

# United States Senate

WASHINGTON, DC 20510

October 3, 2022

The Honorable Xavier Becerra  
U.S. Department of Health and Human Services  
200 Independence Avenue SW  
Washington, DC 20201

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

Re: Comment on Notice of Proposed Rulemaking, RIN Number 0945-AA17, Nondiscrimination in Health Programs and Activities

Dear Secretary Becerra and Director Fontes Rainer:

We write in support of the Department of Health and Human Services' (the Department or HHS) proposed regulations implementing Section 1557 of the Affordable Care Act (ACA). Section 1557 of the ACA is a landmark health care civil rights law that prohibits discrimination on the basis of race, color, national origin (including language proficiency), sex (including sex stereotypes, sex characteristics, pregnancy status or related conditions, sexual orientation, and gender identity), age, and disability. Recent and ongoing threats to health care access underscore why eliminating discrimination in health care programs and activities remains such an essential goal. The Supreme Court's devastating decision in *Dobbs* upended abortion rights and left tens of millions of women without access to critical, lifesaving care and in danger of grave health consequences. The COVID-19 pandemic exposed and exacerbated existing health inequities, particularly in communities of color and for people with disabilities. And the transgender community is facing a barrage of discriminatory attacks that deny patients access to gender-affirming care and create barriers to treatment.

In the face of such obstacles, it is as important as ever that the Administration work to ensure everyone has the right to get the care they need—and undo the harm caused to patients by the Trump Administration's rule.

We applaud the Department's proposed regulation which helps to realize Congress's broad purpose in passing Section 1557: eliminating discrimination in health care. We appreciate that this proposed regulation restores protections for people who face significant barriers to quality, affordable health care, including women, people of color, and members of the LGBTQIA+ community. It further clarifies enforcement of important protections against discrimination, articulates important notice requirements, and promotes health equity and equitable coverage for historically underserved communities. Moreover, the Department's rule recognizes intersectional

discrimination, and makes important progress to reflect developments in civil rights case law and address confusion regarding compliance and enforcement of Section 1557.

This proposal is an important step forward to help ensure no one in our country has their health care undermined by discrimination or bigotry, and we urge the Department to further strengthen protections for people with disabilities, trans people, and people seeking to access care for pregnancy, infertility, or related conditions. We offer the following comments on the proposed rule.

### **The Proposed Rule Clarifies and Expands the Scope of Nondiscrimination in Covered Health Programs and Activities**

We applaud HHS for clarifying that the scope of Section 1557 covers an expansive range of programs and activities, consistent with Congressional intent. We support the Department's proposal to return to the 2016 interpretation that applies Section 1557 to all health programs and activities receiving funding from the Department or administered by the Department, such as state or federally-facilitated Exchanges, health insurance issuers that receive federal financial assistance, and third-party administrators like Pharmacy Benefits Managers.<sup>1</sup> We also support the proposed rule's expanded enforcement of nondiscrimination in health insurance coverage to include discriminatory health plan designs adopted by group health plans as well as marketing practices.<sup>2</sup>

We strongly agree with the Department's interpretation that Medicare Part B payments to health care providers and entities are federal financial assistance for the purposes of civil rights enforcement.<sup>3</sup> In practical effect, this clarification will ensure a single standard across Medicare providers that will reduce confusion and ensure that the nearly 65 million older adults and people with disabilities covered by the Medicare program have the same protections regardless of whether they receive care in a hospital, outpatient hospital, or physician's office.<sup>4</sup> These changes will be particularly important for ensuring access to care and language assistance services for the estimated 14 percent of Medicare beneficiaries with disabilities<sup>5</sup> and eight percent of Medicare beneficiaries who have limited English proficiency (LEP).<sup>6</sup>

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<sup>1</sup> Nondiscrimination in Health Programs and Activities, 87 Fed. Reg. 47824, 47838 (proposed Aug. 4, 2022) (to be codified at 42 CFR Parts 438, 440, 457, and 460).

<sup>2</sup> 87 Fed. Reg. at 47876, 47912 (Proposed § 92.4).

<sup>3</sup> *Id.* at 47887, 47912 (Proposed § 92.4); Katie Keith, "HHS Proposed Revised ACA Anti-discrimination Rule," HEALTH AFFAIRS (Jul. 27, 2022) <https://www.healthaffairs.org/content/forefront/hhs-proposes-revised-aca-anti-discrimination-rule>.

