

# People's CDC

May 29, 2023

## People's CDC Statement with regards to May 8, 2023 ADA Webinar

People's CDC May 8 ADA training was created by a team of disabled People's CDC members. People's CDC as a whole is made up of a majority of multigenerational individuals who identify as disabled, or who are high-risk for severe COVID according to the CDC, but do not identify as disabled. Some of us have identified as disabled all our lives, some are newly disabled by COVID, and others have more recently come to understand our lifelong experiences as ones of disability. In this, we have all benefited from the wisdom offered from the disability community in online and offline spaces, empowering us to understand that our life experiences of disability are valid. These spaces connect us to a rich, longstanding and diverse lineage of disability movements. Those of us whose experiences of disability intersect with race and colonialism, are grateful to disability justice workers, elders and ancestors, for providing and cultivating an expansive framework for understanding our experiences, including why the label of "disabled" was often less available to us, as people of the global majority, living in the US. Our work builds on this intersectional and imaginative tradition, even if we do not often articulate it that way - and we continue to learn from and amplify our elders' perspectives as we create and work.

In the face of a relentless pandemic where evidence suggests repeated COVID infections boost the risk of severe outcomes like hospitalization, death, and chronic illness, and with over 90% of people believed to have contracted COVID at least once, we aim to unite. Our goal is to bring together those identifying as disabled, those who do not, and individuals who are newly recognizing, or yet to recognize, their own disabilities. Together, we strive for an empowered movement focused on health, safety, collective wellbeing, and accessibility.

This is especially urgent as the Biden administration, CDC, and the media weaponize structural ableism to divide and conquer: by misinforming that only \*vulnerable people\* are at risk, further isolating people who are aware of our vulnerabilities; by spreading headlines like "normal people don't mask," "the last holdouts," and employing "anxious" in a derogatory way that uses mental health stigma to invalidate acts of care. We understand this unprecedented moment requires a distinct and new coalitional response. It requires varied forms of creative collective action.

One such form of collective action could involve disabled and high-risk people invoking the ADA collectively to request to be seen in "universally-masked" healthcare settings, a simultaneously powerful way to push back against the ADA's individualizing structure, and hopefully to influence healthcare systems' masking policies. We also know that to be protected and have full access to society – as disabled people and others – we need and must fight for new and more expansive legislation that aims for universal access rather than a scarcity-based model of accommodations.

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When we wrote “the ADA protects everyone’s right to safe healthcare,” our aspiration was that everyone who is at high risk for severe COVID, or cares for someone who is, could request universal masking as an “accommodation.” If we could get masses of disabled/high risk people and our caregivers to do this, our hope was to restore universal masking for everyone – thereby protecting disabled people. This movement strategy (not a legal strategy) was devised by disabled people who wanted to use the tools and ideas of community care and universal access in an expansive way. Our aim is to protect all so none would be left to fight for this alone. We did our best to convey this nuance in our May 8 training, which you can watch or read the transcript of on our website.

We realize our May 8 ADA rights training and public communications around it are the subject of debate: the US disability legal tradition involves varying interpretations and opinions of the law (we expand on legal questions below). At the outset of our training, we acknowledged the immense movement that culminated in the creation of the Americans with Disabilities Act (ADA). We noted that the ADA, though comprehensive, doesn't extend its protection to "everyone." It does, however, protect everyone if, and when they become disabled. We acknowledged that many people remain unaware that the law applies to them. Furthermore, we articulated that the ADA's provisions have always provided insufficient protection and access for disabled people.

The ADA is built on a medical model of disability that inherently excludes those on the margins of society; institutional healthcare disparities and inequities entail unequal access to legal protections under the ADA for those whose care is impacted by medical bias (e.g., racism, classism, misogyny, ableism, transphobia, homophobia, etc.). We emphasized the need for more robust legislation to safeguard disabled people and those becoming disabled due to COVID. Further, because COVID is a highly-transmissible airborne virus, we emphasized that ADA protections must apply to people who live with, or care for, disabled people. We are all interconnected. In order to protect disabled people from COVID, you must protect our caregivers and loved ones as well.

