August 13, 2019

Submitted via the Federal eRulemaking Portal

The Honorable Alex M. Azar II
Secretary
Department of Health and Human Services
Attention: Section 1557 NPRM, RIN 0945-AA11
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue SW
Washington, DC 20201

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

Dear Secretary Azar:

We are writing on behalf of the Chronic Illness and Disability Partnership (CIDP), which consists of national organizations representing individuals living with a wide range of chronic illnesses and disabilities, including cancer, cystic fibrosis, diabetes, HIV, Hepatitis C, behavioral health concerns, multiple sclerosis, and renal disease. We represent the 117 million Americans estimated to be living with a chronic illness and/or disability, many of whom rely upon the Marketplaces to obtain needed care.[1] While our organizations are national in scope, we also affiliate with strong regional, state, and community based advocacy networks. We appreciate the opportunity to provide comments to the Department of Health and Human Services ("HHS" or "the Department") on "Nondiscrimination in Health and Health Education Programs or Activities" ("Proposed Rule"), the proposed changes to the current regulations ("Final Rule") implementing Section 1557 of the Patient Protection and Affordable Care Act ("ACA").

We are deeply concerned that the proposed regulatory changes fail to reflect the broad protections provided by law, and that the changes would obfuscate and weaken one of the nation's strongest nondiscrimination protections for vulnerable communities. Section 1557 protects individuals from discrimination on the basis of race, color, national origin, sex,

[1] Centers for Disease Control and Prevention, *Chronic Disease Overview* (February 23, 2016), https://www.cdc.gov/chronicdisease/overview/.

age, and disability in certain health programs or activities by incorporating four civil rights laws.[2] Section 1557 protects against intersectional discrimination, or discrimination based on multiple protected characteristics, by allowing people to file complaints of such discrimination with an enforcement agency. While the Department does not have authority to change law, the Proposed Rule attempts to change implementation in a way that is contrary to the plain language of the law and, if finalized, would create a vague, unworkable rule with significant impacts on people living with chronic illnesses and disabilities, lesbian, gay, bisexual, transgender, and queer ("LGBTQ") people, people who need reproductive health care (including abortion), women of color, and people whose primary language is not English – all people who already experience significant barriers when accessing health care.

Given the numerous uncertainties and flaws that arise from the Proposed Rule, CIDP strongly urges the Department to rescind its proposal in its entirety and avoid a devastating misinterpretation of a key nondiscrimination provision that has and continues to protect people in a wide range of health programs and activities.

I. The Department impermissibly narrows the scope of nondiscrimination regulations by limiting the types of covered entities that will be subject to Section 1557 enforcement.

The Proposed Rule dramatically narrows the scope of the Department's Section 1557 enforcement by applying inappropriate restrictions to the types of health programs and activities that must comply with the nondiscrimination provision of the ACA. By carving out entities who are not principally engaged in the business of providing health care services, HHS proposes a limited understanding of a "health program or activity," unnecessarily distinguishing "health insurance" from "health care."[3] For people living with significant medical conditions, consistent access to affordable and nondiscriminatory health insurance is often the *only* way to access the health care needed to manage chronic conditions. The coverage and design of health insurance can have a significant impact on health care access and health outcomes for people living with major illness.[4]

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[2] Patient Protection and Affordable Care §1557, 42 U.S.C. §18116.

[3] The Department chose to forgo such a distinction when proposing changes to regulations protecting religious refusals in health care settings, defining a health program or activity to include "the provision or administration of any . . . health related insurance coverage . . . or any other service related to health or wellness . . . through insurance, or otherwise." Protecting Statutory Conscience Rights in Health Care; Delegations of Authority, 83 Fed. Reg. 3,880, 3,893 (Jan. 26, 2018).

[4] Approximately 60% adults in the United States have at least one chronic disease, with 42% of all U.S. adults having two or more chronic conditions. CHRISTINE BUTTORFF, ET AL., RAND CORPORATION, MULTIPLE CHRONIC CONDITIONS IN THE UNITED STATES 6 (2017), https://www.rand.org/content/dam/rand/pubs/tools/TL200/TL221/RAND_TL221.pdf. Adults living with multiple chronic conditions are more likely to use the health care system, including visiting the emergency room, receiving outpatient care, filling prescriptions, and staying in a hospital for inpatient care. *Id*. at 14. Adults with chronic conditions are also more likely to incur out-of-pocket spending under both public and private insurance, making health plan design and cost-sharing important for financial planning. *Id.* at 17. *See also* JILL BERNSTEIN, ET AL., MATHEMATICA POLICY RESEARCH, HOW DOES INSURANCE COVERAGE IMPROVE HEALTH OUTCOMES (April 2010), available at

The Proposed Rule's attempt to narrow the scope of Section 1557 runs counter to the underlying broad remedial purpose of the statute. Federal civil rights laws governing sex-based discrimination are appropriately given "a sweep as broad as its language."[5] The Civil Rights Restoration Act of 1987 was even enacted to "[r]estore the broad scope of coverage and to clarify the application of" disability-based discrimination law.[6] Moreover, a close reading of the ACA undermines the proposed distinction that health insurance lies outside of the reach of Section 1557 generally. Within the same statutory section as Section 1557 is a provision adopting the definitions of the Public Health Service Act, 42 U.S.C. § 300gg-91. Those definitions, in turn, describe a wide array of health insurance plans, even using the word "program" as synonymous with "group health plan."[7]

In the Proposed Rule, HHS introduces a convoluted framework to determine whether an entity is considered a covered entity and thus subject to the Department's enforcement of these civil rights protections.[8] These carve outs and distinctions are not only confusing to health programs and activities (who now must expend resources to clarify the required extent of their own compliance), but people living with chronic illnesses and consumers who may not fully understand the intricacies of a health care organization will have difficulty determining when to expect compliance with nondiscrimination protections.

