IN THE UNITED STATES DISTRICT COURT FOR THE DISTRICT OF COLUMBIA

WHITMAN-WALKER CLINIC, INC., et al.,

Plaintiffs,

v.

Case No. 1:20-cv-1630

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, et al.,

Defendants.

DECLARATION OF NASEEMA SHAFI, CEO, WHITMAN-WALKER HEALTH

- I, Naseema Shafi, declare as follows:
- 1. I am the Chief Executive Officer of Whitman-Walker Clinic, Inc., d/b/a Whitman-Walker Health ("Whitman-Walker"). I received a J.D. degree from the University of Maryland School of Law in 2005. I have served at Whitman-Walker for more than thirteen years, first as a Compliance Analyst and Director of Compliance; then as Chief Operating Officer, and subsequently as Deputy Executive Director. I assumed the CEO position in January 2019.
- 2. I am submitting this Declaration in support of Plaintiffs' motion for a preliminary injunction to prevent the revised regulation under Section 1557, published by the U.S. Department of Health and Human Services ("HHS") on June 19, 2020 (the "Revised Rule"), from taking effect.
- 3. The mission of Whitman-Walker is to offer affirming community-based health and wellness services to all with a special expertise in lesbian, gay, bisexual, transgender, queer and questioning (LGBTQ) and HIV care. We empower all persons to live healthy, love openly, and achieve equality and inclusion.
 - 4. Whitman-Walker was founded in 1973, and legally incorporated in 1978 to respond

to the health care needs of the LGBTQ community. In the early 1980s, we were one of the first nonprofit health clinics in the nation to respond to the HIV/AIDS epidemic. We became a Federally Qualified Health Center Look-Alike in 2007 and received full FQHC status in 2013. Our team provides a range of services, including primary medical care; HIV and lesbian, gay and bisexual (LGB) specialty care; medical, behavioral and care coordination services specific for transgender and gender expansive people;; behavioral-health services; dental services; legal services; insurance-navigation services; community health services that include HIV and STI testing; prevention counseling; women's health services; and youth and family support. These services are provided not only to people that live in Washington, DC, but also to people from neighboring states like Maryland and Virginia, and from across the region, including people from Pennsylvania, West Virginia and Delaware. Without nondiscrimination protections in health care, such as those contained in the 2016 Final Rule, many of these patients are unable to find nondiscriminatory, welcoming and competent care in their own communities.

- 5. In 2019, Whitman-Walker provided health care services to more than 20,760 individuals.
- 6. Whitman-Walker's patient population is incredibly diverse and reflects Whitman-Walker's commitment to being a health care home for individuals and families that have experienced stigma and discrimination, or have otherwise encountered challenges in obtaining affordable, high-quality health care. We are nationally known as experts in HIV and Hepatitis C specialty care and in gender-affirming care for transgender and gender expansive persons.
- 7. In 2019, more than 10% of the health care patients and clients we serve identified as transgender or gender expansive. Almost 45% of health care patients—60% of those who provided information on their sexual orientation—identified as lesbian, gay, bisexual, or otherwise

non-heterosexual. More than 9% of patients we served had limited English proficiency.

