

International Journal on Responsibility

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A publication of the *Mahatma Gandhi Center for Global Nonviolence* at James Madison University

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The ***International Journal on Responsibility (IJR)*** is an international, peer-reviewed, interdisciplinary forum for theoretical, practical, and methodological explorations into the various and complex issues of responsibility, animated by the question, “Who or what is responsible to do what for whom?” ***IJR*** is a broad-ranging journal that incorporates insights from the full range of academic and practical inquiry from the humanities and the social and natural sciences related to addressing the diverse aspects of responsibility.

IJR publishes papers, comments, and other writings on responsibility. The contents examine intellectual, practical, policy and ethical issues relating to responsibility. In addition, the journal encourages research and reporting on ways in which responsibility relates to issues ranging from individual to broad public concern, past, present, and future. Topics in ***IJR*** include the use of responsibility in academic and nonacademic settings; structural and ideological dimensions affecting the development of new perspectives on the topic of responsibility; the ethics of research, teaching, and practice of responsibility; the application of a focus on responsibility in practical problems; the historical and interdisciplinary roots of responsibility; and the contributions of a focus on responsibility for interpersonal, policy and public issues.

The journal accepts submissions on the full range of topics related to responsibility as well as special editions dedicated to one topic. Manuscript submission guidelines for authors appear on the final page of each issue.

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IJR 4.1 Disability & the Pandemic

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Prologue

By Daisy L. Breneman

It was a cool November day, the coming of winter signalled by the chill of the weather, the browning trees and landscape, and the bad Christmas music playing over the speaker at the side-of-the-road farmer's market where we sat outside, three colleagues, friends, talking about this special issue.

I sipped tea, Earl Grey, while my colleagues sipped coffee.

Before the pandemic, IJR editors Terry Beitzel and Howard Carrier hosted a reception for the editorial board of the IJR, and invited participants to share ideas for special issues; I suggested an issue on disability and responsibility. During the pandemic, when Terry contacted me about perhaps following through with the suggestion, we knew the focus needed to shift to disability and the pandemic.

This issue on disability in the pandemic: so urgent, so important. That November day at the farmer's market, Howard, Terry, and I talked of paradoxes of access for people with disabilities--that while the pandemic increased access for some, such as those able to, finally, work from home, it shut down access for others. We talked of the ways the pandemic laid bare so much hidden ableism and its intersections with racism and other forms of oppression, other crises. The ways it exposed whose lives we do, and do not, value, and the ways money is prioritized over human life, too often.

The three of us talked of the exigence of getting this issue out, and our responsibilities to do so, even as none of us felt we really had the energy or resources. We were exhausted. We were lost.

Our colleague left, as the sun began to set over the green and blue hills to the west. Terry and I stayed, continuing our conversation as the setting of the sun removed any last semblance of warmth. But we enjoyed the camaraderie, perhaps all the more because of the ways the pandemic had cut off so many opportunities for connection. I was very glad to see my friend.

Two months later, he was gone, one of over half a million Americans to lose their lives to this terrible disease, leaving us trying to figure out a world without him.

The central question of Terry's work, and life--and this journal--is "who is responsible to do what and for whom?" Many people failed in their responsibilities to Terry. There were many decisions at crossroads, and the paths chosen led to this terrible place.

To be honest, at first, the thought of doing this journal was too painful. It still is. At every turn, I have wanted to talk to him--give him updates, get his thoughts, share the victories, work through the frustrations. Make really bad jokes about it. Terry had many drole one-liners, including "This is why I don't get paid to tell jokes."

Doing this without him has been excruciating. But I have been grateful to have had the opportunity to collaborate with my longtime friend and colleague, Susan Ghiaciuc. And, also, doing this has been better than not doing it: this conversation is too urgent.

Terry never let anything stop his work. No matter what he was going through at any given moment, he picked up a book, he had a conversation, he answered email, he went to meetings, he put down his thoughts on the page (usually over coffee).

He knew how important the work is, and he was committed to upholding his responsibilities, to serving, to bearing, when he could, others' burdens. He still has so many contributions to make to the world.

Here, in one small way, we hope to keep your work moving forward, Terry.

Introduction: Disability and the Pandemic

Daisy L. Breneman & Susan Ghiaciuc

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This issue of the *International Journal on Responsibility* is about the impossible and improbable production of knowledge through a pandemic.

The intersecting crises of 2020-2021, including the pandemic, racial and other forms of injustice, the climate crisis, economic instability, political and social division, and more, continue to disproportionately impact people with disabilities across the global community. While these crises may increase access for some, disability activists argue it is telling that it took a pandemic to fully recognize the universal importance of accessibility. The rapid pace at which problems were solved through innovations such as remote work, virtual events, or curbside services demonstrates that, when we devote effort and resources, we can create accessibility. That it took able-bodied people asking for access to make it happen highlights society's pre-existing ableism and points to our larger responsibilities to address inequities.

In truth, any gains related to improved adaptability are far outpaced by new and amplified barriers to access, including to public spaces, health care, education, and employment. In-person requirements on college campuses and places of employment, for example, create differential and inequitable access, furthering social isolation. Technology presents other barriers, such as fatigue from overreliance on screens, and lack of reliable captioning. And, the possible waning of the pandemic at the time of this writing, which remains threatened by factors such as dangerous new variants, high numbers of unvaccinated people, and relaxed prevention measures, has led many to want to just move beyond the pandemic, or, in some cases, return to a non-existent, and non-ideal, "normal." We feel it is our collective responsibility to pause, reflect, and take in the lessons from this terrible moment.

Our authors wrote under the challenging circumstances of the pandemic, and during a time when so many people continue to seek escape, these authors work to make sense of the senseless. We want to acknowledge and honor the challenges and grief, while also emphasizing it's not just about the grief—it's about what we're going to do with it. The surreal nature of this moment makes this a challenging time to be creating this journal, but also the perfect moment.

This special issue of the *International Journal on Responsibility* includes a compilation of five mixed genre works in which authors critically examine the issue of responsibility in relation to Covid-19, disability studies, disability rights, access, and equity. Intersectional approaches are illuminated here by authors engaging with such urgent considerations as gender, socioeconomic, racial, and disability justice on a national and international front.

In addition, this issue seeks to disrupt academic norms, patterns, priorities, and conceptions of time that have excluded so many. This issue was created in crisis and chaos, so we will not pretend things are “normal” (whatever that might mean). The author’s work presented here documents the ways the world has been disrupted, and the responsibility we all share in remaking it into something new and better. Late *IJR* founding Editor-in-Chief Terry Beitzel recognized in a June 2020 presentation on racial justice and the pandemic that “The greater the challenge, the greater the opportunity [. . .] the only time we can really do a huge change, like a social revolution, is when there is a huge challenge. [. . .] The irony of this is that there’s an incredible opportunity for change, and I think many people are trying to grasp that. That’s the very hopeful side of this incredible challenge.”¹

Building on Beitzel’s point, we want to acknowledge the kairotic nature of this issue of *IJR*. Ancient rhetoricians claimed the concept of *kairos* as a situational, opportune time to make an argument or initiate a discussion around a relevant issue. While it would be easy to suggest this special issue of *IJR* was chosen as a kairotic moment, or an apt time to address how the pandemic has disproportionately impacted people with disabilities across the global community, we think it’s equally important to note how the authors of this issue lend us their compellingly humanistic insights in a temporal moment, one that can facilitate moving us past a limited, ableist mindset.

While the Sophists believed every argument had at least one contrary argument, the work presented in this issue of *IJR* are arranged not as contradictory pairs, but as *kairos*-based exchanges of perspectives and experiences that engage readers in a variety of assertions that illuminate the complementary relationship between *crip-time* and *kairos*.

Just as *kairos* denotes an opportune moment, in *crip-time*, as Ellen Samuels explains, participants “break time” by adopting new rhythms, patterns of thinking, feeling, and moving through the world. As authors in this issue of *IJR* clearly highlight, everyone links to the concept of *Kairos*, but some reshape it and prioritize aspects of it that may have otherwise been unclaimed or unnoticed. Although *crip-time* challenges normativity and ableist conceptions of time, it notably underscores how socially accepted environments (mental and material) must change, instead of forcing the bodies of those with disabilities to change. We believe *crip-time* is essentially kairotic, not in the typical *Kairos*-based sense of a fleeting moment that will be lost if not seized in normative time, but in terms of the shifts and turns of attention *crip-time* creates.

In this destabilized moment—this destabilized *time*—everyone is operating in *crip time*: it bends, moves forward/back, and is not only not a “normal” clock, but challenges and resists the notion of normal time. This pandemic has been a nanosecond, and it has been an eternity; as we try to recall an event, it could have happened last week or ten years ago. Without the rhythms of our habitual use of time, we have had the burden and opportunity of remaking time and refashioning our relationship to it.

And, yet, we also enter this conversation with a sense of urgency. We worked too hard during the pandemic, and lost too much, to ignore or forget the lessons learned. While the lessons might not be worth the loss, especially to human life, they happened, and we don’t want to lose the shifts we’ve made toward accessibility. This is not to reinforce false (white supremacist, patriarchal, ableist, neoliberal) notions of urgency, but rather to hold both the fierce urgency of now *and* the dignity, needs, and humanity of the people coming together to weave the stories of this experience into something we can use to create better stories. It is possible to respond to the exigence of the pandemic and its traumas with both swiftness and compassion.

As we talk about the challenges of the pandemic, we recognize how marginalized groups have been experiencing this same shit their entire lives. The pandemic stripped away the comforts that people with privilege used to experience. We should not recreate inequity and go back to a flawed and unsustainable “normal” that should never, ever have been normalized. This will require us to do things

¹ See also Terry Beitzel’s Introduction to *IJR* Volume 1, Issue 2, 20218, “Types of Responsibility: Challenges and Opportunities.

differently—something we tried to model in both the process and product of this journal, and something we can all do in our daily lives. Some lessons to take away might include:

Centering care, relationship and connection

The pandemic required a lot of improvisation, and expanded the possibilities of what can happen when we work together to solve crises. We all experience individual crises, but typically in a context where others around us are doing okay. The pandemic happened to all of us at once, albeit in different degrees and kinds. Because we experienced many things together (trauma, crisis, transition, destabilization, etc.), the challenges became more salient and demanded a collective, and compassionate, response. As/if the pandemic ends, let's keep that priority, and work, as Margaret Price (2021) emphasizes, to care for each other, and take collective accountability to ensure, as much as possible, everyone's needs are met. The collective grief of this moment should be used to fuel collective empathy and care.

Academic Communication and Collaboration

Academic processes and procedures became more transparent during the pandemic. In many cases, they were distilled, and higher education became even more invested in the most important parts of the academic venture, such as caring for the well-being of our students, which also helped remind us of our priorities. Faculty were invited, in some cases, into conversations about budgets and other administrative matters, spaces we don't often enter. Many faculty gained an appreciation for the challenges of keeping a university running, and administrators gained insight about the hard work of creating learning opportunities, potentially creating connections and opportunities for stronger communication and collaboration.

Increased access and equity

As well-documented by scholars such as Jay Dolmage (2017) and Margaret Price (2011), the academy pre-COVID has been, by design, a site of exclusion. The pandemic offers an opportunity, since many structures were torn-down, to recreate campuses that truly reflect, and serve, the wide variety of students, faculty, and community members who participate (or want to participate) in them.

Prioritizing life

Work environments, including academia, can be toxic and often value production over people. We center human beings, independent of what they make, do, write, teach, or serve. As emphasized by the overwhelming loss due to the pandemic (over 4 million individuals globally, at the time of this writing), more than our material output, we must honor our inherent value and prioritize our connections to one another.

Embracing (messy) process

While we are excited to share this finished product, we also want to affirm the value of the process, and what we gained from our conversations with each other, our contributors, and others about this special issue of IJR. We center relationship and process, and, in line with Robert McRuer's argument in *Crip Theory*, highlight how a focus on process can disrupt compulsory able-bodiedness and heterosexuality. Engagement with the process of making our way through a pandemic, and making meaning in it, is in itself significant.

Honesty and vulnerability

This year, many of us have learned to say "I'm not okay." In meetings, we are taking time to be human together, asking how others are doing and expressing what we need. Deadlines have become flexible, and less important. We are being honest when we're not in a mental/physical space to do something, and/or asking for what we need in order to be in that space, and helpfully receiving those same requests from others. Actively taking responsibility to create inclusive and caring spaces is a practice that should continue.

As we reflect on our responsibilities, we know that what we've learned isn't something we can unlearn. We can't have experienced this for nothing. However, at the time of this writing, we are witnessing a push to get back to a non-existent "normal". For example, many companies and campuses are forcing workers back into physical workplaces, often without considerations for access. Many states and localities are abandoning safety protocols, even as new COVID cases continue. We invite the readers of this journal to explore with our authors both the tragic losses and injustices of the pandemic, but also the hopeful potential for more positive innovations. It will take all of us, together, bearing responsibility for creating this change.

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Sickening Responsibility: Thoughts on Care Work from a Chronically Ill Scholar Activist

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Abstract

What does it mean to focus practices of responsibility around sick/unwellness during pandemic times? Using a disability justice framework and drawing from my experiences as a chronically ill / sick person, in this article, I argue that responsibility takes on different meanings when examined through a critical framework that recognizes sickness as an ordinary aspect of life under interlocking systems of power, such as capitalism, White supremacy, ableism/sanism, and cisheteropatriarchy. In particular, I contend that beginning conversations about responsibility from the assumption of sickness – that everyone is either sick or has the potential to become sick and that sick people are always impacted by individuals' actions – generates space for relational transformation towards more meaningful, substantive practices of responsibility. Moreover, because of the ways that pandemic times have disproportionately harmed chronically ill, sick, and immunocompromised peoples, I assert that sickening responsibility is both an urgent task for social justice activists and organizers and one which has the capacity to support the life of individuals and communities in the midst of great uncertainty, fear, suffering, and loss. The purpose of this paper is to intervene in and expand conversations about responsibility that so often marginalize and exclude disabled/crip folks, and sick people especially.

For many sick, chronically ill, and immunocompromised people, the Coronavirus pandemic has not constituted a break from our “normal” lives and experiences so much as it has led to an amplification of realities that were already present for us. The world around us had surely changed, in ways both good and bad, and there are emergent and worsened dangers to be sure, but lots of sick² people were already existing in “crisis mode” prior to the official pronouncement of the pandemic times. Many of us were already afraid of leaving our houses or going to crowded places because of the potential harm other people could cause to our bodyminds. Many of us were already taking safety precautions like social distancing and wearing masks because of how often we have witnessed other people act irresponsibly or unkindly towards us. And many of us were already strategically thinking about ways to care for each other in the midst of collective unwellness – for example, by building interdependent networks or “care webs” that help to ensure all our needs are dependably being met (Piepzna-Samarasinha 2018). The pandemic times have most certainly thrown a wrench into sick people’s lives, especially for those of us who are simultaneously disadvantaged or oppressed in relation to other axes of power (e.g., race, class, gender), yet many of us and the people practicing solidarity with us have been finding creative ways to generate access for much longer than the pandemic times have been going on.

That said, the social, political, economic, and relational shifts brought about by the pandemic times as well as the heightened possibilities of violence and harm make it urgent for sick folks and our relatives³ to collectively think about what responsibility means in this moment and as we keep moving forward. I define responsibility as a commitment to build just and equitable relationships and to always act from the understanding that everything we do affects our own well-being in addition to the well-being of people around us. Because our actions have consequences, practicing responsibility means doing what we can to minimize the harm we cause and to contribute to a society in which all peoples are supported in leading meaningful, worthwhile lives. This definition of responsibility is meant to align with the disability justice framework, which values intersectionality, interdependence, cross-disability solidarity, collective access, and collective liberation (Sins Invalid 2016; Lewis, 2019; Mingus 2018). In contrast, irresponsibility both emerges from and leads to suffering, inequity, and injustice; it is the very foundation of systems of power and oppression that disability justice defines itself against. In this article, I use the lens of sickness during the pandemic to think critically about what an anti-ableist, disability justice-centered approach to responsibility could look like. The guiding concept that I examine and develop throughout this paper is the idea of *sickening responsibility*, which broadly speaking describes a process of redefining or recentering responsibility around a generative practice of solidarity with sick folks. For the purposes of this paper, solidarity “in contrast to charity and philanthropy... is a form of reciprocity rooted in the acknowledgment that our lives are intertwined” (Taylor and Hunt-Hendrix 2019).

² For the purposes of this essay, I will use “sick” as an umbrella term that encapsulates sick, chronically ill, and immunocompromised folks as well as any other related identities. I recognize that many people do not identify with this term and that it is not perfect in its representation, yet it is the term that best fits my need in making the arguments of this paper.

³ I use the term “relatives” to describe anyone that sick people are in relationship with rather than just biological associations. People become relatives to one another as a result of building kinship networks that allow for deeper and more meaningful expression of interdependence. My use of “relatives” here is informed by Alison Kafer’s work (2019) on crip kinship as well as Mia Mingus’ writing on intimacy between disabled people (2017).

What does it mean to focus practices of responsibility around sick/unwellness during pandemic times? Using a disability justice framework and drawing from my experiences as a chronically ill / sick person, I argue that responsibility takes on different meanings when examined through a critical framework that recognizes sickness as an ordinary aspect of life under interlocking systems of power, such as capitalism, White supremacy, ableism/sanism, and cisheteropatriarchy (Barlow 2018; Cvetkovich 2012; hedva 2016; Helm-Hernandez 2013; Page 2013). In particular, I contend that beginning conversations about responsibility from the assumption that everyone is either sick or has the potential to become sick and that sick people are always impacted by individuals' actions – generates space for relational transformation towards more meaningful, substantive practices of responsibility. Moreover, because of the ways that pandemic times have disproportionately harmed chronically ill, sick, and immunocompromised peoples, I assert that sickening responsibility is both an urgent task for social justice activists and organizers and one which has the capacity to support the life of individuals and communities in the midst of great uncertainty, fear, suffering, and loss. The purpose of this paper is to intervene in and expand conversations about responsibility that so often marginalize and exclude disabled/crip folks, and sick people especially.

Sickening Responsibility in the Search for Disability Justice

Similar to other forms of disability⁴, sickness and chronic illness are socially, politically, and historically constructed in relation to intersecting systems of power and oppression. Even though they are located within individual bodyminds, the representations and meanings assigned to sickness, the communities of people most impacted by sickness, and sick people's access to social and material resources are all mediated by violent systems and structures (hedva 2016; Mingus 2015; Piepzn-Samarasinha 2018; Wendell 2017). For instance, capitalism has organized Western society in such a way that poor and houseless people are *more* likely to become sick (e.g., because of food scarcity, lack of safe and stable housing, and worker exploitation) at the same time that they have *lessened* access to quality healthcare and healthy environments. Similarly, White supremacy functions to protect White wealth, health, and power through perpetual enactments of hatred, violence, and terror against Black, Indigenous, and people of color (Barlow 2018; Levins Morales 1998), and through the historical trauma of segregation, slavery, and settler colonialism (Goodkind et al. 2012). These enactments range from the routine state violence against Black and Brown bodies, to the exploitation of people of color through manipulative medical testing, to the tendency to position landfills and hazardous waste sites near communities of color – all of which lead to inequitable experiences of sickness and disease across racial lines.

Accordingly, sickness is as much a structural or political production as an internal reality, which means that substantively attending to the needs and experiences of sick folks requires a combination of social and medical interventions – activists and doctors alike. Medicine alone cannot remedy the imbalances in power and the neglected responsibilities between people underlying the many health crises affecting marginalized and oppressed peoples. And, overlooking the social dimensions of unwellness to focus exclusively on the medical has contributed greatly to the erasure and marginalization of oppressed people's experiences and needs. Ana Clarissa Rojas Durazo (2006) defines medicalization as the process that occurs when “institutionalized, ‘mainstream’ or western medicine reconstitutes social problems as ‘diseases’ or individual pathologies in need of medical intervention.” The danger of medicalization (and the related process of pathologization) is that we start to focus on what is “wrong” with individual people rather than how social realities are negatively impacting their health. We stop talking about how systems of power and oppression cause irresponsibility between people in a multitude of forms, such as intimate violence, food injustice, economic exploitation, and so

⁴ Describing sickness as a disability is an intentional choice that frames my arguments throughout this paper. There are notable differences between sickness and other kinds of disability, and holding them together creates a tension that, due to the constraints of this paper, I cannot fully explore here. For an extended account of this tension, see Wendell (2017).

on. Medicalization is insufficient for understanding sick people's experiences, and it cannot lead to a more responsible society.

