

JUSTICE IN AGING

FIGHTING SENIOR POVERTY THROUGH LAW

October 3, 2022

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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

Justice in Aging appreciates the opportunity to comment on the Department of Health and Human Services' Office for Civil Rights (HHS OCR) Nondiscrimination in Health Programs and Activities Notice of Proposed Rulemaking (NPRM).

Justice in Aging uses the power of law to fight senior poverty by securing access to affordable health care, economic security, and the courts for older adults with limited resources. We have decades of experience with Medicaid and Medicare, with a focus on long-term services and supports (LTSS) and the particular needs of those dually eligible for Medicare and Medicaid coverage. Our advocacy focuses on populations of older adults who have historically faced discrimination, including women, LGBTQI+ people, people of color, people who have limited English proficiency (LEP), and people with disabilities. Therefore, ensuring that programs and services are delivered without discrimination based on race, ethnicity, language, disability, gender identity, sexual orientation, sex characteristics or age is at the heart of our work. We advocate for culturally competent, person-centered care in programs like Medicare and Medicaid to meet the diverse needs of seniors with limited incomes and resources across the country. Every day, we work with a network of advocates and professionals serving older adults who both benefit from the non-discrimination protections of Sec. 1557 and have been harmed by rollbacks in the 2020 rulemaking, so the implementing regulations for the statute are critically important to us, the advocates we support, and ultimately older adults.

We are pleased to offer strong support for the proposed changes to restore and strengthen the Sec. 1557 anti-discrimination provisions and health care rights more broadly. Our comments focus on aspects of the NPRM that are particularly important to older adults, and we offer several recommendations to further the rule's impact on equitable access to quality health care and LTSS.

General Provisions

Application (§ 92.2)

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,

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Oakland, CA

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 Sec. 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 is 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. **We recommend that in the final rule, HHS clarify that this change in interpretation is applicable across 1557 and the underlying statutes (Title VI, Title IX, Section 504, and the Age Act). We also recommend HHS reiterate this change of interpretation in discussing the applicability of Sec. 1557 in § 92.2.**

Most importantly, this change will eliminate confusion for older adults, people with disabilities, and advocates in accessing health care and enforcing their rights and 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 (MA). Bringing all Medicare providers under this rule will also help increase access to quality health care for all members of marginalized communities who face significant discrimination and barriers whether or not they are Medicare enrollees. For example, if all Medicare providers are required to comply with this rule, transgender people of color will benefit as many Medicare providers serve people with other forms of insurance.

This change in interpretation is well-supported by how the Part B program has evolved, the fact that most Part B providers are already receiving other forms of FFA, and the clear intent of the Sec. 1557 statute. In Justice in Aging’s experience, explaining this carveout to advocates has been challenging because the justifications HHS previously relied on were strained and made little sense in the context of the modern health care delivery system. We look forward to this simplification.

From the beginning, the underlying reasons for the exclusion of Medicare Part B providers were discriminatory,¹ making HHS’s previous position to continue this exclusion under Sec. 1557 improper. Nonetheless, even the previous justifications for the exclusion are no longer applicable.

First, we agree with HHS that there is no longer a valid basis for treating Part B differently than Part A given the vast similarities in how the programs currently operate and how providers are paid. In both Part A and Part B, the program subsidizes the health care services provided to the Medicare enrollee by paying financial assistance to the providers and suppliers. As HHS notes, the operation of Medicare Part B has changed since the program began and now provides payment directly to providers for health services rendered instead of the Part B enrollee paying for the services out of pocket and receiving reimbursement from Medicare. This change renders the primary historical justification for not treating Part B as federal financial assistance moot.

We also agree with HHS’s reasons for treating all providers enrolled in the Medicare Part B program, both “participating” and “non-participating,” as recipients of FFA. Namely, non-participating providers

¹ David Barton Smith, Racial and Ethnic Health Disparities and the Unfinished Civil Rights Agenda, *Health Affairs* (Mar/Apr. 2005), <https://www.healthaffairs.org/doi/full/10.1377/hlthaff.24.2.317>.

agree to provide Medicare-subsidized health services to Part B enrollees and are thus indirect recipients of FFA. Furthermore, both participating and non-participating providers must sign an assurance of compliance with these civil rights laws as a condition of receiving federal funds.

Finally, we agree with HHS that the rationale for excluding Part B as a contract of insurance is no longer applicable, and that even if it were a contractual insurance payment, the statutory language of Sec. 1557 explicitly *includes* “contracts of insurance” within the definition of FFA.

With respect to HHS’s question about the impact that this proposed change may have on Part B providers who do not receive other FFA, we believe any impact is minimal and greatly outweighed by the benefits of ensuring people with Medicare are protected by this rule. First, few Medicare providers are not already covered entities under this rule. We agree with HHS’s proposal in the cost analysis discussion to adopt the 2016 rule’s finding that almost all practicing physicians were likely covered by the rule because they accept FFA from sources other than Medicare Part B. This finding is bolstered by the continued growth of MA, which now serves 48% of Medicare enrollees compared to 31% in 2016,² because providers who contract with an MA plan are already covered under this rule.

HHS seeks comment on the time Part B providers should be allowed to come into compliance with these civil rights statutes and their implementing regulations and what resources it can provide to assist newly covered entities. We urge HHS to ensure Part B providers’ compliance with these rules along the same timelines as all other covered entities. First, there are few providers who have not already been covered by these rules due to receipt of other FFA. Second, the burden on these entities to comply with the new requirements of Sec. 1557 is not particularly different from entities that are currently covered. The materials HHS is already preparing, such as sample notices that are translated, should help these entities as well.

Definitions (§ 92.4)

Limited English proficient individual

We urge HHS to consider revising its terminology with respect to people whose primary language is not English. The term “limited English proficient” is deficit oriented. Alternatives to LEP include “non-dominant language users” and “linguistically marginalized communities.” We recognize the term LEP is a defined term and used in other regulations and laws, and changing it is beyond the scope of this rulemaking. However, at a minimum, we urge HHS to use person-first language to describe people with limited English proficiency (e.g., individuals with LEP) in the final rule.

Definitions of Qualified Interpreter

As written, the proposed definition of “*Qualified Interpreter for a limited English proficient individual*” requires demonstrated proficiency in speaking and understanding spoken English and one other spoken language. **We recommend the term be expanded to recognize qualified interpreters who have demonstrated proficiency in speaking and understanding two non-English languages and otherwise meet the requirements under the definition.** Such qualified interpreters, in combination with other qualified interpreters, may need to be utilized in “relay interpretation” situations to ensure effective communication with individuals who use emerging languages or are part of smaller linguistic communities (e.g., an interpreter who is qualified to interpret between an Indigenous language and

² Kaiser Family Found., Medicare Advantage in 2022: Enrollment Update and Key Trends (Aug. 25, 2022), www.kff.org/medicare/issue-brief/medicare-advantage-in-2022-enrollment-update-and-key-trends/; [growth of Medicare Advantage](#).

Spanish, or a Deaf Interpreter who is qualified to interpret between American Sign Language and other sign languages).

We also propose that this and other definitions include the concept of linguistic variants as a distinct form of a language used by people from a specific community or region. It is important to recognize that many languages spoken in the U.S. are actually language families with many distinct linguistic variants or “dialects” that may be used in the same country of origin, but are frequently not mutually intelligible.

We further recommend that the definition of “Qualified interpreter for an individual with a disability” be aligned with the definition of “Qualified Interpreter for a limited English proficient individual.”

Designation and responsibilities of a Section 1557 Coordinator (§ 92.7)

We support the proposal to require covered entities to have a designated Sec. 1557 coordinator. HHS requested comment on whether this provision should apply to entities with fewer than 15 employees, and we recommend that it should. Regardless of size, one person at a covered entity should be responsible for 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 entity. We believe that the duties of the coordinator as proposed in this rule allows for necessary variation so that smaller entities will not be burdened. For example, a smaller entity would not have to have the coordinator role be a full-time job.

While preventing discrimination is critical in all health care settings, having a coordinator to ensure that Sec. 1557 is implemented is essential to daily life for someone who resides at a covered entity such as a nursing home or receives home- and community-based services (HCBS). It is common for entities providing LTSS, such as assisted living and group homes, to be small. And older adults and people with disabilities often prefer small providers because the nature of LTSS, such as personal care, requires longer and intimate interaction often on a daily basis.

