



**CONSORTIUM FOR CITIZENS  
WITH DISABILITIES**

March 2, 2021

Norris Cochran  
Acting Secretary  
U.S. Department of Health & Human Services  
200 Independence Avenue, S.W.  
Washington, D.C. 20201

Robinsue Frohboese  
Acting Director  
Office for Civil Rights  
U.S. Department of Health & Human  
Services  
200 Independence Avenue, S.W.  
Washington, D.C. 20201

Elizabeth Richter  
Acting Administrator  
Centers for Medicare and Medicaid Services  
U.S. Department of Health & Human Services  
7500 Security Blvd.  
Baltimore, MD 21244

**Re: HHS OCR Request for Information, “*Discrimination on the Basis of Disability in Critical Health and Human Service Programs or Activities,*” RIN 0945-AA15; HHS OCR “*Proposed Modifications to the HIPAA Privacy Rule To Support, and Remove Barriers to, Coordinated Care and Individual Engagement,*” RIN 0945-AA00; HHS OCR Final Rule, HHS CMS and OCR, “*Nondiscrimination in Health and Health Education Programs or Activities, Delegation of Authority,*” RIN 0945-AA11.**

Dear Acting Secretary Cochran, Acting Director Frohboese, and Acting Director Richter:

The undersigned members of the Consortium for Citizens with Disabilities (CCD) Rights and Health Task Forces write to urge HHS to move forward with rules and guidance on the topics that are the subject of the above-captioned Request for Information, to withdraw and revise the above-captioned proposed rule concerning health privacy rights, and to revisit the above-captioned final rule implementing the Affordable Care Act’s non-discrimination provisions. 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.

**Disability Discrimination in Health Programs or Activities:** We strongly support HHS moving forward with rulemaking and guidance on the topics identified in the Request for Information, “*Discrimination on the Basis of Disability in Critical Health and Human Service Programs or Activities*,” RIN 0945-AA15. These topics—discrimination in organ transplantation, discrimination in life-saving or life-sustaining care decisions, discrimination in suicide prevention services, discrimination in crisis standards of care, discrimination in health care value assessment methodologies, discrimination in child welfare systems, and auxiliary aids and accessible medical equipment—are all of critical importance to people with disabilities and addressing these issues is a top priority for the disability community. In each of these areas, people with disabilities experience systematic and pervasive discrimination based on unfounded assumptions concerning the quality and value of their lives or their capabilities. There is a long history of devaluing disabled lives and older lives in medical decision-making and in child welfare systems.

With respect to crisis standards of care, however, we urge you to move forward first with guidance rather than waiting to complete a rulemaking. Discrimination on the basis of disability and age remains a critically important issue as the COVID-19 pandemic continues, and discriminatory provisions in crisis standards of care have the potential to end the lives of people with disabilities and older adults across the nation. We are now also seeing critical delays in vaccinations for people with disabilities due to flawed vaccine allocation and prioritization systems in many states. The lengthy period required to complete a rulemaking process is ill-suited to the urgent nature of these problems and the need for immediate guidance from HHS to ensure that states and hospitals eliminate discriminatory provisions in their crisis standards of care and vaccine allocation systems. We urge HHS to issue immediate guidance on these topics, expanding on the initial [guidance](#) issued on March 28, 2020. Since that initial guidance, HHS has resolved a number of complaints challenging discriminatory crisis standards of care and further guidance is warranted to articulate the principles forming the basis for those resolutions. Notably, the National Academy of Medicine, American Medical Association and others have [called for immediate action](#) to ensure non-discriminatory crisis standards of care. The time to act is now.

With respect to discrimination in child welfare systems and auxiliary aids and accessible medical equipment, we hope and expect that HHS would proceed jointly with the Justice Department, which has authority to enforce the ADA in these areas, has previously issued joint guidance documents with HHS concerning disability discrimination in child welfare systems, and previously issued an ANPRM concerning accessible medical equipment that was [withdrawn](#) by the Trump Administration.

