

Secretary Becerra
U.S. Department of Health and Human Services
200 Independence Ave SW
Washington, DC 20201

Dear Secretary Becerra:

Thank you for meeting with us earlier this month. We appreciated the time and attention you gave our community, and we look forward to working together on the issues we discussed. A strong working relationship between the US Department of Health and Human Services (HHS) and the disability community has and continues to be particularly important to ensure that people with disabilities can access substantive public health and health care protections as the nation works to move forward and live with COVID. The Biden administration must pursue concrete policy steps to safeguard against people with disabilities being trapped in our houses or dying at disparate rates. In this letter, we detail our recommendations in several policy areas key to achieving an equitable COVID-19 recovery that centers the disability community. We look forward to further dialogue, and will work with your office as discussed to schedule follow-up meetings with agency leadership on these issues.

1) Address Disability Bias in Health Care:

Crisis Standards of Care:

We were delighted to see the recent additional guidance on nondiscrimination during the Public Health Emergency (PHE)¹, including specific discussion related to crisis standards of care (CSCs) and reasonable accommodations for people with disabilities who require in-person support. The guidance provides important clarifications and reminders, including that Long COVID can be a disability under federal civil rights laws. This is especially crucial given evidence that physicians frequently lack understanding of their legal obligations to their patients under the Americans with Disabilities Act (ADA)² and that physicians often hold ableist views that contribute to disparities for people with disabilities.³ While the guidance is a welcome starting point, additional steps are needed to effectively implement it. As mentioned, CSCs can be difficult to locate online, making it harder for advocates to ensure the standards are in compliance and challenge those which are not. Some states, such as California, require the publication of CSCs. We would urge HHS to require that each entity publish their CSCs, as

¹ <https://www.hhs.gov/civil-rights/for-providers/civil-rights-covid19/disability-faqs/index.html>

² <https://www.healthaffairs.org/doi/abs/10.1377/hlthaff.2021.01136>

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

recommended by the COVID Equity Task Force.⁴ Equally challenging, no state has created mandatory state-wide standards, which forces people with disabilities and older adults to deal with variable CSCs by facility. We strongly support the COVID Equity Task Force's recommendation that the federal government convene a multidisciplinary panel, including community members with disabilities and older adults, to review and update the National Academies of Science, Engineering, and Medicine's work on CSCs. HHS should also take steps to encourage states to standardize CSCs across health facilities, or at a minimum, adopt state-wide standards on transparency and adherence to civil rights. To that end, we look forward to the HHS Office for Civil Rights publishing a CSC toolkit to assist states with compliance with federal standards. A toolkit would also allow for additional and more specific discussion of the topics covered in the guidance, including:

- More specific examples re: support persons, including for non communication-related needs and in vaccination contexts;
- Discussion of mobile and "housecall" testing and vaccination services as potential reasonable accommodations;
- Acknowledgement that disability discrimination can disproportionately impact communities of color due to long-standing health disparities and discussion of intersectional discrimination against people with disabilities, with specific examples of ways that seemingly neutral criteria can disproportionately screen out disabled people of color or LGBTQ+ people;
- Expanded antidiscrimination guidance, including prohibiting discrimination by weight-related disabilities or weight/size⁵;
- Recognition of the language access needs of people with disabilities who are Limited English Proficient; and
- Guidance specifically addressing age discrimination. We continue to see age being used as a tie-breaker in many CSCs, which particularly harms older adults with disabilities by effectively double-counting someone's older age.

⁴https://www.minorityhealth.hhs.gov/assets/pdf/HETF_Report_508_102821_9am_508Team%20WIP11-compressed.pdf

⁵ See [California Department of Public Health, California SARS-CoV-2 Pandemic Crisis Care Guidelines](#) (June 2020): "Healthcare decisions, including allocation of scarce resources, cannot be based on age, race, disability (including weight-related disabilities and chronic medical conditions), gender, sexual orientation, gender identity, ethnicity (including national origin and language spoken), ability to pay, weight/size, socioeconomic status, insurance status, perceived self-worth, perceived quality of life, immigration status, incarceration status, homelessness, or past or future use of resources."