<sup>4</sup> CMS, May 2022 Medicaid and CHIP Enrollment Trends Snapshot, <https://www.medicaid.gov/medicaid/national-medicaid-chip-program-information/downloads/may-2022-medicaid-chip-enrollment-trend-snapshot.pdf>; ASPE Office of Health Policy, Issue Brief: Medicare Beneficiary Enrollment Trends and Demographic Characteristics, Mar. 2, 2022, <https://aspe.hhs.gov/sites/default/files/documents/f81aafbba0b331c71c6e8bc66512e25d/medicare-beneficiary-enrollment-ib.pdf>.

<sup>5</sup> ASPE Office of Health Policy at 7.

<sup>6</sup> CMS: Understanding Communication and Language Needs of Medicare Beneficiaries (Apr. 2017) <https://www.cms.gov/About-CMS/Agency-Information/OMH/Downloads/Issue-Briefs-Understanding-Communication-and-Language-Needs-of-Medicare-Beneficiaries.pdf>.

A new provision proposed by the Department seeks to eliminate the potential discrimination that patients may face when providers overly rely on algorithms in decision-making by replacing or substituting their clinical judgment.<sup>7</sup> Clinical algorithms, automated or augmented decision-making tools and models, including machine learning and artificial intelligence (AI), are useful tools to help diagnose and inform the health care services a person will receive. But, clinical algorithms can contribute to discrimination and bias against people of color and people with disabilities, from screening out certain populations for treatment priorities, to incorrectly focusing on health care costs as a proxy to care, to decreasing the quality of care patients receive.<sup>8</sup> While complex and ever-changing, we applaud the Administration for working to ensure entities' usage of algorithms do not perpetuate patterns of discrimination against marginalized and underserved communities, and to encourage more transparency and accountability in the development and use of algorithmic technologies.

We also support that the proposed rule clarifies prohibitions on discrimination in the delivery of health programs and activities through telemedicine—which includes videoconferencing, streaming media, terrestrial and wireless communications, and the internet.<sup>9</sup> The use of telemedicine has risen, particularly following the COVID-19 pandemic, and it is critical the Department ensure equitable access to telehealth services continues.<sup>10</sup>

### **The Proposed Rule Improves Communication Access Requirements and Processes**

We applaud HHS's restoration and expansion of communication access requirements, processes, and training, which would allow LEP individuals and people with disabilities to better access health care. The proposed rule would require covered entities to provide a notice of rights on an annual basis and upon request and outlines requirements for available language services and reasonable modifications for LEP individuals and people with disabilities.<sup>11</sup> Further, the proposed rule adds a definition and new requirements for machine translations and updates standards for video remote interpretation.<sup>12</sup>

The proposed rule includes additional changes that specifically support the LEP community. It restores requirements to provide meaningful access for LEP individuals and includes a nuanced definition of LEP that recognizes that a person who is competent in some communications may still require assistance in other contexts.<sup>13</sup> The rule also obligates entities to provide a qualified interpreter, which includes a limitation that relying on a minor child, family member, or friend

<sup>7</sup> 87 Fed. Reg. at 47880, 47918 (Proposed § 92.210).

<sup>8</sup> See e.g. Kara Manke, "Widely used health care prediction algorithm biased against black people, BERKELEY NEWS (Oct. 24, 2019) <https://news.berkeley.edu/2019/10/24/widely-used-health-care-prediction-algorithm-biased-against-black-people/>.

<sup>9</sup> 87 Fed. Reg. at 47884, 47918 (proposed § 92.211).

<sup>10</sup> Robert Pierce and James Stevermer, Disparities in use of telehealth at the onset of the COVID-19 public health emergency, JOURNAL OF TELEMEDICINE AND TELECare (Sept. 13, 2020)

[https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7578842/pdf/10.1177\\_1357633X20963893.pdf](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7578842/pdf/10.1177_1357633X20963893.pdf); Daniel Young and Elizabeth Edwards, Telehealth and Disability: Challenges and Opportunities for Care, NATIONAL HEALTH LAW PROGRAM (May 6, 2020) <https://healthlaw.org/telehealth-and-disability-challenges-and-opportunities-for-care/>.

<sup>11</sup> 87 Fed. Reg. at 47852, 47915 (Proposed § 92.10).

<sup>12</sup> *Id.* at 47912-13 (Proposed § 92.4).

