2013 Request for Information

Cited Comments

U.S. Department of Health and Human Services
Office for Civil Rights
Attention: 1557 RFI (RIN 0945–ZA01)
Hubert H. Humphrey Building
Room 509F
200 Independence Avenue, SW
Washington, DC 20201

To whom it may concern:

The Center for American Progress is pleased to have the opportunity to comment on the request for information published by the Department of Health and Human Services (HHS) regarding health care discrimination in health programs and activities in the context of Section 1557 of the Affordable Care Act. We join the Department of Health and Human Services in strongly supporting efforts to promote health and equal access to health care, with the eventual goal of ensuring that no individual will be unfairly denied the care and coverage they need.

A population that has faced significant barriers across healthcare systems in our country is the lesbian, gay, bisexual, and transgender (LGBT) population. Sources such as the Institute of Medicine,[i] Healthy People 2020,[ii] the Substance Abuse and Mental Health Services Administration,[iii] and the *National Healthcare Disparities Report*[iv] indicate that LGBT individuals and their families are disproportionately likely to live in poverty, to be uninsured, and to face substantial barriers to quality health care, including refusals of care, substandard care, inequitable policies and practices, and exclusion from health outreach or education efforts.[v] As a result, the LGBT population experiences significant disparities in health indicators such as smoking,[vi] obesity,[vii] experiences of abuse and violence,[viii] mental and behavioral health concerns,[ix] and HIV infection.[x] These inequities may be even more pronounced for LGBT people who are also members of other groups that are disadvantaged on the basis of factors such as race, ethnicity, geography, or disability.

These comments provide information regarding the experiences of LGBT people in health care and coverage systems, and details the reasoning – based both in practical and legal foundations – for including and addressing gender identity and sexual orientation-based discrimination under the sex-based nondiscrimination protections included in Section 1557. In these comments, we address several of the questions posed by HHS with regard to experiences of discrimination and the scope and breadth of Section 1557's applicability. This includes:

- Experiences of discrimination against LGBT people in health programs and activities
- Programs and activities that should be considered health programs and activities under Section 1557
- The impact of discrimination against LGBT people in health programs and activities
- Considerations in the applicability of Title IX sex-based nondiscrimination protections
- Enforcement mechanisms provided by Section 1557

Below, we discuss each of these issues in turn.

Question 1: Experiences of discrimination against LGBT people in health programs and activities

Discrimination in healthcare has adversely and disproportionately impacted the LGBT community.

Lesbian, gay, bisexual, and transgender Americans have too often faced health care and coverage systems that have provided inequitable and sometimes hostile treatment on the basis of their sexual orientation or gender identity. Discrimination has touched the lives of many LGBT people at all points in the health care system – from being unable to access insurance coverage, to outright refusals to provide care, to verbal and physical abuse at the hands of medical professionals.

Discrimination in Insurance Coverage

Prior to passage of the Affordable Care Act, few nondiscrimination protections applied to insurance, and these laws and regulations had only a limited effect in ensuring fair coverage for all consumers.[xi] Exclusions on the basis of preexisting conditions, variations in rates and charges based on personal characteristics, and arbitrary revocation of coverage were among the discriminatory practices that persisted in private insurance markets, but are being ended by the reformed introduced by the Affordable Care Act.

However, discrimination in benefits design has also been pervasive in both public and private systems of health coverage, and eradicating such discrimination has historically been a challenging process for both consumers and regulators.[xii] For example, in the private insurance market, breast reconstruction following mastectomy was widely considered cosmetic and routinely excluded from coverage until the passage of the Women's Cancer Recovery Act of 1998. Similarly, private market carriers continue to argue that exclusions for services or drugs commonly provided for the treatment of conditions such as HIV/AIDS are not discriminatory because they apply to all plan enrollees, regardless of their specific negative effect on people with these conditions. As a result, these discriminatory exclusions persist – and an estimated 30 percent of Americans living with HIV are unable to access coverage – despite nondiscrimination laws such as the Americans with Disabilities Act (ADA) and the Health Insurance Portability and Accountability Act (HIPAA).[xiii] These exclusions have disproportionately impacted the LGBT community, in that lesbian and bisexual women have higher rates of breast cancer than heterosexual women, and HIV infection rates are elevated among gay and bisexual men, as well as transgender women.[xiv]