The ongoing Coronavirus pandemic has demonstrated the urgency of attending to both medical and social interventions: even as vaccinations are becoming widely available, and even as people have been made widely aware of safety guidelines, many continue to act irresponsibly by not wearing masks in public, by refusing to social distance, and by choosing not to get vaccinated. While some may argue that it is their choice to do these things and that they should be supported in whatever decisions they make, their actions affect more than just themselves. And it is exploited and oppressed peoples who have been and continue to be most impacted by these kinds of social irresponsibility. I think here of how capitalism has remained operational during the pandemic and how many workers – particularly minimum wage, working class people – have been expected to put their bodies and health at risk for the sake of someone else's profit or gain in a spectacular display of exploitation, which is one of the five faces of oppression described by Young (2011). For many, social distancing and isolation have been luxuries too expensive to afford, which is another example of how Western society is structured around health inequity.

Recognizing that sickness is systemic and structural at the same time as it is internal and personal starts the work of *sickening responsibility*, by which I mean reframing the concept of responsibility through an anti-ableist perspective centering solidarity with sick, chronically ill, and immunocompromised people. Sickening responsibility means acknowledging that all people will experience sickness in their lifetimes, but that interlocking systems of power and oppression influence how and how often different groups of people are exposed to sickness as well as their access to restorative and/or life-sustaining resources. Genuinely making this acknowledgment changes the meaning and practices of responsibility to include actions that counteract the harm sick people experience in a capitalist, White supremacist, xenophobic, cisheteropatriarchal, ableist, and otherwise oppressive society. If we explain responsibility as acting in ways that promote *interdependence* and reduce harm through the dismantling of inequity and injustice, then it must include a commitment first to dis-inhabit systems and structures that contribute to our collective unwellness – whether of ourselves, other living beings, or of the land – and second to listen to and honor the lived experiences / needs of sick peoples. In this essay, interdependence refers to the recognition that the “liberation of all living systems and the land [is] integral to the liberation of our own communities” (Sins Invalid 2016, 18). In other words, all living beings are inherently connected, so rather than pursuing the colonial, White supremacist, patriarchal, and capitalist falsehood of independence, seeking interdependence encourages us to prioritize responsibility towards one another in order to promote equity, justice, and togetherness.

The dual reality of sickness that makes it necessary for us to generate access is that it is at once internal and external: sickness is an experience positioned within individual's bodyminds, yet the environments and social contexts in which bodyminds are situated have the power to subject people to sickness and /or to impact their experiences of being unwell (Clare 2017; hedva 2016). This dual reality leads to a split meaning of responsibility, which is partly internal and partly external. Internal responsibility involves listening to our bodyminds and doing what we can to build our lives in ways that honor our lived experiences and needs as they evolve over time. This might involve ensuring we get adequate rest, that we eat nutritious meals, and finding ways to enter into relationships with other people that help us to love ourselves (Taylor and Duguay 2016). The external responsibility of sickness that all people share entails collectively, collaboratively building worlds in which all people have a full and unhindered capacity to be responsible to ourselves and others. In other words, fulfilling the external or social responsibility for sickness means contributing to social structures and systems that enable people to practice internal responsibility – because they have reasonable access to safe, stable housing, healthy food and clean water, consensual and competent healthcare, and other access needs that they may have. This paper primarily focuses on the external responsibility of sickness in order to offer tangible pathways to practicing solidarity with sick folks.

Part of this work of sickening responsibility is letting go of assumptions that sickness is about morality, that sickness is a mark of wickedness or wrongness, that sick people somehow deserve to be punished (Clare 2017). Moral attributions are especially dangerous and harmful when sickness has been correlated, empirically or in the popular imagination, with oppressed peoples. Sickening responsibility must include actions that intervene in these kinds of associations, for it urges us to shift away from oppressive individualism that leads to individual blame and towards a critical consciousness of systemic and structural realities. For instance, how many times has HIV/AIDS been weaponized against queer folks in support of heteronormative political agenda or belief systems? How many medical personnel have refused to help queer folks because they see HIV/AIDS as a sign sent from above to punish sinners or an otherwise deserved condition resulting from tainted morality? In the early years of the HIV/AIDS crisis, the Reagan administration's negligent and bigoted policies resulted in the suffering and death of numerous infected people and incited radical resistance from the queer left (Hobson 2016). Though it may be true that the illness ultimately took their lives, the systemic hatred of and structural violence against queer and trans people – especially queer and trans people of color – contributed to a social landscape in which the HIV/AIDS crisis was able to fester and to ravage entire communities of oppressed people, many of whom were multiply oppressed or marginalized.

Connecting sickness to the supposed morality of individuals is a sinister way that systems of oppression operate to obscure themselves from critique and therefore limit resistance to their reproduction, which is another way of saying that it empowers and enables dominant groups to continue acting from their positions of social and material advantage. This reproduction of power is one of the primary dangers of medicalization (Durazo 2006). For example, “obesity” discourses are in and of themselves problematic for several reasons, the first of which is that they make moral judgements about the health and well-being of fat people, especially poor and fat people of color, typically without recognition that bodies are diverse in their forms and needs and without acknowledging that food injustice is structured into Western society (Finley 2014; Stewart 2018). As with many other socially constructed diseases, the logics underlying “obesity” discourses are based in Eurocentric value systems which normalize and promote Whiteness, maleness, and able-bodiedness (Strings 2019). Moreover, these logics are medicalized and pathologized, meaning that they have oftentimes been neglectful of the social and political realities impacting people's lives. For example, if people are working multiple jobs just to get by, then they likely do not have time to cook home meals for themselves, and fast food is cheaper anyway. Worker exploitation contributes to a society in which health is made into a luxury reserved for the wealthy. Medicalization and pathologization are methods for shifting attention away from inequity and injustice toward individual people's decisions – that is, for taking attention away from the need for external or collective responsibility through victim-blaming.

Disrupting moral attributions and individualism is especially urgent during pandemic times because of the ways COVID-19 had been made shameful and used to punish people. Shame leads to secrecy and silence, both of which, in this case, underlie failures in responsibility that can lead to worsened harms (BCRW 2019; brown 2019; hooks 2000; Russo 2018). Consider how much different the pandemic might be in the United States if people felt safe and supported in naming their experiences with COVID-19 – if we could communicate openly about our experiences without being shamed and/or disciplined for doing so? What opportunities might that generate for us to show up for one another in different, more meaningful ways? Moving beyond shame, I believe, has the potential to get folks into alternative habits of togetherness that are more just, more kind, and more responsible. For one thing, it might open up vital space for people to have critical conversations about power and oppression as they contribute to the well-being and unwellness of our bodyminds. johanna hedva (2016) explains that sickness is a normative outcome of capitalism (and other systems of power) because practices of caring and caretaking go against expectations of productivity and independence. Shame is bound up in this equation because White supremacist, cisheteropatriarchal, ableist, capitalist social structures pressure us to feel bad about ourselves whenever we cannot successfully overcome “weaknesses” or need assistance from other people. Sickening responsibility inverts the source of this shame by starting with an understanding of interdependence – or with the understanding that people always need one another because that's the only way we can survive and lead meaningful lives (Mingus 2017).

Moving away from morality towards sickened responsibility also allows for us to think more critically about how people became infected due to their own irresponsibilities as well as how people were exposed because they were set up by social inequities and injustice, that is, because of society's normalized and routine irresponsibility towards them. Describing someone as acting irresponsibly is different from a moral attribution because the former is about how people's behaviors affect themselves and their relatives (i.e., those they are in relationship with) while the latter is a criticism of an individual's character or spirit. Responsibility calls for changes in behavior that make continued relationships possible, but moral attributions negatively assert that kind and loving relationships can only happen if people stop being who they are. As a sick person, the few relationships that I am able to build are cherished parts of my life, and I do everything I can to preserve them. When my relatives do wrong by me, or I do wrong by them, approaching the situation from a generative mindset of responsibility gives us room to do the work required to restore or repair our connection (Benaway 2019). Moreover, rather than focusing on what's "wrong" with us as individual people, we are able to think / talk about how our own identities and positionalities within an oppressive society affected the relationship and were connected to our irresponsibility. Accordingly, the change we request of one another can be centered around taking accountability for ourselves rather than determining if we are "good" or "bad" people.

In terms of reimagining accessibility and solidarity with sick people during the Coronavirus pandemic, there is a lot of space for growth when applying the concept of responsibility. In particular, it can help us to distinguish between situations where individual or group actions are the primary source of harm and those where harm is more a consequence of oppressive systems. Much of the time, a combination of individual action and oppressive systems is at play, and so responsibility helps to illuminate multiple opportunities for intervention. Because responsibility is attentive to relational change instead of moral judgements, it opens up space to imagine how we can use our relationships to promote equity and social justice within our chosen families and communities. For instance, there are easy questions about what we can do to reduce the spread of illness and how we can better follow safety guidelines. At the same time, there are harder questions to ask about what we can do to practice responsibility / solidarity with folks around us, especially those who have been systemically or structurally set up to be vulnerable during the pandemic. If our relatives are unable to follow isolation and social distancing guidelines, if they are routinely at risk of exposure yet unable to reduce that risk (e.g., due to worker exploitation or their living conditions), then what are we doing to protect them and help ensure their needs are getting met?

Building on this thought, I want to return to the questions of vaccinations and where they fit into this concept of sickening responsibility. From my perspective as a chronically ill and immunocompromised person, and as someone with multiple sick relatives who are particularly vulnerable to COVID-19, the simple act of getting vaccinated, particularly for able-bodied and able-minded people, is a fundamental, vital part of being responsible to ourselves and to others with whom we are in contact. Vaccines pose limited risk to most people, yet COVID-19 has well-demonstrated its capacity to end lives. Not all of the time, but much of the time, reluctance to get vaccinated seems to me to come from a causal ignorance of others' fear and suffering, especially for people who occupy dominant social positions like cisgender, heterosexual white men. People will often choose not to get vaccinated because they value their comfort more than other people's continued existence – because they see the lives of sick people through a lens of disposability, especially sick people who are multiply marginalized and/or oppressed (Kukla 2021). Much of the resistance to vaccination also rises from ableism and neuronormativity, which have been crucial aspects of the growing anti-vaccination or "anti-vaxxer" movement (Crowe 2020). So, disability is doubly present here as people are devaluing disabled, particularly sick, people's lives at the same time as they are utilizing the "threat" of becoming disabled to rationalize their irresponsibility and to extend that irresponsibility outward.

Of course, some people's resistance to vaccination comes from a legitimate fear of what might happen to them. For example, many people are afraid that vaccines will affect their reproductive ability. While this belief is problematic (e.g., because it privileges the *potential* life of a child above the lives of

real sick people), I can understand where people are coming from, especially considering the historical androcentrism, heteronormativity, coloniality, and Whiteness of Western medicine. There are also some people who refuse vaccination for religious and cultural reasons, or because they have medical trauma and/or a legitimate distrust of the “medical industrial complex” (Mingus 2015). The ways in which the medical industrial complex has violated and betrayed people, especially people of color, women, and queer and trans folks, is reason enough to treat vaccines with skepticism, to say the least. Part of the power of thinking through sickened responsibility is that rather than just discarding or “canceling” unvaccinated people, we can imagine and figure out alternative methods for solidarity and care.

We can ask of them, “If you won’t get vaccinated, then how else are you practicing responsibility and solidarity with sick peoples? Are you staying home? Are you wearing masks? (How) are you organizing for universal healthcare, housing, food, etc.? (How) are you involved in movements for worker’s rights or living wages? (How) are you supporting movements against environmental racism, pollutants, and other causes of sickness? And, if you aren’t doing these things, then how are you practicing responsibility to sick folks?” Vaccination is a single action, an important action, but far from all that an individual can do. Moreover, sickened responsibility is a means of talking back to the medical industrial complex and demanding more from the people and institutions who claim to provide healthcare. The legitimate fear and distrust that many people have for the COVID vaccine is indicative of much broader problems that need to be addressed. How are medical professionals demonstrating a substantive commitment to social justice, collective access, and collective liberation? How are they working to transform ongoing histories of systemic oppression and harm that have rendered so many communities distrustful of them? Where are the doctors at Black Lives Matter protests? How are they showing up for affordable housing or universal healthcare? What are they doing to say, “We recognize our history, and we are working to become better”?

Because responsibility is not a single pathway or set route, it requires ongoing conversation and actions that move us in multiple directions. Just because someone will not get vaccinated, whether or not they have a genuine explanation for their decision, does not mean that they are excused from pursuing other avenues for being responsible. It is when they decline to explore these other paths that their complicity in ableism and the multiple other systems of oppression with which ableism intersects becomes apparent. And, people who do get vaccinated should not be exempt from finding other ways to practice responsibility and solidarity: it’s not as easy as just checking off a box because responsibility and solidarity are *relational processes* – they are ongoing and never completed for as long as people remain in relationship with one another (Price 2011, 2021). Vaccinations are a point of entry from which a continuous dedication to equitable and just action can grow, from which people can begin or further the process of figuring out what exactly it looks like to show up for one another in substantive, liberated ways. These points of entry are cherished and invaluable, but they have to be kept up so we don’t get stuck in the doorway to a better future.

From Crisis Response to Pandemic Remedies

Sickening responsibility means acknowledging that sickness is as much a structural and political reality as an internal or private experience and, accordingly, that our actions and relationships have important consequences for the (un)wellness of other living beings. This acknowledgement is particularly crucial during pandemic times considering just how many people are struggling for their own survival against not only a life-endangering illness, but also the converging, destructive forces of oppression that have augmented the pandemic’s reach. Many sick, chronically ill, and immunocompromised peoples cannot leave our homes without great fear of the harm that will befall our bodyminds. For many, going outside into public spaces could quite literally kill us. As I stated above, this learned fear comes partially from the knowledge of how many people are continuing to act irresponsibly toward one another in spite of the staggering infection count and mortifying death toll. The world was unsafe for sick folks prior to this most current pandemic, and so the emergence of COVID-19 has forced many of us into greater isolation. Social distancing and isolation, accompanied by notable shifts in professional, familial, and intimate relationships, has also contributed to heightened

rates of violence against disabled people as well as emergent barriers to resources and support (Author 2021; Katz 2020).

Throughout the pandemic times, many people, perhaps the majority of people, have been existing in a prolonged *crisis response*. A crisis response is the body's natural reaction when trauma is occurring or feels dangerously close by; it describes the defensive procedures we undergo when our internal alarms have been sounded. Crisis response is a vital, evolutionary mechanism that has enabled human survival in the face of a multitude of harms because it gets us through life-and-death moments. However, crisis is another socially constructed and politicized term: it can refer to natural disasters like floods or fires, but it can also emerge as a result of the way that systems and structures of power *un-prepare* people for harms that could have been prevented or greatly lessened. Inequities arising from structural violence render a society in which numerous people do not have access to vital resources, like food or shelter, and are, therefore, ordinarily responding to one crisis or another (Berlant 2011). Pandemic times have evoked a crisis response among many people in the United States because our White supremacist cisheteropatriarchal ableist and capitalist society is not set up to promote collective access or to ensure that people's needs can be reliably met (Piepzna-Samarasinha 2018; Sins Invalid 2016). To the contrary, a great many people in the U.S. live perpetually on the verge of hunger, houselessness, sickness, and financial collapse. So, when the pandemic times began, there was great uncertainty and fear about how people would survive. The absence of a meaningful social safety net is a foundation of crisis, and it is a big part of the reason why the pandemic has gone on for so long and been so impactful.

A *pandemic remedy* is different from crisis response. Etymologically speaking, "remedy" is derived from the Latin word *remedium*, which means "that which restores health" or "that which is healing." And so a pandemic remedy describes spaces, tools, or resources for healing amidst the outbreak of widespread unwellness and vulnerability to sickness. Unlike crisis response, which is about staying alive, pandemic remedies extend beyond mere survival to include the restoration of body, mind, and/or spirit. I do not use healing here to refer to "cure," which is an ableist concept from the medical industrial complex (Clare 1999, 2017; Mingus 2015; Piepzna-Samarasinha 2018). Rather, I use healing to describe a consensual practice of care-taking through which people cooperatively respond to the sources of suffering in their/our lives by creatively organizing for alternative systems, structures, institutions, etc. that promote love, kindness, compassion, and interdependence. Accordingly, a remedy then is not something that just "fixes" individual people, but instead should be understood as holistic – as something that seeks to restore and honor wholeness by intervening in the denial of people's humanity, agency, or continued life. Put another way, remedies move people beyond crisis by transforming the socio-political conditions that cause them to be targets of irresponsibility. In terms of the pandemic, remedies create space for relational change towards the reclamation of responsibility and solidarity between living beings.

Crisis response means acting in the moment by responding to individual needs as those needs arise – putting out fires whenever the smoke becomes visible. Pandemic remedies, on the other hand, require acting from an understanding that most of us are all differently living in crisis mode right now, and so we need more than just "in-the-moment" responsiveness. Instead, we must collectively work to create networks and systems through which we can better anticipate and listen to people's needs and ensure that those needs are being met consistently through mutual aid and community building (Spade 2020). For instance, the pandemic has been a time of heightened intimate violence, especially against disabled folks. People are simultaneously experiencing more frequent acts of violence as well as changing relational dynamics that can make it more difficult to reduce harm or stay safe (Author 2021). Sick folks, who were already disproportionately vulnerable to intimate violence prior to the pandemic, may now be struggling even more to care for ourselves, which means that those of us in abusive relationships are often even more dependent on our partners than before. A crisis response here would mean waiting until violence takes place – until some kind of severe harm has manifested. A pandemic remedy, on the other hand, would entail working with our relatives to ensure that they always have options for escaping or reducing the violence enacted against them. Further, we can work with our

relatives to collectively learn alternatives to relational violence, whether that be tools for de-escalation, spaces for taking accountability without shame or judgement, or groups that promote more gentle, compassionate, and responsible visions of masculinity (Dixon and Piepzna-Samarasinha 2020; Mingus 2019).

Attention to temporality further differentiates crisis response from pandemic remedies, given that the former is inherently temporary (i.e., only lasts until the crisis is abated) whereas the latter should have long-term implications. Returning to the previous example, we might consider the difference between offering someone emergency shelter when they flee from or leave a violent relationship and working to build communities wherein decent housing is accessible and affordable. Emergency shelter depends on the generosity of those providing it and comes with an expectation of being reasonably short-lived. Organizing for affordable and accessible housing, on the other hand, helps to ensure that people have alternative places to go whenever the need arises and that they are not dependent on the generosity of other people. Having resources for housing can be especially important for sick folks who are isolated from our relatives or who do not have a community of supporters. Accordingly, activism and mutual aid calling for rent moratoriums, working against evictions, and organizing for affordable housing can all be looked at through the lens of solidarity with sick people who have experienced intimate violence, and especially so during a pandemic when great numbers of people are struggling to make ends meet.

As another example of temporal differences that is especially relevant to the pandemic, I think of the accessibility options for remote work/learning that have become common during the last year and a half. The transition to remote work/learning constituted a crisis response because it was undertaken with haste and in an overwhelming moment of uncertainty. People were so pressed to go remote when they could that the access needs of marginalized and oppressed people were often disregarded (Pettit 2020). And a lot of folks were expected to perform additional labor without compensation – such as many teachers who had to create materials for remote/online learning in a matter of weeks. Yet, how different might the transition to remote work/learning have been if employers and schools had already done the work of figuring out how to implement these alternative pathways? Disabled, and especially sick, folks have been requesting accommodations for remote work/learning for a long time now, so I can only wonder how much smoother the transition could have been if employers and schools had been more invested in doing the collaborative work of building accessibility. Now that many places are reopening for in-person work/learning, I fear accessibility options will quickly be taken away because the crisis response is nearing its end. But, what if we kept these options in place and embraced a diversity of methods for togetherness that were not dependent on any one mode of interaction? How much more collectively resilient could we become, and what kinds of beneficial shifts could that lead to in terms of practicing responsibility and solidarity with sick people?

As I talk here about the differences between crisis response and pandemic remedies, I find it beneficial to connect to *spoon theory*, which emerged as a non-academic, community-based term among sick folks (Miserandino 2003). Spoon theory is a common way for sick, chronically ill, and immunocompromised folks, often referred to as “spoonies,” to explain the embodied / enminded impacts of our disabilities from one day to the next. Simply put, this metaphorical theory asserts that each of us begins our day with a certain number of spoons. Each spoon represents the energy available to us to complete the various tasks we need to get done throughout the day. Different tasks might require different numbers of spoons – for instance, we might need more spoons to drive to work than we do to get ready in the morning, or vice versa depending on our specific bodyminds, capacities, and needs. Some days we might start off with more spoons and some days we might start with less, such as when our symptoms are flaring up or if we were exhausted the day before. More able-bodied and able-minded people have a different relationship to spoons than crip folks – they often do not have to consider their spoon count or really worry about what happens if they run out. Spoonies, however, often know that we have a limited number of spoons, and we may have to be strategic in how we spend them because not doing so can be detrimental to our health and mental well-being.

