

## PERSPECTIVE

# Disability, Deadly Discourse, and Collectivity amid Coronavirus (COVID-19)

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As COVID-19 crosses the globe, disabled people are subject to new medical and discursive realities. Focusing on the consequences of the latter, we utilize news reports from Canada and the UK to argue the current language of pre-existing conditions represents disability as non-life, explaining away the material realities facing disabled persons. This language ignores the distribution of care work in our societies, poverty, and other forms of exclusion facing disabled people and the population more generally. Work on ventilator users points to these existing inequalities, obscured as they may be. This story is not new. Outlining existing narratives within disability studies challenging disability as deadly biological and economic deficiency and situating the 'pre-existing' terminology therein, we look to work in disability studies and bioethics to challenge the disability–death equation. We end reviewing counter-narratives by and for disabled people, highlighting the ongoing and life-affirming resistance throughout the disability rights movement.

**Keywords:** COVID-19; Care Work; Ventilators; Death and Dying; Disability

## Introduction

The COVID-19 Pandemic is deadly. It is not uniformly so, neither epidemiologically nor discursively. The people at risk for deadly infection and the words, thoughts, and actions we use to address those people is a disability studies issue. Disabled people are put in further risk through acts that would discredit their worth and livelihood through a language of pre-existing threat. This seemingly benign descriptor, we argue, has direct and deadly consequences for so many marginalized groups. This extends past disabled people to their allies, the health and social care workers across the globe, the essential workers delivering our soap and scanning our groceries, and those teaching critical disability studies the world over. In this paper we argue the descriptor 'pre-existing condition' represents a harmful reality that must be combatted. We first outline the violence of that term and highlight its extremely partial version of disabled life. Next we consider some bioethical consequences of its life-obscurating worldview, mapping the ongoing resistance to the term. This means thinking about disability as way of living through the pandemic—like any other. We write as events unfold and primarily from what we see emerging in our respective countries of Canada and the UK. We end this brief meditation on an optimistic note: COVID-19 is deadly, but it is a space for disability studies to support human flourishing—with ableist uses of 'underlying conditions' left behind.

## Pre-existing Conditions

In the UK, the terms 'pre-existing' and 'underlying health conditions' quickly became a shorthand for a significant othering of people affected by the virus (Ktenidis 2020). Each announcement of deaths in the first week was caveated with the 'reassurance' that most if not all of the people who had died had such conditions. In an early television interview with the UK prime minister, it was mooted that one possible approach to the virus was to let it run a natural cause of events in the population—lives likely to be lost would be lost. When the first death of a child, aged five, was reported there was a clamour to establish whether they had an underlying health condition. Parts of the nation breathed easier when this was confirmed, much like when a natural disaster is announced: 'But wait, it's not here, it's somewhere else, somewhere foreign.'

In response to what became a familiarly phrased news strapline, '91% of people dying with coronavirus have an underlying health condition, ONS figures show' (BBC News 2020a), Gem Turner (2020), a disabled blogger and consultant writes,

It's disappointing to see this kind of headline. I know some people will read this & secretly sigh with relief – what about us that DO have health conditions? Why is this being shared so matter of fact? Are we not shocked? Sad? Angry that we don't have enough resources? Baffling.

Discussion about access to ventilators in the UK quickly became foregrounded. In the likely (though not as yet actual) lack of ventilators for everyone who might need them, how would they be rationed? In some parts of the country, families and some organisations received letters telling them that whilst they 'would not be abandoned' they should put in place plans for themselves to expect not to be resuscitated in the event of severe covid-related illness (BBC News 2020b). (Explicit echoes of the sometimes abandonment of disabled people in times of natural disasters, see Abbott and Porter 2013.) Various guidance documents that included 'frailty scales' with associated points assigned suggested disabled people might have a lot to fear from catching the virus and from the possible denial of the full range of medical treatments (Lintern 2020). As Ryan (2020) highlights,

Being considered not worthy of life is a jobbing hazard when you don't fit narrowly defined normative expectations of what it is to be human and it wasn't long before people were receiving template DNR [Do not resuscitate] forms.

Early versions of the guidance were challenged by lawyers and activists on social media. At the time of writing, a judicial review of government decision making on guidance to allocate and/or restrict access to healthcare is in train (Channel 4 News 2020). (The fruitful coalition of Twitter, law, supportive lawyers, and disability activism is something worth reflecting upon and returning to after the crisis.)

