September 30, 2013

U.S. Department of Health and Human Services
Office for Civil Rights
Attention: RIN 0945-AA02
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue SW
Washington, D.C. 20201

RE: Request for Information Regarding Nondiscrimination in Certain Health Programs or Activities

Dear Director Rodriguez:

The National Partnership for Women & Families commends the Department of Health and Human Services (HHS) for the extraordinary effort that has gone into developing comprehensive regulations, guidance, and grant programs to implement the Patient Protection and Affordable Care Act (ACA). The National Partnership represents women and families who are eagerly anticipating the October 1 launch of health insurance marketplaces and the promise of quality, equitable coverage in 2014. Women across the country are counting on the ACA and HHS to finally put in place a health care system that works for them.

One of the key issues that the ACA tries to address is the history of discrimination against women in the health insurance market and in the provision of health services. While multiple provisions in the health care law are already working to put an end to past practices that unjustly denied women access to needed health care benefits and services, Section 1557’s prohibition against discrimination on the grounds of race, national origin, sex, age, or disability in health programs or activities will provide women with the legal protection they need to ensure and enforce their ability to receive equitable, timely access to a full range of health care services. A landmark provision, Section 1557 marks the first time that federal civil rights law has prohibited discrimination on the basis of sex in health programs or activities, thus significantly expanding the protections afforded to individuals seeking and receiving health care.

We commend the Department as well on taking the first step towards implementing Section 1557 of the Affordable Care Act. Individuals face discrimination on the basis of sex and gender identity at every step in the health care system, and this type of discrimination takes many forms. Robust implementation of the law’s nondiscrimination provision is necessary to ensure that all applicable actors in the health care industry – health plans, marketplaces, navigator assistors, hospitals, providers, federally funded researchers, etc. – are held accountable to Section 1557’s prohibition on discrimination in health programs and activities. Moreover, it is critical to ensuring that consumers are well-informed of their
rights and the enforcement mechanisms and remedies that are available to them if they are unlawfully subjected to discriminatory practices.

While the National Partnership appreciates this step toward implementing Section 1557, we respectfully reiterate the vital and immediate need for robust guidance on nondiscrimination in health programs and activities, and we urge the Department to issue implementing regulations as quickly as possible following the completion of the Request for Information period. Entities created under Title I of the Affordable Care Act – including qualified health plans, state-facilitated marketplaces, federally facilitated marketplaces, and Navigators – are being constructed and launched now, for enrollment beginning October 2013 and coverage beginning January 2014, without crucial guidance on the issue of discrimination. While the Department undertakes the rulemaking process, we urge continued close engagement and communication with marketplaces and qualified health plans, so as to ensure that (a) all plans offered in the marketplace provide all protected classes with equitable, accessible services and benefits and (b) marketplaces have in place the procedures necessary to prevent discriminatory practices – including compliance assurances from participating health plans, notices to enrollees of their rights, case management facilitation, and periodic reviews and enforcement.

Thank you for the opportunity provided at this time to submit additional information on discrimination on the basis race, national origin, gender, age, and disability in health programs or activities. In keeping with our organization’s legal and policy expertise, we have focused our response on sex discrimination in the provision of health care coverage and services and on questions concerning health information technology. The following includes information on the nature, form, and impacts of discrimination on the basis of sex and recommendations for how to structure implementing regulations so as to ensure strong protections against discrimination. Below we provide specific suggestions to help ensure that the regulations and your agency are as strong as possible.

**Question 1. Please describe experiences that you have had, or examples of which you are aware, with respect to the following types of discrimination in health programs and activities: (a) Race, color, or national origin discrimination; (b) Sex discrimination (including discrimination on the basis of gender identity, sex stereotyping, or pregnancy); (c) Disability discrimination; (d) Age discrimination; or (e) discrimination on one or more bases, where those bases intersect.**

**Response to Question 1**

Section 1557 provides that no health program or activity receiving federal financial assistance, program administered by an executive agency, or entity established by Title I of the ACA may discriminate “on the ground prohibited under title VI of the Civil Rights Act of 1964, title IX of the Education Amendments of 1972, the Age Discrimination Act of 1975, or section 504 of the Rehabilitation Act of 1973.” Therefore, section 1557 prohibits discrimination on the basis of race, color, national origin, sex, age and disability in health programs or activities that receive federal financial assistance, in programs administered by an Executive agency, or by entities established under Title I of the ACA.
Discrimination by health programs and activities can take many forms and manifests at every step in the health care delivery system – from obtaining insurance coverage, to accessing a provider, to receiving a proper diagnosis and treatment, to utilizing health information technology (health IT). Such unlawful discrimination can have significant, often detrimental, consequences.

Prior to the enactment of the ACA, women faced a number of barriers to accessing affordable, quality care. Women were frequently denied health coverage because of pre-existing conditions that included chronic conditions, complicated past pregnancies, breast and cervical cancer, and seeking medical treatment for domestic violence. Even when enrolled in a health plan, women were often charged more than men for the same coverage policies and frequently did not have coverage for basic services central to women’s health such as maternity care, family planning counseling, and contraceptive supplies.

Before the ACA’s inclusion of maternity care as a required essential health benefit, most individual health plans failed to provide any coverage for maternity services. As a result, women who gave birth without any complications faced average out-of-pocket expenses of $10,652 or more.¹ A 2008 study revealed that only 21 percent of the 3,500 plans reviewed offered any sort of maternity coverage for a 30-year-old woman, and only 12 percent provided comprehensive maternity coverage.²

Contraceptives and family planning counseling are additional health care services that have been inaccessible for many women, despite the fact that contraceptive use is practically universal in the United States.³ For many uninsured women, paying the full cost of contraception, such as birth control, was simply not feasible. Additionally, cost sharing – co-pays, deductibles, and co-insurance – associated with covered contraceptive services put care out of reach for millions of insured women: studies show that even minor co-pays and cost-sharing requirements reduce use of preventive health care services, including contraceptives.⁴ The ACA’s identification of family planning and contraceptive services as a key preventive health service for women that must be covered, at no cost, by all new health plans will greatly improve women’s access to these services. By eliminating cost sharing for contraceptive care, the ACA has already begun to play a key role in breaking down financial barriers to needed family planning care and to improving women’s ability to transition to more effective contraceptive methods.

In addition to denials of coverage and the absence of essential covered benefits, discrimination on the basis of sex often manifests itself in the quality of the medical treatment that women receive, as compared to men. For example, studies have shown that women often receive inequitable care for heart disease. Women are less likely to have an

⁴ Id.
angiogram than men,\textsuperscript{5} diagnostic mistakes are more frequent for women than for men presenting with chest pain in the emergency department,\textsuperscript{6} and women experience worse treatment for an acute myocardial infarction than men.\textsuperscript{7} In a study on care received in emergency departments, findings showed that, of emergency room patients reporting similar symptoms, men were more likely than women to receive morphine to help treat pain.\textsuperscript{8} A 2002 study of Medicare beneficiaries in their last years of life concluded that women were less likely than men to receive expensive high-technology services, such as dialysis and transplantation.\textsuperscript{9}

Discrimination on the basis of sex is also evident in non-sex-specific medical trials. In 2000, only one quarter to one third of the studies funded by the National Institutes of Health (NIH) that were non-sex-specific studies and included women analyzed or stratified data by sex.\textsuperscript{10} While the NIH has modified its policies to support increased inclusion of women and minorities in clinical research,\textsuperscript{11} more recent data suggest that women remain underrepresented in studies and trials. A 2009 study found that women were underrepresented in 75 percent of cancer studies. Even though women make up 45 percent of lung cancer diagnosis, they only made up 31 percent of lung cancer study participants.\textsuperscript{12} That pharmaceuticals and treatments are prescribed to both women and men, but tested primarily on men only, is particularly disconcerting.

