The Disability and Aging Collaborative

October 3, 2022

Melanie Fontes Rainer
Director, Office for Civil Rights
Department of Health and Human Services
Washington, DC

Submitted electronically via regulations.gov

Re: RIN 0945-AA17 Nondiscrimination in Health Programs and Activities

Dear Director Fontes Rainer:

The undersigned members of the Disability and Aging Collaborative are writing to comment on the notice of proposed rulemaking (NPRM) on Section 1557 of the Patient Protection and Affordable Care Act (ACA) issued by the Office for Civil Rights (OCR) at the U.S. Department of Health and Human Services (HHS).

The Disability and Aging Collaborative (DAC) is a coalition of approximately 40 national organizations that work together to advance long-term services and supports (LTSS) policy at the federal level. Formed in 2009, the DAC was one of the first coordinated efforts to bring together disability and aging organizations. We are committed to ensuring older adults and people with disabilities are able to access the support and services, including health care, they need to live in the community. Fundamental to this access are strong non-discrimination protections.

The Health Care Rights Law (Section 1557 of the ACA) prohibits discrimination in health care on the basis of race, color, national origin, sex, age, and disability. We appreciate HHS's proposals in this rulemaking to restore and strengthen these important anti-discrimination protections, including the proposed broad regulatory language to prohibit discrimination on the basis of sex that specifically includes sex stereotypes, sex characteristics, including intersex traits, sexual orientation, and gender identity; and the language access provisions to restore the notice of availability of language access services and clarify the covered entity's duty to take reasonable steps to provide meaningful access to *each* individual with limited English proficiency (LEP) eligible to be served or likely to be directly affected by its health programs or activities. We support the more detailed comments submitted by members of the Consortium for Constituents with Disabilities (CCD), particularly with respect to auxiliary aids and services, effective communication, structural accessibility and reasonable modifications, accessible medical and diagnostic equipment standards, and data collection. Our comments below focus on the provisions regarding the scope of covered entities, the notice of nondiscrimination and notice of availability, the need for stronger protections against intersectional discrimination, benefit design and Sec. 504's integration mandate, and automated decision making tools.

Application of 1557 to Health Programs and Activities

We strongly support the proposal to restore regulatory provisions recognizing that Sec. 1557 applies to federal health programs like Medicaid, Medicare, CHIP, the ACA's state and federal Marketplaces and the plans sold through them, as well as other commercial health plans if the insurer receives any form of federal financial assistance. People with disabilities and aging adults are enrolled in all types of health coverage and should be protected from discrimination regardless. Ensuring broad access to coverage and nondiscrimination have become even more critical during the COVID-19 pandemic. As of the end of 2021, 1.2 million more adults in America have become disabled due to COVID-19. While some may

qualify for Medicare and/or Medicaid, many will not and will rely on employer coverage and Marketplace insurance.

HHS asks for comment on whether these nondiscrimination protections should be extended to non-health programs and activities of the agency. We strongly encourage HHS to undertake separate rulemaking to adopt equally robust protections as those proposed here. HHS operates many programs that are not "health" programs but contribute directly to social determinants of health, including disability and aging services programs, and are nonetheless vital to the well-being of people with disabilities and aging adults. We also urge HHS to work with the Department of Justice and other agencies that administer health programs to develop a common rule to implement section 1557. We believe establishing unified standards and nondiscrimination protections across all HHS programs and among health programs of other agencies would provide clarity both for covered entities and program participants as well as promote consistent enforcement.

Medicare Part B Meets the Definition of Federal Financial Assistance

We strongly support HHS's proposal to treat Medicare Part B payments as federal financial assistance (FFA) and Part B providers and suppliers as recipients under 1557, Title VI, Title IX, Section 504, and the Age Act. As HHS explains in the preamble, this change in interpretation is well-supported by the evolution of how the Part B program operates, making it illogical to distinguish between Part A and Part B in this context. Furthermore, most Part B providers are already receiving other forms of FFA, minimizing the impact this change will have on Medicare providers. Most importantly, this change will help ensure that people with Medicare have the same protections and rights regardless of the Medicare provider they choose, the Medicare-covered service they are receiving, or whether they are in Original Medicare or Medicare Advantage and it will eliminate confusion for older adults and people with disabilities who are not in the position to know whether their Medicare provider receives other FFA. The vast majority of non-pediatric physicians participate in Medicare, and the benefits of their compliance with 1557 will be across all lines of business. Thus, bringing all Medicare providers under 1557 and the other civil rights statutes will also help increase access to quality health care for people who are not covered by Medicaid, especially people with disabilities, people of color, people with LEP, and LGBTQ+ people who face the most discrimination and barriers.