Interestingly, in some of our previous research with men who use ventilators all the time, such devices were seen as both life-giving and sources of stigma and prejudice (Abbott and Carpenter 2014). The men with Duchenne muscular dystrophy in our study had to assert their likely shorter lives were nonetheless lives worth living. As debate about limited resources, such as ventilators, sharpened in the UK, disabled people, including activist and DMD campaigner Dr Jon Hastie (2020), took to YouTube and then national television news to voice fear that he—and others—would not be given continued access to ventilation or treated in hospital on equitable terms. Lives intertwined with medical technology previously thought not worth living were suddenly lives the rest of the population wanted to be reassured that they could access. As disability activist Alice Wong (2020) writes,

Were I to contract coronavirus, I imagine a doctor might read my chart, look at me, and think I'm a waste of their efforts and precious resources that never should have been in shortage to begin with. He might even take my ventilator for other patients who have a better shot at survival than me.

The underlying casual brutality (see also Liddiard 2020) of the discourse of 'under-lying and pre-existing health conditions' was, in England, soon heard alongside 'deaths in hospitals excluding those in care homes and in the community.' The number of daily deaths took no account of the unfolding picture in social care settings and in care homes for older people. These lives, too, seemed expendable and not to be counted (Henwood 2020; Rightful Lives 2020). In fact, it was eventually revealed coronavirus-related deaths were 41% higher in England and Wales than the government's hospital-only figures up to 10 April once deaths in care homes were taken into account (Office for National Statistics 2020).

In a prescient piece of writing by Jenny Morris (2016), she unpacks how and why the UK government was systematically undermining access to the category and reality of citizen and citizenship for disabled people and repeated a question posed to the government: 'What's your plan for these people whose lives we apparently can't afford?' Morris writes,

...we have to recognise what are the fundamental causes of the problems we face. A denial of the common good; an attack on the idea that we can pool resources to promote the common good; a removal of democratic accountability from government and local government and their replacement by the accountability of the market.

Though use of the phrase 'pre-existing conditions' sounds actuarial, we suggest the term has manifold meanings. Not all of these are negative. The first (1) simply suggests an additional medical issue faced by a person. One of us (Abrams, Abbott and Mistry 2020) has Becker muscular dystrophy. In light of this, he has a pre-existing condition. This is likely the most common use of the term. But we would suggest two more uses: (2) a *normal* division, established between 'normal' persons and those with additional pathologies, and (3) a *moral* division, which relates one's condition to desirable conduct or courses of action. We do not, at the outset, prefer one of these definitions. We simply want to ask what, exactly, pre-exists and in what context, be it medical, social, or moral. This use of moral is descriptive, describing societies by what they take disability to be—too often only as a problem to be solved, either medically or in terms of resource allocation. Along with most, if not all, disability scholars, we call this the *bio-economic* loss model of disability.

One reading of disability studies is to say this: we should move from disabled bodies to the collective life in which they dwell. That is, moving from the 'pre-existing conditions' language to one of human flourishing, regardless of ability (from definition one to three). In doing so, we are not disregarding that disabled people may have comorbid conditions—many do, and this is cause for collective action on their behalf—but disability is much more than the morbid. It is an expression of collective life. This means moving strictly from lacking bodies to highlighting a cruel division of labour, where the most socially vulnerable are the most likely to die of COVID-19. It means moving from platitudes of essential work to real change in caring practices. Ultimately, it means attending to the very real problems we face by COVID-19 with a critical disability politics in hand.

### Bioethical Considerations

Disability research into bioethics, particularly that done by Shakespeare (2013), has taken as its object the so-called expressivist claim. That is we express who we want to be part of the world through claims made in moments of crisis, be they personal (as in prenatal testing) or collective (as in the current crisis). While finding the expressivist objection weak philosophically, Shakespeare (2011: 40) highlights its emotional nature and relationship to discourses of bio-economic loss:

Disabled people are not necessarily criticising particular decisions, but often are expressing deep concern about the general 'direction of travel' of reproduction and pregnancy, with screening out disability increasingly considered as an issue of quality control.

Like our disability approach, the expressivist claim moves from a simple description of disability as a medical state to the normal and the moral. These are not abstract arguments about potential life and situations. Their time is now.

The disability rights movement and its allies have not been silent on the extremely dangerous rhetoric and practices in the initial days of the COVID-19 pandemic. Writing from Ontario, Ignagni et al. (2020) chart the consequences of health care rationing allocated on a strict utilitarianism of productivity. In all too common rhetoric, disability moves from a state of life to a state of death, placed in the way of those who might live more meaningful, more productive, and more worthwhile lives. This is not new with the current pandemic—there is a long history of these arguments—but this is the event currently before us. Eugenics is not simply a part of pseudoscientific past. It is staring us in the face now, when human worth is allocated and denied according to ableist notions of contribution.

