

July 23, 2018

### VIA ELECTRONIC TRANSMISSION

Alex Azar, Secretary of Health and Human Services Attention: Family Planning U.S. Department of Health and Human Services Hubert H. Humphrey Building, Room 716G 200 Independence Avenue SW Washington, DC 20201

Valerie Huber, Senior Policy Advisor, Assistant Secretary for Health Attention: Family Planning U.S. Department of Health and Human Services Hubert H. Humphrey Building, Room 716G 200 Independence Avenue SW

Washington, DC 20201

Diane Foley, Deputy Assistant Secretary for Population Affairs Office of the Assistant Secretary for Health, Office of Population Affairs Attention: Family Planning U.S. Department of Health and Human Services Hubert H. Humphrey Building, Room 716G 200 Independence Avenue SW Washington, DC 20201

# 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:

On behalf of the Center for Law and Social Policy (CLASP), we appreciate the opportunity to comment on the Department of Health and Human Services' (hereinafter "the Department") proposed rule on the Title X Family Planning Program, entitled *Compliance with Statutory Program Integrity Requirements* ("the proposed rule" hereafter). CLASP writes with strong objection to the proposed rule on the Title X Family Planning Program. This rule will have a devastating impact on women and families across the country, particularly women and families of color and those who are low-income. For this reason and those expanded on below, we urge the Department of Health and Human Services to maintain the integrity of the Title X program in its current form and rescind the proposed rule.

CLASP is a national, nonpartisan, anti-poverty nonprofit advancing policy solutions for low-income people. We work at both the federal and state levels, supporting policy and practice that makes a difference in the lives of people living in conditions of poverty. In particular, these comments draw on CLASP's experience with Medicaid and specifically in mental and behavioral health, areas where Title X funding helps to supplement and strengthen current supports to ensure low-income people get and retain benefits.

We believe that quality, affordable healthcare is critical for everyone, but for many women, children, and families, particularly women and families of color and those who are low-income, medical care often remains inaccessible. Almost two-thirds of those attending Title X-funded clinics come from households with incomes below the federal poverty level. Nearly 90 percent of Title X recipients have incomes below 200 percent of the federal poverty level, and 48 percent are uninsured.¹ Planned Parenthood health centers serve over 40 percent of Title X patients; hospitals, family planning

 $<sup>^1</sup>$  C.I. Fowler and others, "Family Planning Annual Report: 2015 National Summary" (Research Triangle Park, NC: RTI International, 2015), available at https://www.hhs.gov/opa/sites/default/files/title-x-fpar-2015.pdf



councils, federally qualified health centers, and other private nonprofit organizations make up the rest of the Title X network. Further, out of the 4 million family planning clients who Title X serves, more than half are women of color: 30 percent identify as either Black, Asian, Asian or Pacific Islander, or American Indian or Alaska Native, and another 32 percent of clients identify as Latinx.<sup>2</sup>

Title X is an essential source of public funding for communities of color, especially those living with low-incomes and living in poverty.

CLASP's work focused on Girls and Women of Color highlights the need to strengthen the current system of mental and behavioral health, in part due to the challenges presented from ongoing trauma and adverse childhood experiences (ACEs). Title X providers are often the first line of care for clients for essential services, including mental health screening in preconception care (PCC).<sup>3</sup> Restructuring Title X funding in this manner would create more barriers to needed mental and behavioral health supports.

The proposed rule is problematic for the following reasons as if it was implemented, it: a) interferes with the doctor-patient relationship, denying Title X patients essential information to stay healthy; b) provides an underestimate of the costs it will impose on patients, providers, and on society, and c) will exacerbate existing health disparities---impacting essential access to health for communities of color at much higher rates.

# I. The Proposed Rule would interfere with the doctor-patient relationship and denies patients information that they need to make the best decisions for themselves and their families.

The proposed rule would ban Title X providers from giving women full information about their health care options. Title X providers offer health care services to uninsured and underinsured individuals who otherwise would not have access to care because of the additional barriers communities of color face in accessing coverage. This proposed rule is an attack on the Title X program and a gamble with the health and economic stability of Black, Latinx, and Asian and Pacific Islander (AAPI) women, families, and communities.