Much of the time, sick peoples' spoons are swiftly depleted as an outcome of living in an ableist society that views us as burdensome, less-than-fully human, and at times even altogether disposable. Sick people are often forced into situations where we have to account for ourselves – situations where we have to “prove,” for instance, that we are deserving of medicine (especially true for people with chronic pain), or in which receiving meaningful care depends on us routinely performing vulnerability (Mingus 2017). Accordingly, there are many important connections between spoon theory and responsibility, the most notable being that the experience of irresponsibility is spoon stealing. Or, put another way, oppression, marginalization, and harmful treatment are exhausting realities that force people to become “resilient” for their/our own survival (Ahmed 2013). If irresponsibility steals spoons, then building equitable and just relationships depends, in part, on an intentional redistribution of spoons in defiance of systems and structures of dominance. I argue that practicing responsibility and solidarity with sick people requires that all people learn to act with an awareness of their/our spoons and how those spoons are indicative of their/our positionalities relative to one another. Responsibility means organizing society in such a way that people can reliably expect to have enough spoons to get through their day without suffering or misery because we are all invested in a generative practice of spoon sharing.

Spoon theory has some important implications for redefining crisis response and pandemic remedies. In this metaphor, crisis might be described as a spoon shortage, as being caught up in a situation where our spoons are consistently too few for the tasks we need to get done from one day to the next. Crisis response, accordingly, would involve dealing with the spoon shortage as it becomes a problem – for example, by going to people and aiding them when their spoons are spent, which has been predictably occurring all throughout these pandemic times. Remedy, which can happen simultaneously with crisis response, would require substantively addressing the underlying sources of the spoon shortage, or the sociopolitical and relational irresponsibilities that lead people to become so depleted in the first place. For example, a remedy might ask how current social arrangements are putting pressure on sick people to overspend our spoons because space is not being made for our access needs. From this questioning, a remedy would then encourage us to consider options and implement changes, in conversation with the most impacted sick people, to better and more consistently meet those unmet access needs. Many of our spoons are spent dealing with enabled people who have not intentionally moved into a practice of solidarity with us, so doing this kind of transformative, relational work could go a long way towards reducing the politically produced suffering and harm present in our lives.

Conclusion

Responsibility, as I have been using it in this essay, describes a commitment to act in ways that promote justice and center interdependence. Within this commitment is an acceptance that all people need both to receive and to give care because care is the foundation of anti-oppressive relationships. For disabled and especially sick folks, care has oftentimes been a source of harm against us, particularly where it is non-consensual or where the people providing it expect vulnerability from us in return (Mingus 2017). Too much of the time, care becomes ensnared in the logics of dominance that simultaneously impact most other parts of our lives. That said, care work is vital to the work of social justice, and I understand disability justice in particular as advancing a vision of liberatory care that serves as a basis for freedom from intersecting systems of oppression (Piepzna-Samarasinha 2018; Sins Invalid 2016). For spoonies, this liberatory vision of care might be described as a method of sharing spoons for collective survival. In this definition, care work does not include things which cause unnecessary exhaustion or harm, for those things are rooted in irresponsibility. Rather care brings rest and restoration, frees up spoons for other things, and serves as a basis for right relationships.

The task of sickening responsibility requires finding ways to act from this liberatory vision of care that are simultaneously grounded in the lived experiences and needs of sick people. Responsibility is about justice and interdependence, and these concepts must purposefully center sick folks because we have oftentimes been neglected and not recognized as a group of people who have historically been targets of normalized irresponsibility. Particularly during a transnational pandemic, throughout which a great many

of us have been remarkably vulnerable to harm, it is vital for us to collaboratively imagine worlds against ableism, worlds beyond ableism wherein we can peacefully co-exist and substantively show up for one another.

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Crippling and Deafening COVID-19: Re-Framing a Pandemic in Higher Education

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Abstract

This article looks at ways institutions of higher education (IHEs) can use the models of disability, disability studies, and Deaf studies to “crip” and “Deafen” their response to COVID-19. A review of previous epidemics and pandemics, including yellow fever, the 1918 influenza epidemic, polio, and HIV/AIDS shows how each pandemic increased IHEs’ sense of responsibility for matters regarding disease, disability, and Deafness. Health services, counseling centers, and disability resource centers expanded over time, and IHEs still rely heavily on them for health, disability, and Deaf concerns. By crippling and Deafening COVID-19 responses, higher education can use a more holistic view of the pandemic, making illness, mental health, disability and Deafness the responsibility of entire campuses, which can then proceed to do intersectional anti-ableist and anti-audist work that includes people with disabilities.

Keywords: higher education, Deaf culture, disability studies, COVID-19, pandemic

Institutions of higher education (IHEs)⁵ have dealt with epidemics and pandemics throughout their history, with the world shaping diseases just as diseases shaped the world (Hammond 2020). As early as the 15th century, Manchester College in London was not allowing students to enter or remain if they had “horrible or contagious infirmities,” and in 1826, Thomas Jefferson set up a “dispensary” at the University of Virginia, with responsibility for giving out free smallpox vaccinations (Turner and Hurley 2002, 1). So while media and higher education administrators may claim the COVID-19 pandemic is unprecedented (e.g., Chronicle Staff 2020; Polikoff, Silver and Korn 2020; Thomas and Foster 2020), diseases like COVID-19 have affected most generations in higher education. This article examines how IHEs responded to influenza, yellow fever, HIV/AIDS, as part of a historical continuum leading to COVID-19. Using frameworks from disability studies and Deaf studies⁶, I consider how IHEs managed previous epidemics and pandemics, and conclude with a discussion of how “crippling” and “Deafening” responses to COVID-19 can support individual, departmental, and collective responsibilities for intersectional anti-ableism and anti-audism work in higher education.

Higher Education’s Historical Responses to Epidemics and Pandemics

During the late 1800s and early 1900s, three higher education fields took root: college health services (originally conceived as athletics, hygiene, and health centers); counseling and mental health services; and disability resources and services⁷, which began after World War I (WWI) with vocational rehabilitation services and educational support to disabled veterans, but few to none actual offices or personnel assigned specifically to disability matters⁸) (Belew Huff and Meder 2002, Madaus 2011, Turner

⁵ The author acknowledges the word “institution” is historically associated with segregation and oppression of people with disabilities (see, e.g., Ben-Moshe 2020; Blatt and Kaplan 1974; Hirschmann and Linker, 2014). This article uses the term “institutions of higher education” (IHE) to conform to language of the U.S. Department of Education (ED) and to use a term familiar to higher education researchers who may not study disability.

⁶ Culturally Deaf people are deaf people who identify as part of Deaf culture through the use of American Sign Language (ASL) and an identity within Deafhood (see discussion later in this paper). Members of Deaf culture typically identify as Deaf (with a capital “D”), while people diagnosed as deaf who do not use ASL are identified as deaf (with a lowercase “d”). The broad deaf community (including Deaf signers and deaf non-signers usually uses a lowercase “d”. For further explanation see, e.g., Bauman and Murray 2014, xiii, Lane 2005, and Padden and Humphries 2005. As the author of this paper and a Deaf woman, I personally consider deafness a disability and experience Deafness as a culture at the same time, and do not consider it a contradiction, which is why I often use the term “disabled and Deaf” in this paper.

⁷ Many employees have received disability services, accommodations, and resources from their human resources department, although some are also served by disability resource offices. This paper focused primarily on disability services for students and campus-wide disability concerns related to them, so the omission is intentional.

⁸ Guidelines from the National Center on Disability and Journalism (2018) recommend person-first language (e.g., “students with disabilities” that put the person before the disability term) as the default for authors, unless disability-first language (e.g., “disabled students”) is specifically preferred by a person or group. In fact, many disability activists and disability studies scholars consider disability part of their identity or otherwise prefer disability-first language. Likewise, many Deaf people prefer “disability-first” language, and some do not even identify as being disabled. The Association on Higher Education And Disability (AHEAD) also uses disability-first language (<https://www.ahead.org/professional->

and Hurley 2002, Whitaker 2002). This time period was the Progressive Era, when scientific expertise and social change were both valued (Navarro and Markel 2021). Some science was questionable or outright racist, like the anthropometric measurements favored by Dr. Edward Hitchcock (the “Father of American College Health services”) to prove inferiority of non-Caucasian races (Gould 1996, Turner and Hurley 2002). Similarly, the field of mental health developed at universities, as researchers sought ways to build on testing personality, intellectual capacities, and social natures of students, norming tests with roots in eugenics and a bias toward wealthy White men (Fluehr-Lobben 2013, Whitaker 2002).

Around this same time, Gallaudet University for the deaf was created and Helen Keller went to Radcliffe College, although students with disabilities were still rare, given exclusionary policies in higher education, including entrance medical exams (Madaus 2011, Turner and Hurley 2002). By the time WWI ended, college health services were viewed as necessary to “prevent and correct physical defects,” shifting health services’ emphasis from promotion of athletics and wellness to addressing problems of disability and disease (Turner and Hurley 2002, 5). IHEs relied heavily on health science, mental health, and a mix of local, state, and federal disability/rehabilitation professionals to respond to issues of disability (and prevention of disability) and health. Subsequent wars and epidemics would continue to shape higher education’s ongoing question of who should be responsible for addressing disability in IHEs, and related fields of students’ mental, emotional, and physical health and well-being. Examining how IHEs responded to epidemics and pandemics can offer insight into this question. This section includes brief summaries of higher education’s response to yellow fever in 1878, influenza in 1918, polio in the 1950s, and HIV/AIDS in the 1980s, concluding with a description of the COVID-19 pandemic, which started in December of 2019.

Yellow Fever

Yellow fever has existed around the world since the 17th century. In March 1878, yellow fever began to spread in a particularly brutal epidemic throughout the southern U.S. (Thomas and Foster 2020). Even as cities and states began quarantines and focused on stopping the spread of the disease, IHEs were not as united in their response (Hammond 2020, Thomas and Foster 2020). IHEs faced the same problems that persisted through every epidemic and pandemic that followed: students traveling and spreading diseases, a contagious disease in a place encouraging gatherings of all types, a lack of campus policies and protocols for what to do, and the balance between pressures and decision-making by campus administrators, and local, state, and federal efforts to stop the contagion and treat those who were already ill (Hammond 2020, Thomas and Foster 2020). Some IHEs could not survive the epidemic and closed, but most IHEs remained in “bystander” mode (Thomas and Foster 2020, 188), with a mild response and little effort or involvement. Even as students crossed quarantines and continued to have expectations of regular social activities, most IHEs did not form any protocols to deal with yellow fever and didn’t increase staff for student health measures (Thomas and Foster 2020). IHEs gave local newly-formed health departments control over local responses and “shotgun” quarantines, cancelled classes, or delayed openings as deemed necessary (Hammond 2020; Thomas and Foster 2020, 188). Some IHEs formed infirmities or isolation wards (with yellow fever following typhoid epidemics requiring quarantines), but this was not the norm (Turner and Hurley 2002).

At this point in time, disabilities among IHE students and employees were addressed in an *ad hoc* manner, and Deaf students were not likely to attend any university except Gallaudet (Madaus 2011). Disabilities, deafness, and diseases were handled on a case-by-case basis, but only medical resources were

resources/accommodations/statement-on-language). However, in this article, I use both person-first and disability-first terms to convey these nuances, but also for stylistic choices. I acknowledge that choices about language, illness, disability, and Deafness are highly controversial. For further discussion of language about disability, Deafness, and identity in higher education, see Bauman & Murray (2014), Dolmage (2017), Kroeger and Kraus (2017), Nario-Redmond (2020), Padden & Humphries (2005), and Price (2011).

available, and IHEs were not providing any form of accommodations (Turner and Hurley 2002). Disease and disability were generally not a concern of higher education.

The Influenza Pandemic of 1918

By the time the global influenza epidemic was happening in 1918, IHEs could no longer be passive bystanders. Influenza was especially devastating for young adults, including college students and WWI soldiers (Hammond 2020, Turner and Hurley 2002). WWI was happening at the same time influenza spread, but many doctors and surgeons had been called up by the military, so as the flu spread, medical school staff and students, newly formed health services staff, and military medical staff were all working side-by-side (C. Brown 2018). During the 18 months of the pandemic, one quarter to one half of people across the globe had symptoms of flu and 50 million had died (Hammond 2020). Catching the flu was often a death sentence, with medical personnel and science researchers helpless as people became sick and died (C. Brown 2018, Hammond 2020). The flu disproportionately affected people (including college students and soldiers) from disadvantaged and poor households (Navarro and Markel 2021), and Indigenous communities were hit especially hard (C. Brown 2018, Hammond 2020).

Despite the deadly nature of influenza, IHE measures to control the spread of the flu were controversial. Many of higher education's efforts sound similar to those of pandemics to come, including COVID-19 (Guterman 2006, C. Brown 2018, Hammond 2020):

- Social distancing
- Cancelling classes
- Closing campuses
- Delaying graduation
- Sending medical students and interns to assist hospitals and other medical centers
- Dealing with deaths of students and employees
- Creating dorms and wards for sick students
- Creating rules to protect students, and dealing with students when they broke rules or quarantine
- Collaboration with local and state health officials (including military personnel), often deferring to their guidance and advice.

President Woodrow Wilson remained silent about influenza, even as officials tried to link masks and other compliance campaigns to patriotic wartime duty (Navarro and Markel 2021). Nevertheless, people frequently protested against such policies or fought to have them rescinded, with some people even resorting to violence (Navarro and Markel 2021). It was often difficult to get education, military, and political leaders to take the advice of health officials when they argued for masking measures, closing schools or classes, setting up quarantines, forbidding public gatherings, or beginning vaccination campaigns (C. Brown 2018).

The predominantly White influenza survivors and disabled WWI veterans going to college would have experienced a system very much like those during the yellow fever epidemic of 1878. Veterans were able to receive limited rehabilitation and job training, and the Veterans Health Administration could offer care for physical and mental disabilities and illnesses (Madaus 2011). However, mental health treatment at IHEs was nearly non-existent, with many students and former soldiers afraid of commitment to institutions if they revealed any mental or emotional illnesses (Shay 2012). The health and hygiene movement had expanded, and thanks to influenza among soldiers, college students could now receive information about and treatment for venereal diseases, promotion of physical fitness, and prevention of diseases (Turner and Hurley 2002). Disability resource offices, accommodations, and other services were virtually non-existent, and Gallaudet University remained the only real postsecondary option for Deaf students, although it had just started accepting women and was not accepting any BIPOC⁹ students at

⁹ Biracial, Indigenous, and People of Color

this time. At most colleges and universities, specific services for disabled or Deaf students did not exist, largely because these populations were still systematically excluded in higher education – students who did have disabilities would have been pressured to hide them and pass as nondisabled.

Polio

Just a few decades after WWI, the U.S. experienced significant “rolling epidemics” in waves of polio during the 1950’s (Hammond 2020, 394–396). Many people in the United States were somewhat shielded from previous smaller outbreaks, which were often related to poor sanitation among marginalized people (Hammond 2020). After WWII, however, polio spread across the United States, raising alarm as many children in middle class families contracted polio (Hammond 2020). Most children with polio had mild symptoms, but others would have lifelong disabilities or not survive (Hammond 2020). After polio vaccines emerged, polio became much like the flu in the United States: an issue of annual or childhood vaccinations, something routine, and certainly not an issue of concern or a pandemic (even though polio is still a real and present problem in many countries) (Hammond 2020). Because polio largely affected children, IHEs and college students were not directly affected.

However, some survivors of polio would incite a disability movement that would create radical changes in higher education. Many of the children who lived through polio grew up, went to camps together, had rehabilitation and schooling together, and began to realize a “normal” life was not possible if there were numerous obstacles in society (Hammond 2020, Lebrecht, Newnham and Radcliff 2020, Shapiro 1994). Groups of polio survivors began working with disabled veterans and other groups to break down structural ableism and access barriers, creating a disability rights movement (Hammond 2020, Shapiro 1994, Lebrecht, Newnham and Radcliff 2020). Disability rights work also began on campuses, with University of Illinois students forming a “crip ghetto” on campus, creating wheelchair sports, and even doing activism like smashing curbs so the city would rebuild them to be accessible (Hammond 2020, 410–411, Shapiro 1994). At the University of California Berkeley, Ed Roberts and a group of quadriplegic students (called The Rolling Quads) forced the university to create a comprehensive disabled services program for students and worked together to create California’s first Center for Independent Living (Hammond 2020, Shapiro 1994).

Polio survivors also changed higher education through legislation – their efforts helped lead to passage of Section 504 in the Rehabilitation Act and the Americans with Disabilities Act (ADA), both of which define disability, require accessibility and reasonable accommodations, and prohibit discrimination for students, faculty, staff, and visitors (Hammond 2020, Kanter 2011, Madaus 2011). Polio survivors were part of a generation of disabled people working for disability rights, inclusion, and a collective identity. Their work led to new sociopolitical models that challenged ableism. They also inspired activism among Deaf people and students at Gallaudet (e.g., the Deaf President Now movement) (Shapiro 1994). Their rallying cry of “Nothing About Us Without Us” was starting to happen not only at IHEs, but in society as a whole (Hammond 2020, 413).

As with previous epidemics and pandemics, after the initial crisis passed, polio was considered an “afterthought” in the United States (Hammond 2020, 406). But over the next few decades, disability rights and Deaf activists answered two essential questions in higher education: yes, IHEs as a whole were responsible for people with diseases, disability, and deafness; and they could be held liable if any discrimination occurred. Health services and counseling could care for students’ physical and mental health, but IHEs relied heavily on disability resource centers (DRCs) to address access, accommodations, and other disability-related matters, beginning a trend that continues today (Harbour and Greenberg 2017, Madaus 2011). Deaf students were no longer limited to Gallaudet, the National Technical Institute for the Deaf (NTID) at the Rochester Institute for Technology, the SouthWest Collegiate Institute for the Deaf at Howard County Junior College, California State University, Northridge, and a handful of other IHEs that were willing to hire Sign Language interpreters. Under Section 504 and the ADA, d/Deaf students could attend any IHE they chose. With basic questions of responsibility being answered, the next step was expanding definitions of disability and d/Deafness, and acknowledging diversity within each group.

The HIV/AIDS Pandemic

In June 1981, the CDC published a report on clusters of gay men who were dying from very rare illnesses (Hammond 2020). While the HIV virus and AIDS it caused may have been circulating quietly for decades (Hammond 2020), that was the first time medical professionals and the government noticed its existence. As with yellow fever and polio, large swaths of the general public associated HIV/AIDS with stigmatized marginalized people: homosexuals, African Americans, homeless people, drug users, and prostitutes (Hammond 2020, Ruel and Campbell 2006). Silence and stigma became defining features of the pandemic, with the Reagan administration devoting no time, money, or effort toward prevention, research, or cures until four years had passed and a generation of gay men were gone (Bell 2007, Hammond 2020, Ruel and Campbell 2006, Volkert, et al. 2021). When the federal government finally did respond, college students were one of the primary targets for prevention efforts, testing, and services, so higher education as a whole had to address the crisis, even as middle class America was just beginning to learn about AIDS from public figures like Princess Diana and Magic Johnson (Centers for Disease Control and Prevention 2006, Hammond 2020, Ruel and Campbell 2006). Twenty years later, 11.8 million people between 15-24 were living with HIV/AIDS around the world, and more than half of all new infections were among young people ages 15-24 (i.e., pre-college and college-aged adults) (Kelly, 2004). Yet many higher education students and employees with HIV or AIDS were still defined by their diagnosis and little else (Bell 2007).

As the pandemic grew, groups of college activists and LGBTQ+ networks sprang up across the country, working on domestic and global issues related to HIV/AIDS (Kelly 2004, Miller 2018). Higher education administrators who had previously supported *in loco parentis*¹⁰ realized they would have to address previously taboo topics like the existence of LGBTQ¹¹ people in higher education, racism, drug use, unplanned pregnancies, abortion, and sex, as well as the impact of HIV/AIDS (Keeling 2002, Turner and Hurley 2002). Stigma and discrimination of AIDS and gay people were common, which contributed to higher infection rates (Hammond 2020). Academics revealing their HIV-positive status risked losing their jobs if they “came out” about their status, but also were often struggling with risks of staying quiet, which allowed silence and stigma about HIV/AIDS to thrive (Bell 2007, 218). Those at higher risk of infection (e.g., gay men, African Americans, drug users) were more likely to distrust health care providers, including college health and disability professionals (Hammond 2020).

