



Leadership Council of Aging Organizations

Debra B. Whitman, Chair

August 13, 2019

Roger Severino, Director
Office for Civil Rights
U.S. Department of Health and Human Services
200 Independence Avenue SW
Washington, DC 20201

Dear Director Severino:

The Leadership Council of Aging Organizations (LCAO) appreciates this opportunity to comment on the **Nondiscrimination in Health and Health Education Programs or Activities** proposed rule. 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 the policy-making arena. Our coalition serves as a source of information about issues affecting older adults and provides leadership and vision as America works to meet the challenges and opportunities presented by our aging society. Our organizations have expertise in health care, economic security, nutrition and food security, housing, and other issues facing older adults and people with disabilities and are universally committed to advancing public health and promoting access to care.

The Health Care Rights Law (HCRL) found in section 1557 of the Affordable Care Act (ACA) clarified how important civil rights statutes specifically apply to health care, better protecting older adults and other marginalized communities from discrimination. The final rule established by the Department of Health and Human Services (HHS) in 2016 appropriately implemented these protections. Today we write to encourage the Office for Civil Rights to withdraw a new proposed rule that would undermine the current rule's interpretation of the HCRL and lead to discrimination, confusion, and suffering.

The Importance of LGBTQ Protections and Language Access

Discrimination hinders a population's ability to thrive. The HCRL, along with its implementing rule, is an important part of HHS's arsenal to protect older Americans from discrimination based on age, race, color, national origin, limited English proficiency, disability, or sex—including discrimination on the basis of gender identity or sex stereotypes. The statute and regulation together are vital to addressing health disparities, improving health care access and delivery, and in turn lowering health care costs for both the Medicare and Medicaid programs by providing protections and information for vulnerable populations that will help them access preventative and early care. While this rulemaking will not affect the underlying statutory provisions of the HCRL, it would undercut the final rule which implements it and increase the risk of older adults losing access to the care they need—which is at odds with LCAO's goal of a diverse, healthy, and vital population of older adults.

Older adults, particularly older adults of color, those with limited English proficiency (LEP), and those who identify as LGBTQ, often face discrimination in accessing health care services. LGBTQ older adults face pronounced health disparities and higher poverty rates compared to their heterosexual and cisgender peers due in large part to historical and ongoing discrimination.¹ HIV disproportionately impacts the LGBT community,² and it is affecting an increasing number of older adults.³ The Aging and Health Report, funded by the National Institutes of Health (NIH) and the National Institute on Aging (NIA), outlines a number of other disparities: lesbian, gay, and bisexual older adults face higher rates of disability and mental health challenges; older bisexual and gay men face higher rates of physical health challenges; bisexual and lesbian older women have higher obesity rates and higher rates of cardiovascular disease; and transgender older adults face greater risk of suicidal ideation, disability, and depression compared to their peers.⁴

There is significant evidence that discrimination in health care contributes to these disparities: LGBTQ older adults may be denied care or provided inadequate care, or they may be afraid to seek care for fear of mistreatment.⁵ For example, many LGBTQ older adults and their loved ones experience discrimination in long-term care facilities ranging from verbal and physical harassment, to visiting restrictions and isolation, to being denied basic care such as a shower, or being discharged or refused admission.⁶ Fear of discrimination has been shown to deter LGBTQ people from seeking health care even when needed.⁷

Furthermore, transgender older adults in particular experience discrimination in coverage of medically necessary care related to gender transition, as well as in coverage of lifesaving tests and treatments typically associated with one gender.

In addition, robust language access in health care and protections from discrimination based on language spoken are critical for older adults. U.S. Census data from 2017 estimates that more than 10 million older adults over age 60 speak a language other than English at home and 6 million speak English less than “very well.” More specifically, 4 million Medicare beneficiaries—older adults and people with disabilities—are limited English proficient, and 12% of Medicare beneficiaries living in the community report that English is not their primary

¹ The National Gay and Lesbian Task Force, “No Golden Years at the End of the Rainbow: How a Lifetime of Discrimination Compounds Economic and Health Disparities for LGBT Older Adults” (August 2013), <https://nwnetwork.squarespace.com/s/2013-TF-No-Golden-Years.pdf>.

² Centers for Disease Control and Prevention, “HIV in the United States: At a Glance” (June 2017), www.cdc.gov/hiv/statistics/overview/ataglance.html.

³ Centers for Disease Control and Prevention, “HIV Among People Aged 50 and Over” (June 2017), www.cdc.gov/hiv/group/age/olderamericans/index.html.

⁴ Fredriksen-Goldsen, *et al.*, “The Aging And Health Report: Disparities And Resilience Among Lesbian, Gay, Bisexual, And Transgender Older Adults” (November 2011), www.lgbtagingcenter.org/resources/resource.cfm?r=419.

⁵ *Id.*

⁶ Justice in Aging *et al.*, “LGBT Older Adults In Long-Term Care Facilities: Stories from the Field” (*updated June 2015*), www.justiceinaging.org/customers.tigertech.net/wp-content/uploads/2015/06/Stories-from-theField.pdf.

