JUSTICE IN AGING

FIGHTING SENIOR POVERTY THROUGH LAW

March 27, 2018

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U.S. Department of Health & Human Services
Office for Civil Rights
Hubert H. Humphrey Building
200 Independence Avenue SW
Washington, DC 20201

Re: Protecting Statutory Conscience Rights in Health Care; Delegations of Authority Notice of Proposed Rule Making (RIN 0945-ZA03; Docket No. HHS-OCR-2018-0002)

Justice in Aging appreciates the opportunity to respond to the Department of Health and Human Services (HHS) Notice of Proposed Rule Making entitled "Protecting Statutory Conscience Rights in Health Care; Delegations of Authority." For the reasons below, we strongly urge HHS not to finalize the proposed rule. This submission supplements the comments of the Leadership Conference on Civil and Human Rights, which we also support.

Justice in Aging is an advocacy organization with the mission of improving the lives of low-income older adults. We use 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 Medicare and Medicaid, with a focus on the needs of low-income beneficiaries and populations that have traditionally lacked legal protection such as women, people of color, LGBTQ individuals, and people with limited English proficiency.

Ensuring that all consumers are protected from discrimination in health care is integral to the mission of the HHS Office for Civil Rights (OCR). This mission cannot be carried out without also ensuring that providers, whatever their religious beliefs or moral convictions, adhere to nondiscrimination laws and the medical and health-related standard of care. The proposed rule would greatly expand current "conscience" protections and religious refusals, and we are deeply concerned that it would allow employees in health care settings to discriminate against and deny care to older adults and people with disabilities. Existing law already provides ample protection for health care providers to refuse to participate in a health care service to which they have religious or moral objections. As proposed, the rule will harm consumers by increasing barriers to care, allowing health care professionals to ignore established medical guidelines, and undermining open communication between providers and patients.

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I. The proposed rule's expansion of conscience protections and religious refusals could seriously compromise the health, autonomy, and well-being of older adults and people with disabilities.

The extremely broad language proposed in the rule would allow any individual or entity with an "articulable connection" to a service, referral, or counseling described in the relevant statutory language to deny assistance due to a moral or religious objection. The rule's definitions could both undermine nondiscrimination laws that are meant to protect consumers and even foster health care settings and interactions between patients and providers that are informed by bias instead of medically accurate, evidence-based, person-centered care. This would seriously jeopardize the health, autonomy, and well-being of older adults and people with disabilities.

We are concerned that the rule's proposed definitions and applicability, which HHS repeatedly states are meant to be "broadly defined" and "illustrative, not exhaustive," could allow any member of the health care workforce to refuse to serve a patient in any way. Under the proposed rule's definitions, any individual who is a member of an entity's workforce could refuse to assist in the performance of any services or activities that have any "articulable connection"[1] to a procedure they object to. This includes "volunteers, trainees or other members or agents of a covered entity, broadly defined when the conduct of the person is under the control of such entity."[2] Also, the definition of "referral"[3] would allow an entity to refuse to provide any information distributed by any method, including online or print, regarding any service, procedure, or activity if that information would lead to a service, activity, or procedure that the entity objects to.

The proposed rule does not articulate a definition of moral beliefs. This opens the door to a provider's own prejudices serving as the basis of denying services or care based on an individual's characteristics. For example, could a nurse assistant refuse to serve lunch to a transgender patient? Could office staff refuse to schedule an appointment for a person whom they believe to be from another country or who does not speak English well?

II. The expansion of religious refusals under the proposed rule is contrary to the mission of HHS and OCR and would disproportionately harm communities that already lack access to care

HHS OCR has worked for decades to ensure that the health programs and activities it regulated comply with vital nondiscrimination laws, including Title VI of the Civil Rights Act of 1964, Title IX of the Education Amendments of 1972, the Age Discrimination Act of 1975, Section 504 of the Rehabilitation Act of 1973, and Section 1557 of the Affordable Care Act (ACA). HHS has enforced these laws by ending overtly discriminatory practices such as race segregation and segregation of people with disabilities in health care facilities, categorical insurance coverage denials of care for gender transition related services, and insurance benefit designs that

[1] 83 Fed. Reg. 3880, 3892 (Jan 26, 2018).
[2] *Id.* at 3894 (Jan 26, 2018).
[3] *Id.*

discriminate against people who are HIV positive. OCR has also sought to ensure compliance with civil rights statutes by requiring covered entities to provide auxiliary aids and services to ensure effective communication for individuals with disabilities and taking steps to ensure that individuals with limited English proficiency have meaningful access to health facilities, such as providing interpreters free of charge. These actions have gone a long way towards combating discrimination and disparities in health care.