Transgender people have also experienced discrimination in the form of exclusions for otherwise-covered services when provided for the purpose of treating Gender Identity Disorder, gender dysphoria, or related conditions. Like anyone else, transgender people need acute care when they are sick and preventive care to keep from becoming sick, including services that are traditionally considered to be gender-specific, such as pap smears, prostate exams, and mammograms. In addition, transgender people need access to medically necessary care related to gender transition, and access to these transition-related services is integral to the meaning of gender identity nondiscrimination. For transgender people, their identity – the essence of who they are – is closely connected with a medical condition.[xv] The medical diagnosis that correlates with a transgender identity is most frequently referred to as gender identity disorder, or GID, which the American Medical Association,[xvi] the American Psychiatric Association,[xvii] and the World Health Organization[xviii] all recognize as a serious medical condition. To fail to provide equal coverage for services when provided to transgender people for the purpose of gender transition is to engage in discrimination on the basis of gender identity.

In the private market, carriers have often excluded benefits from coverage in a manner that discriminates on the basis of gender identity. Examples of such discriminatory designs include exclusions for "any procedure or treatment, including hormone therapy, designed to change your physical

characteristics from your biologically determined sex to those of the opposite sex," or for "all services related to gender dysphoria or gender identity disorder."[xix] In public or government-provided health benefits programs, these discriminatory exclusions also frequently block coverage for medically necessary care provided to transgender people. For example, Medicaid programs have adopted exclusions for "treatment of gender dysphoria including gender reassignment surgeries"[xx] among others. Health plans offered to federal government employees through the FEHB program have contained exclusions targeting transgender enrollees,[xxi] as have benefits offered through the VA[xxii] and Medicare.[xxiii]

These exclusions arbitrarily target transgender people for discrimination by forcing them to pay out-of-pocket for the same medically necessary services provided to non-transgender people. Moreover, coverage determinations based on these exclusions are sometimes used in practice to deny transgender people coverage for basic services that are unrelated to gender transition. For example, a transgender woman in New Jersey who was denied coverage for a mammogram on the basis that it fell under her plan's sweeping exclusion for all treatments "related to changing sex." It took a two-year appeal process and intervention from the Transgender Legal Defense and Education Fund before the insurer agreed that the exclusion had unfairly prevented her from receiving medically necessary care and reimbursed her for the mammogram.

These transgender-specific exclusions contradict the consensus of leading professional medical associations regarding the medical necessity of these treatments for many patients, and they unacceptably limit access to otherwise covered benefits on the basis of gender identity. Major expert associations also agree that transition-related medical services, including mental health services, hormone therapy, and surgery, are medically necessary for many transgender people. The American Medical Association; the American Psychological Association; the American Psychiatric Association; the American Academy of Family Physicians; the American Congress of Obstetricians and Gynecologists; the Endocrine Society; the National Association of Social Workers; and the World Professional Association for Transgender Health have all issued public statements to this effect. According to these expert associations, determination of the medical necessity of any particular transition-related service for an individual patient properly rests with medical providers, not insurance companies. Additionally, according to the American Medical Association, "GID, if left untreated, can result in clinically significant psychological distress, dysfunction, debilitating depression and, for some people without access to appropriate medical care and treatment, suicidality and death."[xxiv]

People living with HIV, a population that disproportionately includes gay and bisexual men and transgender women, also face significant barriers in accessing health care and treatment due to discriminatory benefits designs in public and private health insurance plans. Examples of these designs include: monthly limits on prescription drugs or the exclusion of drugs recognized as the standard of care for HIV and utilization management techniques used primarily to deny or restrict access to care for people with chronic and complex health conditions. In addition to discriminatory plan designs, people living with HIV are also more likely to experience adverse coverage decisions, including service denials and rescission of coverage.

Discrimination in the provision of health care

For LGBT people who have been able to access health care despite barriers in coverage and benefits programs, many experiences have been colored by discriminatory experiences in the provision of that care.