With respect to the issue of disability-based discrimination in suicide prevention services, we believe this issue is of tremendous importance. We urge HHS to avoid suggesting that individuals with disabilities lack the capacity to make healthcare decisions or that their disabilities should make them ineligible for services offered to others. Rather, the appropriate focus of a rulemaking should be decisions to deny suicide prevention services to individuals based on their disabilities or steer them away from such services based on unfounded assumptions about the quality or value of their lives. We are also concerned that suicide prevention services too often involve involuntary treatment and institutionalization; while it is crucial that people with disabilities be protected against discrimination in access to suicide prevention services, HHS should focus on voluntary, community-based suicide prevention services such as engagement and counseling.

**Modifications to the HIPAA Privacy Rule:** We urge HHS to withdraw the proposed rule published in the Federal Register on January 21, 2021 for review and to reissue a new proposed rule that removes the proposals to weaken important HIPAA protections by eliminating the requirement to exercise professional judgment in determining whether various exceptions apply, by eliminating the requirement that harm be imminent for the “imminent danger” exception to apply, by focusing specifically on individuals with serious mental illness and substance use disorders and suggesting that they deserve lesser privacy protections, by adding language that would treat mental health professionals’ obligations differently from those of other health professionals, and by eliminating the requirement to disclose only the minimum information necessary for providers engaged in case management or care coordination.

These proposed provisions would cause serious harm and interfere with the ability to receive effective treatment. The current HIPAA rules strike an appropriate balance that allows individuals to seek treatment without fear that information disclosed in confidence will be disclosed against their wishes except in very narrow circumstances. Moreover, the proposed rule fails to point to any specific instances in which the current HIPAA regulations posed a problem. The proposed rule simply cites generalized statements from individuals complaining that the current rule creates “uncertainty”—precisely the type of statements that the Supreme Court has said are not a sufficient basis to enact a regulatory change. *Motor Veh. Mfrs. Ass'n v. State Farm Ins.*, 463 U.S. 29, 52 (1983). Moreover, the types of uncertainties described have been addressed and clarified through guidance documents issued by HHS concerning HIPAA’s application to situations involving individuals with serious mental illness. Indeed, Congress specifically considered and rejected provisions that would have made changes similar to those in the proposed rule, but opted instead, in the 21<sup>st</sup> Century Cures Act, to direct HHS to issue guidance explaining HIPAA’s application to particular circumstances involving individuals with serious mental illness.

**The Affordable Care Act's Non-Discrimination Protections:** We urge HHS to issue a new proposed rule reversing the harmful rule implementing Section 1557 of the Affordable Care Act issued by the Trump Administration. While the new rule has received a great deal of attention for its misinterpretation of the law concerning discrimination based on sexual orientation and gender identity, it also misinterprets the law in many other important respects. For example, it largely eviscerates Section 1557's non-discrimination protections with respect to insurance coverage, inappropriately excludes HHS's own activities from the reach of Section 1557, and eliminates protections against discrimination in benefit design. It also guts critical protections for people who are limited English proficient and eliminates the notice that informs individuals of their rights and how to complain if they are discriminated against. We urge HHS to issue a new rule restoring the protections from the prior Section 1557 rule and strengthening those protections, including by identifying what types of actions constitute discrimination in benefit design.

Thank you for your attention to these important issues.

Sincerely,

Allies for Independence

American Council of the Blind

American Foundation for the Blind

American Occupational Therapy Association

American Physical Therapy Association

American Speech-Language-Hearing Association

American Therapeutic Recreation Association

The Arc of the United States

Autism Society of America

Autistic Self Advocacy Network

Bazelon Center for Mental Health Law

Center for Public Representation

Children and Adults with Attention-Deficit/Hyperactivity Disorder

Christopher and Dana Reeve Foundation

CommunicationFIRST

Disability Rights Education and Defense Fund

Easterseals

Epilepsy Foundation

Justice in Aging

National Association of Councils on Developmental Disabilities

National Center for Parent Leadership, Advocacy, and Community Empowerment

National Council on Independent Living

National Disability Rights Network

National Down Syndrome Congress

National Health Law Program

The National Multiple Sclerosis Society

RespectAbility

Spina Bifida Association

TASH

United Cerebral Palsy

United Spinal Association

United States International Council on Disabilities

World Institute on Disability

cc: Alison Barkoff, Acting Administrator and Assistant Secretary for Aging and Principal  
Deputy Administrator, ACL  
Tom Coderre, Acting Assistant Secretary for Mental Health and Substance Use