August 13, 2019

VIA ELECTRONIC SUBMISSION

U.S. Department of Health and Human Services
Office for Civil Rights
Attention: Section 1557 NPRM, RIN 0945-AA11
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue SW
Washington, DC 20201

Re: Nondiscrimination in Health and Health Education Programs or Activities [RIN 0945-AA11]

Dear Director Severino:

The Medicare Rights Center (Medicare Rights) appreciates the opportunity to comment on the proposed rule, "Nondiscrimination in Health and Health Education Programs or Activities." Medicare Rights is a national, nonprofit organization that works to ensure access to affordable health care for older adults and people with disabilities through counseling and advocacy, educational programs, and public policy initiatives. Each year, Medicare Rights provides services and resources to over three million people with Medicare, family caregivers, and professionals.

The Health Care Rights Law (HCRL) found in section 1557 of the Affordable Care Act (ACA) is the health law's key nondiscrimination provision.[1] It clarifies how important civil rights statutes specifically apply to health care, better protecting older adults, people with disabilities, and marginalized communities from discrimination. The HCRL prohibits discrimination in health programs and activities receiving federal financial assistance, health programs and activities administered by the executive branch, as well as entities created under the ACA, including the Marketplaces and health plans sold through the Marketplaces. Its protections extend to discrimination on the basis of age, disability, race, color, and national origin—including language access—by building on existing civil rights laws. Importantly, it is the first federal law to ban sex discrimination in health care.

The Department of Health and Human Services (HHS), through its Office for Civil Rights (OCR), appropriately implemented these protections in a 2016 final rule. The current HHS and OCR have proposed a revised rule that would undermine the extant rule's interpretation of the HCRL

[1] Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (Mar. 23, 2010); 42 U.S.C. § 18116.

and lead to discrimination, fear of accessing care, confusion about civil rights, and increased suffering from lack of confidence in the health system and lack of health care.

Medicare Rights strongly opposes these proposed changes. We are especially concerned that this proposal removes critical protections and access to information and recourse for LGBTQ+ individuals, individuals with disabilities or chronic diseases, and individuals with limited English proficiency (LEP individuals). While the proposal cites alleged cost savings of removing protective regulations,[2] no cost savings should come at the expense of necessary antidiscrimination protections and access to needed medical services. Further, all claims to savings must also account for cost increases caused by less preventive and early-stage care and increased need for high acuity or emergency care—which the proposal fails to do. Consumers, families, and the health care system as a whole are harmed when individuals are afraid, or unable, to access care.

Accordingly, and as outlined in more detail below, we urge HHS and OCR to withdraw the proposed changes and work instead to strengthen the access to care the HCRL guarantees.

General Comments

The proposed rule eliminates key provisions in the 2016 final rule that currently protect people living with chronic illnesses and disabilities. Such populations regularly face discrimination in health care settings, including the refusal of health care, the provision of lower-quality health care, and the approval of insurance plans that place covered nationally-recommended medications on the highest cost-sharing tier.[3] The 2016 rule clearly describes how certain insurer and provider practices are discriminatory and in violation of the HCRL, including: Section 92.206 "Equal program access on the basis of sex"; Section 92.207 "Nondiscrimination in health-related insurance and other health-related coverage"; Section 92.208 "Employer liability for discrimination in employee health benefit programs"; and Section 92.209

[2] 84 Fed. Reg. 27876.

[3] Health advocates have filed multiple complaints with the Office of Civil Rights highlighting discriminatory practices experienced in health programs and settings. *See, e.g.*, Discrimination Complaint (UPMC Health Plan), Center for Health Law and Policy Innovation of Harvard Law School & AIDS Law Project of Pennsylvania (U.S. Dep't of Health and Human Services, Complaint), http://www.chlpi.org/wp-content/uploads/2013/12/PA-UPMC.pdf; Discrimination Complaint (Independence Blue Cross), Center for Health Law and Policy Innovation of Harvard Law School & AIDS Law Project of Pennsylvania (U.S. Dep't of Health and Human Services, Complaint), http://www.chlpi.org/wp-content/uploads/2013/12/PA-IBX.pdf; Discrimination Complaint (Highmark), Center for Health Law and Policy Innovation of Harvard Law School & AIDS Law Project of Pennsylvania (U.S. Dep't of Health and Human Services, Complaint), http://www.chlpi.org/wp-content/uploads/2013/12/PA-Highmark.pdf; Discrimination Complaint, Center for Health Law and Policy Innovation of Harvard Law School & Nashville CARES (U.S. Dep't of Health and Human Services, Complaint), http://www.chlpi.org/wp-content/uploads/2013/12/TN-Cigna.pdf; Discrimination Complaint, Center for Health Law and Policy Innovation of Harvard Law School (U.S. Dep't of Health and Human Services, Complaint), Discrimination Complaint, Center for Health Law and Policy Innovation of Harvard Law School & Nashville CARES (U.S. Dep't of Health and Human Services, Complaint); National Health Law Program & The AIDS Institute, "Re: Discriminatory Pharmacy Benefits Design in Select Qualified Health Plans Offered in Florida, Administrative Complaint filed with the HHS Office for Civil Rights" (May 28, 2014), https://healthlaw.org/resource/nhelp-and-the-aids-institute-complaint-to-hhs-re-hiv-aids-discrimination-by-fl/. These complaints have included instances where insurers have used discriminatory insurance design to sell products on the Marketplace that place most or all of the nationally-recommended front-line medications for HIV on the most expensive cost-sharing tiers (or do not cover them at all).

