About this issue

More beautiful for breaking

This COVID-themed issue continues a global conversation about the experience of disability in unusual times. It begins with a shared editorial collectively created by the editorial team. Given the extraordinary nature of this moment, we felt an extraordinary form was the most appropriate response. It looks at how we may best leverage this challenging time and circumstances to be, as Kaya Ayers suggests, "more beautiful for breaking," as we as communities reflect, invent and collaborate together.

A Global Perspectives editorial from Sona Kazemi and Hemachandran Karah launches the long-awaited multilingual initiative to ensure more global voices are part of this important conversation about disability in culture.

Cassandra Evans' personal account "The Longest Blizzard" captures in narrative the impact of the pandemic on the author's family, her students, and those with whom she works. It considers the pressures, the unique opportunities for learning and reflection, and the ever-present possibility of breakthrough.

Ananya Kapoor's "Cinema on the Spectrum: Representation of Persons with Autism in Mainstream Filmography" offers a cross-cultural look at representation of autism in media and points to the role these images may play in this larger global conversation, especially with the unprecedented consumption of content during the pandemic.

Returning to the U.S., "Activism among college students with disabilities and the move beyond compliance to full inclusion," by Brenda Smith-Logan, Jeff Sheen-Logan, and Keith Christensen-Logan provides examples of strategic student activism that has resulted in meaningful change. It uses these cases to offer a framework to inspire other activists.

We are also pleased to feature an invited work by Steve Brown, a founding editor of *Review of Disability Studies,* who for many international readers has helped articulate what 'disability culture' means. The excerpt from his upcoming book *Disability Culture 20/20* revisits the concept in the age of the pandemic. He also considers the work of activists using the current moment to push for meaningful change.

In our book reviews this issue, Shu Wan reviews Etieyibo and Omiegbe's *Disabilities in Nigeria: Attitudes, Reactions, and Remediation*, the first comprehensive monograph on issues

of disability for contemporary Nigerian society. And Maria Teresa Houar's review of Petra Kuppers's latest work of new and recent poetry, *Gut Botany,* considers the ways in which Kuppers travels through borders between bodies and species to better understand her body and experience.

Finally, Global Perspectives brings together a host of international voices to broaden our understanding of disability as shared global experience. It also features original language contributions in various forms including Nibel Genc's "The Engraved Lighter" in Turkish, a personal narrative looking at the ways in which objects can remember brutal life- and body-changing conflicts. Zarana Maheshwary's "Against Social Isolation: Disability Metaphors and Personal Battles" considers the limits of the disability metaphors in frequent use during the pandemic, placing those in contrast with insights from the author's own embodied experience. And "two poems" in Polish, by Magda Szarota, speaks to the continuing power of art and personal expression to help us make sense of experience.

Collective Editorial Response to This Global Moment:
What can bringing a disability lens to this moment offer us?

A protracted global pandemic. Widespread uprising and global cries for social justice. Together as an editorial board, we have struggled to think of the best way to respond to this moment in a meaningful way. We have collectively decided that our traditional editorial model is insufficient to fully address this extraordinary time.

Instead, what follows are a few immediate short thoughts. They may take different forms, informed by our unique vantage points as academics, activists, workers, parents, racialized immigrants, people with disabilities and non-disabled allies, but all are unified by our understanding that critical disability perspectives are more important than ever for understanding--and leveraging--this historic moment:

Responses

Mary Jean Hande - The pandemic and global uprisings have underscored the fault lines and gaping social inequalities that structure our world today. We must chart a new world. The struggles of poor, BIPOC disability people teach us many of the necessary lessons on interdependence, mutual aid, and solidarity that we will need.

Sona Kazemi - Inspired by a decade-long organizing with multiple global communities, seeking justice for mass atrocities and state-sponsored oppression (e.g., anti-immigrant sentiment, mass execution of political prisoners, mass incarceration, theocracy, religious-fundamentalism, violence against women, and punitive limb amputation), I personally take an optimistic approach to the pandemic's impact on our lives as a global community. I advise not to be so quick to take what existed before and attempt to recreate it for a post-pandemic world. This crossroads provides us a unique opportunity to consider what old ideas and normative way of thinking - without challenging the status quo, have overstayed their welcome in myriad industries that rule our world and what can be part of our new normal? Disabled/mad/traumatized people could be incredible public pedagogues, leading us ahead and enlightening our pathway with their invaluable insights and experiences with the malfunctioning old "normal," from poverty to ableism, sexism, racism, and incarceration. Many of them have already developed survival tactics and strategies from mutual aid to

community-building and story-telling, simply because they have already dealt with isolation, marginalization, imposed solitude, and systemic ableism and racism for most of their lives.

Susan Levy - The year of 2020 has led to tumultuous emotions, immeasurable challenges, enhanced and multiple divisions. It has also led to re-imagining how we understand and conceive of 'normal', what it means to do things differently. 'There is a crack in everything, that's how the light gets in', wrote Leonard Cohen (1992). One such 'light' to emerge from the darkness of COVID-19 is how digital technology is articulating new opportunities to communicate at a distance and in different formats, re-defining accessibility and how lives are lived. We need to identify and make visible the catalysts of change and ensure the voice of inclusion is embedded in all our futures.

Jenifer L. Barclay - As we reflect on the challenges, struggles, and triumphs of 2020, it is imperative that we also reflect on the ways in which different groups of people have experienced the COVID-19 pandemic differently. As one widely circulated social media post noted very early on, "we might all be in the same storm, but we're not all in the same boat" (Tett, 2020). If ever there was a time to use the lens of intersectionality now is it since this perspective allows us to think critically about a global event that simultaneously connects and disconnects us. Numerous resources advocate the importance of intersectionality, but for a concise starting point I recommend: https://blogs.bmj.com/bmj/2020/05/15/intersectionality-offers-a-radical-rethinking-of-covid-19/

Kara Ayers - One of my favorite proverbs is the Japanese story of repairing broken pottery with gold. The crack in the pottery is highlighted as a unique piece of history. It is more beautiful for breaking. I hope I will someday look back on 2020 as a year of resilience and the initiation of meaningful change. For now, we are still surrounded by such brokenness and loss-including an entire disregard for disabled, black, brown, and immigrant lives-that it is difficult to imagine a time of rebuilding and regrowth to the extent we desperately need. I find hope in advocacy communities, who have never stopped fighting, and know I must do the same.

Hemachandran Karah - Myriad care infrastructures thrive so as to aid people in handling disasters, emergencies, and unknown structural impingements. We need to invent transdisciplinary approaches so that novel and yet hidden infrastructures of care begin to surface. Also, we may have to begin rethinking deeply entrenched academic habits that raise artificial barriers. A slavish devotion to jargonism, ableism, and ideology, for example, permit

us to reach out only so far. They may never facilitate connection with human infrastructures that are shaped differently.

Pat Morrissey - The pandemic will reveal many things — disparities and inequities, unconditional kindness, and unparalleled resilience. My hope is that brings about sustainable fairness in our treatment of and interactions with each other.

Raphael Raphael - It's easy to forget. A global pandemic claiming 1 to 4 million souls. Unprecedented international attention to global justice. The year was 1968, and the world saw widespread protests against both the excesses of capitalism and authoritarian communism, all amidst the grim backdrop of the global spread of the Hong Kong Flu. As this moment echoes with history and, like 1968, invites us collectively to look towards best possible futures, how do we now best leverage the possibilities of our shared extraordinary moment? A crucial part of this is our continued critical exploration of what disability means and how together we can best create and nurture inclusive communities, something at least as important as it has ever been.

Together, we renew our commitment to bringing disability analyses of race, social inequality, gender, sexuality, and immigration that are critical and global in orientation.

Dear RDS Readers: After reading our short responses, we invite you to join the conversation at https://twitter.com/revofdisstud or https://www.facebook.com/rdsjournal/ to share your thoughts about what you think a disability lens can help bring to our understanding of this moment and whatever our individual and collective responsibilities may be.

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Editorial

Disability and Multilingualism: A Global Perspective

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It is with great honor and privilege that we report our long envisioned, and politically imperative issue of the Global Perspective Section of the journal has finally materialized. As we had imagined this section, we hoped to create a space for multilingualism as a framework, political endeavor, accessibility commitment, and a cultural setting where languages appear more than an identity marker or private possession of a community. We have long believed that in some sense, multilingualism thrives when seemingly rigid monolingual communities see the need for crossing linguistic borders. All the same, crossing linguistic borders need not always involve bridge-making across languages. Instead, it can flourish amidst a spectrum of human expressions that can animate from nowhere. Because they are required to subvert rigid institutional arrangements, including the ones that accrue via linguistic hegemonies, disabled people and survivors of disabling traumas do go on to become active agents of such a multilingual crossover.

For example, disabled people may straddle across myriad expressions and registers so as to handle a life replete with activism, corporeal pain, structural violence, discriminatory interpersonal bonding, and caregiving. In all these situations, disabled people feel the need to break open regularized linguistic borders that they are routinely pushed into. Very often, these linguistic borders remain constrained by a monochromatic idiom with a penchant for ableism. Apparently, when disabled people break free from such linguistic borders by a million means, they end up inventing novel modalities of multilingualism.

Additionally, creating this section, we have hoped to complicate what it means to be, become, and remain disabled under exploitative social relations and oppressive historical continuities and discontinuities. To this end, we have strived to create a space that challenges what we think as "normative" disability expression, "normative" disabling conditions, and "normative" generational traumas mobilized by colonial, fascist, theocratic, and imperialistic legacies.

In this issue we have included two poems in Polish by a disability rights activist, Magda Szarota, and a story in Turkish by Nibel Genc, a political activist imprisoned in Turkey since 1994 defending the freedom and autonomy of Kurdish people.

Magda Szarota's poems in her own words are her:

> *way of using poems to probe what it means to feel 'whole' and in tune with oneself vis-à-vis delineations and interventions imposed by medicine and culture. Specifically, as a disabled woman with invisible impairments [she] often face[s] people's reactions that meander between harsh ableism and privileged treatment. Contradictory lived experiences that are interconnected with [her] 'untypical' and non-apparent impairments inform [her] poetry as well.* (Szarota, 2020).

Nibel Genc's fiction story "The Engraved Lighter" is about a great-grandfather who survived the 1938 Dersim massacre with his son, whom he managed to rescue from the hands of the Turkish soldiers. When they were caught and waiting for their fate to unfold, another prisoner gave his engraved lighter to the great-grandfather just before the prisoner was shot.

Stories like Nibel's, besides possessing literary aesthetic, have the power to challenge what we already know about resisting unequal power relations such as colonialism, patriarchy, and ableism. The story is that of struggle, humility, and interdependence, all values that social movements for autonomy and agency share. It is critical we realize that disabled people's struggle for freedom, access, autonomy, and equality is connected to Indigenous people's anti-colonial struggle for self-determination.

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Research & Essays

The Longest Blizzard:
Pressure Cookers and Gifts from the Pandemic

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Abstract

Personal thoughts and reflections on navigating my own mental health, trying to do research and teaching pandemic ethics during a pandemic.

Keywords: bioethics, disabilities, mental health, contingent spaces, pandemic

The Longest Blizzard

One chilly March day in early 2020, my daughter reminded me that we have not had one snow day on Long Island in two years. *Not one*. We moved here 10 years ago this month. Having lived in Southern California half of my life, people thought I would never survive moving to the "the horrific cold" of the East Coast. *I came here for the pizza and bagels; I stay for the weather,* I tell them. Though I loathe de-icing the car to make the short drive to the train, curse the mess on the salt-laden platforms, and feel denigrated by pushes and shoves for a space on LIRR and New York MTA subways, each of these demeaning acts (as I try not to think of comfortable 70-degree California January days), intensifies my worship of the snow day. *Silly, Southern Californians. Horrific cold indeed. You will never know the joy of a snow day*.

The snow day forces you to stay put. You don't have to de-ice the car. You don't have to wonder if you will get a seat on the train. You don't have to navigate the disgusting bathroom on the train to empty a catheter's Foley bag. You won't panic running from your office to catch the train, slipping on ice, falling ass over teakettle while the rest of Manhattan sloshes the brown slushy snow of gutters around you.

The southern part of New York is what I call the *banana belt* of New York. But since we moved here, until now, it was good for at least one to two blizzards which would equate to

about three to four snow days at home with the family throughout the winter months, spanning from late December through late March. (Though popular television and film shows depict New York City covered in pure white snow before Christmas, since I have been here, the main large snows that stick occur mainly *after* Christmas.) Sure, as an academic, even when a blizzard hits, I am still expected to meet deadlines remotely, keep writing grant proposals, continue grading papers (maybe even grade more), and answer students' questions via phone, text, and email in between stoking the fire. Even with these persistent expectations, I can always find extra time—with no trains to run after and shove into—to enjoy the long, meditative motions of slow cooking a pot of steel cut oats over the stove, to watch "Hops," my emotional support Labrador, frolic in the powder and track it in all through the house for me to wipe up off the couch, and to make hot chocolate for the family when they return from sledding. These are frigid days, but ones in which we all don't have to rush into the trains.

The winter snow day is a magical time for us to pause, go outside, build snow people, snow animals, snow forts and an igloo. We then figure out how we can lure the dog in the igloo with us, teasing him with beef jerky, juggling a cup of hot chocolate which we will sip inside, and engineering ways to build indents into the igloo walls that hold tea light candles. When the sun goes down, we leave the candles in the igloo on and watch the ivory glow of our candle lit igloo. Then Hops wiggles out of the small hole we burrow out, and we watch him pee on the igloo. It is the unscheduled holiday we all pine for and take bets on as to which day it will occur first—December 28? January 4? January 13? Hopefully *not* a Saturday or Sunday.

For someone with physical, emotional and psychiatric disabilities, the snow day sword can cut both ways. On the one hand, being at home reduces risk of multiple compulsions that play out in public (on a train, in a subway, in traffic) and the inaccessibility issues that public transit presents. On the other hand, some people who need to get away from shared living space, who mark calendars and occupy time with mental health programs and other services, can have issues exacerbated and pressures build when they are forced to stay inside.

I think about how my family longed for a snow day in February 2020, before the pandemic hit, as we were nearing the end of the official snow season. I recognize the privilege that event bestows on us, but the pressure it can create on others. Even after two days of a blizzard, I recognize my own need to get back out into the world for my own mental health and that complaining and bickering can and often does occur within my household. Yet, I

have the privilege of moving to another part of the house when that happens, reading a book quietly to escape, or even going for a long walk in the snow alone. So many do not have these options. So, many do not have extra space to move about or to isolate from others in.

"We haven't had a snow day in two years, Mama," my daughter reminds me. "What the heck?"

Then, March 13, 2020 came.

Luckily, I had the forethought, before leaving my office in Manhattan March 12, to pack several library books, *just in case* I had to be at home Monday and could not access them electronically. Fortuitously, I was also messaged that three additional Inter-Library Loan (ILL) books I requested were at two other campuses nearby. If I walked quickly, I could fetch those books on a quick lunch break. Before my lunch walk/ILL scavenger hunt, campus announcements stated, "We will be closed for a protective deep cleaning for the virus on Sunday and Monday. You can expect to return to campus Tuesday." Additionally, "Put food items in plastic bags to avoid exposure to chemicals," our academic directors and deans told us. The library ILL circulation desks were still open, but as I walked through the city—Lexington down to Flat Iron, back up to the Empire State—crude notices in windows scribbled, "Sorry, due to COVID-19, we are closed until further notice." *I wonder if we will really re-open Tuesday.*

"We may have a pseudo blizzard for a few days," I told my daughter in a sing-song voice, trying not to frighten her. She said, "Mama, should I be worried? My friends said people are going to die; I could die; we could all die."

"Well, as you know, Honey, like I've told you, we are *all* going to die *at some point*," I said. "But this is not that bad, I don't think. We just don't know for sure how many people will get sick and what that illness will look like, so we need to stay home for a while so more people don't get sick. I am not sure how long it will take."

Clearly, no one did.

Six months later, she says, "This has been the longest blizzard ever, but not as fun." *I know*.

As the pandemic rages on through Spring and Summer, I think about whether we will have snow months from now, whether the fires in the West will receive rain, whether the riots

will get worse before they get better. Most of all, I think about people whose contingent living spaces must be psychically bursting at the seams.

I am now checking in with participants from a previous ethnographic study and trying to enroll participants in my new study, an evaluation of the phenomenology of living in mental health housing during a pandemic. I fear that some people may be worse off than before the pandemic. Beyond the masks, the social distancing and the lack of "program" for mental health classes and services, there is the intensified isolation for those living alone and the increased aggravations for those sharing space.

"My roommates have had coronavirus, and I hope I don't get it," says Tao, an Asian-American male who was hoping to move out of a county-funded mental health "CR" (community residence) the last time we checked in. "I can't move now because of the pandemic, but I can't get along with my roommates and some of them have been sick."

He went on to tell me how people taunt and tease him for seeming "slow" or "mental" and how this infuriates him and makes him feel even more alone.

Reavey et al. (2017) describe situations such as Tao's as a "space pressure cooker," a shared living space or a therapeutic landscape (TL) that is supposed to be supporting his mental health but is undermining it. A former homeless shelter resident, Steven Frischmuth (2013), details a similar phenomenon in his own biographical essay. He foregrounds how safe and secure accommodations are necessary to promote mental health, but often end up creating more social defeat. An individual often is rescued from the street and out of harm's way, only to find new dangers inside the haven of a shelter or mental health housing site. These vulnerabilities are exposed even further during a pandemic. While navigating the *space*[i] in housing sites or in mental health programs, people like Tao report having to endure deeper pressure-cooker-type interactions with others than in housing before the pandemic.

Though he would normally go places to get away, like the library or even Target for a coffee in the Starbucks inside the store, Tao said has to stay at home. If he does go do grocery shopping, he has to shower immediately after entering the CR. Before the pandemic, when people moved in between scheduled time in program or part-time jobs if they could work, tensions arose, but there was at least some respite in between. With the pandemic, everyone is home all the time, working a lot less or not working at all, and the pressure cooker top has lost its lid. Tao and others are forced, as Reavey et al. designate (2017), to manage the delicate

emotional ecology of the CR occupying time in what I call a *chosen for* space (a venue "chosen for them" and not *by* them), while they wait (and wait) for some breakthrough in the COVID-19 numbers, while they wait for some word of program opening up, or someone coming to visit.

