

Nos. 19-15974, 19-15979

IN THE UNITED STATES COURT OF APPEALS
FOR THE NINTH CIRCUIT

STATE OF CALIFORNIA,

Plaintiff-Appellee,

v.

ALEX M. AZAR II, in his official capacity as Secretary of the United States
Department of Health and Human Services; UNITED STATES DEPARTMENT
OF HEALTH AND HUMAN SERVICES,

Defendants-Appellants.

ESSENTIAL ACCESS HEALTH, INC., *et al.*,

Plaintiffs-Appellees,

v.

ALEX M. AZAR II, in his official capacity as Secretary of the United States
Department of Health and Human Services; UNITED STATES DEPARTMENT
OF HEALTH AND HUMAN SERVICES,

Defendants-Appellants.

On Appeal from the Northern District of California

No. 3:19-cv-01195-EMC

BRIEF OF *AMICI CURIAE* NATIONAL HEALTH LAW PROGRAM, ET AL.
IN SUPPORT OF PLAINTIFFS-APPELLEES

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CORPORATE DISCLOSURE STATEMENT

Pursuant to Fed. R. App. P. 26.1 and Circuit Rule 26.1(a), undersigned counsel certifies that the *amici curiae*, The National Health Law Program, Advocates for Youth, American Medical Student Association, American Society for Reproductive Medicine, Community Catalyst, The Endocrine Society, Families USA, HIV Medicine Association, In Our Own Voice: National Black Women’s Reproductive Justice Agenda, Juvenile Law Center, The Leadership Conference on Civil and Human Rights, National Council of Jewish Women, NARAL Pro—Choice America, National Abortion Federation, National Immigration Law Center, National Institute for Reproductive Health, National Latina Institute for Reproductive Health, National Partnership for Women & Families, National Women’s Health Network, National Women’s Law Center, Northwest Health Law Advocates, Positive Women’s Network—USA, Power to Decide, Union for Reform Judaism, Central Conference of American Rabbis, Women of Reform Judaism, Men of Reform Judaism, Unite for Reproductive & Gender Equity, Whitman-Walker Health, WomenHeart, and YWCA USA are not subsidiaries of any other corporation and no publicly held corporation owns 10 percent or more of any *amici curiae* organization’s stock.

Dated: July 5, 2019

/s/ Jane Perkins
Jane Perkins

TABLE OF CONTENTS

CORPORATE DISCLOSURE STATEMENT	i
TABLE OF AUTHORITIES	iii
INTEREST OF THE AMICI	1
SUMMARY OF ARGUMENT	2
ARGUMENT	3
I. Congress Enacted Title X to Ensure High Quality, Accessible, and Affordable Care for Low-Income and Underserved People	3
II. Title X Programs Currently Operate to Provide Access for Underserved Populations	6
A. The regulations will harm underserved population groups whose particular needs have been met by Title X providers.....	9
1. People of Color	9
2. People in rural areas	13
3. People with disabling conditions	17
B. The regulations will harm adolescents whose particular health and service delivery needs are being met by Title X providers.....	20
1. The need for comprehensive reproductive health services	20
2. Special circumstances and limited access	22
3. The critical need for confidentiality	23
4. The essential role of Title X providers.....	24
CONCLUSION.....	25
CERTIFICATE OF COMPLIANCE.....	27
CERTIFICATE OF SERVICE	28

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INTEREST OF THE *AMICI*¹

The *amici curiae* are organizations that work extensively with and for low-income and underserved populations. *Amici* are The National Health Law Program, Advocates for Youth, American Medical Student Association, American Society for Reproductive Medicine, Community Catalyst, The Endocrine Society, Families USA, HIV Medicine Association, In Our Own Voice: National Black Women’s Reproductive Justice Agenda, Juvenile Law Center, The Leadership Conference on Civil and Human Rights, National Council of Jewish Women, NARAL Pro—Choice America, National Abortion Federation, National Immigration Law Center, National Institute for Reproductive Health, National Latina Institute for Reproductive Health, National Partnership for Women & Families, National Women’s Health Network, National Women’s Law Center, Northwest Health Law Advocates, Positive Women’s Network—USA, Power to Decide, Union for Reform Judaism, Central Conference of American Rabbis, Women of Reform Judaism, Men of Reform Judaism, Unite for Reproductive & Gender Equity, Whitman-Walker Health, WomenHeart, and YWCA USA.

¹ Pursuant to Fed. R. App. P. 29(a)(4)(E), counsel for *amici curiae* states that no counsel for a party authored the brief in whole or in part, and no person other than *amici curiae*, their members, or their counsel made a monetary contribution to its preparation or submission. All parties have consented to the filing of this brief.

While each *amicus* has particular interests, they collectively bring to the Court an understanding of how Title X-funded sites play a critical role in improving health outcomes for underserved populations. The *amici* file this brief to bring information to the Court about the health status of low-income populations and how reduced access to Title X-funded programs will affect their health access and health status.

SUMMARY OF ARGUMENT

Congress designed Title X to ensure that low-income and underserved populations have access to effective family planning services. According to Congress, Title X grantees must provide non-directive counseling, and the U.S. Department of Health and Human Services cannot issue regulations that interfere with patient-provider communication regarding the full range of treatment options. The challenged regulations violate these statutory prohibitions.

The predictable result of the regulations is that health care providers will be unable to accept Title X funds, and care sites will become limited or close. These cutbacks will fall disproportionately on individuals who face significant health disparities. There will be serious consequences for adolescents. The health of other underserved groups, including people of color, people in rural areas, and those living with disabilities, will be negatively affected.