HHS also proposes to redefine the types of federal financial assistance that could make an entity subject to Section 1557 enforcement and the extent to which a covered entity must then comply with regulation. The Proposed Rule would limit the definition of federal financial assistance to money that HHS directly administers.[9] In doing so, some health-related federal assistance would no longer subject entities to antidiscrimination protections because HHS only plays a role in (and is not directly responsible for) administering the funding. Such an interpretation is contrary to a plain reading of the statute as Section 1557 not only uses the broad term "Federal financial assistance" (without a modifier to limit financial assistance to that which the Department administers directly) but also includes "credits" as an example of relevant Federal financial assistance.[10]

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https://www.mathematica-mpr.com/our-publications-and-findings/publications/how-does-insurance-coverage-improve-health-outcomes; Benjamin D. Sommers, et al., *Health Insurance Coverage and Health – What the Recent Evidence Tells Us*, 377 NEW ENG. J. MED. 586 (2017).

[5] Grove City College v. Bell, 465 U.S. 555, 564 (1983) (quoting North Haven Board of Education v. Bell, 456 U.S. 512, 521 (1982)).

[6] Civil Rights Restoration Act of 1987, Pub. L. No. 100-259, 102 Stat. 28 (1988).

[7] 42 U.S.C. § 300gg-91(a)(3).

[8] For example, the Proposed Rule suggests that while the Department would expect state Medicaid programs to comply with the Proposed Rule due to receipt of federal financial assistance, it would not require the Centers for Medicare & Medicaid Services to fully comply with Section 1557. Nondiscrimination in Health and Health Education Programs or Activities, 84 Fed. Reg. 27,846, 27,862 (proposed June 14, 2019).

[9] The Department notably chose to define federal financial assistance more broadly in other regulations. Protecting Statutory Conscience Rights in Health Care; Delegations of Authority, 84 Fed. Reg. 23,170 (May 21, 2019).

[10] The Affordable Care Act helped make health insurance more affordable by providing advanced premium tax credits to most consumers purchasing private insurance on the Marketplace. According to the Proposed

Furthermore, the Department proposes to split the operations of entities who are not principally engaged in providing health care services, and only require the operations receiving federal financial assistance to comply with Section 1557 regulations. This interpretation is also contrary to a plain reading of Section 1557, which states that a person shall not "be excluded from participation in, be denied the benefits of, or be subjected to discrimination under, any health program or activity, *any part of which* is receiving Federal financial assistance[.]"[11] By keeping "any health program or activity" as the object of the sentence and not "any part of a health program or activity which receives Federal financial assistance," the statute clearly indicates that the receipt of federal financial assistance in one part of a covered entity will subject the larger entity to Section 1557.

If these inaccurate interpretations of Section 1557 are finalized, people living with chronic illness will have difficulty knowing when and to what extent an entity must comply with federal regulations. People living with significant health needs require access to health programs and affordable health care plans that do not openly discriminate against members due to their race, color, national origin, sex (including gender identity, sexual orientation, and sex stereotypes; and pregnancy, childbirth, and related medical conditions), age, and disability. When they do not have access to affordable, non-discriminatory health care coverage, people living with chronic illnesses and disabilities face medical debt, are unable to access specialist care, and have difficulty managing their chronic conditions. Additionally, the proposed changes would be unduly burdensome on consumers who would have to follow a vague, illogical scheme to determine when and where they can file complaints with HHS about discrimination in health settings.

II. The Department's proposed deletion of provisions that explicitly describe prohibited discriminatory practices would make the regulations vague and burdensome for people living with chronic illnesses and disabilities, and fails to include adequate discussion regarding whether proposed deletions are indicative of shifts in policy.

The Proposed Rule eliminates key provisions in the Final Rule and unnecessarily and inappropriately burdens people living with chronic illnesses and disabilities. People living with chronic illnesses 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 guideline regimens on the highest cost-sharing tier.[12] The Final Rule clearly describes how certain insurer and

Rule however, such credits would not qualify as federal financial assistance as HHS only plays a role in the administration of the credits.

[11] Patient Protection and Affordable Care §1557, 42 U.S.C. §18116 (emphasis added).

[12] 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), 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), 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

provider practices are discriminatory, in violation of Section 1557, 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 "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, the Department 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 Section 1557. People living with chronic illnesses and disabilities, people of color, and LGBTQ people have historically been subject to such discrimination in health settings.[13] Any change in policy regarding enforcement against these discriminatory practices would significantly impact all protected classes.[14]

Without more explanation as to how the deletions reflect HHS' enforcement policies, consumer groups, health providers, and other covered entities – particularly those who regularly serve people living with chronic illnesses and disabilities – are unable to provide complete and robust comment about the Proposed Rule's "balance" or address whether these policy changes are in line with congressional mandate and judicial interpretation, or whether the changes are properly addressed in the Department's regulatory impact analysis. Despite the Department's lack of enforcement towards some forms of discrimination,[15] Section 1557 and the Final Rule have been instrumental in addressing

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School & AIDS Law Project of Pennsylvania (U.S. Dep't of Health and Human Services), 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), http://www.chlpi.org/wp-content/uploads/2013/12/TN-Cigna.pdf; 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 places 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).