"Hell, even the Amazon delivery truck is exciting," Ricardo, a CR resident notes. "I am sure it's that way for people not living in a CR, but for us, it's worse. You want one moment of joy. No family can visit."

Ricardo, a Black Puerto Rican is transitioning from male to female and refers to himself as he/him/his. His CR staff "don't know what to do with [him]." They are unsure how long he can keep rooming with a female as the transition is behind schedule because the pandemic. "So, am I a man or a woman still? I don't care, but the teasing and mean looks I get is [sic] cruel."

The coronavirus numbers—though encouraging—are still requiring caution, and because group CRs are considered vulnerable sites, people with mental health disabilities get further steamed in these pressure cooker sites.

While both Ricardo and Tao are in custodial, monitored housing, off the streets, they both note they have to work on what Reavey et al. (2017) describe as their "deferral of emotions" (p. 214), those reactions that could be triggered by living in close quarters with others managing with mental health disabilities. Some days, people do not succeed in deferring emotions. Ricardo said he yells at roommates for bullying him and saying mean things about his newly emergent facial hair. He tells them to shut up and that he wants to punch them; then he realizes this does little for his compliance and the CR protocol. He will not "move up on the list to get a new ATP [apartment treatment program]," he said. Without delaying his outbursts, he is sanctioned, "almost like being sent back to the start line again or the back of the line." If he cannot move, he is forced to stay in this same site and work harder on the deferral of emotions. This is tricky in any environment, but add a pandemic, name-calling, gender discrimination and hormone treatments to the equation, and it is a real storm.

Another participant who was successful in deferral of emotions long enough to navigate her own ATP says the pandemic is still teaching her new lessons. She feels the staff at housing sites now have more justification for letting services lapse. She has learned to ask different housing representatives different things and when not to ask at all. She requests

housing accommodations with trepidation. "I know for valid reasons I can't get certain things. I can't expect my carpet will be cleaned. I can't expect my toilet to be fixed. All of this [sic] coronavirus reasons are real, but I am still living with these inconveniences."

After several attempts at suicide, living in her car, then hospitals and several larger CRs, she has finally arrived at the ATP. It has been a long stormy journey, she said, so she wants to make her home nice. "However, I am at the mercy of the agency people," she said. So, while she waits for plumbing fixes, exterminators and mediation appointments for menacing neighbors, she tries to busy herself doing other things. During the pandemic in the early days, she said, she may not have made good choices. This lessened her ability to comply and defer her emotions, which led to arguments with neighbors and roommates. "Like many people," she said, "I drank, I ate. I watched too much news. I gained weight. I normally go to the gym; no gyms were open. I drank instead. That probably did not help my relations with others. I could not hold my tongue. Now they often won't help me, and I will wait longer."

Back on (off) campus.

Fall of 2020 certainly looks differently for all educators, especially those who teach. I normally spend my fall teaching at least one section of bioethics. This fall is no different. I have one bioethics section. I had already been teaching online off and on for years and recently began working full-time for a campus that has been the premier online campus of our university system and the state for 15 years. I transitioned here in January 2020, so when March 12 and 13 arrived and we were sent home *for cleaning*, I had already completed training in how to facilitate Blackboard courses, was using Zoom, teaching both Spring courses online, and knew how to create videos for my virtual, asynchronous classes. I studied the literature about online pedagogy and how to captivate people, what types of learning styles I had to be mindful of, how to use universal design in my course sites, how to use VoiceThread to engage students and what efforts online educators can use to try to cultivate online campus communities. Nothing much changed for me, except the delicate emotional ecology of my own home and an increase in questions I could not answer for my daughter.

What I really did not expect was how much my students would mature during this last six months. Neighbors and other colleagues tell me they believe this event will adversely affect students long-term. "Students will not be able to think or write after the pandemic," one community member said. I cannot say what it will do to their math and English skills, but I can say I have not ever seen a more perceptive and participatory group of introductory ethics

students. I have been teaching introductory ethics and bioethics now for 16 years. Never have students grasped the theories so concretely. Never have they offered their own examples—such as delay of medical services, burying family members without funerals, fighting with insurance companies for coverage—without me prodding them. The discussions are not at all forced or deliberate. They are real-time ethical dilemmas. They teach me more than I can teach them. I am sorry for the reasons they have matured and are more engaged with medical, feminist, racial and environmental ethics, but it is an outcome of the pandemic I feel honored to witness.

The principles of utility and the greatest good for the greatest number, ethical subjectivist approaches, cultural relativism and concepts of deontology were normally very abstract content. I always worked hard to bring in examples for each. Often, I had nurses doing palliative care as guest speakers to drive home what end-of-life choices and lack of insurance look like in real time. This may have included a paramedic or ambulance driver to describe the embodiment of trauma care, and a physician assistant who worked in the 2005 earthquake in Pakistan to talk about triage and lack of basic medical supplies and running water. This year, I need none of that.

Students are reading the material and presenting their own lives as case studies. These vignettes typically begin with something like, "My disabled parent…" or "My disabled grandparent…" or "My sister…" or "I contracted COVID-19 and then I could not get to the doctor." Or worse yet, "They turned us away…" or "We did not have medical insurance…" and "I did not get to see my [family member] before they died."

When a student tells the class he recently lost his mother to COVID-19, he immediately offers what utility and consequentialism mean to him. This academic year, no one has to stretch their mind to think about what that means. It means his family could not see his mom in person before she died.

What does deontology mean to the student whose best friend just committed suicide? He tells me, "I am in a dark place." He is wondering why his religion, a deontological approach to ethics, would condemn his friend for taking his own life, because out of duty, as deontology instructs us, one should never take their own life. But to know what his friend endured in tragedy and trauma, losing a number of family members to COVID-19, and not being able to share their last moments with them, he asks, "There must be a more forgiving ethical theory to apply to this situation, right?" He is still pondering *the greatest good for the*

greatest number of people and wants to consider what ethical futures for people with disabilities means to him and to his friend. What is an ethical future? And what does it mean to be disabled during the time of the pandemic? And now, to be disabled during the time of catastrophic unprecedented wildfires, to be Black during the time of civil unrest, to be a cop in Compton.

There is no stretching for ethical "case studies." Our students have their lives and experiences, not merely simulations, to ponder. And, while I am profoundly honored to be facilitating the learning of theories to apply to these dilemmas, as with the climate and the civil unrest, I want it to change.

As my participants' vignettes amplify, in between the *weighing in* and the waiting, conditions are ripe for potential harms like social defeat, trans-institutionalization, interlocking forms of discrimination, and long-term depression. Even the most idyllic spaces, like stand-alone homes in suburban or rural ecologies outside the asylum, these venues can and do promote containment, control and pressure-cooker situations. We hear the pandemic is bringing with it a new "mental health crisis." As with the coronavirus, we may not have a vaccine for this crisis, and we may not know how to mitigate while we wait for more services for people. Meanwhile, the pressure cooker continues to boil.

Breakthroughs

The other thing I love about the weather in New York is the fall. Summer in New York is oppressive. I want nothing of its humidity and mosquitoes. By late June, my daughter and I complain about mugginess and long for dry Southern California, mosquito-free nights. After my first dozen mosquito bites, I think of snow again. By the time mid-September is here, I feverishly watch the weather thinking, *When will the bloody humidity break? When will it be in the late 50s or early 60s at night? When can I turn off the swamp cooler, breathe normal air again and sleep well at night? When will this pressure cooker simmer and cool?*

I realize these questions hardly seem urgent as we watch the fires raging in the West, as people riot in the streets for change, and as I think of participants and those in my own family housed in contingent mental health disabilities sites trying to live within the confines of real pressure, real pressure cookers. I try not to fixate on animals and people I know in the fires, literally cooking with no escape—disabled animals and disabled people who need help

breathing, who may not be able to evacuate on their own. I want snow for them too, but I would be satisfied with some rain.

I concentrate on the morning's meditation:

> Breakthrough:
>
> In late summer, heaven's breath is damply hot.
>
> It smothers the earth with dullness.
>
> Suddenly, thick clouds gather.
>
> A wave of polar air passes like a frigid rake.
>
> Acorns fall like bullets,
>
> And a new wind breaks through. (Ming-Dao, 1992)

I can open the windows this evening. The forecast calls for a low of 56 tonight. I am chilly and dancing through the house, taking these moments of joy, but I am also pushing raging fires, dying people, and contained residents with disabilities out of my mind.

"Will we have snow this year," my daughter asks again? "When will the vaccine come? When can we stop wearing the masks?"

"I don't know Honey, but I am looking at this small breakthrough as a start."

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[1] In emerging work, I describe how, in some cases, people endure community-based, state-sponsored mental health housing and programming while they occupy time in these spaces. I explore people's descriptions of living quarters with the analytic of "place versus space" (See Jennings) as a way to evaluate housing versus homes. I also consider the differences between those venues and occupations that I characterize as *chosen for* someone by others versus venues and occupations that are *chosen by* individuals themselves. The latter, I argue, renders them more of agents over themselves, and I consider what this means for their well-being.

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As I learned of this article's publication (on December 11, 2020), the world learned of the Pfizer and BioNTech COVID-19 vaccine's emergency use authorization (EUA) in the United States, and the first doses were being arranged for deployment for the following week. This has us now wondering, to whom, when and how? We know people with disabilities are some of the most vulnerable, yet often the most overlooked or underserved. Though the vaccine is a remarkable accomplishment, my thoughts now turn to the following questions: *What are the most egalitarian approaches to immunizing people with intersecting vulnerabilities? Will people of color with physical, cognitive and/or mental health disabilities, and those living in public mental health sites or long-term care facilities be prioritized appropriately? And, will neurodiverse and other variations of human lives be honored and well cared for with this vaccine's rollout?*

Also, ironically as of this week, the weather gurus report a "nor'easter" storm carrying wind snow and rain may dump "up to between 12 and 18 inches of snow" on New York and New England for the first time in 11 years, and, notably *before* Christmas. Our family, fatigued by the pandemic, our own isolation, and bickering has some hope. A vaccine and some snow. Hops has taken extra rest, is waiting patiently by the sliding glass door, and of course, it is finals week for me. I have mounds of papers to grade, and I have a federal grant due the day the blizzard is forecast to shut down the trains. I know where the hot chocolate and everyone's gloves are though.

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Research & Essays

Cinema on the Spectrum: The Importance of Representation of Persons with Autism in a Post-COVID World

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Author Note

The first draft of this article was completed in 2019. However, as 2020 unfolded and many turned to their screens for an escape, the growing influence of media on its audience became impossible to ignore. So, my article now explores this development in the context of those who have historically been sidelined by media - an active pursuit that I believe is imperative in a rapidly changing, post-COVID world.

Abstract

Be it the cooky sidekick or the awkward genius, mainstream media has seen many variations of the autistic character – some more realistic than others. This essay explores some reasons why representation of persons with autism in mainstream cinema can be important for their successful integration into society. It also suggests this need is exacerbated during the worldwide COVID-19 pandemic. These ideas are explored through the analysis of landmark representations of autism in both Hollywood and the Indian Film Industry. These two geographic zones (United States and India) are chosen as they are the two largest film industries in the world, collectively contributing over 2500 moving pictures per year. The findings indicate that there are noticeable distinctions between the different types of representations. Moreover, it is evident that there exist specific steps which can and should be taken by content creators in the field to achieve a responsible array of media representation which both benefits and entertains our increasingly conscientious society.

Keywords: autism, cinema, film, representation, media

Cinema on the Spectrum: The Importance of Representation of Persons with Autism in a Post-COVID World

I've learned that every human being, with or without disabilities, needs to strive to do their best, and by striving for happiness you will arrive at happiness. For us, you see, having autism is normal - so we can't know for sure what your 'normal' is even like. But so long as we can learn to love ourselves, I'm not sure how much it matters whether we're normal or autistic.

-- Naoki Higashida, *The Reason I Jump*

Media is often referred to as the mirror of society. Audio-visual mediums, film and television in particular, have an increasingly significant effect. The coronavirus pandemic has exacerbated this influence. As the world went into lockdown, media consumption hit a record high. In India, the first month of lockdown saw a 75% increase in video streaming (Keelery, 2020). Netflix reported a total of 16 million new users worldwide in the first 3 months of 2020, double the amount it saw in the three months prior. Netflix's share also rose by 30% as investors placed their bets on people remaining indoors for the foreseeable future (Thomas, 2020).

Ironically, however, six months into the global pandemic, Wells Fargo's Steven Cahall cut down his estimate for Netflix's third quarter subscriber growth over outrage regarding the French film *Les Mignonnes [The Cuties]* which faced allegations of oversexualizing minors (Szalai, 2020). So among a backdrop of skyrocketing media consumption as well as "outrage culture," viewers demand an increase in both quantity and quality. An increasing number of modern audiences expect the media they consume to also align with their personal values and morals. Therefore, not only is film and television media being consumed by more people than ever before, its impact may be unprecedented.

In this context, discourse surrounding representation in media gains newfound importance. As posited by W. J. T. Mitchell's seminal work *Picture Theory*, representation constructs knowledge (Mitchell, 1995). In other words, representation *matters*. This belief is affirmed in the contemporary post-COVID world as industry leaders such as the Academy of Motion Picture Arts and Sciences begin to call for broader inclusion and representation in the industry (Academy of Motion Picture Arts and Sciences, 2020). In India too, this

conversation has brought attention to challenging the "ideal" of fair skin and more recently, the caste hierarchy.

Discrimination based on skin color, race, ethnicity and gender is endemic. The Clark Doll Experiment, first conducted in the 1940s to gauge the destructive impact of segregation, consisted of children between the ages of 3 and 7 asked to pick out who is "nice," "bad," "pretty" and "ugly" from a pair of two dolls - one black and one white. When picking the "prettiest" and "nicest" doll, most children, regardless of their own ethnicity, picked the white doll. If we were to now consider adding a quadriplegic doll to this mix, it would not be unreasonable to assume that a black, disabled doll would be chosen even less frequently by young participants.

Such attitudes towards race and disability stem at least in part from stereotypes and misinformation perpetuated by media. For better or worse, media images are often the principal exposure many non-disabled people have to persons with disabilities. In 1991, a poll conducted in the wake of the 1990 Americans with Disabilities Act showed that Americans were less likely to feel awkward around persons with disabilities after having viewed a fictional television show or movie featuring a disabled character (Harris, 1991). This suggests that many people rely on these fictitious accounts and portrayals to, at least in part, construct their view towards people with disabilities.

In the case of autism, specifically, this issue becomes even more pertinent because the condition is not often easily understood. Autism was first defined by in 1943 as an 'innate' disorder (Kanner, 1943). However, its definition continues to evolve. Currently, it is defined as a "spectrum disorder," on a continuum of severity, as well as a "syndrome," encompassing a wide variety of traits" (Strate, 2006). Three specific symptoms - deficiency in social interaction, repetitive and restricted patterns of behavior and childhood manifestation - *are* defined, but most characteristics outside of these are subjective and vary by person. Hence, the difficulty with accurately representing autism in media in part stems from the fact that autism is a spectrum on which a myriad of abilities, behaviors and personalities lie. Attempting to reflect this complexity in media has had mixed results.

Methodology

For the purpose of this article, only portrayals from the United States of America and India will be analyzed. As the top two film industries in the world with a collective viewership of over 6.2 billion, their impact can be assumed to be objectively higher than any other regional industry in the world. Moreover, only films and series which have either had a theatrical release or have been aired on television or major streaming platforms are considered as the objective is to assess media with the highest possible viewership. The chosen films and series, thus, are those which are recognized in the mainstream and/or can be defined as pop culture stalwarts by the general public.

Media Analysis

Hollywood

In the well-known 1989 film, *Rain Man*, directed by Barry Levinson, Dustin Hoffman stars as Raymond, an autistic savant (a person with autism who has an extraordinary ability or area of knowledge). Tom Cruise plays Charlie, his selfish brother. The character of Raymond is consistent with the 'savant' stereotype, an extremely common representation of autism in mainstream media (Prochnow, 2014). This style of portrayal can be seen in contemporary television shows such as *The Good Doctor*, which is based on the premise of a genius autistic medical professional. Such portrayals are also often seen in characters which are "autistically coded," i.e., they display symptoms and characteristics of being autistic, but the condition is never explicitly addressed in the script. Sheldon from *The Big Bang Theory* and Sherlock Holmes from BBC's *Sherlock* are examples of non-canonical autistic characters who play into the "savant" stereotype.

In a telling scene from *Rain Man,* Charlie takes Raymond to a doctor to be evaluated. The doctor informs Charlie that Raymond is an "idiot savant," i.e., he is actually extremely intelligent and high functioning but that his autism "causes him to have a problem communicating and learning." This statement rings true to the extent that most persons with autism appear to have a functioning and layered consciousness, which they may be unable to express due to the disconnect between their mind and physical body. However, while this stereotype appears to be a positive one at first glance, it may do more harm than good. By focusing on the small minority of "autistic geniuses," the media places this archetype on a pedestal, making it the "model neurominority" (Toon Ruins, 2019). These representations skip past the majority of persons with autism who are of average or low intelligence, forming an inaccurate image in the mind of the uninformed viewer. Hence, such stereotypes place

undue expectations on persons with autism, as the media representing them primarily only focuses in on and romanticizes this fantasy of an awkward prodigy.

Whether accurate or not, these images in media can have a profound impact on public perception of disability. It is well documented that in preparation for his role as Raymond, Hoffman spent a year studying real-life savants such as Temple Grandin, and he also worked closely with an expert (McCarthy, 2018). The problem then emerges not necessarily because such portrayals ring untrue but because, at the time of release, it was the *only* portrayal the general public had access to. This has helped perpetuate the ever-pervasive myth of "special abilities" in autistic individuals.

