

August 13, 2019

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

Submitted electronically

Re: Docket HHS-OCR-2019-0007, Department of Health and Human Services, Office for Civil Rights, RIN 0945-AA11, Proposed Revision to Section 1557 of the Patient Protection and Affordable Care Act: Nondiscrimination in Health and Health Education Programs or Activities

Dear HHS Office for Civil Rights Desk Officer:

YWCA USA submits these comments on the proposed rule published at 84 FR 27846 (June 14, 2019), RIN 0945-AA11, with the title “Nondiscrimination in Health and Health Education Programs or Activities” (the “Proposed Revisions” or “Revisions”).¹

As detailed more fully below, the Proposed Revisions would undermine or eliminate key protections of the ACA’s nondiscrimination provision, section 1557, from individuals who have experienced discrimination in health care programs and settings.² More specifically, the Proposed Revisions would cause significant harm to the transgender community, LGBTQ individuals, immigrant families and people with limited English proficiency (LEP), people with disabilities, survivors of gender-based violence, and many others, as well as impede access to the full spectrum of reproductive healthcare. **Based on our extensive experience working with LGTBQ individuals, immigrant women and families, disabled individuals, survivors of domestic and other gender-based violence, and women from all walks of life, YWCA USA urges the Office for Civil Rights to reject the Proposed Revisions to Section 1557 of the Patient Protection and Affordable Care Act (ACA).**

¹ U.S. Department of Health & Human Services, “Nondiscrimination in Health and Health Education Programs or Activities”, 84 FR 27846 (June 14, 2019), available at <https://www.govinfo.gov/content/pkg/FR-2019-06-14/pdf/2019-11512.pdf>.

² U.S. Department of Health & Human Services, “Nondiscrimination in Health and Health Education Programs or Activities”, 84 FR 27846 (June 14, 2019), available at <https://www.govinfo.gov/content/pkg/FR-2019-06-14/pdf/2019-11512.pdf>.

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Background: YWCA

As one of the oldest and largest women's organizations in the nation, YWCA USA is dedicated to eliminating racism, empowering women, and promoting peace, justice, freedom and dignity for all. Today, we serve over 2 million women, girls, and their families through a network of more than 200 local associations in 45 states and the District of Columbia. YWCA combines programming and advocacy to generate institutional change in the areas of racial justice and civil rights, empowerment and economic advancement of women and girls, and health and safety of women and girls. YWCA has been at the forefront of the most pressing social movements for more than 160 years.

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YWCA's comments on Proposed Revisions to Section 1557 of the ACA are informed by our significant expertise in working with LGBTQ communities; immigrant women, children, and families; and survivors of domestic and sexual violence. Each year, across our vibrant network, we are proud to provide:

- 535,000 women, children and families with gender-based violence support services that are trauma-informed, and which include domestic violence and sexual assault programs and services (e.g., emergency shelter, transitional housing, crisis hotlines, counseling and court assistance, and other community safety programs).
- 170,000+ children and parents with child care, teen and parenting programs, which include child care programs that specifically integrate trauma-informed practices to meet the needs of homeless children, and children who have witnessed and experienced domestic violence and other trauma.
- 155,000+ YWCA and community members with racial justice and civil rights programs, including programs and services specifically designed to meet the needs of LGBTQ communities.
- 145,000 women, children and families with housing, food assistance and immigrant assistance programs.

YWCAs across the country pride themselves on addressing the needs of their communities and thus YWCA's network has a rich understanding of the many ways in which marginalized and underserved communities access – or are unable to access – resources such as health care.

YWCA believes that quality, affordable healthcare is critical for everyone, regardless of race, color, national origin (including language access), sex, gender (including expression), age, disability, and medical history.

I. The Proposed Revisions Will Eliminate Nondiscrimination Protections for LGBTQ Individuals in Multiple HHS Regulations

A. The Proposed Revisions Will Place Undue Burdens on the Transgender Community

Transgender individuals often face discrimination and mistreatment in the health care system based on their perceived or actual gender identity. According to a 2017 representative survey, 29% of transgender individuals were refused care by a health care provider based on their perceived or actual gender identity and 29% experienced unwanted physical contact from a health care provider.³ Additionally, 22% of transgender individuals avoided or postponed needed medical care because of disrespect or discrimination from health care staff.⁴ Moreover, 23% of transgender individuals who responded to the 2015 U.S. Transgender Survey did not seek needed health care at all due to fear of mistreatment or discrimination.⁵ Finally, when seeking health care related to gender transition, 12% of individuals were refused care.⁶

Current regulations define discrimination on the basis of sex to include someone's gender identity and thus prohibit such discrimination.⁷ The Proposed Revisions would completely eliminate the inclusion of gender identity as a part of the definition of discrimination on the basis of sex, thus removing protections for transgender individuals facing discrimination and mistreatment. Elimination of this definition would put transgender individuals at greater risk of experiencing this mistreatment, remove avenues for justice for these individuals, and increase the already-high levels of fear and mistrust of health care providers throughout the transgender community.