A 2009 survey conducted by Lambda Legal provides data illustrating the gravity of discrimination in health care settings. Among lesbian, gay, and bisexual respondents, 56 percent reported experiencing discrimination ranging from health care workers being physically or verbally abusive to outright refusals of treatment.[xxv] Among these experiences were harsh or abusive language (10 percent), refusal to touch (11 percent), or being blamed for their health status (12 percent). 8 percent of LGB respondents were denied healthcare as a result of their sexual orientation.[xxvi] Transgender respondents to the Lambda Legal survey experienced even higher rates of discrimination in health care settings. Overall, 70 percent of transgender or gender non-conforming respondents reported experiencing discrimination while receiving care – nearly a quarter reported being subjected to abusive language, over 20 percent were blamed for their own health conditions, and almost 8 percent reported experiencing physically rough or abusive treatment from a health care professional.[xxvii] One-third of these respondents were refused care altogether because of their gender identity.[xxviii]

A second national survey of transgender people conducted by the National Gay and Lesbian Task Force and National Center for Transgender Equality details the experiences of discrimination among transgender Americans to an even greater degree. Transgender and gender nonconforming people seeking health care were denied equal treatment in doctor's offices and hospitals (24 percent), emergency rooms (13 percent), mental health clinics (11 percent), by EMTs (5 percent) and in drug treatment programs (3 percent).[xxix] Discrimination reported among transgender people of color is especially high. Nearly one in five African American respondents reported being refused treatment, and 6 percent reported being physical attacked in doctor's office.[xxx] Nearly one in three Latino/a respondents reported unequal treatment by a doctor or hospital.[xxxi] 36 percent American Indian respondents were refused medical care.[xxxii] These figures are only some of the findings regarding discrimination in health care settings reported in the survey.

In addition, stigma associated both with the LGBT community and HIV status serves as a significant barrier to care for people living with HIV or AIDS. People living with HIV report provider refusal to treat them as well as excessive provider precautions with regard to treatment of people living with HIV that do not comport with federal HIV treatment or health professional safety guidelines.[xxxiii] HIV providers also report challenges with linking their patients to other specialty services.[xxxiv] Provider refusal to treat as well as excessive precautions when treating people living with HIV has occurred across provider types, including private physicians, dentists, and community health centers.[xxxv] Some services providers have gone so far as to put in place blanket policies refusing to provide services to people living with HIV.[xxxvi] Black gay men and other men who have sex with men (MSM) also report high rates of stigma when accessing health care. In 2011, the National Alliance of State and Territorial AIDS Directors (NASTAD) and the National Coalition of STD Directors (NCSD) designed and implemented a survey to explore how community- and institution-level stigma within public health practice negatively affects HIV- and STD-related outcomes.[xxxvii] The survey was completed by more than 1,300 health department and community-based organization (CBO) staff, health providers, and community members representing 54 different states and territories.[xxxviii] Survey results showed high levels of perceived community-level and institutional stigma directed at Black and Latino gay men and other MSM.[xxxix]

Individual stories of health care discrimination lay bare the results of these extraordinarily high rates of discrimination against LGBT patients – and transgender patients in particular. The tragic reality is that discrimination against LGBT people and people living with HIV, solely because of their sexual orientation, gender identity, and/or HIV status, has resulted in deaths and undue hardships that were likely preventable:

In August 1995, Tyra Hunter, a transgender woman, was injured in a serious car accident. The paramedics arrived and began treatment. In the course of that treatment, paramedics discovered that Tyra was transgender, and withdrew care. As she laid in the street, the paramedics who had been charged with saving Tyra's life laughed and directed slurs at her. Tyra died later that evening in the emergency room at DC General Hospital.[xl] At trial, medical experts testified that if Tyra had been properly treated, she would have had "an 84-86 percent change of surviving."[xli]

Robert Eads, a transgender man and parent of two children, was rushed to the hospital in 1996 while experiencing severe abdominal pain. While in the hospital, he was diagnosed with ovarian cancer. As he desperately sought treatment for his cancer, he was repeatedly turned away by medical providers. Over a dozen doctors refused to treat Eads' cancer, fearing that treating a transgender patient would damage their reputations. Finally, after a year of being diagnosed, Eads found that would treat him. But it was too late – his cancer has metasized to other parts of his body, and Eads died two years later.[xlii]

