CCD
CONSORTIUM FOR CONSTITUENTS
WITH DISABILITIES

April 26, 2022

Secretary Becerra
U.S. Department of Health and Human Services

Dear Secretary Becerra:

The undersigned members of the Consortium for Constituents with Disabilities write to urge you to issue updated regulations on Section 504 of the Rehabilitation Act. The Consortium for Constituents with Disabilities (CCD) is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.

Section 504 guarantees equal opportunity for people with disabilities of all ages to receive health program benefits and services. These regulations have not been updated for decades and do not address many of the issues facing adults, youth, and children with disabilities today. It is long past time to revise these regulations. In particular, there are several issues we believe these regulations should now address. We will address each in turn.

1) Discrimination in Organ Transplants and Medical Futility Decisions, the Use of Quality Adjusted Life Years, and Assisted Suicide

In late 2019, the National Council on Disability issued a series of reports[1] on bioethics and disability, highlighting key areas of disability discrimination in the health care system. We believe each of these topics should be addressed in updated regulations on Section 504 and that the Office for Civil Rights (OCR) should consider the specific recommendations made by NCD. We strongly agree with these recommendations. These recommendations include clarifying that 504 applies to the following entities:

- Organ transplant centers and hospitals, who often discriminate against people with disabilities in the allocation of organs and by not providing effective communication;
- Federal health insurance programs or health insurance programs or activities that receive federal financial assistance, which often discriminate against people with disabilities when they use Quality-Adjusted Life Years in coverage decisions;
- Health care providers and facilities when making medical futility decisions, who often devalue the lives of people with disabilities, and let stereotypes and assumptions about quality-of-life influence their determinations about continuing medical treatment; and
- Physicians providing information on assisted suicide, who are often not aware of and/or do not share information with patients about disability services and supports when

patients seek assisted suicide, and who may rely on stereotypes and assumptions about quality-of-life when assisting a disabled patient toward suicide but may refer a different patient to suicide-prevention care.

We urge OCR to incorporate the recommendations of the NCD from this report series into an updated regulation on Section 504.

2) Crisis Standards of Care and Health Care Rationing During Times of Scarcity

The COVID-19 pandemic illustrated the myriad of ways in which people with disabilities continue to experience discrimination in access to health care services – be it in Crisis Standards of Care, or the absence of program modifications ensuring equal access to information, testing, vaccination, and protective equipment.[2] From State agencies to private health care entities, the prevalence of explicit and implicit bias in health care decision-making was unmistakable, driven by misguided assumptions about the quality of peoples' lives, and by the view that treatments extending the lives of persons with disabilities or other co-morbid conditions are inherently less valuable.

Equally troubling were the ways in which adults and children with disabilities found themselves deprived of the reasonable accommodations they needed to participate in their own care and treatment, and to make and communicate informed medical decisions, including access to designated support persons.

Although brought into stark relief by the pandemic, these issues predated our current public health crisis, and can be found in all levels of care.[3] These forms of discrimination will continue to result in avoidable health care disparities unless structural barriers in access to health care are systemically dismantled. Using the lessons of the pandemic, and building on recent HHS bulletins and guidance, we urge the Department to expressly codify the following obligations for both public and private entities in its proposed rulemaking:

- that federal civil rights laws like Section 504 of the Rehabilitation Act and its prohibitions against discrimination on the basis of disability remain in effect during public health emergencies;
- that Section 504's non-discrimination provisions, reasonable accommodation, and program modification requirements apply to standards of care, including policies or practices defining eligibility for specific levels of care, emergency triage procedures, and assessment tools used to prioritize access to treatment;
- that Section 504 prohibits treatment allocation decisions based on the assumption that a person with a disability has a lower prospect of survival, a lower quality of life, or will require the use of greater treatment resources;
- that covered entities must take affirmative steps to ensure people with disabilities are able to access, participate in, and benefit from medical treatment, and to make informed decisions regarding their own care, through access to designated support persons, and other communication strategies facilitated by interpreters or assistive technology/auxiliary aids;

- that covered entities must not discriminate by delaying or denying access to diagnostic testing or vaccination because the appointment process or testing/vaccination locations are inaccessible or do not provide an equal opportunity to participate in or benefit from the service, and must consider reasonable accommodations including curbside testing/vaccination, home visits, or testing/vaccination at other, accessible locations.