- 8. Whitman-Walker also employs a dynamic and diverse workforce that reflects the diversity of the populations we serve. At the present, we employ over 315 medical and behavioral-health providers and support staff, medical-adherence and insurance-navigation professionals, community health-workers, lawyers and paralegals, researchers, administrators, and professionals working in finance, development, human resources, and external affairs. We have employees of many races, ethnicities, genders, sexual orientations, religious and spiritual traditions, and life experiences. What unites us all is our shared commitment to creating and sustaining a welcoming, inclusive health care home for everyone who seeks our care.
- 9. Over the years, Whitman-Walker health care providers, lawyers and paralegals have encountered many instances of discrimination against our patients and legal clients by health care providers and staff outside of Whitman-Walker, based on sex assigned at birth, gender identity, transgender status, sexual orientation, HIV status, or actual or perceived ethnicity or immigration status. Our health care providers, lawyers, and other staff also have many years of experience advocating for patients with health insurance plans that discriminate against genderaffirming care, same-sex couples, and patients living with HIV or Hepatitis C who need specialized care. As such, Whitman-Walker was extensively involved in the proceedings that resulted in the rule published by HHS in May 2016 ("2016 Final Rule"), the Request for Information in 2013, and the Notice of Proposed Rulemaking in 2019.
- 10. Whitman-Walker receives various forms of federal funding from HHS and from institutions affiliated with or funded by HHS, including but not limited to funds under the Public Health Services Act ("PHSA"), direct grants, funding under the Ryan White Comprehensive AIDS Resources Emergency Act of 1990, 42 U.S.C. § 300ff et seq. ("Ryan White funding"), funds under

the 340B Drug Discount Program, research grants from the Centers for Disease Control and Prevention and the National Institutes of Health, and Medicaid and Medicare reimbursements. Whitman-Walker also receives funds from the Health Resources and Service Administration ("HRSA") and is a Federally Qualified Heath Center. In 2019, Whitman-Walker's federally funded research contracts and grants totaled more than \$7 million.

- 11. As an entity principally engaged in the business of providing health care that receives federal funding from HHS, Whitman-Walker is a "health program or activity" subject to the Revised Rule.
- 12. By eliminating the regulatory protections and clear guidance provided in the 2016 Final Rule, the Revised Rule presents a grave threat to the health and wellbeing of the patient population that we serve, most specifically LGBTQ patients and patients with LEP. The Revised Rule also frustrates our ability to provide referrals to our patients and imposes increased costs on Whitman-Walker.

Harms to Whitman-Walker's LGBTQ Patients

- 13. The Revised Rule eliminates the definition of "on the basis of sex" and the specific prohibition of discrimination on the basis of gender identity, transgender status, and sex stereotyping. The Revised Rule also eliminates specific provisions related to discrimination against transgender individuals, as well as the provision relating to the discrimination on the basis of association. The elimination of these provisions will result in direct harms to the LGBTQ patients that Whitman-Walker serves.
- 14. The LGBTQ patients and clients Whitman-Walker serves, especially Whitman-Walker's transgender and gender-expansive patients, already face particularly acute barriers to care and health disparities that will be compounded by the Revised Rule. It is quite likely that the

Revised Rule will result in a substantial increase in discrimination against LGBTQ individuals by health care providers and institutions outside of Whitman-Walker, as well as by health insurance companies.

- 15. Dr. Henn's and Dr. Pumphrey's declarations describe a number of incidents of discrimination that our patients have encountered in other health care facilities and offices that our patients have reported to our medical and behavioral health providers. In addition, the lawyers, legal assistants and volunteer attorneys in our Legal Services Department have learned of many similar incidents from their clients.
- Department. Our attorneys and legal assistants provide information, counseling, and representation to Whitman-Walker's patients, and to others in the community who are LGBTQ or living with HIV, on a wide range of civil legal matters that relate directly or indirectly to health and wellness including access to health care and discrimination based on HIV, sexual orientation, or gender identity. They also oversee legal clinics, staffed largely by volunteer attorneys, which assist transgender and gender-nonconforming individuals to change their legal names and to correct their birth certificates, driver's licenses, passports, Social Security records, and other identity documents to reflect their new names and actual gender identities.
- 17. Over the years, Whitman-Walker Legal Services staff and volunteer attorneys have encountered many instances of discrimination by health care providers and their staff based on the sexual orientation or gender identity of patients. Recent examples include:
 - a. As recounted in Dr. Henn's Declaration, Whitman-Walker transgender patients seeking gender affirming surgery have been rejected at local hospitals, even for procedures that are often performed on non-transgender patients (such as breast

