

October 3, 2022

Melanie Fontes Rainer
Director
Office for Civil Rights
U.S. Department of Health and Human Services
Attention: 1557 NPRM (RIN 0945–AA17)
Hubert H. Humphrey Building
Room 509F
200 Independence Avenue SW
Washington, DC 20201

Submitted electronically via https://www.regulations.gov/commenton/HHS-OS-2022-0012-0001

Re: Nondiscrimination in Health Programs and Activities (87 F.R. 47824, published August 4, 2022)

Dear Director Fontes Rainer:

On behalf of the National Association of Social Workers (NASW), I am writing to comment on the notice of proposed rulemaking (NPRM) addressing 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).

NASW represents more than 110,000 social workers nationwide. Social workers play an essential role in serving clients of all ages in numerous health care settings. Social workers are the largest provider of mental, behavioral, and social care services in the nation at 700,000+ and serve on interdisciplinary health care teams. Social workers support individuals with complex medical and social needs and witness the adverse consequences of health disparities in hospital and community settings. The social work profession is guided in our Code of Ethics to promote well-being and act against discrimination and inequities. In keeping with NASW's mission to advance sound social policies, we are committed to advancing equity in all health programs and activities.

NASW strongly supports the following measures:

- Protections against sex discrimination including sex stereotypes, sex characteristics (including intersex traits), sexual orientation, gender identity, and gender expression
- Protections against sex discrimination based on pregnancy or related conditions
- Access to language access services for Limited English Proficient Individuals
- Making reasonable modifications available to provide access to people with disabilities

- Prohibition of discrimination in telehealth services
- Prohibition of discrimination in use of clinical algorithms
- Requirements to inform consumers and train staff/ health care providers on the above provisions

NASW applauds the HHS Office for Civil Rights for fully implementing and strengthening Section 1557 protections in health care programs and activities. NASW is pleased to see the applicability of nondiscrimination provisions to a broad array of health care providers and insurers. The unprecedented medical and mental health needs that have emerged throughout the COVID-19 pandemic have highlighted the importance of consistent access to health insurance coverage and health care services. This access is particularly important for populations that are underserved, experience discrimination, and health inequities, including LGBTQIA2S+ individuals, people of color, pregnant women of color, individuals with limited English proficiency, people with disabilities, and others. NASW supports efforts to end discrimination, racism and bias in health programs and health care services, which contribute to health inequities in the United States.

Section 1557, commonly known as the Health Care Rights Law, prohibits discrimination in health care on the basis of age, color, disability, race, sex, and national origin. NASW appreciates HHS's proposals to restore and strengthen these important nondiscrimination protections. Our comments address the following topics:

- applicability of Section 1557 nondiscrimination protections
- Medicare Part B
- language access
- notices to people receiving health care services
- Section 1557 coordinator role
- age-related intersectional claims
- sex discrimination and LGBTQIA2S+ people
- structural accessibility
- benefit design
- automated decision making
- telehealth services
- demographic data collection

Broad Application of Section 1557 Nondiscrimination Protections

NASW strongly supports the proposal to restore regulatory provisions recognizing that Section 1557 applies to federal health programs such as Medicaid and Medicare; the ACA's state and federal Marketplaces and the plans sold through those entities; and other commercial health plans if the insurer receives any form of federal financial assistance. This application is consistent not only with statutory language, but also with the ACA's purpose of promoting broad access to and coverage of health care.

HHS has requested comment on whether these nondiscrimination protections should be extended to its programs and activities that do not focus on health. NASW strongly encourages the adoption of such protections for these other programs in separate rulemaking, and we urge HHS to make those protections as robust as those proposed for health programs and activities. HHS operates many

programs and activities that are not "health" programs. Many of these programs improve the health and well-being of people served by addressing social needs, mitigating social risk factors, and strengthening social determinants of health (SDOH). For example, programs authorized by the Older Americans Act—including the Eldercare Locator, Aging and Disability Resource Centers, Senior Medicare Patrol, nutrition programs, disease prevention and health promotion services, family caregiver support, long-term care ombudsman programs, Elder Abuse, Neglect, and Exploitation Prevention Programs, and services for American Indians, Alaska Natives, and Native Hawaiians—play vital roles in the lives of millions of older adults. Moreover, increasing numbers of Area Agencies on Aging and community-based organizations contract with health care entities to meet the social care needs of older adults. An adults. 2,3

Just as NASW urges HHS to apply Section 1557 nondiscrimination to its non-health-focused programs and activities, we urge HHS to work with the U.S. Department of Justice and other federal agencies that administer health programs to develop a common rule to implement Section 1557. We believe that establishing unified standards and nondiscrimination protections across all HHS programs and among health programs of other agencies would not only provide clarity for program participants and covered entities but would also promote consistent enforcement of nondiscrimination protections.