Additionally, older women are frequently underrepresented in clinical trials, even when the subject of the trial disproportionately affects elderly women. In a recent trial studying the efficacy of chemotherapy treatment for breast cancer patients, only 8 percent of the trial patients were aged 65 or older and only 2 percent were aged 70 or older. This is despite the fact that 50 percent of new breast cancer diagnoses are made in women aged 65 or older.\textsuperscript{13}

Included in the definition of discrimination on the basis of sex is discrimination based on one’s gender identity. Such discrimination is also prevalent in the health care sector, particularly for transgender individuals. Indeed, 70 percent of transgender and gender non-

\textsuperscript{5} See C. Daly, F. Clemens & J.L. Lopez Sendon, \textit{Gender Differences in the Management and Clinical Outcome of Stable Angina}, 113 \textit{Circulation} 490, 490-498. The study controlled for multiple clinical factors, including the results of exercise testing. \textit{Id.}


\textsuperscript{7} M. Penco et al, \textit{Gender Differences in the Outcome of Noninvasive Cardiovascular Treatment}, \textit{Italian Heart J.}, Aug. 2003, at 514, 514-517.


\textsuperscript{9} C.E. Bird, L.R. Shugarman & J. Lynn, \textit{Age and Gender Differences in Health Care Utilization and Spending for Medicare Beneficiaries in Their Last Years of Life}, \textit{J. Palliative Med.}, Oct. 2002, at 705, 705-712.

\textsuperscript{10} See Regina M. Vidaver et al., \textit{Women Subjects in NIH-Funded Clinical Research Literature: Lack of Progress in Both Representation and Analysis by Sex}, \textit{J. Women’s Health & Gender-Based Med.}, June 2000, at 495, 495-504. The authors also emphasize the necessity of including adequate numbers of women in clinical research to allow for a valid analysis of study results by sex. \textit{Id.}


\textsuperscript{13} Phoebe Weaver Williams, \textit{Age Discrimination in the Delivery of Health Care Services to Our Elders}, MARQ. ELDER’S ADVISOR, Fall 2009, at 1, 24; Mike Milka, \textit{Too Few Older Patients in Cancer Trials: Experts Say Disparity Affects Research Results and Care}, 290 J. Am. Med. Ass’n 27, 28 (2003).
conforming respondents report experiencing some form of discrimination in health care.\textsuperscript{14} For example, one transgender individual who visited a doctor about a sore throat was forced to have a pelvic exam by that provider. The provider invited others to look at the patient while he examined the patient and talked to them about the patient’s genitals. For some transgender individuals, it can be difficult to receive medical care at all. Twenty-seven percent of transgender and gender non-conforming respondents reported being refused needed health care because of their gender identity.\textsuperscript{15} Transgender and gender non-conforming individuals have reported unequal treatment in doctor’s offices, hospitals, emergency rooms, mental health clinics, and drug treatment programs, as well as unequal treatment by EMTs.

Discrimination in health care settings can be particularly pronounced when individuals identify with more than one protected class. For example, African American women generally receive a lower quality of health care than White women, with disparities in early diagnosis of breast cancer and maternal death rates worsening in recent years.\textsuperscript{16} In addition, the percentage of women reporting that their provider did not listen, explain things clearly, respect what they had to say, or spend enough time with them was higher amongst women of color than White women.\textsuperscript{17}

Compound discrimination can also impact the medical treatment individuals receive. Hispanic women and non-Hispanic Black women were less likely to be screened for osteoporosis than White, non-Hispanic women.\textsuperscript{18} Asian American, Native Hawaiian, and Other Pacific Islander women had the lowest rates of mammography and Pap tests of all racial and ethnic groups.\textsuperscript{19} In addition, the percentage of women who indicated that their provider did not include them in making decisions about their care was higher for Asian women than for White women.\textsuperscript{20} American Indian and Alaska Native women were less likely to receive prenatal care during the first trimester and less likely to have their blood cholesterol checked than women of other races and ethnicities.\textsuperscript{21}

Compound discrimination also affects health outcomes. According to the Centers for Disease Control, African American women are over three times more likely than White women to die from pregnancy-related causes.\textsuperscript{22} Further, infants born to non-Hispanic

\textsuperscript{14} \textbf{Lambda Legal}, \textit{When Health Care Isn’t Caring: Lambda Legal’s Survey on Discrimination Against LGBT People and People Living with HIV (2008), available at} http://www.lambdalegal.org/publications/when-health-care-isnt-caring/.

\textsuperscript{15} \textit{Id.}


\textsuperscript{17} \textit{Id.}

\textsuperscript{18} \textit{Id.}


\textsuperscript{20} \textit{Id.}

African American mothers are more likely to be born preterm and nearly twice as likely to have low birth weights as infants born to White mothers.23 The preliminary U.S. infant mortality rate in 2010 for African American infants was more than twice that of White infants. Even more striking is the fact that this disparity persists even when controlling for educational attainment: college-educated African American women suffer an infant mortality rate almost triple that of their White counterparts, and significantly greater than that of white women with less than a high school education.24

Women with disabilities also face compound discrimination in health care programs and activities. Women with disabilities receive less preventive health care, including mammography, Pap tests, colon cancer screenings, dental care, and health promotion interventions to prevent chronic diseases such as obesity.25 A major factor in this disparity is the lack of accessibility in health care facilities: for example, facilities do not have elevating exam tables or mammography equipment that can accommodate women who cannot stand.26 One study found that gynecology practices were the least accessible group of the subspecialties it measured, with 44% of gynecology practices being inaccessible to disabled patients.27

Additionally, women with disabilities are less likely to be given information on sexual and reproductive health and often face obstructed access to family planning services. Women with mobility disabilities were 70 percent less likely to be asked about contraception during routine checkups. When they do receive such services, disabled women are often steered toward a limited set of birth control methods that require less frequent use, such as Depo-Provera, IUDs, and even forced sterilization. Condoms and oral contraceptives are not considered viable options for disabled women because of the need for frequent and regular use.28

Pregnant disabled women are less likely than nondisabled women to have access to prenatal, labor and delivery, and postnatal services. Disabled pregnant women will often be turned away from midwifery services on the grounds that they would require specialty care or a Cesarean section, which is not necessarily true. Yet upon seeking such services, these

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24 P. Lee et al., The Nation’s Health 523 (2003).
28 Alvarez et al., supra n. 25.
women are frequently turned away again, often being told that they should not have gotten pregnant.  

Finally, discrimination on more than one basis, or where bases intersect, can manifest in how patients are treated when attempting to seek health care services. While transgender individuals of all ethnic and racial groups reported unequal treatment, Latino/a individuals faced the highest rate of unequal treatment. Many transgender and gender non-conforming individuals also reported being verbally, and sometimes physically, harassed in medical settings, with African American and undocumented individuals. 