ARGUMENT

I. CONGRESS ENACTED TITLE X TO ENSURE HIGH QUALITY, ACCESSIBLE, AND AFFORDABLE CARE FOR LOW-INCOME AND UNDERSERVED PEOPLE.

Title X of the Public Health Service Act is designed to ensure that low-income and underserved populations have access to effective family planning methods and services. Title X programs must give priority to low-income persons living at or below the federal poverty level (\$12,490 annually for one person in 2019) and provide services to those individuals free of charge. *See* 42 U.S.C. § 300a–4(a). Priority is also given to individuals with higher income, but who are “unable, for good reason,” to pay for services. 42 C.F.R. §§ 59.2, 59.5(a)(7). Individuals with family income between 101-250% of the federal poverty level (FPL) are charged for their care based on a sliding fee scale. *Id.* § 59.5(a)(8). Longstanding regulations have also acknowledged the special circumstances of adolescents by making it clear that unemancipated minors wishing to receive confidential services must be considered only on the basis of “their own resources” in determining whether they qualify as “low-income.” *Id.* at § 59.2.

Since 1996, Congress has specified the type of counseling that Title X grantees must provide, mandating that “all pregnancy counseling shall be nondirective.” Pub. L. No. 104-134, 110 Stat. 1321, 1321-22 (1996); *see, e.g.*, Pub.

L. No. 115-245, Div. B., Tit. II, 132 Stat. 2981, 3070-71 (2018). The Affordable Care Act similarly prohibits HHS from

promulgat[ing] any regulation that . . . creates any unreasonable barriers to . . . appropriate care; impedes timely access to health care services; interferes with communications regarding a full range of treatment options between the patient and the provider; restricts the ability of health care providers to provide full disclosure of all relevant information to patients making health care decisions; violates the principles of informed consent and the ethical standards of health care professionals; or limits the availability of health care treatment for the full duration of a patient's medical needs.

42 U.S.C. § 18114.

The challenged regulations violate the congressional instructions. Among other things, they require providers and clinics to refer pregnant patients to prenatal care and prohibit clinic staff from offering an abortion referral or information, even when the patient requests a referral for an abortion. *See* 84 Fed. Reg. 7714, 7728 (Mar. 4, 2019) (promulgating 42 C.F.R. § 59.19). The regulations eliminate requirements for patients to be offered non-directive counseling on the comprehensive range of contraceptive options so that patients can make informed decisions about the method that will work best for them. *Id.* at 7787-88 (promulgating 42 C.F.R. § 59.5). The regulations also impose extreme separation requirements on providers who offer, refer for, support, or present abortion as an option with non-Title X funding. *Id.* at 7789 (promulgating 42 C.F.R. §§ 59.15) (stating that financial separation is no longer sufficient and grantees must have separate facilities, emails, phone numbers, websites, and staff).

These regulations offer a stark choice for health care providers. Health care providers work according to standards of conduct that require them to “[p]resent relevant information accurately and sensitively, in keeping with the patient’s preferences for receiving medical information,” including “burdens, risks, and expected benefits of *all options*, including forgoing treatment.” Am. Med. Ass’n, *Informed Consent, Code of Medical Ethics, Opinion 2.1.1*, <https://www.ama-assn.org/delivering-care/informed-consent> (emphasis added). Health care providers seek to ensure informed consent that “includes a mutual sharing of information ... between the clinician and the patient to facilitate the patient’s autonomy in the process of making ongoing decisions.” Am. Coll. of Obstetricians and Gynecologists, *Committee Opinion Number 439: Informed Consent* (reaffirmed 2015), <https://www.acog.org/-/media/Committee-Opinions/Committee-on-Ethics/co439.pdf>. Health care providers also have policies related to adolescent health that address confidentiality for particular health care settings, special populations, and specific services, including testing and treatment for sexually transmitted diseases (STDs), contraception, and pregnancy-related care. Am. Med. Ass’n, *Code of Medical Ethics’ Opinion on Adolescent Care*, 16 AM. MED. ASS’N J. OF ETHICS 901-902 (2014), <https://journalofethics.ama-assn.org/article/ama-code-medical-ethics-opinion-adolescent-care/2014-11>.

By limiting what providers can say and do, the revised Title X regulations “will force health centers to choose between allowing federal regulations to dictate what they discuss with their patients and losing a critical source of revenue that supports patient care. Either way, patients w[ill] not be well-served.” Amy Simmons, *NACHC Statement Regarding New Rules for Title X Family Planning Program*, National Association of Community Health Centers (Feb. 28, 2019), <http://www.nachc.org/nachc-statement-regarding-new-rules-for-title-x-family-planning-program/>. The predictable result is that providers will forego Title X funding in order to honor medical standards and their ethical obligations to their patients. In Title X programs across the country, that will result in fewer services, shorter hours of operation, health center closures, and worsening health outcomes.

II. TITLE X PROGRAMS CURRENTLY OPERATE TO PROVIDE ACCESS FOR UNDERSERVED POPULATIONS.

In 2017 alone, Title X sites provided high quality family planning services to more than four million patients.² Sixty-seven percent of these patients had family incomes at or below FPL, while 23% had incomes ranging from 101% to 250% FPL.³ Thus, 90% of all patients qualified for subsidized or no-charge services.

