely needed actions to improve emergency response, Part III, "*Before the Next Pandemic*," is especially future-oriented. Dealing again with long COVID, Sarah Clark Miller's chapter highlights the need for ongoing societal transformation in the face of this widespread and debilitating post-viral syndrome. As a mass disabling event, Miller argues, the COVID-19 pandemic refuses the neat before-and-after structure of an event and makes a return to "normal" pre-pandemic life both practically impossible and undesirable given the denial of ongoing harm it would require. Picking up where Evans' chapter left off, Miller shows the relevance of Sins Invalid's principles of disability justice for those grappling with long COVID disablement. In particular, she underscores the need for long haulers to learn from and ally with disabled communities rich in the wisdom of confronting systemic ableism.

Emergency response strategies informed by disability justice will need to extend beyond healthcare institutions. In this vein, Kevin Timpe explores what disability justice demands of the American public education system, both during and beyond times of crisis. Because of its necessary link to child development, Timpe boldly—and rightly, we think—argues that education should be treated as a central domain for bioethical analysis and that bioethicists should be particularly concerned about the disproportionate damage done to disabled students during the COVID-19 pandemic. Though public education in general was confronted with the massive task of adapting to remote learning, Timpe's research shows that special education programs suffered particularly: where it emerged at all, the provision of virtual special education lagged far behind the establishment of online forms of mainstream education. Timpe argues that clarified federal guidelines and more district-level accountability are key for minimizing the negative effects of future crises on the educational attainment of disabled students.

Finally, Corinne Lajoie considers how a shift toward *institutional trustworthiness* and away from "public trust" better captures the proper locus of responsibility for emergency management. Lajoie argues that healthcare institutions, in particular, have proven themselves to be untrustworthy through entrenched and ongoing histories of violence that have disproportionately damaged disabled people, and especially multiply marginalized disabled people. To begin to remedy the justified losses of trust that have resulted from these harms, Lajoie argues for increased transparency and greater involvement of disabled people in decision-making processes.

Together, the essays in this collection present disability justice as a multifaceted approach that can both diagnose the failures of existing emergency response measures and generate constructive proposals for avoiding such failures in the future. The essays, in other words, articulate how a disability justice approach to emergency preparedness and management provides substantive resources that promise to benefit all. The commitment to intersectionality built into disability justice makes clear that forms of marginalization are multiple and intersecting, resulting in significant variations in what people experience and what kinds of changes are necessary. Disability justice cannot, for instance, focus only on people whose disabilities have been diagnosed and officially recognized; rather, it must consider the logistical and economic barriers to receiving a diagnosis that leave many people without official recognition. Furthermore, attention to marginalized groups is necessary for all emergency planning and management, not merely as a guard against the exacerbation of already existing conditions of scarcity and domination. Those with experience living under emergency conditions already possess vital and transferrable knowledge and skills for navigating them. The recommendations issued here are initial steps toward the substantive involvement of disabled communities and disability advocates in public health emergency planning. If our aim is to achieve a more just emergency response in the future, then we need to heed the insights of disability justice and of disabled people here and now.

Notes

1 Zack herself has written about COVID-19 as a multifaceted series of disasters (2021). See also O'Mathúna, Dranseika, and Gordijn (2018).

2 As reflected in the statistics here, viruses know no national boundaries. Moreover, the dramatically uneven distribution of global wealth and power has meant that emergency conditions and efforts to respond to them have differed widely. This volume takes an admittedly narrow approach by limiting its focus to the U.S. context. Disability justice, however, demands a transnational scope (see Erevelles 2016; Meekosha 2011). We hope to collaborate with colleagues abroad to address the complexities of emergency conditions at a global scale in a sequel to this book.

3 The baseline of inequality that shapes the distribution of emergency burdens from the start motivates ethical approaches like prioritarianism, which seek to address the needs of those worst off first (see Parfit 1995).

4 Compare this response, as many have, with the decidedly carceral and militaristic approach of the War on Drugs in the 1980s and 90s. Notably, the face of the opioid crisis tends to be white while the target of the War on Drugs was almost invariably Black. See also Shachar et al. 2020.

5 See Andrews 2021; Ne'eman et al. 20201; Solomon, Wynia, & Gostin 2020; Guidry-Grimes et al. 2020; and Mello, Persad, and White 2020.

6 In the United States, 36% of disabled people of color live in poverty, compared with 26% of all disabled people (Gupta 2021; National Disability Institute 2020).

7 It is worth mentioning that some disability scholars, including Marta Russell (2002), argue that the passage of the ADA set the disability movement back by accepting its insufficiently transformative focus on anti-discrimination and civil rights law.

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DISABILITY JUSTICE IN PUBLIC HEALTH EMERGENCIES

Disability Justice in Public Health Emergencies is the first book to highlight contributions from critical disability scholarship to the fields of public health ethics and disaster ethics. It takes up such contributions with the aim of charting a path forward for clinicians, bioethicists, public health experts, and anyone involved in emergency planning to better care for disabled people—and thereby for all people—in the future. Across 11 chapters, the contributors detail how existing public health emergency responses have failed and still fail to address the multi-faceted needs of disabled people. They analyze complications in the context of epidemic and pandemic disease and emphasize that vulnerabilities imposed upon disabled people track and foster patterns of racial and class domination.

The central claim of the volume is that the ethical and political insights of disability theory and activism provide key resources for equitable disaster planning for all. The volume builds upon the existing efforts of disability communities to articulate emergency planning priorities and response measures that take into account the large body of qualitative and quantitative research on disabled people's health, needs, and experiences. It is only by listening to disabled people's voices that we will all fare better in future public health emergencies.

The book will be of interest to scholars and graduate students working in bioethics, disability studies, public health policy, medical sociology, and the medical humanities.

Joel Michael Reynolds is a Senior Research Scholar at the Kennedy Institute of Ethics, an Associate Professor of Philosophy and Disability Studies at Georgetown University, Faculty in the Pellegrino Center for Clinical Bioethics and the Department of Family Medicine at the Georgetown University School of Medicine and Medical Center, and a Senior Advisor to and Fellow of The Hastings Center. They are author or coauthor of six books and over sixty publications spanning philosophy, public health, and biomedical ethics.

Mercer E. Gary is an Assistant Professor of Philosophy at Drexel University and a Presidential Scholar at The Hastings Center. Her first book, *The Limits of Care: Making Feminist Sense of Technology Relations*, is under contract with Oxford University Press.

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