Below, we submit a few examples that illustrate some types of discrimination on the basis of sex that are prevalent in the health care industry. Under Section 1557, these practices are unlawful:

1. A health plan’s provider network does not include a sufficient number or breadth of providers to meet female beneficiaries’ specific health needs.
2. An insurance company or health plan recruits and/or markets to consumers in such a way as to discourage women from enrolling in coverage offered by that company.
3. A health insurance plan excludes maternity coverage for direct beneficiaries, such as dependents of the primary policyholder.
4. A state marketplace allows an insurance company to participate in the marketplace even though the company’s marketplace plans fail to administer adequately benefits for maternity and family planning services, including contraception, as required by the Affordable Care Act.
5. Women are charged different premiums than men for the same health insurance coverage.
6. A health insurance company bases the rate it charges for a group health plan on the relative proportion of men and women in that group.
7. A provider refuses to provide sexual health information, family planning counseling, or contraceptive services to a woman because she is disabled.
8. A provider refuses to prescribe a desired contraceptive to a woman because she is disabled.
9. A full service medical center has sub-standard maternity facilities, in comparison to the facilities provided for other services.
10. A hospital or clinic refuses to treat a woman for complications related to an abortion.
11. A drug rehabilitation program refuses to treat a pregnant woman solely because she is pregnant.
12. A transplant board has in place a facially neutral policy that has the disparate effect of disfavoring women from receiving organ transplants.
13. A clinic has a policy of refusing to prescribe contraception to unmarried women or refusing to prescribe certain types of contraception, such as long-acting reversible contraceptives (e.g., copper intrauterine devices), to women based on their marriage or reproductive status.
14. An insurance company excludes coverage for gynecological services.

29 Id.
An employer exclusively links premium discounts for participation in an employer wellness program to biometric measures for diseases that primarily affect women.

A surgical residency program has a policy that directly discourages or has the effect of discouraging women from applying to its program.

A provider subjects a patient to unnecessary or intrusive physical examinations as a condition of treatment because the patient is transgender.

A provider refuses to treat a patient because the patient is transgender.

A clinic refuses to provide medically indicated gynecological services for transgender men that they provide to women.

A hospital that receives federal financial assistance refuses to provide sexual assault evidence collection to a man because he is male or because of his failure to conform to gender stereotypes.

A health insurance plan, provider, or employer utilizes confidential health information or health information technology in a manner that discriminates against women or violates their privacy rights.

All of the above are examples of the types of discrimination that Section 1557 was intended to address, and all should be considered unlawful under the ACA.

**Question 2.** There are different types of health programs and activities. These include health insurance coverage, medical care in a physician’s office or hospital, or home health care, for example. What are examples of the types of programs and activities that should be considered health programs or activities under Section 1557 and why?

**Response to Question 2**

Section 1557 prohibits individuals from being excluded from participation in, denied the benefits of, or subjected to discrimination under any health program or activity, any part of which is receiving Federal financial assistance, including credits, subsidies, or contracts of insurance, or under any program or activity that is administered by an Executive Agency or any entity established under Title I of the ACA. The Department must promulgate regulations and guidance to cover the full reach of Section 1557 and apply Section 1557 to all health program and activities receiving, in part or in whole, federal financial assistance; to all programs and activities administered by an Executive agency; and to all entities established under Title I of the ACA. Each of these categories of programs, activities, and entities that are required to comply with Section 1557 is described in further detail herein.

**A. Any Health Program or Activity, Any Part of Which Is Receiving Federal Financial Assistance, Including Credits, Subsidies, or Contracts of Insurance, Must Comply with Section 1557.**

The reach of Section 1557 is broad and applies to any health program or activity that receives federal financial assistance. “Program or activity” has the same meaning in Section 1557 as it does under the Civil Rights Restoration Act of 1987 (CRRA): the term applies to
public and private entities as well as departments and agencies of state and local governments that receive federal financial assistance.

Whether a particular program is sufficiently health related, like the question of whether a program is educational in nature, will be a fact-specific inquiry. However, in order to effectuate Section 1557’s nondiscrimination principle, the determination of whether a program is a “health program or activity” should be made consistent with existing interpretations of the meaning of the term “health” offered by the World Health Organization (WHO). The WHO defines health to include not just the absence of disease but also “physical, mental and social well-being.” Based on this widely accepted definition of health, a health program or activity includes any program or activity that is designed to promote, maintain or prevent the decline of the physical, mental and social well-being of an individual or population’s health.

Section 1557 applies to all operations of a health program or activity if any part of that program or activity receives federal financial assistance. Section 1557’s use of the phrase “program or activity” must be read together with the phrase “any part of which.” The CRRA was passed specifically to ensure that nondiscrimination protections applied to all operations of an entity receiving federal financial assistance, and not just to the program or activity within the entity that directly received such assistance. Following the enactment of the CRRA, courts have consistently given the term “any part of which” a broad reading, and found it to mean that if any part of a program or activity receives financial support from the federal government, the entire program or activity must comply with the prohibition against discrimination. Thus, if a program, activity, or entity has health as its purpose, Section 1557 prohibits discrimination in all of its programs or activities. Examples of such entities include state and local health departments, providers and provider networks, health insurance companies and health plans, health or medical research institutions, and health or medical training schools.

Additionally, Section 1557 prohibits discrimination in health programs and activities administered by entities that do not themselves have a health focus, if any part of that entity receives federal financial assistance. Thus, any entity receiving federal financial assistance may not discriminate in its operation of a health program or activity. For example, we urge the Department to promulgate regulations that ensure that employer-
sponsored health plans and employer-sponsored wellness programs comply with Section 1557.

Section 1557 applies to applicable sub-recipients of federal financial assistance as well as to primary recipients. A recipient may also include any successor, transferee, or assignee of the federal financial assistance. For example, if a state department of health receives federal financial assistance that is intended for distribution to a local entity for distribution to an ultimate beneficiary, all recipients and transferees are subject to Section 1557.

Additionally, the Supreme Court has found that there is no reason to distinguish between funds paid directly to or received indirectly by a recipient. For example, courts have held that educational institutions receiving federal financial aid paid directly to students are recipients of federal financial assistance. In Grove City College v. Bell, the Supreme Court held that the fact that the students of the college received federally guaranteed student loans subjected the school to Title IX. Therefore, an entity need not receive the federal financial assistance directly for compliance with Section 1557 to be triggered.

Federal regulations and guidance have made clear that “federal financial assistance” includes grants, loans, donations of property (and interests in property), detail of federal personnel, the use of property, and federal contracts and agreements. Direct payments from the federal government to a non-federal entity are the most straightforward form of federal assistance. Courts have consistently held that Medicare Part A and Medicaid payments constitute federal financial assistance. Direct payments to providers authorized by the ACA or other statutes, such as the incentive payments for implementing Electronic Health Records (EHR), would constitute federal assistance subject to the requirements of the nondiscrimination statutes.

Under Section 1557, federal financial assistance specifically includes but is not limited to “credits, subsidies and contracts of insurance.” Thus, each is a type of federal financial assistance and triggers Section 1557 application. In the case of subsidies, courts have routinely considered them to be federal financial assistance. Credits, including tax