We also believe additional regulatory and subregulatory steps are still needed to prevent and stop discrimination against people with disabilities, including updated regulations for both § 1557 of the Affordable Care Act and § 504 of the Rehabilitation Act.

Medically Underserved Population Designation:

Designating people with disabilities as a Medically Underserved Population (MUP) under 42 U.S.C. § 285t(d)(1) would provide another way to better address healthcare disparities faced by people with disabilities. As the recent National Council on Disability (NCD) letter made clear, substantial evidence shows people with a wide range of disabilities experience severe and pervasive health disparities.⁶ These disparities are not the inevitable result of disability—they are the result of systemic failures. Structural ableism manifested as routine barriers to accessing care, provider bias, insufficient numbers of qualified providers, and a lack of a culturally representative workforce; and compounding intersectionalities such as poverty and racial marginalization are just a few of the many factors that contribute to the significant disparities people with disabilities. We have never seen a clearer example of these systemic failures than the COVID pandemic.

The disability community more than meets the statutory requirements for designation as a MUP, except that people with disabilities are not confined to a specific geographic location. This geographic diversity is thanks to the community's efforts over the past 50 years to ensure that all people with disabilities have the right to live where everyone else does, a right enshrined in federal civil rights law. This geographic requirement functions as discrimination against the disability community and keeps us from accessing badly needed resources to address health disparities. The geographic requirement has been lifted before for special medically underserved populations.⁷ While we will continue to engage in Congressional advocacy to include people with disabilities in the statute, the Secretary has the authority in the meantime to designate groups as MUP. Negotiated rulemaking in 2010 recommended a number of innovations and flexibilities in the designation process which may increase inclusion for people with disabilities.⁸ No final rule was issued. We would be happy to work with the Health Resources and Services Administration to review the report from the Negotiated Rulemaking Committee and issue updated guidance and regulations, affirmatively exploring all possible avenues to include people with disabilities in the designation. In

⁶ <https://ncd.gov/publications/2021/ncd-letter-nimhd-ahrq-health-disparity-population-designation>

⁷ For example, under the Health Centers Consolidation Act, "migratory and seasonal agricultural workers, the homeless, and residents of public housing" were designated special medically underserved populations.

https://autisticadvocacy.org/wp-content/uploads/2014/04/MUP_ASAN_PolicyBrief_20140329.pdf

⁸ <https://www.federalregister.gov/documents/2010/05/11/2010-11214/designation-of-medically-underserved-populations-and-health-professions-shortage-areas-intent-to>

addition and as an immediate, albeit intermediate, step, we urge you to work with the National Institute on Minority Health and Health Disparities to designate people with disabilities as a health disparity population, as requested by NCD in their December letter.

Telehealth:

For some people with disabilities, the exponential rise of telehealth services during the pandemic has meaningfully reduced barriers to health care access and improved their quality of care. However, for others telehealth presents new accessibility challenges. To further address disability bias in healthcare, it is also crucial that HHS issue guidance on accessibility of telehealth.⁹ This guidance should specifically address the need for integrated American Sign Language interpreters (including a Deaf Intermediary relay option), integrated captioning in the user's primary language, and best practices for including the chat box. This guidance should also address accessibility of telehealth platforms for the wide range of people with disabilities who utilize assistive technology to navigate the web and web-based applications. Like many other health disparity populations, disabled individuals experience the digital divide, with 15% (in comparison to 5% of nondisabled individuals) stating that they never go online. Moreover, people with disabilities are less likely than the general population to own the hardware that they need to use telehealth.¹⁰ This lack of digital access, coupled with a lack of hardware, can lead to canceled appointments, technical difficulties during appointments, and misinterpretation of the information exchanged.¹¹ While the recent passage of the Infrastructure Investment and Jobs Act will go a long way to address the digital divide, the adoption of telehealth will outpace the implementation of this important legislation. We encourage HHS to work within its many technical assistance centers to increase the availability of devices and digital health literacy for people with disabilities. Given its long history of marginalization, the disability community is vulnerable to potential unintended consequences of telehealth expansion. During the pandemic, HHS put in place HIPAA flexibilities that allow health professionals to use a variety of platforms to deliver telehealth services. While such flexibilities may allow for greater access, they also have the potential negative, unintended consequence of breaches in cyber security. We encourage HHS to issue further guidance focused on privacy and data monitoring for telehealth that centers marginalized populations. We also encourage the Office of the National Coordinator for Health Information Technology to create more comprehensive standards related to the design of accessible solutions. It is important that all guidance on telehealth promotes broad availability and accessibility of the