Policies and procedures (§ 92.8)

We strongly support this provision which requires covered entities, regardless of size, to adopt Sec. 1557 policies and procedures. In addition to the policies and procedures outlined in the proposed rule, **we recommend HHS require covered entities to develop a communications access plan that addresses the needs in their service area for language access and accessibility for individuals with disabilities.**

Communications Access Plan

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 the effective “language access procedures” and “communications procedures” described in § 92.8 such as how to schedule an interpreter, how to identify whether an individual has LEP, etc. that the proposed rule requires. Managed care plans should be required to include in their plan how the providers in their network will access interpreter services and other communication supports.

To support development of the plans and compliance with these provisions, HHS can assist covered entities by providing a template plan that includes key questions the entity should answer about the language and communications-related demographics of their service area, target population, and/or existing client base. HHS can also direct entities to resources for finding this information. For smaller entities and non-profit community-based providers, HHS should consider facilitating access to

interpreter and translation services. For example, HHS could contract with a language line and allow smaller entities to opt in to using that service, which may help defray costs for an entity otherwise negotiating their own contract. HHS, through its regional offices, could also help connect providers with local community-based organizations who have qualified interpreters and can translate documents and provide other language services. This approach would be especially beneficial for smaller language communities concentrated in particular geographic areas. Similarly, the regional offices could connect covered entities with organizations and vendors who may be able to provide materials in plain language, Braille or other alternative formats.

We also recommend HHS provide guidance on other language access measures such as effective phone trees that allow callers to access an interpreter immediately with minimal English-only instructions. As much as possible, phone trees should provide in-language instructions for connecting to an interpreter, i.e., a translation of “press # for [language]” in the top languages in their service area. We also recommend that HHS work to develop standardized protocols for phone trees and help provide public education. Similar to how pressing “0” is widely known and used to reach an operator or agent, pressing another specific digit could become standard for connecting to an interpreter.

Finally, we recommend HHS work with the Department of Education and other agencies to invest in medical interpreter training for smaller language communities that may not have qualified interpreters nor access to training in their language. For example, there are over 20 indigenous language communities in the Los Angeles area.³ Investing directly in these communities would yield not only language services for people who might otherwise not have access, but also higher quality health care because of the additional benefits of cultural competency native-language speakers bring.

Training (§ 92.9)

We strongly support this new proposed requirement that covered entities train their employees on their Sec. 1557 policies and procedures. 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. We recommend that HHS should clarify in the final rule that relevant individuals includes temporary staff who are interacting with the public or clients. This is especially important in LTSS settings where that staff person may be the only person interacting with an individual.⁴

Notice of Nondiscrimination (§ 92.10)

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. This has been especially harmful to older adults with LEP who do 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.

³ CIELO, UCLA AISC, UCLA Promise Inst. for Human Rights, UCLA Bunche Ctr., We are Here: Indigenous Diaspora in Los Angeles (Jan. 2022), <https://storymaps.arcgis.com/stories/618560a29f2a402faa2f5dd9ded0cc65>.

⁴ See discussion of nursing facility guidance for surveyors *infra* under meaningful access.

To improve the effectiveness and accessibility of this notice, we recommend that covered entities be required to provide them in large print (18-point font minimum) and plain language. We also recommend that any entity that receives an exemption due to the application of a Federal conscience or religious freedom law under § 92.302 be required to include the exemption in its notice of nondiscrimination. It is essential for individuals to have this information when choosing a provider.

Notice of Availability of Language Assistance Services and Auxiliary Aids and Services (§ 92.11)

Justice in Aging strongly supports HHS's proposal in § 92.11 to require covered entities to provide a notice of availability of language assistance services and auxiliary aids and services. We agree with HHS that the 2020 rule did not appropriately consider the costs to individuals with LEP in eliminating the 2016 rule's tagline requirements and that the benefits of providing notice of availability of language access services outweigh the costs to covered entities. As HHS notes in the preamble and as was discussed in the litigation we filed challenging the 2020 rule, eliminating these taglines was particularly harmful to older adults with LEP and community-based organizations that provide language access services.⁵ For example, we learned about a recent incident where call center staff for a Medicare Advantage plan were unfamiliar with the plan's own interpretation services. As a result, a community-based organization in Southern California spent many hours and made several attempts to access and schedule a qualified interpreter through the plan. The ordeal exacerbated the older adult's stress and their anxiety about their medical condition, not knowing whether they would be able to communicate with their provider. This is a common experience for many older adults with LEP.

We agree with HHS's general 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. In addition to more detailed recommendations below to ensure consistency and the strongest available protections for people with Medicare, **we recommend that HHS require covered entities to also include a large print notice of availability (minimum of 18-point font) in English at the beginning of any document listed in proposed § 92.11(c)(5).** To help ensure the notice of availability is as informative as possible and to assist covered entities in complying with this section, 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, a notice of availability should indicate that a response is required or that the communication contains information about one's rights or benefits.

Harmonizing Medicare Rules

In the final rule, **we urge HHS to consider the requirements of § 92.11 on related authorities in the Medicare Advantage program and harmonize potential inconsistencies with policies that are most protective of the individual with LEP.**⁶ Over 53 million older adults and people with disabilities are enrolled in a Medicare Advantage or Medicare Part D plan (MAPD).⁷ The MAPD regulations (42 C.F.R. §§ 422.2267(e)(31) and 432.2267(e)(33)) mandate that these plans provide a multi-language insert (MLI)

⁵ 87 FR 47854; Compl., *Chinatown Serv. Ctr. v. U.S. Dep't of Health & Human Servs.*, No. 1:21-cv-00331 (D.D.C. Feb. 5, 2021).

⁶ Although our discussion centers on harmonizing proposed § 92.11 with Medicare Advantage and Part D regulations, we encourage HHS to review other federal regulations already in effect that may overlap with § 92.11 and other parts of the proposed Sec. 1557 implementing regulations.

⁷ CMS, Medicare Advantage, Cost, PACE, Demo, and Prescription Drug Plan Monthly Contract Summary Report, (Data from Sep. 2022), available at www.cms.gov/research-statistics-data-and-systems/statistics-trends-and-reports/mcradvpartdenrolldata/monthly/contract-summary-2022-09.

notifying enrollees that the plan provides free interpreter services.⁸ It must be provided in 15 languages as well as any additional language that meets a five percent (5%) service area threshold.⁹ Plans also have the discretion to include the MLI in additional languages below the threshold. The MLI is required on over 20 documents as set forth under 42 C.F.R. § 422.2267(e)(31) and § 432.2267(e)(33), including the Evidence of Coverage, Explanation of Benefits, Formulary, Provider/Pharmacy Directory, and many more.

There are at least four key ways the proposed notice of availability differs from what is currently required by MAPD regulations: (a) the content of the insert/notice, (b) on what documents the notice/insert is required, (c) what languages the insert/notice is made available, and (d) the availability of an opt-out mechanism. We believe that the MLI can be subsumed within the Sec. 1557 notice of availability in a way that is still protective of individuals with LEP, minimizes confusion and eases compliance efforts for MAPD plans. We make recommendations to address each of the specific differences below.

Subsuming the MLI in the Notice of Availability Is Appropriate Given the Overlapping Content

Subsuming the MLI within the notice of availability makes sense because of their overlapping content. The MLI does not include information about the availability of appropriate auxiliary aids and services, a key improvement between proposed § 92.11 and what was previously required in the 2016 tagline requirement. Awareness of the availability of auxiliary aids and services is critical to ensuring effective communication and access to services for older adults and people with disabilities. In contrast, the availability of language assistance services is part of both the MLI and proposed § 92.11. Therefore, we believe that HHS should clarify that MAPD plans should be deemed compliant with both Sec. 1557 and the MAPD regulations as long as they are providing notices of availability that contain the contents as set forth in proposed § 92.11(a). Doing so will alleviate the burden on both consumers and plans; consumers will not be flooded with partially overlapping notices, and MAPD plans can follow Sec. 1557 notice requirements while also fulfilling essentially what is required under 422.2267(e)(31) and 432.2267(e)(33). This approach also comports with the notion that Sec. 1557 is an omnibus non-discrimination rule for health programs and activities.

Cross walking All Documents Requiring the MLI to § 92.11 Will Protect Medicare Beneficiaries with LEP

The MAPD regulations also differ from proposed § 92.11 with respect to which documents plans are required to include the notices. The MAPD regulations include 20 plus documents that must include the insert, while proposed § 92.11(c)(5) identifies only ten types of documents. In cross-referencing both lists, we believe the vast majority of documents under the MAPD regulations would be included in the proposed ten categories, but there are some ambiguities. For example, provider directories and drug formularies are identified in the MAPD regulations; however, it is unclear whether and where these critical documents would be encompassed under 92.11(c)(5).¹⁰ Similarly, the MAPD regulations include

⁸ 42 C.F.R. § 422.2267(e)(31) governs Medicare Advantage, and 42 C.F.R. § 432.2267(e)(33) governs Medicare Part D plans. The MLI states: “We have free interpreter services to answer any questions you may have about our health or drug plan. To get an interpreter, just call us at [1-xxx-xxxx-xxxx]. Someone who speaks [language] can help you. This is a free service.”