Higher education’s response to HIV/AIDS was focused on four parts: 1) the disease and its effects (including testing, prevention, health education programming, and services); 2) incorporation of HIV/AIDS into the curriculum and programming so students could understand the disease and its broader context; 3) research to find treatments and a cure; 4) work with agencies and individuals, addressing and solving problems in communities around IHEs (Keeling 2002, Kelly 2004). IHEs (including health, counseling, and disability services) needed to address HIV/AIDS as more than individuals’ concerns, with issues of structural inequality, difference, diversity, prejudice, and inequity emerging as critical concerns of HIV/AIDS, disability, and Deaf activists (Hammond 2020, Keeling 2002, Shapiro 1994, Volkert, et al. 2021). During this time, attorney Kimberlé Crenshaw created the term intersectionality to recognize that multiple identities could exist simultaneously, and understanding those multiple identities and oppressions could offer diverse perspectives to understand and resist racism and oppression (Miller 2018). Indeed, from the beginning of the pandemic, levels of HIV infection were higher in LGBTQ+ people and African Americans (Hammond 2020, Johnson and Gordon Jr. 2018).

During this time, college health, counseling, and disability services were also growing as professions, with IHEs increasingly relying upon medical and service-based professionals (as well as academics working in medical and disability service fields) to be responsible for all work related to diseases and disability. As with the polio epidemic preceding it, IHEs had also learned to work with local authorities, and state and federal governments to be sure they handled their responsibilities in an

¹⁰ A Latin term in higher education that translates as IHEs acting “in place of a parent”.

¹¹ LGBTQ is an acronym for Lesbian, Gay, Bisexual, Trans, and Queer

appropriate manner (Hammond 2020, Keeling 2002, Turner and Hurley 2002). But as with previous epidemics and pandemics, eventually the urgency of HIV/AIDS faded after antiretroviral treatments (ART) were developed in the 1990s and HIV was no longer a death sentence (Volkert, et al. 2021). In a way that was similar to vaccines, ART was the “beginning of the end” for the crisis phase of HIV/AIDS, even if the pandemic persists (Volkert, et al. 2021, 2). In most Western countries like the United States, the goals have now shifted to prevention, testing and services, and research (Centers for Disease Control and Prevention 2006).

The COVID-19 Pandemic

China was the first country to deal with the coronavirus (SARS-CoV-2) and the illness it causes – COVID-19. As COVID-19 quickly spread around the world, it resembled the HIV/AIDS pandemic in unfortunate ways, with the United States making similar mistakes from the 1980s: spreading misinformation, scapegoating, and panic “marked by hateful rhetoric, fear, and most of all, loss” (Volkert, et al. 2021, 1-2). As with all previous pandemics, COVID-19 also disproportionately affected BIPOC communities, as well as those from lower socioeconomic groups and people with disabilities (National Governors Association 2021, Volkert, et al. 2021). Even as higher education, governmental, private and public sectors had unprecedented coordination and collaboration, none of them were fully ready for COVID-19 and its many demands (Guterman 2006, Remick, Carr and Elster 2021).

In higher education, nearly every IHE moved to online instruction mid-semester in the spring of 2020, as states began shutting down schools and businesses to stop contagion (Patel and Field 2020). E-Learning had previously been seen as optional or trendy for faculty, but it was suddenly a very real necessity (Müller, et al. 2021). In March and April of 2020 and April of 2021, *Inside Higher Ed* surveyed higher education presidents and chancellors about their COVID-19 related concerns. Each survey showed at least 50% of their top ten concerns were related to disability: the mental and physical health of students, the mental and physical health of employees, and accessibility of online learning platforms (with “accessibility” including access to WiFi and computers) (Inside Higher Education and Hanover Research 2020, March, Inside Higher Ed and Hanover Research 2020, April, Jaschik and Lederman 2021, March).

Their concerns had merit. Data from the Center for Collegiate Mental Health surveyed 50,000 college students and found that one-third of students who sought care from a college counseling center during the second half of 2020 were having problems related to effects of COVID-19 (Anderson 2021). Another research study with 30,099 undergraduates at nine research universities found that students with disabilities (including d/Deaf students) experienced COVID-19 related problems to a much greater degree than nondisabled peers. They were more likely to have financial hardships, food and housing insecurity, live in unsafe environments, and have high rates of depression and anxiety, while also being less likely to feel like they belonged on campus or that the campus supported them during the pandemic (Soria, et al. 2020). Campus accommodation policies for disabled students and employees generally required testing and disability documentation before new accommodations were granted, but tests and visits to doctors’ offices were more difficult during the pandemic – especially during shutdowns (Harbour and Allegra 2020, Patel and Field 2020). The federally-funded National Center for College Students with Disabilities (NCCSD) reviewed technical assistance requests and meetings with disabled student leaders, and found problems similar to research findings – top student concerns were accessibility, mental health, work and financial matters, and experiences of marginalized disabled students and disabled student participants in Black Lives Matter¹² (Harbour and Allegra 2020). Students also expressed concerns about faculty and DRC becoming more strict about accommodations, had questions about continuing courses remotely after colleges re-opened, and said there was a need for COVID-19 information specifically tailored to disabled and d/Deaf students (Harbour and Allegra 2020). Researchers found that students’

¹² Black Lives Matter was founded in 2013 to “eradicate white supremacy and build local power to intervene in violence inflicted on Black communities” while “creating space for Black imagination and innovation.” During the COVID-19 pandemic, Black Lives Matter organized many protests against police brutality of Black and BIPOC people. (Black Lives Matter n.d.)

mental health suffered throughout the pandemic, even as students' resiliency increased (JED Foundation 2020).

Despite IHE administrators and faculty typically relying heavily on DRCs, the outlooks and understandings of DRC directors did not always reflect students' experiences. Scott, Aquino, and Banerjee (2020) surveyed 605 DRC administrators, and slightly more than one-third of respondents (36%) said they had experienced increases in new students registering for disability accommodations and services during the pandemic. The DRC administrators agreed that students with disabilities had greater difficulty than nondisabled students in dealing with every aspect of COVID-19, but did not believe students with disabilities were faring worse than nondisabled students in food and housing insecurity (even though students were reporting these as major problems). The NCCSD also reviewed how DRC and disability professionals discussed COVID-19 in online professional forums, and their main concerns were student accommodations, disability policies and procedures, and debates about whether COVID-19 and "at risk" populations could be defined as disabled (Harbour and Allegra 2020) – concerns that also do not correspond with disabled students' concerns.

IHEs could not rely solely on DRCs anyway. The work of DRCs, counseling services and health services had to be distributed across campus. IT departments struggled with access problems with online courses and platforms (Patel and Field 2020). Administrators enforcing masking policies and social distancing learned how they affected hard-of-hearing, d/Deaf, and deafblind students, who were unable to lip-read through standard masks or be close to ASL interpreters. Faculty realized that many online courses frequently had sketchy captions or remote interpreters unfamiliar with courses (Patel and Field 2020).

With the killing of George Floyd and other Black people, heightened attention to the need for anti-racism work, and ongoing activism by Black Lives Matter, 84% of presidents and chancellors said that even with COVID-19 concerns, it would still be more important to address race during the 2021-2022 academic year than in previous years (Jaschik and Lederman 2021, March). Disabled and Deaf BIPOC students who were already struggling or marginalized were hit hard by COVID-19 (Hirt 2020). BIPOC and people from low socioeconomic groups were infected by COVID-19 at disproportionate rates and were more likely to risk their health by needing to work and continue bringing in incomes (Volkert, et al. 2021). BIPOC college students (and BIPOC students with disabilities or deafness) were also traumatized in multiple ways (JED Foundation 2020), as police brutality and racism affected students as much as inequities of COVID-19. Students were trying to focus and prepare papers and tests, "while coping with many obstacles in a time of enormous social turbulence" (Agrawal 2020, B1, Harbour and Allegra 2020). Asian American and Pacific Islander (AAPI) people (especially immigrants) also experienced increasing discrimination and mental health needs as people (including then-President Trump) blamed China and Asian people for COVID-19, using racist terms for the illness and blaming China for its spread (Nakamura 2020, Wu, Qian and Wilkes 2020). Even while struggling to deal with racism and COVID-19 concerns, BIPOC students were still reluctant to get mental health services (Zamudio-Suarez 2021). As with previous pandemics, everyone could get the disease, but an understanding of structural barriers and systemic inequities changed perspectives on how people are exposed to the virus, who is "high risk," and how people access treatment, vaccines, or accommodations (Volkert, et al. 2021). Many IHEs responded in creative ways, with scholarships, help with groceries, laptops, free Wifi, regular e-mails and communication, and other tangible support, but inequities still existed (Hirt 2020, Haneklau 2020, Aspegren 2020, Agrawal 2020).

Comparing IHE Responses to Epidemics and Pandemics

As illustrated by these examples, in each generation, IHEs were caught off-guard when seemingly unprecedented diseases spread quickly and affected college students and norms of higher education (e.g., socializing and taking classes in person as part of the college experience). Likewise, IHEs also influenced how the pandemics played out, shaping which topics were urgent or worthy of study, and which professionals should handle issues like prevention, testing, treatment, and services. Each epidemic and pandemic forced campuses to also take increasing responsibility for students with diseases and disabilities

(including d/Deafness). However, during each public health crisis IHEs continued to shift those responsibilities to medical and disability professionals. HIV/AIDS helped IHEs begin earnest efforts to look at diversity and inequities, and COVID-19 was a time to specifically discuss race and how to be anti-racist and embrace diversity through an intersectional lens. But disability and Deaf culture are still not typically a part of those discussions, even though disability and Deafness are part of campus diversity, and disabled and Deaf students can also be BIPOC or from other marginalized groups

Unfortunately, with each epidemic and pandemic reviewed here, IHEs and society in general had short memories and habituation to diseases once they seemed manageable or the initial crisis had passed. All diseases become mundane at some point and survivors are expected to strive for a return to “normal” (Hammond 2020, 409). However, the examples presented here also show that long-term changes to higher education persist even after initial panic diminishes. The next section discusses the models of disability, ableism, audism, disability studies, and Deaf studies. I conclude with ways higher education can use this information to deliberately “crip” and “Deafen” views of disability, Deafness, and disease, making the entire campus responsible for anti-ableism and anti-audism work, while also aiming for intersectional disability justice.

Higher Education, Disability Studies, and Deaf Studies

Medical and Sociopolitical Models of Disability

When the field of disability studies emerged in the 1990s, a central concern was the way society treated disability as a problem, with the unobtainable goal of normalcy for everyone (Connor and Gabel 2013, Taylor 2011). Scholars identified systemic discrimination, exclusion, and inequitable treatment of people with chronic illnesses and disabilities as ableism (Connor and Gabel 2013, Dolmage 2017, Nario-Redmond 2020, Navarro and Markel 2021), and recognized the “compulsory able-bodiedness and ablemindedness” of society and higher education that stigmatized anything suggesting physical or intellectual weakness (Dolmage 2017, Kafer 2013, 7-8). IHEs and higher education often put pressure on students, faculty, and staff with disabilities to appear as normal as possible, expending great energy on marginalizing disability and then justifying that in various pedagogical, legal, and cultural ways (Connor and Gabel 2013, Dolmage 2017).

In the medical model¹³, people with disabilities are regarded as fundamentally abnormal, broken, or not even really human (Ashmore and Kasnitz 2014, Kafer 2013, Kanter 2011). The medical model affects everyone; people with or without disabilities can be seen as deviating from the norm, and the medical model can play out in attitudes, policies, and procedures unrelated to medicine (Dolmage 2017, Kafer 2013). In higher education, this means problems with accessibility, burdensome paperwork to qualify for accommodations, segregation, learning about disability only as an inherently negative problem to be fixed, and pervasive ableism that is reinforced through higher education policies, procedures, and ideas about the curriculum and what it means to be a normal student (Andersson, Sadgrove and Valentine 2012, Ashmore and Kasnitz 2014, Dolmage 2017, Ho, et al. 2020, Kanter 2011).

Disability studies scholars contrasted the Medical Model with a “Social Model,” also called the “Socio-Political Model” (Ashmore and Kasnitz 2014, Kafer 2013, Kanter 2011). This model took a very different approach, framing disability as part of the diversity of humankind, and instead of understanding a disabled individual as the problem, it assumes the barrier was created in the environment around an individual (Connor and Gabel 2013, Dolmage 2017, Kanter 2011). If a blind student cannot read a sign on the door, is that because the student is the problem, or the lack of Braille and large print signage is the

¹³ I discuss three disability models here, but there are many others, including the Moral Model, legal/political models, the functional model, and many others. Disability studies continues to explore how these models may compare, contrast, or merge [need different word] with feminism, Queer, theory, anti-racism work, intersectionality, frameworks and fields that study the construction of identity, culture, and society. For further information about models of disability, please see, e.g., (Ashmore and Kasnitz 2014, Dolmage 2017, Kafer 2013, Kanter 2011).

problem? The social model also expanded upon who could “fix” a situation or eliminate barriers – anyone could do this work (including disabled people themselves) (Ashmore and Kasnitz 2014, Kafer 2013, Kanter 2011). Disability studies is therefore rooted in activism, a desire for social change, and ever-expanding notions of disability (Connor and Gabel 2013, Kafer 2013).

Alison Kafer provided another model of disability in 2013. She critiqued the medical and social models, using feminism and Queer theory (Kafer 2013). People with disabilities often need legal help, medical treatment, or cures for their disabilities – all things that have been associated with a medical model orientation. Kafer’s dialectical social relational model (i.e., the relational model) acknowledges this, and gives people the option of simultaneously using the medical and social models in non-oppressive ways. People with disabilities can appreciate what medicine and other professionals can do, while still fighting ableism and working toward disability rights and social justice for people with disabilities (Kafer 2013).

In higher education, the relational model is not yet widespread. Some groups use this model without necessarily understanding the name or origin of it. For example, the national college student group Active Minds (<https://www.activeminds.org/>) works to end stigma around mental and emotional illnesses, while also encouraging students to seek out the help they may need from doctors and therapists. Even disability cultural centers are largely open to students getting whatever medical help they need, while also supporting students in learning about disability and creating disability community on campus.

The medical and social models of disability did lead to significant shifts in many disability resource offices, where providers of disability services and accommodations considered how institutional norms and practices could create barriers for disabled members of the campus community (Beck, et al. 2014). Some offices have even changed the name of their offices to reflect a focus on accessibility or provision of resources to the entire campus (e.g., Disability Resource Center, Access Center), instead of being disability *services* offices that seem to focus solely on individual accommodations (Beck, et al. 2014, S. S. Scott 2019). And because people with disabilities are part of campus diversity doing anti-ableism work, opportunities emerged for disability community, mentoring, courses, and events (Harbour and Greenberg 2017, Dolmage 2017, Taylor 2011). The social model influenced the development and use of universal design to foster inclusion, with buildings, technology, courses, policies, and activities designed for flexibility and the broadest “universe” of users, including people with disabilities (Ashmore and Kasnitz 2014, Burgstahler and Cory 2010, Dolmage 2017, Harbour and Greenberg 2017, Hehir 2002, O’Keefe, et al. 2020, Tobin and Behling 2018). The social model also led to the neurodiversity movement among autistic people and people identified as having learning disabilities or ADHD (Bauman and Murray 2014). It even led to the disability justice movement, which centered experiences of BIPOC, LGBTQ+, and poor people with disabilities or d/Deafness in movements for social justice (Sins Invalid, 2019), which is critical as there is a long history of racism and marginalization in disability work, and illnesses and disability can be “being weaponized against communities of color in our society and used as a way to spark fear and animosity toward immigrant populations” (Bell, 2006; Redden 2020, n.p.).

Deaf Studies, Culture, and Identity

While disability studies focused on models of disability, Deaf studies focused on cultural and linguistic aspects of d/Deaf people. Before the 1960s and 1970s, deafness was purely biological and viewed through a medical model lens identifying deafness only as a disability (Reagan, Matlins and Pielick 2020). But after linguists realized American Sign Language (ASL) was a unique and complete language, Deaf studies emerged with a sociocultural view of Deaf people as a cultural and linguistic minority group (Reagan, Matlins and Pielick 2020, Ladd 2003).

As Deaf studies evolved, it clarified how Deaf people had their own culture and could not simply be categorized as “disabled” or part of disability studies, which was often audist in its marginalization of Deaf scholars (Monts-Trévica 2019). Audism is defined as the discrimination of people who are Deaf, with hearing and speaking people viewed as superior to d/Deaf people and those using signed languages (H.-D. L. Bauman 2004, Simon 2019, Stapleton 2015). In fact, in ASL, the sign for “hearing” is the same

as the sign for “speaking”. Deaf people began to explore their Deafhood within the DEAF-WORLD¹⁴ where ASL is the preferred language, Deaf can be a cultural identity, and there is great diversity among Deaf people (Bauman and Murray 2014, Lane 2005, Monts-Tréviska 2019, Reagan, Matlins and Pielick 2020, Simon 2019). The concept of DEAF-SAME described the ways Deaf people around the world using their countries’ signed languages were still connected as a Deaf diaspora (Emery, 2015). Another concept that emerged was Deaf gain (as opposed to hearing loss) (Bauman and Murray 2014). Deaf gain (and Black Deaf gain that followed) acknowledged and celebrated the cognitive, creative, historical, and cultural gains in society that are created through Deaf people’s unique “way of being in the world” (Bauman and Murray 2014, xv, Tsegay Moges 2020). As with disability critical theory, Deaf studies and Deaf critical theory built on intersectionality and critical race theory as a way to talk about audism and the marginalization of Deaf people, with attention to the multiple identities and diverse experiences within Deaf culture, including Deaf BIPOC experiences of racism and sexism (Connor, Ferri and Annamma 2015, Johnson n.d., Reagan, Matlins and Pielick 2020, Stapleton 2015, Tsegay Moges 2020). Deaf students, like disabled students, often struggle with assumptions of “Deaf” as a monolithic category, with Deaf people defined only by their d/Deafness, skill with ASL, or use of cochlear implants and hearing aids (Ko 2019, Johnson n.d., Mauldin 2016, Ruiz-Williams, et al. 2015). This topic has even been explored in the popular TV show *Deaf U*, featuring students at Gallaudet University (Martin 2020).

Crippling and Deafening COVID in Higher Education

Defining “Crippling” and “Deafening”

Since the COVID-19 pandemic emerged in December of 2019, it has forced higher education to ask many difficult questions about the purpose of higher education institutions (IHEs), teaching and learning, and many other aspects of colleges and universities, including disability. Given the current availability of vaccines and re-opening of campuses as this article goes to press in 2021, some people in higher education are already talking about a “post-pandemic” world. With the COVID-19 pandemic there is a chance to change higher education’s response from one rooted in medicine and cures, to one also rooted in disability, using the relational model of disability. IHE students and employees can also frame this as “cripping” and “Deafening” COVID-19 responses.

In disability studies, “cripping” is a verb that deliberately reclaims the historically pejorative word “crip,” making it a positive action-oriented word rooted in sociopolitical models of disability (including the Relational Model). Crip theory is also rooted in intersectional disability justice work with resistance to all forms of oppression, while honoring and celebrating complexities of disabled people’s identities (Abes and Wallace 2020, Sins Invalid 2019).

For example, if an instructor wanted to crip the curriculum, they may decide to use universal design and critical race theory, as ways to make their courses more inclusive and welcoming, while also educating themselves and students about equity and diversity. Student affairs or multicultural centers could have events discussing how IHE responses to COVID-19 can be anti-racist and anti-ableist. Administrators could invite diverse disabled and Deaf students and employees to participate in committees shaping COVID-19 policies. When medical and counseling centers on campus meet newly disabled students, professionals could share information about the models of disability and disability resources on campus. IT centers can be sure the online course platforms are accessible, inviting disabled and Deaf people to help with usability and access tests. Crippling higher education means to “imagine a future in which disability does not need to be denied or hidden or tokenized or erased” (Dolmage 2017, 190) and where the campus climate for disability and Deaf people is a priority (Harbour and Greenberg, 2017).