<sup>13</sup> *Id.* at 47916-17 (Proposed § 92.201)

for interpretation can only be used as a temporary measure in an emergency until a qualified interpreter is found.<sup>14</sup> Language access remains a barrier to care for the over 26 million households in the U.S. who are LEP.<sup>15</sup> For example, recent studies suggest that LEP individuals—who are more likely to be Latino or Asian—have lower rates of COVID-19 vaccinations and have higher cases of COVID-19 infections, hospitalization, and deaths.<sup>16</sup>

In addition to improvements to language access, this proposed rule provides clear standards for effective communications and reasonable modifications that benefit the disability community.<sup>17</sup> Specifically, the proposed rule’s clarification of the scope of discrimination prohibited under Section 1557 to include telehealth and the accessibility of information and communication technology would reduce the barriers to care for people with disabilities. While there have been advancements in health care access for people with disabilities, entities still deny care or fail to provide the necessary supports and accommodations to people with disabilities. Therefore, we ask that the rule consider incorporating the U.S. Access Board’s standards related to accessible medical diagnostic equipment.<sup>18</sup>

### **The Proposed Rule Continues to Recognize Protections for Intersectional Discrimination**

We applaud the Department’s recognition of the many ways people often experience discrimination based on their intersecting race, national origin, sex, age, disability, and other protected categories. The preamble of the proposed rule highlights the serious health consequences of discrimination on the basis of pregnancy or related conditions, especially for Black and Latino women.<sup>19</sup> The preamble also notes the prevalence of discrimination against people who experience transphobia and racism and discrimination against women with disabilities.<sup>20</sup> To better ensure that Section 1557 applies to intersectional discrimination, we urge the Department to include a clear reference to discrimination based on a combination of protected categories in the relevant provisions of the proposed rule.<sup>21</sup>

### **The Proposed Rule Strengthens Protections for LGBTQIA+ Individuals**

We applaud HHS’s proposed rule for making explicit that Section 1557’s protections against discrimination on the basis of sex includes gender identity, which is consistent with the interpretation of the Supreme Court decision in *Bostock* and federal anti-discrimination laws. We

<sup>14</sup> *Id.*

<sup>15</sup> Question and Answers on the 2022 Proposed Rule Addressing Nondiscrimination Protections under the ACA’s Section 1557, NATIONAL HEALTH LAW PROGRAM (Aug. 15, 2022) <https://healthlaw.org/resource/questions-and-answers-on-the-2022-proposed-rule-addressing-nondiscrimination-protections-under-the-acas-section-1557/>; American Community Survey, 2020; Table S1601, Language Spoken at Home, American Community Survey 5-Year Estimates, available at <https://data.census.gov/cedsci/table?q=S1601&tid=ACSST5Y2020.S1601>; Table S1602, Limited.

<sup>16</sup> Jie Zong and Jeanne Batalova, “The Limited English Proficient Population in the United States in 2013, MIGRANT POLICY INSTITUTE, <https://www.migrationpolicy.org/article/limited-english-proficient-population-united-states-2013>.

<sup>17</sup> 87 Fed. Reg. at 47917 (Proposed § 92.204).

<sup>18</sup> U.S. Access Board, Medical Diagnostic Equipment Accessibility Standards, <https://www.access-board.gov/mde/>

<sup>19</sup> 87 Fed. Reg. at 47832.

<sup>20</sup> *Id.* at 47870.

<sup>21</sup>

support the proposed rule for clarifying that discrimination on the basis of sex in health care programs and activities includes sex stereotypes, sexual orientation, gender orientation, gender identity, and sex characteristic including intersex trait, and marital, parental, or family status.<sup>22</sup> Sex stereotypes, such as expectations about how people should present or communicate, have historically created barriers to equitable health care access and services. We also support the restoration of enforcement of protections against discrimination on the basis of association, which should protect LGBTQIA+ couples who may be turned away from care.<sup>23</sup>

We also appreciate the Department's inclusion of equal program access which explicitly includes provisions that programs may not deny or limit services based on sex assigned at birth, gender identity, or gender.<sup>24</sup> This provision includes protections for gender transition or gender affirming care, which clarifies that a provider's beliefs are not a sufficient basis for judgement that health services are not clinically appropriate. LGBTQIA+ people experience barriers to accessing health care, from providers refusing care based on their actual or perceived gender identity, to discriminatory attacks on gender affirming care as well as litigation regarding employer coverage of care. These changes will better ensure that health providers, insurers, and other programs and activities cannot refuse care or provide discriminatory care or treatment.