- surgery), and even though the patients had health insurance or were otherwise able to pay for the procedures.
- b. In one instance, a health care worker at a dialysis clinic confronted a Whitman-Walker patient with end-stage renal disease and objected to being involved in the patient's care because of hostility to his sexual orientation.
- c. In another case, a transgender woman who was about to have surgery at a Washington, DC hospital for an inner ear condition (unrelated in any way to her transgender-related health care) was confronted and harassed by hospital staff objecting to her gender identity. She was repeatedly and intentionally referred to as "he" and as "a man" by staff in the radiology department when she went for a pre-surgical scan; by desk staff at the surgery center; and by the nurse preparing her for surgery. Several nurses talked about her with each other and laughed. One staff person refused to talk with the patient when she addressed them. Even the anesthesiologist who she was expected to entrust with her life in one of her most vulnerable moments before surgery, mocked her and intentionally referred to her as a man. Health care providers are supposed to provide comfort to patients when they seek health care. Instead, the staff increased her fear just before her surgery because they showed complete disrespect and lack of care for the patient's health and wellbeing.
- d. Another transgender woman went to the office of an ophthalmologist at the same medical center for an eye exam. She arrived on time, filled out the initial paperwork, and then waited for about 45 minutes without being called for her appointment. The patient went to the desk to inquire, and was treated rudely by

the staff. The staff then arbitrarily called a security guard to eject her from the office. As the patient spoke to the security guard, one of the clinic staff came to her and said, loudly and offensively, "Sir, your kind needs to go away. We're not serving your kind." She complained to the Office of the Chief Medical Officer and was eventually seen by the ophthalmologist on another day, after considerable effort by her and Whitman-Walker staff.

- e. A transgender woman was seen by a medical provider at Whitman-Walker, who examined her and determined she might have broken her ankle. She was sent to the Emergency Room at a Washington, DC hospital. She identified herself to the ER check-in staff as a woman and presented a driver's license that contained a female gender marker. She then waited for a number of hours (she remembers five or six) without being examined. When she inquired about the delay, she was treated rudely and misgendered by ER staff. She was finally called from the waiting area, but was taken to the men's dressing room, rather than the area for women patients, to undress and put on a gown for a scan. During the four or more hours before she received the scan, examination and treatment, she suffered very significant physical pain.
- 18. By eliminating the explicit protections against discrimination based on gender identity, transgender status, and failure to conform with sex stereotypes, the Revised Rule invites an increase in discriminatory experiences for LGBTQ patients seeking health care services, such as those documented above. This result in harm to the patients and community that Whitman-Walker serves.
 - 19. The discriminatory experiences LGBTQ patients have with other health care

providers erode patients' trust in health care providers overall and thus also challenges the ability of Whitman-Walker to treat its patients effectively and provide appropriate services and referrals.

- 20. The Revised Rule also empowers religiously-motivated discriminatory behavior by health care providers that is corrosive to fundamental professional standards, threatens patients' welfare, and places a significant strain on our ability to fulfill our critical mission. For example, the Revised Rule undermines our ability to provide referrals and our patients' ability to access health care. A significant amount of medical care in the United States is provided by religiously affiliated hospitals. This is illustrated by the fact that more than one in every six hospital beds in the country are in religiously-affiliated hospitals. To the extent that the Revised Rule leads these institutions (or even a fraction of the medical professionals and staff at these institutions) to rely on the Rule's broad religious exemptions and refuse to provide care to LGBTQ patients, many patients will be left without other treatment options and there will be fewer specialists to whom we can refer our patients and feel confident that we are not exposing our patients to religiously-motivated discriminatory behavior.
- 21. The discrimination invited by the Revised Rule will also encourage LGBTQ patients to remain closeted to the extent possible when seeking medical care outside Whitman-Walker. When patients remain closeted to a health care provider, however, they are exposed to significant adverse health consequences. For instance, a patient who conceals or fails to disclose a same-sex sexual history may not be screened for HIV or other relevant infections or cancers, or may not be prescribed preventative medications such as PrEP, which is extremely effective at preventing HIV transmission. Patients who fail fully to disclose their gender identity and sex