Deaf studies and disability studies have always influenced each other, even if disability studies struggled with audism, Deaf studies struggled with ableism, and they both struggled with racism and homophobia (Burch and Kafer 2010, Monts-Tréviska 2019, Ko 2019, Sins Invalid 2019). Building upon

¹⁴ “DEAF-WORLD” and “DEAF-SAME” are capitalized because this is how they are written in translations from ASL into English gloss.

that relationship, as well as concepts of d/Deafness, Deaf culture, DEAF-SAME, Deaf Gain, and Deafhood, I propose the term “Deafening” as a Deaf culture equivalent of “cripping”. Culturally Deaf people have ingrained habits, skills, and attitudes that they’ve learned through interactions with other Deaf people, affecting the way they see the world around them – something education is only beginning to address (Graham and Tobin 2019). While hearing culture privileges speaking English and hearing, Deaf culture values signing and being Deaf. In many facets of Deaf culture, Deaf people intentionally (or unconsciously) analyze the environment, including the behavior of themselves and others, and then alter that to make it more accessible or Deaf-friendly (H. Bauman 2014, Graham and Tobin 2019). For example, architects at Gallaudet University have researched and implemented the idea of Deaf space and how to effectively “Deafen” architecture, tailoring it to Deaf people by having features like open sightlines (H. Bauman 2014). This process of “Deafening” surroundings would be a Deaf equivalent of crippling.

Crippling and Deafening higher education responses to COVID-19 would involve:

1. Assuming disability and deafness are the responsibility of the entire campus, and not just the domain of groups like health services, counseling, special education, disability studies, Deaf studies, or ASL programs;
2. Taking disability and Deaf culture perspectives to understand how ableism and audism are present, including expectations of able-bodiedness and able-mindedness as “normal,” privileging hearing and using English, and whether definitions of diversity automatically exclude Deaf and disabled people;
3. Using a relational model where medical aspects of disability and deafness do not exclude sociopolitical and cultural perspectives (and vice versa);
4. Learning about, sharing information regarding, and deconstructing audism and ableism to better understand them and how they interact with racism or other forms of oppression;
5. Using universal design as a way to reduce barriers in the curriculum and campus, designing for the maximum diversity of users, including disabled, Deaf, and BIPOC users;
6. Embracing disability studies and Deaf studies through courses and departments in those fields, but also through the infusion of disabled and Deaf perspectives in courses;
7. Doing intersectional anti-ableism and anti-audism work as part of diversity, equity, and inclusion efforts, using Deaf and disability narratives, writing, and research (Abes and Wallace 2020, Connor and Gabel 2013, Fraser 2013; Kafer 2013).

Many higher education students and employees never learn about disability as anything more than a legal and medical construct, to be addressed through adherence to the minimum requirements of Section 504 and the ADA, as well as a reliance on disability, medical and counseling professionals to provide individualized services and accommodations. Even student affairs professionals, who are trained in various aspects of oppression, diversity, and social justice, usually do not know very much about concepts like Deaf studies, disability studies, ableism, or universal design (Shallish 2017, Vaccaro and Kimball 2017).

But as the National Academies of Sciences, Engineering, and Medicine recommended in 2021, COVID-19 must be addressed in cross-campus holistic ways (National Academies of Sciences, Engineering, and Medicine 2021). As students return to campus with disabilities, d/Deafness, chronic health conditions, high-risk family members, and mental and emotional health conditions and illnesses, depending on a few departments will not be enough for IHEs to address all of students’ needs. Epidemics and pandemics of history have expanded higher education’s notions of who is responsible for disability issues, and now COVID-19 is offering opportunities to expand upon that work through “cripping” and “deafening” COVID-19 responses.

Conclusion

“At extraordinary historical moments, there will be correspondingly extraordinary opportunities to stretch boundaries in more radical ways, to abolish old roles, and establish novel ones in service of a

new social order" (Zheng 2018, 877-878). This article discussed how IHEs responded to yellow fever, the 1918 influenza outbreak, polio, and HIV/AIDS, placing the COVID-19 pandemic into a continuum of health crises that have affected (and been affected by) higher education. Throughout previous epidemics and pandemics, IHEs expanded the roles of health and disability departments, and expanded understandings of structural and systemic inequities. Crippling and Deafening COVID-19 gives IHEs a chance to build on this work, using campus-wide collaboration instead of relying on health services, counseling centers, and disability resource centers. Crippling and Deafening use a relational model of disability, where COVID-19 can be a medical condition, but also a socio-political one. It gives IHEs an opportunity to expand the way students, faculty, and staff understand disability and Deafness as part of campus diversity, equity, and inclusion work. All of this places disease, disability, and Deafness into an important part of higher education history, while encouraging IHEs to prepare for other pandemics to come.

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Hierarchy of Life: Whose Lives Do We Value?

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Abstract

COVID-19 has heightened already existing health disparities amongst marginalized communities within the United States. In crisis, whose lives do healthcare systems value most and how are these decisions rooted in ableism and racism? Who is responsible for these inequities and in what ways? This multimedia presentation and companion paper explore these important questions.

Access [the multimedia version on YouTube](#)

The COVID-19 pandemic has uprooted the globe. Especially within the United States, a country in a predicament of division and confusion, COVID has permanently impacted life as we knew it. Lacking support and leadership for almost an entire year, every aspect of disability and disability studies was impacted by COVID. This displacement, worry, and confusion created more barriers for Americans as we ticked through long months of worsening progression. Throughout the past year, the unjust systems of our government were highlighted in this heightened time. Now, more than ever, it is apparent that our healthcare system is failing us. All Americans are susceptible to COVID, but marginalized individuals died at a disproportionate rate—stressing inequalities already in place. America’s resources are immense, but our government structures, healthcare systems, and leadership fell short, often at the expense of marginalized communities. The United States, and the Trump administration, broke its duty to protect the most vulnerable. We can note in the discriminatory crisis standards of care, the lack of legislation to combat climbing COVID cases, the anti-science statements, unequal vaccine rollout, and the lies told by the Trump administration (Appendix), that the administration valued the election, economy, and power over citizens’ lives. Their abdication of responsibility is now reflected in hundreds of thousands of American lives lost, millions impacted with long-term side effects, and an unknown number of families who still grieve. Unfortunately, as long as the United States continues to abdicate responsibility for the most vulnerable, unnecessary and disproportionate deaths will continue at the fault of those in government. We know what happens when leadership takes responsibility and protects citizens; for example, New Zealand experienced only 26 COVID deaths from March 2020 to May 2021. New Zealand was able to achieve this remarkably low death total with the Prime Minister’s detailed “elimination strategy” which included weeks of intense lockdown (Baker 2020). Because of these strict guidelines, New Zealand was one of the few countries in the world with zero active cases, giving citizens the freedom to go maskless at concerts and safely attend large events with over 50,000 people (as of January). We must demand more from our government because we know that capitalist priorities and a lack of responsibility have led to hundreds of thousands of avoidable deaths. There’s a level of responsibility and accountability necessary to govern, a level that needs to be provided— especially if it’s hard. As disability studies scholar Margaret Price puts it: “The problem, as always, is structure. The problem is discourse... We do want things to get better, but we don’t always want to be accountable” (Price, 2021). Those in government chose to be in a position of accountability and responsibility. Abdicating their responsibility is to ignore the job description.

On December 14th, 2020 the United States began administering COVID vaccines and press filmed as Sandra Lindsay received the first Pfizer vaccine in New York. On the same day that the United States began vaccinations, December 14th, deaths were up 70%, as the country reached a new milestone of 300,000 Americans who had already died from COVID. In January of 2021, the U.S. began averaging 200–250k new COVID cases each day, with the total number of cases just shy of 17 million (Coronavirus 2021). As cases skyrocketed, hospitals became overwhelmed with responsibility, patients, and death.

The U.S.’s Lack of Leadership: The Impact of a Reckless Administration

In the United States, the Trump administration did little to properly educate citizens on the pandemic. Rather than confronting the pandemic with a united, thoughtful approach, President Trump allowed reckless herd immunity ideology, anti-mask propaganda, and ignorance to overshadow factual

information about the virus. On December 16th, 2020 the Trump administration was publicly called out for their dangerous disregard of life— email evidence can be read in Appendix 2:

Trump Administration official, Paul Alexander, acknowledged on May 30th that a draft statement from the CDC on how Covid-19 was disproportionately affecting minority populations was "very accurate," but he warned HHS and CDC communications officials that "in this election cycle that is the kind of statement coming from CDC that the media and Democrat [sic] antagonists will use against the president." As the virus spread throughout the country, these officials callously wrote, 'who cares' and 'we want them infected,' according to South Carolina congressman James Clyburn. Clyburn added, "They [HHS officials] privately admitted they 'always knew' the President's policies would cause a 'rise' in cases, and they plotted to blame the spread of the virus on career scientists." Alexander wrote in an email on July 3rd, to the health department's top communications officials, "So the bottom line is if it is more infectiousness [sic] now, the issue is who cares? ... If it is causing more cases in young, my word is who cares...as long as we make sensible decisions, and protect the elderly [sic] and nursing homes, we must go on with life....who cares if we test more and get more positive tests (Diamond 2020).

From: Alexander, Paul (HHS/ASPA) (VOL) [/O=EXCHANGELABS/OU=EXCHANGE ADMINISTRATIVE GROUP (FYDIBOHF23SPDLT)/CN=RECIPIENTS/CN=BC4EDA8AD333439EB3D296AE0E0F9634-ALEXANDER,]
Sent: 5/30/2020 7:29:10 PM
To: Pauley, Scott (CDC/OD/OADC) [REDACTED]
CC: Murphy, Ryan (OS/ASPA) [REDACTED]; Hall, Bill (HHS/ASPA) [REDACTED]; Caputo, Michael (HHS/ASPA) [REDACTED]; OS - Interviews [REDACTED]; Robinson, Michael J (HHS/ASPA) [REDACTED]; CDC OADC ASPA Clearance [REDACTED]; Hensley, Gordon (HHS/ASPA) [REDACTED]
Subject: Re: CDC Proactive Statement: COVID-NET racial/ethnic hospitalization data

Thanks Ryan you are so right and I agree.

Here is the issue: if the communication is left with just the statement that minority groups are at higher risk then on its face this is very accurate, however, in this election cycle that is the kind of statement coming from CDC that the media and Democrat antagonists will use against the president. They are already doing it and accusing him directly of the deaths in the African American community from COVID. This is very wrong for those deaths have more to do with socioeconomic status and each time we talk about these deaths we need to tell the nation why these deaths happened. This was due to decades of democrat neglect, case in point New York.

The Trump Administration and HHS department hired reckless individuals to lead, allowed facts to be skewed, and requested that credible CDC information be withheld from the public. Uncovered within this email chain was explicit support of herd immunity (refer to Appendix 2 for full text). This discovery is especially damaging, as we can now confirm Trump officials were intentionally relying on this ideology. Herd immunity espouses that we should not fear COVID because only 1-2% of those that are infected with COVID will die. Restrictions and health guidelines, under this problematic line of thinking, are viewed as unnecessary to reach herd immunity status, as citizens are called on to keep living as usual—which would supposedly result in a majority being infected without long term consequences. Those who do not develop the supposedly positive impacts of herd immunity would essentially be categorized as a necessary casualty. This ideology is a dangerous, capitalist solution that threatens our shared understanding of viral pandemics. For starters, the exact figures of how many could die is unimaginable, considering 1-2% of millions of infected Americans means thousands of unnecessary deaths. That would be a tragedy so large it is incomprehensible: for those worried about the economy, this would break it; for those worried about their lives and their family's lives, this would threaten them; for those who care for their community, this would destroy it. Herd immunity might

sound non-threatening, since 1-2% appears small, but the unknown number of cases needed to reach herd immunity is a gigantic iceberg and the US is the titanic. It is unfathomable why an administration would harm citizens so openly, treating a pandemic in this manner, while recognizing that marginalized people will be impacted by the most severe consequences.

Sweden was highlighted by some supporters of anti-lockdown policies as a good example of herd immunity. Those opposing lockdowns cited Sweden's loose COVID policies as a prime example of a workable solution, noting that they would quickly achieve herd immunity and then be able to live a normal life. However, Sweden achieved quite the opposite. Nine months into the pandemic Sweden had not yet achieved herd immunity; rather, Sweden was facing the highest death totals compared to neighboring countries: "Sweden's failed coronavirus herd immunity gamble came at a high cost of lives and the country could still have to implement a lockdown to tackle the spread, experts say... Professor Goldsmith examined what went wrong with Sweden's policy and why its case mortality rate is about triple that of its Scandinavian neighbours: "They thought they were going to get this herd immunity nonsense"' (Mann 2020). In November, the Swedish government began abandoning previously lax regulations, closing businesses and imposing more restrictions in order to control the virus. International help was requested as they struggled with peak rates of COVID. Importantly, when looking at who died in Sweden, it is clear that the most vulnerable are impacted at higher rates. One Swedish science group says,

The price for Sweden's laissez-faire approach has been too high. The country's cumulative death rate since the beginning of the pandemic rivals that of the United States, with its shambolic response. And the virus took a shocking toll on the most vulnerable. It had free rein in nursing homes, where nearly 1000 people died in a matter of weeks. Stockholm's nursing homes ended up losing 7% of their 14,000 residents to the virus. The vast majority were not taken to hospitals (Vogel, 2020).

In August of 2020, it became clear that herd immunity was not working for Sweden, yet the Trump Administration continued vocal support of Swedish approaches.

The Trump administration needed to take responsibility for causing a lack of unity, creating distrust in science, and shrinking away from their duty to educate and calm citizens in a global pandemic (Appendix). Instead, harmful, anti-mask rhetoric plagued understanding of how COVID spread, further politicizing safety. Trump continued to spew inaccurate herd immunity propaganda, posted baseless tweets that called to *liberate* states from science-backed regulations, and refused to encourage proper social distancing measures. These deadly decisions impacted, and continue to impact, marginalized communities at a heightened level.

Since we know that the myth of herd immunity leads to exponential, unnecessary death, and we understand that marginalized lives are disproportionately impacted by COVID, if we still choose to accept herd immunity's fate, we are actively, purposefully killing marginalized communities. Stating that "most" will live is a tragic misconception that places the harsh realities of death at a distance. Herd immunity ideology accepts that those who have pre-existing conditions will be at the highest risk, therefore essentially arguing that their lives are less valuable to attempt saving. Older populations, those with disabilities, and anyone concerned of the long-term potential consequences of COVID infection must converge together and reject the concept of herd immunity. Returning to "normal life" is not worth hundreds of thousands of families suffering from loss. The ignorance towards responsibility accompanied by the fascination of "normal life" is seen throughout the U.S. from governors who remove mask mandates to President Trump pushing for the reopening of schools without proper safety (Appendix). Government officials are responsible for creating safe environments that don't kill citizens before they are responsible for in-person bars and a return to movie theaters.

Restrictions were lifted way too early, as hospitals were already near capacity and struggling from months without proper support. However, the Trump administration ignored its responsibility to citizens and continued promotion of an anti-science agenda, which led to the fateful overcrowding of hospitals.

Hospital Overcrowding Fueling a Hierarchy of Life

Hospital overcrowding is one of the greatest threats COVID-19 creates for our healthcare system. When outbreaks occur in states and cities, generating record high hospitalizations, doctors reach their limits, beds fill, ventilators become scarce, and PPE gear is rationed, and patients don't stop coming through the doors. Throughout the fall and winter of 2020-2021, hospital waiting times skyrocketed, with some patients being turned away from ambulances and others waiting over a day to receive care (Meeks, Maxouris, & Yan 2020). At that level of hospital overcrowding, the system reaches its breaking point— meaning that every life in the region is in perpetual danger. Once hospitals are overcrowded, there is no space for any emergency or illness, regardless if it is COVID or not. Strokes, car accidents, overdose victims: no one is able to receive treatment if the entire system is overwhelmed. All surgeries are put to the side to be debated on whether they are truly necessary or not:

"We have a big backlog in hysterectomies ... knee replacements, hip replacements -- anything that can be put off. Is it optimal? Never. If somebody needs a spine surgery or a hysterectomy, it's borderline whether it's truly elective. But we're so crunched for staff, we have to make those decisions" (Yan 2020).

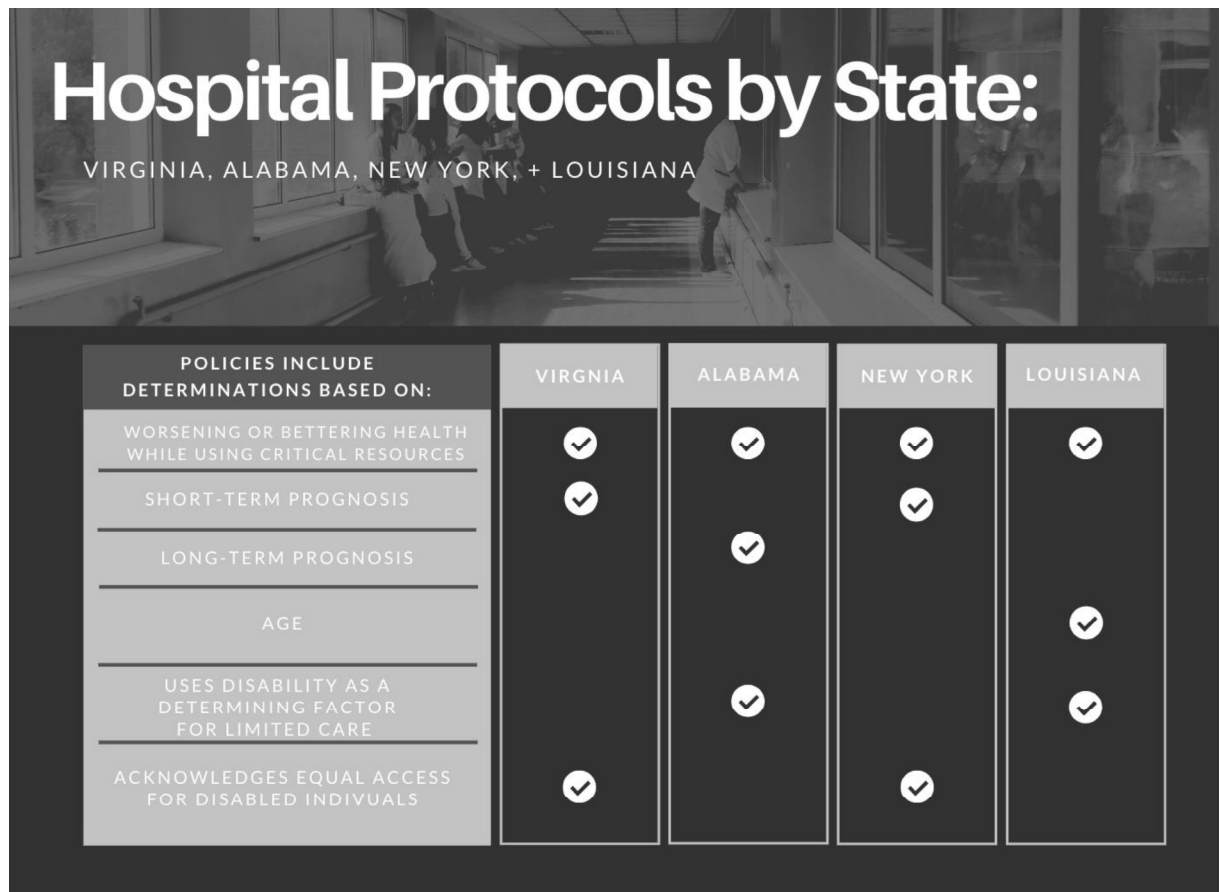
In late summer of 2020, only some regions of the U.S. were facing this immense overcrowding which resulted in travelling volunteers relocating to the most impacted states. Later on in December and January, most states were experiencing their highest rates of COVID and there wasn't enough power or capital to tackle every case at once. Hospital overcrowding is one of the most serious consequences of COVID: the implications of the virus are extreme and far-reaching, meaning that every patient is at greater risk.

As I discuss the implications of hospital overcrowding, it is important to keep in mind that the United States was put in this position because of incompetent, irresponsible leadership. By ignoring science and furthering dangerous living conditions, U.S. officials contributed to hospital overcrowding. Doctors were put in these positions because government officials blatantly ignored their own responsibilities. State health officials had to enforce crisis standards of care because state politicians and government officials didn't enforce needed COVID restrictions. Dr. Birx, the White House Coronavirus Response Coordinator during the Trump Administration, stated that hundreds of thousands of COVID deaths, "in my mind, could have been mitigated or decreased substantially" (Wade 2021). This comment furthers the assertion that the United States did not do enough for its citizens when leaders *could have*. Trump, and his administration, failed Americans by ignoring their responsibility for public health and safety.

The most ethically challenging issue of hospital overcrowding is choosing which lives will be prioritized. Strategies on how to choose between lives vary between regions and hospitals; however, many states responded to the problem by utilizing crisis standards of care, a set of standards used to determine patient prioritization. In some regions, age was a deciding factor between patients in similar situations; depending on the protocols, a younger person may be overtly valued because of their youth and chances of survival, while in other locations medical professionals may assume that an elderly person is the priority for life-saving treatment. Protocols for ventilator removal also varied: some policies specifying that bettering health should result in removing a patient from a ventilator, while other protocols use bettering health as a measure for continuing ventilator usage. The standards for receiving care depended on the location because there was, and is, no nationwide mandate for which patients to treat first in a pandemic crisis.