Finally, we support the Department's proposed amendments to the Centers for Medicare and Medicaid Services (CMS) regulations to prohibit discrimination on the basis of sexual orientation and gender identity for programs including Medicaid, Children's Health Insurance Plan (CHIP), Program of All-Inclusive Care for the Elderly (PACE), the Exchange, and Qualified Health Plans.<sup>25</sup> Additionally, the prohibition of insurers from marketing practices and benefit designs that discriminate, in particular, would help deter discriminatory practices such as insurers charging people with HIV/AIDS higher costs or placing their medications in higher cost tiers.<sup>26</sup> We request that the Department's changes to CMS regulations are consistent with the language in the proposed rule section 92.101(a)(2).<sup>27</sup>

Considering the onslaught of discriminatory attacks on transgender and nonbinary people, we recommend the proposed rule add explicit inclusion of "transgender status" to the relevant provisions of the regulatory text. We further urge the Department to provide more explicit examples of prohibited discrimination in coverage and services, such as clarification on whether Section 1557 nondiscrimination protection includes coverage of, and treatment for, infertility. Many insurers refuse to cover in vitro fertilization or limit coverage of in vitro fertilization to cisgender heterosexual couples and exclude LGBTQIA+ couples.<sup>28</sup>

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<sup>22</sup> *Id.* at 47916 (Proposed § 92.101).

<sup>23</sup> *Id.* at 47918 (Proposed § 92.209).

<sup>24</sup> *Id.* at 47918 (Proposed § 92.206).

<sup>25</sup> *Id.* at 47891.

<sup>26</sup> *Id.* at 47868, 47918 (Proposed § 92.207); Jane Perkins and Wayne Turner, NHeLP and the AIDS Institute Complaint to HHS re HIV/AIDS discrimination by FL, NATIONAL HEALTH LAW PROGRAM (May 28, 2014) <https://healthlaw.org/resource/nhelp-and-the-aids-institute-complaint-to-hhs-re-hiv-aids-discrimination-by-fl/>.

<sup>27</sup> 87 Fed. Reg. at 47916 (Proposed § 92.101(a)(2)).

<sup>28</sup> Shira Stein, "LGBTQ Couples' IVF Hopes Hinge on New Infertility Definition," BLOOMBERG LAW (May 17, 2022) <https://news.bloomberglaw.com/health-law-and-business/lgbtq-couples-ivf-hopes-hinge-on-new-infertility-definition>.

### **The Proposed Rule Clarifies Protections for Pregnancy or Related Conditions**

We support that the Department’s proposed rule explicitly includes “pregnancy or related conditions” in its definition of discrimination on the basis of sex.<sup>29</sup> Congress intended Section 1557 to prohibit discrimination against patients because of their medical history or needs, which includes if they had an abortion, miscarriage, or other pregnancy-related care. We also support HHS’s proposal to repeal 45 C.F.R. § 92.6, which incorporates the language of Title IX’s abortion provision.<sup>30</sup>

We urge the Department to include broader reproductive and sexual health care in its language around prohibited sex discrimination. Specifically, the “equal program access” section of the regulatory text should include clear prohibitions on denying or limiting services or the ability for professionals to provide services for pregnancy or related conditions including, contraception, termination of pregnancy, miscarriage management, fertility care, maternity care, and other health services.<sup>31</sup> This is especially important as people of color, immigrants, LGBTQIA+ people, low-income people, and people from rural areas, face insurmountable barriers and stigma to reproductive health care in the wake of the *Dobbs* decision and the ongoing attacks on abortion.

### **The Proposed Rule Creates a Separate Process for Raising Potential Religious Freedom Objections.**

We support HHS’s proposal to not import the Title IX exemptions and create a separate fact-specific process that balances the interest of providing nondiscriminatory health care and the conscience and religious freedom laws.<sup>32</sup> This decision to provide a case-by-case analysis will better ensure that patients will not be refused the care they need because of discriminatory practices. Retaining the previous religious refusal and abortion exception would cause delays in abortion care in order to determine compliance, which given the existing barriers to abortion, would permit providers treating patients in medically dangerous situations to put them further at risk.<sup>33</sup> We request the Department consider requiring institution’s or provider’s notice requirements be transparent about any refusal of care granted so people can be fully informed about any potential lack of full health care access.