[13] *See, e.g.* INTERSECTING INJUSTICE: A NATIONAL CALL TO ACTION 62-76 (Lourdes Ashely Hunter, Ashe McGovern & Carla Sutherland eds., 2018), available at http://socialjusticesexuality.com/intersecting_injustice/; S.E. JAMES, ET AL., NAT'L CTR. FOR TRANSGENDER EQUALITY, THE REPORT OF THE 2015 U.S. TRANSGENDER SURVEY 247 (2016), https://transequality.org/sites/default/files/docs/usts/USTS-Full-Report-Dec17.pdf.

[14] *See generally* Susan Reif, et al., *The Relationship of HIV-related Stigma and Health Care Outcomes in the U.S. Deep South,* AIDS & BEHAVIOR (2019), available at https://link.springer.com/content/pdf/10.1007%2Fs10461-019-02595-5.pdf; Gina M. Wingood, et al., *HIV Discrimination and the Health of Women Living with HIV*, 46 WOMEN & HEALTH 99 (2007).

[15] *See* Douglas B. Jacobs & Benjamin D. Sommers, *Using Drugs to Discriminate – Adverse Selection in the Insurance Marketplace*, 372 NEW ENG. J. MED. 399 (2015); NATIONAL ALLIANCE OF STATE & TERRITORIAL AIDS DIRECTORS, DISCRIMINATORY DESIGN: HIV TREATMENT IN THE MARKETPLACE (2016), https://www.nastad.org/
sites/default/files/Discriminatory-Design-HIV-Treatment-in-the-Marketplace.pdf. Discriminatory benefit

many discriminatory practices, including inappropriate provider behavior and condition-based categorical exclusions in health insurance,[16] and are vital parts of helping address chronic illness in the United States.[17] Changes to these HHS policies would be monumental and deserve adequate clarity and an opportunity for the public to provide meaningful feedback.

III. The Department's proposed deletion of provisions specific to sex discrimination are unnecessary, inappropriate, and contrary to law.

The Proposed Rule removes sections of the Final Rule that provide explicit protections against sex-based discrimination. Sex discrimination in health care has a disproportionate impact on LGBTQ people, women of color, and individuals living at the intersections of multiple identities–resulting in them paying more for health care, receiving improper diagnoses at higher rates, being provided less effective treatments, and sometimes being denied care altogether. As the first broad prohibition against sex-based discrimination in health care, Section 1557 is crucial to ending gender-based discrimination in the health care industry. In addition to personal stories and lived experience, advocacy groups have submitted surveys, studies, and reports documenting discrimination in health care against these communities and their families.[18]

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design (targeting nationally-recommended regimens for people newly diagnosed with HIV) continues to be sanctioned on the 2019 Marketplace.

[16] Tovar v. Essentia Health, 342 F. Supp. 3d 947 (D. Minn. 2018); Boyden v. Conlin, 341 F. Supp. 3d 979 (W.D. Wis. 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.

[17] Increased access to these medications and nondiscriminatory medical coverage are crucial to efforts to end the HIV epidemic. AIDS UNITED & ACT NOW: END AIDS, ENDING THE HIV EPIDEMIC IN THE UNITED STATES: A ROADMAP FOR FEDERAL ACTION 40-62 (2018), available at https://www.aidsunited.org/resources/ending-the-hiv-epidemic-in-the-us.

[18] The Department's 2013 Request for Information (RIN 0945-ZA01) resulted in over 400 comments, half of which were from transgender individuals sharing their own experiences. Nondiscrimination in Health Programs and Activities, 80 Fed. Reg. 54,172, 54,172 (Sept. 8, 2015). The Department's 2015 Proposed Rule (RIN 0945-AA02) resulted in several thousand comments, many of which were from civil rights/advocacy groups, individuals who had experienced discrimination, medical providers, legal service organizations, and medical-legal partnerships. Nondiscrimination in Health Programs and Activities, 81 Fed. Reg. 31,376, 31,376 (May 18, 2016).

Additional examples of discrimination have been described in the media and in the courtroom. *See* Katelyn Burns, *It sucks to go to the doctor if you're trans*, Vox (June 21, 2019), https://www.vox.com/first-

The Proposed Rule deletes provisions from the Final Rule which accurately define the term "sex" and appropriately acknowledge that sex-based discrimination includes discrimination on the basis of gender identity, sex stereotyping, and termination of pregnancy. The Proposed Rule removes the entire definitions section,[19] incorporating a few definitions into other sections and concluding that terms not otherwise defined in the Proposed Rule are "clear enough to obviate the need for further definition."[20]

According to discussion in the preamble however, HHS has an inaccurate understanding of sex-based discrimination that is unnecessary, inappropriate, and contrary to law. HHS' justification for deleting the definitions section fails to adequately consider the totality of case law interpreting the term "sex" in civil rights protections and ignores the weight of Supreme Court and appellate court decisions. In 1989, the Supreme Court ruled that discrimination on the basis of sex (as prohibited in Title VII) included behavior based on expectations about how one should act or behave based on their sex.[21] In doing so, the Supreme Court recognized that existing federal law prohibited discrimination on the basis of sex stereotypes.[22]