El Paso, Texas is one example of a region that experienced excessive loss due in large part to Covid's impact on minority populations. In El Paso, residents frequently reside in intergenerational housing, which according to reports allowed the virus to spread even more rapidly. In October, regional hospitals were wrecked with patients, leading to some being airlifted as far as San Antonio, which is over 550 miles away. El Paso was forced to convert the convention center into a makeshift hospital, while other employees worked in parking lot tents (Yan).

This range in care, due to the lack of a national policy, allowed some states to create unjust, biased, and ableist determinations. Alabama is one state that narrowed in on disability, calling for doctors to provide those with disabilities less quality of care. Alabama's exact policy is that those with: "severe mental retardation [*sic*], advanced dementia or severe traumatic brain injury may be poor candidates for ventilator support", even though "the average life expectancy of persons with mental retardation now spans to the seventh decade and persons with significant neurological impairments can enjoy productive happy lives" (Fink, 2020). Clearly, Alabama used outdated and offensive terminology and information to make inconsistent, life-threatening assumptions during the pandemic. Furthermore, the use of this discriminatory language highlights how policymakers did not, and do not, listen to disability groups and consider this vulnerable population appropriately. Disability advocates filed federal complaints against Alabama's blatantly ableist policies. Other states used policies that were flagged as discriminatory, too—for example, in Louisiana, doctors could exclude patients with severe dementia as candidates for ventilator support. Initially, Alabama ranked those with AIDS as low priority, using AIDS as a determining factor in whether a patient would receive a ventilator (Fink 2020). Maryland and Pennsylvania assigned points to patients to determine who would receive treatment first. Age was usually used as a tie-breaking point factor, but pregnancy could add additional points as well (depending on how far along the fetus is developed). Some states considered how patients' pre-existing conditions would impact their life in 10+ years, while others only looked at the next year when determining life expectancy chances. These rationing policies are described as "crisis standards of care" and in response, the U.S. Department of Health and Human Services issued a [bulletin](#) on March 28, 2020 reminding states that their plans should not discriminate (Whyte 2020).



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When considering crisis standards of care, it is important to analyze what standards are discriminatory versus medically necessary. These standards inadvertently created artificial barriers to access and treatment. In a state of emergency with limited availability, there can be medically necessary reasons for prioritizing some lives over others. For example, Virginia and New York used short-term prognosis to identify which patients had terminal conditions that would likely impact them within the next year. In these situations, imagine a patient with end-stage cancer; in this scenario it may be most ethical to prioritize another patient in a similar situation without any short-term prognosis concerns. From a purely statistical standpoint, if there are lives that have stronger chances of survival, and decisions must be made quickly, using guidelines to decide health practices is not necessarily discriminatory. However, policies like Alabama's were clearly grounded in a medical model framework that privileged particular lives. Alabama used long-term prognosis, a standard that attempted to envision how underlying conditions a patient had would impact them in the future in order to determine the value of their life compared to another patient. This is a discriminatory health standard because it involves a morally qualitative assumption. If a policy assumes that life for a disabled person has less worth, because the policymaker has deemed disabled quality of life lower than the normative standard, the policy is inherently ableist. Assuming that one's quality of life should be a measure for further care is an inexcusable rationale for reducing said care. These standards pave the way for ableist and racist

¹⁵ (Virginia Department of Health, 2020), (Louisiana Department of Health, 2019), (New York State Department of Health, 2015), (Alabama Department of Health: Crisis Standards of Care, 2020)

practices to persist in a healthcare setting, giving too much power and responsibility to individual providers. Taking health factors into account is important, but what are the assumptions? Some of the states above used outdated and vague generalizations to assume the worth of patients. Disability groups had to challenge these policies in court, arguing for equitable treatment because the federal government didn't ensure equitable care to begin with. The subconscious, societal norm of disabled lives being worth less was heightened in the pandemic: "The idea that poverty, isolation or even early death is somehow natural for disabled people is still worryingly prevalent" (Crippen 2020). The fact that disability groups even needed to argue for their own care during a pandemic, highlights the implicit and ongoing shortcomings of our health system.

The Hippocratic oath binds healthcare workers to treat the ill to the best of one's ability, but how does this promise shift in a pandemic state? A third-year medical student wrote:

Yet in this virtual and sheltered limbo, we are faced with the difficult process of redefining what this oath now means. Over the coming weeks, the path to honoring our oath is no longer so clear as we navigate the uncertainties of virtual clerkships, postponed licensing exams, and where to best extend our efforts outside of the clinic (Zhou 2020).

Students are graduating into a torn healthcare system, expected to perform duties that were taught while the system was still, at least somewhat, intact. The hippocratic oath has a completely different meaning in this overwhelming era of crisis. For new medical professionals who don't have the experience or perspective to navigate such complexities, this oath is tangled even further. How are doctors expected to treat to the best of their ability if resources are nonexistent and systems are clogged beyond what is fixable from an individual level? Individually, doctors can only do so much in order to treat patients when the overarching system is failing.

Using social media as a tool, I found interviews and comments from healthcare workers across the country in order to understand specific instances of overcrowding in different U.S. cities. Furthermore, these quotations show the level of stress healthcare workers faced throughout the pandemic. Interviews from across the country detailed exhausting work conditions, worry, and fear. In Wisconsin, the state set up makeshift beds at the Wisconsin State Fair Park, leaving the doctors spread thin: "that means that I had the challenge of managing ICU-level care in my ER for hours, which is obviously not routine" (Stone & McMinn 2020). In Long Beach, healthcare workers reflected on peak levels of COVID, "St. Mary Medical Center officials said the effects of the winter surge remain, with staff being emotionally, mentally and physically exhausted" (Richardson 2021).

In order to better understand the impact COVID created for healthcare workers, here are some more comments from responders across the country:

- *"We are depressed, disheartened and tired to the bone,"* said Alison Johnson, director of critical care at Johnson City Medical Center in Tennessee, adding that she *"drives to and from work some days in tears"* (Weber 2020).
- *"You have to be really clear about what you are trying to achieve,"* said Christina Pagel, a British researcher who studied the problem during the 2009 H1N1 flu pandemic. *"Maybe you end up saving more people but at the end you have got a society at war with itself. Some people are going to be told they don't matter enough"* (Fink 2020).
- Dr. Lee Daugherty Biddison said that it's *"uncomfortable excluding patients with underlying health issues. Preconditions don't always predict survival from respiratory viruses, and having chronic diseases like diabetes, kidney failure and high blood pressure often tracks with access to medical care. Rationing based on these conditions would be essentially punishing people for their station in life"* (Fink 2020).

These comments from doctors across the nation represent a small part of the story. At the crux of this pandemic are healthcare workers who are taking on the weight of a global pandemic, and they feel alone.

Dr. Calvin Sun, an ER doctor in NYC, wrote on Instagram about his concerns for the long-term repercussions of an overwhelmed healthcare system. Dr. Sun has spoken online before about the “final wave” of COVID, not necessarily meaning the final peak in cases, but more so a cumulation of exhaustion that the country will face in the months and years to come. Some healthcare workers are already in the final wave of exhaustion, hitting a wall of mental capacity. This final wave that Dr. Sun foresees could result in lasting trauma for essential workers, and potential mental health concerns such as PTSD. Sun also wrote of the changing perception of healthcare workers from March to December, “We have come a long way from the 7:00pm applause.” With this changing perception, and the impact of the “final wave,” he requested, “Don’t forget us when this is all over, and one day, we will all get through this together” (Sun, 2020). Dr. Sun articulates what healthcare workers are describing across the country, as new extremes of COVID are overwhelming hospitals, without recognition or support for our doctors. Doctors and nurses are forced to choose between patients: who receives the ventilator, what ages are prioritized first, who is given an ICU bed, all without proper support for themselves. The long-term impacts of working long hours without seeing family, risking their lives to save others, and working in field hospitals for healthcare professionals are concerning. Healthcare workers are already citing heightened levels of anxiety, with some using their time off to avoid making more of these intense ethical decisions.

We cannot forget intersectionality, either; Black, Indigenous, doctors of color, are often placed in more vulnerable positions of work in health care settings (Shoichet, 2021). It would be a disservice to healthcare workers to not acknowledge intersectionality. Those impacted by multiple marginalized identities are often ignored, yet we know and must acknowledge that racism, ableism, sexism, classism, and other forms of oppression all intersect and can further dismiss the assumed value of life in care settings (Bowleg 2020). With standards of care that attack lives deviating from the medical norm, intersectionality increases the risk of dismissive harm. Furthermore, healthcare workers may be asked to work in these traumatic conditions while also managing their own mental illness or disability—and they need a break just like every other human. The pandemic has added an enormous amount of stress. PTSD, anxiety, depression, and other concerns are valid and expected in a crisis period like this. Healthcare workers are overworked, without vacation or paid time off, working double time without seeing family, and when they are able to see family they have heightened fears of spreading COVID. There is a larger responsibility to those working in these conditions, and to the most vulnerable communities across the U.S., a responsibility that has been ignored by leaders who promised to protect us.

COVID’s Impact on Disability: Privilege in a Pandemic and Disproportionate Risks

Those with disabilities are put in a stalemate position, unable to receive the same amount of assistance as before COVID, or having to risk COVID exposure in order to receive this assistance and care. Caretakers are also put in the ethical dilemma of remaining safe outside of work in order to not spread COVID to patients with pre-existing conditions. One research study looked at 11,000 individuals with intellectual and developmental disability throughout the first 100 days of COVID:

In the first 100 days of the COVID-19 outbreak in the USA, we observed that people with IDD living in congregate care settings can benefit from a coordinated approach to infection control, case identification and cohorting, as evidenced by the low relative case rate reported. While all congregate living settings pose challenges for infection control with a highly contagious pathogen, we believe that vigilant infection control procedures, case and exposure documentation and real-time data analysis can be enablers of optimal, coordinated outbreak response. (Mills 2020)

Living in a care setting is a unique challenge for those with disabilities throughout COVID. Caretakers are in a dynamic position, bringing the responsibilities of their job with them as they navigate their personal life. Mills’ study explains how care settings can work to be the safest place during COVID for those who need live-in care treatments. However, not all individuals who need care are in the position to afford live-in care. Many rely on appointments, therapy, or rehabilitation treatments regularly, all of which are more difficult to safely replicate during a pandemic. Choosing

between maintaining safety without receiving care or risking safety while receiving care is a difficult decision to make, and one that shouldn't have to be made.

While it is hard to navigate these decisions, a decrease in care cannot be accepted, especially as COVID stretches on for an undetermined amount of time. There have to be compromises that can work for both caretakers and patients. In the first few months of COVID, many dental care providers stopped providing care due to COVID restrictions. Since, individuals with intellectual disabilities are at an increased risk for dental hygiene complications, they may lack the same access to direct support systems which can help them maintain daily hygiene. This is one example that shows how eliminating all care options throughout COVID is ableist, and virtual options are not always comparable or even accessible. In a response to this denial of care, Viroj Wiwanitkit wrote that, "it is necessary to have a good adjustment aiming at the best advantages for the patients" arguing for the importance of continuous support for vulnerable patients (Wiwanitkit 2020).

For those with disabilities, COVID may also impact rehabilitation and emotional communication: "Forbidding access to visitors or strongly limiting their access to hospitals not only has had a terrible psychological impact on severely ill patients but is going to limit the occasions for fruitful interactions amongst patients, caregivers and operators in rehabilitation settings" (Leocani 2020). Limiting access to visitors is a decision that is made for the *greater good*, but this generalization creates inequitable care. Some individuals cannot navigate hospital settings alone and need access to support systems such as family, communication professionals, or mental health professionals. With rigid restrictions offering no flexibility for a range of patients, quality of care becomes unequal. Healthcare settings must offer some flexibility for those with disabilities so that individualized care can be achieved in medical settings that are most crucial to maintain throughout a pandemic.

Educational concerns in the COVID pandemic

Another space that has become more challenging throughout COVID is education. For children with disabilities, the transition online was not always smooth. Some locations did not give children with disabilities proper structures to continue distanced learning effectively, even during the pandemic (Diamant 2020). To create equitable education, children with disabilities may need more support in these new learning spaces: "Finally, the closure of schools may deprive disabled children of dedicated personalized teaching activities in a social and stimulating environment, and a higher price will be paid by all in the future. A massive investment is needed to develop dedicated facilities, human and technological resources to overcome and limit the risks that disabled children become neglected and isolated" (Leocani 2020). The massive investment Leocani calls for is unlikely in an area that is consistently underfunded, especially during a pandemic in which the previous administration provided limited funding to crucial structures. The Trump Administration had a choice in what they funded throughout the pandemic, and chose to fund tax cuts for large corporations rather than support local infrastructure like schools. Disruptions to these academic settings hurt children, especially those who were already struggling, further displacing them from peers:

As courses are designed, deliberate choices can be made to prevent barriers imposed by a "one size fits all" instructional model... the individual medical condition of each student, any change in the prevalence of COVID-19 infections during the academic year — is a key issue, and flexibility is an important response (Charmatz 2020).

The COVID-19 pandemic also raised stress and anxiety levels for many, contributing to mental health concerns for students. For students labelled with anxiety, attention concerns, or other disabilities who already faced barriers, the transition to online class exacerbated these concerns. Individualized, flexible learning is easiest to accomplish in-person, and asking faculty to create flexible learning plans for each student in an online platform is hard. Furthermore, in spaces that have returned to in-person instruction, students may contract the virus and ultimately deal with a serious case that leads to long-term health consequences. The number of individuals impacted by COVID grows the longer COVID progresses. In an article on preparing to serve students with COVID-19-related long-term disabilities,

including COVID longhaulers, Bedrossian (2020) asserted that schools must work with students to ensure that equitable education can be created for all:

In these unprecedented times, DS professionals must recognize the long-term effects of COVID-19 and its impact on students, then actively disseminate relevant disability support services information. Encourage, engage, and evaluate self-identifying students who may have recently acquired COVID-19-related disabilities, and thoughtfully accommodate both virtual and on-campus students through the interactive process.

Long-term impacts

With a virus as unpredictable as this, there is no knowing how long symptoms will last for those with serious health conditions or those contracting more dangerous strains. The long-term impacts of COVID-19 are still unknown, yet millions are treating the pandemic as a two-week journey. Dr. Fauci urged close monitoring of survivors who may experience fatigue syndrome, PTSD, PICS, respiratory issues, heart issues, blood clots and additional dangerous side effects. After 14 days, some may assume that the symptoms will subside and normal life will continue on. However, research shows that COVID victims can suffer with the virus for months after, some facing permanent health damage:

In late July 2020, the CDC reported that 39% of nonhospitalized people, most under 49, experienced lingering effects two to three weeks after testing positive, and projected that as many as one-third of COVID-19 patients will have even longer-term symptoms, including young, healthy people and nonhospitalized patients (Bedrossian 2020).

Disabled individuals needed proper care and support throughout the pandemic; however, the United States didn't even provide basic care to citizens in the first year of COVID. Proper systems of support needed to be created for all, including stimulus checks early on, mandatory lockdown orders to stop the initial surge in spread, and national mask laws. Unfortunately, in most cases, the lack of basic support for all meant that support for disabled individuals moved to the back burner.

Skewed Vaccine Distribution

Vaccine distribution in 2021 created an opportunity for the new U.S. administration to prioritize equity. Like COVID hospital protocols, the responsibility of vaccine distribution was mostly delegated from or at the state level. While the federal government continued to secure doses of the COVID vaccine, they often distributed them directly to state governments for further distribution. Most states began by prioritizing healthcare workers, the elderly, and those with pre-existing conditions. However, officials had to monitor many considerations (including vaccine registration, identification protocol, and travel distance) to create the most efficient and responsible distribution plan. Vaccine distribution needed to be held to a standard of equity—a standard that wasn't seen in pandemic protocols during the Trump Administration (i.e.: hospital policies, distrust in science, misleading and incomplete information from officials.)

The digital divide in the United States is apparent when analyzing the efficacy of online vaccine registration. Those with unstable internet or improper technology are at a marked disadvantage, unable to register to receive the vaccine even when they qualify. Furthermore, those operating without tech literacy face similar struggles; some are unable to find registration sites or complete the information properly. (Saha 2021). Even when someone is eligible to receive the vaccine, if they lack convenient access to wifi, they won't receive the dose on time or at all. Additionally, Universal Design is often absent from the registration websites, between hard to find web pages and poor UX registration tools. Many of these sites are provided in English only, creating further unnecessary barriers.

Another factor that initially delayed the vaccination process was the limited number of vaccination sites, which contributed to the distance that one had to travel in order to receive a vaccine. Some states prioritized multiple options for vaccination sites better than others depending on the infrastructure, financing, and supply of workers. Typically, wealthier areas had more vaccination sites than low-income or rural locations. In Florida, white, wealthy Americans were four times more likely to

have had the vaccine than Black Americans in the same state (Gandel 2021). Furthermore, politics strongly influenced vaccination distribution as well. For example, Ron DeSantis was accused of “using the vaccine distribution plan to appeal to donors; he has raised more than \$2.7 million in February alone since he began the “pop-up” clinics, the Herald reported” (Shepherd 2021). The governor of Florida played a role in at least two specific and concerning incidents. First, in January, an ultra-wealthy and exclusive community in Key Largo received enough COVID vaccine doses for 1,200 residents over the age of 65, while the rest of the state’s seniors struggled to gain vaccine access. The way in which the community received them is still unclear, but the contrast of waiting, registering, and traveling for vaccination was quite drastic compared to the vaccine delivery and short wait times for the wealthy Key Largo community. Importantly, this community has donated hundreds of thousands to the DeSantis campaign just within 2021 (Goodhue & Klas 2021).

Another hardship in accessing vaccine doses was the act of defending one’s disability as legitimate. Depending on the state, proving disability and need for a vaccine was arduous. Illinois, for example, stated that those eligible for the vaccine because of medical reasons could expect that “Providers, as a best practice, will also request documentation or proof, such as personal identification, employee verification, or documentation of a qualifying health condition or disability to confirm the individual is in the priority population being served” (LA Times 2021). As a result, an individual needed a doctor’s note, prescription medication, a disability ID, or proof of disability income to prove that they are eligible for the vaccine. By contrast, other states, such as Virginia and California, didn’t require any proof of disability to confirm eligibility to receive the vaccine (VDH). After a full year of living in a pandemic, requiring proof could be difficult as individuals may not have the required documentation or their documents may have expired. In these cases, pandemic life didn’t make it easy to access your doctor in order to receive a note or other ID form. Disability groups took charge, calling for streamlined access and the removal of these barriers, but some states still failed to prioritize accessibility (Musumeci & Chidambaram, 2021). However, it is worth noting that the Biden Administration was able to increase vaccine supply and administer doses at a much faster pace, exceeding original predictions for vaccine rollout. Within the first 100 days of the Biden Administration, over 2 million vaccines were administered. At the time of this writing, May of 2021, most states have simple walk-in appointments for citizens still needing the vaccine.

Equity across communities was not achieved in the early stages of the COVID vaccination process. Vulnerable communities often lacked the access and tech literacy that online registration requires. Between limited vaccination sites in low income areas and assuming levels of internet stability, there was a widening gap in healthcare accessibility. This divide extended beyond vaccine hesitancy, a concept which oversimplified the inequity and blamed marginalized victims for lower vaccination rates (Corbie-Smith 2021). Often, lack of access to information in marginalized communities (on how to register, where to go, what locations are currently vaccinating, and so forth) is one reason for lower vaccination numbers—which many mislabel as hesitancy. This isn’t to discredit the concern of vaccination hesitancy, as marginalized people have every reason to be hesitant about medical innovation as their bodies have been sacrificed and abused in some truly unethical ways. Using hesitancy as a scapegoat is an unfair burden upon those who are already at a disadvantage in receiving vaccination.

Furthermore, it’s important to recognize hesitancy that all communities are susceptible to through misinformation. For example, according to one poll, “at least 41 percent of Republicans don’t plan to get vaccinated” (Alcindor, Y., Fritz, M., Wellford, R., & Murrey, 2021). Additionally, this statistic of Republican hesitance should not be overlooked, as it is a direct result of the Trump Administration’s anti-science rhetoric, among other factors, including socioeconomic disadvantage. From this poll, we can note that the damage done by Trump’s communication or lack of has continued, leaving the Biden administration with the task of both vaccinating millions of Americans *and* having to create trust in the vaccine.

