Congress of the United States

Washington, DC 20515

May 26, 2021

Xavier Becerra Secretary Department of Health & Human Services 200 Independence Avenue, SW Washington, DC 20201

Dear Secretary Becerra:

We write to you today to express our strong encouragement for continued action on the Department of Health and Human Services' (HHS) Request for Information (RFI) regarding Section 504 of the Rehabilitation Act, "Discrimination on the Basis of Disability in Critical Health and Human Services Programs or Activities" (RIN: 0945-AA15).¹ While we understand that the Biden Administration placed a freeze on various regulatory actions taken near the end of the previous Administration, we are in full support of this RFI and urge your Administration to prioritize its advancement. We know that discrimination is still all too common in the provision of health care services and, as such, we also encourage HHS, under your stewardship, to pursue interim steps to clarify, emphasize, and enforce existing disability anti-discrimination requirements in health care, especially during the ongoing COVID-19 pandemic.

In 2019, the National Council on Disability (NCD), an independent federal advisory agency, released a series of reports to policymakers that provided extensive documentation of persistent and prevalent forms of disability discrimination in medical decision-making across the whole of the U.S. health care system.² Individuals with disabilities are less likely to receive vitally needed organ transplants,³ are less likely to receive suicide prevention services,⁴ are highly likely to visit doctors or other health care providers who can't serve their needs,⁵ and are more likely to be

¹ [Docket No.: HHS-OCR-2021-0004] RIN: 0945-AA15, 45 CFR Part 84, Discrimination on the Basis of Disability in Critical Health and Human Service, Programs or Activities, Department of Health and Human Services (2020), available at: <u>https://www.hhs.gov/sites/default/files/504-rfi.pdf</u>

² National Council on Disability, Bioethics and Disability Report Series (2019), available at: <u>https://ncd.gov/publications/2019/bioethics-report-series</u>.

³ Push Is On for States to Ban Organ Transplant Discrimination, Kaiser Health News (2021), available at: <u>https://khn.org/news/article/organ-transplant-discrimination-disabilities-state-legislation/</u>

⁴ "Submission re: Draft General Comment on Article 6 of the International Covenant on Civil and Political Rights." Not Dead Yet. October 6, 2017. <<u>https://www.ohchr.org/Documents/HRBodies/CCPR/GCArticle6/NotDeadYet.docx</u>>

⁵ For the disabled, a doctor's visit can be literally an obstacle course — and the laws can't help, Washington Post (2018), available at: <u>https://www.washingtonpost.com/national/health-science/for-the-disabled-a-doctors-visit-can-be-literally-an-obstacle-course--and-the-laws-cant-help/2018/10/26/1917e04c-d628-11e8-aeb7-ddcad4a0a54e_story.html</u>

discriminated against by insurers.⁶ In addition, the COVID-19 pandemic has exposed numerous chilling examples of systemic discrimination against people with disabilities with respect to crisis standards of care, quality of life assessments, and access to treatment.^{7,8}

In addition to the strong body of research substantiating the need for such regulatory action, several diverse coalitions of disability rights, civil and human rights, and racial justice groups have also indicated to the Department's Office for Civil Rights (OCR) their strong support for further regulatory action on the topics addressed in the Section 504 RFI during the regulatory freeze. HHS OCR is uniquely poised to address the ongoing discrimination against those with disabilities in the delivery of health care services, as outlined in the Section 504 RFI. Regulatory action will help our nation take great strides forward to help people with disabilities make health care decisions in a non-coercive environment, in which their lives will be rightfully valued on an equal basis with others. We urge you to issue a proposed rule without delay and to prioritize this RFI and interim guidance given all that is at stake, particularly in view of the ongoing COVID-19 pandemic.

Thank you for prompt attention to this matter, and we look forward to working with you on this critical issue.

Respectfully,

Kirsten Gillibrand United States Senator

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United States Senator

Christopher H. Smith Member of Congress

Katie Porter Member of Congress

 ⁷ Oregon Hospitals Didn't Have Shortages. So Why Were Disabled People Denied Care?, NPR (2020), available at: <u>https://www.npr.org/2020/12/21/946292119/oregon-hospitals-didnt-have-shortages-so-why-were-disabled-people-denied-care</u>
⁸ The Disability Community Fights Deadly Discrimination Amid The COVID-19 Pandemic, Forbes (2020), available at:

⁶ COVID-19 and Disability-Based Discrimination in Health Care, American Bar Association (2020), available at: <u>https://www.americanbar.org/groups/diversity/disabilityrights/resources/covid19-disability-discrimination/</u>

The Disability Community Fights Deadly Discrimination Annu The COVID-19 Pandemic, Forbes (2020), available at: <u>https://www.forbes.com/sites/andrewpulrang/2020/04/14/the-disability-community-fights-deadly-discrimination-amid-the-covid-19-pandemic/?sh=50550df9309c</u>

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Margaret Wood Hassan United States Senator

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Don Young Member of Congress