Nevertheless, further work is needed to address discrimination and reduce these disparities. Older adults are no exception to the stark health disparities that persist across race, national origin, gender, sexual orientation, and poverty lines. For example, a larger share of Black and Hispanic Medicare beneficiaries report fair or poor health status than white beneficiaries.[4] Similarly, Black and Hispanic adults age 65 and older are almost twice as likely as white older adults to develop diabetes.[5] Older adults who are limited English proficient (LEP), including over four million Medicare beneficiaries,[6] face difficulties finding providers, especially for in-home supports and services, who speak their preferred language and often are forced to rely on family members to interpret for them. 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.[7] HIV disproportionately impacts the LGBTQ community, and it is affecting an increasing number of older adults.[8]

However, the expansion of religious refusals under the proposed rule would only make these disparities worse by disproportionately harming communities that already face barriers to care: women, people of color, people living with disabilities, people with limited English proficiency, and Lesbian, Gay, Bisexual, Transgender, Queer (LGBTQ) individuals, as well as people living in rural communities. The harmful effects would be compounded for individuals who hold multiple disadvantaged identities. For example, an older adult who is gay might also have limited English proficiency, or a physical or mental disability, and may not have a choice of providers and therefore nowhere to go if they are refused care in the rural community where they live.

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[4] Kaiser Family Foundation, *Profile of Medicare Beneficiaries by Race and Ethnicity*, (March 9, 2016), *available at* http://kff.org/medicare/report/profile-of-medicare-beneficiaries-by-race-and-ethnicity-a-chartpack/.

[5] Centers for Disease Control and Prevention, *The State of Aging and Health in America*, (2013) at Figure 2, *available at* www.cdc.gov/aging/pdf/state-aging-health-in-america-2013.pdf

[6] CMS Office of Minority Health, Understanding Communications and Language Needs of Medicare Beneficiaries, at 8 (April 2017), *available at* www.cms.gov/About-CMS/Agency-Information/OMH/Downloads/Issue-Briefs-Understanding-Communication-and-Language-Needs-of-Medicare-Beneficiaries.pdf

[7] Fredriksen-Goldsen et al., *The Aging And Health Report: Disparities And Resilience Among Lesbian, Gay, Bisexual, And Transgender Older Adults* (Nov. 2011), *available at* www.lgbtagingcenter.org/resources/resource.cfm?r=419

[8] *See* Ctrs. for Disease Control & Prevention, HIV in the United States: At a Glance (June 2017), available at www.cdc.gov/hiv/statistics/overview/ataglance.html; Ctrs. for Disease Control & Prevention, HIV and Transgender Communities (2016), www.cdc.gov/hiv/pdf/policies/cdc-hiv-transgender-brief.pdf.

A. The proposed rule would harm LGBTQ older adults who continue to face widespread discrimination and health disparities.

We are particularly concerned that the proposed rule would exacerbate the barriers to care that LGBTQ older adults face and the effects of ongoing and pervasive discrimination by potentially allowing providers to refuse to provide services and information vital to LGBTQ health. In addition to experiencing the health disparities described above, LGBT elders are more likely to be single, childless, estranged from their biological family, and reliant on families of choice, such as friends and other loved ones. Because they do not have traditional support systems in place, many LGBT elders rely on nursing homes or other long-term care facilities to receive needed services.[9] Results of a recent survey by AARP show that at least a third of LGBT adults are worried about having to hide their LGBT identity in order to have access to housing options that are suitable for older adults.[10] Over half of LGBT adults fear discrimination in health care as they age and are especially concerned about neglect, abuse, and verbal or physical harassment in long-term care facilities.[11] These concerns are even greater among Black and Latino LGBT adults and individuals who identify as non-binary.[12]

Unfortunately, these fears are a reality for many LGBT older adults. In a survey of LGBT seniors reported in our publication, *Stories from the Field*, we found numerous cases where LGBT older adults experienced 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.[13] In addition to being denied care or provided inadequate care, LGBT older adults and their loved ones may be afraid to seek care because they are not treated with dignity and respect. Several LGBT older adults reported being "prayed over" without their consent or being told they would go to hell—violating their right to practice their own beliefs.[14] These discriminatory actions by facility staff could be protected under this ill-advised rule.