36 See, e.g., 24 C.F.R. § 8.3 (2011) (defining recipient as including “any entity ... to which Federal financial assistance is extended ... directly or through another recipient ...”) under Section 504 of the Rehabilitation Act; City of Chicago v. Lindley, 66 F.3d 819 (7th Cir. 1995) (local agency subrecipients of Title VI are subject to Title VI requirements).
37 See, e.g., 42 C.F.R. §§ 42.102(h), 84.3(f), § 91.4 (2010); see also U.S. DEP’T OF JUSTICE, TITLE IX LEGAL MANUAL 37 (2001).
38 Note that the ultimate beneficiary does not typically receive a “distribution” of federal money, but instead enjoys the benefits of enrollment in the program. TITLE IX LEGAL MANUAL, supra n. 37, at 36-37.
41 Id. at 573-74.
42 See, e.g., 34 C.F.R. §§ 106.2(g), 84.3(h), 91.4 (2010); see also U.S. DEP’T OF JUSTICE, TITLE VI LEGAL MANUAL 10-11 (2001); TITLE IX LEGAL MANUAL, supra n. 37, at 27 (2001); U.S. Dep’t of Transp. v. Paralyzed Veterans of Am., 477 U.S. 597, 607 n.11 (1986).
43 United States v. Baylor Univ. Med. Ctr. 736 F.2d 1039 (5th Cir. 1984); see also Bowen v. Am. Hosp. Ass’n, 476 U.S. 610, 624 (1986) (affirming hospital was recipient of “financial assistance” through its participation in the Medicare and Medicaid programs); Fobbs v. Holy Cross Health Sys. Corp., 29 F. 3d 1439, 1447 (9th Cir. 1994); United States v. Harris Methodist Ft. Worth, 970 F. 2d 94, 1447 (5th Cir. 1992) (holding that anti-discrimination provisions of Title VI apply to staff privileges at hospital receiving federal funds); 238 F Supp 512 (D.C. 1965) (state or private hospitals receiving federal funds bound by Title VI).
44 In applying civil rights laws, courts have held that Medicare and Medicaid payments are federal financial assistance. See, e.g., Baylor, supra n. 42.
exemptions, have also been considered federal financial assistance when the intent of the exemption was to provide a subsidy.44

The explicit inclusion of “contracts of insurance” in the language Section 1557 marks a departure from how federal financial assistance has been defined in other relevant legislation, such as Title VI, Title IX, and the Rehabilitation Act. While contracts of insurance have been interpreted not to be federal financial assistance under other civil rights legislation, Congress has expressly defined it as such in regards to Section 1557. Accordingly, “federal financial assistance” has a broader meaning and scope under section 1557 than it has had in other statutes.

Inclusion of “contracts of insurance” demonstrates explicit Congressional intent to consider insurance companies and health plans as health programs and activities that are recipients of federal financial assistance. Perhaps the most direct example of an insurance company or health plan covered by Section 1557 is a qualified health plan sold in a state insurance marketplace. Such plans will receive federal subsidies for certain eligible enrollees in the form of advance premium tax credits. The specific inclusion of “credits” as a form of federal financial assistance under Section 1557 demonstrates that Congress intended for the extension of premium credits to a health insurance company to trigger compliance with Section 1557. Additionally, receipt of credits subjects qualified health plans to Section 1557 not only because “contracts of insurance” and “credits” are specifically identified as federal financial assistance, but also because premium credits are themselves a subsidy. Courts have consistently recognized subsidies as a form of Federal financial assistance.45 (Premium tax credits subsidize not only the individual purchasing health insurance, but also the health insurance companies selling qualified health plans to subsidized individuals.)

Insurance companies that provide insurance to Federal employees and eligible family members through the Federal Employee Health Benefit Program (FEHBP) are also covered by Section 1557. Insurance companies that participate in FEHBP receive Federal financial assistance, in the form of a contract of insurance from the federal government. Because contracts of insurance were explicitly included as a form of federal financial assistance under Section 1557, participation in FEHBP makes an insurance company subject to the requirements of Section 1557. Moreover, the FEHBP is covered by Section 1557 by virtue of the fact that it is a health program administered by the Office of Personal Management, an executive agency.

Additionally, while payments to physicians under Medicare Part B have traditionally been excluded from the definition of federal financial assistance because they are characterized as “contracts of insurance” with private doctors,46 they are considered federal financial assistance under Section 1557. Section 1557’s specific inclusion of “contracts of insurance” in its statutory language demonstrates that Congress intended to bring contractual insurance payments such as Medicare Part B payments within the scope of Section 1557.

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44 See, e.g., McGlotten v. Connally, 338 F. Supp. 448, 462 (D.D.C. 1972) (holding that a tax exemption for a fraternal order is federal financial assistance because it “operates in fact as a subsidy in favor of the particular activities these groups are pursuing.”).
45 See id.
Finally, we note that the source of the assistance is irrelevant as a trigger for compliance with Section 1557. Under the plain language of Section 1557, federal financial assistance is not limited to assistance provided under, or specifically authorized by, the ACA or another health-related fund. (An analogy to Title IX, which also is restricted to a specific type of program, is instructive. Despite its limitation to education programs and activities, federal financial assistance under Title IX has not been restricted to education funds.47) When Congress limits the scope of federal funding, it says so explicitly. Without such limiting language, the purpose of assistance is not relevant for purposes of rendering the recipient subject to Section 1557.

B. Programs or Activities Administered by an Executive Agency Must Comply with Section 1557.

Section 1557 prohibits discrimination in all programs or activities administered by an Executive Agency. Such a reading of Section 1557 is in line with Section 504 of the Rehabilitation Act (which applies its nondiscrimination provision to any program or activity conducted by any Executive Agency) and with Executive Order 13,160.48 The term “federally conducted programs or activities” has been defined to include “anything a federal agency does.”49 Thus, “any program or activity that is administered by an Executive Agency” means that anything an Executive Agency does is subject to the nondiscrimination requirement of Section 1557.

Section 1557 clearly applies to all programs and activities administered by the Department of Health and Human Services (HHS), such as Medicare. It also applies to programs jointly administered by HHS and state governments, such as Medicaid and the Children’s Health Insurance Program. The Federal Employee Health Benefits Program, a federal health program administered by the Office of Personnel Management, an executive agency, must also comply with Section 1557. Likewise, TRICARE, the health benefits program for U.S. military personnel, military retirees, and their dependents, must also comply with Section 1557, because it is administered by the U.S. Department of Defense, an executive agency.

C. Entities established under Title I of the ACA must comply with Section 1557.

Under the plain language of Section 1557, any “entity established under” Title I of the ACA is prohibited from subjecting any individual to discrimination under any health program or activity. While these comments do not include an exhaustive list of all entities established under Title I of the ACA, we do emphasize certain examples – such as marketplaces,

47 See Title IX Legal Manual, supra n. 37, at 20-21 ("[F]ederal funds distributed to a Department of Corrections for a non-educational operation such as the provision of medical services would subject all of the Department’s educational operations to coverage under Title IX.")


qualified health plans, and Navigators. We also refer you to comments submitted by the National Women’s Law Center and by the Leadership Conference on Civil and Human Rights on this subject, but note that examples included in those comments are likewise in no way intended to be self-limiting.

All state marketplaces, regardless of whether they are facilitated by a state government, by the federal government, or by a partnership agreement between a state and the federal government, are entities established by Title I of the ACA, and therefore subject to Section 1557. Additionally, if a state chooses to create and administer a state-facilitated marketplace, that state may choose to establish a government agency or nonprofit entity as its marketplace. In either circumstance, the agency or entity designated as the marketplace is a product of Title I of the ACA and therefore covered by Section 1557.

To comply with Section 1557, marketplaces are not only barred from themselves discriminating against individual on prohibited grounds, they are also prohibited from providing assistance to an entity, program or activity that discriminates on the basis of race, color, national origin, sex, age or disability. Title IX’s regulations provide, for example, that an educational institution may not, “[a]id or perpetuate discrimination against any person by providing aid or assistance to any agency, organization or person which discriminates on the basis of sex in providing any aid, benefit, or service to students or employees.” An institution that provides aid or assistance to an independent, but discriminatory, entity essentially adopts the discriminatory policies as its own.

Aid or assistance provided by the marketplace to an insurance company need not be monetary for Section 1557 to be triggered. Insurance companies will benefit greatly from mere participation in state marketplaces through access to consumers who purchase health insurance with the help of premium credits. Because the premium credits may only be used in a marketplace, health insurance companies must participate in a marketplace to have access to these consumers. The insurance marketplaces are therefore barred from allowing insurance companies that discriminate to participate in the marketplaces because to do so would be to provide assistance to discriminatory companies and would mean that the Marketplaces were adopting those discriminatory policies themselves.