Notice of Nondiscrimination and Notice of Availability of Language Assistance Services and Auxiliary Aids and Services

We strongly support the proposed requirements for covered entities to provide a notice of nondiscrimination. Notifying individuals of their rights is fundamental to successful implementation and enforcement of any civil rights law, including Sec. 1557. Without such notice, individuals who experience discrimination may not know that they can file a complaint or grievance or how to do so. When discrimination goes unreported, it cannot be addressed and the health disparities it causes will only worsen. We recommend that notices be provided in plain language, both in English and non-English languages, as well as American Sign Language (ASL).

We also strongly support the proposal to require covered entities to provide a notice of availability of language assistance services and auxiliary aids and services in the top 15 languages in each state where they operate. Such notice is a basic step covered entities should take to inform people with disabilities about how to access necessary auxiliary aids and services and people with LEP how to get language access services. We agree with HHS's approach to clarifying the requirements for when this notice must be made available and providing individuals with the opportunity to opt out of receiving these notices.

To maximize the effectiveness of this notice, we recommend that HHS require covered entities to include a large print notice of availability (minimum of 18-point font) at the beginning of the communication. We also suggest that HHS develop and provide covered entities with model notices that are tailored to the different types of communications they accompany. For example, a notice of availability should indicate that a response is required or that the communication contains information about one's rights or benefits.

Designating a Section 1557 Coordinator, Establishing Policies and Procedures, and Training Employees

We support the proposal to require covered entities to have a designated Section 1557 coordinator. HHS requested comment on whether this provision should apply to entities with fewer than 15 employees, and we recommend that it should. Even in smaller covered entities, it is essential that someone is responsible for coordinating implementation of Section 1557 including developing the required policies and procedures, ensuring relevant employees are trained, receiving and addressing grievances, and informing individuals of their rights when they interact with the covered entity. We believe this is especially important for entities providing long-term services and supports (LTSS) to older adults and people with disabilities. Smaller LTSS providers are common and often preferred by older adults and people with disabilities because the services they provide are often intimate and needed on a daily basis. While preventing discrimination is critical in all health care settings, having a coordinator to ensure that 1557 is implemented is essential to daily life for someone who resides at a covered entity or receives home- and community-based services. We believe the proposed description of the coordinator's duties allows for necessary variation (e.g., part-time job) and minimizes burden on smaller entities.

We strongly support the provisions requiring covered entities to adopt Sec. 1557 policies and procedures and to ensure their employees are trained on them. We agree with HHS that both employees in "public contact" positions and those who make decisions about these policies and procedures should receive training so they understand the requirements of Sec. 1557.

Communication Access Plan

We recommend that HHS specifically require covered entities to develop a communication access plan that addresses both language access and accessibility for individuals with disabilities, including supporting disabled people who are LEP. This information gathering and advanced planning is necessary to develop "effective communications procedures" that the proposed rule requires.

Intersectional Discrimination and Enforcement

We appreciate HHS's discussion in the preamble of the ways in which intersectional discrimination harms older adults and people with disabilities. People with disabilities and older adults often have multiple marginalized identities as disabilities are more common among certain marginalized populations. For example, 30% of American Indians and Alaska Natives and 25% of Blacks have disabilities compared to 20% of whites; and 40% of transgender adults and bisexual men, and 36% of lesbian and bisexual women report having a disability. Additionally, more than 1 in 3 older adults have a disability, with higher rates among older adults of color. When these individuals experience discrimination in health care, the discrimination itself may be intersectional or the basis may not be clear. For example, if an older Filipino-American bisexual man who uses a wheelchair goes to the doctor and his complaints of pain are dismissed, he should be able to seek recourse for the discrimination without having to sort through whether the discrimination was based on his race, sexual orientation, disability, age or a combination. Therefore, we strongly urge HHS to identify ways to address intersectional discrimination in the regulatory provisions of the rule itself, including making an explicit reference to intersectional discrimination in the regulatory text of Sec. 92.101.

Furthermore, as Sec. 1557 is its own statute enforceable by private right of action in the courts, an older adult who is discriminated against based on age *and* race, national origin, sex, and/or disability should not be at a disadvantage for seeking recourse due to the Age Act's administrative exhaustion requirements. Therefore, we recommend that HHS include regulatory language in the final rule that clarifies that administrative exhaustion is *not* required to bring an intersectional claim including age under Sec. 1557.

