

WHEN ABLEISM MEETS A PANDEMIC: NARRATIVES,  
DISABILITY AND COVID-19

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## ABSTRACT

The United States' response to the COVID-19 pandemic of 2020 has been shaped by the country's pre-existing narratives around disability. The master narrative of disability presents disability as a static condition that inherently lowers a person's quality of life. This creates bias in physicians dealing with disabled patients, since under the master narrative's logic disability is a negative trait that must be eradicated or cured. This troubling view has wider ramifications during a global pandemic as well. The COVID-19 pandemic has reshaped everybody's relationship with time, bringing even nondisabled people closer to the experience of disability. However, the federal government and many state governments adhered as closely as possible to able-bodied conceptions of time. This has hindered the United States' pandemic response by misprioritizing "reopening the economy" even at the expense of people's lives. This creates a cycle, because this mismanaged response has led the country into even greater uncertainty about the pandemic, which moves everybody even closer to disabled conceptions of time. Had the master narrative not been so powerful, perhaps the United States could have responded more effectively to the COVID-19 pandemic.

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## CHAPTER 1: THE MASTER NARRATIVE

When the COVID-19 pandemic struck the United States early in 2020, everybody in the country had to adjust to a rapidly changing world. Policymakers at every level of government responded to the crisis with varying levels of success initially, but throughout the year every corner of the country was overrun by the virus. This was not an inevitable outcome. Many other nations struggled to contain the pandemic, but many were also successful in doing so. Many people have written about various problems with the United States' pandemic response, both on a social and a political level. In this thesis, I argue that the United States' history of ableism and its refusal to grapple with the disabling effects of the pandemic has been a key factor in the botched response.

The United States' failed response is frustrating but not surprising. It fits neatly into the history of ableism in our policies and culture. Ableism is broadly described as discrimination against disabled people. Ableism can affect disabled people in many different ways. One of the most common ways is for a government policy to result in some sort of biased outcome against people with disabilities. This can be either intentional or unintentional. One clear example of ableist policy is section 14c of the Federal Labor Standards Act. This law allows employers to apply for a "special wage certificate" which allows them to pay employees with disabilities a wage below the minimum wage. This is often referred to as a "subminimum wage" law (Friedman).

This law is a good starting place when analyzing ableism in government. It is based in the belief that people with disabilities are less productive than people without

disabilities. However, this is not how the law plays out in actuality. Companies that are issued the certificates pay their disabled workers less than minimum wage, regardless of their productivity levels relative to able-bodied coworkers (Friedman). It doesn't matter whether the employee is actually productive, what matters is that the employer perceives them as unproductive. This status is determined only by the disability status of the employee. The law upholding this reality is still on the books because of the prevailing belief that if someone is disabled, they can be paid less because disability inherently makes someone unproductive. It is worth noting that repealing this law was going to be part of the minimum wage hike included in the Biden Administration's COVID-19 relief bill, but that part of the bill was struck down by the Senate parliamentarian on procedural grounds (Luterman).

Moreover, the US government itself found forty years ago that 60% of the workplaces operating with an FLSA certificate were underpaying workers "even according to subminimum wage standards" (Friedman). This is not surprising because the United States is a capitalist economy. Under capitalism, the primary goal of a business is to make money. Therefore, if a business is given a government certificate that allows them to underpay certain workers, it makes sense purely from a financial standpoint for that business to push the limit of that rule as much as possible without fear of punishment. After all, the governmental organization that would be in charge of punishment is the one that provides the certificate in the first place.

The negative effects of ableism on the lives of disabled people have become even more devastating in the response to COVID-19. A useful case study involves the treatment of a Black man named Michael Hickson, who was hospitalized with COVID-

19 in South Austin Medical Center in Austin, Texas in early June 2020. Mr. Hickson had been dealing with the effects of a cardiac arrest in 2017, and was learning to live with quadriplegia and recover his baseline cognitive ability. Within three days of his admission to the Intensive Care Unit, his condition had deteriorated. Hickson's attending physician decided to withhold hydration and nutrition (Shapiro 2020 1).

Hickson's wife, Melissa, who was not permitted to visit him due to COVID-19 related restrictions, recorded a conversation in which the physician said "So as of right now, his quality of life — he doesn't have much of one." Mrs. Hickson responded "'What do you mean? Because he's paralyzed with a brain injury, he doesn't have quality of life?'" and the physician answered "Correct.'" Mr. Hickson died within a week (Shapiro 2020 1).

This is, first and foremost, a tragedy. But it's also a microcosm of how ableism takes hold in individual encounters. The back-and-forth recorded above is a succinct summation of how disability is commonly perceived: The existence of a disability inherently lowers a person's quality of life. This is a troubling belief, but a widespread one in society and even among medical professionals. It has long been established that nondisabled physicians under-estimate the quality of life of disabled patients (Gerhart 808). In a medical setting like we have seen in Hickson's case, this can have deadly consequences.

