

January 13th, 2022

The Honorable Dr. Rochelle Walensky
Director, Centers for Disease Control and Prevention
1600 Clifton Road
Atlanta, GA 30329

Dear Director Walensky,

The undersigned organizations write in response to your comments on Friday, January 7th, 2022.

Together we represent millions of people with disabilities, patients, and people with chronic illnesses across the United States, and we are extremely concerned by your comments. People with disabilities and pre-existing conditions have been disproportionately killed by COVID-19. This is particularly true for those who live in congregate settings. Each of these deaths is a devastating loss to families, friends and to our broader communities. Your comments about the results of a research study referred to the fact that a disproportionate number of deaths due to COVID-19 occurred among “people who were unwell to begin with” as “encouraging news”. We understand you were speaking about a research study and that segments of your remarks were cut by ABC from the aired interview. Your full remarks were subsequently released, and our concerns remain. We understand these were the full remarks:

“If I may just summarize it: A study of 1.2 million people who are vaccinated between December and October. And demonstrated that severe disease occurred in about 0.015% of people who were – received their primary series– and death in 0.003% of those people. The overwhelming number of deaths, over 75%, occurred in people who had at least four comorbidities. So really, these are people who were unwell to begin with. And yes, really encouraging news in the context of Omicron. This means not only just to get your primary series but to get your booster series. And yes, we’re really encouraged by these results.”

People with four or more comorbidities are people with disabilities. People with four or more comorbidities are also disproportionately Black people, Indigenous people, Latina/o/x and other people of color, poor people, older people, and people who experience intersecting forms of oppression and marginalization that create barriers to quality healthcare, stable housing, and more. Even in full context, describing the deaths of people with four or more comorbidities as “encouraging” because they were “unwell to begin with” encapsulates the exact problem that we, people with disabilities and our family members and allies, have faced the entire pandemic: **The public health response to COVID-19 has treated people with disabilities as disposable.**

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. We saw this as the health care

system discriminated against people with disabilities and older adults in crisis care standards. We saw this when people with disabilities were barred from bringing necessary support staff, including those necessary for assisting with communication, into hospitals as they sought care. We saw this in the difficulties that direct support workers, personal care attendants, and other frontline healthcare providers for people with disabilities had obtaining personal protective equipment. We saw this in confusion about prioritization and eligibility of people with disabilities for vaccines and booster shots resulting from unclear and inadequate CDC guidance. We saw this as the CDC addressed concerns regarding the spread of the virus in congregate settings, including jails and prisons, in a piecemeal manner, contributing to the deaths of almost 200,000 people with disabilities.¹ And we have seen this recently in the CDC's confusing, conflicting, and inadequate guidance on isolation periods for health care workers who have COVID-19. **The dismissal and devaluation of people with disabilities has been our daily experience throughout this pandemic.**

These failures predate the pandemic, and the inequities² experienced by people with disabilities in health care settings³ on a routine basis⁴ 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.⁵ These failures and inequities are also serving as fuel to the COVID-19 pandemic, which continues to devastate our communities and our country.

We write to express our frustration and disappointment not only in your comments, but in the consistent policy choices they represent. The disability community's faith in the government agencies responding to the pandemic has taken hit after hit with repeated policy choices that devalue disabled lives. For every step in the right direction, there have been steps backwards or actions delayed. It is necessary for the public health of our nation that the CDC and other agencies responding to the pandemic take immediate, concrete policy steps to rebuild that trust, protect disabled and high-risk people, and enact an equitable vision of pandemic recovery that centers on those communities most at risk and begins to shift long-standing systemic inequities.

We urge you to take the following actions to help rebuild our trust in this critical institution and get our pandemic response on the right track:

1) Commit to regular ongoing meetings and consultation with disability stakeholders and CDC Leadership.

¹ <https://autisticadvocacy.org/covid19/>.

² <https://www.healthaffairs.org/doi/10.1377/forefront.20210325.480382/full/>.

³ <https://www.healthaffairs.org/doi/10.1377/hlthaff.2020.01452>.

⁴ <https://www.healthaffairs.org/doi/abs/10.1377/hlthaff.2021.01136>.

⁵

https://scholar.google.com/citations?view_op=view_citation&hl=en&user=DcLhDMAAAAAJ&citation_for_view=DcLhDMAAAAAJ:Zph67rFs4hoC

The CDC leadership has not meaningfully involved the disability community in its response to this pandemic. As a result, we saw widespread confusion at the state, local and individual level about which disabilities qualified as high-risk conditions, who should be prioritized for vaccinations, and what counted as a congregate setting—among many other examples. We expected that to change under the Biden administration. But confusion remains, for example about the details of booster or additional doses for high-risk and immunocompromised people. While a public apology to the disability community is needed, it must represent the beginning of a new relationship on the part of the CDC with the disability community. We believe that regular meetings with disability organizations at both a staff and a leadership level will help to ensure that the CDC is conducting necessary internal education, including the needs of disabled Americans in policy development, improving the accessibility and inclusivity of its public health messaging, and implementing best practices going forward.