Additionally, current regulations expressly prohibit coverage exclusions for gender-affirming care.⁸ Moreover, current regulations prohibit plans that limit or restrict services provided to transgender persons that would be provided to

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³ Shabab Ahmed Mirza & Caitlin Rooney, *Discrimination Prevents LGBTQ People from Accessing Health Care*, Center for American Progress (Jan. 18, 2018), available at: 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.

⁴ *Id.*

⁵ National Center for Transgender Equality, *The Report of the 2015 U.S. Transgender Survey* (2016), available at: <https://transequality.org/sites/default/files/docs/usts/USTS-Full-Report-Dec17.pdf>.

⁶ Shabab Ahmed Mirza & Caitlin Rooney, *Discrimination Prevents LGBTQ People from Accessing Health Care*, Center for American Progress (Jan. 18, 2018), available at: 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.

⁷ 45 C.F.R. § 92.4.

⁸ 45 C.F.R. §§ 92.206, 92.207(b)(3)-(5).

cisgender persons.⁹ The Proposed Revisions also remove sections of the existing regulations that prohibit health plans from excluding gender-affirming care. If implemented, the Proposed Revisions would unfairly disadvantage transgender individuals and create more barriers to accessing quality, affordable health care for the transgender community, particularly for low-income individuals and people of color.

B. The Proposed Revisions Will Place Undue Burdens on LGBQ Individuals

Lesbian, gay, bisexual, and queer (LGBQ) individuals also face extremely high rates of discrimination and mistreatment in the health care system. In 2017, 8% of LGBQ individuals were refused care by a health care provider based on their perceived or actual sexual orientation and 7% experienced unwanted physical contact from a health care provider. Research also shows that LGBQ individuals also face disparities in health and health outcomes because of the social stigma, discrimination, and mistreatment incurred because of their perceived or actual sexual orientation.¹⁰ LGBQ individuals are more likely to attempt suicide, experience homelessness, have HIV and other STDs, and are at risk of several other health disparities which require increased and specific attention from health care professionals.¹¹

Current regulations protect against discrimination based on sexual orientation by explicitly prohibiting discrimination based on sex stereotypes.¹² Sex stereotypes includes stereotypical notions of masculinity or femininity, including expectations of how individuals represent or communicate their gender to others, such as behavior, clothing, hairstyles, activities, voice, mannerisms or body characteristics as well as gendered expectations related to the appropriate roles of a certain sex.¹³

The Proposed Revisions remove sex stereotyping from the definition of discrimination on the basis of sex.¹⁴ Further, the Proposed Revisions eliminate all references to “sexual orientation” appearing in other HHS regulations. Elimination of “sex stereotyping” in the definition sex discrimination and purging “sexual orientation” from other regulations puts

⁹ Id.

¹⁰ U.S. Department of Health and Human Services, *Healthy People 2020, Lesbian, Gay, Bisexual, and Transgender Health*, available at: <https://www.healthypeople.gov/2020/topics-objectives/topic/lesbian-gay-bisexual-and-transgender-health>.

¹¹ Id.

¹² 45 C.F.R. § 92.4.

¹³ National Health Law Program, “Questions and Answers on the Proposed Rollback of Nondiscrimination Protections Under the ACA’s Section 1557,” available at: <https://9kqpw4dcaw91s37kozm5jx17-wpengine.netdna-ssl.com/wp-content/uploads/2018/12/18-546-Amicus-Brief-PDFA.pdf>.

¹⁴ 45 C.F.R. § 92.4.

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LGBQ individuals at even greater risk of experiencing mistreatment, removes avenues for justice for these individuals, increases fear and mistrust of health care providers, and increases the erasure of LGBQ individuals in the health care system.

