

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: <u>Nondiscrimination in Health Programs and Activities [HHS-OS-2022-0012,</u> <u>RIN 0945-AA17]</u>

Dear Director Fontes Rainer:

The undersigned members of the Coalition to Preserve Rehabilitation (CPR) 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*. CPR is a coalition of national consumer, clinician, and membership organizations that advocate for policies to ensure access to medical rehabilitation so that individuals with injuries, illnesses, disabilities, and chronic conditions may regain and/or maintain their maximum level of health and independent function.

CPR strongly supports the proposed rule and urges HHS to finalize it as expeditiously as possible—with modifications to strengthen the rule where necessary. CPR submitted comments to the previous proposal rule impacting Section 1557 in 2019 and strongly opposed the changes the HHS put forward at that time. 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 and chronic conditions. 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.

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.

CPR 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 we saw no reason to replace the regulation in 2019 without a compelling rationale for doing so. As such, we asked HHS to withdraw the 2019 proposed rule along with myriad organizations in the disability and broader civil rights community. CPR 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 rehabilitation community because these individuals face substantial disparities in access to health care and frequently face discrimination in access to care. We see this when survivors of brain injuries and spinal cord injuries are limited to a rehabilitation benefit package that was designed for simple orthopedic injuries, resulting in woefully insufficient coverage of medical rehabilitation of sufficient scope, intensity, and duration, limiting the ability to regain function and live as independently as possible. Most recently, we witnessed the Supreme Court of the United States reinterpret the Medicare Secondary Payer Act to explicitly permit private health plans to restrict benefits to enrollees with End Stage Renal Disease (ESRD), a chronic condition that requires kidney dialysis three times per week to survive, thereby driving these enrollees to leave their private individual or family coverage earlier than they otherwise would in order to have Medicare serve as their primary insurer. Under Section 1557, we believe differentiation of benefits based on an individual's health condition should be prohibited.

Given the importance of the proposed rule, CPR felt compelled to offer our comments. 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.

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).

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

II. Disability Policies, Procedures, and Discrimination

CPR hereby provides summary comments on each of these critical aspects of disability policy contained in the proposed rule, in the following manner:

- **Purpose and Effective Date:** CPR 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: CPR 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. As we discussed in our letter commenting on the 2019 proposed rule, a restrictive reading of the scope of Section 1557 is inconsistent with the plain language of the statute, Congressional intent, and case law. More specifically, CPR supports the application of Section 1557 to Medicare Part B, Medicare managed care plans, and Medicaid plans, as well as short term limited duration plans and those plans with benefit exemptions.
- **Definitions:** CPR 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. CPR 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 brain injuries and other conditions with cognitive effects, as well as individuals with sensory disabilities, are critical to effective communication of very sensitive and important medical information.
- Section 1557 Coordinators: CPR 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:** CPR 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

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

⁴ 28 C.F.R. §§ 35.104; 36.104.

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: CPR 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.
- 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. CPR 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.
- **Disability Discrimination and Accessibility for Individuals with Disabilities:** Proposed § 92.101(b)(1) applies regulations implementing Section 504 of the Rehabilitation Act to health programs or activities that receive federal financial assistance, State Exchanges, and Federally-Facilitated Exchanges. Specifically, the proposed section incorporates by reference 45 C.F.R. Parts 84 and 85, regulations pertaining to program accessibility. CPR supports HHS' general goal of explicitly incorporating into paragraph (b) the prohibitions on discrimination found in each of the civil rights laws on which Section 1557 is grounded. We think this approach is prudent, given that some health care entities may not be readily familiar with the specific regulatory standards and obligations that apply to them under Section 504 and the ADA.

However, CPR asks HHS to proceed with caution as care must be taken not to incorporate standards that do not fully reflect the requirements of Section 1557 or the changes the ACA brought to nondiscrimination in health care. We share the concerns of the Consortium of Constituents with Disabilities (CCD) expressed in their comment letter that the incorporation of 45 C.F.R. §§ 84.22, 85.42, and Section 504's regulations pertaining to the accessibility of existing facilities, will create inconsistencies regarding the obligations of covered entities. In addition, we do not support the incorporation of

Section 84.23(c), which applies an outdated standard (the Uniform Federal Accessibility Standards) to new construction of facilities.

