



The National  
**CONSUMER VOICE**  
for Quality Long-Term Care

October 3, 2022

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

*Submitted electronically via [regulations.gov](https://www.regulations.gov)*

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

Dear Director Fontes Rainer:

National Consumer Voice for Quality Long-Term Care is 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).

National Consumer Voice for Quality Long-Term Care (Consumer Voice) is the leading national voice representing consumers in issues related to long-term care, helping to ensure that consumers are empowered to advocate for themselves. We are a primary source of information and tools for consumers, families, caregivers, advocates, and ombudsmen to help ensure quality care for the individual.

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 to restore and strengthen these important anti-discrimination protections for older adults. These protections are particularly critical for residents of long-term care, who can face various forms of discrimination. Nursing homes are unique, in that not only do they provide roughly 1.3 million individuals with medical care, but for hundreds of thousands of individuals these facilities are their homes and communities. Our comments focus on how important these prohibitions on discrimination are for residents in order for them to receive high quality care in an environment free from discriminatory practices.

### **Section 1557 Should Apply Broadly 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 and Medicare, 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. This is consistent with the statutory language and the purpose of the ACA to ensure broad access to and coverage of health care.

HHS asks for comment on whether these nondiscrimination protections should be extended to non-health programs and activities of the agency. We strongly encourage the adoption of such protections for these other programs in separate rulemaking and urge HHS to make those protections equally as robust as those proposed here for health programs and activities. HHS operates many programs, including some authorized by the Older Americans Act, that are not “health” programs but are nonetheless vital to older adults’ well-being and often contribute directly to social determinants of health. Similarly, we 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. This change in interpretation is well-supported by the evolution of how the Part B program operates, the fact that most Part B providers are already receiving other forms of FFA, and the clear intent of the Sec. 1557 statute. 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. And, most importantly, it 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. Bringing all Medicare providers under this rule will also help increase access to quality health care for marginalized communities who face the most discrimination and barriers, as many Medicare providers also serve people with other forms of insurance.

### **Ensuring Meaningful Access to for Individuals with Limited English Proficiency**

It is especially critical that older adults have robust language access resources and protections from discrimination. These provisions are key to ensuring the more than 6.5 million seniors over age 60 and four million people with Medicare who are limited English proficient (LEP) can access care and services, receive important healthcare information in a language they understand, and are informed of their rights and how to enforce them.

The ability to receive and provide health care information is critical for nursing home residents, many of whom are among the most vulnerable individuals in the United States. Unlike most other medical settings, nursing home residents reside in institutions designed to meet their complex health needs, often for extended periods of times. For many residents nursing facilities are their home. It is critical that each resident be able to provide and receive health information in their primary language.

It is all too common for nursing homes to rely on family members to serve as interpreters for residents, even though family members may not be qualified to interpret medical information. This practice can result in residents receiving incomplete or inaccurate health information. Additionally, this practice assumes that all residents have access to family members who can speak the resident's primary language and English. This is not true for many residents. Significant numbers of residents have no family or other visitors on a regular basis. Further, family members are not always present in nursing homes. For instance, during the COVID-19 pandemic, families were barred from facilities for months. The provision of language access services became even more critical, as nursing homes could no longer improperly rely on family members to interpret for residents.

Residents' medical conditions requires regular and ongoing communication with medical staff and cannot be dependent upon the presence of a resident's family members. Further, a resident may choose not to use a family member, because they feel that it violates their privacy. Many older adults may be less inclined to ask for language assistance, out of a fear of inconveniencing others, even if the language assistance is necessary for them to truly understand their health care. Nursing homes may make residents feel guilty or that they are a burden when they ask for interpretive services. To address all of these barriers to communication, it is absolutely critical that nursing homes provide each resident access to medical information in the residents' preferred language.

We strongly support the regulatory provisions to restore and clarify the covered entity's duty under Sec. 1557 to take reasonable steps to provide meaningful access to *each* individual with LEP eligible to be served or likely to be directly affected by its health programs or activities. The 2020 rulemaking's watering down of this requirement, along with the elimination of the in-language taglines and notices discussed below, harmed access to quality care for LEP older adults. Residents of nursing homes suffer when they are unable to effectively communicate their medical needs to staff. When residents are not afforded the opportunity to communicate with health staff in their primary language necessary care may be forgone, physical or mental suffering may go unaddressed or increase, and residents can even die. Nursing homes are communities. Residents live together in congregate settings. Failing to provide meaningful access to each resident not only poses risks to their health but alienates them from their community.

