

CCD Comments Summary on the Notice of Proposed Rulemaking on Discrimination on the Basis of Disability in Health and Human Service Programs or Activities

Members of the Consortium for Constituents with Disabilities (CCD) Emergency Management, Employment, Health Care, Long Term Services and Supports, Rights, and Technology and Telecommunications Task Forces came together to draft comments in response to the historic HHS proposed rule, Discrimination on the Basis of Disability in Health and Human Service Programs or Activities. A link to the proposed rule, fact sheets and additional resources can be found at https://acl.gov/504rule.

The Joint Task Force CCD comments (CCD Comments) addressed questions regarding continued discrimination in medical treatment, value assessment methods, child welfare programs and activities, website and mobile applications accessibility, telemedicine portal access with assistive technology, accessible medical equipment, and integration. The comments also addressed supported decision-making, obligations during public health emergencies; raise concerns regarding the use of algorithms and its biased application, the need for greater clarity in the discussion of service animals and the construction of the phrase "solely by reason of his or her disability" among other issues. Summaries of each section are below. The full draft of the final CCD HHS 504 comments submitted November 13, 2023 is available online (url: https://www.c-c-d.org/fichiers/CCD-HHS-504-Comments-DocketNo2023-19149-111323.pdf).

CCD JOINT TASK FORCE HHS 504 NPRM COMMENTS SUMMARY

A. New Provisions Addressing Discrimination on the Basis of Disability Under Section 504

Medical Treatment and Value Assessment Methods

The CCD Comments strongly support the new regulatory provisions on discrimination in medical treatment (§84.56) and value assessment methods (§ 84.57). The commentary set forth in the Preamble presents a compelling rationale and a persuasive legal analysis of the doctrinal basis for these provisions. The comments also endorse, and wish to emphasize the importance of, language that prohibits disability-based discrimination in the informed consent process (§ 84.56(c)(2)(ii)), including the provision of medical advice and the process for providing information on available treatment options. These new regulatory requirements address the key forms of discrimination that were long standing even before the pandemic and that were elevated during the pandemic, and they are consistent with both the purpose and case law of Section 504. The proposed provision on value assessment methods (§ 84.57) should be amended include a prohibition on the discriminatory use of such tools that devalue either: (a) the extension of life years for people with disabilities; or (b) their quality of life, including provision of treatment that alleviates suffering.

Children, Parents, Caregivers, Foster Parents, and Prospective Parents with Disabilities in the Child Welfare System (§84.60)

The CCD Comments strongly support the inclusion of the new child welfare provisions in the proposed regulation, especially the intentional focus on the discrimination that is rampant in the child welfare system, which will be extremely helpful to the field. The comments ask that HHS make clear that the proposed child-welfare-specific regulatory language is not comprehensive of all requirements applicable to child welfare agencies under Section 504 and must not be seen as narrowing or limiting covered entities' existing and long-standing obligations under Section 504 or the ADA. Instead, this proposed language helpfully addresses and clarifies several aspects of discrimination that are particularly common and problematic in this context to help ensure better compliance and strengthen the existing protections in Section 504. The comments also make several specific recommendations to clarify the statutory language by adding specifics that will assist government actors and the field in meeting the requirements of the integration mandate and working to end disability discrimination throughout the child welfare system. This section of the comment proposes specific revisions to the regulatory language, as well as the preamble and commentary, with separate subsections on parents and children in the supporting comments.

Subpart I: Web, Mobile and Kiosk Accessibility

The CCD Comments applaud the department for adopting an accessibility requirement for websites, mobile apps, and kiosks. The comments suggest that the Department consider requiring all information and communications technology to be accessible. The comments urge the Department to adopt the latest WCAG standard, which would be WCAG 2.2, Level AA, for all entities and all content. We also call for the adoption of a functional definition of accessibility that would ensure compliance focuses on actual lack of access, in addition to

addressing conformance with the WCAG standard. However, we categorically oppose the seven exemptions which will make certain kinds of content inaccessible in perpetuity, which would reduce the incentives for vendors and third parties to provide accessible content, and which could increase in some cases the burdens on recipients to provide accessible formats on a case-by-case basis. The department should instead rely on existing undue burden and fundamental alteration exemptions.

Subpart J - Accessible Medical Equipment

The CCD Comments urge HHS to adopt the Access Board's MDE Standards and a 17-inch low transfer height. HHS should also require 100 percent of new purchased, leased, or acquired medical diagnostic equipment (MDE) meet these standards, regardless of the provider or clinic's medical specialty. Until 100 percent accessible equipment is achieved, CCD recommends recipients provide other disability accommodations needed, like accessible transportation at no cost to the patient. The CCD Comments propose that recipients have an accessible weight scale in one year and accessible exam tables and chairs in two years. In addition, HHS should adopt a reasonable, but not delayed, timeframe for other types of MDE. The CCD Comments request HHS collaborate with the Access Board to develop standards for non-MDE and equipment standards for patients with sensory disabilities, intellectual and developmental disabilities, and multiple disabilities. The comments also advocate for significant staff training, to ensure staff are qualified to book, maintain, and safely use accessible MDE.

