Leadership Council of *Aging Organizations*

October 3, 2022

Melanie Fontes Rainer
Director, Office for Civil Rights
Department of Health and Human Services
Washington, D.C.
*Submitted electronically via [regulations.gov]*

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

Dear Director Fontes Rainer:

The Leadership Council of Aging Organizations (LCAO) appreciates this opportunity 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). We encourage the Department to fully implement the proposed rule, incorporating the amendments we suggest in these comments.

LCAO is a coalition of national nonprofit organizations concerned with the well-being of America's older population and committed to representing their interests in policy-making arenas. LCAO serves as a source of reliable information about issues affecting older adults and provides leadership and vision as America meets the challenges and opportunities presented by our aging society. Our organizations have expertise in economic security, nutrition and food security, housing, health care, long-term services and supports (LTSS), and other issues facing older adults and people with disabilities, and we work to reduce barriers and celebrate the contributions of these diverse populations.

Based on our collective experience advocating for and serving older adults, we strongly support HHS's proposals to restore and strengthen Sec. 1557's important protections against discrimination in health care on the basis of race, color, national origin, sex, age, and disability. Sec. 1557 will particularly benefit older adults, who frequently [encounter ageism in our health care system]—experiences such as having their concerns dismissed, being over-medicated, and being subjected to demeaning comments and paternalistic language. For older adults who are people of color, LGBTQ+, live with disabilities, and/or have limited English proficiency, both discrimination and fear of discrimination are more common and their effects compound, resulting in poorer health outcomes and excess costs to the health care system. LCAO's comments focus on how implementation and strengthening of Sec. 1557 regulations will enhance protections for older adults, help end this discrimination, and lessen these disparities.

**1557 Should Apply Broadly to Health Programs and Activities**
LCAO strongly supports the proposal to restore the provisions recognizing that Sec. 1557 applies broadly to any health program or activity that receives any form of federal financial assistance, including: all federal health programs, like Medicaid and Medicare; the ACA's state and federal Marketplaces; the plans sold through those marketplaces; and other commercial health plans receiving federal financial assistance. This proposal is consistent with the ACA's language and purpose of ensuring broad access to health care.

Further, we strongly encourage HHS to extend the same nondiscrimination protections in separate rulemaking to non-health programs and activities of the agency. Many programs that HHS operates—including those authorized by the Older Americans Act (e.g., home-delivered and congregate meals), are vital to older adults' health, though they may not be considered "health" programs as defined in this rule.

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 Sec. 1557. While Medicare and Medicaid are primary sources of coverage for many older adults, many are also enrolled in health programs administered by other agencies, such as the Veterans' Administration. Establishing unified standards and nondiscrimination protections across all HHS programs and health programs of other agencies will not only provide clarity both for covered entities and participants but will also promote consistent enforcement.

**Medicare Part B Meets the Definition of Federal Financial Assistance**

LCAO strongly supports HHS's proposal to treat Medicare Part B payments as federal financial assistance (FFA) and, therefore, to treat Part B providers and suppliers as covered "recipients." This provision will help ensure that people with Medicare have the same protections regardless of the Medicare provider they choose, the service received, or whether they are in Original Medicare or Medicare Advantage. It will eliminate confusion for enrollees enforcing their rights, who are not in the position to know whether a provider receives any FFA other than Part B. This change will be especially helpful for enrollees who rely on care from small, specialty providers (e.g., durable medical equipment suppliers) that participate in Part B, but no other form of Medicare, Medicaid, or other FFA. Given that the vast majority of non-pediatric physicians participate in Medicare, this change in interpretation will also help ensure more consistent nondiscrimination protections and enforcement across the health care system, benefiting not only Medicare enrollees, but everyone.

**Ensuring Meaningful Access for Individuals with Limited English Proficiency (LEP)**

We strongly support the provisions to restore and clarify a covered entity's duty to take reasonable steps to provide meaningful access to *each* individual with LEP who is either eligible to be served or likely to be directly affected by its health programs or activities. To implement this, we recommend requiring covered entities to note in each individual's relevant medical record their language access needs.