² U.S. Dep’t of Health & Human Servs., Office of Population Affairs, *Title X Family Planning Annual Report: 2017 National Summary* at ES-1 (Aug. 2018) [hereinafter “HHS Report”], <https://www.hhs.gov/opa/sites/default/files/title-x-fpar-2017-national-summary.pdf>.

³ *Id.* at 21.

Of the four million patients, 42% were uninsured.⁴ While a significant majority of them were women, 12% were male.⁵ One-third identified as Hispanic or Latino, and 13% were limited English proficient.⁶ About 22% identified as African American or Black; 4%, Asian; 1%, either American Indian, Alaska Native, Native Hawaiian, or Other Pacific Islander; 4% identified as two or more of these.⁷

The family planning services provided at these Title X sites resulted in significant reductions in unintended pregnancies, unplanned births, and abortions. Without them, the U.S. rates of unintended pregnancy, unplanned birth and abortion each would have been 33% higher; the teen pregnancy rate, 30% higher.⁸ These reductions correspond with improvements in women's health, as unintended pregnancies are associated with negative outcomes, including depression, physical violence, and maternal mortality.⁹ Unintended pregnancies also increase the risk of

⁴ *Id.*

⁵ *Id.* at 9.

⁶ *Id.* at 12, 22.

⁷ *Id.* at 12.

⁸ Jennifer J. Frost et al., *Contraceptive Needs and Services, 2014 Update*, Guttmacher Inst. at 1 (2016), https://www.guttmacher.org/sites/default/files/report_pdf/contraceptive-needs-and-services-2014_1.pdf.

⁹ Healthy People 2020, *Family Planning*, <https://www.healthypeople.gov/2020/topics-objectives/topic/family-planning>.

dropping out of school, limited educational attainment and employment opportunities, and lower income in the long term.¹⁰

During 2017, approximately 2.8 million women who were served at Title X sites adopted or continued use of a medically approved form of contraception.¹¹

Title X centers also provided: pap testing for 649,266 people, with many receiving additional evaluation and treatment; breast cancer screening for 878,491 women, with 5% referred for further evaluation; HIV testing for 1.2 million women, roughly 2,000 of whom tested positive; gonorrhea testing for 2.4 million women; chlamydia screening for 939,250 women under age 25; and syphilis testing for 709,161 women.¹²

Family planning services such as those provided at Title X sites offer “highly effective evidence-based strategies for reducing infant mortality.”¹³ Title X-funded sites also addressed substance use disorders (SUDs). Title X clinics are often the point of entry for women and young people to receive any preventive

¹⁰ Ronnie Cohen, *Denial of Abortion Leads to Economic Hardship for Low-income Women*, Reuters Health (Jan. 18, 2018), <https://www.reuters.com/article/us-health-abortion-hardship/denial-of-abortion-leads-to-economic-hardship-for-low-income-women-idUSKBN1F731Z>; Inst. for Women’s Pol. Research, *Reproductive Health and Women’s Educational Attainment: Women’s Funds Strategies to Improve Outcomes for Women* at 8 (Oct. 2015), <https://iwpr.org/wp-content/uploads/wpallimport/files/iwpr-export/publications/R465-WFN%20Women's%20Reproductive%20Health%20Status%2010.23.2015.pdf>.

¹¹ *HHS Report*, *supra* note 2, at 27.

¹² *Id.* at 41, 44.

¹³ Michael C. Lu et al., *Toward a National Strategy on Infant Mortality*, 104 Am. J. of Pub. Health S13 (Feb. 2014).

services, thus enabling interventions that prevent the development of opioid misuse.¹⁴ HHS said a major focus for 2019 would be “[p]roviding the tools necessary for the inclusion of substance abuse disorder screening into family planning services offered by Title X applicants[.]”¹⁵ Unfortunately, this prioritization stands to be overshadowed by reductions in access to SUD services as Title X sites limit care or close due to the challenged regulations.

As discussed below, the health services provided at Title X sites are essential for patients across the gender, racial and ethnic, disability, and age spectrums.

A. The regulations will harm underserved population groups whose particular needs have been met by Title X providers.

Millions of people in the United States are members of underserved population groups with high health care needs. Millions of them have been served by Title X providers and would be harmed if their access to care were limited.

1. People of color

Due to historical and ongoing racial discrimination, people of color experience high rates of poverty.¹⁶ People of color also confront persistent

¹⁴ *Id.*

¹⁵ Office of Population Affairs, U.S. Dep’t of Health & Human Servs., *Fiscal Year 2019 Program Priorities* (Nov. 16, 2018), <https://www.hhs.gov/opa/title-x-family-planning/about-title-x-grants/program-priorities/index.html>.

¹⁶ Kaiser Family Found., *Poverty Rate by Race/Ethnicity, 2017*, <https://www.kff.org/other/state-indicator/poverty-rate-by-raceethnicity> (noting 20% poverty rate for Blacks, 16% for Hispanics, and 22% for American Indian/Alaska Natives, compared to 8% for Whites).

structural and personal biases and discrimination when seeking health care.¹⁷ These factors create barriers to obtaining timely and quality care with devastating health consequences.