We recommend that HHS add a requirement that a “companion” of an LEP individual who needs language services be provided meaningful access including qualified interpreters and translated materials. People who are LEP, including older adults, may be parents/guardians for minors, may have legal decision-making authority, or may be accompanying their spouse or other family member as a caregiver or support person. Their understanding of the information is often as critical as the person receiving health care services. Providing a clear right to language services for companions will also help deter inappropriate reliance on family members and others as interpreters.

This requirement would be particularly beneficial to many nursing home residents, who have lost the ability to communicate their health needs or receive information about their condition. These residents may suffer from a variety of cognitive impairments, including Alzheimer’s disease and dementia. In these instances, a companion stands in the place of the resident when it comes to the receipt of medical information. Additionally, companions may be empowered legally to make healthcare decisions for residents. As a result, it is critical that a companion be provided healthcare information in their primary language.

To facilitate timely access, we recommend requiring covered entities to note in the record (including electronic health records, client/patient files) for each individual they serve whether language access is required and, if yes, what language.

We also 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. It is important for covered entities to plan in advance of what types of language services and communication supports it may need to provide by gathering data about the LEP population in its service area, for example. This information is necessary to develop effective “language access procedures” of how to schedule an interpreter, how to identify whether an individual is LEP, etc. that the proposed rule requires.

### **Providing Notice of Nondiscrimination and Notice of Availability of Language Assistance Services and Auxiliary Aids and Services**

We strongly support the requirements related to providing notice of nondiscrimination. Notifying individuals of their rights is fundamental to successful implementation of any civil rights law, including Sec. 1557. After the 2020 rulemaking eliminated this provision, individuals receiving health care and long-term services and supports (LTSS) were no longer made aware of their rights under 1557. For many nursing home residents, this means they did not know that they have a right to an interpreter or how to access other language access services, and to people with disabilities who may not have the information they need to access necessary auxiliary aids and services. In addition, without this notice,

people who experience discrimination may not know that they can file a complaint or a grievance or how to do so.

Consumer Voice works closely with nursing home residents and their families. We repeatedly hear how the posting of notices resulted in residents learning of rights and resources they had not been told were available. For instance, nursing homes are required to publicly post the contact information of the local long-term care ombudsman. 42 C.F.R. § 483.15(g)(5). For many residents, this notice is the only way they have learned of this important resource for residents. Additionally, residents must be provided notice for a variety of rights, including a right to file a complaint about care. Notice is essential to assuring residents are aware of their rights and how to exercise them.

We strongly support the proposal to require covered entities to provide a notice of availability of language assistance services and auxiliary aids and services and that this notice be translated. 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 inform people with vision impairments of their rights and help them access these services, we recommend that HHS require covered entities to also include a large print notice of availability (minimum of 18-point font). With regard to the translated notice, we agree with the proposed approach of using the top 15 languages by state as the minimum standard. However, we recommend clarifying that a covered entity which operates across multiple states must provide the notice in the top 15 languages in *each* of those states. We also urge HHS to consider a more localized standard, such as the standard for Medicare Advantage Plans and Prescription Drug Plans which considers the plan service area. Using service area or counties, rather than states, could help ensure smaller language communities that are often concentrated in a particular area of a state are also receiving in-language notices.

To help ensure the notice of availability is as informative as possible, we also suggest that HHS develop and provide covered entities with model notices that are tailored to the different types of communications they are included on. For example, rather than having the same generic notice on all communications, 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 daily and intimate. 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. The coordinator role will likely vary from entity to entity and we believe the proposed description of the coordinator's duties allows for such variation and minimizes burden on smaller entities. For example, a smaller entity would not have to have the coordinator role be a full-time job.

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.

It should not be incumbent upon a nursing home resident to ensure their rights are protected under Sec. 1557. As noted previously, many residents will be afraid to speak up and assert their rights under Sec. 1557, because they do not want to inconvenience staff or face repercussions. For Sec. 1557 policies to be effective, they must be implemented institutionally, so that their efficacy is not dependent upon a resident's constant invocation. As discussed above, we recommend that HHS require entities to develop a communication access plan that addresses both the needs in their service area for language access and accessibility for individuals with disabilities.

### **Intersectional Claims that Include Age Should Be Allowed to Proceed without Administrative Exhaustion**

We appreciate HHS's recognition in the preamble of the unique and compounding harms intersectional discrimination causes older adults and others. We support clear, accessible procedures for filing, investigating, and remediating discrimination complaints, including intersectional claims. 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. We 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 regulatory text of Sec. 92.101.