As proposed, the rule could allow individuals and facilities to not only refuse to provide treatment for LGBTQ individuals, but to also deny doctors and other professionals the ability to provide that treatment in their facilities. Such refusals implicate standards of care that are vital to LGBTQ health. Medical professionals are expected to provide LGBTQ individuals with the same quality of care as they would anyone else. The American Medical Association recommends that providers use culturally appropriate language and have basic familiarity and

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[9] SAGE (Services and Advocacy for Gay, Lesbian, Bisexual & Transgender Elders) and Movement Advancement Project, *Improving the Lives of LGBT Older Adults,* (March 2010), *available at* www.sageusa.org, www.lgbtmap.org.
[10] Houghton, Angela, AARP, *Maintaining Dignity: Understanding and Responding to the Challenges Facing Older LGBT Americans.* (Mar. 2018), *available at* https://doi.org/10.26419/res.00217.001.
[11] *Id.*
[12] *Id.*
[13] Justice in Aging et al., *LGBT Older Adults In Long-Term Care Facilities: Stories from the Field* (updated June 2015), *available at* www.justiceinaging.org.customers.tigertech.net/wp-content/uploads/2015/06/Stories-from-the-Field.pdf
[14] *Id*. at 11.

competency with LGBTQ issues as they pertain to any health services provided.[15] The World Professional Association for Transgender Health guidelines provide that gender-affirming interventions, when sought by transgender individuals, are medically necessary and part of the standard of care.[16] The American College of Obstetricians and Gynecologists warns that failure to provide gender-affirming treatment can lead to serious health consequences for transgender individuals.[17] The proposed rule would interfere with the ability of providers to meet these standards since they would not be able to rely on the consistent support of the facilities and care teams where they practice.

B. The proposed rule will harm older adults and people living with disabilities who rely on long-term services and supports.

Many older adults and people with disabilities receive long-term services and supports, including home and community-based services (HCBS), from religiously-affiliated providers. However, some people who rely on these services have faced discrimination, exclusion, and a loss of autonomy due to provider objections to providing specified care. For example, individuals with HIV–a recognized disability under the ADA–have repeatedly encountered providers who deny services, necessary medications, and other treatments citing religious and moral objections. One man with HIV was refused care by six nursing facilities before his family was finally forced to relocate him to a facility 80 miles away.[18]

Older adults and people with disabilities often live or spend much of their day in provider-controlled settings where they receive supports and services. They may rely on a case manager to coordinate necessary services, a transportation provider to get them to community appointments, or a personal care attendant to help them take medications and manage their daily activities. Under this broad new proposed language, any of these providers could believe they are entitled to object to providing a service covered under the regulation and not even tell the individual where they could obtain that service, how to find an alternative provider, or even that the service is available to them. In these cases, a denial based on a provider's personal moral objection can potentially impact every facet of life for an older adult or person with disabilities – including visitation rights, autonomy, and access to the community. For example,

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[15] Gay Lesbian Bisexual & Transgender Health Access Project, *Community Standards of Practice for the Provision of Quality Health Care Services to Lesbian, Gay, Bisexual, and Transgender Clients*, *available at* www.glbthealth.org/documents/SOP.pdf; A.M.A., *Creating an LGBTQ-friendly Practice*, *available at* www.ama-assn.org/delivering-care/creating-lgbtq-friendly-practice .

[16] World Prof. Ass'n for Transgender Health, *Standards of Care for the Health of Transsexual, Transgender, and Gender Nonconforming People* (2011), *available at* https://s3.amazonaws.com/amo_hub_content/Association140/files/Standards%20of%20Care%20V7%20-%202011%20WPATH%20(2)(1).pdf.

[17] Am. Coll. Obstetricians & Gynecologists, *Committee Opinion 512: Health Care for Transgender Individuals*, (Dec. 2011), *available at* www.acog.org/Clinical-Guidance-and-Publications/Committee-Opinions/Committee-on-Health-Care-for-Underserved-Women/Health-Care-for-Transgender-Individuals.