⁹ The required languages are Spanish, Chinese, Tagalog, French, Vietnamese, German, Korean, Russian, Arabic, Italian, Portuguese, French Creole, Polish, Hindi, and Japanese.

¹⁰ This depends on whether HHS’s interpretation of § 92.11(c)(5)(x) “patient and member handbook” is inclusive of these types of directories. If it is, we recommend HHS clarify this in the regulatory text by adding these specific documents.

documents specific to the Medicare program and Medicare plans, like the Annual Notice of Change (ANOC).

For provider directories and prescription drug formularies, we recommend HHS enumerate those in § 92.11(c)(5) of the final rule. These are documents that are not unique to Medicare and are some of the most useful and important documents to utilizing health coverage. **We also recommend HHS review all of the documents identified in the MAPD regulations and crosswalk any that are not included under the current list in 92.11(c)(5) to the final implementing regulation for Sec. 1557.** HHS should enumerate any additional documents in the final rule that are not specific to Medicare, as well as provide MAPD plans with the final cross-walked list to explain that the lists in the MAPD regulations and in Sec. 1557 are not in conflict. MAPD plan members should continue to receive critical information about the availability of key consumer protections on vital plan documents; that list of documents should not be reduced because HHS has implemented a separate regulation with a similar goal.

Adopting a Service Area Threshold Benefits Smaller Language Communities

With respect to languages required, the MAPD regulations and proposed § 92.11 also differ. The MAPD regulations require the notice in the top 15 languages in the U.S.¹¹ as well as any other language that meets a five percent service area threshold.¹² The proposed § 92.11(b) requires the notice of availability top fifteen languages per state or relevant states. **We urge HHS to revise § 92.11(b) to clarify that in addition to the top 15 languages in each state, covered entities be required to provide the notice of availability in any additional languages meeting the five percent service area threshold,** as is required in Medicare Advantage and Part D. The additional five percent service area threshold trigger is important because it captures smaller, more geographically isolated language communities who might not otherwise rise to the top fifteen languages in a particular state. This more localized standard recognizes the racialized segregation in America's residential communities and the clustering of specific language communities. It also would likely capture those languages that HHS has already identified under the top 15 standard.

Although HHS is understandably concerned about the burden on covered entities to provide the notices in an abundance of languages, MAPD plans have been providing the inserts in these languages for many years. Any reduction in the number of languages from those identified in the MAPD regulations will only potentially harm Medicare beneficiaries, especially those in smaller language communities who may no longer receive important information about their language access rights. Therefore, if HHS is not going to add a service area threshold to § 92.11(b), we recommend HHS retain the current MAPD requirements for which languages the notices must be provided in in the MAPD context as they are more protective for Medicare enrollees.

Opt-Out Provision Properly Balances the Importance of the Notices with Minimizing Unnecessary Costs

Finally, the MAPD regulations do not contain an opt out provision as is proposed in § 92.11(d)(1). We believe the proposed opt out provision properly balances the importance of providing individuals with LEP and people with disabilities with critical information about their rights and the potential burdens on covered entities, large and small, to provide such information. This is particularly true if HHS adds a five percent service area threshold trigger on the languages required and includes the MAPD regulations' documents under 92.11(c)(5), as doing so potentially increases the number of languages and documents

¹¹ The top 15 languages nationwide are Spanish, Chinese, Tagalog, French, Vietnamese, German, Korean, Russian, Arabic, Italian, Portuguese, French Creole, Polish, Hindi, and Japanese.

¹² 42 C.F.R. § 422.2267(e)(31)(i); 42 C.F.R. §. 432.2267(e)(33)(i).

that require the notices of availability. Therefore, for simplicity, **we support including the proposed opt out provision in the final rule and applying it to Medicare plans as well.** In addition, providing an opt-out with appropriate guardrails for all healthcare consumers will be easier to administer and minimize confusion for consumers who may not understand why they can opt out of such notices in one context but not in Medicare.

With respect to how the opt-out provision operates, we appreciate the clarity around individuals who opt out retaining the right to ask for translated documents on a case by case basis. We also appreciate that the opt out notification and process be required annually. We recommend HHS similarly clarify in the final rule that an individual can opt back in to receiving the notice of availability on all relevant documents at any time (not only annually).

The Benefits of Providing Notice Outweigh the Costs

The greater purpose of Sec. 1557 and these regulations is to prevent discrimination in the first place and ensure meaningful access to high-quality, necessary health care and LTSS. We agree with HHS that benefits of this rule include reducing obstacles to accessing care by requiring covered entities to provide language and communications access and train their employees on policies and procedures. Without meaningful access, individuals with LEP and/or disabilities are more at risk of negative health outcomes. In addition to this real harm to individuals, which must not be minimized in considering the costs of the rule, missed diagnoses, poorer health outcomes and inefficiencies (e.g., more time, rescheduling, appeals) imposes costs on the entire healthcare system, like providers and payers, including those publicly-funded by Medicare and Medicaid.

It takes time to educate the public on any type of law or regulation. The best way to ensure that effective education is through repetition. When an older adult receives a notice that a gender-affirming service has been denied, for example, or is told that the clinical tests showed nothing is wrong, or is misunderstood because a qualified interpreter was not offered, they will probably be frustrated and feel wronged, but they may not recognize what they experienced as discriminatory or understand their right to challenge it as such.

The proposed notice of nondiscrimination and notice of availability are key to filling this information gap for individuals and to enforcement of the law—someone who is aware of their rights because they have been repeatedly notified can both proactively enforce those rights and challenge violations. This enforcement in turn is key to better health care for the individual and to ending systemic discrimination and the disparities it produces.

Data Collection

In the NPRM, HHS acknowledges that demographic data collection and civil rights enforcement are inextricably linked. We agree. 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 rule (race, ethnicity, language, disability, age, sex, sexual orientation, gender identity, pregnancy status, and sex characteristics) and allow for intersectional analysis among multiple demographic characteristics. We support the more detailed comments on data collection submitted by the National Health Law Program.

Nondiscrimination and Specific Applications to Health Programs and Activities

Discrimination Prohibited (§ 92.101)

We strongly support this proposed section outlining specific types of discrimination that are prohibited. Below we discuss the importance of these protections for older adults and recommend changes to further strengthen this provision.

Age Discrimination

We appreciate HHS's discussion in the preamble to this NPRM of the pervasiveness and harms of age discrimination to older adults, and the particular disparities that the COVID-19 pandemic highlighted and amplified, especially for older adults in nursing facilities. In addition to interpersonal discrimination that older adults face in health care such as having their concerns ignored or dismissed as a "normal" part of aging, examples of more systemic ageism harm older adults' access to proper diagnoses, treatment, and services. Two examples are from the U.S. Preventive Services Task Force (USPSTF). First, in its recommendations for HIV screening,¹³ the USPSTF concludes that all adolescents/adults 15-65 should be screened for HIV but that adults over 65 should only be screened if they have "risk factors." This assumes that individuals age 65 and over do not engage in sex or drug use—a very ageist presumption—and it makes an arbitrary distinction between someone age 64 and someone age 65. As a result, it is challenging to get Medicare to cover more than one HIV screening per year, which is necessary for PrEP to be administered. More recently, the USPSTF issued a draft recommendation for anxiety screening for all adults under age 65.¹⁴ In declining to extend the recommendation for people 65 and older, the panel said there was no clear evidence regarding the effectiveness of screening tools in older adults because anxiety symptoms can also result from aging. This reasoning points to the ways in which ageism shows up in health care. Instead of focusing on alternatives to ensure older adults are screened and treated for anxiety, their symptoms are dismissed as a "normal" part of aging.

Intersectional Discrimination

Often the discrimination that older adults experience in health care and LTSS is at the intersection of their identities as an older person *and* as a person with a disability, a person of color, a person with LEP, an LGBTQI+ person, and/or as a woman. For example, during focus groups Black and Latino Medicare enrollees age 65 and older reported experiencing discrimination based on their multiple identities, including their age, like being both Black and a woman or being Latino and having LEP or an accent.¹⁵ Many of the examples we share below and throughout this comment illustrate this intersection.

Discrimination based on intersectional identities was not understood, overlooked, and/or ignored by the drafters of most civil rights laws, including Title VI, Section 504, Title IX, and the Age Act. So often,

¹³ USPSTF, Final Recommendation Statement Human Immunodeficiency Virus (HIV) Infection: Screening (Jun. 11, 2019), <https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/human-immunodeficiency-virus-hiv-infection-screening>.