YWCA is concerned that the Proposed Revisions will further undermine the ability of transgender and LGBQ individuals to receive quality, affordable, and comprehensive health care as well as increase discrimination and mistreatment while removing protections. As outlined in this section, the Revisions would substantially harm LGBTQ individuals and communities.

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II. The Proposed Revisions Will End Provisions to Support Immigrant Families and People with Limited English Proficiency in Accessing Health Care

Throughout the United States more than 66 million people speak a language other than English at home and approximately 25 million – nearly 10% of the US population – may be considered limited English Proficiency (LEP).¹⁵ Individuals considered to be LEP refers to anyone above the age of 5 who reported speaking English less than “very well” to the U.S. Census Bureau.¹⁶ Language-related barriers, like LEP, often limit an individual’s ability to access health care and assistance, as well as to communicate options, choices, and questions. Moreover, most LEP individuals are immigrants and/or were born to immigrant parents and thus face multi-faceted language-related, cultural, and discriminatory barriers to health care.¹⁷

Under the current regulations, covered entities –hospitals, clinics, health care provider’s offices, and issuers selling health insurance plans within and outside of the ACA Marketplaces – are required to take reasonable steps to provide meaningful access to services for LEP individuals.¹⁸ These reasonable steps include the creation and inclusion of taglines, translation services, and access to quality interpreters. Current regulations also require these same entities to post notices informing patients of the availability of language access services.

The Proposed Revisions remove such requirements for taglines and notices, thus decreasing LEP individual’s ability to understand and access health care

¹⁵ National Health Law Program, “Questions and Answers on the Proposed Rollback of Nondiscrimination Protections Under the ACA’s Section 1557,” available at: <https://9kqpw4dcaw91s37koz5jx17-wpengine.netdna-ssl.com/wp-content/uploads/2018/12/18-546-Amicus-Brief-PDFA.pdf>.

¹⁶ Migration Information Source, “The Limited English Proficient Population in the United States” (2015), available at: <https://www.migrationpolicy.org/article/limited-english-proficient-population-united-states>.

¹⁷ Id.

¹⁸ 45 C.F.R. §§ 92.201–92.204, 45 C.F.R.



providers and insurers.¹⁹ Moreover, the Proposed Revisions would remove the recommendation that health care providers and insurers develop language access plans, which help provide services to LEP individuals. These changes would result in the further marginalization of immigrant families and communities by denying access to quality, affordable health care and by further alienating these communities from the health care system.

YWCA is concerned that these Proposed Revisions would impact the immigrant women, children, and families we see every day who already face immense barriers to accessing health care. Through our experience running programs specifically aimed at serving immigrant communities, we know the importance of language-accessible materials and programming. Removing these supports for immigrant families and communities would have extremely detrimental health effects on the people and communities we serve.

III. The Proposed Revisions Will Stifle Access to Health Care for Disabled People and Individuals with Chronic Illnesses such as HIV/AIDS

A. The Proposed Revisions Will Eliminate Requirements to Publicly Post Notices of Patients' Rights and Available Accommodations

Although current regulations require health care providers and insurers to post notices informing patients of the availability of auxiliary aids and services for people with disabilities, the Proposed Revisions would eliminate these requirements.²⁰ Thus, disabled individuals may not be able to access the aids and services they need to get quality care.

Moreover, the Proposed Revisions eliminate the requirement to post public notices informing individuals about their rights and how to file complaints when they face discrimination.²¹ This particularly impacts disabled persons, as they will not be notified of their right to aids and services, free of charge and in a timely manner.²² This means that many disabled individuals will not know that their rights are being violated and thus will not be able to adequately seek justice.

B. The Proposed Revisions Will Remove Protections Against Discriminatory Health Plan Benefit Design

¹⁹ National Health Law Program, "Questions and Answers on the Proposed Rollback of Nondiscrimination Protections Under the ACA's Section 1557," available at: <https://9kqpw4dcaw91s37kozms5jx17-wpengine.netdna-ssl.com/wp-content/uploads/2018/12/18-546-Amicus-Brief-PDFA.pdf>.

²⁰ 45 C.F.R. §§ 92.201–92.204, 45 C.F.R.

²¹ National Health Law Program, "Questions and Answers on the Proposed Rollback of Nondiscrimination Protections Under the ACA's Section 1557," available at: <https://9kqpw4dcaw91s37kozms5jx17-wpengine.netdna-ssl.com/wp-content/uploads/2018/12/18-546-Amicus-Brief-PDFA.pdf>.

