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Office for Civil Rights Department of Health and Human Services 200 Independence Avenue, S.W. Washington, D.C. 20201

Submitted via Regulations.gov

Re: Discrimination on the Basis of Disability in Health and Human Service Programs or Activities (88 FR 63392)

The AAMC (Association of American Medical Colleges) is a nonprofit association dedicated to improving the health of people everywhere through medical education, health care, medical research, and community collaborations. Its members are all 158 U.S. medical schools accredited by the <u>Liaison Committee on</u> <u>Medical Education</u>; 13 accredited Canadian medical schools; approximately 400 teaching hospitals and health systems, including Department of Veterans Affairs medical centers; and more than 70 academic societies. Through these institutions and organizations, the AAMC leads and serves America's medical schools and teaching hospitals and the millions of individuals across academic medicine, including more than 193,000 full-time faculty members, 96,000 medical students, 153,000 resident physicians, and 60,000 graduate students and postdoctoral researchers in the biomedical sciences. Following a 2022 merger, the Alliance of Academic Health Centers and the Alliance of Academic Health Centers International broadened the AAMC's U.S. membership and expanded its reach to international academic health centers. Learn more at aamc.org.

The goal of the AAMC Center for Health Justice (the Center), founded in 2021, is for all communities to have an opportunity to thrive — a goal that reaches well beyond medical care. Achieving health equity means addressing the common roots of health, social, and economic injustices and implementing policies and practices that are explicitly oriented toward equal opportunity. The Center for Health Justice partners with public health and community-based organizations, government and health care entities, the private sector, community leaders, and community members to build a case for health justice through research, analysis, and expertise. For more information, visit aamchealthjustice.org.

General Comments

The AAMC and the Center appreciate the opportunity to comment on the Department of Health and Human Services' (HHS) proposed amendments to Section 504 of the Rehabilitation Act of 1973 (section 504). HHS has added new and clarifying requirements "prohibiting recipients of financial assistance from the Department [] from discriminating on the basis of disability in their programs and activities, including in health care, child welfare, and other human services."¹ These long-awaited revisions mark the first major update to Section 504 in nearly 50 years and will facilitate equitable and effective health care for people with disabilities, currently the largest minority group in the United States.² As noted in the Preamble, "[p]eople with disabilities are often excluded from health care."³ HHS goes on to emphasize "[t]hat discrimination contributes to significant health disparities and poorer health outcomes than persons with disabilities would experience absent the discrimination.⁴ We agree and add that uprooting ableism and

¹ 88 Federal Register 63392.

² American Community Survey, 2021. U.S. Census Bureau, available at <u>https://data.census.gov/table?q=disability</u>

³ 88. Fed Reg. 63394.

⁴ *Id*.

ensuring equitable access to healthcare, health programs, and related activities for people with disabilities is critical for ensuring overall health and advancing health equity, especially since historically marginalized groups with disabilities have unequal access to adequate health care and experience poorer health outcomes.⁵

The Center expresses strong support for the proposed changes to section 504 and the broader steps HHS is taking outside of this rulemaking process to engage other federal agencies (e.g., Department of Justice, Centers for Medicare and Medicaid, Centers for Disease Control), as well as state and local entities in this effort. As noted in the Center's letter to the White House Office of Management and Budget in response to a 2021 request on *Methods and Leading Practices for Advancing Equity and Support for Underserved Communities Through Government*, we reiterate the importance of interagency coordination to ensure successful implementation of this proposed rule, as well as the Administration's broader commitment to a whole-of-government approach to *Advancing Diversity Equity, Inclusion and Accessibility* pursuant to Executive Order 14035⁶ and HHS' plan for *Equitable Long-Term Recovery and Resilience*.⁷

We believe these updates will improve consistency with developments in the legislative, legal, regulatory, and sociotechnical landscape, together are critical for advancing nondiscrimination in HHS-funded programs and activities and achieving equity for people with disabilities. Our comments respond to three key changes in the proposed rule and express support for the following:

- Revisions to the definition of disability, including removal of the word "handicapped"
- Expansion of electronic technology (i.e., web, mobile, kiosk accessibility) to increase accessibility
- Prohibition of discrimination in medical treatment and decision-making.

