

U.S. Department of Health & Human Services
Office of the Secretary
200 Independence Avenue, S.W.
Washington, D.C. 20201

February 11, 2021

Re: Support for “Discrimination on the Basis of Disability in Critical Health and Human Service Programs or Activities” (RIN: 0945-AA15)

Dear Acting Secretary Cochran:

As the new administration undertakes its important role of regulatory review, we, the undersigned, write in full support of HHS’s continuation of regulatory action in the form of proposed rulemaking on the important issues related to disability nondiscrimination and Section 504 of the Rehabilitation Act raised in the recently issued Request for Information (RFI), “Discrimination on the Basis of Disability in Critical Health and Human Service Programs or Activities” (RIN: 0945-AA15).¹ In addition, we urge HHS to release guidance rapidly on Crisis Standards of Care, as explained below.

Even though much has been accomplished in the near 50 years of the Rehabilitation Act, and having just celebrated the 30th anniversary of the Americans with Disabilities Act, we all recognize that much is left to be done. The COVID-19 pandemic has only underscored and further uncovered discriminatory actions and attitudes in the provision of healthcare against Black and Indigenous people, other people of color, elders, and people with disabilities. With regard to the latter, as recent reports from the National Council on Disability show,² people with disabilities still face significant disparities and obstacles to access in healthcare. The issues addressed in this RFI look to root out the common thread they all share: too many medical professionals see life with a disability as less worth living and less worthy of care, sometimes so much less so that they view death as the correct course. Continuing to allow those sentiments to influence the provision or denial of healthcare in any area addressed by these Section 504 issues is a threat to the integrity and equity of all

healthcare, particularly because anyone at anytime can acquire or age into a disability.

The RFI addresses important protections for people with disabilities such as life-sustaining care, including in times of crisis, such as during natural disasters and pandemics, and the equitable distribution of scarce medical resources in organ transplants. Since HHS has been playing a critical role in investigating and addressing civil rights complaints regarding Crisis Standards of Care across the country, you are no strangers to the fact that triage teams are deprioritizing care to patients with disabilities based on prognoses after COVID survival; and some payers are using subjective “quality of life” metrics such as QALYs as well as “life cycle considerations” which are both subjective and presumptive, not clinically based, and always cut against older adults. Because these discriminatory Crisis Standards of Care continue to be promulgated by states and the lives of people with disabilities are currently at risk, we urge both immediate guidance and long-term, enforceable regulation on this issue. The RFI ensures the accessibility of suicide prevention programs and services, auxiliary communication aids, and support personnel. It also addresses the issue of potentially mandatory accessible medical device standards—an ongoing healthcare access priority for the community. The RFI also speaks to equality in social services so that people with disabilities cannot be summarily barred from custody of their own children or from consideration to adopt; it also solicits comment on the important issue of the *Olmstead* obligations of child welfare entities to ensure children with disabilities are served in the most integrated setting appropriate. Thus, an update as proposed in the RFI to the Section 504 regulations could not be more timely.

In light of these considerations and your Department’s concern for and enforcement authority over the civil rights of people with disabilities and all people in healthcare, we strongly support continued regulatory action in the form of proposed rulemaking as outlined in “Discrimination on the Basis of Disability in Critical Health and Human Service Programs or Activities” (RIN: 0945-AA15).

Thank you very much for your time and consideration.

Sincerely,

American Association of People with Disabilities (AAPD)
Maria Town
President & CEO

American Civil Liberties Union (ACLU)
Ronald L. Newman
National Political Director

American Council of the Blind
Clark Rachfal
Director of Advocacy and Governmental Affairs

Association of Programs for Rural Independent Living
Billy Altom
Executive Director

Autistic Self Advocacy Network (ASAN)
Julia Bascom
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Autistic Women & Nonbinary Network
Sharon daVanport
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Center for Disability Rights, Inc. (CDR)
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National Disability Rights Network
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National Federation of the Blind
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National Organization of Nurses with Disabilities
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Not Dead Yet
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CC:

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Alison Barkoff
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Principal Deputy Administrator
Administration for Community Living

¹ <https://www.hhs.gov/sites/default/files/504-rfi.pdf>

² <https://ncd.gov/publications/2019/bioethics-report-series>