The Uncertain Future of the United States

Through baseless herd immunity governance, ableist and inconsistent hospital protocols, and racist vaccine distribution plans, the United States has failed to support Americans equitably. When we return to the question of whose lives have been valued throughout the pandemic, it's tough to answer. Not because there isn't a clear answer, there is, but because the principles we hope America stands for, equality and justice, have failed. While it may not be surprising, in light of many other inequalities that burden the U.S., it's still hard to accept where we currently find ourselves. The longer the United States attempts to operate through the pandemic, the more obvious it is that Americans are polarized to a new extreme. The age-old concept of Americans binding together in tough times, coming together for the sake of, and goodness within, is revealing itself as untrue. We won't emerge from this pandemic if we work individually, "it's become obvious that not only are there rarely individual solutions available... there are also rarely individual villains involved" (Price, 2021). As we grow numb to the number of deaths and cases that plague our towns, watching as protests emerge discrediting science and empathy: the collapse of humanity begins. What began as a few weeks of quarantining became, and for some continues as, a politicized era of distrust, in the hands of incompetent former leadership. There are always struggles faced by the disabled community, but this pandemic increased those concerns across every aspect of healthcare. Films and novels have typically shown the triumph and the greatness that emerges in a time of defeat, but a new consensus is forming. Maybe, when there is no limit on what we are willing to compromise in order to keep our *freedoms*, there is a limit to what Americans can defeat. Our collective defeat may be so crushing that we do not emerge unanimous, united.

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Author Addendum:

I initially wrote this piece last fall, November 2020, in a graduate-level disability studies course. I was fully online (still am), living at home immersed in COVID and election news as cases continued skyrocketing. And while this article has held my interest for seven months now, writing it has felt close to impossible. Every single day there is more information that comes out, implicating the Trump administration and shining light on further inequalities that have happened and continue to happen. In this COVID chamber, there is constant noise that needs to be filtered though— but this noise is *all* important. I've edited, revised, and added to this work almost every week for the last half of a year, but it still doesn't encompass even a fraction of the disparities COVID has heightened. I'm sure that by the time this is published, and in the future, even more important information will have emerged, but I can't write forever! Instead, this work looks to question *who* the U.S. has prioritized and valued in the past year. In no way is this complete—it can't be. It's important to publish and archive the U.S.'s response to COVID, but there are further research avenues to pursue in the future. While this article looks to some specific hospital policies as a guide for determining what lives were valued, there are other denominators that would be interesting to seek out. I would also be interested in aftermath research, surveying specific communities to identify what aspects of COVID were most detrimental with more certainty than my article is able to.

Appendix 1:

The Timeline of COVID Events and Presidential Communication in the U.S:

Green	tweet: △
Blue	statistic/fact: □
Purple	interview: ○

□First case of COVID detected in the U.S.	January 21, 2020
△“We have it totally under control. It’s one person coming in from China. It’s going to be just fine.”	January 22, 2020
○“It’s also more deadly than even your strenuous flu... This is deadly stuff.” [to Bob Woodward in a private interview]	February 7, 2020
△“It’s going to disappear. One day, it’s like a miracle, it will disappear.”	February 27, 2020
△“This blindsided the world.”	March 9, 2020
△“LIBERATE MICHIGAN!” (in reference to mask mandates)	April 17, 2020
△Trump promises hundreds of millions of vaccines distributed within 2020.	May 15, 2020

<input type="checkbox"/> United States COVID-19 death toll surpasses 100,000	May 28, 2020
<input type="checkbox"/> HHS email sent	May 30, 2020
<input type="checkbox"/> “I think we have one of the lowest mortality rates in the world”	July 19, 2020
<input type="checkbox"/> “OPEN THE SCHOOLS!!!”	August 3, 2020
<input type="checkbox"/> “Don’t be afraid of Covid.”	October 5, 2020
<input type="checkbox"/> “But it’s going to disappear, it is disappearing.”	October 10, 2020
<input type="checkbox"/> Trump tests positive for COVID-19	October 12, 2020
<input type="checkbox"/> “Cases up because we TEST, TEST, TEST. A Fake News Media Conspiracy. Many young people who heal very fast. 99.9%. Corrupt Media conspiracy at all time high. On November 4th, topic will totally change. VOTE!”	October 26, 2020
<input type="checkbox"/> Promise to vaccinate 20 million, with 40 million doses, by the end of December.	December 4, 2020
<input type="checkbox"/> First vaccine distributed in the U.S.	December 14, 2020
<input type="checkbox"/> 250,000K new cases per day in the U.S.	December 19, 2020
<input type="checkbox"/> 2.8 million people had received vaccines, short of the 20 million promise.	December 4, 2020
<input type="checkbox"/> Roughly 16.5 million vaccines <i>administered</i> in total.	January 20, 2021 - last day of Trump presidency
<input type="checkbox"/> Biden promises 100 million <i>shots</i> within the first 100 days of his presidency.	January 20, 2021
<input type="checkbox"/> After 58 days of the Biden presidency, 100 million <i>shots</i> were administered.	March 18, 2021
<input type="checkbox"/> After 100 days of the Biden presidency, over 200 million shots were administered	April 28, 2021

Appendix 2:

From: Alexander, Paul (HHS/ASPA)

Sent: 5/30/2020 7:29 PM

To: Pauley, Scott (CDC/OD/OADC) [REDACTED email address]

CC: Murphy, Ryan (OS/ASPA) [REDACTED email address]; Hall, Bill (HHS/ASPA) [REDACTED email address]; Caputo, Michael (HHS/ASPA) [REDACTED email address]; OS-Interviews [REDACTED email address]; Robinson, Michael J (HHS/ASPA) [REDACTED email address]; CDC OADC ASPA Clearance [REDACTED email address]; Hensley, Gordon (HHS/ASPA) [REDACTED email address]

Subject: Re: CDC Proactive Statement: COVID-NET racial/ethnic hospitalization data

Thanks Ryan you are so right and I agree.

Here is the issue: if the communication is left with just the statement that minoring groups are at higher risk then on its face that is very accurate, however, in this election cycle that is the kind of statement coming from CDC that the media and Democrat antagonists will use against the president. They are already doing it and accusing him directly of the deaths in the African American community from COVID. This is very wrong for those deaths have more to do with socioeconomic status and each time we talk about these deaths we need to tell the nation why these deaths happened. This was due to decades of democrat neglect, case in point New York.

‘Shad’ Never Made Them Happy: Pandemic and a Dis-abling Educational System - Case of Iran

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Purdue University, USA**

**Abouzar Samiei, PhD candidate in Cultural Policy Making
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Abstract

As the pandemic began, Iran quickly faced the worst outbreak in the Middle East during the winter of 2020. Traditional schools were consequently transferred to an online education without implementing appropriate adaptations, and restrictive policies of low-speed Internet and censorship negatively affected the quality of online education. The situation became even worse for Iranian students with disabilities. The Ministry of Education designed a new application, named Shaad (means happy), which was and remains inaccessible for people with disabilities. This qualitative research study explores the educational challenges of the Iranian students with disabilities during the pandemic. The authors argue physical and attitudinal barriers that Iranian students with disabilities have been systematically grappling with, have, in fact, transformed to an online version. The authors situate the findings in the social and political contexts of the Iranian society, showing how an ableist educational system has dis-abled people with disabilities.

Iran has a 70-year history of providing educational services for students with disabilities who are called ‘exceptional students’¹⁶. The Exceptional Education Organization was established in 1991 to unify various small organizations that were sporadically rendering services to different groups of students with disabilities. The so-called ‘exceptional students’ consist of the individuals labelled with physical, mental, visual, and hearing disabilities, emotional and behavioral disorders, and those on the autism spectrum. 152,000 students with disabilities are identified in Iran 80,000 of whom study at the special schools whereas 72,000 individuals with disabilities benefit from inclusive learning (Moj News, 2020). In Iran, 8,373 students with visual disabilities study at 913 special schools. Out of 15,000 students with hearing disabilities 5,000 individuals study in special schools whereas 10,000 experience inclusive education (IRNA, 2020). Precise statistics on the numbers of the other groups of students with disabilities are not available.

¹⁶ To avoid using the biased term “exceptional” in this paper, the authors have applied “students with disabilities” as a general term.

Online education was rarely practiced in Iran's formal education system before 2020. The COVID-19 pandemic forced a shutdown of schools in Fall 2020, and the Iranian education system (as well as special education) shifted to online education unprepared. It took six months for the state to design and launch a new application for eLearning. Shad, The Educational Network of student (Persian: شبکه آموزشی دانش‌آموز) was launched in April 2020. Meaning 'happy' in Persian, Shad, the country's official communication and educational software, is owned by the Ministry of Education, and its main users are students and teachers with and without disabilities.

Shad marked the first Iranian e-Learning software to be officially used nationwide; yet, its functionality was soon questionable. Many Iranian teachers and students have been criticizing the usability of online education in general and Shad in particular. They also criticized the officials' failure to prepare the country's infrastructure for a sudden shift from traditional to online education. Numerous students, particularly in the rural and underprivileged areas, still do not have access to internet connections, let alone such expensive electronic devices as mobile phones and laptops. A member of the Islamic Parliament announced that 30 to 40 percent of the students in small towns and villages dropped out of online education because of the internet inaccessibility (Khabarban, 2021). For example, in Khorasan Province alone, 40 percent of students with disabilities quit during the pandemic (Bashgah-e Khabarnegaran-e Javan, 2021). Even the non-disabled students and teachers who were more or less able to use Shad criticized this application for its inefficiency and many technical issues (Ghadarkhan, 2020). Learners and educators were pushed to use other apps, such as Telegram and WhatsApp, which are basically designed for interpersonal communications rather than educational purposes.

Designed for the non-disabled students only, Shad left individuals with disabilities behind in online education. Although the Exceptional Education Organization has defined one of its responsibilities as "Continuous modification and adjustment of the current exceptional education system following the latest achievements in the global special education pedagogies" (Exceptional Education Organization, 2015; translated from Persian into English by the authors), the organization did not take any action to either remove the new platform's barriers or develop an accessible platform for the users with disabilities.

While usability and accessibility of Shad for students and teachers with disabilities has been limitedly discussed in the mainstream media, this research investigates the functionality of Shad from the viewpoint of students and teachers with disabilities.

Review of Literature

Disability-related studies in Iran suffer from various issues, including methodological problems, plagiarism, and medicalized approaches towards disability. Therefore, the paucity of authentic and reliable studies that investigate disability in general and online education for students with disabilities in particular makes the review of literature difficult. Instead, a brief review of the non-Iranian studies on online education for people with disabilities might help the Iranian disability community with the development of online education and its necessities in both theory and practice.

The earliest studies on online education and people with disabilities analyzed the technical aspects of eLearning at its first stages of development. Most studies focused on online education technical concerns, usability, accessibility, applications, and universal design, suggesting ways to make online education fully accessible for various types of students with disabilities (e.g. Kim-Rupnow, Dowrick and Burke, 2001; Cook and Gladhart, 2002; Abell, Bauder, and Simmons, 2004; Tobin, 2004; Keeler and Horney, 2007; Burgstahler, Anderson, and Litzcow, 2011; Lazar and Jaegar, 2011).

For sure, eLearning initially had a number of technical issues. Cook and Gladhart (2002), for example, listed the shortcomings of online education for students with disabilities as: the lack of awareness of how students with disabilities use online content, increased but inaccessible online resources, issues with translating text to voice, not labelling various parts and graphics, confusing pages with too many hyperlinks, and dependency on the hard copies (prints) of the instructional materials.

They also provided a list of software and hardware options for users with disabilities. In 2004, Abell, Bauder, and Simmons suggested that future online assessment tools would apply universally designed online assessment, enabling teachers and students to provide immediate individualized feedback. Keeler and Horney (2007) investigated elements of online course design to see if they met the needs of students with disabilities. The findings indicated that the courses included design elements necessary to meet the basic needs of students with disabilities. The authors recommended using universal design principles or a specified target population in online designing methods.

Once online education was progressing to reach its peak of usability and accessibility, more studies delved into the deeper aspects of online education for people with disabilities, particularly from an inclusivity viewpoint (e.g. Moeller and Jung, 2014; Burgstahler, 2015; Newman, et. Al, 2017; Smith, Jeffery and Collins, 2018; Kotera, et. Al, 2019; Stone, et. Al, 2019). Moeller and Jung (2014) argued that online education promotes normalcy, suggesting that “cultural narratives about online education function as discursive sites of normalcy by marking both online education and its users as less-than substitutes for the “real” versions.” According to them, “by constructing online education as a prosthetic technology, these narratives persuade marginalized bodies to recognize themselves as problems in need of solution.” Burgstahler (2015) focused on social inclusion through online practices, concluding that accessible and usable courses promote the social inclusion of all students. Smith, Jeffery and Collins (2018) suggested that online programs can limit potentials for equity and inclusion in educational spaces. Nevertheless, some studies show that the number of students with disabilities in online courses is growing as a result of increasing accessibility (Kotera, et. Al, 2019; Burdette, Greer, & Woods, 2013; Thompson, Ferdig, & Black, 2012). For instance, Kotera, et. Al (2019) reported that the number of students with disabilities at a university’s online learning unit in the UK was three times higher than the national average.

Providing accessible online education platforms and accessible course materials are the obligations of the chief institutions, program developers, and instructors to ensure educational equality for all types of students. Cooper (2006) argued that various people, including the institutions and educators devising the course, and the developers implementing its software and web-based components, have responsibilities for making online education accessible. This work notes that to achieve these ends culturally relevant and accessible changes must be adopted by all participants.

Although online educational theory and practices for people with disabilities have a history of over three decades, our study shows that educational efforts in the Iranian disability community have fallen behind the global trend of eLearning in both research and implications.

Methodology

This study used one-on-one phone interviews of 8 persons using the Shad application during the pandemic in Tehran to find answers to the main question of the research: what are the shortcomings of Shad for the users with visual and hearing disabilities? Purposeful sampling (Patton, 1990) was used to select those who fit the criteria of the research question. The criteria included students and teachers with visual and hearing disabilities who had used Shad.

Participants

An email invitation and/or text message was sent to the participants, containing the purpose of the study, questions, and consent forms. Demographic information, including name, age, gender, grade or years of experience, and disability, were collected during the interviews. Participants’ real names are not used in this study. Fifty percent (n=4) participants were blind and 50 percent (n=4) of them were deaf. Fifty percent (n=4) participants were teachers and 50 percent (n=4) of them were students. Fifty percent of them (n=4) were male and 50 percent (n=4) were female. The average age for the teachers and students were respectively 36 and 18 years old. Table 1 shows the participants demographic information.

Table 1: Demographic features of the participants

(Pseudo)Name	Gender	Age	Position	Disability	Years of Experience	Grade
Kian	Male	35	Teacher	Blind	15 years	N/A
Mina	Female	50	Teacher	Blind	28 years	N/A
Saman	Male	18	Student	Blind	N/A	11 th grade
Hoda	Female	18	Student	Blind	N/A	12 th grade
Ahmad	Male	32	Teacher	Deaf	10 years	N/A
Shaida	Female	28	Teacher	Deaf	8 years	N/A
Ali	Male	18	Student	Deaf	N/A	12 th grade
Pouneh	Female	17	Student	Deaf	N/A	11 th grade

Data Collection

Data was collected through semi-structured individual interviews with the participants. Cell Phones were used as the medium of communication, and the interviews were recorded. Interviews were conducted in Persian, and each of them took between 20 to 30 minutes. Interviews were transcribed in Persian and translated into English.

Data Analysis

After the recordings were transcribed, the texts were studied by each author to initiate coding and identify the emerging themes. Structural coding was used to code the data according to the research question. Applied to semi-structured interviews, structural coding is a question-based coding and labeling practice through which researchers can quickly access data (Saldaña, 2013).

Results

Six themes emerged from the participants' interviews on their experience with Shad. The themes include inaccessibility of Shad, alternative apps, external sanctions and internal censorship, slow speed Internet, dropping out of school, and personal feelings and attitudes.

Inaccessibility of Shad

All of the study participants reported unanimously that Shad was (and still is) inaccessible for students with visual and hearing disabilities. Shad's most noticeable issue for the blind users is that the screen readers are not able to read its pages. Kian, a blind computer-savvy teacher stated: "When you download Shad, you confront an absolutely inaccessible page where the main tabs and keys cannot be labeled and read by the voice-over or talk back. I tried many times to label the tabs, but I couldn't. Each tab takes you to a new room full of new keys, all of which cannot be labeled or read for the blind users. It's like entering a huge saloon with ten rooms while you have a thousand keys in hand, not knowing which key would open which door."

The other participants reported the same problem. Saman, a visually impaired high school student, said: “Shad is not accessible for those who use screen readers. When I login into Shad, only a few tabs at the bottom of the page and a couple of items in the setting can be read. The rest of it, including the chat rooms and conversations, are inaccessible.”

The main reason that Shad is not accessible for the visually disabled users is that the accessibility principles were not applied initially¹⁷. Saman explained: “The accessibility of a software or app is not an option or elective, but a standard. Some people argue that a software ‘became’ accessible for the blind users later, while the developers had to originally produce it accessible for everyone. This is the developers’ responsibility to take accessibility into account.”

Shad was not accessible for students with hearing disabilities either. Its limited visual options made online interactions very difficult for the Deaf teachers and students who rely on their eyes and visual aids while teaching and learning. Ali, a high school student with a hearing disability reported that the whole class could not use Shad, because, “The teacher could not see all of the students. Only one person at the time could be present on the screen. Shad was not like Zoom where all students and the teacher can be seen on the screen simultaneously.”

In the absence of full access to the visual options, the students with hearing disabilities have to write their questions and answers in the chatroom. According to Ali: “Writing in the chatroom is difficult for those students who don’t have good writing skills. They prefer not to raise their questions because they don’t feel comfortable with writing.” Shaida, a high school teacher of deaf students, reported similar issues: “Shad offers live-stream and my students really like this option, but the problem is I cannot see all of them on the screen.”

Unlike Zoom where the users can share documents, photos, videos, etc., Shad does not offer this option. Ahmad, a teacher of deaf students, said: “To teach a concept or something new, I always share some visuals beforehand so that my students are familiarized with the components of that concept. Unfortunately, Shad does not let me share videos and pictures.”

Accessibility limitations essentially makes Shad ineffectual for educators and their students with visual and hearing disabilities.

Alternative Apps

While Shad has remained inaccessible, students and teachers with disabilities resorted to the other Internet-based platforms, such as WhatsApp and Telegram, for eLearning. Yet, those apps have their own restrictions. Saman said: “Most of the available apps in Iran, such as Telegram and WhatsApp, are ‘messenger’ type. It means that they are initially designed for personal communications rather than educational purposes. Luckily, they are mostly accessible for the blind users because they have been programmed outside of Iran and the standards of accessibility are applied.”

Although WhatsApp is accessible for the blind users, students have faced many challenges using it for online learning. Mina stated: “In the first days of using WhatsApp, making group calls for the whole class was not technically possible. So, I had to divide the class into 4-5 groups and call each group to teach. It means that I had to teach one lesson 4 to 5 times for one class.” Hoda brought up another issue: “If one student was disconnected from WhatsApp because of the Internet issues (that happens a lot in Iran), the whole voice call had to be aborted and re-established.”

¹⁷ By following basic accessibility principles, app designers and developers allow their users with disabilities to navigate and interact with the app more easily. For example, Android app designers can use Material Design best practices to assure accessibility for the users with disabilities. For more information visit: <https://developer.android.com/guide/topics/ui/accessibility>

Other interviewees reported similar frustrations while using WhatsApp as an educational platform. Pouneh, a deaf student, stated: “WhatsApp did not allow video calls with more than 3-4 participants. So, we could not have all the students in the online class at the same time.”

External Sanctions and Internal Censorship

While Iranian students and teachers with disabilities try to replace Shad with other options, many apps and Internet-based services are not available in Iran because of either the US sanctions or the Islamic regime’s restrictive online policies. The individuals who use Apple products, for instance, cannot reach Apple store or the Apple’s latest updates and services. Pooneh said: “Zoom is the most efficient educational application but unfortunately, it’s not available in Iran. Only a small number of computer savvy people know how to get Zoom through bypassing sanctions, but the majority are denied.”