The power dynamic involved in this situation makes it doubly difficult for patients. Even though Mr. Hickson did not believe that his disability consigned him to a low quality of life, and neither did his wife, his physician ultimately asserted decision-making power in the situation. The evidence that Mrs. Hickson attempted to present that

would overrule this decision was not considered. It did not match what the physician believed to be true. Instead, Mr. Hickson's experience was subsumed into the broad, and false, understanding of disability that had formed in this physician's mind. Given the power dynamic, and Mr. Hickson's physical state, there was not much that the Hicksons could do to challenge the situation.

To be clear, I do not know what would have happened had Mr. Hickson received treatment. It is certainly possible that COVID-19 or the secondary pneumonia he contracted would have killed him anyway. However, it is abundantly clear that he was not even given a chance at survival by the people charged with his care. His life was not deemed to be one worth living.

This also brings us to an important tool to understanding disability's relationship to the United States' response to COVID-19: The master narrative. Here, I will use the case of Michael Hickson as an example.

Master narratives are "repeated themes and stories throughout a culture" that "are educational, they're instructive, they're often about morality — they're just values and characters" (Watson, quoted in Rafford). They are useful shortcuts for us as humans, since they allow us to easily keep track of all the stories we encounter every day. We sort the narratives we encounter into broader categories that we are already familiar with in order to process lots of information at once. But in many cases, they can also result in oppression. The case of Michael Hickson shows this.

In this case, the physician is directly asked: "Because he's paralyzed with a brain injury, he doesn't have quality of life?" and he responds "Correct." But this is not correct according to Hickson's experience. Instead, it is a correct retelling of the master narrative

of paralysis and brain injuries. The presence of these conditions, and disability more broadly, is seen as an insurmountable barrier to a high quality of life. The master narrative states that disability closes off opportunities and severely limits the possible futures for a disabled person, thereby lowering the quality of life of disabled people (Stramondo S30).

It's important to clarify here that according to the master narrative, the source of this restriction and lower quality of life is the disabled body itself. The disabled body is "ontologically intolerable, inherently negative. Such an attitude of mind underpins most claims of social injury within the welfare state and...the compulsion towards therapeutic interventions" (Campbell 43). In other words, there is no way out of this lower quality of life once it is established. A disabled person naturally must want their disability cured, because that is the only way of improving their quality of life. Removal of disability, therefore, becomes a valid moral goal, either through cures, treatments or even death.

This is not an exaggeration at all. Journalist John Hockenberry, writing in his memoir, noted some of the most common disability narratives in fiction: someone "clinging to life after a sports injury, terminally ill, obsessed with suicide, or taking up hang gliding from a wheelchair" (Hockenberry cited in Biklen 347). The disabled character must be in need of tremendous medical care, depressed because of their disability to the point of suicide, or intent on bringing themselves as close to abledness as possible through physical activity. None of these narratives allow the disabled character to view their disability as anything other than a problem that must be solved through eradication.

Disability scholar Rosemarie Garland-Thomson summarizes the master narrative of disability in literature as “embodied otherness,” that exists to contrast with the morally superior non-disabled body. She describes a process wherein disabled characters are often described only by their disability, leaving the reader to fill in the gaps based on their own beliefs about disabled people (Garland-Thomson 1997 2 33). This creates a self-fulfilling cycle of master narrative, since non-disabled people reading stories with these one-dimensional disabled characters often fall back on master narratives of disability that are themselves one-dimensional. Then, having encountered disability in the story, they project that one-dimensional experience they encountered in the story on to disabled people they may encounter in the real world. This reinforces a notion of disability as static and non-narratable, or narratable only by abled people. Thus, the relative lack of disabled people with moral agency in stories our culture tells is a non-trivial problem. It allows disabled people to be continuously “othered” due to their bodies, which by definition contrast with what our society defines as “normal.” In short, the belief goes, disabled people do not physically fit into society in some way, so there must be something inherently wrong with their bodies, since abled people do not have the same problem.

Even the universal logo of disability can reinforce this master narrative. The symbol is a white stick-figure wheelchair with a blank circle for a head on a blue background. It is a static symbol that does not connote motion. This depiction implies that disability is not an active process. It reduces an individual to whatever their medical condition is, and therefore is more harmful than good. It also erases other types of disability besides the wheelchair user, which is already arguably the most visible type of

disability. “In depicting the wheelchair as the symbol of access, a mobility-impaired person who uses a wheelchair comes to symbolize all other forms of disability.

Conceptualized in this way, disability pertains only to a ‘young man in a wheelchair who is fit, never ill, and whose only need is a physically accessible environment’” (Fritsch 140).

This causes non-disabled people to see disability as both a category belonging to “the other” and an experience that does not change over time. If that is true, it makes the master narrative all the more potent. Able-bodied and neurotypical people’s lives change all the time, often without too much difficulty. It’s much easier to find cultural or personal stories about abled people who have an active role in shaping their life and finding happiness than it is to find such a story about a disabled person. Many people relish in their ability to go on a personal journey or explore the world. If disabled people are thought of as unable to have those experiences, it is easy to see how the master narrative of disability as wholly undesirable takes shape.