¹⁴ Draft Recommendation Statement: Screening for Anxiety in Adults (Sep. 20, 2022), <https://uspreventiveservicestaskforce.org/uspstf/draft-recommendation/anxiety-adults-screening#fullrecommendationstart>.

¹⁵ The Commonwealth Fund, What an Ideal Health Care System Might Look Like: Perspectives from Older Black and Latinx Adults (Jul. 21, 2022), www.commonwealthfund.org/publications/2022/jul/what-ideal-health-care-system-might-look-like.

discrimination in both the administrative context and the courts has been viewed through the lens of one marginalized group. However, this is not the case for Sec. 1557. There is a reason Congress enacted a new Health Care Rights Law—that is to bring these anti-discrimination provisions under one enforceable authority. As health care civil rights experts have observed, “If Congress believed that Title VI already provided adequate protections against health care discrimination, the analogous part of Section 1557 would have proven unnecessary. Rather, Sec. 1557 provides an independent basis for protections from discrimination based on race, color, national origin, age, disability, and sex.”¹⁶

In the preamble of this NPRM, HHS recognizes that Sec. 1557 is its own statute enforceable by private right of action in the courts and is intended to address intersectional discrimination. We strongly urge HHS to identify ways to address intersectional discrimination in the regulatory provisions of the rule itself. **Specifically, we recommend making an explicit reference to intersectional discrimination in the regulatory text of § 92.101.** We propose amending 92.101(a)(1) as follows: “Except as provided in Title I of the ACA, an individual must not, on the basis of race, color, national origin, sex, age, or disability, or any combination thereof,”

LGBTQI+

Justice in Aging strongly supports the proposal to clarify that, under Sec. 1557, discrimination “on the basis of sex includes, but is not limited to, discrimination on the basis of sex stereotypes; sex characteristics, including intersex traits; pregnancy or related conditions; sexual orientation; and gender identity.”¹⁷ We agree with HHS that 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. We appreciate HHS’s discussion and definitions of these terms, including the pervasiveness of discrimination against transgender individuals in health care. The terms “gender identity” and “transgender status” are often used interchangeably, and courts have construed the term “gender identity” to encompass “transgender identity.” However, some have sought to justify discrimination against transgender people by distinguishing it from gender identity. **We therefore urge HHS to amend § 92.101(a)(2) to explicitly include “transgender status” in addition to the other bases listed.**

These specific protections are necessary to help reduce the pronounced health disparities and higher poverty rates LGBTQI+ older adults experience compared to their heterosexual and cisgender peers.¹⁸ Discrimination in health care contributes to these disparities: LGBTQI+ older adults have been denied care, provided inadequate care, and have been afraid to seek necessary care for fear of mistreatment.¹⁹

Transgender older adults, like transgender people of all ages, are frequently denied medically necessary gender-affirming care, including gender-affirming surgery, despite letters from their physicians demonstrating the medical necessity of these treatments. We have heard from advocacy partners that many transgender older adults also have difficulty finding providers they can trust and who will treat them with dignity. For example, earlier this year a transgender Asian American woman in her sixties

¹⁶ Jamille Fields Allsbrook & Katie Keith, ACA Section 1557 As A Tool For Anti-Racist Health Care, *Health Affairs* (Dec. 8, 2021), <https://www.healthaffairs.org/doi/10.1377/forefront.20211207.962085/full/>.

¹⁷ 87 Fed. Reg. 47,824, 47,916 (§ 92.101(a)(2)).

¹⁸ SAGE & National Resource Center on LGBT Aging: Facts on LGBT Aging, <https://www.lgbtagingcenter.org/resources/pdfs/SAGE LGBT Aging Final R2.pdf>.

¹⁹ Mary Beth Foglia & Karen I. Fredriksen-Goldsen, Health Disparities among LGBT Older Adults and the Role of Nonconscious Bias, *Hastings Cent Rep.* (Mar. 2015), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4365932/#S1title>.

underwent facial feminization surgery. A part of this surgery involves the Adam’s apple (a tracheal shave), which has the temporary side effect of being unable to speak following the surgery. When this trans woman woke up from her surgery, multiple nurses misgendered her and harassed her. Because she could not talk, she could not stand up for herself. As the advocate who shared this story reported, “Older adults are often at the mercy of their healthcare providers and are unable to fight for themselves when harassed.”

Older adults also experience discrimination based on their sexual orientation, such as doctors making assumptions about their sexual behavior, forcing the older adult to disclose their sexual orientation. Others have been harassed and denied care. For example, an older adult shared his story about visiting a urologist for a health concern not related to a sexually transmitted infection. He reported that when the doctor asked him if he was married, and he said no and that he is gay, the doctor replied, "It's no wonder you're sick. What you people do is disgusting." The doctor refused to examine the man, but he still had to pay for an office visit even though he didn't receive treatment.²⁰ Many older LGBTQI+ adults, especially those age 80 and older, express feelings of hesitation about disclosing their sexuality or gender identity to their health care provider or insurer because they fear being denied care or being dropped from their coverage.²¹ As one study found, this common fear suggests “shared decision-making during the clinical encounter is likely to be compromised, thereby contributing to the perpetuation of health inequalities among LGBT older adults.”²² Others report delaying care due to this fear.

In addition, many LGBTQI+ older adults and their loved ones experience discrimination in long-term care facilities,²³ such as verbal and physical harassment, denial of basic care (such as a shower), visiting restrictions, isolation, improper discharge, and refusal of admission.²⁴ For example, a transgender older woman was discharged from the hospital to a rehabilitation facility after a procedure. When the aide who was assigned to her gave her a sponge bath the next day, the aide discovered that she was transgender. The aide then brought in other nurses and made fun of the woman, who was already in a vulnerable position being older and recovering from surgery.²⁵ Discrimination in LTSS settings can also be systemic. We have heard reports of privately-operated group homes not accepting people living with HIV, for example, or making it clear that LGBTQI+ older adults are not welcome. The harms of this discrimination are compounded for older adults residing in smaller cities and rural areas—they are either forced to re-closet themselves to get the care they need or delay or forgo services altogether.

LGBTQI+ older adults also fear discrimination in LTSS settings. For example, a lesbian older adult who has witnessed discrimination against her own LGBTQI+ clients shared that she worries about where she will end up and whether it will be welcoming if she needs more assistance. Many choose not to receive home- and community-based services, hospice, home health aides, or other assistance because they

²⁰ Story reported to SAGE and shared with permission.

²¹ Mary Beth Foglia & Karen I. Fredriksen-Goldsen, Health Disparities among LGBT Older Adults and the Role of Nonconscious Bias, *Hastings Cent Rep.* (Mar. 2015), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4365932/#S1title>.

²² *Id.*

²³ Justice in Aging et al., LGBT Older Adults in Long-Term Care Facilities: Stories from the Field (updated June 2015), <http://www.justiceinaging.org/wp-content/uploads/2015/06/Stories-from-the-Field.pdf>.

²⁴ Ivette Feliciano, LGBTQ seniors fear discrimination when searching for housing, *PBS News Weekend* (Oct. 10, 2021), <https://www.pbs.org/newshour/show/lgbtq-seniors-fear-discrimination-when-searching-for-housing>; UCLA Williams Institute, LGBT Aging: A Review of Research Findings, Needs, and Policy Implications (Aug. 2016), <https://www.lgbtagingcenter.org/resources/pdfs/LGBT-Aging-A-Review.pdf>.

²⁵ Story reported to SAGE and shared with permission.

fear discrimination. This type of discrimination stings in a unique way because the services are often administered at home or elsewhere in the community where older adults should feel most comfortable and safe.

Restoring Prohibitions on Sexual Orientation and Gender Identity Discrimination in Medicaid & PACE

We strongly support 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). 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, pregnancy or related conditions, sexual orientation and gender identity, including transgender status.