Classifying Medicare Part B as Federal Financial Assistance

NASW strongly supports HHS's proposal to treat Medicare Part B payments as a form of federal financial assistance (FFA). Likewise, we support HHS's proposal to treat Part B providers and suppliers as recipients of FFA under the following statutes: Section 1557 of the ACA, the Age Discrimination Act of 1975 (Age Act), Title VI of the Civil Rights Act of 1964, Title IX of the Education Amendments of 1972, and Section 504 of the Rehabilitation Act of 1973. This change in interpretation is well supported by the evolution of the Part B program, the fact that many Part B providers are already receiving other forms of FFA, and the clear intent of the Section 1557 statute. Classifying Medicare Part B payments as FFA will eliminate confusion for people with disabilities and older adults, who are not in the position to know whether their Medicare provider receives other FFA. Most importantly, it will also ensure that Medicare beneficiaries have the same protections and rights regardless of the Medicare provider they choose, the Medicare-covered service they are receiving, and whether they are enrolled in original Medicare or Medicare Advantage (MA).

Given that many Medicare providers also serve people with other forms of insurance, bringing all Medicare providers under Section 1557 will also enhance access to quality health care for marginalized and historically underserved individuals and communities who face significant barriers to health care. These beneficiaries include people living with substance use conditions and serious mental illness, many of whom are served by clinical social workers, and beneficiaries who are dually eligible for Medicare and Medicaid.

¹ Colello, K., & Napili, A. (2022). *Older Americans Act: Overview and funding* (CRS R43414). Congressional Research Service. https://crsreports.congress.gov/product/pdf/R/R43414

² Aging and Disability Business Institute. (2022). AAAs address social needs through contracts with health care. USAging. https://www.aginganddisabilitybusinessinstitute.org/wp-content/uploads/2022/07/Survey-Spotlight-AAAs-508.pdf

³ Aging and Disability Institute. (2022). *CBOs address social needs through contracts with health care*. USAging. https://www.aginganddisabilitybusinessinstitute.org/wp-content/uploads/2022/07/Survey-Spotlight-CBOs-508.pdf

Meaningful Access for Individuals with Limited English Proficiency (LEP)

Robust language access resources and protections from discrimination are critical in promoting health equity and mitigating disparities among people of all ages. Health care information, including consumer rights, is complex and can only be communicated effectively in an individual's primary language. The importance of language access for older adults cannot be overestimated. Most people's health care needs increase in number and complexity as they age. Furthermore, older adults may be less inclined than younger age groups to request language assistance, for fear of inconveniencing others; some may feel pressure to rely on family members as interpreters, even if those family members are not qualified to interpret health information.

Consequently, NASW strongly supports the proposal to restore and clarify the covered entity's duty under Section 1557 to take reasonable steps to provide meaningful language access to *each* individual with LEP eligible to be served or likely to be directly affected by the entity's health programs or activities. The weakening of this requirement during 2020 rulemaking, along with the elimination of the in-language taglines and notices discussed subsequently, harmed access to quality care for people with LEP. For example, failure to provide language access resources in a timely manner can result in missed follow-up appointments, misunderstandings regarding the plan of care, delayed access to necessary medication, and errors in payment for health care services.

Moreover, NASW recommends that HHS strengthen the language access regulation by incorporating the following changes:

- Add a requirement that a "companion" of an individual with LEP who needs language services be provided meaningful access, including qualified interpreters and translated materials. People who have LEP, including older adults, may be parents or guardians for minors, may have legal decision-making responsibility, or may be a care partner for a family member ("family" being defined by each individual). They may need to comprehend and convey health care information as much or even more than the person receiving health care services. Ensuring a clear right to language services for companions will also help deter inappropriate reliance on family members as interpreters. For example, if a care partner of an older adult living with advanced Alzheimer's disease or a parent of a child with sickle cell anemia cannot communicate with health care providers in the care partner's preferred language, they may not be able to support to communicate effectively with health care providers.
- Require covered entities to note in the record (including electronic health records and client—patient files) of each individual they serve whether language access is required and, if so, in which language. This requirement would promote timely access to and provision of language services.
- Require covered entities to develop a communication access plan that addresses both language
 access and accessibility for individuals with disabilities, including supporting people who live
 with disabilities and have LEP.