These provisions are key to ensuring that older adults with LEP can receive important information in a language they understand. Older adults may not be inclined to ask for language assistance and may, instead, rely on unqualified family members as interpreters. Lack of professional interpretation services may undermine their understanding of their condition and their instructions for care, inhibit forthright conversation, and compromise their privacy. Therefore, it is important that the covered entity be charged with taking steps to inform individuals with LEP of their rights and to provide meaningful access based on each person's situation and needs. For the same reasons, we further recommend that HHS add a requirement that assisting companions with LEP, such as a caregiver or support person, be provided access to language services as well.

**Notices of Nondiscrimination and Availability of Language Assistance and Auxiliary Aids and Services**

LCAO strongly supports the requirements for providing notice of nondiscrimination, as well as the notice of availability of language assistance services and availability of auxiliary aids and services because notifying individuals of their rights is fundamental to successful implementation of any civil rights law.

We agree with HHS's proposed requirements regarding when the notice of availability must be made and how individuals may opt out. We recommend that the notice of availability in English be required in large-print (minimum 18-point font) at the beginning of communications.

Further, we strongly support the proposal to require that the notice of availability be translated, and we agree with the proposed approach of using the top 15 languages by state as the minimum standard. We urge HHS to clarify that a covered entity which operates across multiple states must provide the notice in the top 15 languages specific to *each* of those respective states. We also urge HHS to consider a more localized standard, such as the plan service area (as required for Medicare Advantage and Part D Plans) to ensure appropriate service for smaller, locally concentrated language communities. Such a localized standard should be implemented in addition to, not in lieu of, the top 15 languages for each state.

We also suggest that HHS develop and provide covered entities with model notices that are tailored to the different types of communications on which they are included. Rather than having the same generic language on all communications, a notice of availability should indicate, e.g., that the communication requires a response or contains information about one's rights or benefits.

**Designating a Sec. 1557 Coordinator, Establishing Policies and Procedures, and Training Employees**
LCAO supports the proposal to require covered entities to have a designated Sec. 1557 coordinator, and we urge HHS to apply this requirement to all covered entities, not only those with 15 employees or more. Even in smaller covered entities, it is important that someone be responsible for coordinating implementation of Sec. 1557. We believe this is especially important for LTSS providers, since such entities are often small. Because of the often daily and intimate nature of LTSS, it is essential for the person receiving services that their provider—no matter how small—designate a coordinator to implement 1557 protections.

We strongly support the provisions requiring covered entities to ensure all relevant employees are trained on Sec. 1557 policies and procedures, i.e., both employees who engage in "public contact" and those who make decisions about each entity's policies and procedures. 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 who have LEP, e.g., by gathering data about the LEP population in their service area.

**Intersectional Claims That Include Age Should Not Require Administrative Exhaustion**
In the preamble of the proposed rule, HHS recognized the unique and compounding harms of intersectional discrimination, including for older adults. LCAO appreciates this acknowledgment, and we urge HHS to explicitly recognize intersectional discrimination claims in Sec. 92.101 of the rule itself. As discussed previously, discrimination based on age is a common experience, but an older adult with multiple marginalized identities may experience discrimination based not just on age but also on one or more other protected characteristics of their identity (e.g., race and/or gender identity).

The proposed rule, however, puts an individual with an intersectional claim that includes age at a disadvantage compared to one that does not, because the rule applies the Age Act's mandatory administrative exhaustion requirement to *any* age discrimination claim—a requirement no other type of intersectional claim would face. It would defeat the purpose of Sec. 1557, though, to put an individual who experiences discrimination on the basis of age and another protected characteristic (such as color, disability, sex, national origin, or some combination thereof) at a disadvantage in seeking recourse in court because of the Age Act's administrative exhaustion requirements.

