



April 26, 2023

Susan E. Rice  
Director, Domestic Policy Council  
The White House  
1600 Pennsylvania Ave NW  
Washington, DC 20500

Melanie Fontes Rainer  
Director, Office for Civil Rights  
Department of Health and Human Services  
200 Independence Avenue, SW  
Washington, DC 20201

Re: Health and Human Services Section 504 Regulations

Dear Directors Rice and Fontes Rainer:

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 free from racism, ableism, sexism, and xenophobia, as well as LGBTQ+ based discrimination and religious intolerance.

The undersigned members of CCD's Rights, Long Term Services and Supports, and Health Task Forces write to **urge you to issue the notice of proposed rulemaking for Section 504 regulations now.**

Section 504 regulations are of the utmost importance to the disability community. As we shared during the February 2022 listening session and in our [April 2022 letter](#), people with disabilities face discrimination in health care in numerous ways, including:

- Discrimination in organ transplants and medical futility decisions;
- Health care rationing during times of crisis;
- Inaccessible medical equipment;
- Discrimination in health care benefit design and coverage determinations;
- Inaccessible health care communications; and
- failure to ensure effective communication.

This year we will celebrate 50 years since Section 504 was enacted. However, Section 504 regulations have not been updated for decades and do not adequately address issues facing people with disabilities today. We are concerned that if the notice of proposed rulemaking is not issued imminently, that there will not be sufficient time for meaningful comment and response prior to the end of the Administration's first term. We also urge you to issue finalized Section 1557 rules as soon as possible, to strengthen protections against disability discrimination in health care.

In a year when we mourn the loss of Judy Heumann and remember how she led a 26-day sit-in to urge the federal government to implement Section 504 regulations, it would be particularly appropriate and meaningful for HHS to act swiftly to issue much-needed updates to these essential protections.

Please feel free to reach out to Jennifer Lav at [jav@healthlaw.org](mailto:jav@healthlaw.org) with any questions or concerns.

Sincerely,

Access Ready  
Allies for Independence  
American Association of People with Disabilities  
American Association on Health and Disability  
American Council of the Blind  
American Speech-Language-Hearing Association  
Association of Assistive Technology Act Programs  
Autistic Self Advocacy Network

Autistic Women & Nonbinary Network  
Bazelon Center for Mental Health Law  
Caring Across Generations  
Christopher & Dana Reeve Foundation  
CommunicationFIRST  
Disability Rights Education and Defense Fund  
Epilepsy Foundation  
Family Voices  
Justice in Aging  
Lakeshore Foundation  
Muscular Dystrophy Association  
National Center for Parent Leadership, Advocacy, and Community Empowerment  
(National PLACE)  
National Disability Rights Network (NDRN)  
National Down Syndrome Congress  
National Health Law Program  
Paralyzed Veterans of America  
Perkins School for the Blind  
RespectAbility  
TASH  
The Arc  
United States International Council on Disabilities  
World Institute on Disability

Cc: Alison Barkoff, Principal Deputy Administrator, ACL  
Rachel Patterson, Director of Disability Policy, DPC  
Jennifer Mathis, Deputy Assistant Attorney General, Civil Rights Division, DOJ  
Sam Bagenstos, General Counsel, HHS