Nevertheless, mainstream Hollywood *is* moving towards more realistic portrayals of autism. Prochnow (2014) suggests, "these [realistic] depictions most closely match the criteria laid out for ASD in the DSM-5. The characters are neither over-the-top in their behaviors nor subdued in the display of their symptoms. They are also not portrayed in an overtly positive or negative light" (p. 143). A fitting example of such representation comes from the 2017 Netflix series *Atypical*. The show revolves around the personal and family life of Sam, a teenager with autism. Over the course of three seasons, the web series explores various themes which are prevalent in the lives of intellectually disabled children including - but not limited to - counselling, sexuality, social integration and independent living. The format of the show consists of 8 to 10 30-minute episodes per season. This extended time, coupled with the freedom of producing for an online platform, appears to have allowed the creators to explore these themes at length and in detail, allowing for a more realistic, nuanced portrayal.

Bollywood

Indian media charts a different landscape for its autistic characters. Before 2010, the existence of canonical autistic characters in mainstream media was virtually non-existent. Films which did feature autistically-coded characters, such as *Koi Mil Gaya* (2003), did not outrightly acknowledge the condition. Moreover, these films treated autism as a flaw needing to be fixed, in line with the outdated medical model of disability. 2010's *My Name is Khan* was the first mainstream Bollywood film to feature an autistic protagonist with Asperger's Syndrome. The film has been widely praised for its more accurate and nuanced portrayal of life with autism. It correctly represents some of the quirks observed in people on the spectrum such as constant fiddling or "stimming" (self-stimulating behaviors) and aversion to the color yellow. While Rizwan Khan in the film does display some characteristics of the savant stereotype, this characterization is muted and less exaggerated as compared to

Hollywood films like *Rain Man* (Aiofe, 2017). However, *My Name is Khan* isn't without its fair share of criticism. Ben Belek, an anthropologist from Cambridge University, observes that the overarching theme of the film seems to convey that humans are all the same despite differences in religion, ethnicity and neurological make-up (Belek, 2019). This messaging, while well-intentioned, may overlook the importance of *acknowledging* difference rather than ignoring it, to achieve harmony and equality in society (Bumiller, 2008).

Alternatively, other representations in Indian cinema also portray autism as being linked to certain supernatural phenomena. Malayalam director Vivek's 2019 thriller *Athiran* plays into this sinister stereotype by giving the autistic heroine superhuman reflexes which she utilizes in martial arts. In the first half of the film, the autistic character is portrayed as malicious and potentially supernatural. In the second half, the narrative is flipped to portray her as an object of violence, in need of rescue. For an audience unfamiliar with autism, this kind of representation can lead to the development of dangerously faulty constructs.

Additionally, it is important to note that every character discussed so far is a representation of *verbal* persons with autism. This is because the *non-speaking* section of the autism community is extremely under-represented in film. A mainstream film which attempted to portray this end of the spectrum was Anurag Basu's *Barfi!* (2012). In line with the aesthetic of the film, Priyanka Chopra's portrayal of the autistic character Jhilmil was lighthearted, quirky and romantic. Unfortunately, this aesthetic did not lend to a realistic portrayal as the character's autism diagnosis seemed inconsistent, and malleable according to the needs of the plot, hence reducing the character to a caricature.

Such strategies of simplifying and making the condition of people with autism more palatable to audiences can have serious consequences. Dr. P. N. Sharma, Special Needs educator and author of *Autism: Nature, Needs and Diagnosis* (2018), suggests such representations can be dangerous. Sharma notes that "even films which supposedly feature autistic protagonists such as *My Name is Khan* or *Barfi!* feature them in a manner which is palatable for the general audience." With real-life mannerisms and challenges "watered down to fit an aesthetic, as to not disturb the ignorant Indian populace," audiences are left misinformed and are more likely to be insensitive to actual people with autism. Sharma stresses the importance of more realistic media representation by saying, "In India, people who are uneducated about intellectual disabilities are extremely insensitive towards autistic people. They call them 'pagal' [crazy]. Such attitudes are extremely harmful and this is why media representation is vital in order to educate these masses" (P. N. Sharma, personal communication, March 6, 2020).

Conclusion

Inaccurate representations of people with autism in mainstream media, such as *savant, supernatural* and *quirky* characters, do not represent the average person on the spectrum but instead serve the plot and stylistic choices of the film. By contrast, more realistic portrayals have the following characteristics: (1) they do not embellish the autistic character's personality with traits which lie outside of what would typically be expected for dramatic effect; and (2) they serve as responsible templates for what a real person with autism may look like to an uninformed audience.

An inaccurate representation is not, in and of itself, negative. As Prochnow (2014) states, "it is better to have an unintentional negative representation than to have no representation at all and be ignored as a social group" (p. 148). However, in order for these kinds of representations to exist and not cause harm to the autism community, broader representation and "normalization" must pre-exist and be readily available as realistic alternatives. In much the same way that the Marvel superhero or villain is not mistaken as an average human, audiences must be prevented from seeing limited, atypical representations as accurate models of autism. The American film industry has, in contemporary times, taken strides towards such "normalization" with series like *Atypical*. The Indian film Industry too has moved in a similar direction with films such as *My Name is Khan* but is still behind the United States with respect to the quality and quantity of positive representation.

To conclude, though persons on the spectrum may not always be adept at communication, they earnestly wish, of course, like anyone else, to be parts of society. Summing up the sense of isolation many with autism feel, in the *Reason I Jump*, Higashida (2016) states "We'd love to be with other people. But because things never, ever go right, we end up getting used to being alone, without even noticing this is happening ... it makes me feel desperately lonely" (p.28). Ultimately, more accurate representations, especially in this time of steadily increasing, socially-vigilant viewership, may provide a small but real benefit for many struggling to communicate their own wish for acceptance, and such portrayals could in turn contribute to the development of more inclusive communities in the real world.

Ananya Kapoor, a graduate in Multimedia and Mass Communication from the University of Delhi, is an author and aspiring filmmaker. She has directed several short films, assisted on the sets of popular web-series and was one of the selected participants at the Thailand International Film Destination Festival 2019. When not writing about or making films, she can be found in bed, *watching* films – or as she refers to it, "researching". She is currently pursuing her Masters in Filmmaking and hopes to help make the industry a more inclusive space through her work.

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Research Articles & Essays

Activism Among College Students with Disabilities and the Move Beyond Compliance to Full Inclusion

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Author Note

Author's additional statement on the COVID-19 pandemic:

"The author notes that the addition of COVID-19 to the higher education learning environment has added additional barriers to meaningful inclusion and effective activism that were not included in this article because the study was conducted pre-COVID-19. Research on how COVID-19 has impacted the inclusion of students with disabilities in higher education is needed."

Abstract

This article discusses two case studies of activism by college students with disabilities that have successfully moved disability issues beyond regulatory compliance to a conversation of equity. The two case studies are compared to identify strategies that promoted the success of the campaigns. The article concludes with a discussion of the usage of student activism to ensure equality of opportunity.

Keywords: students with disabilities, postsecondary education, activism

The purpose of this article is to determine what activism strategies utilized by students with disabilities have been successful and what steps Institutions of Higher Education (IHEs) can take to build cultures of meaningful inclusion and equity for students with disabilities. To do this, the article closely examines two case studies involving activism by students with disabilities that successfully pushed IHEs toward building cultures of meaningful inclusion and equity for students with disabilities and moved them beyond mere regulatory compliance. Cory et al. (2010) noted that staff at IHEs often concentrate on regulatory compliance issues, without recognizing a philosophical stance on meaningful inclusion and disability, contributing to distant, unconnected disability service entities on campuses. There is often an assumption that compliance with regulations equates adequate representation of students, staff, faculty, and administration with disabilities at IHEs. The two case studies reviewed here provide examples of student activism that took place after the implementation of the landmark Rehabilitation Act of 1973 and moved IHEs beyond simple compliance to an institutional culture supporting meaningful inclusion of individuals with disabilities at all levels of the IHE. These case studies were chosen specifically because there was adequate documentation and description in the public record of both the overall events surrounding the actions taken by students and, more importantly, the specific strategies that student activists employed to succeed in their social change efforts. This allowed the authors to perform an in-depth comparison and analysis of the strategies employed by student activists that led to the success of their respective campaigns. By clearly identifying these successful strategies, the authors hope to inform future efforts of disability activists to create meaningful change in the cultures of all IHEs around inclusion and equity for students, staff, faculty, and administration with disabilities.

Kimball et al. (2016) combined several diverse definitions of activism to define it as having elements of: a) "involvement in and commitment to social change"; b) ideological motivation to resist "aggression and suppression"; and c) "emotional engagement rooted in larger senses of identity, stigma, and purpose" (p. 247). The two case studies presented in this article were selected with this definition of activism in mind. In both cases, students were committed to social change, ideologically motivated to resist suppression, and emotionally engaged based upon a sense of identity, stigma, or purpose.

It is important to note that the terms "activism" and "self-advocacy" are not used synonymously in this article. As defined by Kimball et al. (2016) "self-advocacy includes the ability to communicate needs and wants, locate services, and obtain necessary supports" for oneself (p. 248). The key difference between activism and advocacy, particularly as used in

this article, relates to the level of change on which they focus. Self-advocacy refers to a person advocating for change at the level of their individual self, while activism is focused on creating change at the broader community level for the collective benefit of a group or groups of people. Activism can still involve the communication and obtainment of needs and wants, locating services, and obtaining necessary supports, but this is done beyond the level of doing so for oneself; instead, it includes commitment to broader social change, aspects of ideological motivation, and emotional engagement at the level of group identity.

Disability Activism

While there were disability activists before the 1970s in the United States, the majority of disability activism that has resulted in policy changes has occurred in the last fifty years. This can be attributed to the civil rights movement as a successful model for activism combined with the attention turned to disability rights through events such as President Kennedy forming the President's Committee on Mental Retardation and the filming of horrific conditions in institutions for people with disabilities famously documented by Geraldo Rivera in 1972. The hallmarks of disability rights activism were the protests surrounding the implementation of Section 504 of the Rehabilitation Act of 1973 and the protests leading to the passage of the American with Disabilities Act (ADA) in 1990.

Other noteworthy disability activism includes numerous protests around inaccessible transportation systems. In 1978, activists blocked buses with their wheelchairs in Denver, Colorado. In 1983, the group Americans with Disabilities for Accessible Public Transportation (ADAPT) began a national campaign advocating for lifts for buses that lasted seven years until the ADA was passed in 1990.

Similarly, the rally at the U.S. Capitol in March of 1990 before the passage of the ADA also garnered national attention. Activists from 30 states gathered at the capitol, and Dr. I. King Jordan, the first non-hearing president of Gallaudet College, stated "If we have to come back, perhaps we'll simply stay until they pass [the bill]" (Eaton, 1990). At the conclusion of the rally, dozens of activists with disabilities left their assistive technology at the bottom of the Capitol steps and crawled to the top. The rally was a quintessential civil rights protest, including chanted slogans and songs, and was important in gaining public attention for legislation that had been delayed since September of 1989 as congressional as congressional committees conferenced and reconciled the different versions of the ADA that had passed the Senate and House.

These noteworthy disability activism events provided successful examples of how

people with disabilities could push for change and provided a foundation for future activism. This article examines two case studies of activism involving students with disabilities who successfully pushed IHEs beyond mere regulatory compliance toward building cultures of meaningful inclusion and equity for students with disabilities. The following case studies are examples that illustrate successful student activism that promoted equity of opportunity, meaningful inclusion, and representation for students with disabilities at IHEs.

Case Study #1 – Deaf President Now

The first example of student activism at an IHE that moved beyond mere compliance is the Deaf President Now (DPN) movement at Gallaudet University in Washington D.C. in 1988. It should be noted that this case study did not focus on a strict issue of compliance. There were no regulations requiring that a university president be representative of student demographics. This case highlights complacency and tokenism regarding inclusion and representation in the spirit of 'nothing about us without us.'

The authors also note that many members of the Deaf community do not consider deafness a disability. However, deafness meets the legal definition of disability under Section 504 of the Rehabilitation Act and the ADA, which makes students who are deaf candidates for activism at IHEs. The authors decided to include the Gallaudet case study because of its potential to guide future activism events. Throughout the article, "deaf" and "Deaf" are both used. The term "deaf" is used to refer to hearing loss. "Deaf" is used when referring to aspects of Deaf culture or the Deaf community.

Gallaudet University was established in 1864 and is the world's only IHE dedicated to deaf and hard of hearing students. Between 1864 and 1987, Gallaudet had six university presidents, none of whom where deaf or had a hearing impairment. When the sixth president left the position in September of 1987, the Board of Trustees set up a committee consisting of Board members, alumni, students, faculty, and staff, to search for a new president. The committee received 87 applicants for the position. By the end of February 1988, the committee announced three finalists – Dr. Harvey Corson, Dr. I. King Jordan, and Dr. Elisabeth Zinser. Dr. Corson and Dr. Jordan were deaf and Dr. Zinser was a hearing person ("History behind DPN").

Momentum for a deaf president had been building well before the search committee announced the three final candidates. In 1983, when Gallaudet's fourth president left his position, he advocated for a deaf president to replace him ("History behind DPN"). Between 1983 and 1987, the idea gained more traction, and advocacy for a deaf president began in

earnest. Groups such as the National Association of the Deaf (NAD), the Gallaudet University Alumni Association, and faculty groups began calling for the change. Letter writing campaigns were organized. The Board of Trustees not only received letters of endorsement for a deaf president from faculty, alumni, and advocacy groups, but from Vice-President George H. W. Bush, Senator Bob Dole, Senator Bob Graham, Senator Tom Harkin, Senator Paul Simon, Senator Lowell Weicker, Congresswoman Pat Schroeder, and the Reverend Jesse Jackson. Despite widespread advocacy for a deaf president, student activism did not mobilize until after the three finalists were announced ("History behind DPN").

Advocates for a deaf president organized a rally for March 1st. Flyers were distributed across campus labeling the DPN movement as a civil rights issue. Over 1,000 demonstrators showed up for the rally. The crowd consisted of Gallaudet students, elementary and high school students from Gallaudet's pre-college programs, staff, faculty, alumni, and local deaf and hard of hearing community members. Over the next four days, students began camping out in tents at the president's home, and several hundred students briefly blocked traffic on a roadway bordering campus. The student body president wrote a letter to Dr. Zinser asking her to withdraw her interest in the position ("The Week of DPN").

Meanwhile, the Board of Trustees met off campus with each of the candidates for a final interview. The Board of Trustees was scheduled to announce their decision on the morning of March 6th, the day after they finished the interviews. Instead, the Board of Trustees had Gallaudet's public relation office send out a press release at 6:30 p.m. on March 5th announcing Dr. Zinser as Gallaudet's new president. This announcement immediately opened the floodgate to student activism ("The Week of DPN").

Students who had gathered to hear the announcement blocked traffic in front of campus and marched to the off-campus location where the Board of Trustees had met. A confrontation occurred between the protestors and Jane Spilman, the chair of the Board of Trustees, as she was being interviewed by reporters. The result of the chaos was that the Board of Trustees agreed to meet with activist representatives that evening. There are conflicting accounts regarding statements made by Spilman during that meeting, but it was reported that she stated that "Deaf people are not able to function in a hearing world" ("Jane Bassett Spilman," 2018). While Spilman denied making the statement, many of the activists believed she did, and Spilman was established as having a dismissive attitude towards the activists' quest for representation in Gallaudet's leadership. The fact that Spilman could not sign did not help her image with the activists. Throughout the remainder of the night,

activists marched to the White House, the Capitol, and the Gallaudet campus ("The Week of DPN").

On March 7th, activists drove vehicles to campus entrances, deflated the tires, and formed a human chain to block administrators from entering campus. Sporadic speeches and rallies occurred throughout the day. Most importantly, protest leaders met and formed a list of demands that they presented to the Board of Trustees. The Board of Trustees rejected the list of demands. The rejection of the list of demands prompted a spontaneous march to the Capitol Building where more speeches were given. The demands were:

1. Dr. Zinser must resign and a deaf president be selected;
2. Spilman must resign from the Board of Trustees;
3. The percentage of deaf members on the Board of Trustees must be increased to at least 51%; and
4. There must be no reprisals against any of the protestors ("The Week of DPN").

On March 8th, students boycotted classes, and speeches were given across campus. By this time, the protest was receiving national media attention. On March 9th, Dr. Zinser arrived in Washington D.C. The Board of Trustees had requested that she quickly assume the role of president. She met with Dr. Jordan and four student leaders. The students urged her to not take up the position of president, and she refused. At this time, Dr. Jordan publicly stated support for Dr. Zinser. On March 9th, Gallaudet faculty and staff also met and voted to support the student-led protests.

On March 10th, in response to rumors that Zinser and Spilman were going to force their way onto campus, students parked Gallaudet owned buses at the entrances to campus and deflated the tires. Rallies continued that day, and buses brought in additional student support from the National Technical Institute of the Deaf in Rochester, New York. Businesses donated supplies and money to the supporters. In the afternoon, Dr. Jordan retracted his support for Dr. Zinser and endorsed the four demands of the activists. He would later state that he was not expecting to be asked to speak at the press conference when he stated that he supported the appointment of Dr. Zinser. Dr. Jordan said that when he had gone home that night he thought "Sure I'm a dean and should support the Board of Trustees, but hell, I'm also deaf and will be for the rest of my life, and that's more important" ("I. King Jordan," 2018). That evening, Dr. Zinser announced she would resign. Afterwards she would say "My resignation was not in response to demonstrations…but to pave the way for the civil rights movement to progress" ("Elisabeth Zinser," 2018). Her term as Gallaudet's president

lasted three days, during which she never entered Gallaudet's campus. The activists had achieved a portion of one of their demands ("The Week of DPN").

On March 11th, rallies continued. It was also the first day of the students' spring break, and they vowed to stay on campus. Another march was held to the Capitol Building. This was the only planned march of the DPN movement and the only one to obtain the required permits.

On March 13th, the Board of Trustees convened an emergency meeting. That evening they held another press conference where they announced that all of the demands of the activists would be granted. Spilman resigned, and a new chair was named to the Board of Trustees. A taskforce was set up to implement the request to have 51% of the Board of Trustees be deaf. It was guaranteed that students, faculty, and staff would have no reprisals for their participation in the protests. Finally, Dr. Jordan was named as the first deaf president of Gallaudet ("The Week of DPN").