Certainly, the disability logo did not cause this to happen, but it implicitly had a part. It creates a label for disabled space and access, which is necessary, but in so doing also separates disabled people into a unique category for whom access may not be guaranteed. This is clearly not correct, as everybody has special access needs. For example, even the most physically fit able-bodied person can not enter a building if there isn’t a door or window. Fritsch describes this by noting that “By naturalizing disability as an inherent and static mode of being, the [disability logo] also obfuscates the ways in which disability appears through the construction of space” (Fritsch 141). In other words, the use of a label indicates that certain public spaces are the only places that disabled

people need to access. This reinforces the false idea only disabled people have unique access needs. Also, by depicting the wheelchair and the wheelchair alone, the symbol indicates that the disabled body itself is what causes access issues and therefore a lower quality of life. It ignores that the built world is often the source of disability. As Garland-Thomson writes, “Stairs, for example, create a functional impairment for wheelchair users that ramps do not. Printed information accommodates the sighted but “limits” blind persons...People who cannot lift three hundred pounds are “able-bodied”, whereas those who cannot lift fifty pounds are “disabled,”” because of the world that we have constructed (Garland-Thomson 1997 28).

The perceived stasis of disability is another formulation of the master narrative. After all, stasis is the opposite of any form of narrative. From the perspective of able-bodied and able-minded people, disability creates a static life with a low quality of life. This low quality of life is created by the disabled body itself and therefore inherent to it, at least until the body can be cured. Therefore, they see a life with disability, especially an incurable disability, as a life without a narrative voice or agency. This is not a big jump to make, because after all, if disability creates a life in stasis, then that life is incompatible with plot and therefore it is unnarratable (Couser 292). Lawyers Frank Munger and David Engel, in seeking to write a paper about disability rights in employment, similarly discovered that disabled people they interviewed were less interested in telling stories about a particular conflict or rights claim. Instead they wanted to incorporate any problems caused by ableism and their disabilities into a fuller life story and relate that story to employment issues (Engel and Munger 88-91). They wanted to take control of their own narrative and not describe their relationship with disability and

ableism as an isolated incident. By doing this, they implicitly rejected the notion that their disability rendered their own lives unnarratable.

Just because disabled people want to tell their stories does not mean that they are listened to by non-disabled people. If disabled people cannot narrate their own stories, it means that a master narrative becomes all the more potent because it is unchallenged. The master narrative replaces individual narratives, and is projected onto the lives of individual disabled people as Garland-Thomson describes. This is dangerous because it removes the need to imagine a disabled life as a full life. Instead, able-bodied people see a disabled person, remember the master narrative of disability, and make broad assumptions about a person's life. This dehumanizes disabled people such as Michael Hickson, but it also causes harm to the rest of society as well.

Donald Trump used this dehumanization for his own political gain. He repeatedly refers to America as "crippled" in order to get his audience to recognize America's struggles. Trump uses "crippled" as a synonym for all sorts of negative words: not winning, not being excellent, being weak, submitting, and being a mess (Harnish 424). He contrasts this with his own self-proclaimed strength and ability to lead the United States back to greatness. This was one of the many factors at the root of his 2016 victory. He relied on the master narrative of disability to explain how he would make the country better. His campaign slogan, "Make America Great Again," can be read in this context as a cure narrative for the supposed disability harming the United States. He blamed these troubles on immigrants, Black people, and Muslims in particular, in repeated statements during his campaign and presidency. Of course, he lied frequently about these issues and many others, but the internal logic was the same as the logic of a master narrative of

disability in need of curing. Instead of learning to live with the disability that he saw as plaguing the United States, which he believed minority groups were, Trump wanted to cure it by removing it from the otherwise-nondisabled body. This metaphor is admittedly imperfect, as it ignores the impact of race and religion, among many other axes of bigotry. But it shows the rhetorical power of the master narrative of disability, since it undergirds other nationwide conversations. It also demonstrates how hegemonic this narrative is. Trump's narrative pushed out all others during the 2016 campaign. He set the terms of the debate on policy, no matter how nonsensical his stances were, because of how well-known they became. Disabled people, along with people in other minority groups, pushed back against his rhetoric. But with Trump purporting such a catchy, easily-digestible solution, those nuanced counter-narratives were much easier to disregard.

When non-disabled people, who comprise a majority of the United States, disregard the stories of disabled people, it means that disabled people do not get to tell their stories accurately to a broad audience. This means that the vast majority of narratives are centered around one type of person: the abled person. This limits our cultural creativity. If only one kind of narrative is told, as a culture we are inherently limiting ourselves to only understanding the world a certain way. Since the world was designed for abled people, by abled people, it means that most of our cultural narratives move in one direction in time. Abled people have fewer obstacles in both time and space than disabled people do, and narratives reflect that reality.

Our dominant cultural lens is that of a non-disabled person, and thus our main (mis)understanding of disability is created by that non-disabled lens. Therefore, the

perspectives of disabled people often do not match the cultural expectation of disability created by the non-disabled lens. This makes them easier to ignore. Obviously, this is not good in any situation. However, in certain moments it is especially problematic, such as the COVID-19 pandemic. At this moment in time, the relative lack of disabled narratives and the prevalence of a harmful master narrative about disability harms everybody.