Qualified health plans (QHPs) sold within state-based marketplaces are required to comply with Section 1557 not only because, as mentioned, they are recipients of Federal financial assistance, but also because QHPs are themselves entities established by Title I of the ACA. Section 1301 of the ACA defines qualified health plans and the required benefits and certification required into to qualify as a qualified health plan. QHPs are therefore required to comply with Section 1557 in the provision and administration of benefits.

50 The pre-existing condition insurance program and the reinsurance program for early retirees both expire January 1, 2014. Patient Protection & Affordable Care Act (ACA), 42 U.S.C. §§ 18001 (pre-existing condition insurance program), 18002 (reinsurance program for early retirees) (2013).
51 Id. at § 18041(e).
52 See, e.g., 34 C.F.R. § 106.31(b)(6) (2010).
53 In Iron Arrow Honor Soc’y v. Heckler, the Fifth Circuit found that the Department of Health, Education and Welfare could terminate federal funding to the University of Miami because the University allowed an all-male honor society to hold a “tapping” ceremony at a monument to the society on University property, in which “tapees” were removed from class before participating in the ceremony. 464 U.S. 67, 70-71. As is demonstrated by the Iron Arrow case, the assistance does not have to be monetary for Title IX to be implicated. Id.
54 42 U.S.C. § 18021.
particularly with regards to the policies’ essential health benefits packages.\(^{55}\) (Essential health benefits packages offered by QHPs sold in state marketplaces are required to have been created in a manner that does not “make coverage decisions, determine reimbursement rate, establish incentive programs, or design benefits in ways that discriminate against individuals because of their age, disability or expected length of life” and that takes into account “the health care needs of diverse segments of the population, including women, children, persons with disabilities, and other groups.”\(^{56}\)

The ACA also requires states to establish a Navigator program to help individuals evaluate their insurance options and steer them to the choice that best meets their needs. Although Navigator programs will be run by the state, they were brought into existence by the ACA and therefore fall under the scope of Section 1557.\(^{57}\) Additional examples of entities established under Title I of the ACA, and therefore subject to Section 1557, include the Pre-existing Condition Insurance Program, Consumer-Oriented and Operated Plans (CO-OPs), and the Early Retiree Reinsurance Program.\(^{58}\) Further, any provider offices and clinics, provider groups, hospitals, managed care organizations (MCOs), and provider education and licensing entities that receive federal funds through Medicaid, Medicare, or funds created under the ACA or by marketplaces must also comply with Section 1557.

Finally, we conclude by noting that the only exception to Section 1557’s nondiscrimination mandate is the single exception explicitly stated in the statute: Section 1557 applies to all identified programs and entities, “[e]xcept as otherwise provided” in Title I of the ACA.\(^{59}\) Courts have read exceptions to general rules like Section 1557 narrowly, and have construed such exceptions to give fullest force to the general rule itself.\(^{60}\) The plain language of the statute bars any other exceptions, and nothing in the language or legislative history of Section 1557 allows for additional limitations regarding its application.\(^{61}\)

**Question 3: What are the impacts of discrimination? What studies or other evidence documents the costs of discrimination and/or the benefits of equal access to health programs and activities for various populations? For example, what information is available regarding possible consequences of unequal access to health programs and services, such as delays in diagnosis or treatment, or receipt of an incorrect diagnosis or treatment? We are particularly interested in information relevant to areas in which Section 1557 confers new jurisdiction.**

**Response to Question 3**

\(^{55}\) *Id.* at § 18022.

\(^{56}\) *Id.* at § 18022(b)(4).

\(^{57}\) *Id.* at § 18041(i).

\(^{58}\) *Id.* at §§ 18001, 18002.

\(^{59}\) *Id.* at § 18116(a).


\(^{61}\) *See, e.g., H.R. REP. NO. 111-448 (2010).*
For comprehensive information on the impacts of discrimination, including the financial consequences of and disparate health outcomes associated with unequal access to health services, we would like to refer the Department to comments submitted on our behalf by the National Women’s Law Center and by the Leadership Conference for Civil and Human Rights. In addition to those comments, we offer the following examples of health and socio-economic consequences associated with discrimination in health care settings.

A. Health Consequences Associated With Unequal Access to Health Care

When women lack access to reproductive health services, they and their children suffer significant health consequences. Without access to family planning services, women are less able to time and space their pregnancies, which puts them at greater risk of low birth weight, preterm birth, and small size for gestational age. Access to women’s health care and family planning is also necessary to preventing unintended pregnancies, which make up approximately half the pregnancies in the United States each year. Unintended pregnancies are linked to negative health outcomes women with unintended pregnancies were more likely to be delayed in seeking prenatal care, less likely to breastfeed, and more likely to suffer depression and anxiety. Access to contraception has correlated with significant declines in unintended pregnancy and abortion. This is particularly true among teens aged 15-17, for whom 77 percent of the decline in unintended pregnancies between 1995 and 2002 is attributable to increased contraceptive use, and teens aged 18-19, for whom the entire decline is attributable to increased contraceptive use.

The negative health effects of unequal access to care are magnified for women of color. African American and Hispanic women had higher rates of cervical cancer than the rates among White women. Out of these, African American women were most likely to die from the cancer, with a mortality rate twice that of White women’s. African American women had higher rates of advanced stage breast cancer and higher breast cancer death rates than White women. African American women had the highest infant mortality rate, more than twice as high as the rate for White women. As noted above, the preliminary U.S. infant mortality rate in 2010 for African American infants was more than twice that of White infants. African American and Hispanic mothers were more likely to have a preterm birth, for which infant mortality rates are substantially higher than for average weight infants. Moreover, African America women are more likely to die from pregnancy-related causes

than White women. Racial disparities in maternal mortality persist after controlling for socio-economic status differences. African American women at any education level have mortality ratios that are three to four times higher than those for White women.\textsuperscript{69}

B. Social and Economic Consequences of Women’s Lack of Access to Health Care

Women’s access to health care imparts significant social and economic benefits that lack of access would threaten. Access to birth control has been cited as a major factor in increasing women’s participation in the workforce.\textsuperscript{70} Moreover, facilitating women’s access to needed preventive care saves federal dollars: nationally, every $1.00 spent on family planning and contraceptive care saves $5.68 in Medicaid services that would have otherwise been needed.\textsuperscript{71} Conversely, women’s inability to access health care creates major financial burdens for the country as a whole. A 2006 report showed that 64 percent of that year’s births resulting from unintended pregnancies were paid for by public insurance programs such as Medicaid, resulting in estimated public expenditures of $11.1 billion. By contrast, only 35 percent of births resulting from intended pregnancies were paid for by public programs.\textsuperscript{72} Further, obstructed access to family planning care not only threatens the economic security of women, but it also jeopardizes the financial stability and well-being of families.

**Question 5.** Title IX, which is referenced in Section 1557, prohibits sex discrimination in federally assisted education programs and activities, with certain exceptions. Section 1557 prohibits sex discrimination in health programs and activities of covered entities. What unique issues, burdens, or barriers for individuals or covered entities should we consider and address in developing a regulation that applies a prohibition of sex discrimination in the context of health programs and activities? What exceptions, if any, should apply in the context of sex discrimination in health programs and activities? What are the implications and considerations for individuals and covered entities with respect to health programs and activities that serve individuals of only one sex? What other issues should be considered in this area?

**Response to Question 5**

We appreciate the Department’s commitment to equitable provision and administration of health benefits and services, and commend its thoughtfulness in inquiring into the unique issues, burdens, and barriers that individuals may face when attempting to access needed health care services. Women, in particular, can face a variety of discriminatory actions when seeking care, especially in regards to reproductive health services.

