

August 8, 2019

Secretary Alex Azar
Department of Health and Human Services
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue SW
Washington, DC 20201

Submitted electronically to www.regulations.gov

Re: Nondiscrimination in Health and Health Education Programs and Activities [HHS-OCR-2019-0007; RIN 0945-AA-11]

Dear Secretary Azar:

The American Nurses Association (ANA) submits the following comments in response to the Notice of Proposed Rulemaking (proposed rule) Nondiscrimination in Health and Health Education Programs and Activities. The proposed rule seeks to make comprehensive changes to regulations promulgated in 2016 to implement Section 1557 of the Affordable Care Act (ACA).¹ Section 1557 bars discrimination in health care against persons based on race, color, sex, national origin, age and disability; provides for enforcement of the protections conferred; and authorizes the Department of Health and Human Services (HHS) to further refine the meaning of Section 1557 through regulations.

ANA is the premier organization representing the interests of the nation's 4.0 million RNs, through its state and constituent member associations, organizational affiliates, and individual members. ANA advances the nursing profession by fostering high standards of nursing practice, promoting a safe and ethical work environment, bolstering the health and wellness of nurses, and advocating on health care issues that affect nurses and the public. ANA members also include the four advanced practice registered nurse roles (APRNs): nurse practitioners (NPs), clinical nurse specialists (CNSs), certified nurse-midwives (CNMs) and certified registered nurse anesthetists (CRNAs).² ANA is dedicated to partnering with health care consumers to improve practices, policies, delivery models, outcomes, and access across the health care continuum.

¹ Nondiscrimination on the Basis of Race, Color, National Origin, Sex, Age, or Disability in Health Programs or Activities Receiving Federal Financial Assistance and Health Programs or Activities Administered by the Department of Health and Human Services or Entities Established under Title I of the Patient Protection and Affordable Care Act. 45 C.F.R. Part 92 (81 Fed. Reg. 31376. May 18, 2016).

² The Consensus Model for APRN Regulation defines four APRN roles: Certified nurse practitioner, clinical nurse specialist, certified nurse-midwife and certified registered nurse anesthetist. In addition to defining the four roles, the Consensus Model

ANA has adopted as a core principle that the health care system must ensure access to health care for all;³ Section 1557 of the ACA is an essential tool to safeguard such access, and one that should be broadly interpreted.⁴ Congress included Section 1557 when it enacted the ACA nearly a decade ago as a comprehensive approach to expanding access to health care while improving quality and patient experience.

As an informed and active stakeholder in the implementation of health care policy, ANA sees the proposed rule as a fundamental change in direction that is antithetical to our principles of health system transformation, namely universal access to a standard package of essential health care services for all citizens and residents.⁵ The proposed rule would remove key definitions and mechanisms in the 2016 rule that make Section 1557 meaningful to all, especially to people who otherwise face discriminatory barriers to care. Though progress has been made on this front since the ACA was enacted, discrimination in health care settings remains a grave and widespread problem and contributes to a wide range of health disparities.

In short, ANA believes this new rulemaking is misguided and irresponsible, and is out of step with the values of the nursing profession. We believe the proposal should be rescinded entirely so that the existing Section 1557 regulations remain available to protect access to health care for all patients. ANA comments are detailed below. Briefly, we summarize key proposals of significant concern to ANA, discuss the implications of these changes for nurses, and outline why we support retaining the provisions in the 2016 rule.

HHS SEEKS TO ELIMINATE SAFEGUARDS AGAINST DISCRIMINATION IN HEALTH CARE

The proposed rule would substantially alter HHS' current approach to discrimination in health care, removing a number of safeguards built into the 2016 regulations. Among the significant revisions proposed, HHS seeks to eliminate provisions clarifying the health care rights of LGBTQ+ individuals. If finalized, the rule's definition of sex discrimination under Section 1557 would no longer include discrimination based on gender identity or sex-stereotyping. Additionally, there would be no prohibition to insurance plans denying or limiting health care

describes the APRN regulatory model, identifies the titles to be used, defines specialty, describes the emergence of new roles and population foci, and presents strategies for implementation. Web: <https://www.nursingworld.org/certification/aprn-consensus-model/>

³ANA's Principles for Health System Transformation 2016 Web: <https://www.nursingworld.org/~4afd6b/globalassets/practiceandpolicy/health-policy/principles-healthsystemtransformation.pdf>

⁴ Congress has repeatedly expressed that it intends civil rights laws to be broadly interpreted in order to effectuate their remedial purposes. 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").