3) Accessibility of Medical Equipment

Millions of Americans with disabilities encounter serious barriers to accessing medical care when equipment, especially diagnostic equipment, is not accessible to them. In particular, items such as examination tables and chairs, weight scales, mammography machines, MRI machines, imaging equipment, and more are often unusable by people with certain disabilities. Oftentimes, patients with disabilities are refused treatment or are unable to undergo necessary parts of their examination due to inaccessibility and the failure to provide reasonable accommodations such as a safe transfer or the concurrent use of a ventilator to ensure these patients can access the care they need.

This can result in undiagnosed and untreated conditions, not to mention inconvenience, burden, and humiliation when people cannot receive care in a provider’s office or other health care settings. Further, the increased use of at-home diagnostic tools, such as blood pressure monitors, thermometers, pulse oximeters, glucose monitors, and others has underscored the need for such equipment to be accessible to and usable by people with disabilities, such as blind individuals or persons with some learning disabilities, who cannot be expected to read the solely visible output of such a device during a telehealth visit.

The Affordable Care Act directed the United States Access Board to develop formal technical standards for accessible medical diagnostic equipment, which were issued after a thorough consensus process in 2017. However, these standards were not further adopted into regulation by an enforcement authority such as OCR or the Department of Justice (DOJ), and thus have had little impact on providers. DOJ had considered rulemaking on this topic itself in 2010, prior to the issuance of the Access Board standards, but these efforts did not progress and were in fact withdrawn entirely in 2017. In 2016, HHS issued a rule, Nondiscrimination in Health Programs and Activities, but deferred proposing accessibility standards for diagnostic equipment since the Access Board was still developing standards. As the National Council on Disability has noted, meaningful systemic improvements in the availability of accessible medical equipment will not be achieved without specific enforceable standards.[4] The Access Board has already developed such standards for people with physical disabilities. As part of HHS’ planned rulemaking on Section 504, we urge you to work with your DOJ colleagues to fully adopt the Access Board standards and add the scoping requirements that will allow the standards to be enforced.

The adoption of the current developed standards is a key first step to ensuring medical equipment accessibility, and one that would meaningfully decrease barriers to access for individuals with mobility, balance, strength, and respiratory impairments. However, equipment must be made accessible across the disability population. Again, we urge the Department to consider the additional accessibility standards needed by individuals with visual, sensory, and other functional limitations. Finally, the Access Board standards are limited by legislative design to a relatively narrow category of diagnostic equipment used primarily in physicians' offices or hospitals. We urge the Department's Section 504 regulations to ensure that all medical equipment is made accessible, including at-home diagnostic tools, telehealth equipment, and other equipment used in the health care setting, such as electronic forms, check-in and billing kiosks, and other frequently inaccessible tools that patients encounter.

4) Discrimination in Benefit Design, Coverage Determinations, and Other

Other frequent forms of discrimination against people with disabilities in health care are when the design of health care benefits excludes certain conditions or disabilities, the structuring of cost-sharing is imposed that discriminates against particular conditions or disabilities, and issuers impose other unnecessary bureaucratic barriers to accessing services such as discriminatory payment structures, non-comprehensive network design, and discriminatory coverage decisions. While Section 1557 also addresses these problems, the anti-discrimination statutes should be clearly aligned. HHS should explicitly address this in regulation by clarifying that Section 504 applies to the design of benefits, cost-sharing, and coverage decisions. At the same time, HHS should reiterate that Section 504, like the ADA, prohibits criteria or methods of administration that have the effect of discrimination. HHS should also clarify that Section 504's antidiscrimination protections extend to discrimination that may be labeled unintentional and to discrimination that results in disparate impacts on protected groups, which should include consideration of defining "solely" to mean proximate cause.

