SYLVIA RIVERA LAW PROJECT

147 W. 24TH ST. 5TH FLOOR NEW YORK, NY 10011 212 337 8550 T 212 337 1972 F WWW.SRLP.ORG

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Department of Health and Human Services
Office for Civil Rights
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue, SW
Washington, D.C. 20201

RE: Nondiscrimination in Health and Health Education Programs or Activities, Proposed Rule RIN 0945-AA11

To Whom It May Concern:

The Sylvia Rivera Law Project (SRLP) respectfully submits the following comment in response to the proposed rule on Section 1557 of the Affordable Care Act (ACA) published by the U.S. Department of Health and Human Services (HHS) on June 14, 2019. SRLP opposes any changes to the existing Section 1557 rule and urges HHS to rescind the proposed version.

Basis for comments from the Sylvia Rivera Law Project

SRLP works to guarantee that all people are free to self-determine their gender identity and expression, regardless of income or race, and without facing harassment, discrimination, or violence. SRLP is a collective organization founded on the understanding that gender self-determination is inextricably intertwined with racial, social and economic justice. Therefore, we seek to increase the political voice and visibility of low-income people and people of color who are transgender, intersex, or gender non-conforming (TGNCI). SRLP works to improve access to respectful and affirming social, health, and legal services for our communities. We believe that in order to create meaningful political participation and leadership, we must have access to basic means of survival and safety from violence.

Since our founding in 2002, we have directly served thousands of TGNCI people who are low-income, of color, or both. Many of our clients also live with disabilities or chronic illnesses, such as HIV/AIDS, and do not speak English as their primary language. Additionally, all of our clients who have health insurance depend on programs like Medicaid or insurance provided through the Affordable Care Act for access to care. Over the course of any given year, we work on over 300 cases involving TGNCI individuals in New York City and New York State, in addition to the work we do educating our communities on their rights and working with them to advocate for policies and laws that support our survival and self-determination.

We know firsthand the persistent and severe discrimination that TGNCI people continue to face in the realms of employment, education, healthcare, immigration, public accommodation, and criminal justice. HHS's proposed rule would effectively make it legal for healthcare providers

and insurance companies to discriminate against a population that already faces profound levels of inequity and violence. For this reason, we oppose the proposed rule.

Discrimination in healthcare and insurance coverage negatively impacts TGNCI people

The TGNCI community faces significant and oftentimes lethal barriers when attempting to access adequate healthcare. From our work, we are intimately familiar with the ways that discriminatory and hostile treatment, whether from insurance providers or the medical community, play a role. According to the 2015 U.S. Transgender Survey: New York State Report, 26% of respondents experienced a problem in the past year with their insurance that was directly related to being transgender. These issues include being denied coverage for care related to gender transition or being denied coverage for routine care because they were transgender.[1] Additionally, 32% of those who saw a healthcare provider in the past year reported having at least one negative experience related to being transgender.[2] These negative experiences ranged from verbal harassment, physical or sexual assault, having to teach the provider about transgender people in order to get appropriate care, or being refused treatment altogether. Everyone has the right to receive safe and medically appropriate care, including TGNCI people. These barriers obviously place undue burdens on TGNCI communities and prevent them from accessing their right to life-affirming medical care.

There are concrete and severe consequences of healthcare discrimination for TGNCI individuals, and healthcare discrimination contributes to the disproportionate rates of adverse health outcomes that TGNCI people overwhelmingly experience. Nearly one in four TGNCI people report postponing or avoiding the healthcare they need due to fear of being disrespected or mistreated as a transgender person.[3] This statistic is especially disturbing given that transgender people are at greater risk for depression, suicidality, and HIV and other sexually transmitted infections,[4] and that many transgender people also need specific and medically necessary interventions in order to survive.