Notice Regarding Nondiscrimination Protections and Availability of Language Access Resources
NASW strongly supports the proposed restoration of requirements related to providing notice
regarding nondiscrimination protections and the availability of language access resources. Notifying
individuals of their rights is fundamental to successful implementation of any civil rights law, including
Section 1557. After the 2020 rulemaking eliminated this provision, many individuals receiving health

care and long-term services and supports (LTSS) were no longer made aware of their rights under 1557. Such lack of notification can be especially harmful to older adults with LEP, who may not know they have a right to an interpreter and other language access services, and to people with disabilities, who may not have the information they need to access necessary auxiliary aids and services. Furthermore, without a notice regarding nondiscrimination protections, people who experience discrimination may not know they can file a complaint or a grievance or may not know how to do so.

Therefore, NASW strongly supports the proposal to require covered entities to provide a notice of availability of language assistance services and auxiliary aids and services. We agree with HHS's approach to clarifying the requirements regarding the timing of this notification and providing individuals with the opportunity to opt out of receiving these notices. We offer the following suggestions to strengthen the proposed requirements in the following manner:

- Require covered entities to include notices in large print (minimum of 18-point font) to inform people with low vision of their rights and help them access services.
- Implement the proposed approach of using the top 15 languages by state as the minimum standard for translating notices, while clarifying that a covered entity operating across multiple states must provide the notice in the top 15 languages in each of those states. Additionally, consider a more localized standard, such as that used for MA plans and prescription drug plans (PDPs), that considers other languages used in the plan service area or county. This process would maximize access for smaller language communities that are concentrated in a particular area of a state.
- Develop, and provide to covered entities, model notices tailored to different types of communication. For example, rather than using the same generic notice on all communications, a notice of availability could indicate that a response is required or that the communication contains information about one's rights or benefits.

Role of Section 1557 Coordinator

NASW supports HHS's proposal to require covered entities to designate a Section 1557 coordinator to, and we believe this requirement should apply to entities with fewer than 15 employees. Coordinating implementation of Section 1557 is essential, regardless of the size of the covered entity. For example, small LTSS providers are common and often preferred by people with disabilities and older adults. Coordination of Section 1557 implementation is essential to daily life for individuals who reside at a covered entity or receives home- and community-based services (HCBS). Yet, NASW recognizes that the coordinator role will likely vary across entities; consequently, we believe the proposed description of the coordinator's duties allows for such variation and minimizes burden on smaller entities. For example, whereas the coordinator role might be a full-time job in a large entity, Section 1557 coordination might be one of multiple responsibilities for an individual in a small entity.

NASW also supports the provisions requiring covered entities to develop Section 1557 policies and procedures and to train their employees regarding these policies and procedures. We agree with HHS that covered entities should provide training both to employees in "public contact" positions and to individuals who make decisions about policies and procedures so that all pertinent staff understand the requirements of Section 1557. For example, clients with LEP are sometimes denied access to interpretation services because some public-facing staff do not understand the entity's responsibility to provide language access resources.

As mentioned previously, NASW recommends that HHS require entities to develop a communication access plan that addresses both the language access needs in their service area and accessibility for individuals with disabilities.

Age-Related Intersectional Claims

NASW appreciates HHS's recognition in the preamble of the unique and compounding harms of intersectional discrimination. We support clear, accessible procedures for filing, investigating, and remediating discrimination complaints, including intersectional claims. Section 1557 is its own statute, topically limited to covered entities in the field of health care and health insurance, and enforceable through a private right of action in the courts. NASW recommends that any individual who experiences discrimination on the bases of age and another protected ground (such as color, disability, sex, national origin, or some combination thereof) should not be put at a disadvantage for seeking recourse because of the Age Act's administrative exhaustion requirements. Consequently, we strongly 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 Section 1557. We also urge HHS to identify other ways to address intersectional discrimination in the regulatory provisions of the rule itself, including making an explicit reference to intersectional discrimination in the text of 45 C.F.R. § 92.101.

