

RE: HHS–OS–2018–0008, Proposed Rule for Compliance With Statutory Program Integrity Requirements

Dear Secretary Azar, Senior Advisor Huber, and Deputy Assistant Secretary Foley:

The Sexuality Information and Education Council of the United States (SIECUS) submits these comments in response to the Department of Health and Human Services’ (the Department’s) proposed rule entitled “Compliance with Statutory Program Integrity Requirements,” which was published in the Federal Register on June 1, 2018.¹ The proposed rule would significantly and detrimentally alter the Title X Family Planning Program (Title X), which has provided vital sexual and reproductive health services to people across the country for more than 40 years. Each year, Title X provides services to four million people across the nation, serving as a vital source of affordable health care for populations that face significant barriers to care.

SIECUS has served as the national voice for sex education, sexual health, and sexual rights for over 50 years. SIECUS asserts that sexuality is a fundamental part of being human, one worthy of dignity and respect. We advocate for the rights of all people to accurate information, comprehensive sexuality education, and the full spectrum of sexual and reproductive health services. SIECUS works to create a world that ensures social justice inclusive of sexual and reproductive rights.

As experts in the field of sexual health and reproductive rights, we write to express our vehement opposition to this proposed rule. Specifically, the proposed rule would interfere with the doctor-patient relationship and deny Title X patients information they need to stay healthy. Furthermore, the rule would exacerbate existing health disparities. Finally, the rule threatens patient confidentiality for minors and could cause many young patients to avoid seeking care at Title X facilities. The combined result of these changes would be disastrous for our nation’s public health.

The proposed rule would ban Title X providers from giving women full information about their health care options. Specifically, the proposed rule would eliminate the existing requirement that patients be provided with referrals upon request for the full range of pregnancy options, including prenatal care and delivery; infant care, foster care, or adoption; and abortion.² That requirement would be replaced with a complete ban on health care providers giving abortion referrals.³ Many experts call this provision a “gag rule,” since it would restrict providers from speaking freely with their patients. The “gag rule” violates core ethical standards and deeply undermines the patient-provider relationship.

This proposal directly conflicts with the requirements of medical professional associations and infringes on the fundamental human right to sexual and reproductive health care. To ensure lifelong health, all people – and especially young people – need information about, and access to, affordable, linguistically, and culturally competent health care, as well as providers who can give

¹ Compliance With Statutory Program Integrity Requirements, 83 Fed. Reg. 25,502 (proposed Jun. 1, 2018) (to be codified at 42 C.F.R. pt. 59).

² 42 C.F.R. § 59.5(a)(5).

³ Compliance With Statutory Program Integrity Requirements, 83 Fed. Reg. at 25,531.

them the information they need to make informed decisions. Far too many young people in the United States face barriers – including stigma and discrimination, lack of knowledgeable providers, cost, transportation, and perceived lack of confidentiality – that prevent them from accessing necessary health services. These barriers contribute to health challenges and disparities, as evidenced by the continued high rates of HIV and other sexually transmitted infections (STIs), and unintended pregnancy among young people.

Yet rather than address these barriers and the threats to public health they represent, this rule exacerbates these problems by preventing honest dialogue between health providers and the patients they serve. Education and information build the necessary foundation for lifelong health; this proposed rule ignores people’s real lived experiences and the recommendations of medical professionals in order to impose ideological barriers on one of our nation’s most vital health care programs.

The harmful impacts laid out above will fall most heavily on the people who are most in need of comprehensive, affordable reproductive and sexual health care services. Because of systemic inequities, the people served by the Title X program are more likely to be people of color and individuals who face language barriers and other barriers to care. This rule will deny vulnerable individuals access to comprehensive care from honest providers.

Since its inception in 1970, Title X has strongly protected patient confidentiality for adolescents and minors. These statutory protections have been reaffirmed by regulations and case law and are among the strongest confidentiality protections in current law. The ability to receive confidential care is one of the reasons individuals seek care at Title X facilities.⁴ Research shows that adolescents and young adults’ decisions to seek care can be influenced by privacy concerns.⁵

The proposed rule would erode patient confidentiality protections in several ways. First, it would require that providers encourage minors to involve their parents in their decision to seek care – and require that providers document this encouragement in detail – before minors can receive confidential services based on their own income. The rule could bar minors from receiving confidential services for free if they are not pressured by Title X providers into sharing their need for family planning services with their parents.

The only exception to this requirement of encouraging family involvement is if documentation shows that minor is the victim of child abuse and that the provider has reported that to the relevant authorities. There are many other legitimate reasons for an adolescent to want to seek care at a Title X facility without informing their parents, but the proposed rule ignores this reality. Instead, it imposes HHS’s ideology over the expertise of medical professionals as to whether encouraging family participation is realistic or healthy for the patient seeking care. This violates the rights of young people and could lead to a chilling effort that would be catastrophic for adolescents.

⁴ Jennifer J. Frost, Rachel Benson Gold, and Amelia Bucek, “Specialized Family Planning Clinics in the United States: Why Women Choose Them and Their Role in Meeting Women’s Health Care Needs,” *Women’s Health Issues* 22 (November 2012): e519-e525.

⁵ Carol A. Ford, Abigail English, and Garry Sigman, “Confidential Health Care for Adolescents: Position Paper of the Society for Adolescent Medicine,” *Journal of Adolescent Health* 35, no. 2 (2004): 160-167.

Title X serves the very communities that face the most significant barriers to care; 78% of Title X patients have incomes below 150% of the poverty line. Approximately 21% of Title X patients identify as Black or African American, and 32% identify as Hispanic or Latinx. Patients in rural areas face geographic barriers to accessing family planning services. Without Title X providers, many of these rural residents could lose access to reproductive care entirely. Youth, immigrants, LGBTQ individuals, and other marginalized groups stand to lose access to the care they need and deserve because of this proposed rule. We ask HHS to fully evaluate the impact of this proposed rule on groups that already face significant health disparities and barriers to care.

In short, the proposed rule would gravely harm the people that we serve and would exacerbate existing public health issues and health disparities. We strongly urge you to not finalize the proposed rule.

Sincerely,

Chitra Panjabi
President & CEO
SIECUS