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.<sup>4</sup> That requirement would be replaced with a complete ban on health care providers giving abortion referrals.<sup>5</sup> 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 undermines the patient-provider relationship.

This proposal directly conflicts with the requirements of medical professional associations, including the American College of Obstetricians and Gynecologists and the American College of Physicians, which assert that patients should receive complete and accurate information to inform their health care decisions. Similarly, the American Medical Association states in its Code of Medical Ethics that

<sup>&</sup>lt;sup>2</sup> Ihid

<sup>&</sup>lt;sup>3</sup> Frost J. U.S. women's use of sexual and reproductive health services: Trends, sources of care and factors associated with use, 1995-2010. New York, NY: Guttmacher Institute; 2013.

<sup>4 42</sup> C.F.R. § 59.5(a)(5).

<sup>&</sup>lt;sup>5</sup> Compliance With Statutory Program Integrity Requirements, 83 Fed. Reg. at 25,531.

<sup>&</sup>lt;sup>6</sup> Kinsey Hasstedt, *Unbiased Information on and Referral for All Pregnancy Options Are Essential to Informed Consent in Reproductive Health Care*, Guttmacher Institute (Jan. 2018), available at

 $<sup>\</sup>frac{https://www.guttmacher.org/gpr/2018/01/unbiased-information-and-referral-all-pregnancy-options-are-essential-informed-consent.}{\\$ 



providers "present relevant information accurately and sensitively, in keeping with the patient's preferences" and that "withholding information without the patient's knowledge or consent is ethically unacceptable." The Code of Ethics for Nursing stipulates that patients must be given "accurate, complete, and understandable information in a manner that facilitates an informed decision." That is why both the American Medical Association and the American Nurses Association, among others, have publicly announced their strong objection to the gag rule.

## II. The Proposed Rule would drastically impact access and affordability of needed health care.

Planned Parenthood plays a critical and outsized role in the Title X program. Nationwide, Planned Parenthood health centers serve more than 40 percent of Title X patients. Eliminating Planned Parenthood from the Title X program would leave many people without access to care. While they are an integral component of the health care safety net, if the current network of Title X providers are unable to receive funding under the proposed rule, Federally Qualified Health Centers (FQHCs) will not be able to absorb the sheer number of individuals needing health care services. FQHCs are community based organizations that provide affordable primary and preventive care for people of all socioeconomic statuses and make up about 26 percent of the Title X network. The burden of providing health care services to this amount of people would not only place unrealistic expectations on FQHCs that are already stretched thin in meeting the needs of their communities, but would also jeopardize the quality of care provided. The proposed changes to the Title X Family Planning Program would drastically impact the access and affordability of preventive and contraceptive care for communities of color with low incomes, communities that would not be able to be absorbed by other federally funded programs.

# III. The Proposed Rule fails to account for numerous costs that will be imposed on women, youth and young adults, providers, and society if it is implemented.

The Department completely fails to take into account most of the costs that will accrue under this rule, and acknowledges that the proposed rule has no quantifiable benefits. At the same time, by erroneously confining its discussion of the rule's costs to include only the costs borne by entities that would have to comply with the rule, but not calculating the considerable additional costs, including for Title X patients who are no longer able to receive the health care services that they need, as well as the resultant health care costs to state and local health systems, the Department significantly underestimates the projected costs. Remarkably, because of that failure, the Department has determined that its rulemaking is not "economically significant" because it believes the rule's economic effects would fall short of a \$100 million threshold. An accurate analysis of the costs would determine that the costs are significantly greater than \$100 million.

<sup>&</sup>lt;sup>7</sup> American Medical Association, Code of Medical Ethics Opinion 2.1.1, Informed Consent, available at https://www.ama-assn.org/delivering-care/informed-consent.

<sup>&</sup>lt;sup>8</sup> American Medical Association, Code of Medicaid Ethics Opinion 2.1.3, Withholding Information from Patients, available at https://www.ama-assn.org/delivering-care/withholding-information-patients.