## CHAPTER 2: NARRATIVES AND COVID-19

The pervasiveness of this master narrative of disability has caused tremendous harm to the entire disability community. This is particularly troublesome in the midst of the COVID-19 pandemic. Disabled people have been at increased risk for severe complications from COVID-19. Some disabled people are also at increased risk of contracting the disease due to social supports that disabled people often need but also require close contact with home health aides (Kendall et al. 1774).

Despite these risks caused by COVID-19 and ableism, disabled people are wary of treatment. This is not to say that they avoid treatment for COVID-19 if it is necessary. But they are well aware of the master narrative around disability and recognize its implications when seeking medical intervention. Michael Hickson is just one in a long line of disabled people who suffered at the hands of physicians under ethically dubious circumstances. In early March 2020, a disability rights organization in Oregon uncovered a troubling pattern of healthcare providers rationing care away from disabled people due to quality of life concerns (Shapiro 2020 2).

In light of these facts, disabled people raised their concerns about COVID-19 treatment or a lack thereof. They saw the standards of care plans that various states rolled out, which discriminated against disabled people. These standards were often couched in terms like “five year-survival rate” and “quality of life.” Disability rights organizations successfully sued to overturn many of these standards of care early in the pandemic. The Department of Health and Human Services eventually released a statement that “civil rights laws protect the equal dignity of every human life from ruthless utilitarianism”

(Fink). Doctors writing in the *New England Journal of Medicine* in May 2020 also pointed out that this utilitarianism penalized disabled people and also people of color due to historical inequities (Mancheda et al. e16(2)). These publications and voices were certainly welcome, but they didn't necessarily assuage the fears of disabled people. The case of Michael Hickson, which occurred after the HHS statement and NEJM op-ed, shows that not every healthcare provider recognized their own ableism.

One of the more common refrains, particularly early in the pandemic, was the notion that “only the elderly and chronically ill people were at risk.” But for the almost 25% of Americans with disabilities or chronic illnesses (Sabatello et al. 1523), this is not really a solace. It just reveals that disabled people are often an afterthought to abled people. As Rabbi Elliot Kukla wrote in the *New York Times*, “More than one chronically ill friend has quipped: “Don't they know sick and old people can read?”” (Kukla).

This belief that disabled people belong to a fundamentally different, more disposable, category of people, is basically just a restatement of the master narrative. After all, if disabled people inherently lack a good quality of life, that means that it does not matter as much if they die. Individually of course, people may object and say that, for example, they would be devastated if their grandmother with Alzheimer's passes away. This is undoubtedly true, but it doesn't negate the overall societal belief in the disposability of disabled people.

The United States' response to COVID-19, both from the government and from our culture, has generally left out disabled people. This is not surprising, but it's also not inevitable. It was a result of what our American capitalist society has chosen to value. We collectively chose to avoid serious lockdowns that may have been necessary. Many

places kept restaurants open for in-person dining, allowed thousands of fans to attend NFL games, and prioritized keeping the economy running as much as possible. These were all deliberate decisions.

These decisions all reflect an unwillingness to adjust the public life of our country. The logic went that time was continuing forward as it always has, and therefore we must do our best to match its progress as well. This belief has failed to account for how the COVID-19 pandemic has radically changed the United States' relationship with time. The entire world has reoriented itself to accommodate COVID-19, as well as various states of lockdown and a steady economic downturn associated with the virus. People have lost their jobs or homes and had to adjust or abandon their life plans they had made prior to the pandemic. And yet, the leaders of the United States (and leaders of individual states as well) have emphasized a need to “move forward” and “get through this together,” (Cuomo) imagery which evokes a state of motion and progress.

However, it has been over a full year since lockdowns began in the United States and only within the last few months have vaccines emerged. This means that for nearly a year of the pandemic, government leaders were urging people to push through the pandemic and its associated economic collapse. There was not an end in sight, but that was how the conversation around COVID-19 was framed: At some point, the United States would move from a COVID-affected world to a COVID-free world. Until that happened, the country ought to do its best to stay alive and not let the economy collapse too much. If we accomplished those dual aims, everything would eventually work itself out.

In this sense, we have indexed ourselves and our response to the pandemic against a theoretical society in which COVID-19 never happened. We recall a time, just over a year ago, when the country was unencumbered by the pandemic and our response to it. The goal of our country's leaders has been to cling as close to that fictional world as possible. The measures listed above have maintained a sense of normalcy in certain places even as the pandemic continues to rage.

This echoes an experience that writer Ellen Samuels calls “crip time as time travel.” She writes that “disability and illness have the power to extract us from linear, progressive time...and cast us into a wormhole of backward and forward acceleration, jerky stops and starts, tedious intervals and abrupt endings.” She writes about her “silent rage” at “at the calm straightforwardness of those who live in the sheltered space of normative time” (Samuels). This experience can be drawn out to the entire country in the time of COVID. The straightforward world of a year ago has gone. In its place is a mishmash of lockdown and reopening. Schools move to virtual education and then back to in-person and then to a hybrid system. Sports leagues have suspended, then restarted at strange times of year. Millions of weddings, funerals, graduations, new jobs and vacations have been postponed, cancelled or dramatically scaled down. The whole country has experienced a shift into something resembling crip time in a way that is unprecedented.