⁷ National Center for Transgender Equality, “Report from the 2015 U.S. Transgender Survey” (December 2016), <http://www.ustransurvey.org/>; Center for American Progress, “Discrimination Prevents LGBTQ People from Accessing Health Care” (January 18, 2018), <https://www.americanprogress.org/issues/lgbt/news/2018/01/18/445130/discrimination-prevents-lgbtq-people-accessing-health-care/>.

language.⁸ Reports from the Office of Minority Health estimate that almost 2 million Medicare beneficiaries speak languages other than English or Spanish, including over 200,000 beneficiaries who speak Chinese, over 150,000 who speak Vietnamese, and over 140,000 who speak Tagalog.⁹ In addition, nearly 8 million Medicare beneficiaries are deaf or hard of hearing and 4 million have blindness or low vision. Over 1.8 million LEP seniors and people with disabilities are also low-income and rely on the tagline and notice requirements in the 2016 implementing regulations to get the information they need across both Medicaid and Medicare.¹⁰

The Role of the Health Care Rights Law and the Risks of Weakening the Implementing Rule

The HCRL and regulations work to correct both of these issues by including protections for LGBTQ (and especially transgender) older adults and requiring health care insurance companies and providers to provide notice—in English and in other languages—of nondiscrimination and rights to language assistance.¹¹ The regulations also clarify that victims of disparate impact discrimination can seek justice and that the HCRL includes a private right of action to allow those who face discrimination to challenge that conduct in federal district court.¹²

The proposed changes include an attempt to eliminate explicit regulatory protections for LGBTQ individuals (both under the HCRL rule and unrelated regulations for the Centers for Medicare and Medicaid Services), roll back nondiscrimination and language assistance notices, and severely limit the scope of health care entities that are required to comply with the regulations. Finally, the proposals would attempt to eliminate the HCRL’s private right of action and undermine disparate impact claims.

These proposed changes, if finalized, would severely undermine the ability of LGBTQ older adults and LEP seniors to access health care free from discrimination and in a way they understand. The proposed rule could also encourage discrimination by providers and deter older adults from seeking health care in the first place. Finally, it would harshly limit the ways victims of discrimination can seek legal redress.

The risks for older adults who are unable to access health care due to language or other barriers are even greater than for much of the general public because most people need more health care as they age. Health care information is complex and can only be communicated effectively in an individual’s primary language. 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

⁸ Centers for Medicare & Medicaid Services, “2017 Medicare Beneficiary Survey Early Look Data Brief” (May 2019), https://www.cms.gov/Research-Statistics-Data-and-Systems/Research/MCBS/Downloads/2017_MCBS_Early_Look.pdf.

⁹ Centers for Medicare & Medicaid Services Office of Minority Health, “Understanding Communication and Language Needs of Medicare Beneficiaries,” p 9 (April 2017), www.cms.gov/About-CMS/AgencyInformation/OMH/Downloads/Issue-Briefs-Understanding-Communication-and-Language-Needs-of-MedicareBeneficiaries.pdf.

¹⁰ Proctor, K., Wilson-Frederick, S. M., & Haffer, S. C., “The Limited English Proficient Population: Describing Medicare, Medicaid, and Dual Beneficiaries,” *Health Equity*, 2(1), pp 82-89 (2018), <https://www.liebertpub.com/doi/full/10.1089/heq.2017.0036>.

¹¹ 45 C.F.R. § 92.206; 45 C.F.R. § 92.8.

¹² 81 Fed. Reg. 31439-40.

necessary for them to truly understand their health care. In this context, affirmative reminders of their rights through notices and taglines are critical and help to counter the stigma of asking for help. If LEP older adults do not understand statements they receive but are not told or have no notice of how to get help in their primary language, they may not ask for an interpreter, resulting in failing to follow up as necessary or paying for a service when their insurer denies coverage because they are not adequately informed of their right to appeal. Especially for older adults with limited income or high health care needs, the consequences of an erroneous bill or forgoing care can be catastrophic.

HHS's implementing rule was six years in development, with multiple public comment periods and broad support from medical professionals, public health experts, and consumer advocates. This new proposal would move our entire healthcare system in the wrong direction and would weaken the rule's landmark patient and consumer protections. It also undercuts HHS's commitment to reducing health disparities and ensuring consumers have access to quality health care.

The Office for Civil Rights is tasked "to improve the health and well-being of people across the nation" and "to ensure that people have equal access to and the opportunity to participate in and receive services from HHS programs without facing unlawful discrimination." In accord with that mission, we strongly urge you to withdraw the proposed changes to the nondiscrimination rule. We welcome an opportunity to work together toward a future of equality and enhanced well-being for all older adults, people with disabilities, and their families.

Sincerely,

Aging Life Care Association
Alliance for Retired Americans
AMDA The Society for Post-Acute and Long-Term Care Medicine
American Association of Service Coordinators
American Federation of Teachers
American Geriatrics Society
American Society on Aging
Association for Gerontology in Human Development – HBCU
Center for Medicare Advocacy, Inc.
Community Catalyst
Families USA
The Gerontological Society of America
International Association for Indigenous Aging
The Jewish Federations of North America
Justice in Aging
LeadingAge
Medicare Rights Center
National Academy of Elder Law Attorneys
National Adult Day Services Association (NADSA)
National Adult Protective Services Association
National Association of Nutrition and Aging Services Programs (NANASP)

National Association of Social Workers (NASW)
National Association of State Long-Term Care Ombudsman Programs
National Committee to Preserve Social Security and Medicare
National Consumer Voice for Quality Long-Term Care
National Council on Aging
National Hispanic Council on Aging (NHCOA)
National Indian Council on Aging
National Senior Corps Association
PHI – Quality Care Through Quality Jobs
Service Employees International Union
SAGE – Services and Advocacy for Gay, Lesbian, Bisexual and Transgender Elders, Inc.
Social Security Works
Southeast Asia Resource Action Center (SEARAC)