### **Additional Provisions**

We support the Department’s requirements that a covered entity develop civil rights policies and procedures and take proactive measures to prevent discrimination through training, as well as the

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<sup>29</sup> 87 Fed. Reg. at 47858, 47916 (Proposed § 92.101).

<sup>30</sup> *Id.* at 47879 (Proposed § 92.208).

<sup>31</sup> *Id.* at 47858, 47918 (Proposed § 92.206).

<sup>32</sup> *Id.* at 47841, 47918-19 (Proposed § 92.302).

<sup>33</sup> *See e.g.* ACOG Committee on Health Care for Underserved Women, Opinion, Increasing Access to Abortion, No. 815 (Dec. 2020), <https://www.acog.org/clinical/clinical-guidance/committee-opinion/articles/2020/12/increasing-access-to-abortion>.

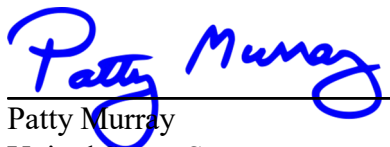
hiring of a Section 1557 coordinator.<sup>34</sup> These provisions will allow OCR to better identify patterns or practices of discrimination through the availability of information on past complaints and aid in delivering effective and efficient care to people.<sup>35</sup>

In response to the Department's inquiry, we encourage the Department to require covered entities to collect and report comprehensive, disaggregated data to ensure civil rights enforcement and allow for better resources to address health disparities and inequities.<sup>36</sup> Data collection should include: race, ethnicity, language, age, disability, sex, sexual orientation, gender identity, and pregnancy status. As these data can reveal deeply sensitive information, we urge the Department, in consultation with relevant agencies such as the National Institute of Standards and Technology and Federal Trade Commission, to require that data collection, use, storage, and sharing is consistent with best practices for sensitive data and adopts the principles of privacy and security by design, in order to ensure providers and patients are protected from data breaches and are not targeted for civil, criminal, or immigration enforcement. We also urge the Department to share any gaps or limitations they encounter in creating and implementing such requirements.

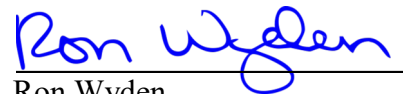
### **Conclusion**

While the proposed rule restores and strengthens civil rights protections for people accessing HHS and federally funded health programs, we urge the Department to further strengthen the rule in accordance to our recommendations. We also ask you to quickly finalize this rule to advance much needed protections for people seeking health care. Thank you for your consideration of our requests.

Sincerely,



Patty Murray  
United States Senator  
Chair, Committee on Health,  
Education, Labor and Pensions



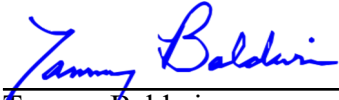
Ron Wyden  
United States Senator  
Chairman, Committee on  
Finance

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<sup>34</sup> 87 Fed. Reg. at 47849, 47914 (Proposed § 92.8), 47915 (Proposed § 92.9).

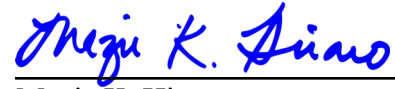
<sup>35</sup> *Id.*

<sup>36</sup> *Id.* at 47856.



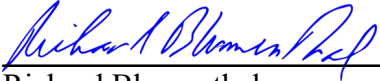
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Tammy Baldwin  
United States Senator



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Mazie K. Hirono  
United States Senator



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Richard Blumenthal  
United States Senator



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Sherrod Brown  
United States Senator



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Bernard Sanders  
United States Senator



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Elizabeth Warren  
United States Senator



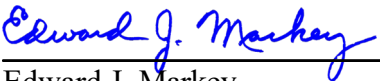
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Maria Cantwell  
United States Senator



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Jeffrey A. Merkley  
United States Senator



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Edward J. Markey  
United States Senator



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Cory A. Booker  
United States Senator





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Tina Smith  
United States Senator



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Martin Heinrich  
United States Senator



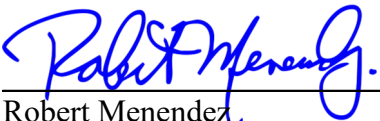
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Jack Reed  
United States Senator



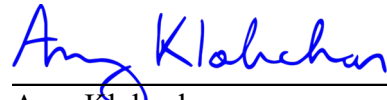
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Alex Padilla  
United States Senator



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Robert Menendez  
United States Senator



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Amy Klobuchar  
United States Senator