¹ Julia Kaye, et al., Am. Civil Liberties Union, *Health Care Denied: Patients and Physicians Speak Out About Catholic Hospitals and the Threat to Women's Health and Lives* (Mar. 2016), https://www.aclu.org/sites/default/files/field_document/healthcaredenied.pdf.

assigned at birth may not undergo medically indicated tests or screenings (such as tests for cervical or breast cancer for some transgender men, or testicular or prostate cancer for some transgender women).

- 22. Furthermore, at a time of public health crisis such as the present COVID-19 pandemic, the delay of necessary health care for fear of discrimination will make it harder for health care providers to help stem the pandemic, thereby potentially exposing more people to COVID-19, to which LGBTQ people are already more vulnerable.
- 23. The Revised Rule further notes that covered entities are not discriminating on the basis of sex if they refuse to use a transgender patient's pronouns consistent with their gender identity; refuse them access to sex-specific facilities that are consistent with their gender identity and instead forces them into facilities/shared rooms based on the sex they were incorrectly assigned at birth; and identifies them by the sex they were incorrectly assigned at birth such as on patient identification bracelets and any signage outside the patient's room. These discriminatory actions, which as documented above, have been experienced by Whitman-Walker's patients at other health care facilities, are inconsistent with the 2016 Final Rule and Section 1557 of the Affordable Care Act. They are also detrimental to transgender patients' health and wellbeing, and can lead to significant distress.
- 24. Whitman-Walker medical and behavioral health providers, care navigators and attorneys assist hundreds of transgender patients every year to navigate private health plans, Medicaid, and Medicare to obtain the gender-affirming services that they need—including a wide range of surgical procedures and hormone therapy. Many private and public plans continue to resist coverage of medically necessary procedures—if not through blanket exclusions of "sex change" or "sex transition" procedures, then through denials of coverage of specific procedures.

- 25. The 2016 Final Rule, which prohibits "categorical coverage exclusion[s] or limitation[s] for all health services related to gender transition" and denials, limitations, or restrictions "for specific health services related to gender transition if such denial, limitation, or restriction results in discrimination against a transgender individual," 81 Fed. Reg. at 31,472 (formerly codified as 45 C.F.R. § 92.207(b)), has been very valuable in persuading Medicaid administrators, insurance company personnel, and employee health plan sponsors to eliminate outdated exclusions and to agree to cover procedures when supported by evidence of medical necessity.
- 26. These provisions and others that specify insurance practices and plan features that constitute forms of unlawful discrimination provide useful guidance, not only for consumers and others advocating on their behalf including health care providers like Whitman-Walker who assist patients in determining coverage of health care being provided or contemplated but also for health insurance companies and plan administrators. For example, one of our Legal Services attorneys used the 2016 Rule to persuade a client's union health plan to eliminate a discriminatory exclusion and cover his mastectomy and chest reconstruction. The attorney also relied on the 2016 Rule to successfully overturn a Blue Cross company's denial of coverage of a transgender client's breast augmentation and genital surgery.
- 27. Based on Whitman-Walker's experience, the Revised Rule, which eliminates the aforementioned provisions, invites health plans to discriminate through the exclusion of gender-affirming procedures, which in turn threatens transgender patients who suffer from crippling gender dysphoria, and through the reinstitution of insurance practices regarding the "tiering" of certain drugs (e.g., to determine co-pays or cost-sharing ratios) that are of great concern to patients living with HIV or other medical conditions or disabilities that require expensive treatments.