Jay Kallio, a New Yorker and transgender man in his 50's, had biopsy that returned results indicating he was living with breast cancer. However, Kallio's attending physician had moral objections to Jay's gender identity, and was so taken aback by the results that he did not inform him about his diagnosis. Jay eventually learned that he had cancer when a he was accidentally informed by a lab technician inquiring about his diagnosis. By this time, Jay's cancer had progressed to where he could not benefit from chemotherapy. Jay later encountered an oncologist who refused to provide treatment advice, and was left to wonder whether his cancer was in remission. Kallio himself said, "I am medically savvy with a medical background, [am] white and speak English…if I have every advantage [and was still discriminated against], it doesn't bode well for other people."[xliii]

Donald Ford went to the dentist because of severe tooth pain. Although his tooth needed to be removed, the dentist refused to do so without proof of his HIV diagnosis. Once the doctor received proof of Ford's status he refused to extract the tooth, claiming that Ford's viral load was too high, and sent him home. Ford was in extreme pain, and eventually became so desperate that he tried to remove the tooth himself.[xliv]

Lupita Benitez, a lesbian who wanted to have a child, was denied access to the full range of infertility treatment by her medical doctor because of her sexual orientation. Her doctors were conservative Christians who claimed their religious beliefs gave them a right to withhold routine care from Benitez. Benitez was denied effective treatment for nearly a year. She subsequently was forced to abandon her course of treatment and seek out a doctor who would provide her with the treatment she needed.[xlv]

At age 75, Dr. Robert Franke, a retired university provost and minister, moved into an assisted living facility. He only lived in the facility for one day before his HIV status was discovered. His daughter was told that she had to remove Dr. Franke from the facility immediately or he would be turned over to Adult Protective Services. For seven weeks, Dr. Franke was forced to sleep on a small bed in his daughter's kitchen and was deprived of human companionship during the day while his daughter was at work.

These stories are reflective of the type of discrimination faced by LGBT patients when trying to access healthcare and related services, but unfortunately, they represent only a small fraction of the cases in which such discrimination is present.

Question 2: Programs and activities that should be considered health programs and activities under Section 1557

Section 1557 Applies to Health Programs or Activities of Recipients of Federal Financial Assistance; Programs or Activities Administered by an Executive Agency; and Entities Established Under Title I of the ACA.

Section 1557 protects individuals from discrimination "on the ground[s] 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" in "any health program or activity, any part of which is receiving Federal financial assistance, or under any program or activity that is administered by an Executive Agency," or any entity established under Title I of the ACA. As is discussed more fully below, these health programs include public and private entities and activities in virtually all aspects of the health care system.

Prior to the enactment of Section 1557, the four laws that it references (Title VI, Title IX, Section 504 of the Rehabilitation Act ("Section 504"), and the Age Discrimination Act ("the Age Act")) provided some protection against discrimination in health care. It is essential that Section 1557 be interpreted consistent with these existing protections in health programs as generally described under the CRRA. In addition, Section 1557's nondiscrimination mandate may overlap with existing protections under Title VI, Title IX, Section 504, and the Age Act. Other federal antidiscrimination laws, like Title VII, apply to aspects of health programs as well.

Section 1557 applies to any health program or activity, any part of which receives federal financial assistance, which for purposes of Section 1557 specifically includes credits, subsidies, and contracts of insurance.

Congress, in drafting Section 1557, used the same language – "program or activity" – as used in the four civil rights statutes Section 1557 references to indicate the entities covered by it.[xlvi] "Program or activity" under Section 1557 thus has the same meaning as it does under those statutes, as defined by the CRRA. A covered "program or activity" thus includes public or private entities, as well as departments or agencies of a state or local government that receive federal financial assistance.