Marketplaces, Navigators, application assistors, insurance brokers benefitting from directing consumers to qualified health plans sold in marketplaces, and any affiliated marketplace vendors are all prohibited from discriminating against individuals on the basis

\textsuperscript{69} Pregnancy-Related Mortality Surveillance, supra n. 22, at 4.

\textsuperscript{70} Sonfield et al., supra n. 64, at 29.


\textsuperscript{72} Unintended Pregnancy Facts, supra n. 63, at 3.
of sex. Under Section 1557, entities are prohibited from deterring women’s enrollment in a particular qualified health plan because she is a woman or because the plan carries benefits for particular women’s health services, such as contraception, abortion care, or any of the preventive women health services required by the ACA. We urge the Department to review marketplaces and marketplace subcontractors, brokers, and vendors closely, to ensure that women encounter no barriers, discouragement, or misinformation when intending to purchase and access qualified health plans that cover the full range of women’s health services, including reproductive health services.

Likewise, we urge the Department to pay particular attention to qualified health plans’ administration of benefits, so as to ensure that plans are not responsible for any undue denials, delays, or cost-sharing for preventive services for which cost-sharing is prohibited. Already, there have been numerous instances of women being unlawfully charged co-pays for contraceptive methods by their health plans. Additionally, the Department should monitor providers and provider networks receiving, in any part, federal financial assistance, to ensure that women are not unlawfully denied care or provided inadequate medical treatment. Providers receiving federal financial assistance should be monitored to ensure that they are adequately equipped to treat persons with disabilities and to maintain a high level of cultural competency that enables them to treat persons equitably, regardless of race or national origin.

We ask that the Department also review carefully and promptly any complaints regarding employer-sponsored health plans offered to employees by health programs and/or entities that receive federal financial assistance. Documentation of unlawful restriction of coverage of maternity services in employee health plans by entities receiving federal financial assistance has already been filed with Office of Civil Rights (OCR). For example, complaints filed by the National Women’s Law Center pursuant to Section 1557 of the ACA identify multiple health programs that receive federal financial assistance that are, in plans offered to their employees, unlawfully denying coverage of maternity services to certain beneficiaries.

Additionally, we also emphasize the need to hold state- and community-level agencies and governance boards accountable to Section 1557. As noted above, a state or local government entity, any part of which is receiving and/or distributing Federal financial assistance, that is engaged in the promotion, maintenance, or prevention of the decline of health is subject to Section 1557, as are all state or local departments or agencies to which that Federal financial assistance is extended. We urge the Department to carefully consider how to ensure that state and local health entities, programs, and activities that are, in any part, receiving federal financial assistance, are complying with Section 1557, particularly with regards to administering benefits and facilitating access to care for protected classes. Women often face state and locally constructed barriers when attempting to access certain

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75 Id.
reproductive health services; under Section 1557, any such attempts to disrupt a woman’s access to services would be unlawful.

Moreover, state insurance regulators have reported that nondiscrimination standards in the ACA do not include sufficient guidance on how to undertake systematic reviews for discriminatory benefit designs in qualified health plans. According to a recent report published by the Georgetown University Health Institute’s Center on Health Insurance Reforms, it does not appear that Section 1557 and other nondiscrimination standards in the ACA have significantly changed how state regulators approach benefit design, particularly with regards to plans’ network adequacy, drug formularies, and exclusion of certain benefits and services. Many states are not issuing guidance on nondiscrimination, but are instead allowing insurers to interpret Section 1557’s nondiscrimination requirements. As a result, state regulators anticipate challenges in enforcing these requirements, due to confusion and lack of clinical expertise.

Finally, Section 1557 regulations should also address how facially neutral policies can have discriminatory impacts on different populations. For example, health plans that, as a matter of policy, do not cover reproductive health services may, on their face, appear to be neutral with regards to sex. However, such policies have a disproportionately negative impact on women, who are likely to require access to reproductive health services, such as contraception and maternity care, over the course of their lifespan. Under Section 1557, such policies should be considered unlawful. In order to realize fully the protections of the civil rights laws on which Section 1557 is based, the Department must promulgate regulations that prohibit both discriminatory intent and disparate impact.

Most agencies have adopted regulations prohibiting practices that have a discriminatory or disparate impact as well as intentional discrimination. An otherwise neutral practice may be prohibited under these regulations if it (1) has a disparate impact on members of a protected class and (2) lacks “substantial legitimate justification.” For example, the Department of Justice regulations prohibit recipients from selecting the location of their facilities “with the purpose or effect of excluding individuals from, denying them the benefits of, or subjecting them to discrimination under any program to which this subpart applies, on the ground of race, color, or national origin.” Regulations implementing Section 1557 should likewise prohibit disparate impact as well discriminatory intent. For example, they could and should require the provider networks created by the ACA to consider the impact of site location on protected groups. Similarly, regulations could and should require an insurance company or health plan to consider whether its benefit packages, drug formularies, and provider networks meet the health care needs of women and other protected groups.

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76 CTR. ON HEALTH INS. REFORMS, GEORGETOWN UNIV. HEALTH POLICY INST., NONDISCRIMINATION UNDER THE AFFORDABLE CARE ACT 15 (2013).
77 Id. at 16.
78 Id. at 13.
80 Larry P. v. Riles, 793 F.2d 969, 983 (9th Cir. 1984); New York Urban League v. New York, 71 F.3d 1031, 1038 (2d Cir. 1995); Elston, 997 F.2d at 1407.
For additional information on this subject, we would like to refer you to various community responses to this question, namely those submitted on our behalf by the National Women’s Law Center and by the Leadership Conference for Civil and Human Rights.

**Question 6. The Department has been engaged in an unprecedented effort to expand access to information technology to improve health care and health coverage. As we consider Section 1557’s requirement for nondiscrimination in health programs and activities, what are the benefits and barriers encountered by people with disabilities in accessing electronic and information technology in health programs and activities? What are examples of innovative or effective and efficient methods of making electronic and information technology accessible? What specific standards, if any, should the Department consider applying it considers access to electronic and information technology in these programs? What, if any, burden or barriers would be encountered by covered entities in implementing accessible electronic and information technology in areas such as web-based health coverage applications, electronic health records, pharmacy kiosks, and others? If specific accessibility standards were to be applied, should there be a phased-in implementation schedule, and if so, please describe it.**

**Response to Question 6**

The federal mandate to build a national infrastructure of electronic health information technology and exchange under the Health Information Technology Economic and Clinical Health (HITECH) Act of 2009\(^2\) entails both health programs and activities receiving Federal financial assistance and programs or activities administered by an Executive Agency.

First, the HITECH Act provides substantial federal financial assistance, totaling approximately $27 billion, to private and public health programs and activities across the nation. The majority of this federal financial assistance takes the form of incentive payments to eligible professionals and eligible hospitals serving Medicare and Medicaid beneficiaries, to encourage them to adopt certified electronic health record technology and use it meaningfully to improve patient and population health and health care.\(^3\) As of July 2013, approximately 375,000 eligible professionals and eligible hospitals in all 50 states had received more than $15.5 billion in federal financial assistance.\(^4\)

Under section 13301 of the HITECH Act, federal financial assistance increases approximately $2 billion more for health information technology architecture, including programs and activities under planning and implementation grants to states to promote health information exchange; health information technology regional extension centers to

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\(^3\) 42 U.S.C. § 1395ww(n) (Medicare, eligible hospitals); id. at § 1396b(t) (Medicaid, States for eligible professional and hospitals); id. at § 1848(o) (Medicare, eligible professionals),

provide technical assistance and disseminate best practices; grants to integrate health information technology into clinical education; and grants to support medical health informatics programs and information technology professionals in health care. Overall, “the Secretary [of Health and Human Services] shall . . . invest in the infrastructure necessary to allow for and promote the electronic exchange and use of health information for each individual in the United States consistent with the goals outlined in the strategic plan developed by the National Coordinator . . . .”