LCAO therefore urges HHS to provide uniform procedures for filing, investigating, and remediating intersectional discrimination complaints under Sec. 1557. Consequently, we recommend that HHS amend the proposed procedures to state that administrative exhaustion is *not* required before one can file a complaint in court based on an intersectional claim that includes age discrimination.

**Strong Prohibitions against Sex Discrimination Are Necessary for the Health of LGBTQ+ Older Adults**
We strongly support the proposal to clarify that "discrimination on the basis of sex" explicitly includes discrimination on the basis of sex stereotypes, sex characteristics (including intersex traits), sexual orientation, and gender identity (Sec. 92.101). 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 such discrimination by distinguishing the two concepts. Therefore, we recommend that HHS amend Sec. 92.101(a)(2) to explicitly include the term "transgender status."

These strong protections are necessary to help reduce the pronounced health disparities and higher poverty rates LGBTQ+ older adults experience compared to their heterosexual and cisgender peers. Discrimination in health care contributes to these disparities: LGBTQ+ older adults have been denied care, provided inadequate care, and have been afraid to seek necessary care for fear of mistreatment. For example, a lesbian in her late fifties was asked by her gynecologist why she was not experiencing any pain during sex, clearly making an assumption that she was heterosexual, making her very uncomfortable and unsure about whether she should disclose her sexuality.

Many LGBTQ+ elders and their loved ones experience discrimination in long-term care facilities, such as verbal and physical harassment, denial of basic care (such as a shower), visiting restrictions, isolation, improper discharge, and refusal of admission. Like many LGBTQ+ older adults, one 71-year-old lesbian felt pressured to re-closet herself just to get the long-term care she needed. In one instance, the staff of a nursing home ignored a resident's pleas for help when other residents verbally and physically abused her for being a lesbian.

Transgender people in particular experience discrimination in treatment , such as denial of physiologically appropriate care (e.g., transgender men who have not had "bottom" surgery being denied needed gynecological exams). Moreover, discrimination and barriers to health care access are even higher for transgender people of color. These experiences compound over the lifetime and lead to poorer health as older adults.

Transgender older adults are also frequently denied medically necessary gender-affirming care, including gender-affirming surgery, despite letters from their physicians demonstrating the medical necessity of these treatments. Medicare enrollees are at a particular disadvantage because CMS has yet to issue a National Coverage Determination for gender-affirming care. These examples underscore the necessity of adding the term "transgender status" to Sec. 92.101.

**PACE and Medicaid**
LCAO strongly supports the reinstatement of prohibitions against discrimination based on sexual orientation and gender identity in Medicaid (including managed care entities and their contractors) and Programs for All-Inclusive Care for the Elderly (PACE). PACE and Medicaid provide vital coverage for many older adults with low incomes, a significant number of whom are LGBTQ+. To improve compliance and enforcement, however, we urge HHS, to harmonize the protections for these programs with the

language proposed in Sec. 92.101(b)—i.e., to include "sex stereotypes, sex characteristics, including intersex traits," as well as "sexual orientation and gender identity."

**Structural Accessibility and Reasonable Modifications**

We support the provisions that preserve prior existing requirements for structural accessibility and reasonable modifications. However, we strongly recommend that HHS incorporate the U.S. Access Board's accessible medical and diagnostic equipment standards in the final rule. Accessible equipment is as necessary as accessible buildings and facilities to maximize health care access for older adults, especially those with disabilities.

**Prohibiting Discrimination in Benefit Design**

LCAO strongly supports the proposed provisions to prohibit discriminatory plan benefit design and marketing practices. Insurers continue to discriminate against people with greater health care needs, such as older adults, by dissuading them from enrolling or shifting more out-of-pocket costs to them. We particularly support the proposal to explicitly incorporate within Sec. 1557 the integration mandate of Sec. 504 of the Rehabilitation Act of 1973. This provision is necessary to help ensure that people with disabilities, including older adults, access the health services they need to live in their homes and communities. One example of benefit implementation that violates the integration mandate is Medicare's requirement that durable medical equipment must be needed for use in the home. This requirement results in denials of coverage for items like wheelchairs, which an individual may not need to move around their house but which they do need to leave their home to go shopping, attend a religious service, or any other essential activities of community life.