Furthermore, Congress structured Section 1557 similarly to the way it structured Title IX. Like Title IX, Section 1557 is written with a term that modifies the phrase "program or activity" ("education" in Title IX, "health" in Section 1557). The term "education" in Title IX does not limit the range of recipients of federal financial assistance that fall under Title IX's jurisdiction; rather, the term indicates which portions of a covered program or activity cannot discriminate. Congress confirmed this interpretation when it enacted the CRRA.[xlvii] Because Section 1557 is structured like Title IX, the analysis used to determine jurisdiction under Title IX should be used to determine jurisdiction under Section 1557.

In the Title IX context, if the entity has education as its primary purpose, like a public or private university, Title IX prohibits sex discrimination in all of its programs or activities.[xlviii] If the entity does not have education as its primary purpose, Title IX bars discrimination in the education portions of the entity, any part of which receives federal financial assistance for any purpose.[xlix] Likewise, Section 1557 should be interpreted to prohibit discrimination in all the operations of a covered entity that has health as its primary purpose.[l] These include entities such as state and local health departments, hospitals and hospital systems, health clinics, nursing homes, home care agencies, health insurance companies, health or medical research centers, and medical, dental, or other schools that focus on training individuals to enter careers in the health field.

Section 1557 also applies to entities that do not have health as a primary purpose. For a covered entity that does not have health as its primary purpose, Section 1557 prohibits discrimination in that entity's health programs or activities, regardless of whether those health programs or activities receive federal financial assistance as long as the entity itself does. This includes, for example, health insurance plans offered by institutions that receive federal financial assistance and health education programs at schools or other entities.[li]

Whether a particular entity or program should be considered "health" related for purposes of Section 1557, like the question of whether a program is educational under Title IX, is a fact-specific question. To effectuate Section 1557's nondiscrimination principle, the determination of whether a program is a "health" program or activity should be consistent with existing interpretations of the term "health" offered by the World Health Organization (WHO). WHO defines health to include not just the absence of disease but also "physical, mental, and social well-being."[lii] 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 health of the physical, mental, or social well-being of an individual or population's health.

Section 1557 applies to credits, subsidies, and contracts of insurance as federal financial assistance.

Section 1557 differs from the civil rights laws to which it refers by expressly identifying "credits, subsidies, [and] contracts of insurance" as federal financial assistance to make clear that each trigger its application. For example, Section 1557's inclusion of "contracts of insurance" as federal financial assistance means that it could have broader application than the other civil rights laws it references. Unlike Section 1557, Title VI, Title IX, and the Rehabilitation Act either explicitly exclude or have been interpreted in some circumstances to exclude contracts of insurance as a form of federal financial assistance.[liii] A contract of insurance that is federal financial assistance is any contract of insurance that is funded, entered into, administered, or guaranteed by the federal government. Thus, for example, an insurance company in an Exchange that receives federally-subsidized payments such as through premium tax credits is covered by Section 1557. In addition, contracts for health insurance entered into by the federal government to provide coverage for federal employees are also federal financial assistance to the contracting insurance company. Because contracts of insurance are explicitly included in Section 1557, its regulations must recognize this fact and ensure that these federal funds are not used to finance discrimination.

Furthermore, the term "contracts of insurance" includes all aspects of such insurance contracts and administration of those contracts, including benefits design. Prior to the Affordable Care Act, few nondiscrimination protections applied to insurance, which had only a limited effect in ensuring fair coverage for all consumers. But several provisions of the ACA, including Section 1557, are designed to

address this gap by prohibiting practices previously viewed as permissible in many insurance markets.[liv] Among these practices is discrimination in benefits design, which has been pervasive in the insurance industry.[lv] For example, carriers have often excluded benefits from coverage in a manner that discriminates on the basis of gender identity. Examples of such discriminatory designs include exclusions for "any procedure or treatment, including hormone therapy, designed to change your physical characteristics from your biologically determined sex to those of the opposite sex," or for "all services related to gender dysphoria or gender identity disorder."[lvi] These exclusions directly target transgender consumers, contradict the consensus of leading professional medical associations,[lvii] and limit access to otherwise covered benefits on the basis of gender identity. Section 1557 should be interpreted to prohibit benefit designs that discriminate in this manner in programs administered by the federal government and in coverage programs or plans that receive federal funds.

Section 1557 applies to programs or activities administered by an Executive Agency.