Separately, the Department of Health and Human Services administers programs with nationwide scope for “electronic exchange and use of health information and the enterprise integration of such information,” “utilization of an electronic health record for each person in the United States by 2014,” “a framework of coordination and flow of recommendations and policies under this subtitle,” and “a governance mechanism for the nationwide health information network.” The Office of the National Coordinator for Health Information Technology and the Centers for Medicare & Medicaid Services actively administer such programs. For example, the National Coordinator is responsible for a strategic plan with specific objectives and milestones for “electronic exchange and use of health information and the enterprise integration of such information,” “utilization of an electronic health record for each person in the United States by 2014,” “a framework of coordination and flow of recommendations and policies under this subtitle,” and for “a governance mechanism for the nationwide health information network.”

Under section 1557, no individual shall “be excluded from participation in, be denied the benefits of, or be subjected to discrimination under” these program and activities on any of the prohibited grounds. But such discrimination, denial or exclusion will occur if these HITECH programs and activities are not designed and used correctly.

A few examples will illustrate the magnitude of the problem and the importance of a solution now. According to the 2010 Census, approximately 60.5 million people ages five and older speak a language other than English at home. But the current proposals would require each of the Medicare and Medicaid providers receiving federal financial assistance to deliver only one patient-specific educational resource to only one patient in that patient’s preferred language other than English. ATM machines, by contrast, are necessarily accessible in multiple languages other than English for all daily transactions.

Question 6 of the Request for Information asks about the impact on people with disabilities across the United States. According to the 2010 census, 56.6 million people had a disability in America, or 18.7 percent of the population. Over 14.9 million people (29.0 percent of

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86 Id. at § 300jj-31(a).
87 Id. at §§ 300jj-11(c)(3)(A), (c)(8).
88 E.g., id. at § 300jj-11.
89 Id. at §§ 300jj-11(c)(3)(A), (c)(8).
people with a disability aged 15 years and older) had a seeing, hearing, or speaking disability. Approximately 15.1 million (29.4 percent) had a mental disability. Nearly 15.8 million people (30.7 percent) had disabilities in two domains, not just one. Yet current proposals would only require the certified electronic health record technology to record disability status, with no requirement to accommodate those disabilities in the ways that the electronic health records share personal health information with the individual.

In its most recent National Healthcare Disparities Report, the Agency for Healthcare Research and Quality summarized the results of measures of quality of care and access to care for people with disabilities. The measures tracked statutory definitions of disability such as that in the Americans with Disabilities Act (ADA) and federal program definitions of disability based upon the ADA. The Agency found:

Among all measures of health care quality and access . . . individuals with basic activity limitations had worse care than individuals with neither basic nor complex activity limitations in the most recent year for 18 measures. Most of these measures showed no significant change in disparities [i.e., no improvement] over time. Such measures included measures for patient-centered care and access to care.

Section 1557 does not countenance such exclusion, denial of benefit, and discrimination, and regulations implementing Section 1557 should require covered programs and activities to incorporate and use some important electronic tools and policies, summarized below, where relevant to identify and reduce health disparities so that people with disabilities (and all members of protected classes) receive full and equal benefits.

The National Institute of Standards and Technology has catalogued the disability factors that electronic health records, and electronic health information technology and exchange in general, must embrace with respect to both access and health care outcomes. Rather than quote at length, we commend the research to the Department’s attention. It covers hearing impairments, physical disability and motor impairment, fine motor control impairment, dexterity limitations, visual impairments, color blindness, and psychological or cognitive disability. For each, it then identifies the respective implications for EHR technology. For example, visual impairments might require accommodation and interoperability with assistive technologies when people cannot see the health information provided by the EHR system; a hearing impairment might affect the ability to hear audible alerts; and psychological or cognitive disabilities might require a range of accommodations in literacy or reading comprehension or in ability to conceptualize, sequence thoughts and actions, and plan.

The magnitude of section 1557 implications extends beyond disabilities, of course. Significant disparities exist by race and ethnicity; by language (national origin); by gender,

93 E.g., MEANINGFUL USE WORK GROUP, supra n. 91.
gender identity, and sexual orientation; and by socio-economic status. The Hispanic population reached 50.5 million, and over 57 million people identifying solely as Black or African-American, American Indian or Native Alaskan, Asian, or Native Hawaiian and Other Pacific Islander. Women account for 50.8 percent of the population. New, more accurate data have begun to emerge as social acceptance has grown and legal systems have become more affirming of the lesbian, gay, bisexual, and transgender (LGBT) populations. While recent studies estimate that overall LGBT individuals comprise 3.8 percent of the national population (or roughly 9 million people), some states report significantly larger populations of people that identify as LGBT.

Health disparities illustrate the problem, but they also present an extraordinary opportunity to implement section 1557 and use health information technology now to reduce health disparities and discrimination. The Consumer Partnership for eHealth, led by the National Partnership for Women & Families, recently developed and submitted to the HIT Policy Committee a Disparities Action Plan setting forth strategic changes that the Department of Health and Human Services should make to programs and activities under development. The Action Plan identifies minimum changes to certified EHR technology and meaningful use of EHR technology in three areas: (1) data collection and use to identify disparities; (2) barriers regarding language, literacy, and communication that exclude protected classes from participation, deny them the benefits of, or discriminate against them in health IT programs or activities receiving Federal financial assistance; and (3) barriers in care coordination and planning which do the same. These changes are essential to meet the requirements of section 1557: As the Health IT Policy Committee (the public advisory body to the Secretary on implementing the HITECH Act) has acknowledged and discussed repeatedly, reducing health disparities is essential yet remains a “key gap” in EHR functionality that the market will not drive alone—and a key gap in current policy.

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101 E.g., MEANINGFUL USE WORK GROUP, supra n. 91, at 6.
Accordingly, regulations implementing Section 1557 should include these important electronic tools and policies to identify and reduce health disparities so that members of protected classes receive full and equal benefits.

1. **Data Collection and Use.** In order to reduce health disparities, they must first be identified and understood in terms of prevalence, root causes, and major contributors. Standardized, granular data collection is foundational to this effort, for which health IT is an essential tool. Ensuring that EHRs can capture and record factors pertinent to individuals’ health, such as sexual orientation, gender identity, occupation, disability status, environmental factors, caregiver presence, and race, ethnicity, and language, ensures that providers see the whole picture surrounding their patients and are more adequately equipped to identify and address factors associated with health disparities. Subsequently using these data to provide care that is patient-centered, such as through automated decision support and reminders, helps to reduce disparities at the point of care. Failure to incorporate more granular collection and use perpetuates disparities.

2. **Language, Literacy and Communication.** Health information technology can be leveraged to address underlying causes of health inequity such as health literacy, access to quality information, and difficulties in communication with providers – but information and communication platforms must be made easily accessible and understandable. The principle of using and making available multiple formats and channels for all electronic communications must be a standard requirement for all patient-facing health IT. All electronic health information must be available in human readable and useable formats, including appropriate health literacy and numeracy levels, languages in addition to English, and formats appropriate for individuals with visual, hearing, cognitive, and communication impairments and physical disabilities. If these requirements are not explicit, then the implementation of health IT will only increase disparities experienced by diverse and underserved patients and communities.

