Hierarchy of Life: Whose Lives Do We Value?

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Abstract

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

Access the multimedia version on YouTube

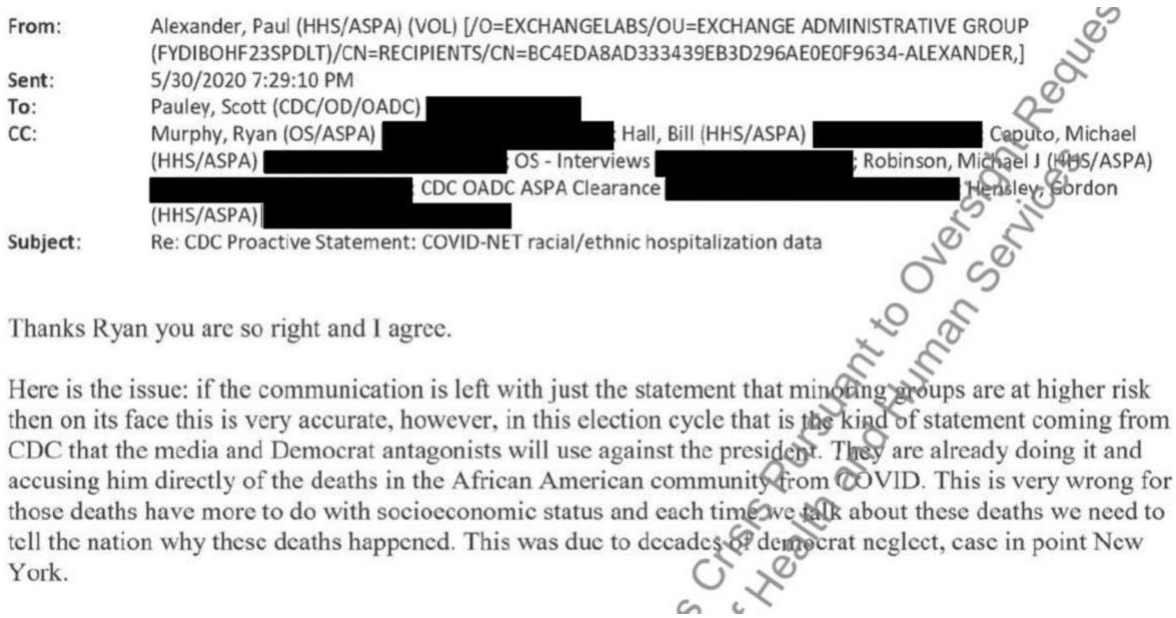
The COVID-19 pandemic has uprooted the globe. Especially within the United States, a country in a predicament of division and confusion, COVID has permanently impacted life as we knew it. Lacking support and leadership for almost an entire year, every aspect of disability and disability studies was impacted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

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

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

In the United States, the Trump administration did little to properly educate citizens on the pandemic. Rather than confronting the pandemic with a united, thoughtful approach, President Trump allowed reckless herd immunity ideology, anti-mask propaganda, and ignorance to overshadow factual information about the virus. On December 16th, 2020 the Trump administration was publicly called out for their dangerous disregard of life email evidence can be read in Appendix 2:

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



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

Thanks Ryan you are so right and I agree.