It is important to note that the DPN activists carefully formulated the protest as a civil rights movement and not a disability rights movement. The flyers that were distributed for the first rally on March 1st were framed with a civil rights lens ("History behind DPN"). The flyer announcing the rally stated that Notre Dame had its first Catholic president in 1842, Wellesley College had its first female president in 1875, Yeshiva University had its first Jewish president in 1875, and Howard University had its first African-American president in 1926. It was clearly time for a deaf president at Gallaudet (Armstrong, 2014). The flyer distributed during the rally further outlined the lack of representation at Gallaudet for the population it served by outlining that only 22% of Gallaudet staff were deaf, some faculty members could not sign well but met minimum teaching requirements, and only 19% of the Board of Trustees were deaf ("Rally Flyers"). The actions of the activists were also quintessential of civil rights protests. The letter writing campaigns, boycotting of classes, marches, blocking of traffic, rallies, and speeches were all peaceful means of protest previously proven successful by civil rights activists.

It is also important to note that the DPN movement embodied the idea of meaningful inclusion. A letter of support for the DPN movement written by the president-elect of the American Society for Deaf Children stated "You have said that the President you appointed is a 'caring' person. Deaf people do not wish to be 'cared' for; they need a Deaf President who respects and empowers Deaf people" ("Notable Quotes," 2018). This statement embodies much of the spirit of the DPN movement. It was a push for representation and

inclusion of students with disabilities at the leadership level and to fully install a climate of empowerment and equity at Gallaudet.

Case Study #2 – Beyond Compliance Coordinating Committee

The second case examined is the formation of the Beyond Compliance Coordinating Committee (BCCC) at Syracuse University in New York (Cory et al., 2010). The BCCC case study provides a comparison of similar activism activities that students at Gallaudet employed, albeit in a less publicized format. It contributes to the discussion by helping to identify successful activism strategies and steps taken by an IHE to build a culture of meaningful inclusion and move beyond regulatory compliance.

The BCCC was formed in 2001 by five doctoral students in the Disabilities Studies program at Syracuse. According to the website of Syracuse's Disability Studies program, "the program is designed to help students examine disability as a social, cultural, and political phenomenon" (Foley, 2018). Three of the five students identified as students with disabilities. The events that precipitated the formation of the BCCC was the continual failure of the Office of Disability Services (ODS) at Syracuse to provide accommodations for two of the students with disabilities. One of the students, who was blind, needed assigned readings converted to e-text. The ODS continually failed to provide the e-text versions of course readings in time for the student to read before class. One of the other students was deaf and had struggled with the ODS providing Computer Assisted Realtime Translation and classroom interpreters. ODS maintained in both situations that the services they were offering were legally compliant although they perhaps did not meet the expectations of the students. This response is evidence that a climate of legal compliance existed within the ODS at that time. When the students met to discuss these events and take action, they decided that as long as ODS was focused on meeting regulatory requirements "there was no possibility of equality of opportunity and meaningful participation in the academic community of the university" (Cory et al., p. 30). This led them to include "Beyond Compliance" in the group's name. Including "Coordinating Committee" in their name was a tribute to the Student Nonviolent Coordinating Committee (SNCC), which had a prominent role in the civil rights movement (Cory et al., 2010).

One of the first actions of the BCCC was to form a platform focused on ways Syracuse could change to increase equality of opportunity. The platform included:

1. Reshaping Syracuse's conception of disability to promote an understanding of disability as a form of diversity;

2. University recognition and funding of the Disability Studies program;

3. Creating model accommodations exemplifying the University's commitment to equality of opportunity for students with disabilities; and

4. Hiring faculty and staff members with disabilities within departments across the University (Cory et al., 2010).

The BCCC expanded by recruiting more graduate and undergraduate students. The assistance of the Director of the Center on Human Policy was also solicited, which resulted in the formation of a list of facility members who were willing to offer assistance to the students. In conjunction with the expansion of the BCCC, the group was able to meet with the Dean of the School of Education. After hearing the BCCC's platform, the Dean invited the group to share their platform at a faculty meeting (Cory et al., 2010).

In the spring of 2002, the BCCC formally solicited the Office of Disability Services (ODS) for change. Many BCCC members were taking a reading seminar. During this course, the ODS again failed to provide a student with a visual impairment with the course readings in time for class preparation. In response, the entire class boycotted reading the materials for the course, and the students penned a letter to the ODS Director outlining the grievance. The letter was signed by all students enrolled in the reading seminar. Copies were also given to the Syracuse Chancellor, Vice Chancellor, Vice President of Undergraduate Studies/504 Compliance Officer, the Associate Vice President of Undergraduate Studies, the Director of Student Service and Retention, and the Dean of the School of Education. The following week, the ODS Director telephoned the student to inform him the course reading for that week was not ready, but that she would be willing to read him the material. The student refused the offer. A response to the letter was also received from the Vice President of Undergraduate Studies/504 Compliance Officer stating that he was not willing to investigate the grievances against the ODS (Cory et al., 2010).

The BCCC replied to the letter from the Vice President of Undergraduate Studies/504 Compliance Officer with documentation of the grievance that included the ODS policy, a timeline of events showing a policy violation, samples of poorly scanned documents provided by ODS that would not work with the software the student used, and all correspondence between ODS and the student. Again, copies of the letter were provided to school leadership. Following the receipt of this letter, a meeting was set between the BCCC and the Vice Chancellor, Vice President of Undergraduate Studies, and the Dean of Graduate Studies. Again, the BCCC presented its platform (Cory et al., 2010).

Following this meeting, the Undergraduate Studies/504 Compliance Officer sent a letter to three students stating that a pilot plan would be put in place for the next academic year to ensure that accessible materials would be provided in a timely matter. The letter stated that the plan would be shared with the students who had written the original letter. When no plan had been shared with the group a month and a half later, the BCCC penned another letter, this time addressed to the Vice Chancellor. This letter expressed frustration with "the arbitrary way that ODS creates policy that impacts students with disabilities" and asked the Vice Chancellor to "develop a formal means for students and faculty to be active participants in the crafting of disability policy" (Cory et al., 2010). Following this, the ODS Director was put on administrative leave, and an Interim Director who would later be hired as the Director was appointed. The new Director was recruited as an individual "who had a deep knowledge of disability and who would develop rapport with the students" (Cory et al., 2010, p. 32).

The work towards meeting the BCCC's platform continued in the fall of 2002. Syracuse formed the Working Group on Disability, which included BCCC members, the Associate Vice President for Undergraduate Studies, the ODS Director, and the Office of Design and Construction. The purpose of the Working Group on Disability was to resolve accessibility issues across the campus and establish a means of communication between students with disabilities and Syracuse staff, faculty, and administrators. Cory et al. reported that the Working Group on Disability reviewed the ODS policy manual, snow-removal procedures, and physical accessibility issues.

Following the formation of the Working Group on Disability, the BCCC continued to focus on accessibility issues and the perception of disability at Syracuse. A major focus of the group was universal design. The group successfully lobbied to gain equitable physical access to the corporate-owned university bookstore for students with disabilities. This effort included the rejection of a separate entrance for people with disabilities. Other issues the BCCC tackled included parking assignments, website accessibility, holding an annual film festival to promote campus-wide disability education, and writing position statements (Cory et al., 2010). Another effect of the BCCC was the formation of a similar organization, the Disability Law Society, at Syracuse in the College of Law. The goals of the Disability Law Society include raising awareness about disability, supporting students who have disabilities, providing information regarding disability, and providing opportunities for students to volunteer in the disability community ("Disability Law Society," 2018).

In order to ascertain if the changes prompted by the BCCC were sustained at Syracuse, a review of the Syracuse website was performed in 2018. This review failed to find mention of the Working Group on Disability. An email to the ODS prompted responses from the ODS Director and Syracuse's Disability Cultural Center Director. They affirmed that the Working Group on Disability was no longer structurally functioning, but that several other groups had taken its place. These included the following: (a) a Disability External Review Committee whose "objective is to address the cultural and structural dynamics of ableism and look toward institutional change to improve the lives of disabled students, faculty and staff"; (b) the Disability Cultural Center, which is overseen by an Advisory Board that includes students, faculty, staff, alumni, and community members; (c) a Disability Studies Consortium; and (d) the Task Force on Digital Accessibility, which resulted in a full-time Accessibility Analyst position and the formation of a campus wide policy on accessible communication and technology (D.R. Wiener, personal communication, November 13, 2018 and P. Possenti-Perez, personal communication, December 12, 2018). In 2018, the co-chair of the Disability External Review Committee was one of the BCCC's founding members. The current ODS Director explained that in 2004, ODS staff, Syracuse leadership, and the BCCC worked together to develop the *Office of Disability Services Policies and Procedures Manual* (P. Possenti-Perez, personal communication, December 12, 2018). According to the Director, this manual is "viewed as a 'work in progress,'" and input from faculty and students is solicited annually to ensure the policies and procedures at ODS "reflect 'best practice.'" It is apparent from these organizations and actions that the BCCC's platform prompted systemic change that has been sustained at Syracuse.

The success of the BCCC can partially be attributed to the formation and focus on their platform and their group cohesion. While the BCCC was formed as the result of ODS' failure to meet accommodation requirements, BCCC members were able to push past compliance issues to promote a climate of equal opportunity at Syracuse through the breadth of their platform. Another important aspect of the BCCC's advocacy was their group cohesion. The letters sent to Syracuse administration were sent by an entire class, instead of just the student whose accommodation hadn't been met. By acting as an activist group, they were better able to push past one grievance and advocate for Syracuse to commit to equality of opportunity for all students with disabilities.

Comparison of Case Studies

While both the DPN and BCCC are successful examples of students with disabilities advocating at the IHE level, the two movements have important differences in their approach

to activism. The DPN was macro focused, involved national politicians, and received heavy media coverage while the BCCC was contained to students and faculty in a specific program and did not receive media coverage. Responses to the activism in both cases were markedly different. The early letter writing campaign and advocacy in the DPN movement resulted in a "hard no" when the hiring committee announced Dr. Zinser as the appointee. While the BCCC did receive a negative response from the Vice President of Undergraduate Studies/504 Compliance Officer, for the most part, their letters were met with a willingness to collaborate. This is likely one reason why the DPN escalated in strategies, which moved the activism to a larger scale and greater publicity while the BCCC did not. As it grew, the DPN movement received extensive support from outside groups – alumni, advocacy groups, elected officials, students on other campuses, and businesses. In contrast to this, the BCCC's support did not extend outside of Syracuse. With the support of Syracuse's administration and its willingness to work with the students, activism stayed localized and never reached the point of national attention. These variances show that outside support can be helpful but may not be necessary when IHE leadership is open to change.

The case studies also share important similarities that may speak to their successes. Both the DPN and BCCC activists set up a four-part, formal platform. While three items of the DPN's list of demands were directly related to personnel, their demand for the majority of the Board of Trustees to be people who are deaf closely relates to the desire of the BCCC to see people with disabilities represented in staff and faculty appointments. Both groups also consistently advocated for their platforms. After Dr. Zinser announced her resignation from Gallaudet's presidency, protestors began wearing pins that said "3 ½" on them, showing that they only had three and half items on their demand list left, and they were committed to gaining all four demands ("The Week of DPN"). Members of the BCCC consistently explained and reiterated their platform in meetings with Syracuse administration and in many of their letters. In discussing actionable leadership, including that of Martin Luther King Jr., Simon Sinek stated that great organizations don't just know what they do, they know why they do it (Sinek, 2009). This statement aptly applies to activism. Student activists who do not develop and adhere to platforms and missions that clearly state why they are pushing for change will be less likely to succeed.

The methods employed by the DPN and BCCC are also related. The DPN movement was initiated with a letter writing campaign. While the work of the BCCC didn't include letters of support from advocates outside of Syracuse, the main method employed by the BCCC activists to communicate their expectations to school leadership was letter writing.

The letters penned by the BCCC were also signed by multiple students. This showed an increased base of support similar to, although not as large as, the multitude of letters received by the Gallaudet Board of Trustees. Both groups also included some form of boycotting. During the DPN movement, Gallaudet students boycotted classes. BCCC members boycotted reading assignments as a sign of solidarity for their classmate. Boycotting services has been a hallmark of civil rights movements for decades.

Self-advocacy was also an important aspect of both case studies. The protests at Gallaudet were largely advocacy for Deaf people, by Deaf people. Moreover, students and alumni played a major role in building momentum and attention for the movement. Similarly, three of the founding members of the BCCC were students who identified as having a disability. It was their experiences with the disability support services at Syracuse that prompted the formation of the group and action.

An additional important aspect of both case studies was the collaboration of students, faculty, and school administration. By ensuring that there was advocacy for change at many layers within the IHE systems, both movements were able to establish necessary support from multiple stakeholders within the system. Without collaboration between students, faculty, and IHE leadership, change would have been more difficult to initiate. The failure in the system at Syracuse that precipitated the formation of the BCCC was that the ODS failed to see itself as an advocate for students with disabilities. Instead of doing so and forming collaborative partnerships across campus, the ODS was limited by a compliance-based approach. Similarly, the Board of Trustees at Gallaudet failed to act as an advocate for students, alumni, and staff. In both cases, activists were able to achieve an outcome that aligned students, faculty, and administration as allies and advocates.

Additionally, both case studies were carefully crafted as civil rights activism. As discussed with the DPN movement, the student rally on March 1st was framed in rally flyers as a civil rights protest, and the actions taken by activists mirror other civil rights strategies. Cory et al. noted that the disability studies program that BCCC members were engaged in was taught by faculty that "based their teaching in the notion that disability studies, as a discipline, necessitates action" (p. 29). With this educational basis, the BCCC framed their platform around the notion of equality of opportunity for students with disabilities and then used the necessary action to promote an equitable climate at Syracuse. While the BCCC did not use the term "civil rights," the language of equity coupled with their choice to partially name their group after a well-known student civil rights group speaks to their civil rights mindset.

In summary, the successful strategies utilized by the DPN and BCCC included:

1. Seeking outside support when IHE leadership was not open to change;
2. Setting up a formal platform;
3. Consistently advocating for the platform;
4. Communicating expectations to IHE leadership in writing;
5. Utilizing boycotting;
6. Including aspects of self-advocacy;
7. Collaboration between students, faculty, and school administration; and
8. Crafting their activism as civil rights issues and maintaining a civil rights mindset.

Also of note, Julian Bond (2014) outlined five guidelines utilized by previous civil rights activism that were also successful in disability rights movements. These guidelines include:

1. Starting with a precipitating event;
2. Using a preexisting social organization;
3. Having catalytic leadership;
4. Tapping outside resources; and
5. Developing a strategy.

Both the DPN and BCCC movements fit within Bond's framework. Table 1 compares which guidelines each of the case studies met. The precipitating event for DPN was the failure to offer the position to a Deaf person. The preexisting social structure of Gallaudet and the larger Deaf education committee was utilized. Several students and faculty members took on leadership roles. Outside resources were used in the form of letters of support and donations from supporters. Finally, DPN activists developed a list of demands and continually met to strategize their obtainment. For the BCCC, the precipitating event was the failure of the ODS to provide accessible materials. The preexisting social structure of the Disability Studies program was utilized. Leadership was provided by students and the school administrators who assisted them. The BCCC formed their platform and developed a letter writing strategy to make their points. The only one of Bond's guidelines missing from the BCCC mixture is the tapping of outside resources since the BCCC did not extend beyond the Syracuse campus.

Table 1
Comparison of activism guidelines across the case studies

	Case Study #1 – DPN	Case Study #2 – BCCC
Starting with a precipitating event	X	X
Using a preexisting social organization	X	X
Having catalytic leadership	X	X
Tapping outside resources	X	
Developing a strategy	X	X

Discussion

Students with disabilities at IHEs advocating for a climate of equity would be well served to engage in actions similar to the students at Gallaudet and Syracuse. Proven strategies such as seeking outside support, setting up a platform, advocating for the platform, communicating expectations in writing, boycotting, including aspects of self-advocacy, collaborating with faculty and administration, and maintain a civil rights mindset should be used with Bond's guidelines in mind. Both the DPN and BCCC case studies provide examples of students with Deafness or disabilities advocating for an IHE to move beyond tokenism and legal compliance to meaningful inclusion and equity according to successful activism strategies. Further, the students in each example demonstrated their "involvement in and commitment to social change," ideological motivation to resist "aggression and suppression," and "emotional engagement rooted in larger senses of identity, stigma, and purpose" as described by Kimball et al. (2016) as hallmarks of focused activism. These are important examples that can be used by other students with disabilities to ensure equality of opportunity and change the climate at IHEs.

While the legal requirements of Section 504 of the Rehabilitation Act, the ADA, and the Higher Education Opportunity Act have set up excellent parameters to promote the success of students with disabilities at IHEs, legal compliance by itself will not ensure true equality. That can only be provided by a climate of meaningful inclusion where students with disabilities are provided with equal opportunities. Just as it is necessary for students with disabilities to advocate for themselves in IHEs, it is necessary for students to advocate for broader changes within their IHE to the benefit of all students.

Another important conclusion of the two case studies is the role of faculty and administrators at IHEs. In both cases, faculty and administrators were able to support student activists and work with them to achieve their platforms. This is especially true in the BCCC example. Besides affecting immediate change, the BCCC activism sprouted a cultural shift in which faculty and administrators continue today to work with students with disabilities at Syracuse to establish meaningful inclusion. IHE administrators that are proactive in moving beyond compliance and include students with disabilities in decisions regarding disability service policies and program structures will do more to promote equality of opportunity than IHEs merely focused on compliance. Many IHEs are missing opportunities to improve outcomes for students with disabilities because legal compliance takes administrative precedence over meaningful inclusion. It is hoped that the DPN and BCCC case studies will promote further successful activism by students with disabilities at IHEs and that IHE faculty and administration will work as partners with students with disabilities to promote important cultural changes. Interest in moving IHEs beyond compliance to support the meaningful inclusion of students with disabilities will continue to grow as students with disabilities find their voice. As IHEs see greater leadership and activism by students with disabilities, the hope is that IHE faculty and administrators will recognize the benefits and evidence for fostering inclusive decision making. Raising awareness in disability studies research is a start, but a greater impact will occur when this awareness reaches a broader audience among IHEs.