It has been well documented that people of color in nursing homes often experience poorer care when compared with white residents.<sup>1</sup> Additionally, many residents face discrimination based on their disabilities. In these instances, it is essential that residents know they have a right to file a complaint under Sec. 1557 and need not meet the administrative exhaustion requirement in the Age Act.

### **Strong Prohibitions on Sex Discrimination are Necessary to Address Health Disparities for LGBTQ+ Older Adults**

We strongly support the proposed broad regulatory language to prohibit discrimination on the basis of sex that specifically includes discrimination on the basis of sex stereotypes, sex characteristics, including intersex traits, sexual orientation, and gender identity (Sec. 92.101). LGBTQ+ older adults experience pronounced health disparities and higher poverty rates compared to their heterosexual and cisgender peers due in large part to historical and ongoing discrimination.

There is significant evidence that discrimination in health care contributes to these disparities: LGBTQ+ older adults may be denied care or provided inadequate care, or they may be afraid to seek necessary care for fear of mistreatment. For example, many LGBTQ+ elders and their loved ones experience [discrimination in long-term care facilities](#)<sup>2</sup> ranging from verbal and physical harassment, to being denied basic care such as a shower, to visiting restrictions and isolation, to being improperly discharged or refused admission

Transgender older adults in particular experience discrimination in coverage of medically necessary care related to gender transition, as well as in coverage of lifesaving tests and treatments associated with one gender. [Transgender people of color face significant barriers to health care access](#)<sup>3</sup>, from denials of gender affirming care to medical abuse.

Supreme Court case law, including *Price Waterhouse v. Hopkins* and *Bostock v. Clayton County*, makes clear that federal sex discrimination law includes sex stereotypes and sexual orientation and gender identity, including transgender status. While the terms “gender identity” and “transgender status” are often used interchangeably, there have been instances in which those seeking to permit discrimination against transgender people have justified it by pressing distinctions between the two concepts. Therefore, we recommend

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<sup>1</sup> Sloane, P. D., R. Yearby, R. T. Konetzka, Y. Li, R. Espinoza, and S. Zimmerman. 2021. Addressing systemic racism in nursing homes: A time for action. *Journal of the American Medical Directors Association* 22(4):886–892.

<sup>2</sup> LGBTQ Older Adults in Long-Term Care Facilities: Stories from the Field, [https://www.lgbtagingcenter.org/resources/pdfs/NSCLC\\_LGBT\\_report.pdf](https://www.lgbtagingcenter.org/resources/pdfs/NSCLC_LGBT_report.pdf)

<sup>3</sup> <https://www.americanprogress.org/article/protecting-advancing-health-care-transgender-adult-communities/>

that HHS enumerate both in the regulatory text and amend Sec. 92.101(a)(2) to explicitly include transgender status.

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 (including managed care entities and their contracts). PACE programs and Medicaid are vital sources of coverage and care for low-income older adults who are dually eligible for Medicare and Medicaid, including LGBTQ+ older adults. Therefore, it is critical to ensure these programs, including managed care plans, are subject to strong and consistent nondiscrimination rules. To provide greater clarity for compliance and enforcement, we urge HHS to harmonize the regulatory protections in these programs with the inclusive language proposed in Sec. 92.101(b).

### **Structural Accessibility and Reasonable Modifications**

We support the provisions that preserve prior existing requirements for structural accessibility and the reasonable modifications. However, we strongly recommend HHS incorporate the U.S. Access Board's [accessible medical and diagnostic equipment standards](https://www.access-board.gov/mde/)<sup>4</sup> in the final rule. Equipment accessibility is as necessary to equally effective healthcare as the accessibility of buildings and facilities, and is equally linked to requests for reasonable modifications in a covered entity's policies and procedures.

### **Prohibiting Discrimination in Benefit Design**

We strongly support the proposed provisions to prohibit discriminatory plan benefit design and marketing practices. Older adults are more likely to have chronic conditions and disabilities, and therefore have 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 by dissuading them from enrolling or shifting more out-of-pocket costs to people with certain conditions.

We particularly support the proposal to incorporate the integration mandate in HHS's Sec. 504 regulations into Sec. 1557's. This provision is necessary to help ensure people with disabilities, including older adults, are able to get the health coverage they need to live in the community and are not unjustly institutionalized. We agree that the proposed prohibition on not providing or administering coverage in the most integrated setting appropriate to the needs of qualified individuals with disabilities should apply both to benefit design and to implementation of a benefit design.