Expanded Definition of Sex Discrimination

NASW strongly supports the proposed regulatory language prohibiting discrimination on the basis of sex, including discrimination on the basis of sex stereotypes, sex characteristics (including intersex traits), sexual orientation, gender identity, and gender expression (§ 92.101). LGBTQIA2S+ people experience pronounced health disparities and higher poverty rates compared to their heterosexual and cisgender peers, in large part because of historical and ongoing discrimination. Discrimination in health care contributes to these disparities. LGBTQIA2S+ people may be denied care or provided inadequate care, or they may be afraid to seek necessary care for fear of mistreatment. For example, many LGBTQIA2S+ older adults and care partners experience discrimination in long-term care facilities; such discrimination can include verbal and physical harassment, denial of basic care (such as assistance with dressing or bathing), visiting restrictions, isolation, improper discharges, and refusal of admission.⁴ Transgender people—especially those who are African American—Black, American Indian—Alaska Native, Asian American—Pacific Islander, and Latino—particularly experience discrimination in coverage not only of medically necessary care related to gender affirmation, but also of lifesaving tests and treatments associated with one gender.⁵

Supreme Court case law, including *Price Waterhouse v. Hopkins* and *Bostock v. Clayton County*, makes clear that federal sex discrimination law includes gender identity (including transgender status), sex stereotypes, and sexual orientation. Although the terms "gender identity" and "transgender status" are often used interchangeably, there have been instances in which those seeking to permit

⁴ Fasullo, K., McIntosh, E., Bucholz, S. W., Ruppar, T., & Ailey, S. (2021). LGBTQ older adults in long-term care settings: An integrative review to inform best practices. *Clinical Gerontologist* (online-only issue). https://doi.org/10.1080/07317115.2021.1947428

⁵ Medina, C., Santos, T., Mahowald, L., & Gruberg, S. (2021). *Protecting and advancing health care for transgender adult communities*. Center for American Progress. https://www.americanprogress.org/wp-content/uploads/2021/08/Advancing-Health-Care-For-Transgender-Adults.pdf

discrimination against transgender people have justified such discrimination by distinguishing the two concepts. Therefore, NASW strongly recommends that HHS enumerate the regulatory text and amend § 92.101(a)(2) to include transgender status as an explicit category. NASW also recommends that the phrase "gender expression" be added to the regulation. This term reflects the ability of all people—transgender, nonbinary, and cisgender—to dress and act in ways that are comfortable for them.

We also strongly support the provisions reinstating prohibitions of discrimination based on sexual orientation and gender identity in Programs for All-Inclusive Care for the Elderly (PACE), Medicaid, and the Children's Health Insurance Program (CHIP). PACE and Medicaid are vital sources of coverage and care for people with low incomes, including people with disabilities and older adults who are dually eligible for Medicare and Medicaid. Therefore, it is critical to ensure these programs (including managed care plans), are subject to strong, consistent nondiscrimination rules. To provide greater clarity for compliance and enforcement, we encourage HHS to harmonize the regulatory protections in these programs with the inclusive language proposed in § 92.101(b).

Structural Accessibility and Reasonable Modifications

NASW supports the provisions that preserve prior existing requirements for structural accessibility (of buildings and facilities) and reasonable modifications. However, we strongly recommend that HHS incorporate in the final rule the U.S. Access Board's accessible medical and diagnostic equipment standards. These standards are essential to improving access to care for people with disabilities and older adults, who may have difficulty climbing on standard scales or exam tables, for example.

Benefit Design and Marketing Practices

NASW strongly supports HHS's proposals to prohibit discriminatory plan benefit design and marketing practices. Despite established protections for people with pre-existing conditions, insurers continue to discriminate against people with greater needs and more expensive conditions. For example, many prescription drug formularies have high-cost sharing, "specialty tiers," or fail to cover drugs commonly used to treat certain conditions; some insurers (such as MA) employ utilization management techniques, including prior authorization or treatment limits, which result in delays in care or arbitrary coverage denials; and some provider networks lack access to specialists. These insidious practices especially affect people with chronic conditions—including mental illness—and older adults.

NASW particularly supports the proposal to incorporate the integration mandate from HHS's Section 504 regulations into the Section 1557 regulations. This provision will enable people with disabilities and older adults to obtain the health coverage and LTSS necessary to live in their homes and communities, in keeping with the Supreme Court's *Olmstead v. Zimring* decision, rather than having to move into institutional settings. We agree that the proposed prohibition on failure to provide or administer coverage in the most integrated setting appropriate to the needs of qualified individuals with disabilities should apply both to benefit design and implementation. For example, Medicare's policy requiring "in-home use" for wheelchairs results in coverage denials when a beneficiary needs a wheelchair to engage in practical, social, and spiritual activities outside the home, such as shopping, congregate nutrition programs, and participating in a religious service. Moreover, even though people who use inpatient rehabilitation hospitals (IRHs) tend to have better outcomes and a greater likelihood

⁶ U.S. Access Board. (2022). Medical diagnostic equipment accessibility standards. https://www.access-board.gov/mde/

⁷ Olmstead v. Zimring, 527 U.S. 581 (1999).

of returning to their homes, access to IRHs tends to be limited both in terms of provider referrals (especially for older adults, who tend to be referred to skilled nursing facilities) and network availability.