<sup>&</sup>lt;sup>9</sup> American Medical Association, AMA Response to Administration's Attack on Family Planning Services (May 23, 2018), available at https://www.ama-assn.org/ama-response-administrations-attack-family-planning-services.

 $<sup>^{10}</sup>$  American Nurses Association, ANA Condemns Title X Funding Cuts Proposed by the Trump Administration (May 22, 2018), available at https://www.nursingworld.org/news/news-releases/2018/ANA-condemns-title-x-funding-cuts--proposed-by-the-trump-administration/.

<sup>&</sup>lt;sup>11</sup> Frost, Jennifer J., Frohwirth, Lori F., Blades, Nakeisha, Zolna, Mia R., Douglas-Hall, Ayana, and Bearak, Jonathan. *Publicly Funded Contraceptive Services at U.S. Clinics, 2015.* New York: Guttmacher Institute, 2017.



### Title X and opioid treatment

Title X sites are uniquely positioned to link people to behavioral health treatment and recovery supports when they are diagnosed with substance use disorders, especially in rural areas where the crisis is severe. Early identification and treatment for behavioral health conditions are essential to address the opioid epidemic. Title X providers are obligated to follow guidelines for <a href="Quality Family Planning">Quality Family Planning</a> that include screening for substance use and appropriate referrals, playing a key role linking women to treatment for opioid-related disorders. Without access and referrals to mental and behavioral health specialists, substance use disorders and untreated mental illnesses will increase, thereby increasing costs to the overall system.

# IV. The Proposed Rule would worsen existing health disparities leaving communities that already experience worse health outcomes with less access to care.

All of the harmful impacts laid out above will fall most heavily on the people who are most in need of comprehensive, affordable reproductive and sexually health care services. Growing disparities in maternal care, morbidity, and mortality in rural areas because of limited care and closing hospitals<sup>12,13</sup> will increase with drastic changes in Title X funding. Because of systemic inequities, the people served by the Title X program are more likely to be people of color and to face language barriers and other barriers to care. This rule will deny people who already face health disparities access to the best possible care through experienced providers.

However, despite recent gains in medical coverage, women of color still face disparities in reproductive health treatment and outcomes. Structural racism and income inequality have raised additional barriers for communities of color attempting to access coverage. Racial or ethnic bias, along with language barriers, often make health care difficult to access. This rule will deny people who already face health disparities access to the best possible care through experienced providers and to all methods of contraception. Women of color will be disproportionately impacted by the proposed rule and, if current protections and policies are eliminated, stand to lose the most. More than half of Title X patients are women of color,<sup>14</sup> more than one-third are Latinx, and 13 percent have limited proficiency in English.<sup>15</sup> Racial and ethnic bias, along with language barriers, often make health care difficult or impossible to access. It will also clearly have implications on how patients see health and can have grave consequences on their stress and anxiety levels, thereby impacting their mental health. Restrictions on Title X will further limit their access to behavioral health care and treatment for opioid-related health conditions.

In Texas, lawmakers created a Task Force on Maternal Mortality and Morbidity in 2013 to address the issue of increasing rates. They found that black mothers have the highest death risk, delivering 11% of babies from 2012-2015, but comprising 20% of maternal deaths. Likewise, Hispanic women had 48% of the state's births and 38% of maternal deaths, and White women delivered 34% of births and had 39% of deaths. 16%

<sup>&</sup>lt;sup>12</sup> Maron, Dina Fine, "Maternal Health Care is Disappearing in Rural America" <a href="https://www.scientificamerican.com/article/maternal-health-care-is-disappearing-in-rural-america/">https://www.scientificamerican.com/article/maternal-health-care-is-disappearing-in-rural-america/</a>, Scientific American, February 2017.

<sup>13</sup> Healy, Jack. "It's 4 A.M. The Baby's Coming. But the Hospital Is 100 Miles Away."

https://www.nytimes.com/2018/07/17/us/hospital-closing-missouri-pregnant.html, The New York Times, July 2018.