- In addition, the Revised Rule perplexingly exempts many forms of health insurance from Section 1557, subjecting LGBTQ patients who rely on those forms of insurance to discrimination based on sex assigned at birth, gender identity, transgender status, sexual orientation, race, national origin, age, or disability. For example, under the Revised Rule, "an entity principally or otherwise engaged in the business of providing health insurance shall not, by virtue of such provision, be considered to be principally engaged in the business of providing healthcare." 85 Fed. Reg. at 37244–45 (to be codified as 45 C.F.R. § 92.3(c)). The Revised Rule also excludes HHS health-related programs and activities from Section 1557, unless the programs were established under Title I of the ACA. This limitation would affect numerous health-related programs and activities, including those of the Centers for Medicare and Medicaid Services. The narrowing of covered entities under Section 1557 will result in discrimination against LGBTQ patients, who already face disproportionate barriers to accessing appropriate care, and eliminate LGBTQ patient's remedies to address such discrimination.
- 29. In sum, the Revised Rule will exacerbate the acute health disparities LGBTQ people already face and send the message that discrimination on the basis of gender identity, transgender status, sexual orientation, and failure to conform with sex stereotypes is permissible under federal law, which will increase the number of Whitman-Walker's LGBTQ patients who will be denied care outside Whitman-Walker.

Harms to Whitman-Walker's LEP Patients

30. As noted above, Whitman-Walker serves hundreds of LEP patients in any given year. Language access protections for LEP patients are essential to ensuring that LEP patients receive adequate care, understand their rights, and are able to communicate fully and effectively with their health care providers. Whitman-Walker has found the clear guidance provided by the

2016 Final Rule to be helpful in improving the health and wellbeing of our LEP patients as they obtain care at Whitman-Walker and elsewhere.

- 31. The Revised Rule, however, eliminates the requirement that covered entities take reasonable steps to provide meaningful access to "each individual with LEP eligible to be served or likely to be encountered" and replaces it with a general reference to "LEP individuals." See, e.g., 85 Fed. Reg. at 37,245. Focusing on LEP individuals in general as opposed to each individual will result in some individuals not receiving the services they need for meaningful access, and thereby result in more acute health problems and outcomes for patients and raises concerns about patient safety.
- 32. The weakening of protections for LEP individuals will harm Whitman-Walker's LEP patients who get care elsewhere or are referred to providers outside our organization for specialty care, as they will no longer benefit from the notices, taglines, and additional language access provisions that are critical to ensure meaningful access to care. The Revised Rule will thus diminish or eliminate meaningful access to health care for Whitman-Walker's LEP patients, who will not be aware of their rights or the programs or services available to them when they go to other health care facilities.
- 33. Whitman-Walker will face increased burdens due to fewer clients being aware of their language access rights and the likelihood that more people will turn to Whitman-Walker for help in their language, rather than other covered health care providers. Whitman-Walker will also be burdened with increased costs because its patients will come to us sicker as a result of inadequate care elsewhere.

Additional Harms to Whitman-Walker

34. Escalating health care discrimination and fear of such discrimination, resulting

from the Revised Rule, is likely to result in increased demand for Whitman-Walker's health care services, which will present considerable operational and financial challenges. Many of Whitman-Walker's health care services lose money due to low third-party reimbursement rates and indirect cost reimbursement rates in contracts and grants which are substantially less than Whitman-Walker's cost of service. Increased demand for Whitman-Walker's health care services, driven by increased discrimination and fear of discrimination outside of Whitman-Walker, would exacerbate that pressure. We likely will be called upon to see more patients, and that patient care does not financially cover itself. As a result, Whitman-Walker may not be able to meet the increased demand and sustain the additional financial burdens resulting from an increased load of patients who either fear discrimination elsewhere or who were discriminated against or denied services at other institutions.