PACE and Medicaid provide vital coverage for many older adults with low incomes, a significant number of whom are LGBTQI+. The estimated 12 million people dually eligible for Medicare and Medicaid are disproportionately low-income, people of color, disabled, and in poorer health.²⁶ Further, as noted above, a disproportionate share of LGBTQI+ older adults also live in poverty, compared to the general population. Both PACE and Medicaid cover LTSS that Medicare does not, making LTSS one of the most common reasons an individual is enrolled in Medicaid. Because of the often daily and intimate nature of the services provided under these programs—including the fact that the services are sometimes provided in the enrollee’s own home—it is essential for the person receiving services that they have Sec. 1557’s protections. As examples in our discussion above with respect to LGBTQ+ discrimination illustrate, individuals receiving Medicaid-funded LTSS are particularly vulnerable to ongoing discrimination in their daily care. Misgendering, including harassing and willful use of incorrect pronouns is a particular issue for individuals relying on care in residential settings, care that overwhelmingly is paid for by Medicaid.²⁷

Discrimination Based on Race and Color

Race-based discrimination in health care is well documented²⁸ and older adults are harmed by it in multiple ways. Analysis of Medicare enrollees shows that compared to white enrollees, people of color are more likely to report being in relatively poor health, more likely to have certain chronic conditions such as hypertension and diabetes, less likely to have one or more doctor visit but have higher rates of hospital admissions and emergency department visits.²⁹

²⁶ CMS Medicare Medicaid Coordination Office, Factsheet: People Dually Eligible for Medicare & Medicaid (Mar. 2020), https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/Downloads/MMCO_Factsheet.pdf; Kaiser Family Found., Racial and Ethnic Health Inequities and Medicare (Feb. 16, 2021), <https://www.kff.org/medicare/report/racial-and-ethnic-health-inequities-and-medicare/>.

²⁷ See, e.g., Justice in Aging Amicus Curiae Brief, *Taking Offense v. State of California*, No. 34-2017-80002749-CU-WM-GDS (Sacramento Co. Superior Ct.), at p. 16 et seq, available at <https://justiceinaging.org/wp-content/uploads/2022/07/Justice-in-Aging-Amicus-Brief-07222022.pdf> (documenting the issue).

²⁸ Jamille Fields Allsbrook & Katie Keith, ACA Section 1557 As A Tool for Anti-Racist Health Care, *Health Affairs* (Dec. 8, 2021), <https://www.healthaffairs.org/doi/10.1377/forefront.20211207.962085/full/>.

²⁹ Kaiser Family Found., Racial and Ethnic Health Inequities and Medicare (Feb. 16, 2021), <https://www.kff.org/medicare/report/racial-and-ethnic-health-inequities-and-medicare/>.

Racism that leads to disparate counseling and treatment for certain conditions, such as heart disease³⁰ and end stage renal disease (ESRD),³¹ disproportionately harms older adults who are at higher risk for such conditions. As one example, Blacks and Latinos with ESRD are less likely than their white counterparts to have timely referral to nephrologists, pre-dialysis nephrology care, adequate dialysis education, and planned dialysis initiation. They are also less likely to receive home dialysis.³²

Another form of harm is when victims of racial discrimination experience poorer health outcomes in old age. For example, studies have shown that Black and Latino people who experience racial discrimination have higher rates of cognitive decline.³³ This helps explain why Black and Latino older adults have higher rates of Alzheimer's and related dementias compared to non-Hispanic white older adults. Discrimination throughout the lifetime also causes "weathering"³⁴ and a lower life-expectancy. Recent plunges in overall life expectancy were most severe among people of color. They have died at younger ages during the COVID-19 pandemic than white Americans due to structural racism that pervades our healthcare, social support, and economic systems. One shocking example is the drop in life expectancy for Native American/Alaska Native people, which fell by 6.6 years from 2019 to 2021.³⁵

Other biases result in disparate harm to older adults of color. For example, many providers do not accept or limit their intake of patients with Medicaid,³⁶ which impacts access to care for older adults of color the most, as these communities are disproportionately dually eligible for Medicaid and Medicare.³⁷ Even providers who accept Medicare may refuse to see someone who is dually enrolled in Medicaid because Medicaid billing may present some additional administrative burdens and providers do not want to forgo the co-insurance that the individual is not required to pay and that the state usually does not pay due to the "lesser of" policy.

In addition to the provisions in the rule addressing race-based discrimination in clinical algorithms, we recommend HHS, both in this rulemaking and in future guidance, take action to ensure equitable access

³⁰ Amber Johnson, Understanding Why Black Patients Have Worse Coronary Heart Disease Outcomes: Does the Answer Lie in Knowing Where Patients Seek Care?, *Journal of the American Heart Association* (Nov. 30 2019), <https://www.ahajournals.org/doi/10.1161/JAHA.119.014706>.

³¹ [CDC Chronic Kidney Disease Surveillance System](https://www.cdc.gov/nchs/data/series/a110011.pdf)

³² Natasha Persaud, Racial Disparities in Home Dialysis Use Documented, *Renal & Urology News* (Apr. 29, 2022), <https://www.renalandurologynews.com/home/news/nephrology/chronic-kidney-disease-ckd/racial-disparities-home-dialysis-less-likely-in-black-and-hispanic-vs-white-patients/>

³³ Univ. of TX at Austin, Cognitive Impairment in Hispanic Adults Linked to Discrimination Experiences (Sept. 19 2022), <https://news.utexas.edu/2022/09/19/cognitive-impairment-in-hispanic-adults-linked-to-discrimination-experiences/>.

³⁴ Ana Sandoiu, 'Weathering': What are the health effects of stress and discrimination?, (Feb. 26, 2021) <https://www.medicalnewstoday.com/articles/weathering-what-are-the-health-effects-of-stress-and-discrimination>.

³⁵ CDC, Life Expectancy in the U.S. Dropped for the Second Year in a Row in 2021, (Aug. 2022), https://www.cdc.gov/nchs/pressroom/nchs_press_releases/2022/20220831.htm.

³⁶ Kayla Holgash & Martha Heberlein, Physician Acceptance Of New Medicaid Patients: What Matters And What Doesn't, *Health Affairs* (Apr. 10, 2019), <https://www.healthaffairs.org/doi/10.1377/hblog20190401.678690/full/>; MACPAC, Physician Acceptance of New Medicaid Patients: Findings from the National Electronic Health Records Survey (June 2021), <https://www.macpac.gov/wp-content/uploads/2021/06/Physician-Acceptance-of-New-Medicaid-Patients-Findings-from-the-National-Electronic-Health-Records-Survey.pdf> ("In 2017 (the most recent year available), physicians were significantly less likely to accept new patients insured by Medicaid (74.3 percent) than those with Medicare (87.8 percent) or private insurance (96.1 percent).")

³⁷ Kaiser Family Foundation, Racial and Ethnic Health Inequities and Medicare (Feb. 16, 2021), <https://www.kff.org/medicare/report/racial-and-ethnic-health-inequities-and-medicare/>

to quality health care and LTSS for people of color. For example, **HHS should issue guidance on affirmative obligations or prescriptive requirements to prevent discrimination based on race and color, akin to its guidance on language access, especially in LTSS.** There is growing evidence of race-based discrimination in the context of nursing facility admissions, hospitalization of residents, facility staffing levels, and more.³⁸ In such guidance, HHS should also explicitly account for the impact of industry changes, such as the growth of Medicare Advantage, on access to health care and insurance by people of color. For example, in 2018, 50% of Black and 54% of Hispanic people with Medicare were enrolled in a Medicare Advantage plan compared to only 36% of white enrollees.³⁹ Yet there is little evidence that MA plans, even those intended to better coordinate Medicare and Medicaid, are better alternatives for older adults of color.⁴⁰ There is also very little data on supplemental benefits offered by MA plans, but advocates have voiced concerns that benefits such as dental care may not be offered in all plan service areas, in particular in service areas that are predominantly Black or lower-income. Yet these MA plans are advertising such benefits broadly. HHS could initiate an MA compliance review (modeled after prior efforts such as OCR’s national HIV/AIDS compliance review⁴¹) focused on oral health coverage and disparities, for example.

Meaningful Access for Limited English Proficient Individuals (§ 92.201)

We strongly support the proposal 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, harmed access to quality care for the more than 6.5 million older adults with LEP.

CMS’s guidance to nursing facilities provides an example of what meaningful access means on an individual level:

“In order to provide culturally competent care, staff must understand the cultural preferences of the individual and how it impacts the delivery of care. A key component is identifying how to communicate with the resident, in order to be able to identify physical concerns and issues, and for developing a trusting relationship with staff. For example, if the resident is non-English speaking, or has limited understanding of English, the facility should identify how communication will occur with the resident. The care plan should identify the language spoken

³⁸ Justice in Aging, Racial Disparities in Nursing Facilities—and How to Address Them (Sept. 2022), <https://justiceinaging.org/wp-content/uploads/2022/09/Racial-Disparities-in-Nursing-Facilities.pdf>.