In addition to the aforementioned need for medical intervention for some TGNCI people, TGNCI people, especially those who are low-income and of color, are disproportionately more likely to be living with HIV/AIDS. In 2017, the CDC reported that the percentage of transgender people who received a new HIV diagnosis was three times the national average, and cited discrimination in healthcare as a contributing reason.[5]

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[1] *2015 U.S. Transgender Survey: New York State Report.* (2017). Washington, DC: National Center for Transgender Equality.
[2] *Ibid.*
[3] James, S. E., Herman, J. L., Rankin, S., Keisling, M., Mottet, L., & Anafi, M. (2016). *The Report of the 2015 U.S. Transgender Survey.* Washington, DC: National Center for Transgender Equality.
[4] *Ibid.*
[5] *HIV and Transgender People.* Centers for Disease Control and Prevention, 4 June 2019, www.cdc.gov/hiv/group/gender/transgender/index.html. Accessed 6 Aug. 2019.

Recent studies also found that delaying or avoiding care due to fear of discrimination is significantly associated with poorer health outcomes in transgender adults[6] and that about one in four transgender people report using drugs or alcohol in order to cope with mistreatment.[7]

Moreover, for many individuals, there is no option to find another provider when discrimination happens. A 2017 study by the Center for American Progress reported that nearly one out of every three transgender people would find it very difficult or impossible to find an alternative provider should they be denied care.[8] We hear many reasons as to why finding alternatives is sometimes impossible. For our immigrant communities who are Limited English Proficient (LEP) in healthcare settings, it is difficult to find a competent provider who can communicate in their primary language. Rural communities lack sufficient providers in general, making it hard for TGNCI people to avoid providers who discriminate.[9] For our incarcerated community members, looking for alternatives is also impossible since they are in state or federal custody.

Individual stories from our clients and members underscore the negative impacts of healthcare discrimination on their lives and the positive impacts of accessing equitable care, while also demonstrating the resilience of the TGNCI community in spite of the systemic inequities they endure:

> *I recently had an experience with a provider who did not give me the transition-related medication I needed. I was forced to seek alternative resources to get necessary care.* ***Finding affirming care has been critical to my well-being****. It has allowed me to accept myself. -Remie*
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> *We need more access to services…we need access to hormones and hormone therapy, and hormones shouldn't be denied. We also need access to surgeries. We need access to therapists and psychiatrists. It's hard to find them and we really need therapists to talk about what it's like to be trans….* ***When I can't go to therapy, I get depressed and anxious****. -Sadaya*
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> *People with developmental disabilities are given CCO's (Care Coordinated Organizations). They are not person-centered, they're overloaded with cases, and* ***they are not taking into consideration special populations like LGBTQ [people] with***

[6] Seelman, Kristie L, et al. *Transgender Noninclusive Healthcare and Delaying Care Because of Fear: Connections to General Health and Mental Health Among Transgender Adults*. U.S. National Library of Medicine, 1 Feb. 2017, www.ncbi.nlm.nih.gov/pmc/articles/PMC5436369/. Accessed 6 Aug. 2019.

[7] Safer, Joshua D, et al. *Barriers to Healthcare for Transgender Individuals*. U.S. National Library of Medicine, 1 Apr. 2016, www.ncbi.nlm.nih.gov/pmc/articles/PMC4802845/. Accessed 6 Aug. 2019.

[8] Mirza, Shabab Ahmed, and Caitlin Rooney. *Discrimination Prevents LGBTQ People from Accessing Health Care*. Center for American Progress, 18 Jan. 2018, www.americanprogress.org/issues/lgbt/news/2018/01/18/445130/discrimination-prevents-lgbtq-people-accessing-health-care. Accessed 6 Aug. 2019.