Automated Decision Making

NASW agrees with HHS that clinical algorithms can be discriminatory. We are concerned that such algorithms are particularly harmful to Black individuals, because they often dictate that Black patients must be more ill than white patients before they can receive treatment for life-threatening conditions such as kidney disease and heart failure. Therefore, we support the proposed provision to prohibit discrimination through the use of clinical algorithms in decision making. Furthermore, we request that HHS broaden this prohibition to include any type of automated decision-making tool or system, such as those described below:

- HCBS assessment tools for both level of care determinations and services allocation; these tools
 discriminate against groups or deny services needed to maintain community integration
- Medicaid eligibility systems that wrongfully deny or terminate coverage
- "gender conflicts" that lead to misdiagnoses and discrimination in health care settings (such as denying coverage of mammography or pelvic exams for a transman)
- utilization review practices that are based on financial motives rather than on generally accepted standards of care

At a minimum, we urge HHS to define the term "clinical algorithms" because it may otherwise be too narrowly construed. For example, crisis standards of care, which frequently lead to intersectional discrimination against people with disabilities and older adults in communities of color, may not be "clinical algorithms" under a narrow definition because they are often policies or ranking systems rather than automated decisions.

Discrimination in Telehealth Services

NASW strongly supports HHS's newly proposed provision on telehealth as a tool to improve health care access for individuals who are unable to receive services in person or prefer not to do so. Yet, as telehealth has expanded during the COVID-19 pandemic, access has not been equitable for individuals with LEP and people with disabilities because the telehealth platforms themselves are sometimes inaccessible. Consequently, we recommend that HHS require telehealth platforms to allow a third-party interpreter or the use of auxiliary aids and services. Moreover, all communication about telehealth that occurs before a telehealth appointment (such as scheduling, system requirements, testing connections, appointment reminders, and login instructions) must be accessible to individuals with LEP and people with disabilities. Similarly, telehealth platforms should be adopted to meet the needs of the following groups: older adults; people who are autistic; people who are Deaf or hard of hearing; people who are blind or have low vision; people who are deaf and blind; people with limited movement; and other people who have difficulty communicating using traditional telehealth models.

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Bazelon Center for Mental Health Law, Lawyers Committee for Civil Rights Under Law, Disability Rights Education & Defense Fund, The Arc, Center for Public Representation, Autism Self Advocacy Network, Justice in Aging, City University of New York School of Law, & National Disability Rights Network (with Chin, N. M., & Harris, J.). (2021). Examining how crisis standards of care may lead to intersectional medical discrimination against COVID-19 patients. https://justiceinaging.org/wp-content/uploads/2021/02/FINAL-Intersectional-Guide-Crisis-Care-2-10-21.pdf

For example, people who are hard of hearing may have difficulty hearing health care providers while using telehealth; individuals with limited mobility in their hands may be unable to operate devices needed for telehealth; and people with aphasia may have difficulty expressing themselves during telehealth appointments.

Demographic Data Collection

NASW concurs with HHS's acknowledgment that demographic data collection and civil rights enforcement are inextricably linked. For example, demographic data have elucidated the relationship between SDOH and health disparities, including disparities in access to mental health services. Therefore, we recommend that HHS adopt a demographic data collection requirement and establish demographic data collection as a function of civil rights monitoring. Demographic data collection requirements should align with the demographic characteristics enumerated within the proposed rule—age, disability, ethnicity, gender identity, language, pregnancy status, race, sex, sex characteristics, sexual orientation—and allow for intersectional analysis. Although covered entities should be required to request demographic data, the responses of people served must be voluntary; if individuals volunteer such information, it should be self-reported to ensure accuracy and privacy. Furthermore, NASW encourages HHS to implement the following practices:

- incorporate existing data collection practices and engage in additional research as needed
- ensure that data collected is maintained safely and securely by the appropriate entities
- implement strict standards to make clear that data cannot be used for negative actions such as immigration, law enforcement, redlining, or targeting of specific groups
- provide appropriate training and technical assistance resources to programs and grantees, including training on how to explain the rationale for data collection to people served

These protections will maximize the use of demographic data to prevent discrimination and mitigate disparities.

Thank you for your consideration of NASW's comments. Please contact me at naswceo@socialworkers.org if you need additional information.

Sincerely,

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Angelo McClain, PhD, LICSW

Chief Executive Officer