



March 30, 2017

The Honorable Thomas E. Price, M.D.
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Roger Severino
Director, Office for Civil Rights
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Robust Enforcement of Section 1557 is Needed

Dear Secretary Price and Director Severino:

On behalf of The Leadership Conference on Civil and Human Rights, a coalition of more than 200 national organizations committed to promoting and protecting the civil and human rights of all persons in the United States, and its Health Care Task Force, we are writing to **urge robust enforcement of Section 1557, the anti-discrimination provision of the Affordable Care Act (ACA)**. The Leadership Conference includes organizations representing Americans who are African-American, Latino, Asian American and Pacific Islander, Native American, women, students, people with disabilities, seniors, young people, LGBTQ, immigrants, people of different faiths, and members of labor unions, and is committed to reducing disparities in health and health care and ultimately achieving equity in both arenas. Our members are strong supporters of Section 1557 and have advocated for its full and complete implementation since its enactment in 2010.

Access to health care is a civil and human right and the opportunity to access quality health care and live a healthy life must be equally available to all and not selectively reserved for a few. Under longstanding laws and principles that have been enforced across Democratic and Republican administrations, entities that receive federal funds are barred from discriminating in the services they provide. It is a core principle of our democracy that federal funds may not be used to subsidize discrimination in programs that serve the American people.

Section 1557 represents the application of that principle in the context of health care and is a major federal civil rights law that is critical to ensuring that everyone in America has access to quality, affordable health insurance coverage and health care. As you know, since it took effect on March 23, 2010, Section 1557 has prohibited discrimination on the basis of race, color, national origin, sex, age, or disability in health programs or activities that receive federal financial assistance or are administered by an executive agency or any entity established under Title I of the ACA. This includes, for example, health care providers receiving federal financial insurance such as Medicare and Medicaid providers; health insurers participating in federally facilitated and state-based Marketplaces; and health

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programs administered by the Department of Health and Human Services. Section 1557 explicitly requires enforcement of its provisions.

The work of the Office for Civil Rights (OCR) is essential to ensuring that all people can lead healthy lives free of discriminatory barriers. OCR has implementation and enforcement authority under Section 1557, and during the previous administration, the agency issued a final regulation interpreting Section 1557 and accepted, investigated, and resolved discrimination complaints alleging violations under Section 1557. In addition, OCR engaged in robust outreach and education efforts with individuals, community organizations, and providers regarding their rights and responsibilities under Section 1557. Importantly, OCR encouraged anyone who believed a violation of Section 1557 to have occurred to contact the agency to file a complaint.

These efforts are important because discrimination in health coverage and care prevents many individuals from getting the care they need to stay healthy and directly contributes to health care disparities in the communities we represent. Such discrimination can take many forms and can occur at every step in the health care system, from obtaining insurance coverage to receiving a proper diagnosis and treatment. For example:

- People of color (including nonelderly Asians, Hispanics, Blacks, and American Indians and Alaska Natives) are more likely to face increased barriers accessing care compared to Whites.ⁱ People of color also are less likely than Whites to utilize care and fare worse than Whites on many measures of health status and health outcomes.ⁱⁱ
- Despite declines in the uninsured rate for all racial and ethnic groups since implementation of the ACA, nonelderly Hispanics, Blacks, and American Indian and Alaska Natives (AIANs) remained more likely than Whites to be uninsured as of 2015.ⁱⁱⁱ
- The Institute of Medicine (IOM) noted in 2007 that between 40 million and 50 million people in the U.S. report some kind of disability. That number will likely grow significantly in the next 30 years as the baby boom generation enters later life, when the risk of disability is the highest. People with disabilities experience significant health disparities and barriers to health care, as compared with people who do not have disabilities.^{iv} In fact, people with disabilities are 2.5 times more likely to have unmet health care needs than non-disabled peers.
- One of the ways in which Section 1557, and OCR's enforcement of it, has been most transformative is with regard to its prohibition of sex discrimination. Section 1557 was the first federal statute to bar discrimination on the basis of sex in federally funded health care and health coverage, and its protections have been critical in ensuring equal access to health benefits by both men and women. The law has been used to address, for example, exclusions of maternity coverage from the benefits provided to certain female plan participants. Treating pregnancy differently, such as by excluding pregnancy care from an otherwise comprehensive insurance plan, is sex discrimination under civil rights laws such as Title IX and Title VII, and also sex discrimination under Section 1557.^v

No less important, the regulation implementing Section 1557 makes explicit that the statute covers discrimination based on sex stereotyping and gender identity. These are critical protections because the record shows that LGBT individuals consistently face health care discrimination, including verbal abuse, physical abuse, and outright refusals of treatment. This is especially true for transgender and gender nonconforming individuals. The National Transgender Discrimination Survey, the largest survey to date of transgender people in the United States, revealed that transgender and gender nonconforming people seeking health care were denied equal treatment in doctors' offices and hospitals (24 percent), emergency

rooms (13 percent), mental health clinics (11 percent), by EMTs (5 percent) and in drug treatment programs (3 percent).^{vi} Moreover, Latino/a transgender individuals reported the highest rate of unequal treatment of any racial category (32 percent by a doctor or hospital and 19 percent in both emergency rooms and mental health clinics). Such discrimination in treatment can lead to death,^{vii} prolong painful conditions,^{viii} and exacerbate underlying conditions.^{ix}