<sup>&</sup>lt;sup>14</sup> C.I. Fowler and others, "Family Planning Annual Report: 2015 National Summary" (Research Triangle Park, NC: RTI International, 2015), available at https://www.hhs.gov/opa/sites/default/files/title-x-fpar-2015.pdf.

<sup>&</sup>lt;sup>15</sup> Karthick Ramakrishnan & Farah Z Ahmad, "Language Diversity and English Proficiency." Center for American Progress (27 May 2014). <a href="https://www.americanprogress.org/wp-content/uploads/2014/04/AAPI-LanguageAccess1.pdf">https://www.americanprogress.org/wp-content/uploads/2014/04/AAPI-LanguageAccess1.pdf</a> (last visited Aug 15, 2017).

 $<sup>^{16}</sup>$  Hollier, Lisa and others, "Preventing Maternal Mortality and Morbidity." Texas Health and Human Services, October 12, 2017.



In many states, a Title X provider is one of the few places women of color can access reproductive health care and preventive health care services. Title X providers are bound by federal law to provide services in a linguistically-appropriate manner and offer a range of reproductive health and family planning services. Title X health care providers also offer services for foreign-born individuals who are less likely to have coverage (46 percent) than U.S.-born people (75 percent).<sup>17</sup> For those who have limited options for care, these services, which are available at an affordable price at Title X funded health centers, can mean the difference of a person receiving care or going without.

Title X funded health centers offer a range of preventive services and life-saving care. Black women have higher breast cancer mortality rates compared to other racial and ethnic groups and Latina women experience cervical cancer at twice the rate of white women. Cancer is the leading cause of death for AAPI communities, and the cervical cancer incidence rate is higher in several Asian-American, Native Hawaiian and Pacific Islander (AA&NHPI) subgroups than in non-Hispanic whites. For instance, the incidence rate is twice as high in Cambodians as in non-Hispanic whites, and 40 percent higher among Vietnamese women. Title X funded health centers enable women of color to access essential health care including breast cancer and cervical cancer screenings. This is critical care since these cancers are highly preventable diseases, which African-Americans, Latinxs, and AA&NHPIs experience at increased rates compared to white women. Title X providers are required to offer all family planning and sexual health services on a sliding fee scale, allowing prevention to be more accessible for those who need it most.

### Black Women

Quality family planning services are essential to ensuring that Black women experience healthier pregnancies and improved post-natal health outcomes for both mothers and infants.<sup>19</sup> Family planning services are also life saving for early detection and treatment of STD/STIs and reproductive cancers, which disproportionately impact Black women.<sup>2021</sup> Of the 4.2 million people served through Title X funded health centers, 92 percent are women and more than 20 percent are Black.<sup>22</sup> Family planning and sexual health services provided by Title X-funded health centers are crucial for the health of Black women. Black women must be able to make our own family planning decisions, access contraceptives, and safeguard our sexual health. Family planning can play a critical role in the lives of Black women when providers and policies center women's rights and decision-making.<sup>23</sup> This proposed rule is a direct threat to family planning services for Black women and will disproportionately impact Black women's health.

### **Latinx Community**

Title X provides critical access to care for Latinxs,<sup>24</sup> the most uninsured group in the United States, who would otherwise be unable to access contraception, STI testing, and preventive services like cervical

<sup>&</sup>lt;sup>17</sup> Kavanaugh, Megan, et al. *Use of Health Insurance Among Clients Seeking Contraceptive Services at Title X–Funded Facilities in 2016*. New York: Guttmacher Institute, 2018. <a href="https://www.guttmacher.org/journals/psrh/2018/06/use-health-insurance-among-clients-seeking-contraceptive-services-title-x">https://www.guttmacher.org/journals/psrh/2018/06/use-health-insurance-among-clients-seeking-contraceptive-services-title-x</a>

<sup>&</sup>lt;sup>18</sup> The term "Hispanic" is used when characterized as such in the primary dataset.