Definition of Disability and Use of "Handicapped" (§ 84.4)

One of the most significant changes in the proposed rule is the update to the definition of "disability" to ensure consistency with statutory changes to the Rehabilitation Act, the American with Disabilities Act (ADA), the Americans with Disabilities Amendments Act (ADAAA) of 2008, the Affordable Care Act, and numerous state and Supreme Court cases. Specifically, the proposed rule broadens the definition to ensure those covered under other statutes will not be unnecessarily excluded in the application of HHS policies — "an individual with a disability who, *with or without* [emphasis added] reasonable modifications to rules, policies, or practices, the removal of architectural, communication, or transportation barriers, or the provision of auxiliary aids and services, meets the essential eligibility requirements for the receipt of services or the participation in programs or activities provided by a recipient."⁸

We support the broadened reach of the proposed definition since it allows "qualified individuals" with a disability increased protections under the ADA. Consistency with the ADA also promotes better compliance by regulated entities and minimizes administrative burden. We also note the important change from the use of the term "qualified handicapped person" to "qualified individual with a disability." This

⁵ Megan Buckles and Mia Ives-Rublee, "Improving Health Outcomes for Black Women and Girls With Disabilities" (Washington: Center for American Progress, 2022), available at <u>https://www.americanprogress.org/article/improving-health-outcomes-for-black-women-and-girls-with-disabilities/</u>.

⁶ AAMC Comments, OMB Request for Information: Methods and Leading Practices for Advancing Equity and Support for Underserved Communities Through Government, OMB 2021-0005, OMB Request for Information: Methods and Leading Practices for Advancing Equity and Support for Underserved Communities Through Government, OMB 2021-0005. This request was in furtherance of Executive Order 13985, Advancing Racial Equity and Support for Underserved Communities Through Federal Government (see also, Executive Order 14035, Advancing Diversity Equity, Inclusion and Accessibility).
⁷ Equitable Long-Term Recovery and Resilience

https://health.gov/our-work/national-health-initiatives/equitable-long-term-recovery-and-resilience (last visited October 27, 2023). 8 88 Fed. Reg. 63404.

change mirrors the Rehabilitation Act Amendments of 1992 which updated the phrase "handicapped person" to "individual with a disability."⁹

The Center is especially supportive of efforts that improve our collective understanding of advancing language that is precise, inclusive, respectful and action oriented. As stated in the Center for Health Justice's and American Medical Association's, *Advancing Health Equity:* A *Guide to Language Narrative and Concepts*, "[d]ominant narratives create harm, undermining public health and the advancement of health equity; they must be named, disrupted and corrected"¹⁰ In the spirit of transparency and public understanding of HHS' rationale for adopting changes to certain definitions and not others, we encourage the inclusion of an evidence-based rationale in the final rule (if finalized). We also recommend close coordination with the disability community to identify *additional* linguistic preferences and to assist with the wide distribution of *accessible* educational material and FAQs related to the key changes in the proposed rule.

Web, Mobile, and Kiosk Accessibility (§80.82–§80.88)

Over the last few decades there have been substantive advancements in health technology, including the deployment of innovative methods for communicating and engaging patients and research participants during the COVID-19 pandemic (e.g., virtual video conference). However, despite improvements to the technological landscape, full and equal access to health-related technology remains an issue. In the proposed rule, HHS describes technology as "crucial gateways to health and human services activities."¹¹ We agree and emphasize that current technological barriers restrict access to services that individuals with disabilities might have otherwise benefited from, especially individuals that solely rely on technology when in person services are inaccessible.¹² To improve accessibility, HHS recommends improvements to web content, mobile applications, and self-service kiosks/transaction machines.

We appreciate HHS' interest in improving accessibility and are also pleased to see the incorporation of recommendations from the DOJ's recent proposed rule on website accessibility.¹³ Given the complicated nature related to both implementing new web-based technology and the adoption of technical standards for web and mobile accessibility,¹⁴ we encourage HHS take additional steps in coordination with other agencies and relevant entities to ensure consistency in implementation and deployment. We also encourage HHS to create additional opportunities for public feedback on additional approaches that better account for diverse experiences by *type* of disability (e.g., kiosks may still prevent/limit accessibility based on the type of disability, telehealth design limitations).