Crip time is a concept that many disabled people are familiar with, even if they may not articulate it as such. Alison Kafer, a professor of feminist studies, describes crip time as “recognizing how expectations of ‘how long things take’ are based on very particular minds and bodies...the flexibility of crip time [is] not only an accommodation

to those who need ‘more’ time but also...a challenge to normative and normalizing expectations of pace and scheduling” (Kafer 26).

Kafer’s description bears an interesting resemblance to the United States in a time of COVID-19. So much change has been created by the pandemic and our response to it. A pandemic, literally, is a disease that is spreading through the entire world. It is not a stretch, therefore, to say that we have entered a global crip time. We are at the mercy of a disease and the societal structures we have set up to attempt to control it. The ableism that permeates our world no longer just affects disabled people, it affects everybody.

Here, I don’t just mean the physical world, although that is important. In a time when social distancing is necessary, it is certainly critical to have enough space in grocery stores and hospitals for bodies of all shapes and sizes to navigate safely. But I also mean cultural structures. Unemployment claims have spiked since last March, and many people have been exposed to the extremely weak social safety net in the United States. Disabled people, many of whom struggle to find work or are barred from work due to asset limits on Medicaid, have been made to cope with inadequate support for a long time. Many disabled people have lamented the inaccessibility of public transit for decades, since many stops in certain cities are not useable for disabled people. Now, mass transit services are forced to reduce frequency of travel and reduce the number of stops in order to avoid crowding and spreading COVID-19 (Cochran 2).

This is not to say that non-disabled people should not complain about these struggles because they have only encountered them for the last year. Far from it. My point here is that they are experiencing many of the same effects of ableism as disabled people do. It is that new experience that has thrust millions of people into a world of crip

time. Everybody who can has had to plan for what to do in the case of a sudden COVID-19 diagnosis in their immediate proximity. Local rules change all the time about who may do what and when, throwing everybody's daily plans into flux. This has fundamentally altered our relationship with time, creating a world that is essentially full of abled people encountering fundamental parts of the disability experience for perhaps the first time.

It may be too far to say that everybody in the United States has a temporary disability due to the pandemic itself (although for many people with long-term COVID-19 symptoms that may be true). But the country more broadly has shifted closer to what we might call a society shaped by disability. Most people still don't embody disability; it's not located somewhere in their body or mind. But the societal problems that disability may create for disabled people have affected more and more people thanks to the pandemic, even those who prior to the pandemic had no reason to identify personally as disabled.

COVID-19 affects everybody differently. Scientists are still learning about the virus, how it spreads, and the most effective ways of stopping the spread as variants of the virus arise. This uncertainty is integral to crip time. Disability is always relational: "How does my particular body-mind interact with this particular world at this particular moment?" is often how disabled people think. This is both due to the variable nature of many disabilities, and also the unreliability of accommodations and accessibility in an ableist world. As a result, disability is a state of near-perpetual uncertainty. This has spread across the broader population due to COVID-19.

This is similar to the muddled sense of time that can develop after a being diagnosed with cancer. A cancer diagnosis creates a new relationship with time for every person, as they grapple with their survival chances and all sorts of statistics and stages. For example, somebody with pancreatic cancer and a 5% chance of survival is either going to 100% live or 100% die. 5% of them is not going to survive. This may be reassuring for some, since a 5% chance of survival is still a chance, or it may be devastating news. Every person handles their situation differently. But no matter a person's attitude, it is nearly impossible for doctors to describe with certainty how a patient's cancer will affect them specifically due to all the uncertainty. As they shift into a life lived in prognosis, they enter a "culture [that], for the person trying to live within it, seemingly revels in confusion" as people attempt to conceive of what their future—or lack thereof—may look like (Jain 78).

This raises the concept of "prognosis time." Prognosis time is the inevitable result of a new diagnosis and a subsequent prognosis. Once a person is labelled as having a certain disease or condition, their life is inevitably disrupted. All of a sudden, a previously healthy person has been thrown into a new sense of self, one that is colored by their diagnosis and prognosis. Their future can be thrown into doubt, and even their perspective on their past can change. Jasbir Puar, a professor of women's and gender studies, writes that "Prognosis time, then, 'severs the idea of a timeline,' puts pressure on the assumption of an expected life span – a barometer of one's modernity – and the privilege one has or does not have to presume what one's life span will be, hence troubling any common view of life phases, generational time, and longevity" (Puar 166).

In other words, after a prognosis, a person is forced to live in the present moment. Death is potentially much nearer in their future than they had anticipated. As a result, people may be forced to challenge their own perspective on what matters in life. If they are indeed going to die as a result of whatever disease they now have, they have to confront that knowledge and figure out how best to spend this final indefinite period of time. Death may not announce itself with much forewarning, so this stage of life is defined by uncertainty. It's a similar experience to crimp time, in that way. A person with a terminal prognosis is forced to account for that prognosis in their short-term and long-term planning. They no longer adhere to the rest of society's able-bodied timeline: Grow up, go to school, start a family, retire, have grandchildren, and die. They may never experience some of those life stages, and therefore they have to reorient themselves along the timeline. It's similar to the ways that a disabled person may have different expectations of themselves compared to non-disabled people because of the limitations caused by ableism and their disability.