## **Access Instead of Accommodations – Our Working Framework**

Our view at the People's CDC, reflected in our May 8 training, is that the ADA doesn't go far enough, isn't strong enough, and is out of date. The ADA coerces acceptance of artificial scarcity. This narrative portrays the fulfillment of some people's access needs as a burden to the institution, forcing disabled people to fight to prove our worthiness of accommodations. Individuals' 'worthiness' is often dependent on whether their access needs have already been identified and validated by a medical and educational system plagued by systemic racism, misogyny and class-based exclusion. Individuals with greater resources are more likely to have health insurance and doctors, medical documentation and diagnoses which can serve to validate disability status, while impoverished individuals and people of color, whose disabilities often result from systemic racism, class-based exclusions or colonial violence, are implicitly led

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to view our disabilities as simply a part of life. Even if we do seek documentation for our disabilities, the aforementioned barriers often stand in the way.

We reject the prevalent paradigm which distinguishes between "deserving" and "undeserving" disabled individuals. We advocate for an inclusive society where everyone's distinct access needs are met without the need to prove worthiness.

The current "accommodations" model is inadequate as it frames access as a favor rather than a basic human right. Disability programs and institutions are generally systematically under-resourced, leaving disabled people to grapple individually with lengthy waits and hurdles to have our access needs met. As it is currently used, the ADA allows institutions to frame access as a "problem" of the individual, not a responsibility of the institution. In this context, disabled people are forced to fight to prove our worthiness for access, whether through burdensome accommodation request processes or years-long civil rights complaints. The concept of "access needs," in turn, suggests a paradigm for society that's designed with the varied needs of different kinds of disabled people in mind. This model has the potential to significantly diminish societal barriers.

People's CDC May 8 ADA Rights training was designed inclusively, aiming to encourage critique of the current system and foster the aspiration that people who may not realize that they are protected by the ADA, such as those who have Long COVID, will join in advocating for this transformative approach. It was also designed with solidarity in mind, encouraging everyone to request universal masking, because hospitals need to hear that the public wants safe healthcare, and to counteract the idea that wearing a mask in healthcare settings is an inconvenience that outweighs anyone's right to health care without COVID exposure.

We believe that everyone should demand universal masking, to demonstrate that we want safe and accessible healthcare. While people may receive a response asking for medical paperwork, we do not believe this is because "non-disabled people" are asking for safe healthcare. Mass General Hospital in Massachusetts, for example, warned us they would defer to medical documentation by indicating on their website that "your provider will decide" if masking is necessary for you. Millions of people have become newly disabled by COVID, many more were always disabled but came to understand their life experience as such amidst the pandemic, and even more "historically-disabled" who have had bad experiences with the accommodations process, might be inspired to request masking accommodations in tandem with others. Institution disability bureaucracies are systematically under-resourced – a fact with which many of us are intimately familiar from years of slow or denied accommodations processes. We can only challenge that artificial scarcity together.

More to the point, our requests for universal masking challenge the articulated position of many powerful institutions – first and foremost the CDC – whose prominence offers a medical veneer for a value judgment. That is, the position that COVID infection control is no longer necessary is

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NOT a medical opinion but a judgment about the value of our lives in relation to healthcare profit margins.

Throughout the pandemic the CDC guidance has repeatedly issued value judgements under the guise of public health guidance. Powerful and moneyed interests have repeatedly pressured the CDC, resulting in weakened public health guidance. As an example, the CDC reduced COVID isolation guidelines from 10 days to 5 days apparently under pressure from Delta Airlines' CEO, despite evidence that 30-50% of people remain contagious on day 5. (See our People's External Review of the CDC for more examples). Those calling to end masks in healthcare argue (inaccurately) that masks offer only an "incremental benefit." Our lives and our health are not incremental benefits.

Institutional guidance which forces risk onto an entire population—without engaging the public in an informed discussion of the evidence and ethical considerations underlying public health guidance— fundamentally undermines all of our autonomy. Individual disabled people alone face a behemoth of medical institutional authority which has discarded COVID infection control. It is completely unsurprising that this behemoth will now send patients to ask for paperwork from doctors who may be loath to contradict the manufactured consensus and/or the policy of their employers. Still, many medical and public health professionals are pushing for COVID infection control like masks and screening testing, alongside us, but their voices have not been amplified by the media. It is increasingly clear that the only solution is a movement solution – we cannot effectively combat medical and public health gaslighting as individuals.

We all have a right to safe healthcare – and we must demand it. And when we do this together – people who identify as having disabilities acting in solidarity with people who do not yet have such diagnoses – we are stronger. And when we fight, we win.