Section 1557 protects individuals from discrimination "under any program or activity that is administered by an Executive Agency." Section 504, too, applies to any program or activity, "conducted by any Executive agency."[lviii] The phrases "administered by" and "conducted by" are generally synonymous.[lix] Federally-conducted programs or activities have typically been defined to include "anything a federal agency does."[lx] Simply put, "any program or activity that is administered by an Executive Agency" means that "anything a federal agency does" is subject to the nondiscrimination requirements of Section 1557.

More specifically, Section 1557 applies to HHS-administered health programs such as Medicare as well as jointly-administered federal and state programs such as Medicaid and the Children's Health Insurance Program (CHIP).[lxi] HHS is not the only federal agency that must comply with Section 1557; indeed, all federal agencies must conduct their programs and activities in a nondiscriminatory way to comply with Section 1557. This includes, for example, the agencies involved in implementing the ACA such as the Department of Labor and the Department of the Treasury. Likewise, Section 1557 applies to the Federal Employee Health Benefits Program (FEHBP), which is administered by the Office of Personnel Management, an executive agency.

Section 1557 applies to entities established under Title I of the ACA.

The third category of entities in which Section 1557 protects individuals from discrimination are entities established under Title I of the ACA. The health insurance Exchanges and Consumer-Oriented and Operated Plans (CO-OPs) are examples of entities that were or will be created pursuant to Title I of the ACA and that are, therefore, subject to Section 1557.[lxii] As under other civil rights laws, a covered entity itself can neither discriminate, nor can it provide assistance—monetary or otherwise—to entities that discriminate.[lxiii]

Question 3: The impact of discrimination against LGBT people in health programs and activities

Discrimination in healthcare programs and activities compounds with institutional and interpersonal discrimination to contribute to negative health outcomes for LGBT people. The Institute of Medicine has recognized that the stigma and discrimination experienced by LGBT people contributes to minority stress, which in turn can cause negative mental health outcomes.[lxiv] Studies have documented such disparities among subpopulations of the LGBT community, including elevated rates of depression, anxiety, and substance use.[lxv] For example, in a 2011 report presented to the American Psychology

Association, researchers found that lesbian, gay, and bisexual people who had experienced prejudice-related events were three times more likely to have suffered a serious physical health problem over a one-year follow-up period than those who had not experienced such events.[lxvi] Also, in a recent study of Latina transgender women, respondents reported high levels of discrimination in various aspects of everyday life, and those who reported higher levels of discrimination were more likely to be identified with moderately severe to severe levels of depression.[lxvii] And while data from the National Transgender Discrimination Survey, conducted by the National Gay and Lesbian Task Force and National Center For Transgender Equality, on the relationship between discrimination in health care and suicidality was not reported, the high lifetime suicide attempt rate among the sample (41 percent) was dramatically higher among those who had experienced bias-motivated victimization in other forms, such as bullying in school (51 percent), loss of a job (55 percent), and physical assault in any setting (61 percent).[lxviii] Ultimately, internalized stigma, experiences of victimization, and fear of accessing health services were all significantly associated with poorer physical health, higher likelihood of disability, and higher degrees of depressive symptoms and perceived stress. [lxix]

In addition to the institutional drivers of health disparities among the LGBT population, discrimination in the health care context can result in more direct negative health outcomes. While in severe instances, acts of discrimination by healthcare providers have resulted in serious injury, disease progression, and death,[lxx] denial of care and delivery of inadequate care can also lead to mistrust and reluctance to seek care on the part of LGBT patients.[lxxi] For example, according to a national survey of transgender adults, 28 percent of respondents reported postponing or not seeking care when sick or injured and 33 percent reported postponing or not seeking preventive care out of fear of discrimination or disrespect from providers. Failure to obtain preventative health care screenings out of fear of discrimination can lead to a delay in diagnosing and treating general health issues and to higher rates of hospitalization.[lxxii]

Discriminatory barriers to health care coverage for LGBT people may also have an impact on health outcomes. For example, a California Department of Insurance studying the impact of removing discriminatory coverage exclusions that target the transgender population found improved outcomes for some of the most significant health problems facing the transgender population, including reduced suicide risk, lower rates of substance abuse, improved mental health outcomes, and increased adherence to HIV treatment regimens.[lxxiii] Thus, while discrimination in health care programs and activities may drive some negative health outcomes for LGBT individuals, *removing* such discrimination may also *improve* the health of the LGBT population.