Prognosis time may be a more appropriate comparison for an entire society effected by COVID-19. Since February 2020, we have attempted to predict what would happen and what course COVID-19 would take in the United States and around the world. This proved difficult since it is a novel virus. But that did not stop prognostications early on, nor did the disease pause itself so we could learn about it before we encountered it for the first time. Indeed then, the experience of prognosis time is an apt comparison. Within a few short weeks of COVID-19 beginning to spread throughout the world, people throughout the United States began to sense that their lives were on the verge of changing dramatically, but they did not know how.

Simultaneously, throughout the past year scientists have been building up a body of knowledge about COVID-19 on the fly. They were not always correct, which provided brief illusions of certainty early in the pandemic which were quickly shattered. At various times, people were told by credible scientists that masks don't protect against COVID-19 (Howard), that children do not get the disease, and that it may recede due to warm weather over the summer months. This is obviously not even addressing the myriad of misinformation that spread through malice or ignorance. This allowed people to imagine that their lives may not have to change too much in the long term. They could stick to the timeline of pre-pandemic life, with COVID-19 only accounting for a short disruption. Certainly, I'm not blaming scientists for getting these things wrong; that happens in a situation like this. Since the early days of the pandemic, scientists have debunked each of those ideas and replaced them with better information. But while there seems to be a scientific consensus about the virus in March 2021, that cannot undo those months of confusion that set the tone for our early response to the pandemic.

As a culture, the United States gravely underestimated the damage that this pandemic would do. People refused to believe that time itself had changed and that everybody was not living in an able-bodied timeline anymore. Accepting that would entail an acknowledgment that the master narrative of disability is an incomplete narrative. The very act of shifting from able-bodied time into disabled time refutes the notion of disability as certainty and stasis. That is an act that the master narrative tells us should not be possible, since the master narrative holds disability as "embodied otherness" that is exclusive to certain kinds of bodies. As a result, the United States' initial response was to resist it and cling to an abled notion of time. But society itself had

been thrust into prognosis time and crip time, with all of the associated uncertainty, whether we liked it or not.

As the pandemic worsened around the start of 2021, the United States had moved into something resembling prognosis time but spread over a whole country. With over half a million people dead due to COVID-19, death has been much more prominent in our cultural consciousness than it was last year. Its shadow lurks in any social interaction, a school or work day, or even an isolated cough and it has affected nearly every aspect of our life. This fits neatly into Jain's description of living in prognosis: "This relation to time makes death central to life in prognosis, death as an active loss—as if there was some right to a certain lifespan—rather than just something that happens to everybody at the end of life" (Jain 81).

The United States' inadequate response to COVID-19 has functioned as a denial of both crip time and prognosis time. The federal government refused to do a complete lockdown in 2020 and instead focused on keeping as many businesses open as possible. Even as the pandemic rages, this prioritization has tried to keep us as close to non-pandemic time and non-crip time as possible. Uncertainty about how to best combat the virus is only created when as a culture we attempt to combat the virus. If that is not the central focus of our national response, uncertainty is diminished. We *know* deaths will happen as a result of an inadequate response to the pandemic. But in the eyes of the previous administration that is better than living in a world filled with uncertainty and ever-changing regulations aimed at saving as many lives as possible, especially since a huge proportion of people dying are disabled or chronically ill. As a result, death hangs over all of us even more than it would otherwise. Focusing on the economy has not even

been a particularly effective strategy—the economy collapsed anyway, nearly everybody’s mental and physical health have been affected at least some way over the last year, and even as I write this in March 2021, we still face tremendous uncertainty about when and how the pandemic will end.

It’s worth noting at this point that this is not an inevitable reality. Other countries around the world handled the threat of COVID-19 far better than the United States. They locked down, paid people to stay home, and paid businesses to stay closed. As a result, deaths in many of these places are far lower than they are in the United States. In New Zealand, for example, non-pandemic life has actually been able to resume quicker due to the widespread embrace of an extraordinary, but temporary, disruption to the status quo. This is not a policy paper, so I will not focus on the details of each nation’s response and their respective successes and failures. Nor do I claim to be familiar with each country’s relationship with disability, so I cannot make any claims about each country’s relative friendliness to disabled people. But it’s important to be cognizant of the contrasts in the responses. It underlines the United States’ unique failure and the intentional decisions that led to this point.

Our government chose to avoid embracing a temporary life in crip time and prognosis time. Those are the domain of the disabled and chronically ill. They are people who are already used to dealing with society-wide access barriers and a strange relationship to time. Even before lockdowns started in earnest in the United States in mid-March 2020, many of the people sharing concerns about COVID-19 were disabled people or people with chronic illnesses (Parodi & Sluzalis). They saw the pandemic coming just over the temporal horizon and were well aware of how it could disrupt life.