People of color rely disproportionately on Title X-funded services for reproductive care. For example, African American individuals represent about 22% of those receiving services at Title X-funded sites but comprise about 13% of the U.S. population.¹⁸ Hispanic or Latino individuals represent 33% of those using Title X sites but comprise 18.1% of the U.S. population.¹⁹ Latino individuals choose Title X sites for a variety of reasons. Title X care sites are more likely to offer linguistically accessible services.²⁰

¹⁷ Monique Tello, *Racism and Discrimination in Health Care: Providers and Patients*, Harvard Health Blog (Jan. 16, 2017), <https://www.health.harvard.edu/blog/racism-discrimination-health-care-providers-patients-2017011611015>; Inst. of Med., Comm. on Understanding and Eliminating Racial and Ethnic Disparities in Health Care, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (2003), <https://www.ncbi.nlm.nih.gov/books/NBK220344/>.

¹⁸ U.S. Census Bureau, *Comparative Demographic Estimates: 2017 American Community Survey 1-Year Estimates*, https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_17_1YR_CP05; *HHS Report*, *supra* note 2.

¹⁹ U.S. Census Bureau, *Comparative Demographic Estimates: 2017 American Community Survey 1-Year Estimates*, https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_17_1YR_CP05; *HHS Report*, *supra* note 2, at A-13.

²⁰ Heike Thiel de Bocanegra et al., *Enhancing Service Delivery through Title X Funding: Findings from California*, Persps. on Sexual and Reprod. Health (Dec. 2012), <https://onlinelibrary.wiley.com/doi/full/10.1363/4426212?>

By reducing and in some places eliminating access to quality reproductive care that current Title X sites provide, the regulations will exacerbate the health disparities that people of color experience. For example, black women experience higher rates of unintended pregnancy, in addition to higher rates of STDs that may lead to pelvic inflammatory disease and infertility if left untreated.²¹ When compared to white women, “black women are 2 to 6 times more likely to die from complications of pregnancy . . . depending on where they live.”²² Overall, “black women have a pregnancy-related mortality ratio approximately three times as high as that of white women.”²³ Black infants also die at dramatically higher rates than

²¹ E. Angel Aztlan-James et al., *Multiple Unintended Pregnancies in U.S. Women: A Systematic Review*, Women’s Health Issues, Jul.-Aug. 2017, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5511571/>; Ctrs. Disease Control & Prev., *Health Disparities in HIV/AIDS, Viral Hepatitis, STDs, and TB: African Americans/Blacks* (Oct. 4, 2016),

<https://www.cdc.gov/nchhstp/healthdisparities/africanamericans.html>; Ctrs. Disease Control & Prev., *Sexually Transmitted Disease Surveillance 2017: STDs in Women and Infants* (July 24, 2018),

<https://www.cdc.gov/std/stats17/womenandinf.htm#pid>.

²² Mary Beth Flanders-Stepans, *Alarming Racial Differences in Maternal Mortality*, 9 J. Perinatal Educ. 50 (Spring 2000),

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1595019/>.

²³ Emily E. Peterson, MD et al., Ctrs. Disease Control and Prev., *Vital Signs: Pregnancy-Related Deaths, United States, 2011–2015, and Strategies for Prevention, 13 States, 2013–2017*, May 10, 2019,

https://www.cdc.gov/mmwr/volumes/68/wr/mm6818e1.htm?s_cid=mm6818e1_w.

white infants.²⁴ Black individuals are disproportionately affected by HIV, representing 43% of new HIV diagnoses in the U.S. in 2017.²⁵

Hispanic/Latino individuals similarly experience significant health disparities. For example, Latinas have higher rates of unintended pregnancy, and they are more likely to be affected by STDs, such chlamydia, gonorrhea, and syphilis, than white women.²⁶ Hispanic/Latino women have “among the highest rates for cancers associated with infectious agents,” including cervical cancer incidence rates that are about 40% higher than those in non-Hispanic whites.²⁷ One study, consistent with others of its kind, found that Latino women “who sought health services at community clinics were more likely to have received cervical cancer screening compared to those who went to private doctors.”²⁸

²⁴ Imari Z. Smith et al., *Fighting at Birth: Eradicating the Black-White Infant Mortality Gap*, at 1, Duke Univ. Samuel DuBois Cook Center on Social Equity and Insight Center for Comm. Econ. Dev. (Mar. 2018), <https://socialequity.duke.edu/sites/socialequity.duke.edu/files/site-images/EradicatingBlackInfantMortality-March2018-DRAFT4.pdf>.

²⁵ Ctrs. Disease Control & Prev., *HIV and African Americans* (Mar. 19, 2019), <https://www.cdc.gov/hiv/group/raciaethnic/africanamericans/index.html>.

²⁶ Ctrs. Disease Control & Prev., *Health Disparities in HIV/AIDS, Viral Hepatitis, STDs, and TB: Hispanics/Latinos* (Feb. 1, 2017), <https://www.cdc.gov/nchhstp/healthdisparities/hispanics.html>.

²⁷ Am. Cancer Society, *Cancer Facts & Figures* at 50 (2017), <https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2017/cancer-facts-and-figures-2017.pdf>.

²⁸ Patria Rojas et al., *Correlates of Cervical Cancer Screening Among Adult Latino Women: A 5-Year Follow-Up*, 9 *World Medical & Health Policy* 239 (Jun. 2017), <https://onlinelibrary.wiley.com/doi/full/10.1002/wmh3.230>.

Losing access to comprehensive reproductive health care offered through Title X programs will only make these problems worse.

2. People in rural areas

Almost 60 million people, nearly 20% of the U.S. population, live in areas classified as rural by the U.S. Census Bureau.²⁹ These people are at increased risk for numerous health problems and limited access to essential health services. Title X providers are critical for people in rural areas.