5) Accessibility of Health Care Communications

Throughout the pandemic, the disability community has been concerned about lack of access to mitigation and protection measures. From the beginning of the process to determine vaccine allocation in late summer 2020, CCD flagged the lack of accessible public information.[5] We wrote to OCR in September 2020[6] and April 2021[7] urging action to ensure people with disabilities had access to information about vaccines, as well as access to the vaccines themselves. We were very concerned by the lack of disability knowledge displayed by the CDC Advisory Committee on Immunization Practices.[8] We wrote to CDC Director Walensky in October 2021 urging the CDC to ensure vaccine information was accessible.[9] We wrote to the White House in January of 2022 expressing concerns with the lack of accessible at-home tests. These are just a few of our communications.[10]

Through every step of this pandemic, people with disabilities have been an afterthought in federal government actions. We urge OCR to promulgate a 504 regulation that addresses the requirement that all HHS communications to the public be accessible, including in braille, ASL, and plain language. All versions, including accessible versions, should be released simultaneously. OCR should also ensure that any public health efforts that receive federal funds, such as mass vaccination sites or public health clinics, be accessible to people with disabilities. This includes people with disabilities who have limited English proficiency and who need accessible information in a language they can understand. The intersection of Section 504 and Title VI of the Civil Rights Act (as well as Executive Order 13166) should be noted so that it is clear to all who are protected by, and who must comply with, Section 504.

This also includes ensuring that information and communications technology is accessible: Recipients of federal financial assistance are becoming more and more dependent on information and communication technology to provide goods and services and to share information and data. For people with disabilities, accessibility of websites and other information and communication technology (ICT) is a necessity—not a luxury or a convenience—that fosters independence, economic self-sufficiency, and active, meaningful participation in civic life. These issues are not limited to those with sensory disabilities; many individuals with other disabilities, such as those who use augmentative and alternative communication devices, those with intellectual and developmental disabilities, and many more find that they are unable to access online systems that are integral to modern daily life.

The abstract of the pending rulemaking on Section 504 in the Fall 2021 regulatory agenda does not include the issue of web accessibility, but we note this is a critical component of any refresh of Section 504 regulations and has a clear nexus to the provision of health care, especially during the COVID-19 pandemic. We urge you to ensure that accessibility of ICT is a key aspect of the Section 504 refresh (which of course would also directly impact health care technology, including telehealth platforms). The Administration should ensure that recipients of federal financial assistance ***procure, design, maintain, and use websites and other ICT that are accessible to and usable by the widest range of people with disabilities possible.***

In order to ensure that these Section 504 regulations meaningfully address ICT accessibility, we urge the Administration to include the following key components:

- The regulations should include clear and enforceable ICT accessibility and usability standards that align with current requirements under Section 508 of the Rehabilitation Act, including the incorporation by reference of the internationally accepted Web Content Accessibility Guidelines (WCAG) 2.1 Levels A and AA.
- The regulations should make it clear that Section 504 applies not only to websites, but mobile applications, online systems, and other forms of ICT operated by recipients of federal financial assistance.
- In line with web accessibility settlement agreements reached by DOJ, the regulations should cite acceptable methods to implement website and ICT accessibility, including: Adoption and Distribution of Accessibility Policy; Written Evaluation, Testing, and Accessibility Plans; Feedback; Training & Guidance; and the appointment of a Responsible Individual/Office Coordinators and Consultants.
- The regulations should clarify that Section 504 applies to recipients of federal financial assistance whether or not they operate a physical location offering the same or similar goods or services as their online presence.