Moreover, ensuring that information and communication platforms are easily accessible and understandable is directly aligned with the mission of the National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care, which provide a framework for delivering culturally and linguistically competent care and services. The CLAS Standards are aligned with the HHS Action Plan to Reduce Racial and Ethnic Health Disparities and the National Stakeholder Strategy for Achieving Health Equity, and meeting them is fundamental to delivering genuinely patient- and family-centered care.

3. **Care Planning and Coordination.** A lack of coordination and communication contributes not only to poor quality and unaffordable care, but health care disparities as well. Oftentimes, underserved populations and members of racial and ethnic minority

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groups suffer from lack of care coordination more acutely than the general population.\textsuperscript{104} While the process of care planning is driven by human interaction, technology can help make necessary information more readily available and actionable, connect all people who have a role in an individual’s care plan, and provide a shared platform for the ongoing maintenance and management of an individual’s care and well-being.

Care plans also offer a place for communication and coordination between not only the patients, caregivers, and providers, but also community entities offering services and supports.\textsuperscript{105} As health care has evolved and advanced, many health conditions have become chronic, rather than acute, shifting the disease burden from acute care to primary care providers and community supports and entities. Therefore, ensuring information sharing and automated connections between health care providers and community-based agencies has become vital.

Health information technology has great potential to bridge divides and reduce disparities. Because those divides currently exist, however, some communities and members of protected classes have disparate access to health information technology. Therefore, the regulations should also direct covered programs and activities to ensure that disparate access to health information technology does not perpetuate or exacerbate these divides and disparities.

Lastly, protecting privacy is especially important in health care, and the Privacy and Security rules implementing the Health Insurance Portability and Accountability Act (HIPAA) provide national minimums to protect patient health data in both paper records and electronic health records. Other provisions of law provide additional privacy protections, some of special importance to members of protected classes, such as reproductive health for women. Members of protected classes who are traditionally denied benefits, excluded from participation, or subjected to discrimination, may also be subjected to disproportionate abuses of privacy rights or misuses of their private health data. While the shift from paper to electronic records can present new challenges to protecting the privacy and security of a patients’ health information, health information technology also presents powerful new ways to improve the privacy and security of patients’ data, including encryption of the patient’s private data, electronic authentication and authorization controls to prevent unauthorized access, and electronic audit trails. Regulations implementing Section 1557 should harness these new tools and provide guidance to protect the privacy rights of members of protected classes and protect against misuse of their health data. Covered entities should be required to put in place strong safeguards that ensure compliance with Section 1557 in the use of health information technology.

In conclusion, the Request for Information’s question regarding health information technology is applicable not just to disabilities but to the range of classes covered by section 1557. The Office for Civil Rights should consider the benefits and barriers all protected

\textsuperscript{104} Id.; Sara Toomey et al., \textit{Disparities in Unmet Need for Care Coordination: The National Survey of Children's Health}, 131 \textit{PEDIATRICS} 217 (2013), available at \url{http://pediatrics.aappublications.org/content/131/2/217.full.pdf}.

classes might encounter in accessing electronic information technology in health programs and activities. If designed, built, and used correctly, health information technology introduces important new solutions and can reduce the disparities in access and outcomes covered by section 1557; but if these programs and activities fail to anticipate and accommodate such needs, then millions of people will continue to be denied the benefits of, or even be excluded from participation in, these programs and activities. Regulations implementing Section 1557 should require covered programs and activities to incorporate and use these important new electronic tools and policies, such as those explained above, to identify and reduce health disparities so that members of protected classes receive full and equal benefits. Likewise, they should enforce Section 1557 where such disparities continue to occur in violation of its provisions. Lastly, the regulations must harness these new tools and provide guidance to protect the privacy rights of members of protected classes and protect against misuse of their health data.

Question 7 [Abridged]. Section 1557 incorporates the enforcement mechanisms of Title VI, Title IX, Section 504 and the Age Act. These civil rights laws may be enforced in different ways. Title VI, Title IX, and Section 504 have one set of established administrative procedures for investigation of entities that receive Federal financial assistance from the Department. The Age Act has a separate administrative procedure that is similar, but requires mediation before an investigation. There is also a separate administrative procedure under Section 504 that applies to programs conducted by the Department. Under all these laws parties may file private litigation in Federal court subject to some restrictions.

Response to Question 7

For legal and policy analysis of enforcement mechanisms that should be employed to ensure proper compliance with Section 1557, we would like to refer the Department to comments submitted on our behalf by the National Women’s Law Center and by the Leadership Conference on Civil and Human Rights. In addition to those comments, we offer some suggestions below on ensuring and monitoring compliance and providing notice of rights to enrollees.

To ensure recipient compliance with Section 1557’s nondiscrimination requirements, federal agencies should require a specifically identified assurance of compliance from all applicable entities, health programs, and health activities applying for federal financial assistance. Additionally, all entities created under Title I of the ACA should submit to the appropriate designated agency, such as the Department of Health and Human Services, an assurance of compliance with Section 1557. To be deemed satisfactory, such assurance should also include a remediation plan that establishes policies and procedures for taking whatever remedial action is necessary to eliminate existing discrimination on the basis of race, ethnicity, national origin, sex, age, and disability or to eliminate the effects of past discrimination whether occurring prior to or subsequent to the submission the statement of assurance.
All entities subject to 1557 should also be required to demonstrate that they have in place mechanisms that allow for timely redress of discrimination complaints and timely remedies. For example, we urge implementing regulations to require that marketplaces and qualified health plans have in place infrastructure designed to process and assist with discrimination complaints expeditiously, so that there is no further delay of benefits or health care services.

Implementing regulations for Section 1557 must also identify and include the entire range of equitable and monetary relief and enforcement mechanisms available under Title VI, Title IX, Section 504, and the Age Discrimination Act. We note that while HHS has primary oversight over Section 1557, the Department of Justice has coordinating responsibility pursuant to Executive Order 12250. Additionally, all executive agencies must promulgate Section 1557 implementing regulations.

Final regulations should emphasize that individuals are entitled to file discrimination complaints directly with OCR or other applicable agencies and should make clear that Section 1557 also affords individuals a private right of action for a full range of relief, including equitable relief and monetary damages. Entities subject to Section 1557 should likewise provide notice to enrollees or beneficiaries of their right to file complaints directly with OCR or other applicable agencies, or to pursue a private right of action for equitable relief or monetary damages. Likewise, we urge that OCR and other applicable agencies be equipped with the policies and processes required for continuous monitoring and auditing of marketplaces, qualified health plans, providers, and other entities subject to Section 1557.

Finally, we note that, prior to the enactment of Section 1557, Title VI, Title IX, Section 504 of the Rehabilitation Act, and the Age Discrimination Act provided some protection against discrimination in health care. Title VI and the Age Discrimination Act prohibit discrimination based on race and age respectively in programs or activities of recipients of federal financial assistance, including health programs or activities. Similarly, Section 504 of the Rehabilitation Act bans discrimination based on disability by both recipients of federal financial assistance and programs that are federally conducted. And although Title IX is limited to education programs, it applies to every part and program of a school, college, or university, including health programs, such as university health clinics or hospitals. It is essential that Section 1557 regulations not limit or narrow established interpretations of existing enforcement mechanisms that protect against discrimination in health programs.

Thank you again for this opportunity to comment. We appreciate the Department’s commitment to reforming our health system to ensure that all individuals have equal access to quality health services. We look forward to continuing to work with the Department to develop urgently needed guidance on Section 1557 and the protections against discrimination in health care settings that this landmark provision provides.

Sincerely,

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