"Nondiscrimination on the basis of association." These sections describe common forms of discrimination on the basis of race, color, national origin, age, disability, and sex.

While proposing to delete entire sections of regulation, HHS neglects to detail whether the deletion of these particular sections reflects a new position that the actions listed, including providing unequal access to programs or activities on the basis of sex, restricting access to gender-appropriate facilities, excluding categories of care in insurance coverage, or mistreating a person due to their partner's identity, will no longer be considered discrimination under the HCRL. People living with chronic illnesses and disabilities, people of color, and LGBTQ people have historically been subject to such discrimination in health settings.[4] Any change in policy regarding enforcement against these discriminatory practices would significantly impact all protected classes and may embolden those who wish to discriminate against these populations.

Without more explanation as to how the deletions reflect HHS's enforcement policies, we are unable to provide complete comments. The HCRL and 2016 rule have already been instrumental in addressing many discriminatory practices, including inappropriate provider behavior and condition-based categorical exclusions in health insurance, [5] and are vital parts of helping address chronic illness in the United States.[6] Changes to these HHS policies would be monumental and deserve adequate clarity and an opportunity for the public to provide meaningful feedback.

The Importance of Protections for LGBTQ+ Individuals and Current Law

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 consumers 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

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[4] *See, e.g.* Lourdes Ashely Hunter, Ashe McGovern & Carla Sutherland editors, *Intersecting Injustice: A National Call to Action,* 62-76 (2018), http://socialjusticesexuality.com/intersecting_injustice/; Susan Reif, *et al.*, "The Relationship of HIV-related Stigma and Health Care Outcomes in the U.S. Deep South, AIDS and Behavior" (2019); S.E. James, *et al.*, Nat'l Ctr. for Transgender Equality, "Report of the 2015 U.S. Transgender Survey 247" (2016), https://transequality.org/sites/default/files/docs/usts/USTS-Full-Report-Dec17.pdf; Gina M. Wingood, *et al.*, "HIV Discrimination and the Health of Women living with HIV," 46 Women & Health 99 (2007).

[5] Tovar v. Essentia Health, No. 16-cv-00100-DWF-LIB (D. Minn. September 20, 2018); Boyden v. Conlin, No. 17-cv264-WMC, 2018 (W.D. Wis. September 18, 2018); Flack v. Wis. Dep't of Health Serv., 328 F. Supp. 3d 931 (W.D. Wis. 2018); Prescott v. Rady Children's Hosp.-San Diego, 265 F. Supp. 3d 1090 (S.D. Cal. 2017); Rumble v. Fairview Health Serv., 2015 U.S. Dist. LEXIS 31591 (D. Minn. Mar. 16, 2015); Out2Enroll, "Summary of Findings: 2019 Marketplace Plan Compliance with Section 1557," https://out2enroll.org/out2enroll/wp-content/uploads/2015/10/Report-on-Trans-Exclusions-in-2019-Marketplace-Plans.pdf; Out2Enroll, "Summary of Findings: 2018 Marketplace Plan Compliance with Section 1557," https://out2enroll.org/out2enroll/wp-content/uploads/2015/10/Report-on-Trans-Exclusions-in-2018-Marketplace-Plans.pdf; Out2Enroll, "Summary of Findings: 2017 Marketplace Plan Compliance with Section 1557," https://out2enroll.org/out2enroll/wp-content/uploads/2015/10/Report-on-Trans-Exclusions-in-2017-Marketplace-Plans.pdf; "The Brooklyn Hospital Center Implements Non-Discriminatory Practices to Ensure Equal Care for Transgender Patients," HHS OCR (July 15, 2015), https://www.hhs.gov/sites/default/files/ocr/civilrights/activities/agreements/TBHC/statement.pdf.