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<sup>4</sup> <https://www.access-board.gov/mde/>



## **Prohibiting Discrimination in Automated Decision-Making**

We agree with HHS that clinical algorithms can be discriminatory and particularly harmful to Black patients, as 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. 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. For older adults and others, there are numerous examples of discrimination in decision-making tools and systems that may fall outside the term “clinical algorithm,” including assessment tools for home and community-based services for both level of care determinations and services allocation that discriminate against groups or deny services needed to maintain community integration; Medicaid eligibility systems that wrongfully deny or terminate coverage; “gender conflicts” in health decisions that lead to misdiagnoses and discrimination in health care settings; utilization review practices that are based on financial motives rather than generally accepted standards of care. 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](#)<sup>5</sup>, may not be “clinical algorithms” under a narrow definition because they were often policies or ranking systems rather than automated decisions.

## **Prohibiting Discrimination in Telehealth Services**

We support the newly proposed provision on telehealth and the recognition of it as a tool to improve access for individuals who, for various reasons, are unable or prefer to receive services in person. As telehealth has expanded during the COVID-19 pandemic, access has not been equitable for LEP individuals and people with disabilities due to the telehealth platforms themselves being inaccessible. Therefore, we recommend that HHS require telehealth platforms to allow a third-party interpreter or use of auxiliary aids and services. Second, all of the communication about telehealth that occurs prior to a telehealth appointment (e.g., scheduling, system requirements, testing connections, appointment reminders, and log-on instructions) must be accessible to people with LEP and people with disabilities. Similarly, platforms should be adopted to meet the needs of older adults and people who are autistic, deaf or hard of hearing, blind, deaf/blind, movement impaired, or otherwise have difficulty in communicating via traditional telehealth models.

## **Demographic Data Collection is Critical to Civil Rights Enforcement**

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<sup>5</sup> <https://justiceinaging.org/wp-content/uploads/2021/02/FINAL-Intersectional-Guide-Crisis-Care-2-10-21.pdf>

The Proposed Rule acknowledges that demographic data collection and civil rights enforcement are inextricably linked. We agree. As noted previously, racial disparities in health outcomes are well documented. This fact was particularly true during the pandemic, where one [study](#) found that in nursing homes where Black residents compose 50% or more of the facility's census, COVID-19 infections were 13.9% higher and COVID-19 deaths were 3.5% higher than facilities with no Black residents. In order to address this inequity and others, we must have facility-level demographic data on all nursing home residents. Currently, state regulatory agencies are not required to collect demographic data regarding race. Data on race is not made publicly available by the federal government, therefore making the examination of racial inequities extremely difficult. Absent this information, researchers and policy makers are significantly limited in identifying and responding to disparities in nursing homes.

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 rule (race, ethnicity, language, disability, age, sex, sexual orientation, gender identity, pregnancy status, and sex characteristics) and allow for intersectional analysis. HHS should incorporate existing data collection practices and engage in additional research where necessary. While covered entities should be required to request demographic data, individuals' responses must be voluntary and should be self-reported to ensure accuracy and privacy. HHS must also ensure that data collected is maintained safely and securely by the appropriate entities and implement strict standards to make clear that data cannot be used for negative actions such as immigration or law enforcement, redlining or targeting of specific groups. Additionally, HHS should provide appropriate training and technical assistance resources to programs and grantees, including training on how to explain why data is being collected. These protections will help to ensure that data collected can be best utilized to prevent discrimination and disparities in health care and access.

## **Conclusion**

We have included numerous citations to supporting research, including direct links to the research. We direct HHS to each of the materials we have cited and made available through active links, and we request that the full text of each of the studies and articles cited, along with the full text of our comment, be considered part of the formal administrative record for purposes of the Administrative Procedure Act. If HHS is not planning to consider these materials part of the record as we have requested here, we ask that you notify us and provide us an opportunity to submit copies of the studies and articles into the record.

Thank you for the opportunity to comment on this important issue. If you have further questions, please contact Sam Brooks, Director of Public Policy, National Consumer Voice for Quality Long-Term Care, [sbrooks@theconsumervoice.org](mailto:sbrooks@theconsumervoice.org).

Sincerely,

*Samuel Brooks*

Director of Public Policy  
National Consumer Voice for Quality Long-Term Care