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Global Perspectives

The Engraved Lighter

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Abstract

"The Engraved Lighter" is a fictional story about Ezima's (main character of the novel) great-grandfather who survived the 1938 Dersim massacre along with his son, whom he managed to rescue from the hands of the Turkish soldiers. While they were caught and waiting for their fate to unfold, another prisoner gave his engraved lighter to the great-grandfather just before the prisoner was shot.

Keywords: Dersim, Turkish, massacre, Kurdish

Author Note

İşlemeli Çakmak / The Engraved Lighter

Dedemin İvrayim'e hayatı boyunca şimdiki kadar yakın olduğu gün, sabahın erken saatlerinde eski bir konağın bitişiğindeki samanlığa benzer bir yerde başlamış. Tabii öncesi de varmış, her hikâyenin upuzun, dile gelmeyen bir öncesi hep olurmuş zaten. Bir de her hikâyenin ne zaman varılacağı belli olmayan bir sonu olurmuş. Samanlığa benzeyen yerde beş balya saman, iki orak, birkaç kürek, üç kazma, sol ayağı kırılmış boz bir at ve dedem İvrayim'le birlikte dokuz çocuk varmış. Dedem İvrayim'in beş balya samandan dolayı samanlığa benzettiği o yerin tavanındaki kirişlerden biri de çatlakmış.

Dedem İvrayim sonraki zamanlarda dönüp o haline baktığında birbirine sokularak uyuyan çocukların tek beden gibi göründüğünü fark etmiş. Yamalı şalvar ve pantolonları üzerlerinde desenli tek parça örtü gibi duruyormuş. Birbirlerine dolanan kolları da ağaç dallarına benziyormuş. Dedem İvrayim onları nelerin beklediğini bilmese de ölümün hiç de uzak olmadığının farkındaymış. Bu onun için gökyüzünü kara bulutların kapladığı bir gün yağmuru beklemek kadar olağanmış. Her an yağabilirmiş de, bulutlar dağılıp kaybolabilirmiş de. Ölmeyeceğine dair içinde belli belirsiz, bazen parıl parıl parlayan bazen de kısıldıkça kısılan bir his de varmış. Hayat bu hissin iki ucu arasında kalmış, zorlukla nefes alan, her nefes alışta kuru kuru öksüren, öksürüğü duyulmasın diye yorganını başına çeken bir yaşlının Azrail'i bekleyişine benziyormuş. Dedem İvrayim ölümden hem korkuyormuş hem de sanki Nuh Nebi'den beri bu dünyada herkes onun yaşındayken ölüyormuş gibi kendini ölüme hiç de uzak hissetmiyormuş.

Uyumadan önce dokuz çocuk, kilitli kapının ardındaki sesleri anlamadan dinlerken kendilerine çeşit çeşit yarınlar kurgulamışlar. Çok ama çok uzaklara götürülebilirlermiş, büyüklerden dinledikleri böyle hikâyeler varmış. Burada kilitli de kalabilirlermiş, bu da olmayacak bir şey değilmiş. Askerler çekip gidebilirmiş. Hepsinin bildiği böyle hikâyeler de varmış. Askerler kimi zaman böyle kalabalık halde gelir, sonra günün birinde girdikleri cenkleri kaybedip çekip giderlermiş. Birileri, mesela mavzerleri olan Demenanlılar gelip onları kurtarabilirmiş. Askerler kapıyı açık unutursa ya da içlerinden biri kapıyı açarsa kaçabilirlermiş. Kar hiç durmadan yağıyormuş ama köylerine, evlerine gitmek çok da zor olmazmış. Kurtlara yakalanmadan, çığın gelebileceği yerlerden uzak durarak yol alırlarsa dağları da vadileri de aşabilirlermiş. Tahminleri gibi soruları da çeşit çeşitmiş, uzak ne kadar uzakmış ki? İnsanlar neden başka başka dil konuşurmuş ki? Onları ne zaman anlayacaklarmış

ve de ölümün sonrası nasıl olabilirmiş? Varken yok olmak, konuşuyorken susuvermek, düşünürken gömülmek ne kadar da tuhafmış sorularına cevap aramaktan yorulduklarında içlerinden biri tilkilerin, cinlerin, yuvarlak memeli kadınların, ay yüzlü kızların ve birbirinden lezzetli yiyeceklerin olduğu masal âlemlerine götürmüş onları. Masalların içinde yorulduklarında da birbirlerine sokularak uyumuşlar.

Dedem İvrayim uyurken büyük dedem birkaç köyü, birinin bittiği yerde diğerinin başladığı vadileri, karlı dağları ve buz tutmuş nehirleri aşıp eski konağın karşısına gelmiş. Nöbetçi askerlerin üşüyüp, sobaların gürül gürül yandığı odalardan birine gitme ihtimalinden umut yapıp beklemeye koyulmuş. Uykunun yumuşacık bir yorgan olup üşüyen bedenini ısıttığı zamanlarda bile nöbetçi askerlerden gözlerini bir an bile ayırmamış. Onlarla birlikte hem geldiği yolları hem de nasıl yaşanacağı belli olmayan günleri geçip çayırlıkların karşısında oturup gelen bahara bakmış. Ot kokularını içine çekip yaban ördeklerinin yüzüşünü, kuşların uçuşunu izlemiş. Meyman köyünü çevreleyen nehirde dedem İvrayim'le birlikte balık avlamış. Aşurenin içindeki cevizleri yiyip tarlaları sulamış. Büyük ninemle birlikte bir ateşin közlerine bakarken çayını yudumlamış. Hatta askerlerden biri üşüyen parmaklarını nefesiyle ısıtmaya çalıştığında, büyük dedem madem buraya kadar onları da getirdim bir bardak çay içip ısınsınlar diye ikramda da bulunmuş. Büyük ninemin çatık kaşlarının altında sakladığı hüznü görünce de geldiği yollardan ve günlerden bir daha geçmiş. Dönüş yolunda sise yakalanmış, acaba geri mi dönsem tereddüdünün içinde dolanmış ve oğlunun diğer çocuklarla beraber götürüldüğü söylenen köyün yolunu kaybetmiş. Yönünü kaybedince son günlerde yaşananları düşünmüş. Hayatın ritminin silah sesleriyle bozulmasına, gecenin ve gündüzün birbirine karışmasına kafa yormuş. Kar çarıklarında tepecik, omuzlarında ağaç dalına konan küçücük bir kuş olduğunda nöbetçi askerler bacalarından dumanların yükseldiği eski konağa doğru yürümüşler. Büyük dedem tam konağın bitişiğindeki depoya doğru adım atacakmış ki konağın kapısından yüzleri soba aleviyle kızarmış başka askerler çıkmış. Giden ve gelen askerlere uzun uzun baktıktan sonra nafile bekleyişine küfürler savurmuş. Saklandığı evin arkasından dolanarak konağın arkasına gelmiş. Karargâh olarak kullanılan konağın arkasında nöbetçi görmeyince yağan kara, üşüten soğuğa şükranla bakmış. Derin bir nefes alıp dedemlerin kilitli tutulduğu yere temkinli küçük adımlarla yaklaşmış.

Dedem İvrayim'in, içindeki beş balyadan dolayı samanlık dediği yerin penceresine çapraz çakılan ağaç dallarının çivilerini dişleriyle gevşetip, tırnaklarıyla milim milim hareket

ettirerek çıkarmış. Pencerenin tahta kepengini söküp içeriye baktığında ilk sol ayağı kırık boz atı görmüş. Küçücük pencereden içeri girişi de çivinin milim milim tahtadan ayrılması gibi zaman almış. Büyük dedem tüm o milimlik ince işleri yaparken sessizliğin içine öyle bir gömülmüş ki zamanla bağı kalmamış. İçeriye girdiğinde de sonrası zamanlarda da o esnada geçen zamanın ölçüsüne dair kafasında hiçbir fikir oluşmamış. Kısacık bir an da geçmiş olabilirmiş çok uzun bir zaman da.

Büyük dedem koyun koyuna yatan çocuklara bakarken zihninde taşların üzerinden akan küçük bir dere canlanmış. Yüzleri o taşlar gibi birbirine benziyormuş. Büyük dedem ilk ağlayışları bile birbirinden farklı olan bu çocukları hangi zaman taşlar gibi birbirine benzer yaptı diye düşündüğünde dönüp pencereye bakmış. Ya Hak nasıl bir zaman aştım diye sormuş. Yoksa zaman değil de aynı yere kapatıldıkları için mi birbirlerine bu kadar benzemişlerdi. Büyük dedem dokuz çocuğun yüzüne tek tek, uzun uzun bakmış ama ne kadar bakarsa baksın dedem İvrayim'i tanıyamamış. Hatıralarındaki oğluna bakmış, çenesindeki beni, ince üst dudağını, sarkık kulaklarını aklına getirmiş ama çocukların yüzüne baktığında görüntüyü de bilgileri de unutmuş. Ya Hak bana yol göster diye dua etmiş. Bir yol görünmemiş, gözlerini kapatmış, dedem İvrayim'i büyük ninemin kucağında hayal etmiş, canlı ve yakınmış hayali, aynadaki sureti kadar tanıdıkmış. Gözlerini dualarla açtığında hayal kaybolmuş. Sanki İvrayim adında bir oğlu olmamış, olmadığı için de koyun koyuna yatan çocuklar içinde oğlunu tanıyamıyormuş.

Çocukları saymış, dokuzmuş. Değil hepsini oğlundan başka tek bir çocuk bile götüremezmiş. Dağ taş her yer asker ve onlara haber uçuranlarla doluymuş. Oğlunu bile götürüp götüremeyeceği tesadüflere bağlıyken dokuz çocukla nereye, nasıl gidermiş? Bir mavzeri de yokmuş, olsa da doğru dürüst kullanmayı bile bilmiyormuş. Dokuz çocukla saklanılmaz, izler kaybedilmezmiş. Belki oğlunu da yarı yolda yine kaybedermiş. Ya da oğlunu kırım günlerinde iyice zayıflayan bedeni taşıyamayıp dağdan yuvarlanıp düşebilirmiş. Bir askerin mermisiyle o da ölebilirmiş. O zaman da büyük ninemin karşısına ölü haliyle çıkar "Bak ben öldüm ama İvrayim'i, en çok sevdiğin oğlunu sana getirdim," dermiş. "Tabii dokuz çocuk vardı, baktım baktım da ilkin İvrayim'i tanıyamadım," demezmiş, böyle bir şey büyük nineme söylenmezmiş.

Ellerini göğe kaldırıp "Günahım nedir ki bana oğlumun yüzünü unutturursun," diye sormuş. Sırtını çocuklara dönünce oğlunun yüzünü duvarlarda, saman balyalarında, hatta boz atın tımarlı gövdesinde görür gibi olmuş. Yorgunluktandır demiş, kendini dostça teselli

ederken. Her biri ayrı ana babadan olan çocuklar hiç birbirinin aynısı olabilir mi? El parmaklarına bakmış, sorusuna cevap bulmak için hepsi de birbirinden farklıymış ama soğuğun sızısını da her parmağında aynı hissediyormuş. Bu mu cevap diye sormuş. Bu çocuklar korkuları, sızılarıyla birbirlerine benzemişse o zaman bu topraklarda yaşayan herkes önce birbirine sonra Kerbela'dakilere mi benzeyecekti? Günlerdir yaşadıkları zulüm, uğradıkları kırım, ruhlarını ezen korku, midelerini kazıyan açlık bunun için miydi? Acı onları birbirine benzetsin, hiçbir farkları kalmasın diye miydi? Büyük dedem sorularını peş peşe dizip düşününce, tepeden tırnağa tedirginlik olmuş. Hayatı boyunca gördüğü yüzlere hatıralarını aralayarak tek tek bakmış. Hiçbiri diğerine benzemiyormuş. Derin bir nefes alıp sızlayan parmaklarının uçlarını ısırmış. Bu dünyadan sayısız insan gelip geçmiş, ölenin yüzü bile yeni doğana verilmemişken, bunlar uzakta birbirlerini hiç görmeden yaşayacaklar aynı yüzü kullansınlar denmemişken neden bu çocukların yüzü aynı oldu diye düşünmüş. Sonra da kendi kendine bundan emin olamam ki belki de ömürleri boyunca birbirlerini görmeyeceklere aynı yüz veriliyordur demiş. Dünyanın bir ucunda ölenin yüzü öbür ucunda doğana belki de bir süre sonra veriliyor olabilir demiş. Büyük dedem kendine böyle daha önce söylemediklerini söyleye söyleye düşünürken belki de herkes aynı yüzle doğuyordur fikrine kapılmış. Fikrini inandırıcı kılmak için de huylar edindikçe yüzler farklılaşıyor diye düşünmüş.

"Ya Ali" demiş çaresiz, biraz da kırgın bir sesle… Sanki Hazreti Ali yanı başında uyuyor, bir türlü uyanmıyormuş. "Bilirim, yanılan gözlerimdir, karanlık gecede yolunu kaybedenler gibiyim, bana bir yol göster," diye yakarınca bir yol görünür gibi olmuş. Güneşin kızıllığının kocaman siyah bir taşa vurduğu bir güne benziyormuş yol, buna bir anlam verememiş. Nöbetçi askerlerin sesini duyunca kapıya doğru birkaç adım atmış, nefesini tutarak sesleri dinlemiş, kar tanelerinin samanlığın damına düşme sesi, sac ekmeğin ısırılma sesi gibi incecik seslermiş bunlar. Nasıl oluyor da bu sesleri duyuyorum demiş, buna da bir anlam verememiş.

Çocukların birini alıp gideyim demiş. Bu olacak şey değilmiş. O tanımasa bile büyük ninem oğlunu mutlaka tanırmış. Hiç kimse tanımasa bile kız kardeşi Ezima abisini tanırmış. Yanı başındaki çocuğa tam dokunacakken vazgeçmiş. Uyuyan çocuğu bırakıp gitmek kolaymış ama uyanan çocuğa sen uyu, ben oğlumu alıp gideceğim diyemezmiş ki... Ölüm çemberinde bile olsa, yüzüne bakan çocuğu bırakıp gidemezmişsin.

Büyük dedem bulunduğu zamandan birkaç adım geriye doğru gitmiş ama dedem İvrayim'i yine tanıyamamış. Bulunduğu zamandan birkaç adım ileri gitmiş yine değişen bir şey olmamış. Dualar edip çaresizliğine bir çobanın kepeneğine sarıldığı gibi sarılmış. Demek ki oğlum burada değilmiş… Tabii ya demiş, ben yaşarken oğlum İvrayim niye babası ölmüş yetim çocuklarla birlikte bir yere kapatılsın ki. Demek ki bir altın için yalan söylemişler. Bazı insanlar değil bir altın, iki avuç un için bile yalan söylerler diye düşününce üzerinden ağır bir yük kalkar gibi olmuş. İvrayim nerede sorusu daha ağır bir yük olup omuzlarına konduğunda dizlerinin üzerine çöküp öylece kalakalmış. İçinden bir ses kal ve bu çocukların kaderi neyse onu yaşa demiş, başka bir ses de başka bir şey demiş ve büyük dedem içindeki sesler arasında debelenip durmuş.

Büyük dedem seslerden birini dinlemek istediği sırada dedem İvrayim rüyasında koşuyormuş. Nefes nefese kaldığı için yavaşladığı esnada büyük dedem nöbetçi askerlerin yükselen sesleriyle bir karara vardığından pencerenin önünde duruyormuş. Dedem İvrayim babasını ona dönük sırtından tanımış, büyük dedem oğlunu ve sesini aynı anda kucaklamış. Dedem İvrayim'e hayatı boyunca şimdisi kadar yakın olan o batımsız gün de o kucaklayıştan sonra bir gölgeye benzemiş.

Birbirlerine sarıldıklarında o an bakışlarıyla uzamış, uzayan an devam ederken arkalarına bakmadan pencereden çıkmışlar, yürümüşler, koşmuşlar, eğilmişler, saklanmışlar bazı yerleri hızla bazı yerleri sürünerek geçmişler. Dedem İvrayim yere düşüp ayağındaki ayakkabısı çıktığında uzayan an bitivermiş. Dedem yere düşen oğlunu kaldırmış, ayakkabısını giydirmiş sonra da sırtına almış. Saklanacakları bir yer bulana kadar baba oğul karın altında iki kafalı bir adam gibi yürümüş.

Büyük dedem mağaraya süzülen ışıkta dedem İvrayim'in yüzüne bir daha unutmamak için uzun uzun bakmış. Dedem İvrayim'in gözlerinin mavisinde ve gülüşünde de onu dokuz çocuk arasında tanıyamayışını unutmuş. Ama bu unutuş hiç de uzun sürmemiş, dedem İvrayim'in yorgunluğundan sıyrılır sıyrılmaz çocukları soracağını düşünüp endişelenmiş. Yüreğine öyle bir endişe çökmüş ki büyük dedem devletin askerleriyle ve memurlarıyla bu topraklara onu günahkâr yapmak için geldiklerini düşünmüş. Böyle düşününce de tek bir damla gözyaşı dökmeden hüngür hüngür ağlamış.

Güneşin ışıkları mağaranın ağzından içeri süzüldüğünde su damlalarının parıltısına elbiselerinden çıkan buharlar karışmış. Büyük dedem kazağının içinden beze sarılmış bir parça ekmek çıkarıp dedem İvrayim'e uzatmış. Ekmek ıslakmış. Dedem İvrayim ıslak

ekmeğin bir parçasını büyük dedeme uzatmış. Kendine ayırdığı küçük parçayı üç lokma yaparak yemiş. Sonra da kafasını büyük dedemin dizlerine koymuş, uyumak istese de uyuyamamış, sadece rüyaya benzer hayaller kurmuş.

Silahların ve bombaların seslerini duyduklarında mağaranın iç tarafındaki kayanın arkasına saklanmışlar. Kaya sanki yıllardır o günler için hazırlık yapmış gibi iki deliğiyle onlara karşı yamaçta olanları gösteriyormuş. Büyük dedem o iki delikten karşı dağda mevzilenen askerlere, mağaranın girişindeki buz sarkıtlarına bakmış. Dedem İvrayim ise sırtını bir kayaya yaslamış avucunun içindeki çizgilere bakıyormuş.