- 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.
- Medical Diagnostic Equipment Standards: CPR recommends that HHS reference and incorporate the 2017 Standards for Accessible Medical Diagnostic Equipment ("MDE Standards"), 36 C.F.R. Part 1195, into § 92.203. The MDE Standards, which implement Section 510 of the Rehabilitation Act, set forth minimal technical criteria for the accessibility of MDE in facilities where health programs or activities are conducted.⁵ Incorporating these standards into Section 1557 is a necessary step towards improving access to health care services for individuals with disabilities.

III. Key Issues to Ensure Access to Rehabilitation Services for People with Disabilities

As a coalition of national organizations focused on access to medical rehabilitation services across multiple settings of care, CPR believes network adequacy, the use of clinical algorithms, and access to telehealth services are three critical issues that the final Section 1557 regulations should address.

• Network Adequacy: 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. ⁶ 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 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.⁷

CPR 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. CPR 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

⁵ 29 U.S.C. § 794f; 36 C.F.R. pt. 1195.

⁶ Nondiscrimination in Health Programs and Activities, 87 Fed. Reg. 47,824, 47,877-878 (Aug. 4, 2022).

⁷ Id.

people with disabilities and chronic conditions have access to affordable and meaningful coverage of rehabilitative services and devices in the most appropriate setting that meets their needs.

For instance, individuals with spinal cord injuries, brain injuries, neurological conditions, limb amputations, major multiple trauma, and other serious injuries or illnesses need access to specialized medical rehabilitation providers to maximize their recovery, functional skills, and ability to live as independently as possible following injury or illness. Health plans that contract with a limited number of inpatient rehabilitation hospitals and units, long term acute care hospitals, specialized outpatient rehabilitation clinics, rehabilitation physicians, and similar providers make it difficult for enrollees with these disabling conditions to access these specialized providers when they need them, compromising patient outcomes. We view provider networks that are so limited as to deny meaningful access to rehabilitation services as discriminatory based on disability.

Additionally, HHS requests comment on whether the lack of access to accessible medical diagnostic equipment (MDE) would constitute network inadequacy. We believe that it does. If a health insurer or managed care entity fails to offer a provider network that consists of an adequate amount of primary care and specialty providers with accessible MDE, it could violate federal and state network adequacy requirements in our view. Medical equipment accessibility should be considered in conjunction with other important components of network adequacy, such as time and distance standards and provider-member ratios.

• Use of Clinical Algorithms in Decision-Making: HHS proposes a new provision, §92.210, prohibiting covered entities from discriminating against any individual on the basis of race, color, national origin, sex, age, or disability when using clinical algorithms in its decision-making.⁸ HHS states in the proposed rule that it is "critical to address this issue explicitly" because, among other forms of discrimination, the Department was made aware of situations where clinical algorithms in state Crisis Standards of Care plans used during the COVID-19 pandemic may have screened out individuals with disabilities.⁹ The administration intends this provision to put covered entities on notice that they may not use discriminatory clinical algorithms and may have to modify their use of algorithms, unless fundamental alterations to their health programs or activities would result from such modifications.¹⁰

Further, the proposal strongly cautions covered entities from relying too heavily on clinical algorithms and potentially "replacing or substituting the individual clinical judgment of providers with clinical algorithms."¹¹ Over-reliance on such algorithms creates a risk of a Section 1557 violation if that over-reliance results in discrimination. The proposal emphasizes that this provision does not hold covered entities liable for any

⁸ Id. at 47,880.

⁹ Id.

 $^{^{10}}$ Id.

¹¹ *Id.* at 47,882.

clinical algorithms they did not develop, but only for decisions made in reliance of those algorithms that result in discrimination.¹²

CPR greatly appreciates HHS's exposure of this issue and the proposed rule's potential to impact the use and misuse of clinical algorithms on appropriate access to care. CPR and its members routinely witness health plans, including Medicare Advantage plans, using and misusing clinical algorithms that are not well-sourced or evidence-based to deny access to rehabilitation care and other services on which people with disabilities rely. Many of these clinical algorithms are proprietary in nature and not available to patients and providers who question prior authorization denials of care based on these algorithms, rather than being based on medical necessity criteria detailed in Medicare regulations or private plans' coverage policies. For instance, the Medicare Payment Advisory Commission (MedPAC) reports that Medicare beneficiaries in Medicare Advantage (MA) plans have one third the access to inpatient rehabilitation hospitals as traditional Medicare (non-MA) beneficiaries.¹³ MA plans routinely use proprietary algorithms to deny patient admissions to inpatient rehabilitation hospitals and units.