Rural or “nonmetro” areas of the country have the highest poverty rates. Overall, the 2017 U.S. poverty rate was 12.9% for metro areas and 16.4% for nonmetro areas, with the highest poverty rates (20% or higher) in the nonmetro areas of 10 states in the South and Southwest.³⁰ An even higher percentage (25%) of the nonelderly rural population, which includes the age group most likely to rely on Title X providers, has a family income below the FPL.³¹

²⁹ Office of Rural Health Policy, Health Resources and Services Administration, U.S. Dep’t. of Health & Human Servs., *Defining Rural Population* (last modified Dec. 2018), <https://www.hrsa.gov/rural-health/about-us/definition/index.html>.

³⁰ Rural Health Information Hub, *Rural Data Explorer*, <https://www.ruralhealthinfo.org/data-explorer> (last visited June 30, 2019).

³¹ Vann Newkirk & Anthony Damico, *The Affordable Care Act and Insurance Coverage in Rural Areas*, at 1, fig. 1 (May 29, 2014), <https://www.kff.org/uninsured/issue-brief/the-affordable-care-act-and-insurance-coverage-in-rural-areas/>.

People in rural areas not only represent different demographics than their urban counterparts, they also have more limited access to health care.³² Rural residents report that their communities do not have enough doctors (33%) or hospitals (23%) and that it is difficult to pay for health care (24%) and their own health is only fair or poor (23%).³³ Rural patients must often travel long distances to obtain care; moreover, rural populations are more likely to experience transportation barriers than those in urban areas.³⁴

Some of the health challenges experienced by people in rural areas are of particular relevance in the context of Title X. Overall, the U.S. population experiences high rates of STDs, with 110 million STDs in men and women and 20 million new infections annually.³⁵ However, the seven states with the highest rates of reportable STDs (chlamydia, gonorrhea, and/or syphilis) were also states with

³² *Id.* at 1.

³³ Liz Hamel et al., *The Health Care Views and Experiences of Rural Americans: Findings from The Kaiser Family Foundation/Washington Post Survey of Rural America*, at 4, fig. 2, Kaiser Family Found., <http://files.kff.org/attachment/Report-The-Health-Care-Views-and-Experiences-of-Rural-Americans>, accessed June 30, 2019.

³⁴ Jonathan M. Bearak et al., *Disparities and Change Over Time in Distance Women Would Need to Travel to Have an Abortion in the USA: A Spatial Analysis*, 2 *Lancet Pub. Health* 493 (2017), [https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667\(17\)30158-5/fulltext](https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667(17)30158-5/fulltext).

³⁵ Bahar Gholipour, *Hidden STD Epidemic: 110 Million STD infections in the US*, LiveScience (Oct. 6, 2014), <https://www.livescience.com/48100-sexually-transmitted-infections-50-states-map.html>.

high rates of poverty in nonmetro areas.³⁶ HIV also has a greater impact on rural areas. Overall, a majority of new HIV diagnoses are in urban areas, but in the South and Midwest a higher proportion are in suburban and rural areas than in other regions.³⁷ States with the highest rates of new HIV diagnoses in 2017 included Florida, Georgia, and Louisiana, which are also among the states with a high poverty rate in nonmetro areas.³⁸ Rural women also experience higher rates of cervical cancer and lower rates of screening than those in non-rural areas.³⁹ Living in a rural area is also predictive of elevated neonatal mortality, post-neonatal mortality, and infant mortality.⁴⁰

Over the years, the Title X program has brought family planning services to rural areas. There is at least one Title X-funded health center in about 75% of all

³⁶ *Id.*; *Rural Data Explorer*, *supra* note 30.

³⁷ Ctrs. Disease Control & Prev., *HIV in the United States by Region*, <https://www.cdc.gov/hiv/statistics/overview/geographicdistribution.html> (last accessed June 30, 2019) [hereafter “CDC, HIV Infection by Region”].

³⁸ *Id.*; *Rural Data Explorer*, *supra* note 30.

³⁹ Am. Coll. of Obstet. & Gynec., Comm. on Health Care for Underserved Women, *Committee Opinion: Health Disparities in Rural Women* (Feb. 2014), <https://www.acog.org/Clinical-Guidance-and-Publications/Committee-Opinions/Committee-on-Health-Care-for-Underserved-Women/Health-Disparities-in-Rural-Women?>

⁴⁰ Danielle M. Ely & Donna L. Hoyert, *Differences Between Rural and Urban Areas in Mortality Rates for the Leading Causes of Infant Death: United States, 2013-2015*, Ctrs. Disease Control & Prev. (Feb. 2018), <https://www.cdc.gov/nchs/products/databriefs/db300.htm>.

counties in the United States.⁴¹ Even with these essential services in place, research indicates there are still 19.5 million women in need of publicly funded contraception living in contraceptive deserts, where they lack reasonable access to a clinic that offers the full range of family planning methods.⁴² Of those women, 1.6 million live in counties with no clinic offering the full range of methods. Without Title X, that number would nearly triple to 4.3 million women.⁴³

In the communities they serve, Title X providers offer quality, comprehensive reproductive care and are more likely than other health care provider sites to dispense contraceptives, including prescription contraceptives, on-site.⁴⁴ When current Title-X sites are forced to reduce their capacity or close entirely, access to these services will be lost, plain and simple. The inevitable loss of Title X centers will be a particular blow to rural America. The track record is not in question. After Texas cut funding to comprehensive reproductive health providers in 2013, 25% of family planning clinics in Texas closed. Many of these were located in rural areas. Title X organizations served 54% fewer clients than

⁴¹ Nat'l Family Planning & Repro. Health Ass'n, *Title X: Helping to Ensure Access to High-Quality Care* at 4 (Mar. 2015), <https://www.nationalfamilyplanning.org/document.doc?id=514>.