[6] Increased access to these medications and nondiscriminatory medical coverage are crucial to efforts to end the HIV epidemic. AIDS United & Act Now "Ending the HIV Epidemic in the United States: A Roadmap for Federal Action," End AIDS 40-62, (2018).

providing protections and information for vulnerable populations that will help them access preventative and early care. While this proposal, if finalized, would not affect the underlying statutory provisions of the HCRL, it would affect its implementation in ways that are likely to increase confusion, reduce access to information, and increase the risk of older adults and people with disabilities losing access to the care they need.

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.[7] For example, HIV disproportionately impacts the LGBTQ+ community,[8] and it is affecting an increasing number of older adults.[9] 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.[10]

There is significant evidence that discrimination in health care contributes to these disparities, causing LGBTQ+ older adults to be denied care or provided inadequate care.[11] According to one survey, 8% of lesbian, gay, and bisexual (LGB) individuals had a recent experience where a doctor or other health care provider refused to see them because of their actual or perceived sexual orientation, while 29% of transgender individuals faced such refusals on the basis of their actual or perceived gender identity.[12] Troublingly, refusal was not even the worst outcome: 7% percent of LGB individuals experienced unwanted physical contact and violence from a health care provider and that number skyrocketed to 29% of transgender people.[13]

In long-term care facilities, transgender adults and their loved ones are especially at risk of discrimination, including verbal and physical harassment, visiting restrictions and isolation, denial of basic care such as showers, or discharge or refused admission.[14] As a result of these discriminatory acts, LGBTQ+ individuals may be afraid to seek care for fear of mistreatment,

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[7] 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.

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

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

[10] 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.

[11] *Id.*

[12] Shabab Ahmed Mirza & Caitlin Rooney, "Discrimination Prevents LGBTQ People from Accessing Health Care," Ctr. for American Progress, (Jan. 18, 2018), https://www.americanprogress.org/issues/lgbt/news/2018/01/18/445130/discrimination-prevents-lgbtq-people-accessing-health-care/?link_id=2&can_id=d90c309ac9b5a0fa50d294d0b1cdf0b2&source=email-rx-for-discrimination&email_referrer=&email_subject=rx-for-discrimination.

[13] *Id.*

[14] 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.

even when the care is necessary.[15] Even HHS's Healthy People 2020 initiative recognizes that "LGBT individuals face health disparities linked to societal stigma, discrimination, and denial of their civil and human rights."[16]

This reality makes HCRL's current protections against discrimination on the basis of sex, including sex stereotypes and gender identity a critical bridge to medical care for these historically marginalized populations.[17]

Proposed Changes to LGBTQ+ Protections

The proposed rule would eliminate sex stereotyping from the definitions section of the current regulations[18] and attempts to go even further by purging references to "sexual orientation" that appear in other HHS regulations.[19] Such deletions could set the stage for a refusal to enforce important and well-established nondiscrimination protections. Changing this rule, however, cannot eliminate thirty years of case law finding that sex stereotyping is part of nondiscrimination protections based on sex. It can only lead to confusion, more litigation, and increased suffering.

Further, although nothing in the current rule impacts the applicability of existing religious exemption laws, the proposed rule incorporates additional religious exemption language.[20] The combination of this additional language and the pullback of explicit protections is likely to lead to an increase in care refusal for some of society's most vulnerable members. As discussed above, many LGBTQ+ individuals already have significant challenges finding providers that are able and willing to provide them with culturally competent care,[21] and older LGBTQ+ individuals in particular experience pronounced health disparities compared to their straight counterparts, underscoring the need for enhanced protections and access to care.[22] This pattern leads to exacerbated health disparities.[23]

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[15] National Center for Transgender Equality, "Report from the 2015 U.S. Transgender Survey" (December 2016), http://www.ustranssurvey.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/.

[16] "Healthy People 2020, Lesbian, Gay, Bisexual, and Transgender Health," U.S. Dept. Health & Human Serv., https://www.healthypeople.gov/2020/topics-objectives/topic/lesbian-gay-bisexual-and-transgender-health.

[17] 45 C.F.R. § 92.4.