The proposed updates to web and mobile accessibility from both the HHS and DOJ are a critical component for creating an inclusive healthcare system that promotes accessibility for all individuals and populations. Notably, both proposed rules are focused on Title II of the ADA, pertaining to public under state and local governments. However, neither include places of public accommodation, as found in Title III of the ADA, leaving a gap in the service to individuals with disabilities in these locations.

⁹ Fed Reg.

¹⁰ Association of American Medical Colleges, American Medical Association, Advancing Health Equity: A Guide to Language, Narrative and Concepts (2021), https://www.ama-assn.org/system/files/ama-aamc-equity-guide.pdf.
¹¹ 63418

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 ¹² U.S. Dep't of Health & Hum. Servs., Off. for Civil Rts., Guidance and Resources for Electronic Information Technology: Ensuring Equal Access to All Health Services and Benefits Provided through Electronic Means (Dec. 21, 2016), Available at https://www.hhs.gov/guidance/sites/default/files/hhs-guidance-documents//ocr-guidance-electronic-information-technology.pdf
 ¹³ 88 Fed. Reg. 63393

¹⁴ "The Department believes that adopting technical standards for web and mobile app accessibility will provide clarity to recipients regarding how to make the programs and activities they offer the public via the web and mobile apps accessible. Adopting specific technical standards for web and mobile app accessibility will also provide individuals with disabilities with consistent and predictable access to the websites and mobile apps of recipients." Fed. Reg. 63424.

Denial of Medical Treatment (§ 84.56(b)(1))

This section proposes that any recipient of federal funding from HHS cannot make treatment decisions rooted in bias or stereotypes about people with disabilities, judgements that an individual will be a burden to others, or the belief that the life of an individual with a disability has less value than the life of an individual without a disability.¹⁵ We appreciate that these changes explicitly clarify that medical decisions should *not* be based on the perception of disability, but rather the treatment's effectiveness or other legitimate reasons (e.g., "[i]n denying access to ventilator support, the doctor has violated proposed § 84.56(b)(1)(iii). If the physician also denied the ventilator support because of a perception that it would be a burden for his husband to care for the patient, the physician would also have violated § 84.56(b)(1)(ii)"¹⁶).

Even when a denial of treatment, limitation, or recommendation for alternative treatment is based on factspecific judgment, ethical and legal challenges may arise. To assist with implementation of these proposed changes and ensure the goals of §84.56 are achieved, we recommend the issuance of supporting FAQs, which should be co-developed with the disability and medical professional communities.

Additional Considerations

As HHS reviews the comments received from this request and considers additional areas for improvement, we suggest the following:

- Accessible Medical Equipment (§ 84.90–§84.94): In a 2021 report, the National Council on Disability recommended the DOJ and HHS adopt the medical diagnostic equipment standards developed by the U.S. Access Board,¹⁷which provides technical criteria for medical diagnostic equipment. In consideration of these recommendations, we encourage HHS work with the U.S. Access Board and the Department of Justice to develop related guidance. Consideration should also be given to the General Services Administration's framework for implementing the technology accessibility standards under Section 508 of the Rehabilitation Act.
- Workforce Considerations: Supporting individuals with disabilities within the federal government is
 important to ensure equal and full participation in the federal workforce. We recommend HHS partner
 with other agencies so they are adequately informed of the updates in this proposed rule and reflected
 in agency strategic plans (e.g., HHS Strategic Plan for Diversity Equity, NIH Inclusion and
 Accessibility).¹⁸ This will assist with the identification of knowledge gaps, trainings, equitable hiring
 decisions, among other things.
- Social Determinants of Health: As HHS considers public feedback in response to this proposed rule, we recommend consideration of the multidimensional impact the presence or absence of the Vital Conditions for Health have on the disability community (e.g., lifelong learning, humane housing, nutritious food, civic muscle, etc.¹⁹) and recommend consideration of the HHS report produced by the

¹⁹ Organizing Around Vital Conditions Moves The Social Determinants Agenda Into Wider Action.