2) **Ground isolation guidance in public health evidence and data and in an understanding of their impacts on those most at risk**

We are particularly concerned about the recent change in the CDC guidance on length of isolation time for people who test positive for COVID-19, particularly in the context of insufficient publicly-available evidence of the impact of this shift on those at heightened risk for infection and/or adverse events due to COVID-19. In particular, we are concerned by the guidance changing the isolation period for COVID-19 positive cases from 10 days to 5 days, with an additional 5 days of masking if asymptomatic or symptoms are resolving, without an accompanying testing requirement⁶. We are also concerned that the guidance does not require quarantine after exposure for boosted individuals. Our concerns are further exacerbated by reporting that the death rate is now spiking, exemplifying that Omicron is still taking an extreme toll despite early claims of Omicron as a milder variant.⁷

Similarly, the updated isolation guidance specifically recommends people with asymptomatic COVID-19 avoid people who are at high-risk, including those in nursing homes and other high-risk settings. At the same time, CDC issued new guidance rescinding work restrictions for boosted and asymptomatic health care workers.⁸ These health care workers, of course, are actively carrying SARS-CoV-2 back to the hospitals, clinics, and congregate settings where immunocompromised people and people otherwise at high risk for severe disease must go for life-sustaining medical care. Taken together, CDC's guidance has the effect of placing high-risk people in the tenuous, terrifying position of trying to determine whether to delay lifesaving, crucial care, or risk catching COVID-19 from the health care workers serving them.

⁶ <https://www.cdc.gov/media/releases/2021/s1227-isolation-quarantine-guidance.html>.

⁷ <https://www.nytimes.com/interactive/2022/01/09/us/omicron-cities-cases-hospitals.html>.

⁸ <https://www.cdc.gov/coronavirus/2019-ncov/hcp/guidance-risk-assesment-hcp.html>.

We request public posting of any evidence or datasets utilized to make these quarantine and isolation recommendations, so that we can fully assess the implications of these revised guidelines for our communities.

3) Take action to center people with disabilities—and other communities disproportionately impacted by COVID-19—by ensuring that all CDC COVID-19 guidance and other response efforts are inclusive of the needs of people with disabilities.

Some of us have written to you repeatedly about issues that people with disabilities have experienced accessing vaccines and the need for additional guidance.⁹ There remain open questions about boosters for people with pre-existing conditions that cause them to be at higher-risk for COVID-19, best practices for high-risk individuals in mixing and matching mRNA and viral vector vaccines, the list of high-risk conditions, and the definition of immunocompromised as it relates to eligibility for 3rd dose.

Immunocompromised people may remain unaware of their eligibility for third doses and boosters, due to confusing messaging. In addition to guidance, the CDC should provide additional resources directly to immunocompromised people and work with professional organizations, medical colleges, and others to ensure that guidance for immunocompromised people is reaching clinicians in the field. This guidance must be available in languages beyond English and Spanish, especially Asian American and Pacific Islander languages given lagging vaccination rates for Asian American and Pacific Islanders with disabilities.¹⁰

Similarly, while the CDC does have some accessible vaccine outreach tools, there is no guidance for state vaccine efforts on how to prioritize people with disabilities,¹¹ including specific materials with a focus on congregate care settings other than nursing homes—where thousands of people with disabilities have died. The heightened risk of congregate care settings requires a focused response from the CDC, as does the compounded risk to people of color with disabilities. Ensuring that the demographic data that CDC collects always includes disability status, whether or not a person resides in a congregate setting, racial and ethnic identity, and other crucial demographic data will be critical for this work.

Additionally, the CDC sets the standards for masks and provides crucially important guidance on testing. It is significantly harder for everyone, especially people with disabilities, to stay safe and protect the health of others when we cannot access regular testing and high-quality masks. Some in the disability community also have difficulty

⁹ <http://c-c-d.org/fichiers/CCD-Comments-to-CDC-Advisory-Committee-on-Immunization-Practices.pdf>; <http://c-c-d.org/fichiers/CCD-letter-to-CDC-on-COVID-vaccine-add-doses-boosters.pdf>.

¹⁰ <https://covid.cdc.gov/covid-data-tracker/#vaccinations-disability-status>.

¹¹ <https://www.cdc.gov/mmwr/volumes/70/wr/mm7039a2.htm>.

wearing, putting on, or taking off masks. There are accessibility concerns with some testing options, including that at-home tests are inaccessible to some people with disabilities, especially low-vision and blind communities.¹² Similarly, using an online form to order at-home tests or masks will create significant access barriers for many people with disabilities and other marginalized communities. The CDC should work with other agencies to ensure that every person in this country has abundant and unrestricted access to free and accessible testing options and is able to obtain high-quality masks. While we know that some responsibility for these efforts lie with others in the administration, such as utilizing the Defense Production Act, we expect that as CDC director—driven by the evidence—you will lead this call.