⁹<https://waysandmeans.house.gov/legislation/hearings/health-subcommitteehearing-bridging-gap-health-equity-people-disabilities>

¹⁰<https://www.pewresearch.org/fact-tank/2021/09/10/americans-with-disabilities-less-likely-than-those-with-out-to-own-some-digital-devices/>

¹¹ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7717308/#ocaa297-B29>

services, while not incentivizing the use of telehealth over in person visits or vice versa in payment structure or in access, including making some communication aids or services available only for one kind of visit or restricting patients to only one type of aid or service.

2) Expand Research into and Address Support for Long COVID:

The pandemic has also been a mass disabling event, with recent estimates suggesting that there are 1.2 million more disabled adults in 2021 than in 2020.¹² Current studies estimate that approximately 16% of all COVID survivors develop Long COVID disabilities.¹³ There are several steps HHS can take to ensure those with Long COVID, also known as Post-Acute Sequelae of SARS-CoV-2 (PASC), have access to the health care services they need. In particular, we urge HHS to ensure that research into PASC also be inclusive of other post-viral illnesses, such as myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and postural orthostatic tachycardia syndrome (POTS). The standard of care for all post-viral illnesses is extremely poor, due to both lack of research and lack of provider training. One of the primary challenges faced by people with PASC or other post-viral illnesses is lack of provider awareness, and frequent provider mistrust of patient-reported symptoms.^{14,15} **What this creates is a healthcare delivery system is not set up to catch, diagnose, or treat chronic illnesses in general, and especially not post-viral illness.** These challenges are exacerbated for people of color, who already face barriers to access to care and are more likely to be considered unreliable reporters of their symptoms by physicians. HHS should:

- Work with the White House to issue an Executive Order on Long COVID that will instruct federal agencies to dedicate resources and work together in an interagency manner to find short-term and longer-term solutions to ensure that our healthcare delivery system works better for post-viral illness patients. This should include interim measures that ensure patients can qualify for treatment and support for Long COVID regardless of access to COVID tests at the time of infection, ensure that people with Long COVID qualify for and know how to access benefits, and provide education and guidance for providers on the complex and multi-systemic nature of Long COVID symptoms;
- Invest in basic and translational research on PASC, ME/CFS, POTS, and other post-viral illnesses;

¹²<https://www.americanprogress.org/press/release-covid-19-likely-resulted-in-1-2-million-more-disabled-people-by-the-end-of-2021-according-to-new-cap-analysis/>

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

¹⁴ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5510655/pdf/nihms873010.pdf>

¹⁵ <https://www.sciencedirect.com/science/article/pii/S2589790X21002316>

- Commit federal resources to utilize findings and recommendations from the above research and Executive Order to make long-term changes to our healthcare delivery system to ensure that patient care can be structured in a way that will allow time diagnosis and adequate assessment and treatment of all post-viral illnesses over time.
- Include ME/CFS and other post-viral illnesses in PASC initiatives;
- Ensure providers are trained on the existence of and treatments for post-viral illness;
- Ensure providers are trained on shared decision making, trusting patient reports, and addressing bias;
- Ensure coding of PASC, ME/CFS, and other post-viral illnesses is accurate and expansive to address both common and uncommon manifestations of PASC; and
- Collect and report data through CDC on PASC, ME/CFS, POTS, and other post-viral illnesses, including disaggregation by demographic groups and specific data on the impact of these and other post-viral illnesses on children.