- 35. In addition, Whitman-Walker has large numbers of patients who require genderaffirming care, including hormone therapy and affirming, supportive mental health services. To
 the extent that the Revised Rule results in insurance plans and insurance companies reducing their
 coverage of such therapies, Whitman-Walker itself as well as our patients will be directly
 harmed by reduced reimbursements. In order to sustain the care that these patients need, we will
 be forced to turn to other measures, such as increasing charges to the patients themselves, and
 increasing our reliance on fundraising and grant revenue (which already is stretched thin).
- 36. The operational and financial pressures we will likely experience due to increased demand for our services as discrimination, and fear of discrimination, mount in the LGBTQ and LEP communities, will come at a time when Whitman-Walker already is struggling with the challenges posed by the COVID-19 pandemic. Since March of this year, many of our services have temporarily closed, and other health care services are being provided entirely through telemedicine

rather than in-person. Telemedicine services are being reimbursed at rates substantially lower than in-person services. The resulting very significant decline in revenues, and the very great operational challenges posed by suspending many services and re-tooling others, are posing challenges unique in Whitman-Walker's history. It will be particularly difficult to respond to increased demand at this already-difficult time.

- 37. At the same time, given Whitman-Walker's mission to provide health care to marginalized communities, including the LGBTQ community and people living with HIV, Whitman-Walker needs to increase its education programs and community outreach to help those affected by the Revised Rule find the health care services that they need and assist them with their trauma resulting from the Revised Rule. Whitman-Walker needs to continue informing the community about its commitment to serving all patients in a nondiscriminatory and welcoming manner and notifying its patients that the Revised Rule will not change Whitman-Walker's commitment to providing exceptional health care services to all members of the community. Whitman-Walker will continue fighting for its patients' rights, including, for example, advocating on behalf of transgender patients who seek treatment for gender dysphoria, but who are rejected because of their sex assigned at birth and gender identity. As a result of the Revised Rule, Whitman-Walker will also need to devote more resources to working with outside providers and organizations to remind them of the importance of providing health care to all patients on non-discriminatory terms.
- 38. The Revised Rule also adversely impacts Whitman-Walker by necessitating a diversion and reallocation of resources in order to provide referrals to patients that it does not have the resources to treat either because Whitman-Walker has reached its capacity for new patients (especially in the behavioral-health departments) or because the patient requires treatment in a

specialty that Whitman-Walker does not offer. These types of referrals are routine at Whitman-Walker where its focus is on primary care and HIV-specialty care. The Revised Rule will make it significantly more difficult and resource-intensive for us to locate, monitor, and provide appropriate referrals. With an increase in referral requests as a result of the Revised Rule, Whitman-Walker will need to allocate additional staff time to pre-screen service referrals to ensure that staff are sending patients to LGBTQ-affirming, LEP-welcoming providers and not to providers who themselves or whose staff would cause additional harm to Whitman-Walker patients.

39. The impact on Whitman-Walker and its patients of a broad, legally unsupported expansion of health care providers' refusal rights is also particularly worrisome. Religiously affiliated hospitals and health care systems occupy a large and growing percentage of health care markets, and providing a broad exemption from Section 1557's nondiscrimination provisions will affect Whitman-Walker's ability to make referrals and result in increased expenditures. It will also cause unnecessary confusion.

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40. Health care systems should be safe places for everyone to seek care; where people's identities are affirmed, regardless of race, religion, sexual orientation, gender identity, disability, national origin, or other characteristics. It is Whitman-Walker's mission to offer affirming community-based health and wellness services to all, with a special expertise in LGBTQ and HIV care, and to empower all persons to live healthy, love openly, and achieve equality and inclusion. The Revised Rule frustrates our ability to live up to our mission by fostering discrimination against Whitman-Walker's LGBTQ patients, LEP patients, and others. The Revised Rule endangers the health, safety, and wellbeing of our patients; inhibits our ability to

provide them with the health care that they need, including the provision of referrals; increases the costs we must incur in order to provide our patients with adequate health care, as well as by the likelihood that more people will turn to Whitman-Walker to fill gaps in care and assistance caused by the Revised Rule; and imposes new compliance costs.

[Signature on next page.]

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I declare under penalty of perjury under the laws of the United States of America that the foregoing is true and correct.

Dated this Later day of July, 2020.

Naseema Shafi