³⁹ Kaiser Family Foundation, Racial and Ethnic Health Inequities and Medicare (Feb. 16, 2021), <https://www.kff.org/medicare/report/racial-and-ethnic-health-inequities-and-medicare/>

⁴⁰ Eric T. Roberts & Jennifer Mellor, Differences In Care Between Special Needs Plans And Other Medicare Coverage For Dual Eligibles, *Health Affairs* (Sept. 2022), www.healthaffairs.org/doi/10.1377/hlthaff.2022.00463 (“Compared with non-Hispanic White dual eligibles, dual eligibles of color (for example, those identifying as Black or Hispanic) were less likely to report receiving better care in D-SNPs versus other Medicare coverage. These findings suggest that D-SNPs altogether have not provided consistently superior or more equitable care, and they highlight areas where federal and state policy could strengthen incentives for D-SNPs to improve care.”)

⁴¹ OCR Issues National HIV/AIDS Compliance Review Report to Strengthen Civil Rights and Health Information Privacy Protections for People Living with HIV/AIDS (May 2017), www.hhs.gov/civil-rights/for-providers/compliance-enforcement/agreements/compliance-review-initiative-report-bulletin/index.html.

and what tools are available to communicate, whether it be with a communication board or other systems, or through translators.”⁴²

Meaningful access goes beyond simply having tools and communications systems in place generally, to actually identifying for each resident the language and which tools are specifically available to effectively communicate with that individual. By restoring the intent of this provision to provide meaningful access to each individual, this proposed rule extends this same principle to LTSS settings outside of the federally regulated nursing facility context. Importantly, Sec. 1557 applies to assisted living facilities that receive Medicaid funding but are not otherwise federally regulated.

Health care information is complex and can only be communicated effectively in an individual’s primary language, and most people’s health care needs increase and become more complicated as they age. Furthermore, 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. Older adults with LEP may feel pressure to rely on family members as interpreters, even if those family members are not qualified to interpret health information, which can inhibit the older adult’s understanding of their health status and instructions from their provider. To facilitate timely access to qualified interpreters, **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.**

A Diabetes Educator in Virginia shared the story of her client, an older man who had immigrated from Haiti. His medical charts indicated that he had refused interpreter services and he had previously been non-compliant with medication. The educator used a language line to secure a French interpreter, as indicated in the patient’s record. She found in communicating through the interpreter that the patient was attentive and eager to learn about managing his care. She also discovered that the patient had in fact *not* been offered interpreter services in any of his prior appointments and that he did not understand diabetes and had never received education about his condition. While he had been depicted in his medical chart as non-compliant with care recommendations, he simply did not understand his condition nor did he have the tools or means to obtain the supplies and information he needed, without access to an interpreter. Because the patient was unaware of his right to an interpreter, he lost valuable time in the management and mitigation of his diabetes.

Research shows how widespread such issues are. In one study looking at care transitions, researchers reported that access to language services was limited and varied significantly by race, ethnicity, and language. More than half of patients in the study with LEP reported lacking access to medical interpreters and translated materials. With respect to disparities, “Hispanic or Latino patients and patients with limited English proficiency were less likely to report access to a computer and less likely to access the Patient Gateway portal. Black or African American patients were also less likely to use the Patient Gateway portal. Asian patients were more likely to be worried about getting home health services.”⁴³

⁴² CMS, State Operations Manual Appendix PP - Guidance to Surveyors for Long Term Care Facilities, (revised July 2022), <https://www.cms.gov/files/document/appendix-pp-guidance-surveyor-long-term-care-facilities.pdf>; see also Justice in Aging, Understanding CMS’s New Nursing Facility Guidance (Jul. 2022), <https://justiceinaging.org/wp-content/uploads/2022/07/Understanding-CMSs-New-NF-Guidance-Issue-Brief.pdf>;

⁴³ 42 C.F.R. § 483.10(c)(1), Resident Rights and §483.21(b)(3)(iii) Comprehensive Person-Centered Care Planning.

⁴³ Esteban A. Barreto et. al, The Role of Race, Ethnicity, and Language in Care Transitions (July 21, 2021), <https://www.ajmc.com/view/the-role-of-race-ethnicity-and-language-in-care-transitions>.

Companions Who Have LEP

We recommend that HHS 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.⁴⁴ People who have LEP, including older adults, may be parents/guardians for minors, may have legal decision-making authority, or may be accompanying their friend, neighbor, spouse, partner or other family member as a caregiver or support person. The companion’s understanding of the information is often as critical as is the understanding of 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.

Other Accessibility Provisions

Justice in Aging endorses the Consortium for Constituents with Disabilities’ (CCD) comments with respect to Effective communication for individuals with disabilities (§ 92.202), Accessibility for buildings and facilities (§ 92.203), Accessibility of information and communication technology for individuals with disabilities (§92.204), and Requirement to make reasonable modifications (§ 92.205). Given that more than one-third of older adults have at least one disability, these provisions are very important to ensuring that people can access quality health care and LTSS as they age. We urge HHS to ensure these provisions and the provisions with respect to language access work together to ensure that older adults and others with disabilities *and* LEP have meaningful access.

Equal Program Access of the Basis of Sex (§ 92.206)

We strongly support this proposed section for the reasons discussed by the National Center for Lesbian Rights. This provision will help to address the numerous forms of discrimination described above and clarifies that while providers may exercise clinical judgment when determining if a particular service is appropriate for an individual patient, they may not refuse gender-affirming care based on a personal belief that such care is never clinically appropriate. With respect to the language regarding providers complying with a state or local law as a justification for denying gender-affirming care, we recommend strengthening this provision to state unequivocally that Sec. 1557, as federal law, preempts any such state or local law restricting access to this care.

Nondiscrimination in Health Insurance and Other Health-Related Activities (§ 92.207)

Justice in Aging supports the proposed provisions in this section 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.

Integration Mandate

We strongly support the proposal in § 92.207(b)(6) to explicitly incorporate the Sec. 504 integration mandate into Sec. 1557 and are pleased to see the examples that HHS is contemplating this provision

⁴⁴ We support the proposed definition of companion in § 92.4: “Companion means a family member, friend, or associate of an individual seeking access to a service, program or activity of a covered entity, who along with such individual, is an appropriate person with whom a covered entity should communicate.”

would apply to, particularly Medicare Advantage and Medicaid. This is an important and necessary step in rooting out the deeply imbedded institutional biases in our health care and LTSS systems.

We agree 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. We offer these additional examples that we believe this rule can help address:

- Medicare’s current narrow reading of the statutory requirement that durable medical equipment must be used *in the home* 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 in order that are necessary for individuals to live successfully at home in the community—to go shopping, attend a religious service, attend congregational social activities or engage in other essential activities of community life.
- Federal Medicaid policy that prohibits federal matching dollars for retroactive coverage of HCBS (despite federal funds being paid for retroactive coverage of nursing facility costs) leaves many older adults who need LTSS with no choice but to enter a nursing facility even if their needs could be met at home or in another more integrated community setting.
- Policies that limit the number or types of services that can be delivered in a single outpatient visit impose particular barriers on people with disabilities who often have more medical care needs. For example, we have heard of state Medicaid programs denying reimbursement for treatment of more than one diagnosis in the same office visit, or limiting the number of “encounters” per visit. These types of limits do not exist in institutional settings. For someone who does not have access to reliable transportation, or for Native elders who live in remote locations and have to travel multiple hours to reach providers, these types of limits can prevent them from getting the care they need while living at home. They also disproportionately negatively impact individuals with mental health conditions, such as anxiety or depression, who find even a single trip outside the home difficult to manage or those who need to coordinate trips with the schedule of an accompanying caregiver.
- Poor quality non-emergency medical transportation (NEMT) and onerous pre-authorization processes are another barrier. For many people with disabilities living in the community, NEMT is essential to get any health services at all and should be easily accessible. Requiring a person needing dialysis, for example, to get pre-authorization for each and every NEMT ride effectively imposes an additional pre-authorization on the dialysis service itself that does not exist in an institutional setting.
- Lack of access to dental care can be a barrier to community living for older adults and people with disabilities because untreated oral health conditions are detrimental to overall health.⁴⁵ Federal skilled nursing regulations mandate that dental services be made available in nursing facilities. There is no similar Medicaid mandate for HCBS. Although some HCBS waivers (typically

⁴⁵ See Justice in Aging, *Adding a Dental Benefit to Medicare: Addressing Oral Health Inequity Based on Disability* (Oct. 2020), <https://justiceinaging.org/wp-content/uploads/2020/10/Adding-a-Dental-Benefit-to-Medicare-Disability.pdf> (noting that 62% of individuals with disabilities under 65 report that they have not seen a dentist in the last year and that lack of accessibility and training contributes to oral health disparities for people with disabilities).

for I/DD populations) include dental, most older adults and other people with disabilities in the community are on their own for dental care.