[18] 84 Fed. Reg. 27855, 27869

[19] Proposal to amend 45 C.F.R. §§ 147.104(e), 155.120(c)(ii), 155.220(j)(2), 156.200(e), 156.1230(b)(3); 42 C.F.R. §§ 438.3(d)(4) 438.206(c)(2), 438.262; 42 C.F.R. §§ 460.98(b)(3), 460.112(a). Note, the EHB nondiscrimination requirements at 45 C.F.R. § 156.125(b) cross reference 45 C.F.R. § 156.200(e).

[20] 84 Fed. Reg. 27864.

[21] Jennifer Kates, *et al.*, "Health and Access to Care and Coverage for Lesbian, Gay, Bisexual, and Transgender (LGBT) Individuals in the U.S.," Henry J. Kaiser Family Foundation, https://www.kff.org/disparities-policy/issue-brief/health-and-access-to-care-and-coverage-for-lesbian-gay-bisexual-and-transgender-individuals-in-the-u-s/.

[22] Karen I. Fredriksen-Goldsen, *et al.,* "Health Disparities Among Lesbian, Gay, and Bisexual Older Adults: Results From a Population-Based Study," 103 Am J Public Health 1802, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3770805/.

[23] *Id.*

Medicare Rights strongly opposes removing or limiting antidiscrimination protections and remedies for LGBTQ+ individuals, as well as others who may not conform to traditional sex stereotypes. While we respect the exercise of religious and conscience rights, these rights must be balanced against the rights of others to receive care that is appropriate, medically necessary, freely chosen, transparent, and person centered.

The Importance of Protecting Rights for Individuals with Limited English Proficiency and Current Law

There are an estimated 25 million people with limited English proficiency (LEP) in the United States.[24] For those individuals, language barriers impede access to quality health care and limit their ability to meaningfully engage in the care they do receive. When individuals are unable to effectively communicate with their health providers, they are more likely to experience adverse health outcomes.[25] LEP individuals may misunderstand important instructions or make medical decisions without fully realizing the implications of that decision.[26] Recent studies have found that patients "suffered death and irreparable harm" due to language barriers and provider failure to ensure access to appropriate language services.[27]

Language access in health care and protections from discrimination based on language are uniquely 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 language.[28] 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.[29]

Communications issues are not solely a result of LEP language barriers. Nearly 8 million Medicare beneficiaries are deaf or hard of hearing and 4 million have blindness or low vision.

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[24] Migration Policy Institute, "The Limited English Proficient Population in the United States" (2015), https://www.migrationpolicy.org/article/limited-english-proficient-population-united-states.

[25] "Individuals whose care is inhibited due to a communication barrier. . .may be at risk for poor outcomes." Wilson-Stronks, Lee, Cordero, Kopp, and Galvez, "One Size Does Not Fit All: Meeting the Needs of Diverse Populations," Oakbrook Terrace, IL: The Joint Commission (2008), https://www.jointcommission.org/assets/1/6/HLCOneSizeFinal.pdf.

[26] Smedley, Stith, and Nelson, editors, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care, Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care,* Board on Health Science Policy, Institute of Medicine (2002), at 17, http://www.nationalacademies.org/hmd/Reports/2002/Unequal-Treatment-Confronting-Racial-and-Ethnic-Disparities-in-Health-Care.aspx.

[27] National Health Law Program, The High Costs of Language Barriers in Medical Malpractice, at 3, https://healthlaw.org/resource/the-high-costs-of-language-barriers-in-medical-malpractice/.

[28] CMS, "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.

[29] 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.

These consumers may be in need of auxiliary aids and services to help them understand, communicate, and engage with providers. The proposed rule would also threaten access to these supports.

The current HCRL regulations work to correct language access issues by requiring health care insurance companies and providers to provide notice—in English and in other languages—of nondiscrimination and rights to language assistance.[30] These notice and tagline requirements help ensure that covered entities inform beneficiaries, enrollees, applicants, or members of the public of the availability of language services and auxiliary aids and services, and that the entity does not discriminate on the basis of race, color, national origin, sex, age or disability. This aligns with longstanding Supreme Court precedent, which holds that language assistance services are required to ensure that LEP individuals have meaningful access, and that the denial of such access is a form of national origin discrimination.[31]

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.[32] LEP beneficiaries rely on notice requirements that allow them to understand and fully engage in their health care through meaningful communication with providers. Consumers must have the opportunity to fully understand their own care in order to make informed decisions and provide critical information to their providers to avoid negative health outcomes.

These protections are particularly important for older 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 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.