3) Collect and Report Robust Disability Data

Almost two years after the declaration by WHO of COVID-19 as a global pandemic, we still have enormous gaps in our understanding of how people with disabilities were impacted by COVID and the PHE. We don't know where, when, and how many people with disabilities were infected, how many were hospitalized, and how many died. We don't know if and when people with disabilities who use home and community-based data achieved full vaccination. We don't know the full extent of the health and health care disparities experienced by people with disabilities and chronic conditions as hospitals were overrun during successive surges of the virus. Our country cannot close these gaps without clear leadership from HHS that prioritizes data on functional limitation as a demographic characteristic.

Diagnosis alone is not demographic data. While electronic health records have diagnostic information, a diagnosis does not indicate a person's level of functioning. A person's diagnosis doesn't give a provider information about if they use a wheelchair or need a ventilator at night or require assistance with activities of daily living or what auxiliary communication aid or service works for them. Demographic information about functional limitations would provide that critical information and provide more information about people with disabilities, and just as importantly, demographic information about functional limitations will provide a fuller picture on the barriers to

travel, food insecurity, foregone or delayed medical care, lower telehealth usage, lost housing, and hospitalization or death from COVID-19 experienced by people with disabilities. Without robust demographic data covering the vast experiences of people with disabilities and types of disabilities, people with disabilities are being undercounted and therefore underserved. Without this information any given individual who undergoes the disparities described above is simply assumed to be suffering the “natural consequences” of having a diagnosis, rather than undergoing systemic healthcare disparities. Collecting this information also must include pushing health care providers to capture this data through self-reporting.

Validated functional limitation questions are already included in the American Community Survey disability question set¹⁶, and Oregon is an example of one state that has expanded functional limitation data as part of their Race, Ethnicity, Language, and Disability (REALD) Demographic Data.¹⁷

The full inclusion in electronic health records and in public health initiatives cannot be achieved without the collection of demographic information on functional limitation.¹⁸ Implementing this practice thoroughly and well will benefit people with disabilities and their families, both as an identifiable population as well as a population of people that intersect broadly with populations characterized by race, ethnicity, age, gender, sexual orientation, and gender identify.

Additionally, data collection on people with disabilities must be disaggregated from people without, especially in congregate facilities. In addition, some state data collection on congregate settings does not differentiate between *residents* and staff of those facilities, leading to lack of data on the barriers faced specifically by people with disabilities.

We ask HHS to undertake the following actions:

- Reprioritize demographic data collection across the full range of congregate care settings (e.g., intermediate care facilities, psychiatric in-patient facilities, board and care homes, assisted living facilities, group homes), including data on functional limitation and specifically disaggregating residents data from staff data;
- Collect information on diversion and transition of people with disabilities across all disabilities and all ages from congregate care facilities;

¹⁶ <https://pubmed.ncbi.nlm.nih.gov/32672921/>

¹⁷ <https://secure.sos.state.or.us/oard/displayDivisionRules.action?selectedDivision=4206>

¹⁸ Swenor BK. Including disability in all health equity efforts: an urgent call to action. *Lancet Public Health*. 2021 Jun;6(6):e359-e360. doi: 10.1016/S2468-2667(21)00115-8. PMID: 34051160.

- Require State and local Departments of Public Health to collect and publicly report functional limitation data by age when reporting vaccination and booster rates, COVID/Delta/Omicron infections and deaths, and for other COVID-related reporting areas; and
- Support the proposal in the US Core Data for Interoperability, Draft Version 3¹⁹ to include detailed functional limitation and mental functioning data elements as part of the electronic health record, and call for self-reported information on functional limitation to be included as a demographic data element.

4) Increase Access to High-Quality Masks, Testing, Vaccines, Therapeutics, Information:

HHS must ensure that there is a readily sufficient supply of high quality masks, at-home tests, vaccines, and therapeutics to meet the needs of all Americans, especially disabled, immunocompromised, and chronically ill Americans. Rationing of these life saving tools because of insufficient supply must not be allowed to occur. It is imperative that no access barriers deny these vital tools to anyone – they must be accessible to all Americans.