The Court's opinion has had strong influence on both Title VII and Title IX jurisprudence because it acknowledged and endorsed the idea that discrimination on the basis of sex encompasses discrimination on the basis of sex-linked characteristics, including dress, personality, and appearance.[23] In the Proposed Rule however, HHS looks

person/2019/6/21/186929
24/trump-transphobia-health-care-discrimination-protections; Oliver Knight, *Catholic Bishops Stopped My Surgery Because I'm Transgender*, ACLU (March 21, 2019), https://www.aclu.org/blog/lgbt-rights/transgender-rights/catholic-bishops-stopped-my-surgery-because-im-transgender; *Faces of Breast Cancer: Jay Kallio*, New York Times (2014), https://www.nytimes.com/interactive/projects/well/breast-cancer-stories/stories/717; Yusef Najafi, *A Life Remembered*, METRO WEEKLY (Dec. 20, 2006), https://www.metroweekly.com/2006/12/a-life-remembered/ ("[Tyra] Hunter's story gained national attention in 1995 when it was discovered that rescue workers had interrupted her medical treatment upon discovering she had male genitalia. Instead of providing treatment for Hunter's severe injuries, rescue workers spent time making derogatory comments.").

[19] Definitions, 45 C.F.R. § 92.4.

[20] Nondiscrimination in Health and Health Education Programs or Activities, 84 Fed. Reg. at 27,860.

[21] Price Waterhouse v. Hopkins, 490 U.S. 228 (1989).

[22] "As for the legal relevance of sex stereotyping, we are beyond the day when an employer could evaluate employees by assuming or insisting that they matched the stereotype associated with their group, for, '[i]n forbidding employers to discriminate against individuals because of their sex, Congress intended to strike at the entire spectrum of disparate treatment of men and women resulting from sex stereotypes.'" Price Waterhouse v. Hopkins, 490 U.S. 228, 251 (1989) (citation omitted).

[23] Some courts have applied this interpretation to extend Title VII's nondiscrimination protections to sexual orientation. *See* Zarda v. Altitude Express, 883 F.3d 100, (2d Cir. 2018), *cert. granted*, 139 S. Ct. 1599 (U.S. April 22, 2019) (No. 17-1623); Hively v. Ivy Tech Cmty. Coll., 853 F.3d 339 (7th Cir. 2017). While some circuit courts do not consider sexual orientation to be actionable under Title VII, they have broadened their interpretation of Title VII to include gender non-conformity. *See* Evans v. Georgia Reg'l Hosp., 850 F.3d 1248, 1254 (11th Cir. 2017), *cert. denied*, 138 S. Ct. 557 (2017); Smith v. Salem, 378 F.3d 566, 574 (6th Cir. 2004) ("After *Price Waterhouse*, an employer who discriminates against women because, for instance, they do not wear dresses or makeup, is engaging in sex discrimination because the discrimination would not occur but for the victim's sex. It follows that employers who discriminate against men because

to implement a more narrow understanding than that taken up by the Supreme Court.[24] The Department also shifts away from broad judicial, legislative, and administrative interpretations of sex that include gender identity, and summarily dismisses the legal authority of four appellate courts in favor of advancing its own view of what constitutes sex-based discrimination under Title IX.[25]

Attempts to erase established Supreme Court and appellate court precedent misleads health providers, other covered entities, and consumers to believe that discrimination on the basis of sex stereotyping and gender identity is sanctioned by the agency and permitted under law. This misunderstanding can significantly impact people living with chronic illness, as studies have shown that LGBT people often have higher rates of chronic health conditions and encounter barriers to care exacerbated by stigma and discrimination.[26] Additionally, the wide variance in state protections for transgender people and the subsequent burdens on consumers, insurers, and state agencies has underscored the need for a federal "floor" of nondiscrimination protections.[27]

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they *do* wear dresses and makeup, or otherwise act femininely, are also engaging in sex discrimination, because the discrimination would not occur but for the victim's sex.").

[24] Nondiscrimination in Health and Health Education Programs or Activities, 84 Fed. Reg. at 27,884.

[25] *See* Doe by & through Doe v. Boyertown Area Sch. Dist., 897 F.3d 518 (3d Cir. 2018), *cert. denied*, 2019 U.S. App. Lexis 3666 (U.S. May 28, 2019) (No. 18-658); Whitaker v. Kenosha Unified Sch. Dist. No. 1 Bd. of Educ., 858 F.3d 1034, 1051 (7th Cir. 2017), *cert. dismissed*, 138 S. Ct. 1260 (U.S. 2018); G.G. v. Gloucester Cty. Sch. Bd., 822 F.3d 709, 718 (4th Cir. 2016), *vacated*, 137 S. Ct. 1239 (U.S. 2017) (vacating judgment and remanding the case back to the Fourth Circuit in light of new Department of Education guidance); Dodds v. U.S. Dept. of Education, 845 F.3d 217 (6th Cir. 2016).