<sup>&</sup>lt;sup>19</sup> U.S. Department of Health and Human Services (HHS), Office of Disease Prevention and Health Promotion, Healthy People 2020 Topics and Objectives: Family Planning, Rockville (MD): HHS, no date. Online: https://www.healthypeople.gov/2020/topics-objectives/topic/family-planning.

<sup>&</sup>lt;sup>20</sup> Centers for Disease Control and Prevention (CDC), Health Disparities in HIV/ AIDS, Viral Hepatitis, STDs, and TB - African Americans/Blacks, Atlanta: CDC, 2017. Online: <a href="http://www.cdc.gov/nchhstp/">http://www.cdc.gov/nchhstp/</a> healthdisparities/africanamericans.html.

<sup>&</sup>lt;sup>21</sup> Centers for Disease Control and Prevention (CDC), Gynecologic Cancers: Cervical Cancer Rates by Race and Ethnicity, Atlanta: CDC, 2016. Online: www.cdc.gov/ cancer/cervical/statistics/race.htm.

<sup>&</sup>lt;sup>22</sup> U.S. Department of Health & Human Services (HHS), Office of Population Affairs, *Title X Family Planning*, Rockville (MD): HHS, 2016. Online: <a href="https://www.hhs.gov/opa/title-x-family-planning/index.html#">https://www.hhs.gov/opa/title-x-family-planning/index.html#</a>.

<sup>&</sup>lt;sup>23</sup> In Our Own Voice. *Our Bodies, Our Lives, Our Voices: The State of Black Women & Reproductive Justice.* Washington, D.C., 2017.

<sup>&</sup>lt;sup>24</sup> "Latinx" is a term that challenges the gender binary in the Spanish language and embraces the diversity of genders that often are actively erased from spaces. Due to the limitations of data collection, we use "Latina(s)" or "women" where research only shows findings for cisgender women, including Latinas.



cancer screenings. Thirty two percent of Title X patients identify as Hispanic; the life-saving care of Title X clinics also expand to Puerto Rico, where 18,982 people were served in 2016.<sup>25</sup> The range of reproductive health services provided by Title X health care providers allow Latinxs to access services that address health disparities and provide preventive services.

Title X funded health centers allow many Latinxs to access contraception that they otherwise would have to go without. Because of the high uninsured rate in the Latinx community, seeing a provider in order to access birth control is not an option for many women and Latinx youth experience pregnancies at about twice the rate of their white counterparts. Because of Title X funded health care centers, Latinxs can continue to receive linguistically-appropriate care and education to prevent against transmission of HIV, as well as receiving testing.

Youth also rely on Title X centers for confidential and affordable services. In 2014, nearly half of U.S. born Hispanics were younger than 18, and about a quarter (14.6 million) of all Hispanics were Millennials (ages 18 to 33). Hispanics comprise the youngest major ethnic group in the United States.<sup>27</sup> In 2015, more than three-fifths of Latinx youth (62 percent) lived in families living with low-incomes (below 200 percent of the official poverty line), twice the proportion for white children (31 percent).<sup>28</sup> Title X providers provide critical services to uninsured and underinsured Latinxs, providing opportunities to make decisions about their bodies, sexuality, health, and families with dignity and determination.

## Asian American, Native Hawaiian, and Pacific Islander (AA&NHPI) Community

The thirteen percent of Title X patients who are Limited English Proficient (LEP) will also lose access to critical language assistance services, on which some Asian American and Pacific Islander (AA&NHPI) women rely to receive sexual and reproductive health services. While the majority of AA&NHPIs speak English well, approximately 35 percent are LEP and experience difficulty speaking, reading, writing, or understanding English.<sup>29</sup> According to U.S. Census data, 20 percent or more of Vietnamese, Korean, Chinese, Bangladeshi, Laotian, Thai, Hmong, Indonesian, and Cambodian households are linguistically isolated, meaning no one in the household 14 years and older speaks English very well; in addition, approximately 6 percent of Native Hawaiian and Pacific Islander households are linguistically isolated.<sup>30</sup> For these communities, the language assistance services that Title X provides offers the best option in seeking reproductive health care and family planning services that other centers may not include.

### Youth and young adults

<sup>30</sup> *Ibid*.