[18] Nat'l Women's Law Ctr., *Fact Sheet: Health Care Refusals Harm Patients: The Threat to LGBT People and Individuals Living with HIV/AIDS,* (May 2014), *available at* https://nwlc.org/wp-content/uploads/2015/08/lgbt_refusals_factsheet_05-09-14.pdf.

could a case manager ignore an individual's request to see an HIV specialist? Could a group home refuse to allow a same-sex couple who are residents to live together in the group home?

Finally, due to limited provider networks, older adults and people with disabilities living in rural areas may have particular difficulty finding an alternate provider. For example, home care agencies and home-based hospice agencies in rural areas are facing significant financial difficulties staying open. Seven percent of all zip codes in the United States do not have any hospice services available to them.[19] Finding providers competent to treat people with certain disabilities increases the challenge, and adding in the possibility of a case manager or personal care attendant who objects to serving the individual under this proposed rule could make the barrier to accessing these services insurmountable. Moreover, older adults and people with disabilities who identify as LGBTQ or who belong to a historically disadvantaged racial or ethnic group may be both more likely to encounter service refusals and also face greater challenges to receive (or even know about) accommodations.

III. The proposed rule undermines longstanding ethical and legal principles of informed consent and would undermine effective provider-patient communication

The proposed rule undermines informed consent, a necessary principle of person-centered decision making and a critical component of quality of care. Informed consent relies on providers disclosing medically accurate information so that patients can competently and voluntarily make decisions about their medical treatment or refuse treatment altogether.[20]

The proposed rule purports to improve communication between patients and providers, but instead, will deter open, honest conversations that are vital to ensuring that patients are able to be in control of their medical care. For example, the proposed rule suggests that a provider could refuse to offer information, if that information might be used to obtain a service to which the refuser objects. By undermining informed consent, the proposed rule could result in providers withholding information far beyond the scope of the underlying statutes and violate medical standards of care.

Additionally, while virtually every state already provides for a conscience objection and a provider's right to refuse to comply with a patient's directive, state laws also impose an obligation on providers to inform patients of their objection and to make some level of effort to transfer the patient to another provider or facility that will comply with the patient's wishes. This proposed rule appears to require neither and may even preempt these state laws which protect patients' rights. If this rule is finalized, which we oppose, HHS should clarify that state conscience rule procedural requirements are not preempted.

In particular, the principles of informed consent, respect for autonomy, and self-determination are important when individuals are seeking end-of-life care or have diminishing capacity. These

[19] Julie A. Nelson & Barbara Stover Gingerich, *Rural Health: Access to Care and Services*, 22 HOME HEALTH CARE MGMT. PRAC. (2010), *available at* http://globalag.igc.org/ruralaging/us/2010/access.pdf.
[20] Tom Beauchamp & James Childress, PRINCIPLES OF BIOMEDICAL ETHICS (4th ed. 1994); Charles Lidz et al., INFORMED CONSENT: A STUDY OF DECISION MAKING IN PSYCHIATRY (1984).

patients should be the center of health care decision-making and they or their representatives should be fully informed about their treatment options. Under the proposed rule, however, providers who object to various procedures could withhold vital information about treatment options— including options such as palliative sedation or declining artificial nutrition and hydration—and refuse to provide a referral to a provider who would honor the patient's wishes. For patients who cannot currently make health care decisions, their advance directives should be honored, regardless of the physician's personal objections, either through immediate assistance or through transfer to another facility. The blanket refusals permissible under this proposed rule would violate informed consent principles by ignoring patients' needs, desires, and autonomy and self-determination at critical times in their lives.

IV. Conclusion

Justice in Aging is deeply concerned that the proposed rule's expansion of conscience protections and religious refusals would be detrimental to older adults' health and well-being and greatly harm communities who already lack access to care and endure discrimination. HHS must ensure that all consumers are protected from discrimination and that all providers treat every patient whom they serve with dignity and respect. The proposed rule would give carte blanche to any provider to withhold care on the basis of prejudice cloaked as "moral conviction." Therefore, we strongly urge HHS not to finalize the proposed rule.

Thank you for considering our comments. If any questions arise concerning this submission, please contact me at jgoldberg@justiceinaging.org.

Sincerely,

Jennifer Goldberg
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