Pandemics Are Chronic

A statement of commitment to Long COVID justice

Endorse this statement here.

We must end practices and policies that ignore, marginalize and deprioritize chronically-ill and disabled people, in and beyond pandemics.

COVID-19, like many pandemic viruses including polio and HIV, leads to disability and chronic disease. COVID-19 survivors worldwide are living with debilitating, life-changing effects of Long COVID. As complex as it can be, Long COVID is just the most recent manifestation of a long under-acknowledged phenomenon of post-infection illness that often drives, worsens, or unmasks a set of understudied complex chronic conditions.

Now, many millions of people are newly, or more severely ill, marginalized and under-served. As we saw with the emergence of HIV/AIDS, pandemics expose the critical need for large-scale change in healthcare, public health, and unjust structures that bring inequitable risks of illness, suffering, and mortality.

Yet even as the pandemic continues to claim lives, we are pressured to return to a "business as normal" that has never centered the needs of disabled people, and ignores the complex chronic conditions.

Up to this point, efforts to address this growing crisis have been siloed and have not centered the voices and experiences of those directly impacted. **This is urgent work with both much peril and opportunity to profoundly shift the way we approach and talk about chronic illness and disability in our lifetimes.** As policy is made, research money is distributed, and a mass-disabling event continues to barrel through our communities with inequitable consequences, we need a coherent analysis and response accountable to those most impacted by this unprecedented historical moment.

Tragically, it is now clear (if often overlooked) that one of the primary failures of the COVID-19 control effort is a **sweeping lack of care for, and considerations of the needs of, sick and disabled people.** Given the long history of neglecting the truth of disability and chronic illness resulting from viruses and infections, it is not surprising – but the impact is massive. For example:

- Disabled and chronically-ill people are frequently back-burnered or neglected in public health measures and policy decisions despite their higher risk of acute COVID-19 harms.[1]
- Millions of people with Long COVID and associated conditions (LCAC) are struggling to manage debilitating symptoms without substantive and accessible clinical care, treatment solutions, or economic support.
- Acutely and chronically-ill people often are unable to access care from an overwhelmed healthcare system and are further sidelined in society due to a lack of infection mitigation efforts.

As the COVID-19 pandemic continues, our world is significantly more disabled and chronically-ill. Even if acute COVID-19 transmission is eliminated, **the COVID-19 pandemic may not end for many of us for the rest of our lives** who are living with organ disease, autoimmune illnesses, and complex chronic conditions spurred or worsened by COVID-19 infection. **We will not succeed in pandemic preparation or prevention if we continue to ignore, marginalize, or deprioritize chronically ill and disabled people before, during, and after the acute phases.**

> We know we need systemic change so that our peoples can literally survive this pandemic alive, but we also know that the kind of changes we need are most likely not coming. It is in the interest of those in power to keep people uncared for, sick and dependent on dwindling crumbs. This is one reason why ableism and poverty are so effective and why they are often inseparable.
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> – Mia Mingus, You Are Not Entitled To Our Deaths, COVID-Abled Supremacy & Interdependence, 3/16/22

Disabled and chronically-ill people were treated as expendable in past pandemics and as this one approached. They were disregarded in the design and application of public policies that prioritize market considerations over those most at risk of severe or fatal COVID-19, including the often ignored consequences of an overburdened healthcare system. They were othered in the language of prevention, treatment, and recovery. **This is not an aberration. This is by design.** It is an extension of the ways that disabled and chronically-ill people are considered, and not considered, in policy, medicine, education, the media, and other public systems.

> The disproportionate deaths our community has faced are the result of *systemic* failures that we have seen over and over again since the start of this pandemic... The dismissal and devaluation of people with disabilities has been our daily experience throughout this pandemic. These failures predate the pandemic, and the inequities experienced by people with disabilities in health care settings on a routine basis have been extensively documented. For disabled people of color, these harms have been compounded by historical and current systemic racism in the health care system, leading to even more dire outcomes. These failures and inequities are also serving as fuel to the COVID-19 pandemic, which continues to devastate our communities and our country.
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> – Letter From Disability Community to CDC Director Walensky, 3/15/22

Disproportionate rates and impacts of disability and chronic illness are driven by the ongoing structural marginalization of Black, Brown and Indigenous people, immigrants, queer and trans people, older people, poor and low-income people, those who are imprisoned and those without access to stable housing.