[26] *See, e.g.*, Kellan Baker & Jeff Krehely, *How Health Care Reform Will Help LGBT Elders*, 21 PUBLIC POLICY & AGING REPORT 19 (2011); Walter O. Bockting, et al., *Stigma, Mental Health, and Resilience in an Online Sample of the US Transgender Population*, 103 AM. J. PUB. HEALTH 943, 943 (2013); CECILIA CHUNG, ET AL., TRANSGENDER LAW CENTER, POSITIVELY TRANS: INITIAL REPORT OF A NATIONAL NEEDS ASSESSMENT OF TRANSGENDER AND GENDER NON-CONFORMING PEOPLE LIVING WITH HIV (2016), http://transgenderlawcenter.org/wp-content/uploads/2016/02/PositivelyTrans-2015-7-border-FINAL.pdf; ANDREW CRAY, ET AL., CENTER FOR AMERICAN PROGRESS, SEEKING SHELTER: THE EXPERIENCES AND UNMET NEEDS OF LGBT HOMELESS YOUTH 18-19 (2013), https://cdn.americanprogress.org/wp-content/uploads/2013/09/LGBTHomelessYouth.pdf; ANN P. HAAS, ET AL., SUICIDE ATTEMPTS AMONG TRANSGENDER AND GENDER NON-CONFORMING ADULTS: FINDINGS OF THE NATIONAL TRANSGENDER DISCRIMINATION SURVEY 2 (2014), https://williamsinstitute.law.ucla.edu/wp-content/uploads/AFSP-Williams-Suicide-Report-Final.pdf (finding that survey respondents living with HIV (51%), survey respondents living with disabilities (55-65%), and survey respondents who have had a health care provider refuse to treat them due to their gender identity (60%) had higher prevalence of suicide attempts); LAMBDA LEGAL, WHEN HEALTH CARE ISN'T CARING: LAMBDA LEGAL'S SURVEY OF DISCRIMINATION AGAINST LGBT PEOPLE AND PEOPLE WITH HIV 9-16 (2010), https://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-report_when-health-care-isnt-caring.pdf; Ilan H. Meyer, *Why Lesbian, Gay, Bisexual, and Transgender Public Health?*, 91 AM. J. PUB. HEALTH 856, 856-57 (2001); Office of Disease Prevention and Health Promotion, *Lesbian, Gay, Bisexual, and Transgender Health*, https://www.healthypeople.gov/2020/topics-objectives/topic/lesbian-gay-bisexual-and-transgender-health (last visited Aug. 13, 2019); Cigna, *LGBT Health Disparities* (Feb. 2017), https://www.cigna.com/individuals-families/health-wellness/lgbt-disparities.

[27] Removal of discrimination protections for the transgender community will create uncertainty for consumers and insurance companies, and increase the burden on state regulatory agencies. Letter from 18 Insurance Commissioners to Secretary Alex M. Azar II (Aug. 5, 2019),

While the Department acknowledges that it has not fully captured how the Proposed Rule would negatively impact the civil rights of transgender and gender non-conforming people, HHS proposes deletions that would allow organizations to reintroduce discriminatory policies and practices. Analyses have shown that Section 1557 has resulted in a number of affordable health care plans removing coverage exclusions for transition-related care.[28] Rescinding these explicit protections would encourage covered entities to return to pre-ACA practices of discriminating against consumers who are transgender or who otherwise seek coverage of transition-related services.

IV. The Department proposes changes to Section 1557 regulations that impermissibly introduce new religious exemptions into nondiscrimination provisions and would allow increased discrimination against vulnerable communities.

Sex discrimination takes many forms and can occur at every step in the health care system—from obtaining affordable insurance coverage to the treatment received in examination rooms. Sex-based discrimination can have serious adverse impacts, including higher costs for health care coverage, improper diagnoses, and less effective treatments.[29] Additionally, the effects of sex discrimination for women of color can compound other forms of discrimination they face, including racial discrimination, and disparities they already experience in access to health care and positive health outcomes.[30]

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https://www.insurance.ca.gov/0400-news/0100-press-releases/2019/upload/nr057LtrToAzarSec1557-080519.pdf. The Proposed Rule would also create an "uneven playing field among insurers." *Id* on 2.

[28] *See, e.g.*, 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 Department suggests that because Judge O'Connor issued a preliminary injunction against enforcement of parts of the Final Rule prior to the 2017 plan year, consumers "could not have developed a reliance interest on the enjoined parts of the rule." Nondiscrimination in Health and Health Education Programs or Activities, 84 Fed. Reg. at 27,886. However, insurers selling Qualified Health Plans in 2017 would have had to complete a multi-month long certification process with the Department and were marketing and enrolling consumers into their plans prior to Judge O'Connor's preliminary injunction on New Year's Eve. Additionally, the Department had finalized Marketplace rules that prohibited insurers from using market practices or benefit designs that discourage the enrollment of people with significant health conditions or discriminate against people due to their gender identity in 2013 and prohibited exchanges and Qualified Health Plan issuers from discriminating on the basis of gender identity in 2012. Patient Protection and Affordable Care Act; Health Insurance Market Rules; Rate Review, 78 Fed. Reg. 13,406, 13,438 (Feb. 27, 2013) (codified as 45 C.F.R. §§ 147.104(e)); Patient Protection and Affordable Care Act; Establishment of Exchanges and Qualified Health Plans; Exchange Standards for Employers, 77 Fed. Reg. 18,310, 18,447 (codified as 45 CFR 155.120(c)(2), 156.200(e)). These rules were well noted by consumer advocacy organizations and highlighted in outreach to the LGBT community.