Another example of coverage that incentivizes institutions over community-based settings is CMS's interpretation of Medicaid's retroactive coverage requirement. Under current federal policy, Medicaid programs cannot claim federal reimbursement under home- and community-based services (HCBS) waivers provided prior to the date on which a Medicaid HCBS service plan is approved—a process that can be time consuming. In contrast, retroactive coverage is routinely afforded to nursing facilities for services provided before the plan of care was approved. This discrepancy in the availability of retroactive Medicaid coverage means that older adults are often forced to enter nursing facilities when they need to access LTSS immediately (before a care plan can be approved).

**Prohibiting Discrimination in Automated Decision-Making**

We support the proposed provision to prohibit discrimination resulting from the use of clinical algorithms in decision-making. We agree with HHS that clinical algorithms can be discriminatory and particularly harmful to Black individuals, who must be more ill than white individuals before they can receive treatment for life-threatening conditions that greatly impact older adults (such as kidney disease and heart failure). We recommend, however, that HHS both broaden the prohibition to include any form of automated decision-making system and define the term "clinical algorithms" to avoid an overly narrow interpretation.

Discrimination in decision-making tools and systems is not unique to "clinical algorithms." For example, assessment tools for HCBS and utilization review practices that are not based on generally accepted standards of care may discriminate against specific groups. Furthermore, under a narrow interpretation, crisis standards of care might not be construed as "clinical algorithms" on the grounds that they are instead "policies" or "ranking systems" rather than automated decisions. Nevertheless, such standards frequently lead to intersectional discrimination against older adults and people of color with disabilities.

**Prohibiting Discrimination in Telehealth Services**
LCAO supports the newly proposed provision on telehealth. As our coalition's telehealth principles emphasize, telehealth has been an important tool during the COVID-19 public health emergency, greatly reducing risk of infection while helping older adults address their rising mental health needs, reduce isolation, access case management assistance and adult day services, and more.

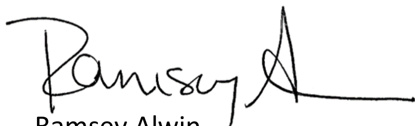
Amid telehealth's rapid expansion, however, researchers have found telehealth disparities associated with older age, race, ethnicity, low income, and preferred language other than English. In some cases, these disparities in access and quality have resulted from inaccessibility of the telehealth platforms themselves. Therefore, we recommend that HHS require telehealth platforms to allow use of a third-party interpreter or of auxiliary aids and services. Likewise, all communication that occurs prior to a telehealth appointment (e.g., scheduling, appointment reminders) must be accessible to people with LEP and people with disabilities. Platforms should therefore be adopted that 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 (such as in their hands); and people who otherwise have difficulty in communicating via traditional telehealth models.

**Demographic Data Collection Is Critical to Civil Rights Enforcement**
We strongly agree with HHS that demographic data collection and civil rights enforcement are inextricably linked. Consequently, LCAO recommends that HHS adopt a demographic data collection requirement and establish demographic data collection as a function of civil rights monitoring. Such 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.

**Conclusion**
Thank you for the opportunity to comment on these proposed changes to the 1557 nondiscrimination rules. Sec. 1557 is critical to the health of the older adults we represent and serve. LCAO strongly supports the proposed rule with the amendments we have recommended. We direct HHS's attention to each of the materials we have cited and made available through active links herein, and we request that the full text of each of the studies and articles cited, along with our comment, be considered part of the formal administrative record for purposes of the Administrative Procedure Act.

If you have questions, please contact Lindsey Copeland, of the Medicare Rights Center (lcopeland@medicarerights.org), and Siena Ruggeri, of Community Catalyst (sruggeri@communitycatalyst.org), co-chairs of the LCAO Health Committee.

Sincerely,



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