## **Legal Interpretations, Written By a Lawyer, Which Inform our Thinking on the ADA**

The interpretation of the Americans with Disabilities Act (ADA) has varied over time, both due to judicial decisions and legislative actions.

Initially, court decisions in the 1990s and early 2000s often interpreted the ADA narrowly, focusing on a restricted definition of who was considered "disabled" under the law. Courts often required individuals to prove that their impairment significantly limited a major life activity, and they compared the individual's condition to the "average person" in the "general population."

This led to several rulings where individuals who had serious health conditions but were able to manage their conditions with medication or other mitigations did not meet the ADA's definition of "disabled". These court rulings were criticized for being overly restrictive and for excluding many individuals with significant health conditions from the protections of the ADA.

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In response to these court decisions, Congress passed the ADA Amendments Act of 2008, which was intended to expand the scope of the ADA and to overturn the narrow interpretations adopted by the courts. The Amendments Act emphasized that the definition of "disability" should be construed broadly and that the question of whether an individual's impairment is a disability under the ADA should not require extensive analysis.

The Amendments Act specifically stated that an impairment that substantially limits one major life activity need not limit other major life activities to be considered a disability, and it clarified that impairments that are episodic or in remission are disabilities if they would substantially limit a major life activity when active.

The Act also stated that the ameliorative effects of mitigating measures, other than ordinary eyeglasses or contact lenses, should not be considered when determining whether an individual has a disability.

So, over time, the interpretation of the ADA has expanded to cover more individuals, largely due to legislative actions responding to earlier, narrower judicial interpretations. However, specific applications can still vary, and legal challenges continue to shape the understanding and enforcement of the Act.

The Americans with Disabilities Act (ADA) has provided indispensable protections for millions of Americans living with disabilities. However, the scope and interpretation of the ADA must continue to evolve in response to our growing understanding of the wide range of conditions that significantly affect individuals' lives. The issue of whether people with under diagnosed, medically stigmatized conditions can get validation that they are "disabled" enough to be protected by the ADA is as old as the legislation itself. Long COVID has only made this question more widely discussed. To protect disabled people, we need better legislation, including a more expansive interpretation of the ADA's protections.

Long COVID, also known as Post-Acute Sequelae of SARS-CoV-2 infection (PASC), is a condition that includes a wide range of ongoing symptoms affecting various systems in the body. These can include fatigue, cognitive impairment, difficulty breathing, and more. Many people with Long COVID have found their lives significantly disrupted by these symptoms, affecting their ability to work, participate in society, and carry out daily activities.

However, the status of Long COVID under the ADA-litigated precedence is not entirely clear-cut. The ADA covers individuals with a physical or mental impairment that substantially limits one or more major life activities, and Long COVID certainly has the potential to meet this criteria. Still, the variability of symptoms and the lack of a standard diagnostic criteria for Long COVID may lead to challenges in determining whether a particular individual with Long COVID qualifies for protection under the ADA.

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This ambiguity underscores the importance of continually reevaluating and expanding the ADA's protections. As our understanding of health and disability evolves, so too should our laws and regulations. This paradigm shift isn't just about the legal technicalities; it's about ensuring that all individuals living with disabling conditions, whether they are socially accepted or stigmatized, frequently or rarely diagnosed, medically well characterized or not, can access the protections they need to participate fully in society.

People who have a condition that may make them extremely susceptible to severe illness if they contract COVID could be considered to have a disability under ADA. ADA itself is not explicit about this, but we do have case law that's specific to it. ADA is intended to be flexible and to encompass a broad range of conditions.

We know in some cases, people with certain underlying health conditions, like heart disease or a compromised immune system, may already be considered to have a disability under the ADA because these conditions substantially limit major life activities, such as working or even simply maintaining one's health. This definition can, and we argue, should apply to those who are at increased risk of severe illness from COVID-19 due to an underlying health condition.

Expanding the interpretation of the ADA also aligns with the spirit of the law, which is to eliminate discrimination and ensure equal opportunities for individuals with disabilities. Ultimately we need to fight for better legislation to ensure people with disabilities can have their differing access needs met, without burdensome barriers like seeking medical diagnosis, or individually negotiating with institutions or employment administrators.

In conclusion, the high prevalence of Long COVID in the U.S. population serves as a potent reminder of the need for a broad, inclusive, and evolving interpretation of the ADA. By ensuring the ADA continues to respond to emerging health challenges, we can help ensure equality and inclusivity for all individuals living with disabling conditions.