While we are dismayed that OCR's enforcement of provisions of the regulation covering gender identity discrimination has been preliminarily enjoined, we are gravely concerned that prior statements made by Director Severino manifest his view that protections for transgender people from discrimination in health care amount to "special privileges" and that OCR has overreached in its protections for this vulnerable population. Particularly because health care can involve situations that literally mean the difference between life and death, it is deeply troubling to us that a Director of this critical civil rights enforcement agency would endorse this view. Moreover, we believe that this position is unsupported by the law, which – as OCR explained at length in its final regulation – clearly covers both gender identity discrimination and sex stereotyping as forms of prohibited sex discrimination. We call on the Department to aggressively defend that interpretation in court and to apply all regulatory provisions to the full extent consistent with court decisions.

As a general matter, we appreciate the strides that HHS has made in the past to advance the requirements of nondiscrimination. These efforts must continue. Specifically, we believe OCR must:

- Vigorously enforce laws that protect individuals' access to health care;
- Investigate systemic discrimination; and
- Continue to provide technical assistance and engage in outreach to ensure that all stakeholders understand their rights and responsibilities.

All individuals need to be protected from discrimination in health coverage or care. Thus, we expect HHS to fully enforce the law. If you have any questions or would like to discuss this matter further, please contact Leadership Conference Health Care Task Force Co-chairs Judith Lichtman at the National Partnership for Women & Families (jlichtman@nationalpartnership.org) and Mara Youdelman at the National Health Law Program (youdelman@healthlaw.org), or Leadership Conference Managing Policy Director Corrine Yu (yu@civilrights.org).

Sincerely,



Wade Henderson
President & CEO



Nancy Zinkin
Executive Vice President



Judith L. Lichtman
Chair

ⁱ Samantha Artiga, et al., *Key Facts on Health and Health Care by Race and Ethnicity*, (Washington, DC: Kaiser Family Foundation, June 2016), <http://files.kff.org/attachment/Chartpack-Key-Facts-on-Health-and-Health-Care-by-Race-and-Ethnicity>.

ⁱⁱ Id.

ⁱⁱⁱ Id.

^{iv} See, e.g.: The National Council on Disability, (2009). *The Current State of Health Care for People with Disabilities*. Retrieved from website: <http://www.ncd.gov/publications/2009/Sept302009>;

Reis, J. P., Breslin, M. L., Iezzoni, L. I., & Kirschner, K. L. (2004). *It Takes More Than Ramps to Solve the Crisis of Healthcare for People with Disabilities*. Informally published manuscript, Rehabilitation Institute of Chicago, Chicago, IL, Retrieved from www.tvworldwide.com/events/hhs/041206/PPT/RIC_whitepaperfinal82704.pdf.

^v See, e.g., Nat'l Women's Law Ctr., *NWLC Section 1557 Complaint: Sex Discrimination Complaints Against Five Institutions*, <http://www.nwlc.org/resource/nwlc-section-1557-complaint-sex-discrimination-complaints-against-five-institutions> (last visited Sept. 17, 2013) (Section 1557 complaints filed against five institutions that exclude pregnancy coverage for plan beneficiaries who are dependent children of employees at institutions).

^{vi} Jaime M. Grant et al., *Injustice at Every Turn: A Report of the National Transgender Discrimination Survey 73* (2011) available at http://transequality.org/PDFs/NTDS_Report.pdf.

^{vii} In 1995, a transgender woman bled to death after paramedics halted emergency treatment for her serious injuries resulting from an automobile accident when they discovered she was transgender. Anne C. DeCleene, Note, *The Reality of Gender Ambiguity: A Road Toward Transgender Health Care Inclusion*, 16 *Law & Sex*. 123, 137 (2007).

^{viii} According to a recent report, one transgender patient was forced to wait two hours in pain in the emergency room without treatment for injuries sustained from a fall on ice after the health care provider discovered she was transgender. Jaime M. Grant et al., *Injustice at Every Turn: A Report of the National Transgender Discrimination Survey 73* (2011) available at http://transequality.org/PDFs/NTDS_Report.pdf.

^{ix} Patients with HIV are particularly susceptible to sudden declines in health, and denial of or substandard treatment puts them at increased risk. For patients with HIV, missing as few as two doses of medication can have a significant impact on maintenance of proper medication levels. See generally R.J. Smith, *Adherence to Antiretroviral HIV Drugs: How Many Doses Can You Miss Before Resistance Emerges?*, 273 *Proc. Royal Soc'y B* 617, 621 (2006).