



October 3, 2022

SUBMITTED ELECTRONICALLY VIA www.regulations.gov

Melanie Fontes Rainer
Director, Office for Civil Rights
Department of Health and Human Services
200 Independence Avenue, SW
Washington, D.C. 20201

RE: Nondiscrimination in Health Programs and Activities [HHS-OS-2022-0012, RIN 0945-AA17]

Dear Director Fontes Rainer:

The undersigned members of the Habilitation Benefits Coalition (HAB) appreciate the opportunity to comment on the Department of Health and Human Services' (HHS') proposal to revise the regulations in Section 1557 of the Patient Protection and Affordable Care Act (ACA), pursuant to *RIN 0945-AA17, Nondiscrimination in Health Programs and Activities*. The HAB Coalition is a group of national nonprofit consumer and clinical organizations focused on ensuring appropriate access to, and coverage of, habilitation services and devices, including benefits within the essential health benefit (EHB) category known as "rehabilitative and habilitative services and devices" under Section 1302 of the Affordable Care Act.

HAB strongly supports the proposed rule and urges HHS to finalize it as expeditiously as possible—with modifications to strengthen the rule where necessary. We are pleased to see that the current proposed rule would reverse many, if not all, of the most egregious changes to the final 2019 rule governing multiple issues impacting people with disabilities. The current proposed rule would restore key provisions from the original regulations promulgated in 2016 by clarifying and strengthening nondiscrimination protections for people with disabilities and other populations that have experienced discrimination and barriers to receiving equitable and effective healthcare.

I. Background

Section 1557 of the ACA was enacted as a broad provision to prohibit discrimination on the basis of the federally protected categories of race, color, national origin, disability, age, and sex in the provision of health care. The rule applies to any health program or activity that receives federal financial assistance, any program or activity that is administered by an executive agency under Title I of the ACA, and any entity established under Title I of the ACA.¹ The protections in Section 1557 are based on a variety of nondiscrimination and civil rights laws with longstanding support throughout the United States, including the Civil Rights Act of 1964, the Rehabilitation Act of 1973, and the Americans with Disabilities Act of 1990, to name a few.

¹ Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 1557, 124 Stat. 119, 260 (210) (codified at 42 U.S.C. § 18116).

Section 1557 of the ACA was particularly important for habilitation benefits, given that before explicit coverage of habilitative services and devices was mandated as part of the EHB package under the ACA coverage of *habilitation* services and devices was much less common in private insurance and prime for discriminatory policies.

On May 18, 2016, the HHS Office of Civil Rights (OCR) finalized its first set of regulations implementing Section 1557 at 45 C.F.R. Part 92.² For historical context, when the Americans with Disabilities Act (ADA) was enacted in 1990, it represented a watershed moment enshrining the civil rights protections of individuals with disabilities. The ADA notably omitted language addressing the field of health care in any significant way. Section 1557 of the ACA acted as a capstone to the ADA by expanding disability discrimination protections in the provision of health insurance. The intent in enacting Section 1557 was to clarify that discrimination in the health insurance arena will not be tolerated and the proposed rule we comment on today would strengthen that national commitment.

HAB was alarmed in 2019 when HHS sought to reopen settled areas of civil rights protections that date back to the ADA and earlier legislation and sought to uproot these long-standing protections. The statutory language and accompanying regulations of Section 1557 were functioning well to protect the rights of individuals with disabilities in the first few years of implementation and there seemed no reasonable reason to attempt to alter the changes. HAB supports the restoration of the original 2016 rule, with appropriate modifications to strengthen the rule further, to ensure the robust civil rights protections in health care Section 1557 affords.

Section 1557 is particularly important to the disability and habilitation community because these individuals face substantial disparities in access to health care and frequently face discrimination in access to care. This, for example, is seen when families experience delays and discrimination in accessing critical speech therapy, occupational therapy, or physical therapy when trying to address early signs of developmental delays.

Following is a summary of our positions on key issues impacting our members, with an emphasis on nondiscrimination protections applicable to health plans and benefit design, access to care, and related issues.