[29] *See generally* ROBERT WOOD JOHNSON FOUNDATION, ET AL., DISCRIMINATION IN AMERICA: FINAL SUMMARY 13 (2018), https://www.rwjf.org/content/dam/farm/reports/surveys_and_polls/2018/rwjf443620..

[30] *See generally* MARTHA HOSTETTER & SARAH KLEIN, THE COMMONWEALTH FUND, *IN FOCUS: REDUCING RACIAL DISPARITIES IN HEALTH CARE BY CONFRONTING RACISM* (2018), https://www.commonwealthfund.org/publications/newsletter-article/2018/sep/focus-reducing-racial-disparities-health-care-confronting.

The Proposed Rule attempts to roll back protections for certain types of sex discrimination under Section 1557, including discrimination on the basis of pregnancy, false pregnancy, termination of pregnancy, or recovery therefrom, childbirth or related conditions. Although HHS acknowledges in the Proposed Rule's preamble that the prohibition against sex discrimination includes termination of pregnancy, the Department refuses to state whether it would enforce those protections. Instead, the Department proposes to delete the Final Rule's clarification that the ban on sex discrimination includes all pregnancy-related care, and in doing so, illegally attempts to eliminate express protections that apply to someone who has had an abortion or has experienced a miscarriage or ectopic pregnancy and needs care for those conditions as well. While the scope of protection under Section 1557 is clear, illegal discrimination is likely to flourish if implementing regulations and HHS enforcement is purposefully ambiguous.

The Proposed Rule seeks to unlawfully incorporate Title IX's "Danforth Amendment", which carves out abortion care and coverage from the ban on discrimination of sex in the education context. Congress did not include the Title IX exceptions, including the Danforth Amendment, either explicitly or by reference, in Section 1557. The Proposed Rule's unlawful incorporation of the Danforth Amendment is yet another attack on abortion care and serves as an additional barrier for people to access affordable and comprehensive health care. These attacks could embolden illegal discrimination that will fall heaviest on those least able to seek health care elsewhere, including women living in rural areas and women of color, who already face harassment and discrimination by providers during pregnancy, contributing to Black and Native American women's unacceptably high rates of health-related pregnancy complications and death.[31]

The Proposed Rule also attempts to impermissibly apply Title IX's religious exemption, along with other unrelated rules, to Section 1557's prohibition on sex discrimination in health programs and activities. The Department's attempt to incorporate these restrictions violates the plain language of the statute and is contrary to the express purpose of Section 1557. If finalized, these new restrictions could allow for religiously-affiliated hospitals and other health care entities to discriminate against patients based on sex, disproportionately harming LGBTQ people, people seeking reproductive health services, including abortion care, and those living at the intersection of these identities.[32]

Allowing a religious exemption to Section 1557's protection against sex discrimination could have far-reaching negative consequences. Incorporating Title IX's religious exemption could create new instances in which health care providers, including insurance

[31] *See, e.g.*, NATIONAL PARTNERSHIP FOR WOMEN & FAMILIES, BLACK WOMEN'S MATERNAL HEALTH (2018), http://www.nationalpartnership.org/our-work/resources/health-care/maternity/black-womens-maternal-health-issue-brief.pdf; Lucy Truschel & Cristina Novoa, *American Indian and Alaska Native Maternal and Infant Mortality: Challenges and Opportunities*, CENTER FOR AMERICAN PROGRESS (July 9, 2018), https://www.americanprogress.org/issues/early-childhood/news/2018/07/09/451344/american-indian-alaska-native-maternal-infant-mortality-challenges-opportunities/.

[32] For more information about how religious exemptions can embolden discrimination against vulnerable communities, see comments made in response to "Protecting Statutory Conscience Rights in Health Care; Delegations of Authority" (RIN 0945-ZA03) submitted by the NMAC (formerly the National AIDS Minority Council) and the Williams Institute.

companies, hospitals, doctors, or nurses, allow their beliefs to determine patient care, opening the door to illegal discrimination and substandard care. The proposed changes would impact a broad range of health care services, including contraception, certain fertility treatments, abortion, gender-affirming care, and end-of-life care.[33] Studies have already tracked the proliferation of entities that use religious beliefs to discriminate against patients and the growing number of religiously-affiliated entities that provide health care and related services, but refuse to provide certain care based on religious beliefs.[34] The Proposed Rule would encourage these entities to engage in illegal discrimination, and would have the impact of blocking vulnerable communities from the health care they need.

V. The Department proposes changes to Section 1557 regulations that impermissibly eliminate and weaken protections for individuals who are limited English proficient.