Network Adequacy

We agree with HHS that narrow provider networks are a growing problem and that Sec. 1557 can and should be used to help stop discriminatory network designs. HHS asks for comment on how Sec. 1557 might apply to provider network development. One factor we recommend to be considered is whether the plan is contracting with existing providers reflective of the populations with LEP in their service area. As discussed above, language is more than interpretation and translation but involves cultural competency as well. For immigrant older adults, it is important that their providers have familiarity with cultural understandings of health and wellbeing in order to provide effective healthcare. For example, a Vietnamese American doctor, who speaks Vietnamese and has some familiarity with Vietnamese culture, is likely in a better position to provide culturally appropriate care to other Vietnamese Americans than is a white doctor. Plans should also be required to analyze their service area and contract with providers, especially essential community providers and providers of color,⁴⁶ to ensure they are not perpetuating redlining or provider shortage areas where people of color live.⁴⁷ Another factor should be adequate access to specialists who treat conditions that disproportionately affect communities of color, such as Alzheimer’s and dementia.

HHS also requests comment on the impact that the lack of accessible medical and diagnostic equipment (MDE) has in limiting or denying access to care. In addition to not being able to find providers, especially specialists, who have this equipment, another way lack of accessible MDE limits access to care is that a person with a disability may be limited to seeing the one provider in network who has accessible MDE, or required to travel farther or wait longer for an appointment. This is discriminatory when people without disabilities do not face these same barriers.

Nondiscrimination on the basis of association (§ 92.209)

We support restoring explicit protections against discrimination on the basis of association. As HHS notes in the preamble, LGBTQI+ people are particularly susceptible to discrimination based on association. For example, gay and lesbian older adults endure repeated questions from doctors about why their partner is with them, and being told that only “family members” are allowed in appointments. This type of discrimination has a negative effect on the health care being provided because it undermines communication and trust among the patient, the partner or friend who provides care, and the treatment providers. As one older woman reported about her experience when her partner was diagnosed with terminal cancer: “Through the 31 months of treatment before her death, I had to identify myself in a variety of medical settings and different hospitals as: the roommate, her significant

⁴⁶ According to a Black older adult focus group participant commenting on the importance of being served by health professionals who relate to their lived experiences or share their identity: “I feel more comfortable with someone who looks like me, who can relate to me, who knows what it’s like to almost be me, . . . There are certain things that you can’t relate to without being in that community.” Commonwealth Fund, *What an Ideal Health Care System Might Look Like: Perspectives from Older Black and Latinx Adults* (Jul. 21, 2022), www.commonwealthfund.org/publications/2022/jul/what-ideal-health-care-system-might-look-like.

⁴⁷ Jamille Fields Allsbrook & Katie Keith, *ACA Section 1557 As A Tool For Anti-Racist Health Care*, *Health Affairs* (Dec. 8, 2021), <https://www.healthaffairs.org/doi/10.1377/forefront.20211207.962085/full/>.

other, her sister. The stress of not being able to be safely out, not being admitted to ICU's as 'next of kin' (hence the 'sister'), added greatly to my pain, sorrow, and stress."⁴⁸

Nondiscrimination in the use of clinical algorithms in decision-making (§ 92.210)

We support the proposed provision to prohibit discrimination through the use of clinical algorithms in decision-making and appreciate HHS's discussion of how some crisis standards of care (CSCs) used during the COVID-19 pandemic were discriminatory.⁴⁹ However, we recommend that HHS broaden the prohibition to include any form of automated decision-making system as well as CSCs, which were often ranking systems or policies and may not be considered automated. It is also important to note that an algorithm or screening tool that is equitable in its development is incomplete without culturally-competent administration, especially considering racial and other traumas that exist for many patients in health care settings.⁵⁰

Racial and other systemic oppression permeate current health data collection, and affect equity efforts because historical data is used to create screening tools and studies. Essentially, "if bias is present in the world it will be present in the data."⁵¹ Groups who have not had equal access to traditional or managed care, had poorer health outcomes, or whose data was not collected are not adequately represented in the data used to create screening tools, and such tools are likely to incorrectly identify or apply to members of such groups. For example, a study found that because Black patients had lower entry to care management programs, the gap between care needed and care received for Black patients was larger than for white patients. There the "neutral" factor of previous health care spending was actually found to be a racially biased factor.⁵² As another example, the Framingham Heart Study was found to work well for white patients because 80% of the collected data used to create the study came from white patients; and so, the study is less applicable and accurate for non-white patients.⁵³ Therefore, as discussed in more detail in the CCD's comments, we urge HHS to ensure this provision also holds accountable both the entities creating such algorithms, as well as the entities that employ them.

Nondiscrimination in the delivery of health programs and activities through telehealth services (§ 92.211)

Justice in Aging supports the comments on nondiscrimination in telehealth submitted by CCD, the Disability and Aging Collaborative, and the Leadership Council of Aging Organizations (LCAO). While recent Medicare data has shown widespread use of telehealth,⁵⁴ including among individuals dually

⁴⁸ Story submitted to SAGE and shared with permission of the storyteller.

⁴⁹ Justice in Aging et al., Examining How Crisis Standards of Care May Lead to Intersectional Medical Discrimination Against COVID-19 Patients (Feb. 2021), <https://justiceinaging.org/wp-content/uploads/2021/02/FINAL-Intersectional-Guide-Crisis-Care-2-10-21.pdf>.

⁵⁰ For example, SAGE USA's resource on [Disrupting Disparities](#) provides best practices for collecting LGBTQ-identity data in a manner that protects privacy and fosters comfort for older adult patients.

⁵¹ Trishan Panch et al., Artificial intelligence and algorithmic bias: implications for health systems, *9 J. Global Health* (2019), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6875681/>.

⁵² See Ziad Obermeyer et al., Dissecting racial bias in an algorithm used to manage the health of populations (2019), *Race, Research, & Pol'y Portal*, <https://rapp.hks.harvard.edu/algorithms-can-replicate-or-remedy-racial-biases-in-healthcare-resource-allocation/>.

⁵³ *Id.*

⁵⁴ CMS, Certain Medicare Beneficiaries, Such as Urban and Hispanic Beneficiaries, Were More Likely Than Others to Use Telehealth During the First Year of the COVID-19 Pandemic (Sept. 2, 2022), <https://default.salsalabs.org/T2b57d7b3-d86b-43e6-b759-2877feb85e3c/c1296d64-f6cc-4611-b6f7-8bf196aac2d2>.

eligible for Medicaid and Medicare, we want to emphasize the importance of ensuring telehealth is always used to supplement, not supplant, in-person services. This is especially important for older adults with chronic conditions for whom care disruptions can be particularly harmful. According to one study comparing ambulatory care use during the pandemic to pre-pandemic levels, disparities existed in delayed and forgone care by race and ethnicity, rural and urban residency, and Medicare-Medicaid dual eligibility status.⁵⁵ We also recommend ensuring nondiscrimination in telehealth includes accessibility for people with LEP and people with disabilities in all aspects of telehealth care—from scheduling, to setting up and using a platform, to the actual appointment and follow-up.

Procedures and Enforcement

As a general principle, we encourage HHS to create procedures and enforcement mechanisms that are clear, easily accessible and recognize the intersectionality of people’s lived experiences. In the context of older adults, this includes acknowledging the ways in which the effects of systemic discrimination compound over the lifecycle. HHS can achieve this by explicitly recognizing intersectional discrimination in the regulatory language; providing for waiver of the Age Discrimination Act’s administrative exhaustion requirement for intersectional claims that include age; applying Title VI procedural provisions for administrative enforcement of intersectional claims including age; recognizing disparate impact; instituting a mandatory deadline for OCR to respond to administrative complaints; and pairing enforcement with robust outreach and education.

Enforcement mechanisms (§ 92.301)

We support clear, accessible procedures for filing, investigating, and remediating discrimination complaints, including intersectional claims. Our recommendations that follow are to further clarify and strengthen the ability for older adults to seek redress for discrimination.

Private Right of Action

We appreciate HHS’s acknowledgement of a private right of action under Sec. 1557 in the preamble discussion of the enforcement mechanisms.⁵⁶ However, we urge HHS to state this clearly and unambiguously in the rule itself, as it did in the 2016 rule. Clarifying the right to bring a civil action in the rule will advance enforcement of Sec. 1557 by informing protected individuals that they can enforce their rights under this statute themselves in court, and are not limited to administrative remedies. Specifically, we recommend amending § 92.301 to include language similar to what was in the 2016 rule: “An individual or entity may bring a civil action to challenge a violation of Section 1557 or this part in a United States District Court in which the covered entity is found or transacts business.”