²² Id.



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Approximately 1.1 million people in the U.S. are living with HIV.²³ The LGBTQ community, communities of color, and other marginalized groups are often more affected by HIV/AIDS and are also less likely to receive the treatment they need. Gay, bisexual, and queer men are at the highest risk of becoming infected with HIV and account for 66% of all new HIV diagnoses.²⁴ African Americans and Latinos are also disproportionately affected by HIV: African Americans account for 43% of HIV diagnoses and Latinos account for 26% of HIV diagnoses.²⁵ Individuals living with HIV/AIDS, and other chronic conditions, need access to quality, affordable health care, but have been historically discriminated against throughout the health care system.²⁶

Currently, Section 1557 of the ACA explicitly prohibits discriminatory plan benefit design and marketing.²⁷ When creating this regulation, the Department of Health and Human Services directly aimed to stop the practice of placing all drugs used to treat a certain condition, such as those to treat HIV/AIDS, in the highest cost sharing tier because it is an example of discriminatory benefit design.²⁸

The Proposed Revisions removes this prohibition on discriminatory plan benefit design, effectively allowing some forms of discrimination against individuals living with HIV/AIDS and other chronic or serious conditions.

YWCA is particularly concerned about the detrimental impact of these Proposed Revisions would have on disabled persons and individuals living with serious chronic conditions. As shown above, the Proposed Revisions would remove protections and disproportionately affect – and further marginalize – LGBTQ individuals and communities of color.

IV. The Proposed Revisions Will Impede Access to the Full Spectrum of Reproductive Health Care

The ACA together with programs such as Medicare, Medicaid, and the Children’s Health Insurance Program (CHIP), are vital to help women and their

²³ HIV.gov, U.S. Statistics (retrieved 2019), available at: <https://www.hiv.gov/hiv-basics/overview/data-and-trends/statistics>.

²⁴ Id.

²⁵ Id.

²⁶ National Health Law Program, “Questions and Answers on the Proposed Rollback of Nondiscrimination Protections Under the ACA’s Section 1557,” available at: <https://9kqpw4dcaw91s37kozms5jx17-wpengine.netdna-ssl.com/wp-content/uploads/2018/12/18-546-Amicus-Brief-PDFA.pdf>.

²⁷ 45 C.F.R. § 92.207(b)(2).

²⁸ National Health Law Program, “Questions and Answers on the Proposed Rollback of Nondiscrimination Protections Under the ACA’s Section 1557,” available at: <https://9kqpw4dcaw91s37kozms5jx17-wpengine.netdna-ssl.com/wp-content/uploads/2018/12/18-546-Amicus-Brief-PDFA.pdf>.



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families manage the cost and accessibility of health care, including the full spectrum of reproductive health care. Before the ACA, women faced discrimination in the health care system because they were not protected in health care coverage. Only 12% of plans sold on the individual marketplace offered maternity coverage.²⁹ In addition, this coverage was often lacking, making women wait up to a year to use the benefit, or charging deductibles of up to \$10,000.³⁰

Under current regulations, the ACA's prohibition on discrimination on the basis of sex includes discrimination based on pregnancy status, termination of pregnancy, and childbirth and related medical conditions.³¹ By contrast, the Proposed Revisions allow for a religious provider to disregard sex discrimination protections in favor of protecting the organization's religious preferences and beliefs. Allowing some entities to get around protections for women's reproductive health care would harm women and individuals seeking health care services and put women at risk for discrimination in the health care and health insurance systems. by incorporating Title IX's exemption on abortion services and additional policies that make accessing abortion and other health care services more difficult.

YWCA opposes efforts to limit the ability of reproductive health service providers to provide accessible, safe, and comprehensive services to patients, as these Proposed Revisions would do. As one of the largest and oldest service providers to women and girls across the United States, YWCA is committed to protecting the rights of women and girls to the full spectrum of reproductive health care and recognizes these Proposed Revisions as limiting those rights.

V. The Proposed Revisions Will Threaten Access to Health Care and Safety for Survivors of Gender-Based Violence

Gender-based violence survivors rely on the healthcare system for many services including: emergency care; recovering services and screening; and reproductive health services. Often, survivors of gender-based violence face increased need for health care services due to the multitude of health issues incurred as a result of violence. Gender-based causes health consequences ranging from physical injury, chronic pain, anxiety and depression to deadly outcomes such as suicide and homicide.³² Moreover, gender-based violence is

²⁹ YWCA USA, "ACA Repeal: What's at Stake for Women" (2017), available at: https://www.ywca.org/wp-content/uploads/BRIEFING_PAPER_ACA_REPEAL_FINAL.pdf

³⁰ Id.