6) Assuring the Right to Effective Communication

Finally, we strongly urge the Department strengthen its current Section 5O4 regulations and enforcement efforts to safeguard and assure the effective communication rights of people with speech-related disabilities. Specifically, OCR must take targeted actions to assure the effective communication rights of the estimated 5 million people in this country who cannot rely on speech alone to be heard and understood. Such individuals instead must rely on a range of methods, collectively known as augmentative and alternative communication, or AAC, for short. AAC includes strategies and technologies that range from gesturing, pointing to letters on cardboard, texting, using a speech-generating device, relying on others to revoice what they say, and many other methods. Those who rely on AAC frequently use multiple means of expression and are diverse in terms of race, disability, age of onset, primary language, where they live, and other socioeconomic factors. The research also indicates Black, Indigenous, People of Color, and people whose primary language is not English are more likely to acquire disabilities and conditions that might require them to use AAC and face greater bias, discrimination, and disparities, when accessing AAC when they need it.

The chief causes of the pervasive discrimination and dehumanization many, and we believe probably most people who require AAC, endure are blatant and implicit biases, unwarranted assumptions, and stereotypes. These biases, assumptions, and stereotypes are often rooted in and spurred on by medical, health care, and human services programs, priorities, and practices that HHS is responsible for creating, leading, stewarding, and regulating. HHS can and must seize on this rulemaking process to own, elevate, and bring new tools and approaches to bear on identifying and eliminating such unlawful and frequently egregious discrimination.

To this day, many who require AAC endure the most egregious forms of bias and discrimination: unjustified isolation, institutionalization, illiteracy, illness, ostracism, abuse, violence, and social death. We must end this together. We strongly urge HHS to consider and act on the following. HHS guidance on the effective communication rights of people with hearing and vision disabilities has justifiably evolved consistent with changes in insight and technology. We certainly applaud OCR for making clear in 2020 that people with significant communication disabilities have the right to in-person support to express themselves and be understood by medical professionals when hospitalized during the pandemic.[11] However, few if any changes have occurred over the years, despite this guidance, technical assistance, and enforcement activities on the effective communication rights of those that need AAC.

In 2014, the Departments of Education and Justice issued joint guidance on the effective communication rights of students with a wide range of communication disabilities.[12] We urge OCR to use that guidance as a model to issue comprehensive guidance on communication rights in health care settings for people with speech-related disabilities. Since the first Section 504 regulations were issued in the 1970s, effective communication has been largely viewed by entities as being about the provision of auxiliary aids and services. Access to such aids and services is vital. But being afforded all the aides and services will not completely stop doctors and others from making snap and irrevocable decisions that such persons have little intelligence, are incapable as well as unworthy of being able to communicate, and at times, unworthy of treatment or simply expendable. The prohibition against such discrimination must be made plain and the penalties for violating, including aiding, abetting, and justifying it, must be strengthened, and strictly enforced.

We thank you for your work to improve the health care services received by people with disabilities and all of the work that your agency does. Please contact Claudia Center (ccenter@dredf.org) and Bethany Lilly (lilly@thearc.org) with any questions.

Sincerely,

Allies for Independence
Access Ready
ALS Association
American Association on Health and Disability
American Association of People with Disabilities
American Council of the Blind
American Dance Therapy Association
American Foundation for the Blind
American Psychological Association
Association of People Supporting Employment First
Autism Society of America
Autistic Self Advocacy Network
Autistic Women & Nonbinary Network
Bazelon Center for Mental Health Law
Center for Public Representation
CommunicationFIRST
Disability Rights Education & Defense Fund
Easterseals
Epilepsy Foundation
Family Voices
Justice in Aging
Lakeshore Foundation
Muscular Dystrophy Association
National Alliance on Mental Illness
National Association of Councils on Developmental Disabilities
National Council on Independent Living
National Multiple Sclerosis Society
National PLACE
Paralyzed Veterans of America
The Partnership for Inclusive Disaster Strategies
Spina Bifida Association
Telecommunications for the Deaf and Hard of Hearing
The Arc of the United States
United Spinal Association

United States International Council on Disabilities
The Viscardi Center
World Institute on Disability

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[1] NATIONAL COUNCIL ON DISABILITY, BIOETHICS AND DISABILITY REPORT SERIES (2019) https://ncd.gov/publications/2019/bioethics-report-series.