⁵Ibid

coverage based on gender identity. Without these protections, providers and payers can deny care to transgender persons and to other LGBTQ+ patients based on sex-stereotyping.

The proposed rule also takes a new approach to women's health care rights that could serve to limit women's access to care. The new definition of sex discrimination under Section 1557 would not explicitly extend to discrimination based on pregnancy, false pregnancy, abortion, or recovery from childbirth. There are also references to existing exemptions that attempt to elevate provider options to withhold care over patients' interests, which we believe will undermine access.

Additionally, the proposed rule would, reduce the reach and scope of the Section 1557 regulations, leaving more patients exposed to discriminatory practices from providers, payers, and programs. Illustrative, but not exhaustive, are proposals to scale back the definition of health care entities governed by the rule, as well as meaningful access for individuals with limited English proficiency (LEP), and notice and grievance provisions.

The proposed rule goes beyond these extensive revisions to rules implementing Section 1557. The proposed rule would also end the protections against discrimination on the basis of gender identity and sex stereotyping that are written into 10 other HHS rules, such as those governing Medicaid managed care and private insurance.

PROPOSED CHANGES ARE INCONSISTENT WITH NURSING VALUES AND ETHICAL OBLIGATIONS

As discussed more below, the impacts of this rule are at odds with the basic tenets of nursing, on which all our patients rely for meaningful access to care. ANA is dismayed by the implications of these changes, which would enable health care practices that are wholly incompatible with the ethics and values of the nursing profession. Provision 1 of the *Code of Ethics for Nurses*⁶ deals explicitly with the moral and ethical obligations in caring for all patients: "The nurse practices with compassion and respect for the inherent dignity, worth, and unique attributes of every person."⁷ This includes respect for the human dignity of the patient and the demand that nurses must never behave prejudicially – which is to say, with unjust discrimination.

These values, and the standards that flow from them, protect patients from experiencing very real harms that result from discrimination in health care. Specifically:

⁶American Nurses Association. *Code of Ethics for Nurses with Interpretive Statements*. 2015: Second Edition.

⁷Ibid: Pg. 1.

- ***Ethical obligations require nurses to address the specific concerns for the health care rights of LGBTQ+ patients.***
- ***Nursing ethics require nurses to respect the health care decisions of their patients, including women exercising their option to terminate a pregnancy.***

Ethical obligations require nurses to address the specific concerns for the health care rights of LGBTQ+ patients. ANA explicitly condemns discrimination based on sexual orientation, gender identity, and/or expression in health care and recognizes that it continues to be an issue despite the increasing recognition and acceptance of LGBTQ+ populations. Nurses are ethically called upon to “lead in the development, dissemination, and implementation of changes in public and health policies that support protection against discrimination due to sexual orientation, gender identity, and/or expression.”⁸

LGBTQ+ populations experience a significant rate of discrimination in health care settings, and also experience negative health outcomes compared with the overall population.⁹ Negative health outcomes that disproportionately affect LGBTQ+ individuals include: Increased instances of mood and anxiety disorders and depression, and an elevated risk for suicidal ideation and attempts; higher rates of smoking, alcohol use, and substance use; higher instances of stigma, discrimination, and violence; less frequent use of preventive health services; and increased levels of homelessness among LGBTQ+ youth.¹⁰

Men who have sex with men (MSM) and transgender women also experience significantly higher rates of HIV/AIDS infections, complications, and deaths; this burden falls particularly heavily on young, African-American MSM and transgender women. Transgender individuals also face particularly severe discrimination in health care settings: 33 percent of transgender patients say that a health care provider turned them away because of being transgender.¹¹

⁸ American Nurses Association. Nursing Advocacy for LGBTQ+ Populations. 2018. Accessible at <https://www.nursingworld.org/practice-policy/nursing-excellence/official-position-statements/id/nursing-advocacy-for-lgbtq-populations/>

⁹ Health and Access to Care and Coverage for Lesbian, Gay, Bisexual, and Transgender Individuals in the U.S. Kaiser Family Foundation. May 2018. Web: <http://files.kff.org/attachment/Issue-Brief-Health-and-Access-to-Care-and-Coverage-for-LGBT-Individuals-in-the-US>

¹⁰U.S. Institute of Medicine Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities. The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding. Washington, DC: National Academies Press; 2011.