Askerler mevzilerinden çıkıp uzaklaştıklarında büyük dedem ve dedem İvrayim mağaranın ağzına gidip sesleri dinlemişler. Mağaradan çıkıp yola koyulduklarında dedem İvrayim yaylalara giderken geçtikleri vadiyi, vadinin sonundaki köyü tanıyamamış. Sanki yabancı insanlar uzaklardan gelmemişler de dedem İvrayim babasıyla birlikte hiç bilmediği, tanımadığı yerlere götürülmüş gibi hissetmiş kendini. Büyük dedem vadiyi kar kaplamış, köyü de yaktılar o yüzden tanıyamıyorsun dediğinde dedem İvrayim başını sallamış ama bu bilgi ona yabancılaşmasını unutturamamış. Karın üzerinde bata çıka ilerlerken dedem İvrayim dalları karla sarkan ağaçlara, karla kapanan yollara bir de baharın gözüyle bakmış. Büyük dedem işaret parmağıyla geçecekleri yolları gösterip hava kararmadan önce büyük ninem ve diğerlerinin saklandıkları yere varacaklarını söylemiş. Yorgunmuş dedem İvrayim, karnı da açmış. Tepelerindeki güneşe ve güneşin bulutların arsından geçeceği yola bakınca adımlarını hızlandırmış. Büyük dedem de adımlarını hızlandırmış. Kilitli kalan çocukları hatırlamış. Mağaradayken bir kurşun yakınlarındaki kayaya çarptığında büyük dedem o çocukları orada bıraktığı için sevinmiş, kendi oğlunu ölüme getirdiği için kahırlanmış. Ama adımlarını hızlandırdıkları sırada oğluyla güvenli bir yere gittikleri için utanmış. Utancını oğlu görmesin diye ona eski zaman masalları anlatmış.

Sonraları ve tabii bu hikâyeyi anlatırken de nasıl olup da askerlerin sesini duymadıklarını, korkuyu hangi adımlarının altında ezip öyle sakınmasız davrandıklarını ne büyük dedem ne de dedem İvrayim hatırlamış. Askerlerin çemberinde diğerleriyle birlikte yürürken uzadıkça uzayan zaman içinde sıkışıp kaldıklarında köylülerinin saklandığı yere yakınlaşmanın sevinciyle, bir askerin bağırışı ve silahının dipçiğiyle geri dönen korku arasında yaşadıklarını hatırlayamamalarının nedeni belki de dedem İvrayim'in hasta yatağında hikâyesini anlatırken dediği gibi, arada hiçbir şeyin olmamasındanmış.

Dedem İvrayim'in askerlerin çemberinde diğerleriyle birlikte yürürken elleri bağlıymış. Büyük dedemin ve diğerlerinin de elleri bağlıymış. Meyman'dan onlarla birlikte birkaç kişi daha varmış. Bazıları komşu köylerdenmiş. Ama dedem İvrayim çoğunu tanımıyormuş. Dünden beri yaşadıklarını düşününce yine büyük dedemden ayrılacağını düşünüp korkmuş. Nereye gittiklerini bilmeden yürümüşler. Elleri iple birbirine bağlı olduğundan ayakları da aynı anda kalkıp aynı anda iniyormuş bazen bu uyum bozuluyor düşüp kalkanlar oluyormuş.

İnce bir çayın aktığı düzlüğe vardıklarında durdurulmuşlar. Adımlarıyla birlikte fısıltılı konuşmaları da durmuş. Askerler kâh bağırarak konuşuyor kâh sessizce bekliyorlarmış. Askerlerin komutanı konuşunca dedem İvrayim ne söylediğini anlamamış ama herkes oturunca o da oturmuş.

Oturmalarını isteyen komutanın elinde bazı isimlerin yazıldığı kâğıtlar, elleri bağlı adamların bazılarının ceplerinde belgeler, izin ya da kafa kağıtları varmış. Komutan yazılı olan her şeye uzun uzun baktıktan sonra işaret parmağıyla içlerinden birini işaret etmiş. O kişinin ellerinin bağı açılmış, iki asker koluna girip uzaklaştırmışlar. Bazıları başlarını çevirip işaret parmağıyla seçilen adamın gidişine bakmış. Dedem İvrayim de bakmış. Birkaç silah sesi duyulmuş. Dedem İvrayim gözlerini kapamış. Saniyeler içinde rüyalar kadar inandırıcı bir kâbus görmüş. Yan yana uzanmış cesetler ve komutanın onu gösteren işaret parmağı… Dedem İvrayim korkarak gözlerini açtığında yüzüne gülümseyerek bakan bir çift kara göz görmüş, gözlerin upuzun kirpikleri varmış. Sanki ölümü değil de baharı bekliyormuş gibiymiş. Duruşu uzun kış gecelerine benziyormuş. Elindeki ipi gevşetip cebinden bir çakmak çıkarmış ve dedem İvrayim'e bu sende kalsın demiş. Dedem İvrayim çakmağı cebine zorlukla yerleştirmiş.

İçlerinden biri ya hepimizi aynı anda şu çayın kenarında öldürecekler ya da bazılarımızı öldürüp bazılarımızı nahiyeye götürecekler demiş. Bu kişi tüm bunları iki komutanın konuşmasından anlamış. Dedem İvrayim'e çakmağı veren adam "Ben bugün kesin öleceğim, belki siz kurtulursunuz ama eğer hepimizi aynı anda öldürürlerse bu çocuğu aramıza alalım, yaşayacak günleri vardır, belki kurtulur," demiş.

Askerler namluları üzerlerine doğrulttuğunda bağıranlar, dua edenler, bildikleri birkaç kelimeyle yalvarıp affedilmeyi isteyenler olmuş. Komutan hâlâ elindeki kâğıtları inceliyormuş. Dedem İvrayim önce bir süre silahların namlusuna bakmış sonra büyük dedeme bakmış. Kara gözlü adam upuzun, iri yarı bir adammış ve dedeme "Korkma

kurşunların sana gelmesini engelleyeceğim," demiş. Askerlerin namlularının çemberinde ölümü bekledikleri zaman uzamış da uzamış.

Başını kâğıtlardan kaldıran komutan işaret parmağının bir hareketi ve ağzından çıkan sözlerle namluları indirtmiş ve yine bir el hareketiyle onları öldürülecekler ve bağışlanacaklar olarak ikiye ayırmış. Dedem İvrayim ve büyük dedem bağışlananlardanmış. Ben bugün kesinlikle öleceğim diyen adam ise öldürülecekler arasındaymış. Dedem İvrayim onun adını, katıldığı savaş ve isyanları sonradan öğrenmiş. Ona tüm bunları sürgün yıllarında büyük dedem anlatmış. Ama geride kalan çocukların hikâyesini hiçbir zaman öğrenememişler, bazen bazı şeyler kulaklarına geliyormuş ama emin olamıyorlarmış. Hatta çok sonraki yılların birinde büyük dedem, dedem İvrayim'e öyle bir şey yok, "Ben ardımda çocuk bırakacak adam değilim," demiş.

Arkalarında ölenleri ve silah seslerini bırakıp yola koyulmuşlar. Dedem İvrayim yol boyunca her yerde komutanın işaret parmağını görmüş. Devletin nahiye müdürü olduğunu söyleyen takım elbiseli bir adamın karşısına çıkarılmışlar. O da tıpkı komutan gibi sizleri bağışladık demiş. Dedem İvrayim o yıllarda Türkçe bilmiyormuş, adamın konuşması tercüme edilince de yarım kulakla dinlemiş. Devletin büyüklüğünden de bahsetmiş, nahiye müdürü olmak için yaptıklarından da. Hem yapmamaları gerekenleri söylemiş hem de razı olmaları gerekenleri.

Dedem İvrayim bağışlanan hayatını bir giysi gibi üstüne giydiğinde, kendi kendine "Sahiden bizi öldürecekler miydi?" diye sormuş. "Peki niye bizi öldüreceklerdi, niye bağışladılar?" diye de sormuş. On iki yaşı bunlara bir cevap bulamamış. Silahların namluları, bekleyişleri gelmiş gözünün önüne. Ölüm bir el hareketiyle yanı başlarına gelmiş, bir el hareketiyle de gitmiş. Bazılarını yanında götürmüş bazılarını da ardında bırakmış, her şey dedem İvrayim'e çok tuhaf görünmüş. Büyük dedemle birlikte oradan uzaklaşırlarken kendi kendine "Şimdi tüm bunları ben bir günde mi yaşadım?" diye sormuş. Emanet çakmağı cebinden çıkarıp gümüş rengine ve üzerindeki işlemelere bakmış. Gün bitmek üzereymiş ama dedem İvrayim'in o günü hiçbir zaman bitmeyen, akşam çöktüğünde bile batmayan bir günmüş ve ona hep şimdisi kadar yakın olmuş. Hikâyesini anlattıktan sonra bana "Canım Ezima'm" dedi, "bazı günlerin bir batımı yoktur, bir gölge olup ömrün diğer günleri üzerinde dolaşırlar. Bırak dolaşsınlar kızım, hayat onlara rağmen de yaşanır." Sonra da kuru kuru öksürdü ve "Bak 73 yaşındayım," deyip hüzünlü bir tebessümle göz kırptı.

Nibel Genc was born in 1972 in Mus, Turkey. She had to leave her studies in law at Istanbul University due to political reasons and has spent years in various prisons since 1994 as a political prisoner defending the freedom of Kurdish people. She is presently being kept in the Bakirkoy Women's Prison in Istanbul.

She was awarded the first prize for story writing by the Aix-Marseilles Mediterranean Forum 2005 in which the theme was Violence Against Women. Her stories have been published in various literary magazines such as Siya, Mahsus Mahal, and Notus Publishing in Turkey.

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Global Perspectives
Against Social Isolation: Disability Metaphors and Personal Battles

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Abstract

The current COVID-19 pandemic has brought about change in the structures and categories of discursive production, while at the same time has successfully retained the institutionalized difference between bodies, gender, class, caste, and race. This article attempts to understand how the "deviant body" continues to be the marker of one's disability despite experiences felt collectively as a result of disabling circumstances caused by COVID-19.

Keywords: disability, social distancing, isolation

Isolation, loneliness, gloominess, and dreariness are words that translate the emotions of many individuals at this moment. Confinement, isolation, seclusion, or quarantine. People are finding this difficult to deal with, and social distancing seems like moving mountains. We are told the world is grappling with physical, social, emotional, and economic disability. From availing healthcare facilities, doing grocery shopping, and socializing with families and friends to going to one's workplace, every single activity has become a hard nut to crack.

Different disability metaphors are being used to recount these experiences generated by the current pandemic. The confinement caused by restrictions on movement or travel is often described as physically disabling. Economic slowdown has been referred to as a paralyzed economy. The inability to socialize has been defined as social atrophy. Moreover, collective unhappiness is being referred to as "depression" or "madness." Casual conversations use disability references at regular intervals. Utterances like "I have gone mad" or "the lockdown has made everyone limp" have gained currency. Due to the lack of words to translate the unfamiliarity of the current pandemic, disability metaphors have come to the rescue to interpret the experiences in familiar terms. These metaphors are not merely linguistic signs. They unfold the tactics of the association between the experiences caused by the situation like the current pandemic and disability experiences in general. This association also unravels the ways in which disability is perceived.

The use of disability metaphors to capture bleakness, gloominess, and despair renders disability as a tragedy and a label to be denied. It fosters notions of dependence, deviance, and abnormality and associates them with disability, as words and phrases such as "normal" and "the new normal" have become everyday words. The association of current experiences with disability further suggests that external factors can cause the inability to carry out day-to-day functions and activities. It also indicates that disability has become a collective experience and hence, various institutions are collectively working on creating a conducive environment which can reduce disability caused by physical and social factors.

However, the use of disability metaphors to make sense of the pandemic does not help in fully grasping the experiences of those living with physical impairment. Occasional and transient episodes of functional impairment, isolation, or dependence differ from those stemming from the interaction between physical impairment and a disabling social environment. The functional impairment caused by the social environment to the persons with "normative bodies" is not

considered as disability, as the locus of their impairment does not lie in their bodies. However, for many people categorized as "disabled," there is a perception that isolation, despair, and penury are their essential traits. As a result, social isolation or social distancing is something with which many with physical impairments are not unfamiliar.

As discussed above, the clichéd understanding of the disabled as dependent, sorrowful, or burdensome compels many with disabilities to hide their pain behind the camouflage of a happy demeanor. Their requests for modification of their environment to make it suitable to their needs is taken as disability. They are frequently urged to pass as non-disabled or, at times, may be relegated to complete isolation. Be it a workplace, a family function, a festival, or a get-together, many with disabilities have to find ways of coping with social isolation. She or he either suppresses her or his emotions or finds solace in talking to a fellow being who shares a similar emotional state. Moreover, this social isolation felt by those with physical disabilities is normalized to such an extent that it goes unnoticed, and, hence many with disabilities may develop "immunity" against social exclusion and isolation.

A considerable amount of time, effort, oscillation, and negotiation have gone into developing an anti-body for social seclusion. "The normalcy of the body" has always been additive to or derivative of the understanding of disability and people with disabilities, and this understanding has rendered many with disabilities invisible from the social scene. This phenomenon has underwritten, circumscribed, and silenced the desire of people with disabilities. People with disabilities are represented in an archetypal manner in various cultural forms, and these representations keep the stereotypes such as "malnourished, disfigured, untidy, and shabby" afloat. These images reinforce the notion that penury, dependence, miseries, and agony are the essence of disability. As a result, a person with a "normative body" is shocked when encountering someone with a physical impairment who is confident, when having to work under a person with a physical impairment, or when a person with a physical impairment is spotted in a bar, a club, a jewelry shop, a rock show, or a pub or is seen on a date with someone. I will now delve into some of the experiences which I as a person with vision impairment have had.

Once at the wedding of my close friend, I was in a traditional outfit with a little makeup on my face and straightened hair. One of my acquaintances came to me and gave me a tight hug. I could make out that she was in tears. When I asked her why, she replied: "how can god be so cruel! Such a beautiful girl is punished with…" Her tears filed a charge sheet against my eyes,

accusing them of not only rendering me functionally impaired but defacing my otherwise good-looking face. She pitied my eyes not for their inability to fulfill their designated function, but for disrupting aesthetic pleasure. My eyes are always ostracized and are told to vacate the unfitting abode and settle down in an ashram which befits them. If I were in shabby attire with uncombed hair, my look would not have generated so much pity, because blindness and untidiness are seen by many to go hand in hand.

The memories of similar exclusionary remarks are resurrected in my mind. Once I accompanied my friend to the bank. While entering, I was stopped by a stranger. He extended his hand towards me and offered me a chocolate. I was completely baffled by his gesture. In the state of cluelessness, I could not react. Meanwhile, my friend who was also taken aback finally asked why he offered a chocolate exclusively to me. He did not answer but started unleashing a series of questions: "Can't she see at all? Why has she come to the bank? How does she pass her time?" His questions answered my friend's question. He offered me a chocolate thinking that it might help me in momentarily relieving myself from the agony and allow me to relish the taste of sensory pleasure. My presence at a public place threatened him, as his eyes were habituated only with having glimpses of imperfect bodies either in a circus or in a fair.

Once I had participated in a drama workshop held by our college and as part of it, we performed a skit. One of my sighted friends played a blind girl, and I played station master. While we were performing, a comment came from the audience: "Such a beautiful girl playing a blind girl!" The girl in the audience could not resolve the disruption caused by surfacing of the image threatening the stereotypical image of the blind. She could not see me playing other than "the blind" and seeing the sighted one playing "the blind."

All these narratives exhibit our intolerance to bodily imperfection. The intolerance worn by people having so called "normative bodies" shuns those deemed deviant from participating in social life, and, as a result, people with physical impairments may gradually start withdrawing themselves from social gathering and public places, which eventually may leave them *socially disabled.*

The current outbreak of COVID 19 has increased the disability of the persons with physical challenges, but it has not altered the ways in which persons with physical challenges are perceived by persons with so-called normative bodies, despite their feeling 'disabled' by the current pandemic. That is to say that the existing obliviousness about the challenges faced by

persons with physical impairment due to the inadequacy of attention paid to their needs (such as accessible and universally designed infrastructure, access to information, healthcare facilities, and so on) is coupled with the complete ignorance on the part of the authorities about the barriers caused by the current pandemic to the physically challenged in carrying out daily activities. Inequities in distributing essential goods, providing essential services, and so on during lockdown has led to the erasure of physically challenged persons from the scene. The very interpretation of notions like "essential goods" and "essential services" did not take into account providing assistive technologies like hearing aids, screen reader software, care giving services to persons with chronic illness, and so on, for example, which are indispensable to mitigating the sufferings and pain caused by physical impairment. These disabling circumstances increase the disability of persons with physical impairments.

As a person with vision impairment, I could not anticipate what would be coming my way. When the lockdown was announced as a precautionary measure to curb the spread of COVID19, I had no idea about its repercussions on my personal and professional life. Like any other citizen, I had to adapt to the new ways of life including behavioral changes at home and in the workplace, buying groceries, availing myself of healthcare services, and attending gatherings. Work from home became the "new normal," and changes began to be introduced to normalize this new normal. Digital platforms became the substitute for physical architecture, and companies developing various applications began to entice consumers by ensuring smooth functioning and uninterrupted work. Online platforms assumed the role of facilitator of communication, and professionals began to dispense their duties online. Teaching and learning also shifted online.

Being moderately good at internet surfing, I could manage to gather information pertaining to the developments that took place due to the outbreak of COVID19. However, my knowledge of internet surfing was not enough to drive me through this sudden transition. In the wake of COVID19, teachers were asked to conduct classes online. Buzz started around which applications were more suitable to the needs of both teachers and students. I found myself stumbling, completely nonplussed, anxious, and confused. My colleagues started imparting lessons online, but I kept on figuring out which application was friendlier to persons with vision impairments. Struck by guilt, I made desperate attempts to educate myself in the new methods of teaching.

During this time, I realized that the discussion around suitability had hardly taken into account persons with physical impairments. While incessant training sessions were held on the use of online platforms to reduce the disability of persons with normative bodies, persons with physical impairments had started feeling more disabled. The strategic ignorance on the part of the so called "normative people" about the challenges faced by persons with physical impairments left the physically impaired to sink or swim. Unlike some who suffered disproportionately due to the unavailability of a support system in terms of linguistic, human, financial, and technical assistance, I could manage to orient myself with the basics of these applications.