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

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

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

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

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

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

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

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

Hospital Overcrowding Fueling a Hierarchy of Life

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

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

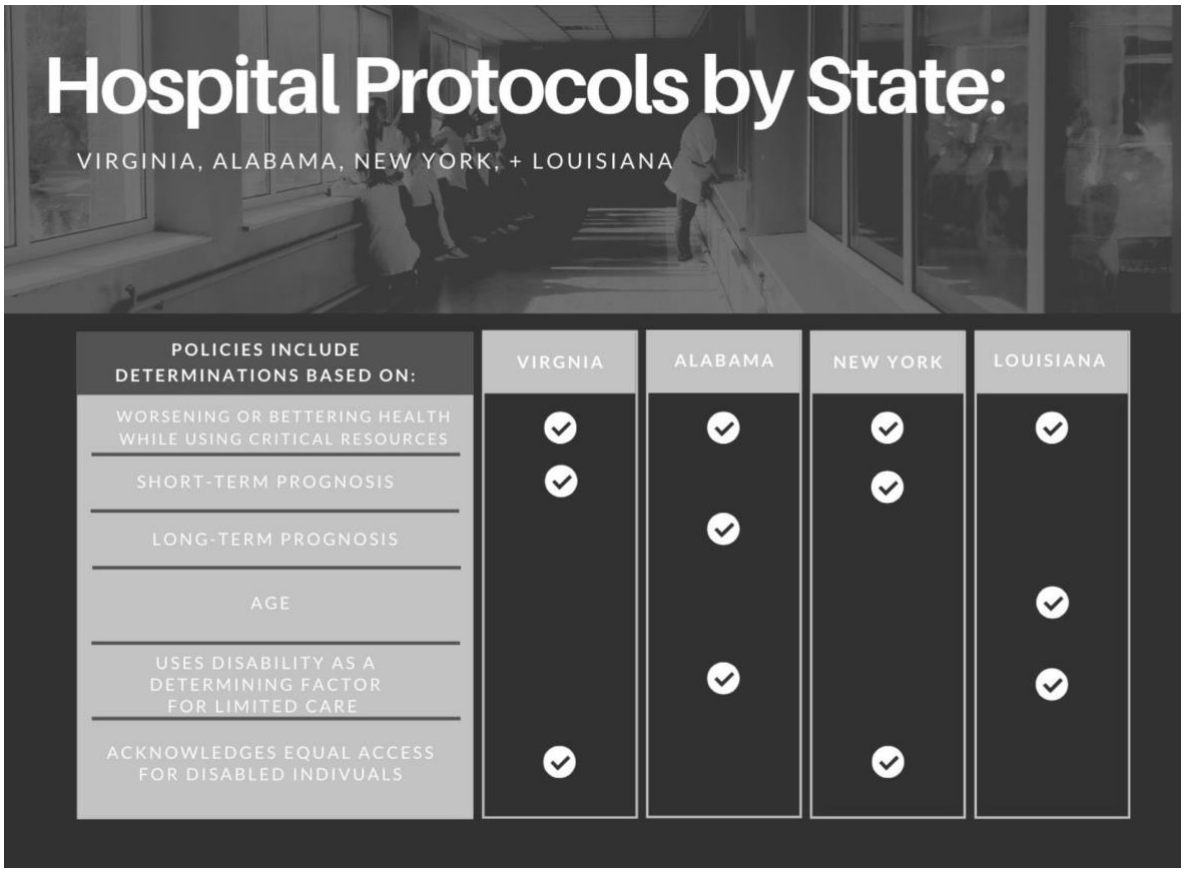
In late summer of 2020, only some regions of the U.S. were facing this immense overcrowding which resulted in travelling volunteers relocating to the most impacted states. Later on in December and January, most states were experiencing their highest rates of COVID and there wasn't enough power or capital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

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

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

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

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



15

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Educational concerns in the COVID pandemic

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

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

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

term health consequences. The number of individuals impacted by COVID grows the longer COVID progresses. In an article on preparing to serve students with COVID 19 related long term disabilities, including COVID longhaulers, Bedrossian (2020) asserted that schools must work with students to ensure that equitable education can be created for all:

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

Long-term impacts

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

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

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

Skewed Vaccine Distribution

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

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

Another factor that initially delayed the vaccination process was the limited number of vaccination sites, which contributed to the distance that one had to travel in order to receive a vaccine.

Some states prioritized multiple options for vaccination sites better than others depending on the infrastructure, financing, and supply of workers. Typically, wealthier areas had more vaccination sites than low-income or rural locations. In Florida, white, wealthy Americans were four times more likely to have had the vaccine than Black Americans in the same state (Gandel 2021). Furthermore, politics strongly influenced vaccination distribution as well. For example, Ron DeSantis was accused of "using the vaccine distribution plan to appeal to donors; he has raised more than $2.7 million in February alone since he began the "pop-up" clinics, the Herald reported" (Shepherd 2021).The governor of Florida played a role in at least two specific and concerning incidents. First, in January, an ultra-wealthy and exclusive community in Key Largo received enough COVID vaccine doses for 1,200 residents over the age of 65, while the rest of the state's seniors struggled to gain vaccine access. The way in which the community received them is still unclear, but the contrast of waiting, registering, and traveling for vaccination was quite drastic compared to the vaccine delivery and short wait times for the wealthy Key Largo community. Importantly, this community has donated hundreds of thousands to the DeSantis campaign just within 2021 (Goodhue & Klas 2021).

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

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

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

The Uncertain Future of the United States

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

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Author Addendum:

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

Appendix 1:

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

Green	tweet: △
Blue	statistic/fact: ▢
Purple	interview: ◯

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

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

Appendix 2:

From: Alexander, Paul (HHS/ASPA)

Sent: 5/30/2020 7:29 PM

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

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

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

Thanks Ryan you are so right and I agree.

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