Tests:

We welcome the direct distribution of at-home COVID-19 tests directly to the American people via USPS. We also welcome the announcement that the NIH RADx Tech program is working to develop tests that are accessible to disabled Americans and that will include non-English support.²⁰ We urge HHS to continue to distribute additional at-home tests, cost free, directly to the American people via USPS. We additionally urge that when accessible tests are available, there is a broad campaign to make those tests readily available and cost free to the American public.

High-Quality Masks:

We now have overwhelming evidence that aerosol transmission is a major mechanism through which SARS-CoV-2 spreads: CDC and WHO have both recognized the scientific reality of aerosol transmission.^{21,22}

¹⁹ <https://www.healthit.gov/isa/sites/isa/files/2022-01/Draft-USCDI-Version-3-January-2022-Final.pdf>

²⁰

<https://www.nibib.nih.gov/news-events/newsroom/nih-radx-tech-tackle-development-home-covid-19-tests-improved-accessibility-users>

²¹

<https://www.who.int/news-room/questions-and-answers/item/coronavirus-disease-covid-19-how-is-it-transmitted>

²² <https://www.cdc.gov/coronavirus/2019-ncov/science/science-briefs/sars-cov-2-transmission.html>

Faced with an airborne virus that spreads via aerosols, it is imperative that all Americans, but particularly disabled, chronically ill, and immunocompromised Americans, have ready access to high quality, effective, accessible PPE. Highly protective masks (e.g. N95s) are one of the most effective non-pharmaceutical interventions we have. As a recent study published in CDC's MMWR found: "Consistent use of a face mask or respirator in indoor public settings was associated with lower odds of a positive SARS-CoV-2 test result (adjusted odds ratio = 0.44). Use of respirators with higher filtration capacity was associated with the most protection, compared with no mask use."²³

As states and localities abandon mask use requirements, access to highly protective masks for disabled people becomes all the more important. We welcome the administration's decision to release approximately 400 million N95 respirators from the Strategic National Stockpile to the American people (primarily through distribution points at pharmacies and community health centers). However, this step alone will be insufficient to provide meaningful protection to disabled, immunocompromised, and chronically ill Americans. We, therefore, ask HHS to undertake the following actions:

- *Distribute N95s directly to disabled, chronically ill, and immunocompromised Americans to the greatest extent logistically possible.* The distribution of rapid antigen tests via USPS represents a more accessible delivery model than requiring disabled people go in person to, e.g., a pharmacy or community health center to acquire N95s. At a minimum, HHS should partner with the Social Security Administration and the Department of Veterans Affairs to mail N95s directly to disabled Americans served by those agencies.
- *Leverage the significant 'buying power' HHS wields through the procurement process to support the development of adaptive, protective PPE.* Just as HHS is leveraging the procurement process to ensure the accessibility of at-home COVID-19 tests,²⁴ HHS should use its significant purchasing power as it backfills N95s released from the Strategic National Stockpile to spur the development of adaptive, accessible PPE.²⁵

Therapeutics:

²³ <https://www.cdc.gov/mmwr/volumes/71/wr/mm7106e1.htm>

²⁴ <https://www.nibib.nih.gov/news-events/newsroom/nih-radx-tech-tackle-development-home-covid-19-test-s-improved-accessibility-users>

²⁵ For example, "The Communicator" a "surgical facemask with clear window" only provides ASTM level 1 surgical mask protection. HHS should spur the development of clear masks that provide a higher level of protection more akin to what an N95 provides.

HHS must ensure a readily sufficient supply of therapeutics in a quantity sufficient to meet the needs of all Americans who may benefit from those products. HHS must not allow rationing, lotteries, or other mechanisms used to deny vital therapeutics to Americans, particularly those who are disabled, immunocompromised, or chronically ill because of insufficient supply.

We welcome the announcement that HHS has increased its acquisition of EvuSheld (tixagevimab/cilgavimab), a biologic intended for pre-exposure prophylaxis for prevention of COVID-19, to a total of 1.7 million doses.²⁶ However, 1.7 million doses is insufficient to meet the needs of immunocompromised Americans.