This is because they were already used to many of those disruptions. A pandemic would exacerbate the barriers to access that get thrown up in an ableist society, but it would not introduce them to disabled people for the first time. So instead of living in denial, many disabled people were prepared for an initial lockdown and potentially more than that.

This, in and of itself, is an act of *crip time*. Preparation for the unknown is crucial for disabled people. Society's ableism makes it harder for disabled people to react in the moment to a crisis without preparation. Therefore, looking into the future and anticipating a worst-case scenario is critical for the survival of a disabled person. In a non-pandemic time, this may mean accounting for a caregiver not showing up for their shift and making a backup plan. It may mean scheduling bathroom breaks hours in advance or finding alternate means of travel in case paratransit is delayed. In the early days of this pandemic, this meant stocking up on food and supplies before a lockdown was even declared. Disabled people saw that there was a severe disruption coming, and no matter what happened they would be affected. Even if COVID-19 would only hurt the elderly and the chronically ill, as people wrongly claimed, that would be a disaster for many disabled people.

Had the governments of the United States and various states taken heed of the disability community's concern, the national response to the pandemic would have almost certainly improved. Indeed, disability is both a different way of experiencing time and also a source of knowledge that the non-disabled person may not be able to access. The act of living and surviving in a world not created for a disabled body can "produce a politicized consciousness or epistemic epiphany regarding the relativity of exclusions that the status quo explains as natural or essentializes as inherent inferiority" (Garland-

Thomson 2017 1 56). Since COVID-19 was already shifting the status quo for everybody, early in the pandemic would have been an excellent time to lean into disability as a unique source of knowledge. This is what abled people missed out on when they ignored disabled voices and focused on maintaining linear, abled time as the primary goal.

Disabled people are unique sources of knowledge. Their collective areas of expertise are alternate ways of living, often uncomfortably. Rosemarie Garland-Thompson describes this beautifully, writing that

“The call and response between flesh and world makes disability. The discrepancy between body and world, between that which is expected and that which is, produces disability as a way of being in an environment. So disability is certainly an index of capability in context but it is also a witness to our inherent receptivity to being shaped by the singular journey through the world that we call our life. Although our modern collective cultural consciousness denies vulnerability, contingency, and mortality, disability insists that our bodies are dynamic.” (Garland-Thomson 2017 2 328)

But the master narrative conceives disability as a static way of being, instead of one constantly in flux. Non-disabled people then can ignore the knowledge and outright positive sides to having a disability, even when those positives could help all people. The pull of living in a linear timeline is too great. Instead of moving towards disability and choosing to embrace a disabled way of living, even temporarily, our government and society has leaned even more into a linear, able-bodied timeline. This further reinforces the master narrative of disability as static and unnarratable, and isolates the disabled experience into only certain kinds of bodies. It would be inaccurate and simplistic to say that the master narrative alone has caused the 550,000 deaths from COVID-19 in the United States. But it has undoubtedly been a factor. It has disproportionately harmed the

disability community and has had dire ramifications for non-disabled people who are struggling to adjust to a disability-esque lifestyle for perhaps the first time.

## WORKS CITED

- Biklen, D. (2000). Constructing inclusion: Lessons from critical, disability narratives. *International Journal of Inclusive Education*, 4(4), 337-353.  
doi:10.1080/13603110050168032
- Campbell, F. K. (2001). Inciting Legal Fictions: 'Disability's' date with Ontology and the Ableist Body of Law. *Griffith Law Review*, 10(1), 42-62.
- Cochran, A. L. (2020). Impacts of COVID-19 on Access to Transportation for People with Disabilities. *Transportation Research Interdisciplinary Perspectives*, 8.
- Couser, G. T. (1998). Disability and Autobiography: Enabling Discourse. *Disability Studies Quarterly*, 17(4), 292-296.
- Cuomo, A. (2021, January 14). Governor Cuomo Updates New Yorkers on State's Progress During COVID-19 Pandemic. Retrieved January 21, 2021, from <https://www.governor.ny.gov/news/governor-cuomo-updates-new-yorkers-states-progress-during-covid-19-pandemic-103>
- Engel, D., & Munger, F. (2007). Narrative, Disability, and Identity. *Narrative*, 15(1), 85-94. Retrieved January 21, 2021, from <http://www.jstor.org/stable/20107406>
- Fink, S. (2020, March 28). U.S. Civil Rights Office Rejects Rationing Medical Care Based on Disability, Age. Retrieved January 21, 2021, from <https://www.nytimes.com/2020/03/28/us/coronavirus-disabilities-rationing-ventilators-triage.html>
- Friedman, C. (2019). Ableism, Racism, and Subminimum Wage in the United States. *Disability Studies Quarterly*, 39(4). <http://dx.doi.org/10.18061/dsq.v39i4.6604>
- Fritsch, K. (2013). The neoliberal circulation of affects: Happiness, accessibility and the capacitation of disability as wheelchair. *Health, Culture and Society*, 5(1), 135-149.  
doi:10.5195/hcs.2013.136
- Garland-Thomson, R. (2017). Building a World with Disability in It. In Waldschmidt A., Berressem H., & Ingwersen M. (Eds.), *Culture – Theory – Disability: Encounters between Disability Studies and Cultural Studies* (pp. 51-62). Bielefeld: Transcript Verlag. Retrieved January 21, 2021, from <http://www.jstor.org/stable/j.ctv1xxs3r.8>
- Garland-Thomson R. (2017). Disability Bioethics: From Theory to Practice. *Kennedy Institute of Ethics Journal*, 27(2), 323–339. <https://doi.org/10.1353/ken.2017.0020>