³¹ 45 C.F.R. § 86.40(b)

³² S. Bott et al., *Improving the Health Sector Response to Gender -Based Violence: A Resource Manual for Health Care Professionals in Developing Countries*, New York.

a risk factor for many physical, mental, sexual, and reproductive health problems.³³

While, survivors of domestic and other gender-based violence are found across all races, ages, classes, and ethnic backgrounds, and gender-based violence disproportionately affects marginalized individuals and communities. Women of color are often at higher risk for experiencing gender-based violence than white women. According to the CDC, 54% of multi-racial women, 46% of American Indian / Alaska Native women, 43% of Black women, 37% of Latinas, 36% of White women, and 20% of Asian or Pacific Islander women have been the victim of intimate partner violence.³⁴ Transgender individuals are also disproportionately impacted by domestic violence and sexual assault. According to a 2015 survey of transgender individuals across the United states, 54% experience some form of intimate partner violence in their lifetimes.³⁵ Because the Proposed Revisions impede access to health care for transgender, low-income, and communities of color, they would also harm survivors of violence, particularly those most marginalized survivors.

Many survivors – including, but not limited to, immigrants, LEP individuals, disabled people, and people living with serious chronic conditions – face forms of violence designed to isolate and control the victim in ways related to their marginalized status. LEP survivors are often controlled and isolated by their inability to speak English.³⁶ Survivors with disabilities may have their medications intentionally withheld or overdosed; experience financial abuse and extortion; receive threats of abandonment; experience inappropriate sexual touching during baths, and dressing; have access to adaptive equipment restricted or taken away; have communication or mobility devices taken away; have their service animals threatened or harmed; and/or have caretakers intentionally ignore personal care and hygiene.³⁷ Because the Proposed Revisions remove protections for these and other groups, as well as remove avenues to know your rights and seek justice, the Proposed Revisions would also allow for the continued mistreatment of survivors of gender-based violence.

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³³ Id.

³⁴ Black, M.C. et al (2011). The National Intimate Partner and Sexual Violence Survey (NISVS): 2010 Summary Report. Atlanta, GA: National Center for Injury Prevention and Control, Centers for Disease Control and Prevention. Retrieved 24 January 2017 from https://www.cdc.gov/violenceprevention/pdf/nisvs_report2010-a.pdf.

³⁵ The 2015 U.S. Transgender Survey Report, National Center for Transgender Equality, available at: <http://www.ustranssurvey.org>.

³⁶ Bui, H. N. (2003). Help-Seeking Behavior Among Abused Immigrant Women. *Violence Against Women*, 9(2), 207-239

³⁷ National Center on Domestic and Sexual Violence, Power and Control Wheel: People with Disabilities and their Caretakers, Based on the model by the Domestic Violence Intervention Project, Duluth, MN. Available at: http://www.springtideresources.org/sites/all/files/People_with_Disabilities_and_Caregivers_Wheel.pdf

At YWCA, we know that all survivors – including those who are transgender, LGBTQ, immigrant, LEP, disabled, living with HIV/AIDS, and seeking reproductive care – deserve access to affordable, quality health care. As discussed above, the Proposed Revisions would negatively impact survivors of gender-based violence and enact undue harm on already-marginalized survivors of violence. Thus, YWCA adamantly opposes the Proposed Revisions in their entirety.

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Conclusion

YWCA's concerns for the LGBTQ community, women, children, and families of immigrant communities, disabled individuals, survivors of domestic and other forms of gender-based violence, and women and girls who would be directly impacted by the Proposed Revisions reflect our long history in providing safety and support to these communities. Because the roll-back of protections for these marginalized communities would cause significant harm as well as significantly impede access to affordable, quality, and safe health care, we urge the Office for Civil Rights in the Department of Health and Human Services to withdraw the Proposed Revisions in their entirety. To implement any or all the Proposed Revisions would put women, families, and communities at risk.

YWCA appreciates the opportunity to share our views with you. If you have any questions, please contact YWCA USA Vice President of Public Policy and Advocacy, Catherine Beane, at cbeane@ywca.org or 202-835-2354.

Sincerely,



Alejandra Y. Castillo, CEO YWCA USA