Philosopher Eva Kittay (2019) counters these utilitarian bioethics in her beautiful book, *Learning from My Daughter*. To take moral worth as mere rational productivity, and to view disability only as anti-productivity—as many philosophers do—is oppressive. This excludes those who do not follow a pre-determined logic of what is rational and who do not express their lives in typical (i.e., vocal) ways. Such base logic of economic and political contribution in applied ethics—mirrored in a base logic of pre-existing situations in the current pandemic—reinforces exclusion. To obscure the flourishing lives of disabled persons, to devalue the care that goes into sustaining *all life*, is a risk we cannot take. Shifting from human flourishing to those most vulnerable in the pandemic, Kittay (2020) writes:

When you speak of the vulnerable, those most likely to suffer worst from this virus, think of grandmas and grandpas, of an uncle with a weak heart, the migrants in crowded detention centers, the prisoners — but think also of those who live graceful lives of love. People like my daughter.

The ableist discourse of pre-existing conditions, we argue, is making people more vulnerable. It forgets who, exactly, is being cared for in our world and the conditions of their care. Disability is more than just a state of bodies; it represents a division of caring labour, one we cannot forget.

As two scholars working on muscular dystrophy care, we argue that ventilator access is a deeply political issue. Common knowledge of what, exactly, a ventilator is and does, and why mechanical ventilation is needed, has increased exponentially in the past month. Prominent news media in Canada, the United States, and the UK producing widely read explanatory pieces can be taken as evidence of this (see BBC News 2020c; Baker 2020; Gellees and Petras 2020). In this paper, and in our personal and professional lives, we find a heartbreaking trend, whereby those who have long required ventilators to live are seen as a misallocation of resources, taking up machines best put to use elsewhere. Again, disability is reduced to breaths not taken by more productive lungs. Along with our allies in this section, we argue this is more than a dangerous potential but a very real threat to disabled persons the world over. As disability studies evaluates and highlights these threats, we hope its practitioners and allies use their capabilities to show the care work obscured in the pre-existing, morbid discourse. To see disability only as a step closer to death is to ignore the living, caring relationships that all humans need to thrive. A disability studies perspective can and must tell us about the labour we do for each other to flourish, and the deadly costs of its neglect.

### Disability Is Not Death

To counter this brutal utilitarianism, bio-economic reductionism, and the expressions of human worth it entails, we draw on a wealth of literature in disability studies on death. Here we return to the politics of definition and naming.

The moral relationship between disability and death is not, we argue, merely a statistical truism. It is also a moral issue, one made plainly evident by the politics of ventilator access.

Reynolds (2017: 153) argues disability is often subject to the ableist conflation, expressed as follows:

1. Disability is conceptualized as a lack or deprivation of a natural good.
2. Deprivation of potential natural goods is considered a harm.
3. Harm is understood to cause or be a form of pain and suffering.
4. Given 1–3, disability is coextensive with (weak version) or causes (strong version) pain and suffering (linked with or even leading to death).

Thus, to perform the ableist conflation is to eclipse the normalizing and moralizing aspects of our threefold definition and to link disability with death. In the politics of ventilator access, disability becomes more than simply a description of bodies.

Titchkosky (2007) argues the disability-death relation is also a normalizing, moral one. Reading through newspaper articles on disability and death, Titchkosky suggests 'disability is worse than death' is an outcome of a society that can only see disability in negative terms. Looking to a piece in Canada's *National Post*, Titchkosky found disabled livelihood is often obscured in light of the lives that could have been were it not for disability already being close to death. In that case, it was the life and death of a girl, Courtney Popken, used only as a device to promote rare disease research, obscuring her life as a person.

We introduce these discussions of disability and death to make a plea—media reports too often link COVID-19 deaths with disability and pre-existing conditions as a caveat. The phrase 'pre-existing condition' is more than simply a reference to an individual's medical history, but rather it obscures the conditions which led up to that death. In Ontario, Canada, for example, as of the time of writing, reports emerge daily of COVID-19 outbreaks in assisted living residences (Toronto Star 2020). Alongside the higher mortality rate for elderly persons from infection, the language of pre-existing conditions cannot, and must not, obscure the fact the living conditions in these residences is a contributing factor. They are not alone here. Other marginalized groups—Indigenous communities, in the case of Canada—are also subject to material realities escaping the discourse of conditions, pre-existing or otherwise. Intersections of ethnicity and gender figure in epidemiological discussion given higher rates of infection in men and people from Black and other ethnic backgrounds. Less attention has been paid to relevant intersections with disability as discussed in the UK by Sisters of Frida (2020), an experimental collective of disabled women.