The Department's proposed changes to language access provisions would eliminate and weaken protections for individuals who are limited English proficient ("LEP individuals"). Limited English proficiency often exacerbates the effects of low health literacy, especially when LEP individuals do not have access to materials that help them better understand basic health information, access preventive services, or avoid adverse events.[35] These barriers can complicate the management of chronic illnesses and disabilities, and lead to poorer health outcomes for already disadvantaged communities.[36] The Department failed to follow its own balancing principles (identified in the 2003 HHS

[33] Many professional associations have issued statements against the denial of care based on religious objections to the services in question or the patient in need. *See, e.g.*, American College of Obstetricians and Gynecologists, *America's Frontline Physicians Urge Trump Administration to Protect Transgender Patients and Women's Reproductive Health*, https://m.acog.org/About-ACOG/News-Room/Statements/2019/Physicians-Urge-Trump-Administration-to-Protect-Transgender-Patients-and-Womens-Health?p=1 (May 28, 2019) (joined by the American Academy of Family Physicians, the American Academy of Pediatrics, the American College of Physicians, the American Osteopathic Association, and the American Psychiatric Association); World Professional Association for Transgender Health, *WPATH Board Responds to Health Care Policies and Practices Imposed by Certain Religious Institutions*, https://www.wpath.org/media/cms/Documents/Public%20Policies/2019/5-16_Religious%20Institution %20Health%20Policies.pdf (May 17, 2019) (joined by the American Medical Association, the American Psychological Association, the American Psychiatric Association, and the American Academy of Pediatrics).

[34] *See, e.g.*, LOIS UTTLEY, ET AL., AM. CIVIL LIBERTIES UNION & MERGERWATCH, *MISCARRIAGE OF MEDICINE: THE GROWTH OF CATHOLIC HOSPITALS AND THE THREAT TO REPRODUCTIVE HEALTH CARE* (2013), http://www.merger watch.org/storage/pdf-files/Growth-of-Catholic-Hospitals-2013.pdf; LOIS UTTLEY & CHRISTINE KHAIKIN, GROWTH OF CATHOLIC HOSPITALS AND HEALTH SYSTEMS: 2016 UPDATE OF THE MISCARRIAGE OF MEDICINE REPORT (2016), http://www.mergerwatch.org/storage/pdf-files/MW_Update-2016-MiscarrOfMedicine-report.pdf.

[35] *See, e.g.*, Tentine Sentell & Kathryn L. Braun, *Low Health Literacy, Limited English Proficiency, and Health Status in Asians, Latinos, and Other Racial/Ethnic Groups in California*, 17 J. HEALTH COMM. 82 (2012).

[36] *See generally* Chandrika Divi, et al., *Language Proficiency and Adverse Events in U.S. Hospitals: A Pilot Study*, 19 INT'L J. QUALITY IN HEALTH CARE 60 (2007).

LEP Guidance[37]) when it created a proposed rule that focused most significantly on the costs of compliance to covered entities, devoting minimal discussion and analysis to the costs to LEP individuals and prioritizing organizations over the communities Section 1557 is meant to protect.

CIDP strongly opposes the repeal of the requirement that covered entities provide a notice of nondiscrimination that informs the public of their legal rights. While this change impacts all individuals, including native English speakers, the change will have a disproportionate impact on LEP individuals and those who are unfamiliar with applicable civil rights protections. The Department has provided no explanation for how individuals will be aware of their rights and how elimination of notices will not deny LEP individuals, individuals living with chronic illnesses and disabilities, and others with meaningful access to nondiscriminatory health care.

We also strongly oppose the Department's proposed repeal of the requirement for covered entities to provide in-language taglines informing recipients of the availability of language assistance on significant documents. Taglines are not only well-supported by long-standing federal regulations, guidance, and practice,[38] but they are necessary to ensure that LEP individuals are made aware of and are reminded that auxiliary aids and services or language assistance services are available. The requirement to include taglines in all significant communications also prompts covered entities to ensure these resources are available for LEP members at all stages of receiving and paying for covered benefits.

CIDP membership strongly oppose the Proposed Rule's repeal of requirements that help LEP consumers understand the protections and resources available to them in health settings. The fact that an "overwhelming majority of beneficiaries speak English" does not provide compelling support to rescind protections designed for beneficiaries who have limited English proficiency.[39] The Proposed Rule repeals provisions that were practical, effective, fiscally responsible, reasonable, and responsive to the circumstances relevant to health care programs and activities, and instead prioritizes covered entities' resources and consumers' "annoyance" over the civil rights of LEP individuals.

[37] "First we must ensure that federally assisted programs aimed at the American public do not leave some behind simply because they face challenges communicating in English." Guidance to Federal Financial Assistance Recipients: Providing Meaningful Access to Individuals Who Have Limited English Proficiency in Compliance With Title VI of the Civil Rights Act of 1964, 68 Fed. Reg. 34,698, 34,699 (June 10, 2003).

[38] *See* DOJ Public dissemination of title VI information, 29 C.F.R. § 42.405(d)(1); HHS Consumer assistance tools and programs of an Exchange, 45 C.F.R. § 155.205(c)(2)(iii); CMS (Medicaid Managed Care) Information requirements, 42 C.F.R. § 438.10(d)(3); DOL Discrimination prohibited based on national origin, including limited English proficiency, 29 C.F.R. § 38.9(g)(3); USDA (SNAP) Program administration and personnel requirements, 7 C.F.R. § 272.4(b); Guidance to Federal Financial Assistance Recipients: Providing Meaningful Access to Individuals Who Have Limited English Proficiency in Compliance With Title VI of the Civil Rights Act of 1964, 68 Fed. Reg. 34,698 (June 10, 2003).

[39] Nondiscrimination in Health and Health Education Programs or Activities, 84 Fed. Reg. at 27,858-59.

VI. In general, the Department inappropriately proposes changes to Section 1557 and other unrelated regulations, and should rescind the Proposed Rule in its entirety to avoid sanctioning the violation of civil rights and weakening robust enforcement mechanisms.