B. Revised Provisions Addressing Discrimination and Ensuring Consistency with Statutory Changes and Significant Court Decisions

Auxiliary Aids and Services

The CCD Comments recommend adding digital readers to definition of Auxiliary aids and services. We also recommend adding "and accessible formats may be considered as technological advancements are made" to definition of Auxiliary aids and services. The CCD Comments support the proposal to make no distinction between public and private programs or activities.

Revisions to Subpart C: Program Accessibility

The CCD Comments support HHS' proposal to require new construction and alterations adhere to accessibility standards. The CCD Comments also urge HHS to include language that recipients must adhere to accessibility standards issued in the future. In addition, if a recipient uses an alternative method for access, the recipient must engage in an interactive process with the patient and give due considerations to the patient's preference.

Reasonable Modifications and Supported Decision-Making

The CCD Comments support express recognition of SDM as a reasonable modification. The comments recommend adding an example highlighting recipients' obligations to allow for designated support person(s) for people with disabilities who need them to enjoy equal access to health and human services and supports.

Revisions to Subpart D: Childcare, Preschool, Elementary and Secondary, and Adult Education The CCD Comments support the proposal to broaden description of covered services beyond "day care" by adding "childcare". The comments support the clarification that Section 504 applies to all recipients of Federal funding, including public or private preschools, childcare centers, family childcare homes, and other entities that receive Federal funds including through a grant, loan, contract, or voucher. The comments support the clarification that recipients must provide auxiliary aids and services; make reasonable modifications; and integrate children, parents, and guardians with disabilities into their programs.

Maintenance of Accessible Features (§ 84.70)

The CCD Comments support the proposal that recipients must maintain all accessible features, but explicitly extends this requirement to auxiliary aids and services.

Service Animals (§§ 84.10, 84.73)

The CCD Comments concur with HHS adding a new "service animals" section to its regulation and with provisions which mirror ADA Title II regulations. The comments request the Department clarify that the service animal's handler is typically the person with a disability and to explicitly recognize the various means through which a person with a disability may establish and maintain control over a service animal. The comments also request that HHS incorporate DOJ guidance to clarify that "care or supervision" means routine animal care; that service animals are not required to wear a vest, ID tag, or specific harness; and that service animals must be allowed in medical settings, including anywhere the public and patients are allowed to go.

Mobility Devices (§ 84.74)

The CCD Comments agree that HHS should adopt the ADA's definition of wheelchair and other power-driven mobility device to ensure blanket bans on mobility devices are not used to exclude people with disabilities.

Direct Threat (§§ 84.10, 84.75)

The CCD Comments generally agree with defining "direct threat" to be consistent with ADA Title I and II regulations, and recommend minor additions from ADA regulations that clarify the limitations of the affirmative defense. In 84.10 commentary, the comments push back against the suggestion that a person determined to pose a direct threat is not "qualified" and suggest alternate language. In 84.75 commentary, we ask HHS to clarify that the direct threat analysis is focused on the individual; requires a fact-specific, individualized assessment; and cannot be used to justify or support blanket bans of wheelchairs, power wheelchairs, or other mobility assistive devices.

Integration (§§ 84.10, 84.76)

The CCD Comments generally endorse this section of the proposed rule. In response to HHS questions, the comments recommend defining the most integrated setting as one that enables people with disabilities to live as much as possible like people without disabilities. The comments agree with HHS, DOJ, and numerous circuit courts that a plaintiff need not wait until

the harm of institutionalization or segregation occurs in order to bring a claim and seek prospective injunctive relief. The comments support the application of civil rights standards to all situations where people with disabilities receive or are eligible for healthcare, including circumstances in which a covered entity is providing healthcare in accordance with Medicaid. The comments cite to an NCD report in calling on HHS to address ways to mitigate discrimination against people with disabilities during public health emergencies and disasters. Finally, the comments respond to HHS questions to clarify what may or may not constitute a fundamental alteration.

C. Additional Considerations

Requesting Further Guidance on "Solely"

The CCD Comments request that the Agency provide more regulatory and guidance language on the construction of the phrase "solely by reason of his or her disability" found in Section 504. The phrase has become a textual battleground in cases that threaten to gut disability civil rights, and additional language would be enormously helpful.

Section 1557

Section 1557 of the Affordable Care Act is the most important and specific nondiscrimination provision operating at the junction of disability rights and healthcare since the passage of the ADA. The CCD Comments strongly urge HHS to further parse out how Section 504 and Section 1557 work together to protect people with disabilities from common discriminatory barriers that arise across multiple types of healthcare entities including automated decision-making, benefit design and the collection of disability data fir demographic purposes.

Burden of Section 504 Complaint-Drive Compliance

DOJ recognized that relying on complaints alone to enforce civil rights was not adequate when it launched Project Civic Access, a tool that utilizes settlement agreements. To successfully facilitate compliance the comments recommend a similar tool be developed, funded, adequately staffed and fully implemented.