[9] Toliver, Zachary. *LGBTQ Healthcare: Building Inclusive Rural Practices*. Rural Health Information Hub, 4 May 2016, www.ruralhealthinfo.org/rural-monitor/lgbtq-healthcare/. Accessed 6 Aug. 2019.

developmental disabilities. *Right now we have a choice, but I fear in the future we won't... as it is the system is broken, we don't need to break it more. -Danielle*

[My doctors] treat me as if I had no rights. As if I weren't human. Many times ***my doctors have refused to treat my asthma and diabetes.*** *They allege my problems are mental, they dismiss the symptoms I describe to them and mock me because I am trans. -Emperatris*

I hate when doctors misgender me...they call me by my birth name...my name is legally changed and they still disrespect me. ***I don't like going to the doctors because they discriminate against me****. -Sheneeneh*

I was consistently misgendered, and being unable to access hormones affected my mental health and made it impossible for me to work. ***The ability to access medically-necessary care saved my life.*** *-Stephanie*

On top of the profound harm caused to TGNCI people, healthcare discrimination also imposes costs on the state and works to offset any calculated savings from denying TGNCI people care or making it more difficult for TGNCI people to claim their rights. TGNCI people who delay care may require significantly more expensive treatment once symptoms become acute. When coverage is denied, low-income TGNCI people who lack the ability to pay out-of-pocket may be forced into desperate situations, such as engaging in crimes of survival that lead to increased risk of arrest, incarceration, or detention by ICE or deportation. The proposed Section 1557 rule cites financial savings as a supporting factor but makes no mention of the very real economic impacts that discrimination has on our communities.[10]

Proposed changes to the Section 1557 rule will threaten lives and cause confusion

The ACA was a significant development in healthcare legislation not only because it provided health insurance to so many otherwise uncovered Americans, including TGNCI Americans, but also because it was the first law to apply broad-based nondiscrimination protections to healthcare providers and insurers, filling important gaps in nondiscrimination law. The removal or modification of provisions around applicability, definitions, taglines, notices, and enforcement will put TGNCI lives, and the lives of other marginalized communities, at risk of increased discrimination when trying to access safe, medically necessary healthcare. These changes will also cause confusion among providers, insurers, and patients about their rights.

[10] Nondiscrimination in Health and Health Education Programs or Activities. 84 FR 27846 § I.D. (June 14, 2019). *Federal Register: The Daily Journal of the United States.*

Applicability

By narrowing the applicability of Section 1557, the proposed rule opens the door for insurance companies to resume harmful practices towards TGNCI people. Prior to the ACA, many health insurers, driven by market forces and sometimes by ideological reasons, engaged in discrimination by excluding coverage of medically necessary treatment and designed insurance plans that discouraged vulnerable populations from enrolling. While we fought hard to ensure state-level protections in our state's Medicaid program in New York,[11] we recognize that 25 states still do not have these protections and that seven states have Medicaid policies that explicitly exclude transgender people, even with Section 1557 in place.[12] As stated above, discriminatory practices in healthcare coverage have particularly devastating effects on TGNCI people, who may have higher health needs than the general population.

Furthermore, many TGNCI people rely on health insurance as the only way to access the care they need. Paying out of pocket for medically necessary care is simply not an option for most low-income TGNCI individuals. Indeed, with U.S. healthcare costs the highest in the world,[13] health insurance is a gatekeeper to care for all except the most privileged among us, regardless of who we are. To interpret health insurers as exempt from nondiscrimination protections because they are "not principally engaged in providing healthcare"[14] is cruel and absurd logic.

Definitions

By removing definitions for gender identity and sex stereotyping, the proposed rule not only makes it easier for providers to discriminate against TGNCI and LGBTQ people, it also contradicts well-established and long-standing jurisprudence. Decisions from *Prescott v. Rady Children's Hospital, Flack v. Wisconsin Dept. of Health Services, Boyden v. Conlin,* and *Tovar v. Essentia Health* have all affirmed the fact that gender identity and sex stereotyping protections are inherent to the law itself and are *not* open to interpretation.[15] The proposed rule therefore sends dangerous and inaccurate messages to providers, and will generate confusion about what is and is not legally permissible.