- Garland-Thomson, R. (1997). *Extraordinary bodies: Figuring physical disability in American culture and literature*. New York: Columbia University Press.
- Gerhart, K. A., Koziol-McLain, J., Lowenstein, S. R., & Whiteneck, G. G. (1994). Quality of Life Following Spinal Cord Injury: Knowledge and Attitudes of Emergency Care Providers. *Annals of Emergency Medicine*, 23(4), 807–812. [https://doi.org/10.1016/s0196-0644\(94\)70318-3](https://doi.org/10.1016/s0196-0644(94)70318-3)
- Harnish, A. (2017). Ableism and the Trump phenomenon. *Disability & Society*, 32(3), 423-428. doi:<https://doi.org/10.1080/09687599.2017.1288684>
- Howard, J. (2020, March 31). WHO stands by recommendation to not wear masks if you are not sick or not caring for someone who is sick. Retrieved January 21, 2021, from <https://www.cnn.com/2020/03/30/world/coronavirus-who-masks-recommendation-trnd/index.html>
- Jain, S. L. (2007). Living in Prognosis: Toward an Elegiac Politics. *Representations*, 98(1). doi:<https://doi.org/10.1525/rep.2007.98.1.77>
- Kafer, A. (2013). Time for Disability Studies and a Future for Crips. In *Feminist, Queer, Crip* (pp. 25-46). Bloomington, IN: Indiana University Press.
- Kendall, E., Ehrlich, C., Chapman, K., Shiota, C., Allen, G., Gall, A., . . . Palipana, D. (2020). Immediate and Long-Term Implications of the COVID-19 Pandemic for People With Disabilities. *American Journal of Public Health*, 110(12), 1774-1779. doi:10.2105/ajph.2020.305890
- Kukla, E. (2020, March 19). My Life Is More ‘Disposable’ During This Pandemic [Editorial]. *New York Times*. Retrieved January 21, 2021, from <https://www.nytimes.com/2020/03/19/opinion/coronavirus-disabled-health-care.html?searchResultPosition=1>
- Luterman, S. (2021, March 02). Minimum-wage misfire also harms disabled people. Retrieved March 26, 2021, from <https://prospect.org/health/minimum-wage-misfire-also-harms-disabled-people/>
- Manchada, E. C., Sivashanker, K., & Couillard, C. (2020). Inequity in Crisis Standards of Care. *New England Journal of Medicine*. Retrieved May 13, 2020, from <https://www.nejm.org/doi/full/10.1056/NEJMp2011359>
- Puar, J. (2009). Prognosis time: Towards a geopolitics of Affect, Debility and Capacity. *Women & Performance: A Journal of Feminist Theory*, 19(2), 161-172.

- Parodi, G., & Sluzalis, S. (2020, March 3). COVID-19 National Disability Rights Call To Action. Retrieved January 21, 2021, from <https://mailchi.mp/disasterstrategies/covid19-national-call-to-action-org-support150>
- Rafford, C. (2019, March 06). Author discusses stigmatization, narratives of 'ordinary abortion'. Retrieved February 16, 2021, from <https://ndsmcobserver.com/2019/03/author-discusses-stigmatization-narratives-of-ordinary-abortion/>
- Sabatello, M., Burke, T. B., McDonald, K. E., & Appelbaum, P. S. (2020). Disability, Ethics, and Health Care in the COVID-19 Pandemic. *American Journal of Public Health, 110*(10). doi:<https://doi.org/10.2105/AJPH.2020.305837>
- Samuels, E. (2017). Six Ways of Looking at Crip Time. *Disability Studies Quarterly, 37*(3). Retrieved January 21, 2021, from <https://dsq-sds.org/article/view/5824/4684>
- Shapiro, J. (2020, July 31). One Man's COVID-19 Death Raises The Worst Fears Of Many People With Disabilities. Retrieved January, from <https://www.npr.org/2020/07/31/896882268/one-mans-covid-19-death-raises-the-worst-fears-of-many-people-with-disabilities>
- Shapiro, J. (2020, December 21). Oregon hospitals didn't have shortages. so Why were disabled people denied care? Retrieved January 20, 2021, from <https://www.npr.org/2020/12/21/946292119/oregon-hospitals-didnt-have-shortages-so-why-were-disabled-people-denied-care>
- Stramondo, J. A., “ Disability and the Damaging Master Narrative of an Open Future,” in *For “All of Us”? On the Weight of Genomic Knowledge*, ed. J. M. Reynolds and E. Parens, special report, *Hastings Center Report* 50, no. 3 (2020): S30– S36. DOI: 10.1002/hast.1153