Finally, not only has the pandemic posed an extreme risk to people who are already disabled, it also has been a mass-disabling event. Current studies estimate that a range from one-third to more than half of all COVID survivors develop Long COVID disabilities¹³. Those millions of people with Long COVID are learning in real-time how difficult it is to access health care, especially for those with post-viral illnesses. We appreciate the significant research funding that has been invested to address Long COVID, but we believe that the CDC, and the federal government as a whole, must do more. Research initiatives on Long COVID must include individuals with similarly presenting long-neglected conditions such as other post-viral illnesses, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Postural Orthostatic Tachycardia Syndrome, dysautonomia, and Fibromyalgia.

The CDC is not the only agency that has failed to address the needs of people with disabilities during the pandemic, but your comments highlighted a trend of long-standing policy failures that have slowly eroded the trust of the people with disabilities in the pandemic response. We know that this trust is important and we are ready to work with you to rebuild it, starting with the important actions described above.

Sincerely,

American Association of People with Disabilities
Autistic Self Advocacy Network
Be A Hero
Disability Rights Education and Defense Fund
Little Lobbyists
The Arc of the United States

#MEAction
ABLE NH (Advocates Building Lasting Equality in NH)
Advocates for Justice and Education, Inc

¹² <https://www.nytimes.com/2022/01/10/health/covid-tests-blind-people.html>.

¹³ <https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1003773#sec016>.

Alabama Disabilities Advocacy Program
Alliance for Disability in Health Care Education
Alstrom Syndrome International
American Association of People with Disabilities
American Behcet's Disease Association (ABDA)
American Council of the Blind of Indiana
American Foundation for the Blind
ANCOR
APNI, Inc.
Association for Special Children & Families
Association of Assistive Technology Act Programs
Association of People Supporting Employment First (APSE)
Association of Programs for Rural Independent Living
Association of University Centers on Disabilities
Autistic Women & Nonbinary Network
Bazelon Center for Mental Health Law
Body Politic
California Foundation for Independent Living Centers
Caring Ambassadors Program
Center for Autism and Related Disorders
Center for Dignity in Healthcare for People with Disabilities
Christopher & Dana Reeve Foundation
Close Concerns
Coalition of Texans with Disabilities
CommunicationFIRST
Community Access Center
Community Legal Services of Philadelphia
Connecticut Parent Advocacy Center
Costello Syndrome Family Network
Count US IN (Count US Indiana)
CRIL
Cure SMA
Davis Phinney Foundation for Parkinson's
Detroit Disability Power
Disability Rights North Carolina
Disability Community Resource Center
Disability Law Center of Utah
Disability Policy Consortium
Disability Rights Arkansas
Disability Rights California
Disability Rights Center - NH
Disability Rights Center of Kansas
Disability Rights CT
Disability Rights Education & Defense Fund

Disability Rights Florida
Disability Rights Maine
Disability Rights Michigan
Disability Rights New Jersey
Disability Rights Pennsylvania
Disability Rights South Carolina
Disability Rights Vermont
Disability SURJ
Doylestown Presbyterian Church
Ensuring Opportunity Campaign
Epilepsy Foundation
Family Based Services Association of NJ
Family Network on Disabilities
Family Voices
Family Voices NJ
Family Voices of North Dakota
Federation for Children with Special Needs
Fireweed Collective
Flathead SURJ
FREED Center for Independent Living
HEARD
Hoosier Alliance for Neurodiversity
I AM ALS
Independence Seekers Project (ISP)
Independent Living Resource Center San Francisco
Indiana Disability Rights
Indiana Statewide Independent Living Council
Individual Patient Advisor
Justice in Aging
Kiva Centers
Little People of America
Maine Parent Federation
Marin Center for Independent Living
Michigan Developmental Disabilities Institute
NAACP Santa Maria-Lompoc
National Organization of Nurses with Disabilities (NOND)
National Association of the Deaf
National Center for Parent Leadership, Advocacy, and Community Empowerment (National PLACE)
National Coalition for Latinxs with Disabilities (CNLD)
National Council on Independent Living
National Disability Rights Network (NDRN)
National Disabled Law Students Association (NDLSA)
National Down Syndrome Congress

National Health Law Program
National Organization of Nurses with Disabilities (NOND)
National Women's Law Center
Neighborhood Access
Neighbors Against White Supremacy (NAWS) Central Queens)
NMD United
North Dakota Protection & Advocacy Project
Not Dead Yet
Oklahoma Disability Law Center, Inc.
One Rare
Organic Acidemia Association
Paralyzed Veterans of America
Partnership for Inclusive Disaster Strategies
Patient-Led Research Collaborative
Placer Independent Resource Services
Resources for Independence Central Valley
RespectAbility
Seed House, Inc.
Service Center for Independent Life
Showing Up for Racial Justice (SURJ) Contra Costa County, CA
Showing Up for Racial Justice (SURJ) — San Diego
Showing Up for Racial Justice Santa Cruz County, CA
SPAN Parent Advocacy Network (SPAN)
Strategies for High Impact (S4HI)
Texas Rare Alliance
The Advocacy Institute
The Arc Michigan
The Coelho Center for Disability Law, Policy and Innovation
The Parents' Place of MD
United Cerebral Palsy
United We Stand of New York
Usher 1F Collaborative
United Spinal Association
Washington ADAPT
World Institute on Disability