Proposed Changes to Language Access Requirements

HHS proposes to eliminate the requirement for posting HCRL notices and including taglines on documents. This would, in part, compromise and diminish the primacy of the non-

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[30] 45 C.F.R. § 92.206; 45 C.F.R. § 92.8.

[31] *See* Lau v. Nichols, 414 U.S. 563, 568 (1974).

[32] 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.

discrimination message of the law and could result in some individuals not knowing their rights or how to exercise them.

HHS has provided no justification for eliminating notice and tagline requirements entirely, instead of making amendments to such requirements. Further, HHS failed to explain why completely eliminating notice requirements is justified given the prior analysis HHS has already undertaken in adopting these requirements just a few short years ago. The elimination of these requirements entirely ignores the challenges faced by LEP individuals in accessing adequate health care.

Medicare Rights strongly supports the existing notice and tagline requirements, which require covered entities to inform beneficiaries, enrollees, applicants, or members of the public of the availability of language services and auxiliary aids and services. These regulations ensure that such entities do not discriminate on the basis of race, color, national origin, sex, age or disability and should not be changed.

We do appreciate that the proposed rule properly makes clear that language assistance services must be provided free of charge, be accurate and timely, and protect the privacy and independence of the individual with limited English proficiency.

Proposed Changes to the Scope of the Proposed Rule

The HCRL, according to the statute and current regulations, applies to health care programs and activities receiving federal financial assistance or funding, programs administered by the federal government, and entities created under Title I of the ACA. Covered entities include hospitals, clinics, and health care provider's offices and issuers selling health insurance plans within and outside of the ACA Marketplaces.[33] If an entity is principally engaged in providing or administering health services or health insurance coverage, and any part receives federal financial assistance, the current regulations state that all of its activities are covered by the HCRL.[34]

However, the proposed rule seeks to limit this scope, by reducing the types of entities and programs that are subject to the HCRL—thereby limiting the ability of the law to provide robust civil rights protections.

For example, the current regulation applies to all entities principally engaged in the provision of health care, where some part of the entity receives federal financial assistance. Under the current regulations, this includes health insurance companies that receive any federal financial assistance. In the proposed rule, HHS posits that providing health care "differs substantially" from providing health insurance coverage.[35] As such, HHS seeks to exempt a broad swath of

[33] 42 U.S.C. § 18116(a); 45 C.F.R. §§ 92.2(a), 92.4.
[34] 45 C.F.R. § 92.4.
[35] 84 Fed. Reg. 27850.

health insurance companies from the application of the HCRL. This would significantly—and inappropriately—reduce the application of the law through regulation.

Importantly, it is also inconsistent the design and intent of the ACA. An insurer does not simply process claims. Insurers design benefits; establish formularies, payment structures, and networks; conduct prior authorization; and evaluate other clinical coverage criteria. Insurers exercise considerable control over the health care of enrollees—deciding what providers a patient may see, what hospitals they may visit, and what treatments or medications they may receive.[36] HHS recognized this in the 2016 Final Rule, emphasizing the application of the HCRL to all the operations of a health insurer, program, or activity, if any part receives federal financial assistance, as being the very purpose of the ACA and its nondiscrimination protections, noting:

> "This interpretation serves the central purposes of the ACA and effectuates Congressional intent, by ensuring that entities principally engaged in health services, health insurance coverage, or other health coverage do not discriminate in any of their programs and activities, thereby enhancing access to services and coverage…"[37]
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> "One of the central aims of the ACA is to expand access to health care and health coverage for all individuals. Equal access for all individuals without discrimination is essential to achieving this goal. Discrimination in the health care context can often lead to poor and inadequate health care or health insurance or other coverage for individuals and exacerbate existing health disparities in underserved communities. Individuals who have experienced discrimination in the health care context often postpone or do not seek needed health care; individuals who are subject to discrimination are denied opportunities to obtain health care services provided to others, with resulting adverse effects on their health status. Moreover, discrimination in health care can lead to poor and ineffective distribution of health care resources, as needed resources fail to reach many who need them. The result is a marketplace comprised of higher medical costs due to delayed treatment, lost wages, lost productivity, and the misuse of people's talent and energy."[38]

This interpretation is further supported by Congress's repeated expressions that it intends civil rights laws to be broadly interpreted in order to effectuate their remedial purposes, as well as a plain reading of the statute.[39] Section 1557 of the ACA clearly applies to "*any* health program or

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[36] See, *e.g.*, Institute of Medicine, "Controlling Costs and Changing Patient Care? The Role of Utilization Management" (1989); Joseph B. Clamon, "Does My Health Insurance Cover It - Using Evidence-Based Medicine and Binding Arbitrator Techniques to Determine What Therapies Fall under Experimental Exclusion Clauses in Health Insurance Contracts," 54 Drake L. Rev. 473, 508 (2006).