The proposed rule would eliminate the ability for youth and young adults to seek services at a discount calculated by their own income and instead rely on parental consent and family resources. The proposed rule undermines patient confidentiality, particularly for youth and young adults, which could lead to many patients avoiding care in Title X settings. Youth and young adults already face unnecessary barriers to care, and further taking away a safe, trusted, and confidential space to seek services will only exacerbate already present health disparities in youth of color.

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<sup>&</sup>lt;sup>25</sup> Office of Population Affairs. *Family Planning Annual Report: 2016 National Summary.* August 2017. https://www.hhs.gov/opa/sites/default/files/title-x-fpar-2016-national.pdf

<sup>&</sup>lt;sup>26</sup> Centers for Disease Control and Prevention. Reproductive Health: Teen Pregnancy. Social Determinants and Eliminating Disparities in Teen Pregnancy. <a href="https://www.cdc.gov/teenpregnancy/about/social-determinants-disparities-teen-pregnancy.html">https://www.cdc.gov/teenpregnancy/about/social-determinants-disparities-teen-pregnancy.html</a>

<sup>&</sup>lt;sup>27</sup> http://www.pewhispanic.org/2016/04/20/the-nations-latino-population-is-defined-by-its-youth/

<sup>&</sup>lt;sup>28</sup> Mather, Mark Trends and Challenges Facing America's Latino Children. Population Reference Bureau. https://www.prb.org/trends-and-challenges-facing-americas-latino-children/

<sup>&</sup>lt;sup>29</sup> Karthick Ramakrishnan & Farah Z Ahmad, "Language Diversity and English Proficiency." Center for American Progress (27 May 2014). <a href="https://www.americanprogress.org/wp-content/uploads/2014/04/AAPI-LanguageAccess1.pdf">https://www.americanprogress.org/wp-content/uploads/2014/04/AAPI-LanguageAccess1.pdf</a> (last visited Aug 15, 2017).



It is critical that youth and young adults have a provider where they can receive comprehensive, medically accurate, evidence-based information in their preferred language from a trusted health care provider. By increasing family involvement beyond what is required in the language of the Title X statute and subverting the judgment and expertise of Title X funded providers to family participation, the proposed rule could cause harm to youth and young adults. Providers have the expertise to evaluate the situation of each individual unemancipated<sup>31</sup> youth and young adult, and we should defer to their judgment.

Providing confidential and affordable services to unemancipated youth and young adults is a critical tenet of the Title X program. The proposed rule has the potential to be especially harmful to unemancipated youth and young adults who are seeking confidential services that they would pay for using their own resources instead of their family's income. By eliminating the ability of youth and young adults to seek services independently and instead rely on parental consent and family resources, this proposed rule would seek to block unemancipated youth and young adults from receiving confidential services for free or at low cost, which is an essential part of accessing affordable and confidential care.

Without these protections, HHS is interfering in the provider/patient relationship unnecessarily and creating additional barriers to health care services like STI testing, contraception, and annual exams. All in all, Title X projects already have appropriate reporting measures in place that protect individuals; however, this proposed rule puts the notification and reporting laws ahead of an individual's needs.

#### \*\*\*\*\*

We believe that the proposed rule would widen the gap in care for needed services for low-income populations in the U.S., and create further strain on communities of color---increasing existing health disparities. Communities of color need essential family planning services to plan their pregnancies, ensure quality health, and protect the future for themselves and their families. The proposed rule as currently written threatens to significantly harm this crucial health care right. To address these and other concerns, CLASP urges the Department to reject the Proposed Rule in its entirety.

Thank you for the opportunity to submit comments. If you have any questions, please contact Isha Weerasinghe, Senior Policy Analyst in Mental Health Policy, at <a href="iweerasinghe@clasp.org">iweerasinghe@clasp.org</a>.

Sincerely,

Isha Weerasinghe

Senior Policy Analyst, Mental Health

**CLASP** 

<sup>&</sup>lt;sup>31</sup> Unemancipated child: A child that is considered to be under the financial care of their parents.