Medicaid, CHIP, and PACE Rules Should Include Strong Prohibitions on Sex Discrimination

We strongly support the provisions reinstating prohibitions of discrimination based on sexual orientation and gender identity in Medicaid and the Children's Health Insurance Program (including managed care entities and their contracts) and Programs for All-Inclusive Care for the Elderly (PACE). These programs are vital sources of coverage and services for people with disabilities and low-income older adults who are dually eligible for Medicare and Medicaid. Therefore, to ensure these programs are subject to strong and consistent nondiscrimination rules we urge HHS to harmonize the regulatory protections in these programs with the inclusive language proposed in Sec. 92.101(b).

Prohibiting Discrimination in Benefit Design

We strongly support the proposed provisions to prohibit discriminatory plan benefit design and marketing practices. Older adults and people with disabilities often have multiple chronic conditions and higher health care needs. Despite established protections for people with pre-existing conditions, insurers continue to discriminate against people with costlier conditions and greater needs, many of whom are people with disabilities and older adults, by dissuading them from enrolling or burdening them with higher out-of-pocket costs. For example, insurers continue to use drug formularies that have high cost sharing, "specialty tiers" or that fail to cover commonly prescribed drugs used to treat certain conditions; utilization management that leads to arbitrary coverage denials and/or delayed care; and narrow provider networks that lack access to specialists

We particularly support the proposal to explicitly incorporate the integration mandate in HHS's Sec. 504 regulations into Sec. 1557's and apply it both to benefit design and to implementation of a benefit design. As organizations that advocate for strengthening HCBS and access to these services, we understand Medicare, Medicaid and private health insurers' role in supporting community living. It is important for HHS to investigate how these programs cover both LTSS and health services through this lens. For example, the prohibition on retroactive coverage of Medicaid HCBS forces people who need LTSS immediately into nursing facilities where retroactive coverage is routinely approved. Policies that limit the number or types of health services that can be provided during a single outpatient visit can impose barriers for older adults and people with disabilities with high health care needs who do not have access to reliable transportation or live in remote areas. Not providing alternatives to institutional services for mental and behavioral health services, or not having certain specialists accessible in outpatient settings have the effect of segregating people with disabilities. Prescription drug formulary design and utilization management practices can prevent people with disabilities from accessing a particular medication with fewer side effects or easier administration, or result in dangerous delays and gaps in treatment. In turn, they may not be able to leave home or experience deteriorations in their health that further isolate them and put them at risk of being institutionalized.

HHS requests feedback on the civil rights implications of value assessment methodologies. As CCD's comments discuss in more detail, the disability community has long been concerned with use of the Quality-Adjusted Life Year (QALY) and similar metrics that aim to measure how much less value (to society and to the individual) a year of life lived with a disability is compared to a year of life in "perfect

health". We are similarly concerned about value assessment methods and metrics that measure the cost effectiveness of treatments relative to health outcomes in a way that discriminates on the basis of race, color, national origin, sex, or age. For example, because older people are expected to live fewer years than younger people, value assessment metrics that value the years of life a treatment adds may discriminate based on age. We urge HHS to prohibit use of such inherently discriminatory metrics in any health program or activity that receives federal financial assistance.

Prohibiting Discrimination in Automated Decision-Making

We support the proposed provision to prohibit discrimination through the use of clinical algorithms in decision-making. However, we request that HHS broaden the prohibition to include any form of automated decision-making system so that it will encompass decision-making tools that are prevalent in programs that people with disabilities and older adults rely on. These include, for example, assessment tools for home and community-based services for both level of care determinations and services allocation; Medicaid eligibility systems, including income data matching; and utilization review practices. At a minimum, HHS should define the term "clinical algorithms" because it may otherwise be too narrowly construed. For example, the Crisis Standards of Care, which frequently lead to intersectional discrimination against older adults and disabled people of color, may not be "clinical algorithms" under a narrow definition because they are typically policies or ranking systems.

Conclusion

Thank you for the opportunity to comment in support of strong nondiscrimination protections for people with disabilities and older adults. If you have further questions, please contact the Disability and Aging Collaborative Co-Chairs: Natalie Kean (nkean@justiceinaging.org), Nicole Jorwic (nicole@caringacross.org), David Goldfarb (goldfarb@thearc.org), and Howard Bedlin (howard.bedlin@ncoa.org).

Sincerely,

American Association on Health & Disability
American Association of People with Disabilities
American Network of Community Options and Resources
Autistic Self Advocacy Network
Caring Across Generations
Justice in Aging
Medicare Rights Center
National Academy of Elder Law Attorneys
National Association of Councils on Developmental Disabilities
National Council on Aging
National PACE Association
National Consumer Voice for Quality Long-Term Care
National Disability Rights Network (NDRN)
Service Employees International Union
The Arc of the United States
Well Spouse Association