## **ADA Protections for “People Who Care for Disabled People”**

Given the highly contagious nature of COVID-19, the documented, high rates of household transmission, and the evidence that more than half of COVID transmission is either asymptomatic or presymptomatic, protection under the Americans with Disabilities Act (ADA) must consider not only the individuals who are classified as having a disability, but also those who are in close contact with them. It is nearly impossible to protect disabled people from COVID without protecting people who have frequent, unmasked contact with them, and people's relative ability to protect themselves from COVID is also shaped by structural inequality (including access to remote work options, socioeconomic status, crowded living situations, access to information, N95 respirators and COVID tests, and more). This is because the exposure of household members, caregivers, or close associates to COVID-19 directly impacts

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the health and safety of individuals with disabilities, particularly if they are at high risk of severe illness from the virus.

For example, it is not enough to protect a disabled person's right to work from home if their child or spouse, who shares the same household, is exposed to the virus in their respective environments, like schools or clinics without layered protections. Similarly, caregivers or family members working in healthcare settings are often at high risk of exposure, creating another potential source of transmission. The current reality of unmitigated transmission means that people cannot meet their basic needs without exposure to COVID-19, and people have been systematically excluded from public space, employment, education and now healthcare. Therefore, broader protections that consider these realities are necessary. The CDC has acknowledged this in its guidance.

The pandemic has laid bare the fundamental concept of human interdependence. Our lives are intricately connected, and the health of one person can impact the health of many others. This underscores the need for collective action and shared responsibility in addressing public health crises like the COVID-19 pandemic. In this light, we need to recognize the ripple effect of disability rights, where ensuring the health and safety of individuals with disabilities is nearly impossible to guarantee without protecting those around them.

Thus, the argument for a more expansive interpretation of the ADA should include a call for protections that consider these broader dynamics. It's not just about accommodating individuals with disabilities; it's about creating safer environments and implementing more comprehensive public health measures that protect everyone, in recognition of our interconnectedness. This could involve strengthening protections for caregivers and household members, and advocating for robust public health measures like widespread masking, vaccination, and improved ventilation in shared spaces. Such an approach would not only be more inclusive, but it would also better reflect the realities of living with a disability in the context of a global pandemic.

## **The ADA and beyond**

Our concern is with a critical public health issue. In healthcare settings, where the likelihood of encountering vulnerable individuals is high, maintaining certain protective measures like masking should ideally be the standard rather than the exception, irrespective of disability status.

The ADA is a powerful tool for disabled people to ensure that they have reasonable accommodations and are not subjected to discrimination. But for public health and safety reasons, even people without qualifying disabilities under the ADA should be able to expect a baseline level of protection from COVID-19 exposure in healthcare settings.

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## **Apart from the ADA, other relevant laws and standards could be invoked to protect people from COVID exposure in healthcare**

Occupational Safety and Health Act (OSHA) - regulates workplace safety and can apply to healthcare settings. OSHA has issued guidance on mitigating COVID exposure in workplaces, and employers could be held responsible for providing a safe and healthy workplace.

Public Health Regulations, of course - state & local health departments have broad powers to enact regulations to protect public health. They could implement regulations mandating certain precautions, like masking, in healthcare settings, and absolutely must keep being pushed on this.

Litigation Risk - even in the absence of explicit regulations, healthcare providers who do not take reasonable precautions to prevent the spread of COVID might be opening themselves up to potential lawsuits if patients contract the virus in their facilities. Negligence law is particularly relevant since, in the healthcare context, providers owe a duty of care to their patients. If a healthcare provider fails to follow accepted standards of practice and a patient is consequently harmed, the provider could be held liable for negligence. This could include instances where a patient contracts a communicable disease due to the provider's lack of appropriate infection control.

Laws and regulations vary by state, and the legal landscape of COVID keeps changing, so each effort needs consultation with healthcare attorneys & professionals of the target jurisdiction. Ultimately, the argument that people should not be forcibly exposed to COVID aligns with fundamental medical bioethical principles: including non-maleficence ("do no harm"), autonomy, beneficence ("do good") and justice. As such, policy makers, healthcare administrators, and the public should advocate for the continued use of successful mitigation strategies like masking, particularly in healthcare settings where the risk is high, using various legal tools available, as appropriate.