The Department's Proposed Rule is inappropriately broad and introduces premature changes to Section 1557 regulations and other unrelated rules. The Department notably proposes changes to sections of the CFR that were promulgated separately from and prior to the 2016 Final Rule.[40] In some cases, these rules arise out of statutes different from Section 1557, statutes that the Department fails to consider in its totality in the Proposed Rule. If the Proposed Rule is implemented, express prohibitions on discrimination based on sexual orientation and gender identity would be eliminated from regulations addressing private insurance, certain Medicaid and Medicare organizations, and education programs. These programs are especially important for LGBT people living with chronic illnesses, as they help patients better manage chronic conditions like asthma, diabetes, mood disorders, diabetes, and cardiovascular diseases.[41]

Additionally, the Department prematurely proposes changes to Section 1557 regulations. The Supreme Court is scheduled to hear oral arguments and address whether sex-based discrimination protections in employment law extend to discrimination based on sexual orientation and gender identity.[42] While these cases rely on Title VII and not Title IX, the Supreme Court's resulting decisions will undoubtedly introduce new considerations for the Department and the public should have the opportunity to address the impact of the Court's decisions on HHS' interpretation of Section 1557.

The Department also includes changes that would undermine the enforcement of and remedies available to protected classes for Section 1557 violations. The Proposed Rule removes provisions that recognize a private right of action in federal court and allow for money damages in administrative and judicial actions bought under Section 1557. The Proposed Rule also attempts to limit available enforcement mechanisms for each protected characteristic to those available under their respective reference statutes (Title Vi, Title IX, Section 504 of the Rehabilitation Act, and the Age Discrimination Act). However, Section 1557 built and expanded prior civil rights laws such that individuals seeking to enforce

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[40] Nondiscrimination in Health and Health Education Programs or Activities, 84 Fed. Reg. at 27,889-94 (proposing 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)).

[41] *The Value of Medicaid: How Coverage Impacts the Care of Serious Chronic Health Conditions* 2018, AMERICA'S HEALTH INSURANCE PLANS (Nov. 2018), available at https://www.ahip.org/the-value-of-medicaid-issue-brief/. *See also* KAISER FAMILY FOUNDATION, THE ROLE OF MEDICAID FOR PEOPLE WITH DIABETES (Nov. 2012), https://www.kff.org/wp-content/uploads/2013/01/8383_d.pdf; KAISER FAMILY FOUNDATION, THE ROLE OF MEDICAID FOR PEOPLE WITH CARDIOVASCULAR DISEASES (Nov. 2012), https://www.kff.org/wp-content/uploads/2013/01/8383_cd.pdf. State-by-state statistics can be found at Matt Broaddus, *On Its Anniversary, a Look at How Medicaid Helps People in Every State,* CENTER ON BUDGET AND POLICY PRIORITIES (July 30, 2019), https://www.cbpp.org/blog/on-its-anniversary-a-look-at-how-medicaid-helps-people-in-every-state.

[42] Zarda v. Altitude Express, 883 F.3d 100, (2d Cir. 2018), *cert. granted*, 139 S. Ct. 1599 (U.S. April 22, 2019) (No. 17-1623); R.G. & G.R. Harris Funeral Homes, Inc. v. EEOC, 884 F.3d 560 (6th Cir. 2018), *cert. granted*, 139 S. Ct. 2049 (U.S. May 13, 2019) (No. 18-107).

their rights would have access to the full range of civil rights remedies and not be limited to only the remedies provided to a particular protected group under a specific law.[43] These proposed changes undermine the plain language of Section 1557 and would produce a weak, confusing mix of legal standards and remedies that would be difficult for federal and state agencies to enforce. The Proposed Rule would also make it more difficult for consumers with complaints of intersectional discrimination to file complaints with HHS.

VII. Conclusion

Given the numerous uncertainties and flaws that arise from the Proposed Rule, CIDP strongly urges the Department to rescind the Proposed Rule in its entirety. The proposed changes would impact the ability for people living with chronic illnesses and disabilities to access health care coverage that fully addresses their health care needs. Implementing the Proposed Rule would bring about additional costs (for both consumers and covered entities) and would encourage the expansion of discriminatory practices among providers, health insurers, and other covered entities. Instead, we urge HHS to more vigorously address complaints of discrimination already on file, and hold covered entities accountable to complying with the Final Rule.

Thank you for the opportunity to comment on the Proposed Rule. Our comments include numerous citations to supporting research, in many cases including direct links for HHS' benefit in reviewing our comments. We direct HHS to each of the sources cited and we request that the full text of each source, along with the full text of our comments be considered part of the administrative record in this matter for purposes of the Administrative Procedure Act. Please contact Robert Greenwald with the Treatment Access Expansion Project (rgreenwa@law.harvard.edu), Amy Killelea with the National Alliance of State & Territorial AIDS Directors (akillelea@nastad.org), or Jean McGuire at Northeastern University (j.mcguire@neu.edu) if we can be of assistance.

Respectfully submitted by the co-chairs of the Chronic Illness and Disability Partnership:

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[43] Section 1557 expressly provides individuals all "rights, remedies, procedures, or legal standards" available under the cited civil rights statutes and gives people access to "enforcement mechanisms provided for and available under such title VI, title IX, section 794, or the Age Discrimination Act shall apply for purposes of violations of this subsection." Patient Protection and Affordable Care §1557, 42 U.S.C. §18116.