On the other hand, many available apps and online services also fall under the restrictive censorship policies of the Islamic regime. Ahmad said: “My students could not sign into Telegram because it is filtered by the Iranian officials. If we use a de-filtering software, it would affect the already slow-speed internet connection.” In fact, slow speed internet and unstable connections are among many difficulties imposed by the Islamic regime, such as controlling the online content and the censorship policy. Saman stated: “The Internet speed is too slow and disconnects frequently happen during online and offline classes that it takes more than 30 minutes to download my teacher’s instructional video.” Kian said: “students get disconnected from the online class constantly. For example, if a person is disconnected from a group voice call through WhatsApp, the whole call should be canceled and reestablished so that the disconnected person can join the conversation again. Imagine how many times the whole class should cancel and make a new call to assure that everyone is included after one person gets disconnected.”

Dropping out of School

The educational switch to online learning during the pandemic imposed additional financial obligations on Iranian families who were already struggling to make their ends meet. Buying new devices compatible with the purposes of eLearning is beyond the budget of many families, making students with disabilities fall behind the class or even drop out of school. Pouneh, a deaf student, said: “The price of a mobile set, even a simple one, is very expensive in Iran. My brother and I have to share the same phone for our online classes. Some days I miss some classes and the other days he misses his classes because we cannot use the phone simultaneously.”

Shaida, a teacher of deaf students says: “Two of my students had to quit because their families could not afford buying phones or laptops for them. Imagine there are 3, 4, 5 children in a family each of whom in need of a cell phone or laptop. How can they keep up with online classes if each child doesn’t have a device?” Ahmad noted: “In more populated families, children with disabilities are more likely to be the first victims of poverty because the needs of non-disabled children are prioritized over the disabled one.”

According to the interviewees, a number of other students dropped out of school because they did not have anyone at home to help them. Saman said: “one of my friends, who is blind, quit last year because he needed help with his phone. His mother was working full time and his younger siblings were too young to be helpful.” Mina says: “I had a blind student in an underprivileged part of Tehran who did not have a mobile set at first. Through fundraising, I was able to buy her a phone, yet she didn’t know how to navigate through the set. Her parents could not assist her either, because they’re not technologically savvy. She eventually quit for not having educational support at home.”

Participants mentioned that more students with disabilities in the rural areas of the country are likely to have fallen behind or dropped out of school during the pandemic, because of the financial problems and the lack of educational support at home.

Personal Feelings and Attitudes

Discovering that Shad was not accessible for students with disabilities, our study participants noted feeling neglected and undervalued. For example, Pouneh, a student with a hearing disability said: “Once again, we were neglected. I feel I don’t exist in this society at all! They [the officials] usually say beautiful words about us but they ignore us in practice. For example, they constantly say that our needs are their first priority whereas it is not true! Or they even appreciate their own work while we, as the users, can barely see such achievements or services in practice.” Kian noted: “If a society does not feel responsibility for the rudimentary needs of its majority, you should not expect it to provide welfare for its minority groups. I experienced it during the pandemic that all people were deprived of their needs, let alone people with disabilities.” Sheida mentioned: “Many times, the officials promised that they would make Shad accessible for the students with visual and hearing disabilities, but it’s almost a year and nothing has happened! From the first day, I was sure that they would not make an accessible app for us, because we have been constantly promised yet ignored! I sometimes get angry but I try to accept the reality; I have no other choice!” Similarly, Hoda felt anger once she noticed that Shad was not accessible: “I became angry knowing that the Exceptional Education Organization had not provided an accessible app for the disabled students and teachers during the pandemic. I called my school and they said it’s beyond the school’s authority to develop an accessible app. They said that we should wait for the Exceptional Education Organization to do something about it, but we all knew that the organization would not do anything!”

Like many students with disabilities, Saman tried to find a solution: “Ever since I’ve accepted my disability, I’ve accepted that I am not able to use anything non-disabled people can use. I know that I have to find another way to meet my needs. For example, I have only four fingers on my right hand, still I play a piano. I have learned how to do the job of the fifth (or missing) finger using the fourth finger. It means that I have accepted the impairment and tried to find an alternative way. Likewise, when I learned that Shad was inaccessible, first I felt undervalued but then, acknowledging that we don’t have a high status in this society, I thought we should do something for ourselves, not expecting the others to recognize us and our needs.”

Similarly, other participants reported that they felt ignored and excluded, but were not surprised to see that Shad was not accessible. Shaida and Mina said that it’s “a routine” in Iran not to include the needs of people with disabilities in public services. Pouneh, Hoda, Saman, and Ahmad stated that Iranians with disabilities are all used to such discriminations. In fact, the country’s responsible sources, including the state’s policy makers in general and the special education authorities in particular have frequently ignored various needs of individuals with disabilities, from accessibility of public places to transportation, housing, employment, and in this specific context, online education.

Discussion

This study sheds light on the poor usability and inaccessibility of Shad and the status of students and teachers with disabilities in online education in Iran, which was accentuated during the pandemic. The results explain why students and teachers with disabilities inside the country cannot benefit from the currently available forms of online education.

Some of the technical issues of Shad, reported by the Iranian students and teachers with visual and hearing disabilities, correspond to a number of the earliest global studies on eLearning that are reviewed here. Cook and Gladhart (2002), for example, had reported technical problems with translating text to voice and labelling various parts and graphics, that are, in fact, identical to what the interviewees reported about Shad. This finding suggests that Iran is still in the first stages of developing online education for people with disabilities, and the officials are seemingly reluctant to apply the achievements of the eLearning pioneers in its novice practices.

The Iranian educational system and even The Exceptional Education Organization are established and governed based on the medical model of disability that sees disability as an abnormality,

impairment, and limitation inside individuals to be fixed (Davis, 1995; Linton, 1998; Michalko, 2002, Goodley, 2011). Such medicalized attitude is reflected not only in the Organization's exclusive labelling, "exceptional students" and the "Exceptional Education Organization", but also in its statute, where its main objectives are defined as: "Designing an educational and rehabilitation system so that it can compensate for the needs of children and students with mental and physical "shortcomings" (disabilities) ...; Helping to prevent any physical, mental, prenatal and postnatal disabilities by raising public awareness about the causes of disabilities and the characteristics of children with exceptional educational needs" (Exceptional Education Organization, 2015; translated from Persian into English by the authors). Accordingly, the medicalized approach of the Organization defines "disability" as "shortcomings" in need of compensation, and something "unpleasant" that should be prevented.

The inaccessible Shad application showcased the dominant medicalized mindset in the education system, requiring students and teachers with disabilities to conform with "the normal way of doing things" (Lewiecki-Wilson and Brueggemann, 2008) or simply be removed from the mainstream current of education. Even the so-called Exceptional Education Organization, as the first and main governmental center to provide accessible educational services for students with various disabilities, ignored disabled students and practitioners' needs during the inevitable shift from in-person education to online schooling.

All participants reported that the Shad application was not accessible for students and teachers with disabilities. In other words, disability has still remained as an "afterthought" in the Iranian education, contrary to what Miles, Nishida and Forber-Pratt (2017) stressed, that "Disability should not be an afterthought; rather carefully considered as an intersectional and integral part of all university operations, visioning and planning." In this developing Middle Eastern country, the structures for access are not even subject to "retrofit" (Dolmage, 2008) which (symbolically) inserts the ramps at the sides of a building, never letting disability come in the front. Case & Davidson (2011) argued that accessibility should be taken into consideration at the conception of online content, because it is easier and inexpensive compared to the expensive and time-consuming process of retrofitting. The Iranian online education platform, however, was not originally created accessible and the officials ignored the users with disabilities' requests for adjusting the inaccessible platform.

According to the interviewees, sanctions and restrictive policies have made online education even more difficult for disabled individuals. Dependency of eLearning on technology and Internet has, in fact, exacerbated the problems for all Iranian people who have been suffering for many decades from both external sanctions imposed by the USA and the internal restrictive policies implemented by the Islamic regime (Clawson, 2010; Aryan, Aryan and Halderman, 2013). Tech companies and service providers, such as Google, Yahoo, Apple, Microsoft, Cisco, Cpanel, Intel, AMD, Dell, HP, McAfee, Ebay and Amazon have been limiting Iranian users from their services for the past two decades. While the international sanctions have limited Iranians' access to the global products of tech companies, the Islamic regime's restrictive online policies have resulted in slowing down the connection speed, filtering the online content, and limiting the users' access to many resources. The community of people with disabilities are more vulnerable to such limitations as their vital needs, particularly technological aids and adjustments, are exponentially restricted.

The participants mentioned that many disabled students in the poor families had to quit mainly because of poverty and not affording electronic devices. In fact, the increasing rate of inflation and poverty directly influenced people's quality of life during the pandemic. Iran's inflation rate rose sharply to 36.4 percent in 2020, marking it the sixth highest inflation rate in the world (O'Neill, 2021). Affected by the pandemic, many Iranian families could no longer afford purchasing new devices for their children, especially in more populated families and rural areas. The country's economic instability and fluctuations in the value of the national currency affected the electronics market to the point that the price of a cell phone was equal to 70 percent of a worker's monthly paycheck (Ahmadi, 2021). According to the official reports, 3 million Iranian students did not possess a phone set or laptop to benefit from online education during the pandemic (Ahmadi, 2021). According to unreliable reports by the Education

Ministry, 85 percent of Iranian students are active in Shad; however, other sources announced it as 62 percent (Ghadarkhan, 2020), meaning that almost 40 percent of Iranian students with and/or without disabilities are not using Shad. Issues with Internet connections and lack of electronic devices are reported as the main reasons for not using Shad, whereas inaccessibility of Shad for the users with disabilities remained undiscussed in many official reports.

It is worth mentioning that financial pressure and online education restrictions also resulted in an increase in the rate of suicide among Iranian students. Out of 28 instances of suicide among children under 18 years old in 2020, 10 cases happened because of poverty, not having a device to attend online school, not having Internet connection, and falling behind the class (Ahmadi, 2021). Although it is not clear whether the victims had a disability or not, the educational, mental, and emotional pressure on students with disabilities in such a situation is undeniable.

Participants reported that they felt undervalued, but the inaccessibility of Shad did not surprise them since they have been frequently ignored, excluded, segregated, and considered as “less than” non-disabled people. This view resonates ‘ableism’ that characterizes people with disabilities as inferior to the non-disabled (Linton, 1998), resulting in a social process of discrimination (Friedman & Owen, 2017). Iranian people with disabilities have been experiencing various forms of ableism in their personal and social life, including education (Goodrich, 2013). The inaccessible Shad application is, in fact, one of the many cases of denying disability rights in an ableist Iranian society.

Although the Exceptional Education Organization has defined one of its responsibilities as “Continuous modification and adjustment of the current exceptional education system following the latest achievements in the global special education pedagogies” (Exceptional Education Organization, 2015; translated from Persian into English by the authors), the participants’ reports indicated that the Organization has not even fulfilled its own defined responsibility during the pandemic. However, as the interviewees mentioned, individuals with disabilities, themselves, are compensating for the officials’ irresponsibilities, by learning how to find alternative ways of doing things independently and in many cases, devoid of governmental aids.

Limitations

This study has a number of limitations. First, the participants were all teaching or studying in Tehran, the capital of Iran. Recruiting interviewees from other cities, particularly the rural areas, would ensure that the voices of culturally, linguistically and financially diverse students and teachers with disabilities were also reflected. Second, other disability groups, such as intellectual disabilities, are absent in this study. Although it is self-evident that the Iranian eLearning in general and the Shad application in particular have ignored the specific needs of users with all types of disabilities, interviewing the students with, for example, autism and their teachers could shed more light on the eLearning accessibility issue in Iran and the extent of irresponsibility of the Iranian officials regarding to the needs of people with disabilities. Finally, the dearth of literature on the experiences of the Iranian individuals with disabilities with eLearning limited the historical background of this research.

Conclusion

The pandemic revealed the new educational challenges of people with disabilities in Iran. They had to deal with an unprecedented situation in which the educational system shifted to an online version devoid of the theoretical and practical knowledge of eLearning.

While Shad, the official application for online education, still is not accessible for students with visual and hearing disabilities, the alternative online applications are also difficult to work with under the global sanctions and internal restrictive policies. During the pandemic, many students with disabilities could not benefit from quality teaching and/or could not pursue their education because of inaccessible apps, poverty, unstable and slow internet connection, lack of electronic devices, and receiving no support at home. It is shocking to know that students with disabilities have been excluded from the mainstream online education; however, many of them are not surprised at all, because the

inaccessible Shad is only one of the many instances of exclusion and segregation they have been experiencing. The online education during the pandemic revealed that the Iranian students with disabilities are invisible online, and that the dis-abling education system of Iran is in an urgent need of a “universal design practice in developing online learning material” (Kent, 2015). The Exceptional Education Organization, as the main source responsible for providing for the needs of students with disabilities, failed at making the Shad application accessible or even retrofitting it after its conception. Also, Shad developers, as the technical arm of the educational system, did not feel any obligations for designing an accessible platform.

The community of people with disabilities in Iran has a long road to pave to fulfill its rights in the heart of an ableist society whose political system is not accountable, nor responsible for meeting their needs.

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Emerging as a Scholar-Advocate Amid the COVID-19 Pandemic

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As an undergraduate, I never thought of the countless papers I wrote as having any “real world” significance or impact. After I submitted a paper and got a grade, it was more or less out of sight, out of mind. This year, however, I had an experience that made me realize that academic writing has the power to initiate tangible change. Being two years post-grad, I do not spend a significant amount of time contemplating much of my writing from college, even the two papers that were published during my senior year. This changed when I was contacted regarding a volunteer copyediting opportunity through my profile on the United Nations Volunteers website in the middle of the COVID-19 pandemic. I had the unique chance to directly witness how my writing motivated members of an influential global organization to hold themselves accountable for their ableist framing of disability.

For a Disability and Justice class I took during my final year at James Madison University, I wrote a paper about how the United Nations, specifically the UNHCR (United Nations High Commissioner for Refugees), has framed disability from a medical model perspective throughout the years in various resolutions and policies, resulting in refugees with disabilities not being prioritized for resettlement and remaining stuck in refugee camps with their lives completely on hold. My paper was published in the 2019 Special Issue of the International Journal on Responsibility. It was critical of the UNHCR, and while I acknowledged progress that had been made, I argued that the progress was far too slow and minimal. Throughout college I dedicated my studies, volunteer work and internships towards promoting refugee justice, and UNHCR is an organization I had always admired. For this reason, I was incredibly disappointed in their irresponsible and ignorant position regarding disability.

The UNHCR has historically been quite dismissive of individuals with disabilities, excluding them from important documents and framing them as a burden when they were discussed. For example, a 2004 UNHCR handbook of 500 pages only included one paragraph on refugees with disabilities, stating that “disabled refugees who are well-adjusted to their disability and are functioning at a satisfactory level are generally not to be considered for resettlement” (United Nations High Commissioner for Refugees, 2004, p. 4.11). My paper acknowledged a clear rhetorical shift in how the UNHCR has since progressed language around disability, ending with a 2019 guidebook that calls for universal design in refugee camps and condemns the medical model (United Nations High Commissioner for Refugees, 2019). Despite the advancement, I concluded that the UNHCR still has much room for improvement regarding refugees with disabilities.

When an employee from UNHCR reached out to me this year regarding the volunteer copyediting position, I was a bit perplexed as to why the UNHCR was interested in having me, someone with scarcely any copyediting experience, edit the final version of a training course they were getting ready to publish after two years of hard work. The aim of the course was to train UNHCR employees on how to effectively interview individuals seeking protection and refugee status, to determine the type of protection they were eligible to receive. During our initial introduction meeting, the UNHCR team informed me that they had seen my published paper on the UNHCR and disability on my CV and read it. I was nervous when they brought it up, given my paper’s critique of their organization. To my surprise, however, they informed me that they had reached out to me for the position largely because of this very paper.

The project I was editing included an entire section on how to interview refugees with disabilities, and the team quickly admitted to me that disability was not “their area of expertise.” As the training course would be taken by every UNHCR employee conducting protection interviews, they did not want to come across as ill-informed. They felt, given my paper, that I could provide valuable insight regarding the content of the section on disability in addition to the basic copyediting tasks required. Rather than taking offense to the paper, the team recognized that my critique was coming from a place of general admiration and respect for their organization, and my desire for them to be even better for those they serve.

Beginning the project, I was curious where this training course would fit in amongst the various documents, handbooks, and policies that I had written about in my paper in terms of its conceptualization of disability. I was immediately disheartened upon seeing their glossary definition for

disability, which included the phrase: “an individual who cannot function normally within society.” I do not need to explain why such an ableist, medical model definition is problematic. I was frustrated that the language UNHCR was using was a massive movement in the wrong direction, undoing the progress they had been starting to make regarding disability. It was certainly a far cry from the Convention on the Rights of Persons with Disabilities (CRPD) 2006 definition: “Disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.” While the definition has its shortcomings, it does recognize that disability is a result of environmental factors. Given the UN’s history of excluding disability entirely from conversations and framing it as a medical condition that should ideally be eliminated, the new 2006 CRPD definition was a mark of progress. Yet here we are 15 years later, reversing the improvements that had been made and reverting to the medical model.

As a large and influential global organization, UNHCR has a responsibility to ensure that the language they use is bringing about positive change. Their actions and language set a standard in the global community, and I knew that their new definition of disability was not the standard that should be advanced and presented to the world. So, on my second day of the project, I found myself requesting a team meeting to discuss the issue. The team listened to me give a well-rehearsed speech about the history of the disability rights movement, the medical and social models of disability, the influence that language has, and the UN’s responsibility to improve its rhetoric surrounding disability. I even quoted my previous paper, stating, “When societal rhetoric surrounding disability changes, and the value and worth of individuals with disabilities is recognized and celebrated, it is likely that policies will reflect this” (Hoagland, 2019). They did not respond defensively or skeptically, but were receptive to what I had to say and open to a discussion on how to change their wording.

Together, we spent the remainder of the meeting crafting a definition of disability much more in line with the social model, emphasizing the fact that disability is a result of ableist environmental factors rather than an individual’s perceived ability. It stood out to me that the UNHCR team, comprised of people who are extremely accomplished in the field of refugee protection and well-versed in educating others about various religions, races, ethnicities, sexual orientations, and sensitive political issues, were completely at a loss when it came to the topic of disability. They acted awkward and almost ashamed when disability was mentioned, and at the beginning of our conversation, in a moment of frustration, even suggested deleting it entirely from the course. I believe it is natural as humans to avoid or ignore subjects that make us uncomfortable and potentially highlight our faults, but these are the subjects that must be leaned into and explored for progress to be made. The UNHCR team fortunately was aware of this and continued confronting their uneasiness around disability to improve as an organization.

While I’m contractually unable to discuss the final version of the project, I feel confident in saying that, after the changes we made, this course would be the most in line with the social model of disability out of all the UNHCR documents that I analyzed in my original paper. The team I was working with did exactly what people should do when confronted with a social justice issue that they are uninformed about: they recognized their shortcomings, responded receptively to critique, accepted responsibility, and worked to educate themselves and improve their understanding.

As I reflect back, I realize I would not have been able to take this opportunity had it not been for the pandemic. I found myself without a job and living back at my parents’ house when COVID-19 hit New York City, where I had been working. To make some income safely from home, I found an online job teaching English to students throughout Asia, but the early morning hours I worked left me with a significant amount of free time during the day. My life felt like it was on hold, as was the case for many during this time. As a society we were grappling with the trauma of COVID-19 taking our loved ones so rapidly and in such large numbers, while at the same time, many of us were also forced to move back to readjust the trajectory of our lives. The pandemic took away a number of opportunities for me personally, yet this volunteer copyediting position ended up opening many doors. During such a collectively disastrous time for the world, a time that made many things in life that we used to take for granted inaccessible, many things actually became more accessible as remote work became the norm. It

is important to remember, however, that for those with disabilities, the world we lived in pre-pandemic was never accessible to begin with. I feel lucky to have had the opportunity to do this project remotely and to have had the time in my day to accept a position that would not have been accessible to me before the pandemic.

One of the things that struck me the most about this experience was the fact that a paper I wrote in college, which at the time of writing I never imagined anybody but my professor and myself would ever read, led me to that position of advocating for and helping bring about real change within a prominent organization. While I initially thought that they might take offense to my paper, in reality, they appreciated the critique and acknowledged that it was the push they needed to hold themselves accountable.

Academic writing always felt a bit removed from reality to me in college. No matter how interested I was in a topic, I could not help but feel as though there was little good that could come from writing about issues relating to justice and advocacy, as no real change would come from writing an essay. My experience with the UNHCR turned this feeling completely upside down. I learned that my words have power, and my passion for disability justice and the calls for change that I wrote about were heard. Never in a million years would I have guessed that my paper would be read by staff at UNHCR, but you never know what will happen when you put your words and ideas into the world. I will carry the experience of changing people's mindsets through my writing with me as I begin my graduate education this Fall, and I will never stop writing about and advocating for disability justice.

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