

August 18, 2022

Melanie Fontes Rainer
Acting Director
Office for Civil Rights (OCR)
Department of Health and Human Services

Samuel Bagenstos
General Counsel (OGC)
Department of Health and Human Services

Dear Acting Director Fontes Rainer and General Counsel Bagenstos,

The Autistic Self Advocacy Network, Disability Rights Education & Defense Fund, Epilepsy Foundation, Justice in Aging, and The Arc of the United States are writing to follow up on areas where HHS Office for Civil Rights (OCR) support is greatly needed for people with disabilities, older adults, and other communities devastated by the impact of COVID-19. Our organizations have raised these issues previously, including in a meeting and with Secretary Becerra in February (see attached memo). We recognize the Administration's helpful efforts to improve access to and accessibility of COVID-19 testing, vaccines and treatment and the ongoing ACA Section 1557 rulemaking to better address discrimination in health care. However, other inequities continue to persist for people with disabilities and older adults that present barriers to accessing treatment for COVID-19 and post-COVID conditions, as well as barriers to receiving quality health care and other services that are necessary for community living. We have listed our concerns below and request a meeting to discuss further advocacy to alleviate these pressing issues.

I. Crisis Standards of Care (CSC)

At our February meeting and other meetings with OCR, we requested that OCR issue a CSC toolkit to ensure states comply with federal antidiscrimination authorities. Although we are now more than two years into the pandemic, several CSCs still contain discriminatory provisions including the use of age as a tie-breaker and consideration of long-term survivability. While HHS has previously issued guidance for disability protection in CSCs, no such guidance has been issued for older adults, despite complaints to OCR regarding disability and age bias. These discriminatory policies deprioritize older adults, people with disabilities, and other marginalized groups from receiving life-saving care. As stated in our February 24 memo, the toolkit should acknowledge existing protections against age and disability considerations, as well as the disparate impact of discrimination in healthcare on individuals at the intersection of age, disability, race, ethnicity, and LGBTQ+ identities. The toolkit should also provide a methodical catalogue of non-discriminatory language and best practices for developing, implementing, and monitoring crisis standards of care at state, health system, and/or institutional levels. We also recommend inclusion of best practices for addressing language access needs for people with Limited English Proficiency; effective

communication needs for people with sensory, cognitive and communication disabilities; expanded guidance prohibiting discrimination based on weight/size related disabilities; further discussion on disability accommodations for support persons; and mobile or house-call testing and vaccination services.

We also previously identified the challenges of different hospitals and healthcare systems adopting their own CSCs instead of a statewide policy. This can lead to an older adult or person with a disability being denied lifesaving care simply because of where they are hospitalized. Additionally, CSCs are seldom made public or easily accessible to the general public making it more difficult to ensure hospitals' policies are not discriminatory. HHS should require all healthcare entities receiving federal financial assistance (and their contracted entities) to publish their CSCs in a manner that is readily available to the public and fully accessible to people with a range of disabilities, and encourage those CSCs to comply with OCR's CSC toolkit.

Lastly, we strongly support the COVID-19 Equity Task Force's recommendation of a multidisciplinary panel of advocates, older adults, and people with disabilities to update the previous CSC guidance written by the National Academies of Science, Engineering, and Medicine (NASEM). This is particularly crucial as newer issues around COVID-19, like healthcare workforce shortages and anti-viral medications, present new challenges for the disability and aging communities.

II. Accessible Medical Exam and Diagnostic Equipment (MDE)

Millions of people with disabilities and older adults with disabilities frequently are unable to access equally effective medical care because basic medical exam and diagnostic equipment remains inaccessible.¹ Examination tables, weight scales, dental and ophthalmology chairs, mammography machines, MRI machines, imaging equipment,

¹ Analyses of data from the systematic third-party physical accessibility review of thousands of Medi-Cal primary care provider offices in California show modest improvement on the availability of accessible weight scales and height-adjustable exam tables over a ten-year period. From 2006 to 2016, the number of provider offices that had an accessible scale increased from 3.6% to 10.9%, and the number of height-adjustable exam tables went from 8.4% to 19.1%. However, that means over 80% of offices still lack the capacity to provide a full body exam to, or take the accurate weight of, a wheelchair user or anyone with mobility or strength disabilities who could not hoist themselves upon a table or balance independently on a typical scale surface. Analysis of accessible equipment in LA County medical offices showed that less than half (47.3%) of zip codes contain at least one office with a height adjustable exam table; 31% had an accessible weight scale; and 15.9% a patient lift. Within any given zip code there mostly was a single site, and not necessarily the same site, with accessible equipment or an accessible toilet room, forcing many patients with disabilities to choose among the one office where they can use the restroom, achieve a safe transfer, receive culturally or linguistically competent services, or an office they can reach on public transportation in a reasonable amount of time. [Nancy R. Mudrick, et al., Physical Accessibility in Primary Health Care Settings: Results from California On-Site Reviews, Disabil Health J. 2012, Jul;5\(3\):159-67;](#) [Nancy R. Mudrick, et al., Presence of Accessible Equipment and Interior Elements in Primary Care Offices, Health Equity \(2019\) Jun 18;3\(1\):275-279;](#) [Mary Lou Breslin, et al, The Geographic Distribution of Accessible Medicaid Participating Primary Care Offices in LA County \[Internet\]; 2020 July 25, 2020. Podcast.](#)