⁴² Ginny Ehrlich, *Too Many Women Lack Birth Control Access*, Power to Decide (May 22, 2019), <https://powertodecide.org/news/too-many-women-lack-birth-control-access>.

⁴³ *Id.*

⁴⁴ Rachel Benson Gold, *Going the Extra Mile: The Difference Title X Makes*, 2 *Guttmacher Pol. Rev.* 15 (Spring 2012), <http://www.guttmacher.org/pubs/gpr/15/2/gpr150213.html>.

they had previously. Women were referred to other clinics, often with wait lists, that did not offer the full range of contraceptive methods and that were usually further away.⁴⁵ Clearly, reduced access to quality reproductive health services will only magnify the health risks facing individuals who live in rural areas.

3. People with disabling conditions

Women are more likely than men to report a disability.⁴⁶ According to the CDC, “disability was more frequently reported by non-Hispanic blacks (29.0%) and Hispanic (25.9%) adults than by white non-Hispanic (20.6%) adults.”⁴⁷

Compared with individuals without a disability, individuals with disabilities earn less money and are more likely to have income below the FPL.⁴⁸

⁴⁵ Kari White K et al., *The Impact of Reproductive Health Legislation on Family Planning Clinic Services in Texas*, 105 Am. J. of Pub. Health 851 (May 2015).

⁴⁶ Research and Training Center on Disability in Rural Communities, *Rates of Disability by Gender – Disability in America Series*, <http://rtc.ruralinstitute.umt.edu/research-findings/geography/rate-disability-gender/> (last visited July 3, 2019).

⁴⁷ Ctrs. Disease Control & Prev., *Prevalence of Disability and Disability Type among Adults, United States – 2013*, <https://www.cdc.gov/ncbddd/disabilityandhealth/features/key-findings-community-prevalence.html#BRFSS> (last visited June 27, 2019).

⁴⁸ Institute on Disability, Univ. of New Hampshire, *2018 Annual Report on People With Disabilities in America*, at 7-10 (2018), https://disabilitycompendium.org/sites/default/files/user-uploads/Annual_Report_2018_Accessible_AdobeReaderFriendly.pdf.

Individuals with disabilities face additional, unique barriers to accessing necessary health care services.⁴⁹ For example, individuals with limited mobility encounter buildings, exam tables, and/or medical equipment that are not accessible.⁵⁰ Lack of accessible transportation to and from medical offices is a problem.⁵¹ In addition, providers often do not offer effective communication for patients with developmental disabilities or for individuals who are deaf or hard of hearing.⁵² What is more, research shows that provider attitudes and knowledge gaps continue to prevent individuals with disabilities from obtaining adequate, patient-centered reproductive health care.⁵³

⁴⁹ Tara Lagu et al., *Ensuring Access to Health Care for Patients with Disabilities*, 175 JAMA Internal Medicine 157 (2015).

⁵⁰ Elizabeth Pendo, *Disability Equipment Barriers, and Women's Health: Using the ADA to Provide Meaningful Access, Examination Tables and Pelvic Exams*, 2 St. Louis U. Health L. & Pol'y. J. 15, 23-27 (2009).

⁵¹ Julia A. Rivera Drew & Susan E. Short, *Disability and Pap Smear Receipt Among U.S. Women, 2000 and 2005*, 42 Persps. Sexual & Reprod. Health 258-266, <https://www.guttmacher.org/journals/psrh/2010/11/disability-and-pap-smear-receipt-among-us-women-2000-and-2005>.

⁵² David A. Ervin et al., *Healthcare for Persons with Intellectual and Developmental Disability in the Community*, 2 Frontiers Public Health 83 (2014); Alexa Kuenburg et al., *Health Care Access Among Deaf People*, 21 J. Deaf Studies and Deaf Education 1 (2016).

⁵³ Heather Becker et al., *Reproductive Health Care Experiences of Women with Physical Disabilities: A Qualitative Study*, 78 Archives Physical Med. & Rehabilitation S26, S31 (1997); Clair Kaplan, *Special issues in contraception: caring for women with disabilities*, 51 J. Midwifery & Women's Health 450 (2006).

As a result of these and other factors, individuals with disabilities experience disparities. People with disabilities “are more likely to experience physical, emotional, or sexual abuse, experience sexual assault, or become infected with HIV and other STIs,” some of which significantly increase the risk of unplanned or coerced pregnancy, and all of which have implications for reproductive health and needs.⁵⁴ They are less likely to receive breast and cervical cancer screening.⁵⁵ A recent study found that women with intellectual or developmental disabilities were almost three times less likely than individuals without a disability to have received a pap test in the past three years.⁵⁶ By making it more difficult, or even impossible, to access quality reproductive health services through Title X, the challenged rules will be especially harmful to the health of individuals with disabilities.

⁵⁴ Nat’l Ass’n Cty. & City Health Officials, *Including People with Disabilities in Reproductive Health Programs and Services* at 1 (June 2015), https://www.naccho.org/uploads/downloadable-resources/Fact-Sheet_Reproductive-Health.pdf.