[37] 81 Fed. Reg. 31386.

[38] 81 Fed. Reg. 31444.

[39] *See* Kang v. U. Lim Am., Inc., 296 F.3d 810, 816 (9th Cir. 2002); *see also* H. Rep. No. 102–40(I), at 88, U.S. Code Cong. & Admin. News at 626 (stating that "remedial statutes, such as civil rights law[s], are to be broadly construed").

activity."[40] Thus, at a minimum, the HCRL's applicability to all of the operations of an entity principally engaged in health care—including health insurers—is the only plausible reading.

Medicare Rights strongly encourages HHS to maintain the current scope of the regulations, such that they apply not only to providers, but also to health insurance companies. Limiting the HCRL's applicability would leave many individuals, including older adults and people with disabilities and chronic illness, at heightened risk of discrimination. Additionally, we urge HHS to maintain a broader interpretation of the federal programs that must abide by the HCRL, encompassing federal programs and activities administered by all Executive agencies in order to maintain appropriate protections for consumers.

Effects of Proposed Changes to the Scope of the Proposed Rule

Exempting health insurers from the rule would have significant implications for individuals with disabilities or chronic illness and older adults. For example, the current regulation prohibits discriminatory "marketing practices or benefit design,"[41] which helps protect against insurance practices that lead to "cherry picking" and "lemon dropping", such that individuals with certain health care needs are disadvantaged by a plan's structure and disincentivized to enroll.

The proposed rule would also eliminate these protections for gender and sexual minorities, and effectively eliminate them for thousands of other individuals. If finalized as proposed, there would be a significant adverse impact on individuals with disabilities and chronic illness, including many older adults. Plans would be free to implement business practices that help them avoid taking on high-cost patients, reducing consumer choice and ultimately increasing costs to beneficiaries—changes that could lead to worse health outcomes.

Proposed Changes to Individual Recourse for Discrimination

In addition to the ways the proposed rule would cause confusion or undermine antidiscrimination protections, it explicitly attempts to eliminate the HCRL's private right of action and undermine disparate impact claims.

Currently, the implementing rule clarifies that the HCRL includes a private right of action to allow those who face discrimination to challenge that conduct in federal district court.[42] Unfortunately, many people who experience discrimination cannot access the court system due to cost,[43] and those who can generally receive little in the form of compensatory relief.[44]

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[40] 42 U.S.C. § 18116(a) (emphasis added).

[41] 45 CFR § 92.207(b)(2).

[42] 81 Fed. Reg. at 31439-40.

[43] *See* Brittany Kauffman, "Study on Estimating the Cost of Civil Litigation Provides Insight into Court Access," Inst. for the Advancement of the Am. Legal System (Feb. 26, 2013), https://iaals.du.edu/blog/study-estimating-cost-civil-litigation-provides-insight-court-access; Michelle Chen, "One More Way the Courts Aren't Working for the Poor," The Nation (May 16, 2016), https://www.thenation.com/article/one-more-way-the- courts-arent-working-for-the-poor.

[44] Maryam Jameel & Joe Yerardi, "Workplace discrimination is illegal. But our data shows it's still a huge problem," Vox (Feb. 18, 2019), https://www.vox.com/policy-and-politics/2019/2/28/18241973/workplace-discrimination-cpi-investigation-eeoc.

By undercutting disparate impact claims and the private right of action, this rule could make it even more expensive and difficult for people to enforce their rights, deterring them from filing complaints of discrimination.

Conclusion

The HCRL is the law. The proposed rule's inconsistency with that statute would cause confusion about what the law requires and who is protected under it. Such changes would ultimately make it harder for people to access needed health care free from discrimination and in a way they understand, while also limiting the ways people who experience discrimination could seek legal redress.

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 HCRL. We welcome an opportunity to work together toward a future of equality for all Americans.

Thank you for the opportunity to provide comments. For additional information, please contact Lindsey Copeland, Federal Policy Director, at 202-637-0961 or lcopeland@medicarerights.org or Julie Carter, Senior Federal Policy Associate, at 202-637-0962 or jcarter@medicarerights.org.

Sincerely,

Fred Riccardi

Frederic Riccardi
President
Medicare Rights Center