[2] NATIONAL COUNCIL ON DISABILITY, THE IMPACT OF COVID-19 ON PEOPLE WITH DISABILITIES, October 29, 2021, available at https://ncd.gov/progressreport/2021/2021-progress-report.

[3] Health Affairs; Lisa I. Iezzoni, Sowmya R. Rao, Julie Ressalam, Dragana Bolcic-Jankovic, Nicole D. Agaronnik,Tara Lagu, Elizabeth Pendo, and Eric G. Campbell; *US Physicians' Knowledge About The Americans With Disabilities Act And Accommodation Of Patients With Disability* (January 2022) https://www.healthaffairs.org/doi/abs/10.1377/hlthaff.2021.01136 (in survey of 714 US physicians in outpatient practices, 35.8 percent reported knowing little or nothing about their legal responsibilities under the ADA, 71.2 percent answered incorrectly about who determines reasonable accommodations, 20.5 percent did not correctly identify who pays for these accommodations, and 68.4 felt that they were at risk for ADA lawsuits); Health Affairs; Lisa I. Iezzoni, Sowmya R. Rao, Julie Ressalam, Dragana Bolcic-Jankovic, Nicole D. Agaronnik, Karen Donelan, Tara Lagu, and Eric G. Campbell; *Physicians' Perceptions Of People With Disability And Their Health Care* (2021) https://www.healthaffairs.org/doi/10.1377/hlthaff.2020.01452 (in survey of 714 practicing US physicians nationwide, 82.4 percent reported that people with significant disability have worse quality of life than nondisabled people. Only 40.7 percent of physicians were very confident about their ability to provide the same quality of care to patients with disability, and just 56.5 percent strongly agreed that they welcomed patients with disability into their practices).

[4] NCD, *Enforceable Accessible Medical Equipment Standards: A Necessary Means to Address the Health Care Needs of People with Mobility Disabilities* (May 2021), available at https://ncd.gov/sites/default/files/Documents/NCD_Medical_Equipment_Report_508.pdf.

[5] Consortium for Citizens with Disabilities, Letter (2020) https://c-c-d.org/fichiers/CCD-Vaccine-Allocation-Comments-9-4-20.pdf.

[6] Consortium for Citizens with Disabilities, Letter (2020) https://c-c-d.org/fichiers/CCD-OCR-Vaccine-Allocation-Letter-9-9-20.pdf.

[7] Consortium for Citizens with Disabilities, Letter (2021) https://c-c-d.org/fichiers/CCD-OCR-COVID-Vaccine-Letter-8-21_FINAL.pdf.

[8] *Id*.

[9] Consortium for Citizens with Disabilities, Letter (2021) https://c-c-d.org/fichiers/CCD-letter-to-CDC-on-COVID-vaccine-add-doses-boosters.pdf.

[10] Consortium for Citizens with Disabilities, Letter (2022) https://c-c-d.org/fichiers/CCD-HTF-Letter-on-Covid-Test-Accessibility-012722.pdf.

[11] CommunicationFIRST, *Significant Victory for Patients with Disabilities in Response to Joint CommunicationFIRST Complaint on Hospital No-Visitor Policies* (2020) https://communicationfirst.org/significant-victory-for-patients-with-disabilities-in-response-to-joint-communicationfirst-complaint-on-hospital-no-visitor-policies/.

[12] U.S. DEPARTMENT OF JUSTICE, U.S. DEPARTMENT OF EDUCATION, FREQUENTLY ASKED QUESTIONS ON EFFECTIVE COMMUNICATION FOR STUDENTS WITH HEARING, VISION, OR SPEECH DISABILITIES IN PUBLIC ELEMENTARY AND SECONDARY SCHOOLS (2014) https://www2.ed.gov/about/offices/list/ocr/docs/dcl-faqs-effective-communication-201411.pdf.