⁵⁵ Susan M. Havercamp & Haleigh M. Scott, *National health surveillance of adults with disabilities, adults with intellectual and developmental disabilities, and adults with no disabilities*, 8 *Disability & Health J.* 165, 169 (2015); W. Horner-Johnson et al., *Disparities in receipt of breast and cervical cancer screening for rural women age 18 to 64 with disabilities*, 25 *Women’s Health Issues* 246 (2015).

⁵⁶ Susan M. Havercamp & Haleigh M. Scott, *supra* note 55, at 169.

B. The regulations will harm adolescents whose particular health and service delivery needs are being met by Title X providers.

Almost 42 million people in the United States are adolescents between the ages of 10 and 19.⁵⁷ Millions of them are being served by Title X providers and would be harmed if their access to those providers were limited.

1. The need for comprehensive reproductive health services

Many adolescents are sexually active. Approximately half of adolescents have ever had sex.⁵⁸ In 2013, more than 450,000 adolescents younger than age 20 became pregnant, with more than 82% of these pregnancies unintended.⁵⁹ Therefore, access to contraceptive services is essential for prevention of unintended teen pregnancy.⁶⁰ Adolescent pregnancy rates have declined dramatically in recent years and, according to the Guttmacher Institute, although multiple factors may have contributed to these declines, “[t]he evidence clearly indicates that more and better contraceptive use has been the main factor driving

⁵⁷ Office of Adoles. Health, U.S. Dep’t of Health & Human Servs., *The Changing Face of America’s Adolescents*, <https://www.hhs.gov/ash/oah/facts-and-stats/changing-face-of-americas-adolescents/index.html>, last visited Jul. 4, 2019.

⁵⁸ Heather Boonstra, *What is Behind the Declines in Teen Pregnancy Rates?*, 17 *Guttmacher Pol’y Rev.* 15, 16 (2014) (assessing data from 2003-2010).

⁵⁹ Kathryn Kost et al., *Pregnancies, Births and Abortions Among Adolescents and Young Women in the United States, 2013: National and State Trends by Age, Race and Ethnicity* at 15 (2017), https://www.guttmacher.org/sites/default/files/report_pdf/us-adolescent-pregnancy-trends-2013.pdf; Boonstra, *supra* note 58.

⁶⁰ Am. Acad. of Ped., Committee on Adoles., *Policy Statement: Contraception for Adolescents*, 134 *J. Pediatrics* e1244, e1258 (2014).

the long-term decline in teen pregnancy.”⁶¹ Between 2003 and 2010, adolescents’ use of the more effective contraceptive methods—including hormonal, dual use of both hormonal and barrier methods, and long-acting reversible contraceptives (LARC)—increased significantly, contributing to the decline in pregnancy rates.⁶²

Adolescents also are at serious risk for STDs and HIV. According to the CDC, half of new STDs each year are in young people ages 15-24; and one in four sexually active adolescent females has an STD.⁶³ In 2017, youth ages 13-24 represented one-fifth (21%) of new HIV infections.⁶⁴ Sexually active adolescents ages 15–19 years and young adults ages 20–24 years are at higher risk of acquiring STDs compared with older adults, for a combination of behavioral, biological, and cultural reasons.⁶⁵ Adolescents and young adults experience multiple barriers to accessing quality STD services.⁶⁶

⁶¹ Boonstra, *supra* note 58, at 15; Laura Lindberg et al., *Understanding the Decline in Adolescent Fertility in the United States, 2007-2012*, 59 J. Adolesc. Health 577 (2016).

⁶² Boonstra, *supra* note 58, at 16-17.

⁶³ Ctrs. Disease Control & Prev., *STDs in Adolescents and Young Adults, 2017* (2018), <https://www.cdc.gov/std/stats17/adolescents.htm>; Sara E. Forhan et al., *Prevalence of sexually transmitted infections among female adolescents aged 14 to 19 in the United States*, 124 J. Pediatrics 1505 (2009).

⁶⁴ Ctrs. Disease Control & Prev., *HIV Surveillance Report, 2017* (Nov. 2018), <http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>.

⁶⁵ Ctrs. Disease Control & Prev., *STDs in Adolescents and Young Adults*, *supra* note 63.

⁶⁶ Elizabeth C. Tilson et al., *Barriers to asymptomatic screening and other STD services for adolescents and young adults: focus group discussions*, 4 BMC Pub. Health 21 (2004).

2. Special circumstances and limited access

Many adolescents are members of vulnerable groups in the U.S. population who have significant health needs and whose access to health care is limited. These include youth in foster care and aging out, youth who have had contact with the juvenile and criminal justice systems, and homeless youth.⁶⁷ Many of these young people are also members of racial and ethnic minority groups.⁶⁸

Hundreds of thousands of children and youth are in foster care in the United States and tens of thousands of adolescents and young adults age out of foster care each year. Adolescents in the child welfare system experience high rates of sexual and reproductive health problems for which they need access to health care.⁶⁹

While in foster care, they are generally eligible for and enrolled in Medicaid, but historically health insurance coverage has been severely limited once they age out; the ACA reversed that trend by requiring states to provide Medicaid coverage for most youth as they age out of foster care up to age 26.⁷⁰

⁶⁷ Abigail English et al., *Implementing the Affordable Care Act: How Much Will It Help Vulnerable Adolescents and Young Adults?*, Ctr. for Adoles. Health & the Law, Nat'l Adoles. & Young Adult Health Information Ctr., at 1–6 (2014), http://nahic.ucsf.edu/wp-content/uploads/2014/01/VulnerablePopulations_IB_Final.pdf.