As people and organizations committed to health equity and justice, we must unite to demand resources to meet the urgent needs of millions of people newly or more severely disabled and ill from Long COVID, while strengthening movements for structural and systemic change.

We commit to a set of principles and practices, outlined below:

We include Long COVID in the narrative of the COVID-19 pandemic. We cannot tell the story of COVID without discussing Long COVID and associated conditions.

- Pandemic harms don't end when acute infections do. **At least 12-30%** of COVID-19 survivors across the world develop long-term effects of the disease,[2] and may live with consequences for years, if not their whole life.
- Like many viruses, SARS-CoV-2 has a chronic component. Long COVID must be centered as an integral component of the COVID-19 pandemic, not as a minor exception to the false binary narrative of acute infections leading to death or full recovery.

We center, platform, and resource those with Long COVID, complex chronic illnesses, and other disabilities at the forefront of policy, advocacy, and action related to these issues. We are experiencing a mass disabling event, and disabled people and those with Long COVID must be at the forefront of addressing this unprecedented moment.

- Those who are most directly impacted by a problem are best positioned to come up with sustainable solutions. To honor our commitment to health equity, we will ensure that expansion of care, services, and support for disabled and chronically-ill people, propelled by this crisis, will reach all in need. We will not succeed in pandemic preparation or prevention if we ignore chronically-ill and disabled people.

We work to end the marginalization of disabled and chronically-ill people, which is a constant and widespread harm, existing outside of and across all aspects of pandemics.

- The remote work, education, and care that was imperative during 2020 must be made available to and improved upon for all who need it in an ongoing way. We fight for all schools, employers, and workplaces and public institutions to provide accommodations for all disabled and chronically ill people at all times, regardless of the status of the pandemic. We will defend those who are facing explicit and implicit discrimination, bias, and harms from inaccessible workplaces and work practices, both within our own institutions and places of work, and across all areas of employment and education.

We recognize that the COVID-19 pandemic and Long COVID have disproportionately impacted already marginalized communities. We call for research justice, community-accountable data, and truly equitable policy based on considerations of race and ethnicity, class, age, immigration status, gender and gender identity, sexuality, religion/spirituality, culture, family structure, incarceration, housing status, disability, and co-morbidities.

- We support the call of disabled people for U.S. federal officials to take action to center the needs of those at highest risk of COVID-19 harms. Already marginalized communities are experiencing increased vulnerability and economic, health, and housing precarity as a result of the pandemic. Current data practices are not adequate to track and address these disparities, yet we must keep in mind the dangers of data collection and the tendency of our systems to take carceral approaches to public health, which are both immoral and ineffective.[3] Therefore, we call for a patient-led, research justice-focused[4] approach to collecting and sharing Long COVID data that does not increase the policing and targeting of these communities.[5]
- We will uphold these principles and practices to honor the powerful lineage and legacies of health justice movements and all those we have lost to pandemics and ableism. We will work to ensure that these harms will cease.

Endorse this statement here.

List of Initiating Endorsers
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1. https://autisticadvocacy.org/2022/01/letter-from-the-disability-community-to-cdc-director-rochelle-walensky
2. https://apnews.com/journals/fampreworksapn/fullarticle/2176560
For a variety of reasons, COVID-19 case counts are likely an undercount, partially because Long COVID has never been successfully tracked on a population level.
3. https://communitysurveillance.org/resources/unmasked-impacts-of-pandemic-policing/
4. https://www.datacenterre.org/services-offered/research-justice/
5. https://www.science.org/content/article/covid-19-data-native-americans-national-divorce-scientist-fighting-be-counted