In the midst of these challenges, discussions with others with similar physical impairments served as a ray of hope and motivation. People in disability sub-cultures with sound knowledge of technology came to the rescue and helped me enhance the skills required for new modes and methods of teaching and learning and helped me survive among the fittest. However, digital technology did not prove to be a magic stick in terms of addressing the challenges posed by digital inequities. Inaccessible websites and electronic journals, the closure of physical libraries, and the absence of human assistance all continued to create challenges in searching relevant materials, thereby rendering both teaching and learning difficult. The circulars on continuation of academic activities during the lockdown gave me pangs of anxiety and guilt, as the disabling physical and social environment made me perceive myself as unproductive.

The pandemic brought about unprecedented challenges on the personal front, too. Many with normative bodies, despite feeling disabled by circumstances, continued to exhibit what might be considered eugenic attitudes towards persons with physical impairment. The casual conversations and the debates and discussions on media were rife with remarks on the necessity of being selective in saving the lives of the able-bodied. The strategic decision of prioritizing the lives of young, able-bodied people by many countries made me question the worth of my own life, and this feeling of worthlessness was reinforced by my helplessness in carrying out my day-to-day activities. Being a person with vision impairment, I use my tactile sense in navigating through places. Moreover, touching various surfaces is something which is quite usual for persons with vision impairment. However, the precautionary measures such as maintaining social distance and keeping oneself away from touching possibly contaminated surfaces made everyday life more difficult and challenging. My hesitation in asking for human assistance grew stronger, and strategies I used during the pre-COVID19 era, such as drinking less water in order to

suppress the urge to urinate in order to come across as less dependent, now became the only viable options in mitigating the fear of infecting others. From withdrawing cash from ATMs to buying sanitary napkins, every single activity appeared as a mammoth task. The fear of aged parents contracting the disease, the absence of any other human assistance, and people's fear of touching a person with vision impairment all hampered my ways of negotiating the world.

In her 1996 book *The Rejected Body*, Susan Vendell suggests disability is relative to one's social, physical, and cultural environment. With my privileged subject position, I could reduce my disability by devising various strategies. That is to say that the knowledge of English, good financial support, educated family, and friends combined to serve as a support system in addressing the challenges thrown up by the pandemic. However, the issues and challenges of those whose disability intersects with lower economic strata, lower caste, and marginalized sexual orientation have gone unnoticed. Their challenges were largely invisible during pre-COVID times, and they are now. Many have lost not only their jobs but their own lives or those of family members due to the lack of adequate familial, societal, and financial support. Hunger and sickness have taken a toll on their physical and emotional well-being. I have come across accounts of visually impaired patients who were stranded with their sickness in healthcare centers and hospitals. They struggled not only in orienting themselves to new surroundings but in finding assistance for sickness. Their humiliation and the reluctance of authorities kept them from articulating their needs.

The current pandemic is wielding its power on humanity. Humans are finding ways of challenging this power and in bringing their lives back to normal. Collective endeavors are being made to reduce the disability caused by these unprecedented times. However, in this survival war, ableism has colored the societal attitude, and the issues of bodies deemed 'deviant' have not been paid adequate heed. While a few efforts have been made to save the lives of individuals with physical impairments, many persons with "deviant" bodies have been segregated from the collective of normative bodies. Biological determinism has relegated their bodies to inhabitable zones.

So called "normative persons" expect the civil society and the state to provide them with adequate means to cope with the crisis. At the same time, demands on the part of the persons with physical impairment are considered as dependence. Here I am reminded of the words of a so-called abled person overheard objecting to the Persons with Disability Act: "Why should

government waste money and resources by investing them in a small section of the society which is incapable of accomplishing most of the tasks." Such majoritarian and utilitarian approaches devalue the disabled community by highlighting their supposed incapability in increasing social, cultural, and economic capital. It is believed that if the factors causing functional impairment are resolved, much of disability can be reduced.

However, the irony is that the attitude shaped by the ideology of normalcy fosters the view that if resources are spent in enhancing the ability of normative bodies during a crisis, it can contribute to the economic growth of the country, whereas persons with physical challenges cannot produce a return. In actuality, the disability of persons with physical impairments can be reduced, and their functionality and productivity can be enhanced by addressing both their needs of accessibility and the challenges posed by rigid and biased societal attitudes. It is high time to understand that developing tolerance for difference is key to the formation of a healthy society. By extending cooperation and support and by ensuring every individual's participation, we can reduce the impact of ableism and the challenges linked to disability. The state, the society, and its resources belong to every individual, and each body should matter to the society and the state.

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Creative Works

two poems / dwa wiersze

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Translated by Natalia Laskowska
Editor with Arab News Pakistan
Middle East

Abstract

Two poems in Polish.

Keywords: Polish, poems, medicine, culture

anatomia i amnezja

wypadek, który się
nie zdarzył
roztrzaskał kręgosłup.

lekarz przesuwa kręgi
jak na liczydle
rok po roku.

kość wszystko wyśpiewa
ja nic nie pamiętam

anatomy of amnesia

accident
that did not happen
left the backbone shattered.

like on an abacus
the doctor moves the vertebrae
year after year.

the bones will squall
I remember nothing.

narkoza

głęboki wdech
schodzę na dno morza
słyszę czyjeś pokasływanie,
poszczekiwanie i popiskiwanie

to ludzie, psy i ptaki
powietrza starczy dla wszystkich

wiatr nami faluje
świat widać po horyzont
jest jak na morzu – na tym dnie

ryby głosu nie mają
teraz to nasze siedlisko
może czekają w głębinach piachu
i gdy powietrze się skończy
zatrą nasze ślady

ja też czekam na przypływ
chce wyjść na powierzchnię.

anesthesia

deep breath

going down to the bottom of the sea

I can hear someone coughing,

barking, shrieking

they are

people, dogs and birds

there's enough air for everyone

the wind is carrying us

the world is visible to the horizon

it's like at sea — on this seabed

fish have no voice

now it's our domain

maybe they are waiting in the depths of sand

to cover our tracks

when the oxygen runs out

I'm also waiting for the tide

I want to resurface.

Magda Szarota, disability & human rights advocate, disability studies researcher, non-governmental organization (NGO) executive & a photographer.

Artist statement: Succinct. Loaded. Disorientating. That is my way of trying to use poems to probe what it means to feel 'whole' and in tune with oneself vis-à-vis delineations and interventions imposed by medicine and culture. Specifically, as a disabled woman with invisible impairments I often face people's reactions that meander between harsh ableism and privileged treatment. Contradictory lived experiences that are interconnected with my 'untypical' and non-apparent impairments inform my poetry as well.

Author's additional statement on the COVID-19 pandemic:

"In the past months, I have often been at a loss...for words. Lives of elderly pitted against profit. Lives of people with disabilities pitted against 'going back to normal'. Such sentiments became blatantly mainstream and...normalized. Yet, violence is still violence. Spell it out."

Creative Works

Disability Culture 20/20

Steven E. Brown

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Co-Founder, Institute on Disability Culture

Arizona, United States

Abstract

In spring 2020, the world changed from the Coronavirus pandemic. My wife and I have been mostly staying at home since then. We've spent a lot of time on social media, communicating with our friends and family. And I've been working on a book about Disability Culture. It includes poetry, mostly my own; and many examples of what other people are doing to contribute to and celebrate Disability Culture. This chapter from the book draft is called *Disability Culture 20/20* and is about disability culture activists during this pandemic.

Keywords: pandemic, poetry, activism, coronavirus, disability culture

SONATA IN THE LINGERING KEYS OF LIFE

Steven E. Brown © 1996

I.

Found Jim Morrison wailing at me on the radio last night:

"C'mon, baby, light my fire,"

Soothed-voice, throaty, alive,

except, of course, he is not...

1969, a magical year in so many of our lives,

A number tipping the consciousness only after meditating upon those thirty years gone,

except, of course, they are not quite thirty years gone...

Morrison, Joplin, Hendrix,

Candles dying through flames bright.

Memories intense,

Lives vivid,

Whole notes remain.

II.

Idol conversations?

Wordphrases streaming daily now

If only I would listen--

But I am.

Voices searching, seeking me out,

Not those of gods and goddesses,

but frail and mighty warriors.

Sometimes screaming from beds

as tightly bound, as completely free,

as prisons.

Sometimes screaming from conferences,

festivals of the soul;

An only outlet

for many of thy voices.

III.

Ali Baba's magic words barely open

any doors

for my people,

whose voice do we have?

the lame and the halt,

the biblical meek,

the Reagan rejects

roaming the streets.

Some slaves of old

Found comfort in the words

of glorious spirituals

and glory in the future

of the spirit.

Their gateways

handed down

to the trodden

of a new century.

Shimmering hope--

heaven unbridled by earthly restrictions.

IV.

The greatest compliment you could once bestow:

"You don't seem any different to me"--

"In my eyes you are normal"--

meaning you are like me

somersaulted into an insult

while you weren't looking.

What makes you,

white man, black man,

red woman, yellow woman,

brown child, rainbow race,

Believe that putting two feet on the ground,

Waving two arms in the air,

Having a face unmarred except caked,

Thinking in a straight line

Or famed, artistic, eccentric convolution

Spells normality,

Meaning if you are not like me

You had better want to be like me...

Normalized?

<div align="center">V.</div>

Rocky, jagged outcroppings

Snagging us.

One-liners dropped into a history book or two

Ed will one day make it into your seventh-grader's notes

But Morrison, Joplin, and Hendrix I don't see replaced by

Zola, Zanella, or Follin-Mace.

<div align="center">VI.</div>

The world has begun to give me

a gift of recognition of my poetry,

my zeal and carefully-planned idolatry.

Pain poems magnify, intensify

Perhaps they'll never rinse away;

Perhaps my purpose, or a part of its part,

Is to have this conversation

To hear this voice

which has found others' listening

and others' straining to hear and

others' needing to hear

and face their own fear.

VII.

Naked truths don't lie...

Still who will believe this difficult excursion?

Not paint it with sugar-coated

candied explanations

of good-heartedness,

god-plannedness?

Who will just listen

nod their head in acknowledgement, contemplation, recognition?

Who will not listen

rush to aggravation, defense, censorship?

"Break on through to the other side."

VIII.

BREATHING

My poetry,

like my body...

survives.

Disability Cultures

There is not one Disability Culture, but many. I've tended to focus on the big picture of Disability Culture, both because I had to start somewhere and because that has been a way to convey its existence, which is still largely unknown, or a mystery, to many. But, like disabilities and cultures themselves, Disability Culture is dynamic.

In spring 2020, the world changed from the Coronavirus pandemic. Lil and I have stayed indoors most days, getting out every week or so in our van, mostly to keep it running and once in a while to go to the bank, because we have yet to be able get cash online. We have a wonderful person doing grocery shopping for us, and before that friends and neighbors offered. We're both in what is considered a vulnerable group: over 65, with pre-existing conditions. We have been cautious and careful. We can do this because we have the privilege of being in our own home (well sort of, we do rent), we have steady (though hardly heady) revenue from retirement funds and are able to pay our bills. And, unlike many of those sheltering at home, we have and like each other. We know we are privileged.

At the same time, our lives have changed. We spend far more time on social media than we ever did and are blessed to communicate with our grandchildren and their family via platforms that support audio and visual communication. We are privileged.

But our privilege has not stopped our friends from dying—a plethora of deaths in the disability community, some directly from the Coronavirus, some impacted by it, and others from diverse causes. Our community is scared to go to hospitals because we are often so badly treated in them, sometimes to the point where we know hospital staff would prefer to see us dead (I speak from personal as well as anecdotal experience here). We listen to news stories that describe how resources might be better used for younger, "healthier" people. We have good reason to be afraid, not only of the virus, but of our own society.

In this time, many communities of disability advocates have rallied. In one such example, in mid-May, Krip Hop and the Longmore Institute co-hosted a livestream concert, the "Corona19 Artistic Flow Benefit," featuring 16 hip hop artists including voices and visual art from Tanzania, Brazil and the U.S. for "The Reality Poets, young brown and black men in New York who use their art to heal from assault, and Warriors on Wheels, a disability organization in Detroit currently committed to pandemic grocery deliveries" (Sullivan, 2020).

In writing about this event for the *San Francisco Examiner*, Denise Sullivan declared, "Leroy F. Moore Jr. is not one to let a physical disability nor a pandemic get in the way of fulfilling his destiny as an artist, a disability rights educator and an activist" (2020).

———————————————————

When I began this book, before we knew about the Coronavirus, I started writing about U.S. activists who describe themselves as Generation ADAers. One of those younger folks is a black woman named Vilissa Thompson, who created the innovative "Ramp Your Voice" website (http://rampyourvoice.com). Vilissa wrote that she'd use "Ramp Your Voice" to: "promote empowerment, education, inclusion, and self-advocacy for disabled people across the United States and abroad" (*Ramp Your Voice*, n.d.). She's been doing this with posts like, "#DisabilityTooWhite: Making the "Good Trouble" in Advocacy" in which she also created the Twitter hashtag "#DisabilityTooWhite." She describes below why she did this:

> Alice Wong, a dear friend and fellow advocate, shared an article about
>
> disability and beauty that showcased the "standard" imagery of beauty for
>
> disabled women: disabled White women. In Alice's tweet and response, she
>
> shared her frustration regarding the lack of diverse representation about who
>
> we are as a collective group, and I and many others, chimed in with similar
>
> sentiments. While I was tweeting my thoughts, an idea popped into my mind, and
>
> I started writing #DisabilityTooWhite in my tweets (Thompson, 2016, para. 2).

I didn't know of Alice Wong, mentioned in the above quote, before moving to the San Francisco Bay Area in 2014 but I quickly learned about her. In 2015, when we in the U.S. were thinking of different ways to celebrate the 25th anniversary of the signing of the ADA, Alice conceived the Disability Visibility Project (DVP), which she describes as: "an online community dedicated to creating, sharing and amplifying disability media and culture" (Wong, n.d.). The first entry under "What Does the DVP do is: "**Believes** that disabled narratives matter and that they belong to us" (Wong, n.d.).

Alice also has the distinction of being the first person to visit the White House robotically. Since she doesn't travel much, she had an opportunity to visit the White House from California in 2015 and talk with President Barack Obama via the technology of a telepresence robot (a remote-controlled, wheeled device that has internet capability and may provide both video and audio) as demonstrated in the photo below of the two talking (See Figure 1).

Figure 1

President Barack Obama greets Alice Wong, Disability Visibility Project Founder and Project Coordinator via robot during the Americans with Disabilities Act 25th Anniversary reception in the Blue Room of the White House, July 20, 2015. Obama White House Archive. https://obamawhitehouse.archives.gov/photos-and-video/photo/2015/07/president-obama-greets-alice-wong-robot

With the onset of the Coronavirus, Alice has roared full steam forward in sharing stories and in being clear about the impact of this devastating pandemic for people with disabilities. She writes in "Disabled Oracles and the Coronavirus," that "disabled people know what it means to be vulnerable and interdependent. We are modern-day oracles. It's time people listened to us" (Wong, 2020).

In this post she eloquently shares part of her own story:

> Even before the coronavirus pandemic, systems have always tried to kill and oppress marginalized people.....These crises and assaults reconfirm who is considered disposable and unworthy of assistance, resources, attention, and treatment.

> I use a non-invasive form of ventilation called a Bi-Pap. My vent is part of my body–I cannot be without it for an hour at the most due to my neuromuscular disability. I have sleep apnea and cannot properly remove carbon dioxide from my body without the Bi-Pap which can lead to respiratory failure. I am so dependent on my ventilator that it is attached to my wheelchair where it draws continuous power from my chair's battery–it is part of my cyborg being.

> So many people see me and presume that I have a poor quality of life because I have a tube attached to my face and that I sound different. I refuse to allow the medical industrial complex [to] reduce me to my comorbidities, risk factors, and inability to perform X number of activities of daily living. (Wong, 2020)

Wong's insistence on leading a life well lived reminds me of our friends Jim and Sheryl Tewksbury, who we met in the early 2000s. At the time, they had an idea that every single person, particularly individuals who experienced cognitive disabilities and who wanted a college education, ought to be able to get one. They believed there was a way to do that and their vision became Global Campuses Foundation (GCF), which celebrates its 20th anniversary in 2021.

The GCF mission is: "facilitating collaborative learning opportunities for adults who experience disability" ("About Global Campuses Foundation," n.d.). One of the unique aspects of GCF is the focus on student ownership of their education or as put on the GCF website:

> GCF's educational philosophy and methodologies promote campus members taking ownership and stewardship of their campus. Global Campus participants are the creators

and producers of their educational experiences and take on leadership opportunities as faculty, students, and administrative staff. ("About Global Campuses Foundation," n.d.)

Another unique aspect of GCF is its international scope. GCF intentionally facilitates a worldwide campuses network that is designed to promote cross-cultural education and exchanges. As I write in late 2020, there are 11 campuses in Vermont, one campus in New Hampshire, and seven in Northern Thailand, with ongoing talks for expanding into neighboring countries continuing even in the age of the Coronavirus.

During the pandemic, a week after suspending in-person classes in the U.S. in early March, GCF provided distance learning classes for 200 participants. The U.S. participants were also involved in some classes and exchanges of curriculum and other information with their Thai counterparts. In Thailand itself, there has also been a lockdown since early March. Many campus participants returned to their homes throughout northern Thailand. In Chiang Mai, home of Chiang Mai University and the base of GCF in Thailand, Global Campus Chiang Mai (GCC) facilitators, Kachakorn Thaveesri (Ka), GCF Regional Director for Southeast Asia and Yutthaphon Damrongchuensakun (Non), GCC Director, both of whom have disabilities themselves, have gathered and delivered face masks and sanitizers to GCF campus leaders in other cities and to villages in rural areas. In a recent report, Ka and Non talked about receiving over 100 bags with fresh vegetables and getting ready to distribute them.

Non added "We are all very grateful that GCF values and supports leaders with disabilities and our activities to be a learning society in the culture of disability in Thailand." ("Global Campus News," 2020).

