

May 15, 2020

Senator Bernie Sanders
U.S. Senate

Dear Senator Sanders,

Thank you for your leadership in responding to the public health, human, and economic impacts of the COVID-19 pandemic. We appreciate the significant resources that have been included for state and local governments, unemployment assistance, and health equity data in the HEROES ACT.

On behalf of The Fenway Institute at Fenway Health in Boston, we respectfully ask that you consider modifications to three provisions. Our suggested changes are highlighted in yellow:

First, on Page 376 there is a provision regarding ACA Exchange outreach and educational activities, which would require that such activities “shall be provided in a manner that is nondiscriminatory, culturally and linguistically appropriate to the needs of the populations being served by the Exchange (including hard-to-reach populations, such as racial and sexual and gender minorities, limited English proficient populations, and young adults).”

It is possible that this provision was fixed by an amendment in the House, but please make sure that sexual orientation and gender identity nondiscrimination language is included in the bill. The Trump Administration is in the process of trying to repeal SOGI nondiscrimination language in the Affordable Care Act, in public and private health insurance, and in the PACE Program.¹

¹ The Fenway Institute. *New rule proposes removal of LGBT nondiscrimination provisions from Section 1557 and other health care regulations.* (2019, July).

We know that LGBTQ people experience discrimination in accessing health care.^{2,3} This correlates with poorer health and well-being for LGBTQ people, and causes LGBTQ people to not access health care.^{4,5} It also exacerbates health disparities that LGBTQ people experience. As you know, the Trump Administration has promoted anti-LGBTQ discrimination in a wide range of policy areas,⁶ including by implementing religion and “conscience”-based policies that could increase anti-LGBTQ discrimination in health care and other areas of society.⁷

Politico reported April 24 that the Administration is seeking to finalize its repeal of the Affordable Care Act’s nondiscrimination rule (implementing Section 1557 of the ACA), which prohibits gender identity discrimination in health care and some forms of anti-LGB discrimination that take the form of sex stereotyping.

Nondiscrimination protections are needed now to ensure that LGBTQ people can access life-saving health care in this time of global pandemic.

Second, on page 557 of the HEROES Act, the CDC is required to report “on the demographic characteristics, including race, ethnicity, age, sex, gender, sexual orientation, gender identity, geographic region, and other relevant factors of individuals tested for or diagnosed with COVID–19.”

LGBTQ people disproportionately work in jobs that are considered essential; they may therefore be more likely to be exposed to the coronavirus. Additionally, LGBTQ people suffer economic disparities that place many in living environments that may make it harder to maintain social distancing.⁸ We need CDC to systematically collect and report sexual orientation and gender identity (SOGI)

² Lambda Legal. 2010. *When Health Care Isn’t Caring: Lambda Legal’s Survey of Discrimination against LGBT People and People with HIV*. New York: Lambda Legal.

³ Ahmed Mirza, Shabab and Rooney, Caitlin (2018). *Discrimination Prevents LGBTQ People from Accessing Health Care*. Washington, DC: Center for American Progress.

⁴ Ibid.

⁵ Reisner SL, White Hughto JM, Dunham E, Heflin K, Begenyi JB, Coffey-Esquivel J, Cahill S (2015). Legal protections in public accommodations settings: A critical public health issue for transgender and gender nonconforming people. *Milbank Quarterly*. 1-32

⁶ Cahill S, Wang T, Jenkins B (2019, January). *Trump Administration continued to advance discriminatory policies and practices against LGBT people and people living with HIV in 2018*. Boston: The Fenway Institute.

⁷ Cha, A., Eilperin, J. (2018, January 17). New HHS civil rights division to shield health workers with moral or religious objections. *Washington Post*.

⁸ Whittington C, Hadfield K, Calderón C (2020, March). *The lives and livelihoods of many in the LGBTQ community are at risk amidst COVID-19 crisis*. Washington, DC: Human Rights Campaign Foundation.
<file:///C:/Users/scahill/Documents/Government%20Relations/HRC%20COVID19-IssueBrief-032020-FINAL.pdf>

data in real time in relation to COVID-19, consistent with its recommendations for seven of 10 essential public health services.⁹

Third, on page 558, there is a provision, sec. 30573, on “FEDERAL MODERNIZATION FOR HEALTH INEQUITIES DATA.” It requires that: “The [HHS] Secretary shall work with covered agencies to support the modernization of data collection methods and infrastructure at such agencies for the purpose of increasing data collection related to health inequities, such as racial, ethnic, socioeconomic, sex, gender, sexual orientation, gender identity, and disability disparities.”

On page 559, there is a provision, sec. 30574, on “MODERNIZATION OF STATE AND LOCAL HEALTH INEQUITIES DATA,” which contains nearly identical language. Please add sexual orientation, gender identity, into this section as well.

LGBTQ people are more likely to have some of the underlying health conditions that correlate with increased vulnerability to COVID-19-related health complications and fatalities. These include higher rates of cardiovascular disease, cancer, obesity, diabetes, and HIV/AIDS, and higher rates of risk factors such as tobacco and other substance use.¹⁰

The provisions on pages 558-559 re federal and state data modernization are very important. It is critical to include sexual orientation and gender identity (SOGI) in both of those provisions of the HEROES Act. The federal provision would provide \$4 million to each of six agencies, including NIH and the Office of the National Coordinator of Health Information Technology. The state and local provision would provide \$100 million to states and localities to modernize data collection. This is sorely needed, as no states are currently systematically collecting and reporting on SOGI data within the COVID-19 pandemic. This important support for data modernization could have an impact over the next decade in line with the impact the ARRA has had since it was enacted in 2009. The shift to Electronic

⁹ Of the CDC’s 10 essential services that every public health system must deliver, at least seven relate to the collection and analysis of data. They include monitoring community health status; diagnosing and investigating health problems and health hazards in the community; mobilizing community partnerships and action to identify and solve health problems; informing, educating, and empowering people about health issues; developing policies and plans that support individual and community health efforts; evaluating the effectiveness of public health initiatives; and conducting research for new insights and innovative solutions.

(<https://www.cdc.gov/publichealthgateway/publichealthservices/essentialhealthservices.html>)

¹⁰ Cahill S and Wang T (2019, June). Quality Innovation Network, Quality Improvement Organizations (QIN-QIO) Sharing Call: “Reducing chronic disease and health disparities in diverse LGBT populations.” National webinar.

Health Records promoted by the ARRA has enabled SOGI data collection in health care settings through the Meaningful Use/Promoting Interoperability program, and through the community health centers' Uniform Data System. This in turn has enabled providers to track, understand, and respond to SOGI-related correlates and impacts on health and well-being.

Thank you very much for considering these requests, and for your steadfast support and leadership in support of LGBTQIA+ equality and health equity.

Sincerely,

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Vice President for Government and Community Relations

Sean Cahill, PhD
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Cc: Senator Markey
 Senator Warren
 Representative Pressley