and other equipment is designed for “typical” bodies that stand, sit, bear weight, hold still, balance, fall within certain weight and height limits, and do not require assistance with constant functions such as breathing or communicating. This remains the case even when we are decades into recognizing the right of people with disabilities who have *atypical* physical, mental, and social capacities to live independently with home- and community-based supports. The ability to receive effective healthcare in one’s own community, with one’s freely chosen provider, in a manner that is as timely and appropriate as the care received by persons without disabilities, is necessarily inherent in the Supreme Court’s 1999 *Olmstead* decision. When the U.S. healthcare system is slowly but surely recognizing the urgent need to address systemic health and healthcare disparities, it is past time to incorporate the Access Board’s Medical Diagnostic Equipment Accessibility Standards, developed in 2017, within enforceable regulation.

Inaccessibility is not only an inconvenience, burden, and often humiliating for people with disabilities; it has real health implications and often results in lack of quality care and undiagnosed or untreated conditions. Substandard care is given every time weight is unknown before surgery, when referrals to specialists are denied, when an MRI exam is delayed for months, and when people with disabilities don’t make appointments because they can’t bring anyone with them who can help with a transfer.

The expansion of telehealth, a benefit for many people with disabilities, has also exacerbated other existing inaccessibility elements, especially for blind individuals, Deaf and Hard-of-Hearing persons, and for people with intellectual or developmental disabilities. The barriers that people with some disabilities encounter in telehealth are not insurmountable, but they cannot be resolved without careful attention to the assumptions that are made about how telehealth users communicate, which can be through technology such as captions or video relay, speech readers, or other communication devices, and intentionally addressing how those technologies can be seamlessly incorporated within telehealth practices. It should not be a matter of catching up later. It should be a matter of building in accessibility ahead of the curve.

III. Section 504

Relatedly, several of our organizations were pleased to participate in listening sessions on desperately needed updates to the Section 504 regulations. In those sessions, we specifically raised how helpful updated regulations would be in the context of crisis standards of care, accessibility of medical equipment, and other areas that address areas of potential future controversy such as telehealth, the use of algorithms in health care decision-making, and other national, state or geographic emergencies. The 504 regulations are the basis for much of the crisis standards of care work and advocacy that prioritizes providing serving persons with disabilities in the most integrated setting, but have not been updated in decades. As disability and aging groups raised in a recent letter, and bipartisan members of Congress raised last year, it is long past time to revise these regulations. We request that the comment period be 60 days to ensure the

disability community and public has adequate time to consider and respond to the proposed rule.

IV. Data

The healthcare system's failure to collect demographic information on disability status has long thwarted efforts to quantitatively analyze health and healthcare disparities experienced by people with disabilities. The dearth of disability-specific information also makes it impossible to identify the compounded barriers that arise when disability is combined with non-white races and ethnicities, LGBTQ+ status, older age or childhood, gender, and/or low income. The COVID-19 pandemic only highlighted these deep gaps in disability data and the dearth of information on, for example, rates of infection, hospitalization, death, and vaccine and treatment access for people with significant disabilities and older adults who receive home and community-based services. Version 3 of the US Core Data on Interoperability (USCDI), released this past July, has finally included disability, functional status, and mental/cognition elements within USCDI recommendations for Electronic Health Records (EHR), but federal leadership on how states and healthcare entities should actually collect this information, the training that should be provided, and the strong desirability of consistent vocabulary and data collection practices is vital as the country moves forward. The USCDI advances will move EHR developers toward including disability-related elements within EHR systems, but getting useful data from those systems that will both help us identify national, regional and state disability-related health and healthcare disparities, as well as achieve quality information that will lead to individual patients getting the reasonable accommodations and policy modifications they need for equally effective healthcare, requires dedicated effort and resources from HHS.

We appreciate your ongoing partnership in addressing these pressing issues and look forward to discussing these priorities with you at a meeting in the near future.

Sincerely,

Autistic Self Advocacy Network

Disability Rights Education & Defense Fund

Epilepsy Foundation

Justice in Aging

The Arc of the United States