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[11] Cruz v. Zucker, 218 F. Supp. 3d 246 (S.D.N.Y. 2016)

[12] *Equality Maps: Healthcare Laws and Policies.* Movement Advancement Project, www.lgbtmap.org/equality-maps/healthcare_laws_and_policies. Accessed 6 Aug. 2019

[13] Papanicolas, Irene, et al. *Health Care Spending in the United States and Other High-Income Countries*. JAMA: The Journal of the American Medical Association. 13 Mar. 2018, www.jamanetwork.com/journals/jama/article-abstract/2674671. Accessed 6 Aug. 2019

[14] Nondiscrimination in Health and Health Education Programs or Activities. 84 FR 27846 (June 14, 2019). *Federal Register: The Daily Journal of the United States.*

[15] Prescott v. Rady Children's Hosp.-San Diego, 265 F. Supp. 3d 1090 (S.D. Cal. 2017).
Flack v. Wis. Dept. of Health Servs., 328 F. Supp. 3d 931 (W.D. Wis. 2018).
Boyden v. Conlin, 341 F. Supp. 3d 979 (W.D. Wis. 2018).
Tovar v. Essentia Health, 342 F. Supp. 3d 947 (D. Minn. 2018).

Taglines, notices, and enforcement

The existing rule requires that taglines and notices be provided and translated into the 15 most-used languages within a state. Taglines provide critical information to individuals with LEP on how to get assistance with their care should they need it (e.g., the proper way to administer a particular medication) while notices provide all people, not only those with LEP, with information about their rights.

Removing language access protections affects a significant amount of people. As of 2013, 2.5 million people in New York, or 10% of the state's population at the time, were individuals with LEP.[16] At SRLP, about 30% of our clients rely on language interpretation support in order to navigate complex administrative systems and gain access to life-affirming and life-saving services. Without language support, our clients are denied the same access to these services as everyone else.

By removing requirements to provide taglines and notices, as well as eliminating any mechanism for administrative redress via the Office for Civil Rights, the proposed rule disadvantages individuals with LEP who deserve equal standards of care as their English-proficient counterparts. These changes also raise hurdles that prevent all individuals from knowing, accessing, and asserting their rights. These hurdles are all the more substantial for members of our community who already face barriers to equal care and who may lack the resources necessary to go to court. Ultimately, limiting the remedies available for people who experience injustice undermines the intent of civil rights law.

Conclusion

All people, regardless of who they are, should be able to access the healthcare they need without fear of disrespect, mistreatment, harassment, or outright denial of care. Even though Section 1557 remains the law, the existing Section 1557 rule plays a vital role in deterring discriminatory behaviors against TGNCI people and providing stronger legal recourse should such discrimination occur. The combined effect of the changes in the proposed rule work to sabotage these protections and put an already vulnerable population at greater risk of harm by creating another path to discrimination.

SRLP also stands in solidarity with other individuals who will be adversely impacted by the proposed rule and who are already more likely to experience inequitable treatment within our healthcare system. This includes LGBTQ people more broadly, cisgender women, people living

[16]Zong, Jie, et al. *The Limited English Proficient Population in the United States*. Migration Policy Institute, 8 July 2015, www.migrationpolicy.org/article/limited-english-proficient-population-united-states#Distribution by State. Accessed 6 Aug. 2019

with a chronic illness and/or disability, and people who may have limited English proficiency in healthcare settings. Individuals at the intersections of two or more of these experiences may face compounded and particular types of discrimination that are not adequately addressed by other nondiscrimination laws. The provisions that are being modified or removed in the proposed rule work in tandem and are critical to an interpretation of Section 1557 that protects *all* of us.

Given the disparities that TGNCI people face in access to care, healthcare treatment, and health outcomes, HHS should focus its efforts on ensuring equitable and competent healthcare for TGNCI people rather than looking for ways to remove protections. For these reasons, SRLP opposes the proposed changes to the Section 1557 rule and urges HHS to leave the current rule in place.

SRLP thanks HHS and the Office for Civil Rights for the opportunity to submit this comment.

Sincerely,

Hannah Walker, Esq.
Director, Survival and Self-Determination Project
Staff Attorney

Sam Barrak
Intern, Survival and Self-Determination Project

Sylvia Rivera Law Project
147 W 24th Street 5th Floor
New York, NY 10011
212-337-8550