The FDA found EvuSheld can provide meaningful protection to those who are immunocompromised and may not be able to mount an adequate immune response to COVID-19 vaccination and also to those for whom COVID-19 vaccination is contraindicated due to a history of severe adverse reaction to a COVID-19 vaccine.²⁷ On that basis, in December of 2021, FDA granted Emergency Use Authorization for EvuSheld for use in adults and children 12 years of age or older.

EvuSheld was developed at Vanderbilt University – VUMC’s research was funded by DARPA and NIAID.²⁸ VUMC licensed the tixagevimab/cilgavimab combination to AstraZeneca. AstraZeneca developed EvuSheld with extensive financial support from the federal government, specifically the Biomedical Advanced Research and Development Authority (HHS) and the Joint Program Executive Office for Chemical, Biological, Radiological and Nuclear Defense (DOD).²⁹

Immunocompromised people comprise approximately 2.7 percent of adults in the United States.³⁰ FDA’s EUA anticipates the need to re-dose EvuSheld after six months. The 1.7 million doses procured by the federal government is insufficient to meet the needs of the immunocompromised population.

Paxlovid (nirmatrelvir co-packaged with ritonavir) is also of critical importance to disabled, immunocompromised, and chronically ill Americans. FDA found that Paxlovid

²⁶<https://www.astrazeneca-us.com/media/statements/2022/astrazeneca-to-supply-the-US-government-wit-h-an-additional-one-million-doses-of-evusheld-long-acting-antibody-combination-for-the-prevention-of-covid-19.html>

²⁷ <https://www.fda.gov/media/154701/download>

²⁸<https://news.vumc.org/2021/12/23/patient-receives-antibodies-discovered-at-vanderbilt-to-prevent-covid-19-illness/>

²⁹<https://www.astrazeneca-us.com/media/statements/2022/astrazeneca-to-supply-the-US-government-wit-h-an-additional-one-million-doses-of-evusheld-long-acting-antibody-combination-for-the-prevention-of-covid-19.html>

³⁰ <https://www.cdc.gov/vaccines/acip/meetings/downloads/slides-2021-07/07-COVID-Oliver-508.pdf> citing Harpaz et al Prevalence of Immunosuppression Among U.S. Adults, 2013. JAMA 2016

may be effective for the treatment of mild-to-moderate COVID-19 in adults and pediatric patients 12 years of age or older who are at high risk for progression to severe COVID-19, including hospitalization or death.³¹ On that basis, in December of 2021, FDA granted Emergency Use Authorization for Paxlovid.

The significant investment from the federal government made the creation of these therapeutics possible, and HHS can take the further step to make these therapeutics available to those who need them. We call on HHS to ensure a sufficient supply of all vaccines and therapeutics – including mAbs (e.g. Sotrovimab), small molecules (e.g. Paxlovid), and LAABs (e.g. EvuSheld) – leveraging all existing federal authorities. A sufficient supply is necessary to ensure that no rationing of these products, vital to chronically ill, disabled, and immunocompromised Americans, is necessary.

Vaccines:

We urge the administration to do everything possible to vaccinate the world, thereby decreasing the odds that further variants of concern evolve.

In addition to the increased risk of severe illness and death from COVID, people with disabilities face substantial accessibility barriers to receiving their COVID vaccines. While adults with disabilities report higher likelihood that they would get vaccinated than adults without disabilities, disabled adults are less likely to actually have received a vaccine.³² Unvaccinated adults with disabilities were more likely than unvaccinated adults without disabilities to report higher endorsement of the vaccine as protection and concern about getting COVID-19, but barriers to vaccination prevented them from doing so.

We urge HHS to address the specific needs of people with disabilities experiencing barriers to receiving their COVID-19 vaccines. This includes encouraging states to provide in-home vaccination and booster programs as a reasonable accommodation as well as ensuring that vaccine clinics are fully accessible - providing effective communication as well as physical, cognitive, and sensory access. We also urge HHS to increase information regarding vaccination in accessible formats, in plain language, and in non-English languages, including via increased dedicated disability outreach.