Disability Policies, Procedures, and Discrimination Issues Impacting Habilitation

- **Purpose and Effective Date:** HAB strongly supports the effective date of 60 days after the publication of the final rule. Any further delay of these protections will have the potential to create serious harm to individuals with disabilities and chronic conditions.
- **Application and Scope of the Rule:** HAB supports the restoration of the 2016 final rule's interpretation of the term, "health programs and activities" and the application of the section to recipients of Federal financial assistance, with modifications as described in the proposed rule. More specifically, HAB supports the application of Section 1557 to Medicare Part B, Medicare managed care plans, and Medicaid plans, as well as short

² Nondiscrimination in Health Programs and Activities, 81 Fed. Reg. 31,376 (May 18, 2016).

term limited duration plans and those plans with benefit exemptions.

- **Definitions:** HAB strongly supports the reinstatement of the definitions section originally promulgated in 2016 to clarify the meaning of key terms and concepts addressed in the rule. HAB also supports the proposal to incorporate the definition of “auxiliary aids and services” from the ADA into Section 1557’s regulations³ as well as the definition of “qualified interpreter for a person with a disability” from the ADA.⁴ Among other things, this would help clarify when a qualified interpreter must be provided to a patient in a health care setting in order to meet the standard of effective communication. Finally, we support the inclusion of the term “companion” in the definitions’ section of the regulation and believe HHS should clarify that such companions should be selected by the patient, not the provider. Companions for persons with certain disabilities, such as non-verbal autism or other sensory disabilities, are critical to effective communication of very sensitive and important medical information.
- **Section 1557 Coordinators:** HAB strongly supports the proposed rule’s designation of Section 1557 “Coordinators” and the responsibilities of such coordinators enumerated in the rule. These coordinators will be highly useful in the provision of key information, education, and enforcement of Section 1557. We also support application of this requirement to all covered entities but recognize the challenges some small entities may have in complying with this provision. Hence, HHS should maximize training and technical assistance to covered entities to reduce the burden of this new requirement.
- **Policies, Procedures, and Appropriate Training:** HAB supports the proposed rule’s provisions requiring covered entities to adopt Section 1557 policies and procedures and to ensure their employees are trained on them. We support the provision that requires training on civil rights policies and procedures for all relevant employees. We agree it is critical that not only individuals in “public contact” positions understand civil rights policies and procedures but also that those who make decisions about these policies and procedures understand the requirements of Section 1557.
- **Notice of Availability of Language Assistance Services and Auxiliary Aids and Services:** HAB supports a notice requirement to ensure that individuals with disabilities and others with language barriers have knowledge of the availability of auxiliary aids and services, as well as language assistance services, including the fact that such services are provided free of charge from providers, in order to enhance effective communication during medical interactions. People with disabilities have improved access to health services when they are able to access appropriate auxiliary aids and services and language assistance to fully understand their medical interactions with providers.
- **Nondiscrimination in Health Insurance Coverage and Other Health-Related Coverage:** We strongly support the reinstatement of § 92.207. The Department is correct that the rescission of this section created a lack of clarity for covered entities as to what constitutes prohibited discrimination in health insurance and health-related coverage. We

³ 28 C.F.R. § 35.104; 28 C.F.R. § 36.303(b).

⁴ 28 C.F.R. §§ 35.104; 36.104.

further agree that the rescission of that section rendered Section 1557 less effective and creates an environment that could foster additional discrimination, including against those with disabilities. People with disabilities frequently need multiple-high cost health care services. Without the prohibition on discriminatory marketing or benefit design, insurers will use marketing and benefit design to try to avoid enrolling people with disabilities in order to maximize their profits.