Back in the U.S., citizen of the world, Petra Kuppers, originally from Germany, but who lived in many different countries and cultures before finding herself as a professor at the University of Michigan, describes herself in part as a "Disability Culture Activist." Kuppers who is an inventive artist/activist/scholar, community performance artist, poet, writer, and creator, was presumptively diagnosed with the Coronavirus in early March 2020. Kuppers, who often shares her life and activities via Facebook, had already begun creating more virtual platforms. At the end

of April, recovered from her bout with the virus, Kuppers did a video interview, "PERFORMING IN VIRAL TIMES," with Amy Sass of the Ragged Wing Ensemble video series, "Moment 2 Moment."

In the interview, Kuppers shares, "coming up with other ways of doing it [creating art/theater] and having as many people as possible involved in the creative process that is what is at the heart of my work" (Kuppers and Sass, 2020).

In discussing her latest poetry book, *Gut Botany*, which explores in part recovery from sexual assault, Kuppers addresses both her work and current times:

> "so much of healing from assault is about being okay with other humans again and this is something we're all gonna face you know when this, when this, pandemic gets to a place where we can be released from sheltering in place which I imagine many of us are doing, I'm doing right now, we will have to find ways of healing ourselves from being afraid of the other person and yet also being aware of what it means to be someone living in the 21st century, someone who lives in a world that has viral loads, toxic loads, you know, all the kinds of things that some of us have been able to ignore for long periods of time but many others have not you know so we hopefully will all emerge as more aware and so a lot of my healing journey is about being aware of what it means to reach out towards the other… (Kuppers and Sass, 2020)

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In further exploring related themes, blogger extraordinaire, among many other roles, Meriah Nichols, who has multiple disabilities, wrote in a spring 2020 blog entry, "It's Like We are in Timeout," that the pandemic:

> happened because the world is intrinsically interconnected but refuses to acknowledge it.

> It happened because we have enormous disparities between the rich and the poor, we have a profit-based healthcare system and rampant ignorance….

> We have been valuing money and work over all else….

The roots of global change happen on a local level, the ripple is generated from the core, and the core of every human being is our own self, which is exactly who we are now required to spend an inordinate amount of time with….

The roots of global change happen on a local level, the ripple is generated from the core, and the core of every human being is our own self, which is exactly who we are now required to spend an inordinate amount of time with….

This pandemic will push us into new directions whether we want to go or not.

We are going to figure out how to come into our own worth – slip into our authentic power and be who we really are.

Because I think that fundamentally changing who we are and how we live is ultimately going to be the only way we can truly get out of Time Out.

That's such a tall order: because it involves love, authenticity.

Honesty.

It involves cultural shifts, education, systems of care, economic justice, rights.

It means being still and reaching in.

But I have confidence that tall order or not, we can do it.

This is, I believe, a part of our evolution, it's becoming more of who we were always supposed to be. (Nichols, M., 2020)

_____

There are so many more examples of ongoing activities in the spring of 2020, including those of disabled activists and Disability Culture promulgators. This is one reason why this book will not be an end point, but a starting one for many and a resting and/or re-creating one in the middle of the process and creation of Disability Culture for many others.

I choose to leave this chapter with the final verse of my poem that opened this chapter, which I find uncannily timely, though the words were written over 20 years ago:

BREATHING

My poetry,

like my body...

survives.

Historian **Steven E. Brown** is a retired Professor and Disabilities Scholar, Center on Disability Studies (CDS), University of Hawaiʻi (UH), and Co-Founder of the Institute on Disability Culture. Brown has published many articles about disability rights and disability culture and is a national and international speaker.

His books include *Movie Stars and Sensuous Scars: Essays on the Journey from Disability Shame to Disability Pride*; *Surprised to be Standing: A Spiritual Journey*, and *Ed Roberts: Wheelchair Genius*, written for Middle Grade ages. He is also a co-editor of the anthology, *Rethinking Disability: World Perspectives in Culture and Society* (2016). He has presented on disability rights and culture throughout the U.S. as well as in Canada; Germany; Hungary; Korea (via remote video) Japan; Norway; Saipan; Sweden; Taiwan; and Thailand.

Brown created the UH/CDS online courses: "Disability History and Culture: From Homer to Hip Hop," and "Disability Through the Ages." Although he retired from teaching these courses, they continue to be taught by a successor.

After retiring from his full-time Professor position, he and his wife (and co-founder of the Institute on Disability Culture), Lillian Gonzales Brown, returned to the mainland, where Brown continues to write, advocate, and teach. He is currently working on a book about Disability Culture.

More information available at: http://www.instituteondisabilityculture.org/

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Multimedia

Review of *Gut Botany* by Petra Kuppers.
Wayne State University Press (2020)

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Abstract

A book review by Maria Teresa Houar of Petra Kuppers' collection of new and recently published poetry *Gut Botany* (2020).

Keywords: poetry, disability, sexuality, trauma, environment

> So I sit down and write, palm tingling with the bark's rough tongue.
>
> --Petra Kuppers, "Wild Tongue," *Gut Botany*

In *Gut Botany*, disability culture activist and artist Petra Kuppers offers a collection of new and recently published poetry, inviting readers to journey through a sensuous, textual mapping of her settler body in relationship to the Indigenous lands of Turtle Island (the North American continent). Her writing presents experiences of sexuality, sexual trauma, and healing as themes which traverse many terrains throughout the text. These regions include the wildness of the Pacific Northwest and Great Lakes, the inside of a courtroom, a craniosacral

Figure 1

Excerpt, "Contours". From *Gut Botany* (p. 16), by Kuppers, P., 2020, Wayne State University. Copyright 2020 by Petra Kuppers.

Water deep   below. My   shirt
                is damp,
                    afterward,
                            my face.
You still look poised.

We bear
        on
            the grass carpet.

therapist's table, the contours of a lover's body, the contact point between tectonic plates, and the topography of a wheelchair. All become the landscapes through which we witness Kuppers celebrate the vulnerability of diverse living bodies.

Kuppers's poetry invites the reader to consider the sensual possibilities within the environmental motifs of water (ice, fish, sex, gut, delta, tears), land (mountain, belly, rock, pelvis, earthquake, skin), and atmosphere (sky, ancestors, wind's curvature, murmurs, moon, spirit). As the text carries us into intimate proximity with the abject and divine, she collapses any boundaries which would have us understand these experiences as discrete phenomena. In doing so, the

volume engages readers in a revaluing of the "gut" as an image of vulnerability which might come to redefine our notions of desire and erotic power. Beyond the gut biome (a natural habitat for intestinal microflora, viscera, and waste) exists *Gut Botany,* offering itself as a study of relationships, the practice of vulnerability, and a renewed vision of existence within economies of intimacies, interdependence, and care.

Figure 2

Excerpt, "Poet Drag Kings". From *Gut Botany* (p. 80), by Kuppers, P., 2020, Wayne State University. Copyright 2020 by Petra Kuppers.

Dylan, we are here. Sip our waters on your unpaid tab.

Liver deltas out
coal towns and ovens,
dampness of spirit
sparks in the summer sun.

Much like a botanist in a scientific study, Kuppers follows the collection with her "field notes" indicating the "empirical conditions" that produced the work, if you will. Of the painful imagery of Court Theatre," Kuppers (2020) writes:

> Healing from sexual assault by a body-worker is central to *Gut Botany's* journey. I
> remediate lines from disabled dance artist Perel's performance experiments and
> Bhanu Kapil's interviews from *The Vertical Interrogation of Strangers* (2001).
> These seeds point outside of the cage of my memories to the frameworks of
> performance as wayfarer, embedment, community. (p. 86)

In this poem, we witness the performance of exhaustive labor required of so many survivors seeking justice. As Kuppers navigates legal and court systems, we are reminded that for people with disabilities, the demand to justify one's right to exist as a sovereign body is unfairly augmented by widespread ableism, not only with the justice system, but in society at large.

Also included are collaborations with dancer/poet Stephanie Heit, visual artist Sharon Siskin, and deceased poet Dylan Thomas. In Poet Drag Kings," Kuppers appears to be reveling in the pleasure of gnawing at the work of poets who populate the American cannon, crafting poetic intimacies which problematize their work in relationship to cultures of toxic masculinity. Addressing Thomas, Kuppers (2020) writes:

> Dylan, you were the life of the party,
>
> thirtynine dead in the Chelsea Hotel.
> You beat your wife
> that's mainly what I remember.
> Some lines of some poems.
> Richard Burton's voice.
> We listen deeper
> un-know colonial living on old-rock land.
>
> I have survived you.
> So has the woman I love,
> most people I know.
> Life in the forties. You missed out
> on laughter lines, the longer duration
> (p. 78)

Kuppers mentions time spent in Michigan with friend Margaret Noodin, the Anishinaabemowin poet and linguist, and the women of the Miskwaasining Nagamo- jig/Swamp Singers, as a primary source of inspiration for the volume. Likewise, reading the work through a lens of Indigenous survivance positions *Gut Botany* to offer a much-needed intersectional framework for connecting our understandings of material embodiment across Indigenous and Disability studies. These themes appear in Kuppers's earlier creative research, such as collaborative dance and performance work with the Olimpias Disability Culture Collective. In *Touching Disability Culture: Dancing Tiresias*, Kuppers (2017) writes:

Disability approaches can learn much from concepts of survivance. Disability is not a cultural formation with narratives of homelands, spiritual connections, and genealogies. But disability is an historical process--one associated with the parsing and categorization of human knowledge in modernity. It is a complex of associations and ideas that merge together different people and makes them an 'other.' Disability and race share a history of devaluation based on a mixture of biological and cultural narratives: certain ways of being in the world are valued more than others, while others are seen as 'less developed,' 'unfit for modern life,' or 'savage.' (p. 608)

The influence of Indigenous epistemologies is deeply felt throughout *Gut Botany,* as Kuppers explores the ways in which settler cultures have constructed both Indigenous and Disabled identity both as biomedical and necropolitical realities. She boldly problematizes the ableism and heteropatriarchal domination of white settler normativity and its many fictions. We see this critique laid bare in "Big Spirit Moon": "I am not spared precarity/ in my occupation of indigenous lands/ I cannot see the lake the way you root/ drum, burn the chitin, an alarm" (Kuppers, 2020, p. 72). It is also evident in the final lines of "Gut Body" on the very first page: primacy of white masculine fear/ close the leaky gut/ body drained of tears" (Kuppers, 2020, p. 1). Kuppers offers a vision of resistance, an unapologetic reckoning of her body's history. It's a story born of navigating through landscapes both hostile and fertile, a counter-narrative that queers all love, bodies, and relationships.

The experiences *Gut Botany* chronicles also seem to pay reverence to Indigenous frameworks of ethnographic refusal in its resistance to classification, interpretation, and traditional poetic form. For example, the final lines of "Contours" are a set of single words and phrases spread almost randomly across the page. They appear as if soaring across a sky with a sweeping draw of birds flying overhead, or water cascading down a slippery rock waterfall. Throughout the collection, Kuppers's work is animated by the performance of intimacies between human and more-than-human in a way that problematizes the anthropocentrism of naturalist poetry portraying the North American landscape. Instead, she presents to the reader a world where we recognize sovereignty as transspecies liberation.

Figure 3

Excerpt, "Contours". From *Gut Botany* (p. 19), by Kuppers, P., 2020, Wayne State University. Copyright 2020 by Petra Kuppers.

Give way

wind

beetle

bird caw.

Circle overhead

on your round,

snail-like,

trace.

Gut Botany is a work that feels. It is a confrontational yet comforting examination of human vulnerability and is highly recommended reading not only for scholars in disability studies but also for those in Performance Studies, Queer Indigenous Studies, Gender and Sexuality Studies, Queer-Crip Theory, ecology, poetry, and American Literature. Much like Kuppers's other works, the generosity of *Gut Botany* desires imitation. As it celebrates acts of communion between land, human, and more-than-human species which often go unnoticed, we find ourselves there, learning of deep reverence, devotion, and healing.

Maria Teresa Houar is a queer scholar of Indigenous Latinx, Mexican, Portuguese and Haole descent, born and raised in Hawaiʻi on the outer islands of Kauaʻi and Maui. Maria Teresa is a PhD candidate in Performance Studies at UH Mānoa researching dance performance through intersectional lenses of sexuality, fetish, queerness, disability, militarism, intimacy, and consent culture as a means of dismantling the colonized view of the body.

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Multimedia
Book Review of Edwin E. Etieyibo and Odirin Omiegbe, *Disabilities in Nigeria: Attitudes, Reactions, and Remediation*, Lanham: Hamilton Books, 2017

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Abstract

A review by Shu Wan of the first comprehensive monograph discussing the issue of disabilities in contemporary Nigerian society, Edwin E. Etieyibo and Odirin Omiegbe's *Disabilities in Nigeria: Attitudes, Reactions, and Remediation*, Lanham: Hamilton Books, 2017.

Keywords: Africa, Nigeria, perceptions of disability, cultural cross-comparisons

Africa

Almost 14 years ago, African historian Julia Livingston published the first academic book regarding disabilities in African countries, *Debility and the Moral Imagination in Botswana*. In it, she investigates the (mis)representation of disabilities in the African nation. Following this book, an increasing number of academic works regarding issues of disability in Africa have followed. With a combination of theoretical analysis and concrete studies of multiple cases, African anthropologists Edwin Etieyibo and Odirin Omiegbe's volume *Disabilities in Nigeria: Attitudes, Reactions, and Remediation* addresses the state of disability in Nigeria. They demonstrate the social construction of visual, mental and physical disabilities in Nigeria and the distinction from similar processes in Western Europe and North America.

Consisting of 12 chapters, the organization of this volume could be divided into three parts. The first part mainly demonstrates prevalent perceptions of disabilities in Nigeria and their causes. In chapter 1, Etieyibo and Omiegbe attempt to establish a theoretical framework for their

further discussion. The model includes the divergence of medical perception, social construction of disabilities and academic discussions regarding disabilities in West Africa. In the following chapter, Etieyibo and Omiegbe proceed to examine the prevalent cultural explanation for disabilities in Nigerian society. Indigenous religious beliefs in Africa have profoundly shaped Nigerians' understanding of disabilities. In these beliefs, disability is blamed on spiritual sins of the disabled people and their families. In chapter 3, the authors review scientific accounts for the actual causes of disabilities. In scientists and medical professionals' views, occurrence of disabilities can be attributed to malnutrition, chronic diseases, drug addiction and other unhealthy behaviors. At the same time, this "scientific view," which represents the medical model of disabilities, may itself stigmatize people with disabilities as the *diseased* and *abnormal*.

In the second part of this volume, Etieyibo and Omiegbe examine many examples regarding the experiences of people with disabilities and their encounters with mainstream society in Nigeria. In chapter 4, the authors present an overview of experiences of different disabilities in Nigeria, including visual, physical, and mental. Chapters 5 and 6 follow up with an exploration of physically and visually disabled people's perceptions of their own conditions through a series of interviews with people with different kinds of disabilities. Despite consistent efforts to struggle with disability-based discrimination, as seen in these interviewee's personal narratives, people with disabilities in Nigeria still suffer unfair treatment in the job market and within intimate relationships. Those frustrations affect the formation of their self-identity; furthermore, some accept the misrepresentation of disabilities as sins and take on the cultural shame of their disabilities.

In chapter 7 and 8, Etieyibo and Omiegbe turn to the role of the family in shaping the experience of people with disabilities. Considering perceptions of family members with visual disabilities, through intense ethnographic fieldwork, the authors examine difficulties family members encounter living with and caring for visually disabled family. With heavy financial and psychological pressure, the parents, spouses and siblings of people with visual disabilities are often also themselves victims of wide-spread discrimination in Nigerian society. As a result, most of the interviewees in this research articulate the discontent of both people with disabilities and their families with the national government's negligence of blind people's basic rights as citizens.

According to a "sister of a person with visual disability": "we still don't regard the disabled as members of the society" (Etieyibo & Omiegbe, 2017, p. 120).

In the second part of the book, Etieyibo and Omiegbe turn to the theoretical foundations of disability studies in Nigeria. The final chapters in this section consider ways to meet the needs of people with disabilities in Nigeria and reviews the legal culture of disability-based discrimination in the national culture and local society of Nigeria.

Through examining the conditions of people with disabilities in Nigeria, Etieyibo and Omiegebe succeed in demonstrating the frustration encountered by many in their everyday lives. The authors' collected testimonies from one hundred people with disabilities and their families give a clear picture of perceptions of disabilities and reactions to the oppression over disabilities in Nigeria. As the first comprehensive monograph discussing the issue of disabilities in contemporary Nigerian society, this volume represents insightful and inspiring research.

Shu Wan is currently matriculating as a PhD student in the Department of History at the University at Buffalo.

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Notes from the Field

Innovate – PacRim 2021

Sandy Shitanishi
University of Hawaiʻi at Mānoa, Center on Disability Studies

The Center on Disability Studies, in the University of Hawaiʻi at Mānoa College of Education, announces its **Annual Pacific Rim International Conference on Disability and Diversity (PacRim)** March 1–2, 2021 (Hawaii Standard Time) – Virtual.

The theme of the conference is **INNOVATE** to rethink, recreate, and bring about changes, new ideas, and opportunities to address the current and future needs of people with disabilities and other underrepresented groups towards inclusion, equity, and social justice. Conference topics include:

- Indigenous Knowledge, Perspectives, and Approaches;
- Education, Teaching and Classroom Practices;
- Deaf Community;
- Family and Community Engagement;
- Flourishing, Well-being, and Social-Emotional Learning;
- Online Learning and Technology;
- Transition, Inclusive Postsecondary Education, and Self-Determination;
- Creativity and the Arts; and
- Employment

Take advantage of the Early Bird Registration rate as an attendee or highlight your organization's most leading-edge products and services as an exhibitor and sponsor by contacting prinfo@hawaii.edu. Questions? Contact prcall@hawaii.edu, visit pacrim.coe.hawaii.edu, or connect through social media at www.facebook.com/PacRimHawaii.

###The Pacific Rim International Conference on Disability and Diversity is organized by the Center on Disability Studies (CDS), an organization that aims to promote diverse abilities across the lifespan through interdisciplinary training, research, and service. Learn more about CDS at cds.coe.hawaii.edu.

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