¹⁵ 88 Fed. Reg. 63395.

¹⁶ 88 Federal Register 63404.

¹⁷ Nat'l Council on Disability, Enforceable Accessible Medical Equipment Standards: A Necessary Means to Address the Health Care Needs of People with Mobility Disabilities (2021), available at https://ncd.gov/publications/2021/enforceable-accessible-medical-equipment-standards

¹⁸ See, HHS Strategic Plan for Diversity Equity, Inclusion and Accessibility, <u>https://www.hhs.gov/sites/default/files/2022-hhs-deia-strategic-plan.pdf</u>, see also, AAMC Comments on NIH Strategic Plan for Diversity, <u>https://www.aamc.org/media/60231/download?attachment</u>.

https://www.healthaffairs.org/content/forefront/organizing-around-vital-conditions-moves-social-determinants-agenda-into-wideraction (last visited October 27, 2023).

Office of the Assistant Secretary for Planning and Evaluation, Addressing Social Determinants of Health in Federal Programs.²⁰

Ongoing Community Input: Finally, continued and robust bi-directional collaboration with members of the disability community, including racial and ethnic minorities and LGBTQIA+ people is paramount to the success of this endeavor. This will help ensure supplementary agency action meaningfully incorporates the diverse wisdom of the disability community. For example, the National Institutes of Health (NIH), National Institute on Minority Health and Health Disparities (NIMHD) recently designated people with disabilities as a population with health disparities for research supported by the NIH,²¹ finding that "persons living with disabilities face tremendous health disparities that impact quality of life, morbidity, and mortality, as well as discrimination, based on their abilities and identity"²² Notably, this decision was made after substantial input from the research community (over 1,000 organizations and individuals) including the AAMC Center for Health Justice.²³ In furtherance of this conjecture, HHS should establish a permanent mechanism for regular community engagement to ensure regulatory decision-making, including agency advisory committee decisions reflect expertise of individuals with disabilities, health equity experts, and other advocates.

The AAMC and the AAMC Center for Health Justice appreciate the opportunity to comment on this important undertaking and would be happy to provide additional information on any of the recommendations offered. The Center works with a very active and engaged health equity community²⁴ and would be happy to facilitate input on related guidance or educational materials as HHS takes next steps to finalize this rule. For questions about these comments, please contact the undersigned or our colleagues, Daria Grayer, Director, Regulation and Policy (dgrayer@aamc.org) and Anurupa Dev, Director, Science Policy and Strategy (adev@aamc.org).

Sincerely,

Philip M. Alberti, PhD Founding Director, AAMC Center for Health Justice Senior Director, Health Equity Research and Policy

cc: David J. Skorton, MD, President and Chief Executive Officer Heather H. Pierce, JD, MPH, Acting Chief Scientific Officer

²⁰ https://aspe.hhs.gov/topics/health-health-care/social-drivers-health/addressing-social-determinants-health-federal-programs (last visited October 26, 2023).

²¹ NIH designates people with disabilities as a population with health disparities (NIH, 2023). Available at https://www.nih.gov/news-events/news-releases/nih-designates-people-disabilities-population-health-disparities

²² Final Progress Report, National Advisory Council on Minority Health and Health Disparities (NACMHD) Working Group on Persons Living with Disabilities (NIH, 2023). <u>https://nimhd.nih.gov/docs/advisory-</u> <u>council/nacmhd_workGrpOnHealthDisparitiesAndPeopleWithDisabilities_report_2023sept.pdf</u>. ²³ Sign-On Letter to HHS Sec. Becerra on Recommendation of the National Institute of Minority Health and Health Disparities

⁽NIMHD) Advisory Committee (2023). Available at https://www.aamc.org/media/69406/download.

²⁴ See, The AAMC Collaborative for Health Equity: Act, Research, Generate Evidence (CHARGE), https://www.aamchealthjustice.org/get-involved/aamc-charge.