¹¹James, Sandy E. et al. The Report of the U.S. Transgender Survey. 2016: 96-97. Web: www.ustranssurvey.org/report

As the lead agency implementing the ACA and a recent champion to end HIV disparities,¹² HHS should be concerned with promoting health care access for LGBTQ+ individuals. Section 1557 and existing nondiscrimination regulations are necessary and essential to protect access, and should be zealously enforced, rather than eliminated.

Nursing ethics require nurses to respect the health care decisions of their patients, including women exercising their options regarding pregnancy. The Code of Ethics for Nurses recognizes patients' rights to self-determination and calls upon nurses to respect the decisions of an individual under their care.

Patients have the moral and legal right to determine what will be done with and to their own person; to be given accurate, complete, and understandable information in a manner that facilitates an informed decision; and to be assisted with weighing the benefits, burdens, and available options in their treatment, including the choice of no treatment.¹³

Provision 2 of the Code of Ethics also holds that a nurse's primary commitment is to the patient.

These core tenets extend to care for pregnant women and safeguard their access to the full range of available reproductive health care, including abortion. The proposed rule, it appears, attempts to give more weight to circumstances in which a pregnant woman may be denied access to abortion. The proposed change would also seek to redefine sex discrimination to exclude discrimination based on pregnancy and related conditions. This change appears intended to allow a provider to deny care to a woman having a miscarriage or who has had an abortion. We believe the overall impact of these changes will be to reduce access with discriminatory effect on women of reproductive age.

We therefore strongly oppose attempts to weaken protections created by Section 1557, including these proposed regulatory changes that we believe would reduce access contrary to our principles of health system transformation and the *Code of Ethics for Nurses*.

EXISTING NONDISCRIMINATION RULES ARE NECESSARY TO ENSURE ACCESS

We believe that existing regulations for Section 1557 and other HHS programs fulfill the intent of Congress to protect people from discrimination in health care that denies them access. The 2016 rules, especially, take important steps to safeguard access for people who often face

¹² Azar, Alex. Ending the HIV Epidemic: A Plan for America. February 2019. Web: <https://www.hhs.gov/blog/2019/02/05/ending-the-hiv-epidemic-a-plan-for-america.html>

¹³ ANA Code of Ethics, Provision 1.4.

unique barriers to care, including LGQTQ+ individuals. For these individuals, sex discrimination may take specific form in health care, such as coverage limitations and encounters with providers who deny them care based on their gender identity or sex-stereotyped characteristics.

The proposed rule extensively cites one court decision supporting HHS' new, narrower reading of the bar against discrimination in health.¹⁴ However, other federal courts have determined that the protections of Section 1557 should be interpreted to allow broad application. For example, a federal court in Wisconsin found the state's Medicaid program could not exclude gender-affirming care. Notably, the court found that this protection against discrimination derived directly from the ACA law.¹⁵

Section 1557 should be implemented in a manner that promotes access for those who are subject to discrimination. In this light, we do not see a rationale for dismantling the protections that are established in the 2016 rules. This proposed rule should be rescinded in its entirety and HHS should follow and vigorously defend the 2016 rules and other nondiscrimination regulations.

If you have questions, please contact Ingrida Lusi, Vice-President, Policy and Government Affairs (Ingrid.Lusi@ana.org or (301) 628-5081).

Sincerely,



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Chief Nursing Officer / EVP

cc: Ernest Grant, PhD, RN, FAAN, ANA President
Loressa Cole, DNP, MBA, RN, NEA-BC, FACHE, ANA Chief Executive Officer

¹⁴Franciscan Alliance, Inc., et al. v. Burwell, et al., 227 F. Supp. 3d 660 (N.D. Tex. 2016).

¹⁵Flack v. Wis. Dep't of Health Servs. 328 F. Supp. 3d 931 (W.D. Wis. 2018). See also Prescott v. Rady Children's Hospital – San Diego, 265 F. Supp. 3d 1090 (S.D. Cal. 2017).