⁶⁸ *Id.*

⁶⁹ Kym R. Ahrens et al., *Laboratory-diagnosed Sexually Transmitted Infections in Former Foster Youth Compared with Peers*, 126 *J. Pediatrics* 97 (2010); Sigrid James et al., *Sexual Risk Behaviors Among Youth in the Child Welfare System*, 31 *Children & Youth Servs. Rev.* 990 (2010).

⁷⁰ English et al., *supra* note 67, at 2.

Millions of adolescents and young adults in the United States have some contact with either the juvenile justice system or the criminal justice system. These youth experience high rates of numerous health concerns and widely varying access to health insurance coverage and the health care they need.⁷¹ They often depend on safety net providers for their health care.

Homeless youth are among those most disconnected from social and adult support and are among the most vulnerable young people. Although the precise size of the homeless population is unknown, there is little doubt that many thousands of youth are homeless for either short or long periods of time. These young people experience very high rates of serious health problems, including sexual and reproductive health issues, and great difficulty accessing needed health care.⁷² Many homeless youth are either uninsured or unable to use their insurance coverage and thus require access to safety net providers such as Title X sites.

3. The critical need for confidentiality

Numerous reasons exist to protect confidentiality for adolescents and young adults. The most compelling is to encourage young people to seek necessary care on a timely basis and to provide a candid and complete health history when they do so, to protect both their individual health and the public health. Decades of

⁷¹ *Id.* at 3-4.

⁷² *Id.* at 5-6; Marcela Smid et al., *The Challenge of Pregnancy among Homeless Youth: Reclaiming a Lost Opportunity*, 21 J. Health Care Poor & Underserved 140 (2010).

research findings have documented the importance of privacy concerns, which influence young people's use of health care in many ways. Many adolescents are concerned about disclosure to their parents of information related to sexual behaviors, substance use, and mental health. This is true even though many adolescents voluntarily share a lot of health information with their parents and other trusted adults. Specifically, concerns about confidentiality and disclosure can affect whether adolescents seek care, where they seek care, and how openly they talk with health care professionals.⁷³ The effect of privacy concerns has been especially well documented with respect to adolescents' use of sexual health services, including care related to contraception, pregnancy, and STDs⁷⁴

4. The essential role of Title X providers

Even though many adolescents have been able to gain public or private insurance coverage for contraceptive services as a result of the ACA, publicly supported family planning centers, including Title X sites, continue to play an especially important role for adolescents, in part because they can provide

⁷³ Carol Ford et al., *Confidential Health Care for Adolescents: Position Paper of the Society for Adolescent Medicine*, 35(2) J. Adolesc. Health 160 (2004).

⁷⁴ Carol Ford, et al., *Confidentiality and Adolescents' Willingness to Consent to STD Testing*, 155 Arch. Pediatr. Adolesc. Med. 1072 (2001); Diane M. Reddy et al., *Effect of Mandatory Parental Notification on Adolescent Girls' Use of Sexual Health Care Services*, 288 JAMA 710 (2002); Rachel K. Jones, *Adolescents' Reports of Parental Knowledge of Adolescents' Use of Sexual Health Services and Their Reactions to Mandated Parental Notification for Prescription Contraception*, 293 JAMA 340 (2005).

confidential services.⁷⁵ In 2010, nearly five million adolescents under age 20 were in need of publicly funded family planning services.⁷⁶ More than one million were served at Title X funded sites, helping to prevent hundreds of thousands of unintended pregnancies, unplanned births, and abortions in this age group.⁷⁷ These young people also have had access through Title X to screening, testing, diagnosis, and treatment for STDs. Limiting adolescents' access to Title X services would almost certainly result not only in higher numbers of pregnancies, unplanned births, and abortions, but also would be associated with more undiagnosed and untreated STDs, with corresponding harms to the health of adolescents, their sexual partners, and the public health.

⁷⁵ Boonstra, *supra* note 58, at 20; Abigail English & National Family Planning & Reprod. Health Ass'n, *Adolescent Confidentiality Protections in Title X* (2014), <https://www.nationalfamilyplanning.org/document.doc?id=1559>.

⁷⁶ Jennifer J. Frost et al., *Contraceptive Needs and Services, 2010*, at 7 (2013), <http://www.guttmacher.org/pubs/win/contraceptive-needs-2010.pdf>.

⁷⁷ *Id.* at 40, App. Tbl. 6.

CONCLUSION

For the foregoing reasons, *amicus curiae* ask the Court to affirm the preliminary injunctions.

July 5, 2019

Respectfully submitted,

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CERTIFICATE OF COMPLIANCE

I certify that this brief complies with the requirements of Fed. R. App. P. 32(a)(5) and (6) because it has been prepared in 14-point Times New Roman, a proportionally spaced font. I certify that the foregoing brief complies with the requirements of Fed. R. App. P. 32(a)(7)(B) and 29(a)(5), and that the total number of words in this brief is 5602 according to the count of Microsoft Word, excluding the parts of the brief exempted by Fed. R. App. P. 32(f).

Date: July 5, 2019

/s/ Jane Perkins
Jane Perkins

CERTIFICATE OF SERVICE

I certify that on July 5, 2019, I electronically filed the forgoing brief with the Clerk of the Court by using the CM/ECF system.

/s/Jane Perkins
Jane Perkins