Disability studies scholars have long pointed to 'crip time,' the multiple timeframes invited through living with disability, to challenge exclusionary demands on excluded bodies (Abrams, Abbott and Mistry 2020). This means more than giving extra time on exams, merely retrofitting normal time; it means challenging visions of the future that do not include disability (Dolmage 2017; Kafer 2015). Ignangi et al. (2020) remind us crip time is found in the global COVID-19 response, but it is not reducible to crisis time. It is how we live in and through disability day-in-and-out, in the past and in the future. Again, to this important work we would add something from our past work: living with disability is living in both timeframes. Disabled youth with DMD, for example, experience *at once* the mundane temporality that characterizes every life *and* the crisis of ventilation found in COVID-19, *and* the cultural projection of a future with *and* without them. To place disability in time is to show how temporal projections are made to matter, for whom, and whose voices we affirm in doing so.

### Examples of Hope, Not of Bioeconomic Loss

We do not want to end this paper on a singularly fatalistic note, because amidst many worrying claims about the 'problem' of disability amidst COVID-19, there exist hopeful voices, unexpected alliances, and surprising benefits. Disabled people, including scholars and activists, have reminded the world of their accumulated wisdom, insight, and practice into, for example, working from home or remotely, managing isolation, maintaining physical space to safeguard health, negotiating rationing, and so on. Alice Wong (2020) writes,

For many disabled, sick, and immunocompromised people like myself, we have always lived with uncertainty and are skilled in adapting to hostile circumstances in a world that was never designed for us in the first place. Want to avoid touching door handles by hitting the automatic door opener with your elbow? You can thank the Americans with Disabilities Act and the disabled people who made it happen.

Mixed with the exasperation that ways of doing things often deemed impossible or impractical have now needed to be embraced, some disabled people point to how some aspects of their lives have ironically opened up. The journalist and disability activist Frances Ryan (2020) writes,

While the coronavirus pandemic has led to unprecedented restrictions for billions of people, for many with disabilities, the lockdown has paradoxically opened up the world. As society embraces 'virtual' living, disa-

bled people – who for years have missed out due to poor access – are suddenly finding themselves able to take part in work, culture, or socialising from their own home.... As well as joy at being offered new opportunities, many feel frustrated that it took the non-disabled world to become house-bound before access was granted.

Fleur Perry (Sisters of Frida 2020) also writes about access to music and the arts and to on-line support and work, the beneficial impact of support networks, and the reminder of inter-dependency and inter-connectedness, even at physical distance:

I can definitely say my overall health has improved since the start of lockdown. It seems strange to say that during a pandemic, but it's measurably true. I know a few others who I've seen grow so much in such a short time. We need that access to stay. We need those new support networks to stay. We need that sense of autonomy and understanding of our own and each other's needs to stay. If we can do that, the post-COVID-19 world will be better than the one we remember.

These wisdoms call all of us not to rush to return to 'normality' but to retain and build upon aspects of our current realities, as Magda Szarota (Sisters of Frida 2020) writes,

I am alarmed every time I hear that 'we should go back to normal asap' because this innocently sounding 'normality' from the perspective of disabled women is underpinned by systemic and daily violations of human rights. Do not resuscitate...this version of the world.

Existing and new alliances are resisting some of the most dangerously ableist aspects of the pandemic. In the UK, user-led organisations and coalitions of disabled people's organisations quickly rallied with a letter signed by several thousand people to assert disabled people's rights to, amongst other things, equitable health care (DRUK 2020). In the US, Sins Invalid are just one example of organizations actively contesting the brutal utilitarianism we read in the media daily. In the UK, researchers are showing existing inequities in work and social life are being amplified by the COVID-19 pandemic, *but* a disability studies perspective is exactly what is needed to challenge them—addressing both individual and structural exclusions (Wilde 2020). Others, like Shew (2020), show us that a disability studies perspective allows us to extend access for all students in our (disability studies) classrooms. Care work sustains decent lives, within the university and without. These voices, too, move us from a descriptive understanding of pre-existing conditions to the fundamental reality disability studies scholars have been making since the beginnings of the discipline. That is to treat ability and disability as solely individual attributes fails to see the deep interconnection *any person* needs to flourish. To take a disability studies perspective on COVID-19 is also to ask about who we treat as essential workers in our society, who we deem worthy of valuable resources, who has value, and, ultimately, what sorts of people we deem as worthy of living in the world. These are not merely abstract pleas. Our hope is that the language of pre-existing conditions be used to highlight, rather than obscure, these crucial moral and ethical questions. We may not fully agree on these questions, but we must ask them, nonetheless.

### Competing Interests

The authors have no competing interests to declare.

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