We applaud HHS for putting covered entities on notice that decision-making based on over-reliance of clinical algorithms can result in discriminatory Section 1557 violations, in particular, disability discrimination. We commend the Department's foresight in contemplating how these technologies may be used to discriminate against marginalized populations, particularly people with disabilities. Because of this potential harm, we agree with HHS's proposal to hold covered entities liable for overreliance on clinical algorithms that results in discriminatory care decisions and plan behavior.

• Nondiscrimination in the Delivery of Health Programs and Activities through Telehealth Services: HHS acknowledges in the proposed rule that telehealth has become more widely used as a result of the COVID-19 pandemic.¹⁴ However, this widespread use of telehealth (and telerehabilitation) has also exposed disparities in access based on race and disability.¹⁵ The proposed rule requires that covered entities provide telehealth services in a manner that does not discriminate on a protected basis under Section 1557, including through the accessibility of telehealth platforms (proposed § 92.204) and by providing effective communication for individuals with disabilities through the provision of appropriate auxiliary aids and services (proposed § 92.202).¹⁶ This requirement would encompass services that include communications about the availability of telehealth services, the process for scheduling telehealth appointments, (including the process for accessing on-demand unscheduled telehealth calls), and the telehealth appointment itself.¹⁷

CPR appreciates that the rapid expansion of telehealth during the COVID-19 pandemic has allowed many beneficiaries, whether covered through the exchanges, Medicare, Medicaid, or other payers, to safely access medically necessary health care while

¹⁵ Id.

¹⁷ Id.

¹² *Id.* at 47,883.

¹³ Medicare Payment Advisory Commission Report (June 2018).

¹⁴ 87 Fed. Reg. at 47,884.

¹⁶ *Id.* at 47,885.

protecting themselves from threat of infection with COVID-19. Further, the ability to receive medical services virtually, including medical rehabilitation, has provided tremendous benefit to many people with disabilities, especially people with mobility, cognitive, and communication disabilities, as well as mental health conditions. Telehealth can ease the complications associated with planning, transportation, and accessibility of in-person visits and the potential to cut down on distractions and hurdles associated with receiving care in an unfamiliar environment.

CPR believes that the proliferation of telehealth may allow patients to receive more stable, continuing access to rehabilitation therapy and other important services and devices. We appreciate HHS's efforts to ensure that these services are provided in an accessible and nondiscriminatory manner. We support increased access to care through the use of telehealth, *as long as it does not come at the expense of providing face-to-face health care services when in-person services are necessary, preferred by the patient, or would enhance the quality of care to people with disabilities.*

It is critical that expansion of telehealth services, and policies encouraging such expansion, does not limit patients' access to in-person care, especially when the services needed by the patient are more effectively and efficiently provided in-person. Beneficiaries with illnesses, injuries, disabilities, and chronic conditions often need the highest levels of medical care in order to maintain, regain, and/or improve their health and function. It is crucial that beneficiaries receiving rehabilitation care are able to access the most appropriate care in the most appropriate settings.

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, telehealth services, decision-making based on algorithms, and the reinstatement of certain notification requirements are critical to people with disabilities and chronic conditions. The proposed changes are consistent with the statutory intent of the ACA to protect people with disabilities and other protected classes of individuals.

The Coalition to Preserve Rehabilitation 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 Joe Nahra, CPR co-coordinators, by e-mailing Peter.Thomas@PowersLaw.com and Joseph.Nahra@PowersLaw.com or by calling 202-466-6550.

Sincerely,

The Undersigned Members of the Coalition to Preserve Rehabilitation

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The ALS Association

American Academy of Physical Medicine and Rehabilitation American Association on Health and Disability American Congress of Rehabilitation Medicine American Medical Rehabilitation Providers Association American Music Therapy Association American Occupational Therapy Association American Physical Therapy Association American Speech-Language-Hearing Association American Spinal Injury Association American Therapeutic Recreation Association Amputee Coalition Association of Academic Physiatrists Association of Rehabilitation Nurses **Brain Injury Association of America *** Disability Rights Education and Defense Fund **Epilepsy Foundation** Falling Forward Foundation * Lakeshore Foundation Muscular Dystrophy Association National Association for the Advancement of Orthotics and Prosthetics National Association of Rehabilitation Providers and Agencies National Association of Social Workers (NASW) National Disability Rights Network (NDRN) National Multiple Sclerosis Society * Spina Bifida Association **United Spinal Association ***

* CPR Steering Committee Member