Intersectional Claims Involving Age

As discussed previously, we appreciate HHS’s recognition of intersectional discrimination and its unique harm for, e.g., older adults of color and “individuals who experience both transphobia and racism.”⁵⁷ In

⁵⁵ Aditi Pathak et al., *Telehealth for Medicare Beneficiaries with Chronic Conditions: No Panacea for COVID-19 Pandemic Access Challenges*, American Institutes for Research (July 29, 2022), <https://www.air.org/resource/brief/telehealth-medicare-beneficiaries-chronic-conditions-no-panacea-covid-19-pandemic>.

⁵⁶ 87 Fed. Reg. at 47,885 (Enforcement Mechanisms (§ 92.301)) (citing *Cummings v. Premier Rehab Keller, P.L.L.C.*, 142 S. Ct. 1562, 1569-70 (2022) (“it is ‘beyond dispute that private individuals may sue to enforce’ [Section 504 and Section 1557]” of the ACA)).

⁵⁷ 87 Fed. Reg. at 47,870.

addition to explicitly stating that Sec. 1557 prohibits intersectional discrimination under § 92.101, we urge HHS to recognize intersectional causes of action in the rule itself. The rule will be a stronger tool against intersectional discrimination if it clarifies that the multiple grounds on which individuals are protected against discrimination under Sec. 1557 are overlapping and additive, and are not to be considered in isolation from each other.

Sec. 1557 provides that the “Secretary [of HHS] may promulgate regulations to implement this section.”⁵⁸ We urge HHS to exercise this authority and discretion to explicitly recognize a cause of action that is intersectional and allow enforcement mechanisms available under *any* of the underlying statutes. **Specifically, we recommend adding regulatory language to § 92.301 that provides for a private right of action without administrative exhaustion for intersectional claims, including those involving age discrimination.**

Applying the Age Act procedures to all claims involving age discrimination puts older adults at a disadvantage because the Age Act procedures require a claimant to exhaust administrative remedies before they may file a civil action.⁵⁹ The administrative exhaustion requirement imposes significant hurdles on an individual’s ability to seek recourse for discrimination based on age: they must file an administrative complaint within 180 days of the event complained of, or lose their right to relief;⁶⁰ to be legally sufficient, they must report facts in their complaint that can be difficult to ascertain;⁶¹ and then they must wait 180 days for HHS to investigate before they can proceed with a claim in court.⁶² No other cause of action under Sec. 1557 imposes such a requirement. Title VI procedures do not.⁶³ Lack of consistency in administrative procedural requirements will only undermine enforcement of intersectional claims and stymies the statute’s intent to fight discrimination in healthcare. For example, an older adult who experiences transphobia, racism, and ageism should not be forced to either forgo their ageism claim or proceed through onerous administrative exhaustion to seek a remedy in court for the intersectional discrimination they experienced.

Notification of views regarding application of federal conscience and religious freedom laws (§ 92.302)

For the reasons discussed by the National Center for Lesbian Rights, we support the proposed approach which contemplates a case-by-case process and expressly acknowledges that HHS must consider the potential harm to third parties when determining whether to grant an exemption. As discussed above, we recommend that HHS require covered entities to disclose any such exemptions in the notice of nondiscrimination.

Procedures for health programs and activities conducted by recipients and State Exchanges (§ 92.303)

We support the proposal in § 92.303(a) to apply Title VI procedural provisions with respect to administrative enforcement actions, except those based exclusively on age. However, for proposed § 92.303(b), we reiterate our request that HHS clarify that for administrative enforcement, it will treat

⁵⁸ 42 U.S.C. § 18116(c).

⁵⁹ 45 C.F.R. § 91.50(a).

⁶⁰ 45 C.F.R. § 91.42(a).

⁶¹ 45 C.F.R. 91.42(b).

⁶² 45 C.F.R. § 91.50(a).

⁶³ 28 C.F.R. § 42.101 *et seq.* (providing Title VI administrative procedures without any exhaustion requirement).

intersectional claims involving age and other protected identities under the same procedural provisions as Title VI.

One ongoing deterrent to filing administrative complaints with OCR is the lack of a mandatory response deadline from the Department in Title VI procedures. **We ask HHS to consider implementing a 90-day deadline for OCR to resolve complaints, and a 120-day deadline for more involved complaints, under Sec. 1557.** The lack of a response deadline deters victims of discrimination, who may try to find other solutions or workarounds outside of administrative enforcement. While this may work in some situations, it does not usually resolve underlying issues between a covered entity and an individual or group of patients. For example, an LGBTQI+ older adult who has been discriminated against by their provider may be inclined to find another provider or forgo the service as opposed to filing a complaint and waiting for OCR to formally investigate. Providing a deadline empowers individuals by properly setting expectations. Although some may find 90 or 120 days too long to address real-time harm, we believe this is an appropriate balance between promptly and efficiently resolving complaints while addressing administrative burden and resources of potentially complex investigations.

Disparate Impact

Furthermore, **we ask HHS to make clear that it will recognize disparate impact theories of discrimination in administrative enforcement actions** for three key reasons. First, recognizing disparate impact will create a more effective remedy for discrimination in healthcare, as the nature of discrimination has evolved. Second, other parts of the rule already appear to embrace a disparate impact theory of discrimination. For example, proposed § 92.210 regarding the use of clinical algorithms in decision-making recognizes the ways in which use of clinical algorithms in healthcare may *result* in discrimination prohibited under Sec. 1557 and that a covered entity may be found liable even if such discriminatory impact was not intended. Finally, recognizing disparate impact would advance other goals in the NPRM, specifically a private right of action as recognized in *Cummings v. Premier Rehab Keller, P.L.L.C.*,⁶⁴ and in the preamble.⁶⁵ Without disparate impact, a private of right of action would ring hollow for older adults of color and other individuals who face systemic discrimination in healthcare. As legal experts have noted, “the ways in which racial discrimination manifests in the health care context has changed in the nearly 60 years since Title VI was enacted. In many (but certainly not all) ways, once-blatant racism in both policies and practice gave way to more subtle, seemingly neutral policies that disproportionately impact people of color. Current de facto segregation perpetuates the very disparities created by an era of de jure segregation.”⁶⁶

For example, during COVID-19, Justice in Aging filed multiple complaints with OCR regarding CSCs that unlawfully discriminated against older adults and people with disabilities, especially in communities of color. Disparate impact theory was critical in fighting this harmful discrimination. In one specific complaint regarding Idaho’s CSC, we argued that the policy disproportionately disadvantaged Black older adults given the inaccuracies in assessing the likelihood of survival of Black patients.⁶⁷ Clarifying that disparate impact is available advances the statutory intent behind Sec. 1557 and better addresses

⁶⁴ *Cummings v. Premier Rehab Keller, P.L.L.C.*,⁶⁴ 142 S. Ct. 1562, 1569-70 (2022) (“it is ‘beyond dispute that private individuals may sue to enforce’ [Section 504 and Section 1557]”)

⁶⁵ 87 F.R. 47885.

⁶⁶ Jamille Fields Allsbrook & Katie Keith, ACA Section 1557 As A Tool For Anti-Racist Health Care, *Health Affairs* (Dec. 8, 2021), <https://www.healthaffairs.org/doi/10.1377/forefront.20211207.962085/full/>.

⁶⁷ Complaint Regarding Idaho’s Crisis Standard of Care (Sept. 22, 2021), <https://justiceinaging.org/wp-content/uploads/2021/09/ID-OCR-complaint-JIA-2021-09-22.pdf>.

discrimination against older adults who face intersectional, systemic discrimination on the basis of age and other identities.

Outreach and Education

We encourage HHS to consider pairing clear enforcement mechanisms with robust outreach and education outside of the administrative rulemaking process. Although the notices of availability and non-discrimination will help with properly apprising individuals about their rights, more must be done to ensure that older adults, people with disabilities, and their caregivers know about their options to enforce Sec. 1557. We believe that robust outreach and education (through, e.g., *promotoras* models, service coordinators in low-income housing, care coordinators through health plans, and social services case managers at community-based organizations) is key to ensuring that individuals are aware of their rights and empowered to fight back against discrimination. An education strategy that relies solely on the notices of availability and non-discrimination is insufficient.

Procedures for health programs and activities administered by the Department (§92.304)

We agree with the proposed approach to apply Sec. 504 procedures. We strongly encourage HHS, and OCR specifically, to be as proactive as possible in enforcing these regulations with respect to its own programs. Several examples of discriminatory policies we have provided in this comment are about Medicare and other programs administered by HHS and we urge HHS to address those without delay.

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 again for the opportunity to comment in support of these important changes to Sec. 1557 implementing regulations. If any questions arise concerning this submission, please contact Natalie Kean, Director of Federal Health Advocacy, at nkean@justiceinaging.org.

Sincerely,



Denny Chan
Managing Director, Equity Advocacy