5) Address COVID-19 Deaths in Congregate Settings

We also remain extremely concerned about deaths in congregate facilities. Despite prioritization for vaccinations and the fact that residents of congregate settings are an

³¹ <https://www.fda.gov/media/155049/download>

³² https://www.cdc.gov/mmwr/volumes/70/wr/mm7039a2.htm?s_cid=mm7039a2_w

extremely small percentage of the U.S. population, deaths in congregate settings continue to make up approximately a quarter of all US COVID deaths.³³ The 200,000 known deaths is likely an underestimate because we do not have complete data that includes deaths among people with disabilities and older adults in congregate settings other than nursing homes. Only 33% of nursing home staff are boosted, putting residents of congregate facilities at even greater risk.³⁴ While we appreciate steps that CDC, ACL, and CMS have taken to broaden the definition of high-risk settings to include congregate settings beyond nursing homes and expand the reach of critical guidance, we believe HHS must do more to educate states and providers so that people living in these settings get the resources necessary. Specifically, we also recommend HHS lead a COVID vaccine campaign to ensure residents of congregate settings have access to additional doses and boosters and easy to understand information about vaccines and eligibility. Leaving it up to individual facilities to ask for HHS's support is insufficient.

6) Issue Accessible Medical Diagnostic Equipment Standards

The HHS Office for Civil Rights should issue a regulation requiring covered health care providers to have accessible equipment that complies with the Medical Diagnostic Equipment (MDE) Standards published by the Access Board, as well as develop a technical assistance document on accessible MDE. CDC data has shown for at least a decade that people with disabilities are less likely to get a cancer screening,^{35,36} in part due to lack of accessible equipment. HHS can address this health access disparity through this rulemaking.

7) Address the Needs of Those Who Use Medicare and Medicaid Services

Many people with disabilities and chronic conditions who are most at-risk from COVID-19 are enrolled in Medicare, Medicaid, or both. Yet coverage for testing under these programs lags behind private insurance, meaning the people who need reliable, unencumbered access to free tests the most do not have it. We appreciate the announcement that Medicare will cover over-the-counter (OTC) COVID-19 tests with no out of pocket costs. We urge CMS to begin this coverage as soon as possible and ensure a robust network of retail and online pharmacies that reaches people with Medicare in every community. The success of this coverage program depends largely on there being sufficient supply and improved accessibility of the tests themselves, as

³³<https://www.kff.org/policy-watch/over-200000-residents-and-staff-in-long-term-care-facilities-have-died-from-covid-19/>

³⁴ <https://data.cms.gov/covid-19/covid-19-nursing-home-data>

³⁵ <https://www.cdc.gov/cancer/dcpc/research/articles/screening-disabilities.htm>

³⁶ <https://www.cdc.gov/ncbddd/disabilityandhealth/breast-cancer-screening.html>

recommended above. In addition, we would urge CMS to waive the provider order requirement for lab tests. Especially as free public testing centers close, it will be more important for people with Medicare to not have barriers to getting tested.

While state Medicaid programs are required to cover OTC tests, this coverage varies by state. Rollout of coverage is just starting in many states, and several states are requiring a prescription. Medicaid beneficiaries are often unaware that these tests are covered, or what steps they must complete in order to access them. We urge CMS to check in with states to ensure they have coverage in place and incentivize states not to impose prescription requirements or other barriers. We also recommend working with the Medicare-Medicaid Coordination Office to provide guidance to states, pharmacies and other entities providing tests on how to process coverage for people dually enrolled in Medicare and Medicaid.

We would like to discuss these and other Medicaid- and Medicare-related policy asks with CMS and specifically request a meeting with Administrator Brooks-LaSure.

We believe based on these priorities, it would be helpful for us to meet with OCR and CMS. We will work with your office to set up these meetings and we look forward to our continued work together.

Sincerely,
American Association of People with Disabilities
Autistic Self Advocacy Network
Be a Hero
Disability Rights Education & Defense Fund
Epilepsy Foundation
Justice in Aging
Little Lobbyists
The Arc of the United States
Matthew Cortland, Senior Fellow, Data for Progress
Mia Ives-Rublee, Disability Justice Advocate