- **Integration Mandate:** We also support the inclusion of § 92.207(b)(6), i.e. the “integration mandate” that requires “services, programs, and activities [be administered] in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” It is necessary for the rule to specifically address the integration mandate given its role in ensuring disabled people are not segregated in health care settings. Far too often hospital systems and providers have pushed people with disabilities into long-term institutionalization due to their dependency on certain services, going against the rights given to disabled people in the Americans with Disabilities Act and the Olmstead Decision and thus necessitating HHS to explicitly add the integration mandate in Section 1557.
- **Request for Information re: Data Collection:** Data collection specific to persons with disabilities is critical to the ability of the federal government, health plans, and health care providers to meet the needs of this population. There is ample evidence of health disparities in the disability population. Health and health care disparities are compounded when disability intersects with race, ethnicity, gender identity, and age. HAB appreciates HHS’ Request for Information on Data Collection and supports enhanced collection of demographic data on disability in order to improve care, reduce disparities in health status and access to health care services, allow providers to better understand and accommodate the needs of the disability population, and better equip the federal government to monitor compliance with civil rights protections. The electronic health record (EHR) is an essential tool in linking demographic and clinical data within and across health care systems and public health databases. Data collected within the EHR is crucial to understanding and addressing inequities that negatively impact health and healthcare outcomes of marginalized communities, including people with disabilities.
- **Effective Communication for Individuals with Disabilities:** We support the provisions in this section regarding effective communication for people with disabilities. Effective communication is critical to ensuring that people with disabilities have access to quality health care.
- **Ensuring Adequate Network Adequacy:** As a coalition of national organizations focused on access to habilitation services, HAB believes network adequacy is a critical issue that the final Section 1557 regulations should address. Section 92.20 of the administration’s proposal provides that it is outside the scope of Section 1557 to establish uniform or minimum network adequacy standards.⁵ However, the proposed rule states that provider networks that limit or deny access to care for individuals with certain disabilities may raise discrimination concerns. While the administration does not propose

⁵ Nondiscrimination in Health Programs and Activities, 87 Fed. Reg. 47,824, 47,877-878 (Aug. 4, 2022).

prescribing specific network adequacy requirements for covered entities under this proposal, it reiterates that to comply with Section 1557, payers must develop their provider networks in a manner that does not discriminate against enrollees on the basis of race, color, national origin, sex, age, or disability.⁶

HAB appreciates the administration's attention to network adequacy and its acknowledgement that certain provider networks may raise discrimination concerns in violation of Section 1557. We believe people with disabilities should have access to disability-specific specialists and services, in settings that are physically accessible, and with a choice of providers—across primary, specialty, and subspecialty care. HAB believes that the adequacy of a plan's provider network dictates the level of access to benefits otherwise covered under the health plan. If a plan covers a benefit but unduly limits the number of providers or specialists under that plan, coverage will be curtailed through a lack of access to providers with sufficient expertise to treat the patient. In light of these concerns, we encourage HHS to help ensure network adequacy that fully protects access to both in-person and virtual care through strict enforcement. It is essential that people with disabilities have access to affordable and meaningful coverage of habilitative services and devices in the most appropriate setting that meets their needs.

The administration's proposed rule bolsters the prohibition of discrimination on the basis of disability as statutorily required by the ACA. The proposed expansions on the scope of the regulations and the reinstatement of certain notification requirements are critical to people with disabilities. The proposed changes are consistent with the statutory intent of the ACA to protect people with disabilities and other protected classes of individuals.

The Habilitation Benefits Coalition strongly supports the proposed rule. A final rule consistent with the proposed rule described above will expand the effectiveness of the prohibition on discrimination and strengthen the protections intended by the letter and spirit of the ACA. Therefore, we urge OCR and HHS to move forward with promulgating a Final Rule as expeditiously as possible. If you have any questions regarding this comment letter, please contact Peter Thomas and Taryn Couture, HAB co-coordinators, by e-mailing Peter.Thomas@PowersLaw.com and Taryn.Couture@PowersLaw.com or by calling 202-466-6550.

Sincerely,

The Undersigned Members of the Habilitation Benefits Coalition

American Association on Health and Disability
American Association of People with Disabilities
American Cochlear Implant Alliance
American Occupational Therapy Association

⁶ *Id.*

American Speech-Language-Hearing Association
American Therapeutic Recreation Association
The Arc of the United States
Lakeshore Foundation
National Association for the Advancement of Orthotics & Prosthetics
National Association of Councils on Developmental Disabilities
United Cerebral Palsy