Question 5: Considerations in the applicability of Title IX sex-based nondiscrimination protections

Section 1557 bars discrimination "on the ground prohibited under . . . title IX of the Education Amendments of 1972," which is sex.[lxxiv] It is critical that regulations issued pursuant to this new statute reflect the long-established jurisprudence of strong protections against sex discrimination in federal law. Regulations, guidance, and case law under Title VII of the Civil Rights Act of 1964, the Pregnancy Discrimination Act (PDA), and Title IX of the Education Amendments of 1972 should inform what constitutes sex discrimination in health care under Section 1557. In addition, Section 1557 may not be misinterpreted to narrow existing interpretations of and protections against sex discrimination.

Section 1557's prohibition of sex discrimination necessarily includes discrimination based on pregnancy, gender identity, and sex stereotypes—as the RFI rightly notes. [lxxv]

Discrimination on the basis of actual or potential parental, family or marital status also violates Section 1557 if this behavior treats women and men differently or is based on sex stereotypes. Title IX's prohibition on sex discrimination encompasses these grounds.[lxxvi] Title IX further prohibits actions based on head of household or principal wage earner status.[lxxvii] Section 1557 regulations should likewise prohibit discrimination on these bases.

Further, Title IX has consistently been interpreted to bar discrimination based on sex stereotyping—including discrimination based on the assumption that someone conforms to a sex stereotype and discrimination against an individual because he or she departs from a sex stereotype—and Section 1557 must be understood to ban such discrimination.[lxxviii] Similarly, the E.E.O.C. has also concluded that discrimination based on gender identity or transgender status is a form of sex discrimination under Title VII,[lxxix] as has the Department of Housing and Urban Development with regard to the Fair Housing Act.[lxxx] Indeed, HHS has already recognized the importance of addressing discrimination against LGBT people in health care when it included explicit prohibitions against sex, gender identity, and sexual orientation discrimination in final rules for health insurance Exchanges, QHPs, and the EHB.[lxxxi]

In addition, HHS should clarify that sexual orientation falls within the sex stereotyping protections under Section 1557. Discrimination on the basis of sexual orientation is itself inherently rooted in sex stereotypes: that men are supposed to be attracted to women, and women are supposed to be attracted to men. Therefore, discrimination against gay, lesbian, and bisexual men and women is also discrimination for failing to conform to stereotypical gender roles.[lxxxii] This reasoning has been accepted by several federal, state, and international courts and furthers HHS's goal to combat discrimination based on sex-stereotyping.[lxxxiii] Given this inextricable link between discrimination based on sexual orientation and nonconformity with sex stereotypes, 1557's prohibition on sex discrimination should be interpreted to include discrimination on the basis of sexual orientation.

Clarification from HHS is also needed to ensure that LGB people are not excluded from bringing traditional sex discrimination claims under Section 1557. In Title VII discrimination cases, many sex discrimination claims made by lesbian, gay, and bisexual plaintiffs who have faced sex based discrimination unrelated to their sexual orientation have been rejected because of a perception that these plaintiffs are trying to "bootstrap" sexual orientation claims into Title VII.[lxxxiv] Like heterosexual individuals, lesbian, gay, and bisexual individuals can and do face sex based discrimination aside from their sexual orientation and should be afforded the same protections under Section 1557. To avoid this misinterpretation and unequal enforcement, Section 1557 regulations should provide clear guidance on the permissibility of traditional sex discrimination claims made by people who may also have lesbian, gay, or bisexual sexual orientations.

The only exceptions to Section 1557's broad nondiscrimination mandate are specifically and explicitly contained in Title I of the ACA.

The Section 1557 ban against discrimination in health programs includes a single exception – that it applies "[e]xcept as otherwise provided" in Title I of the ACA.[lxxxv] Thus, the only exceptions to Section 1557 are those expressly stated in that title. The plain language of the statute bars any interpretation that would suggest any other exceptions apply. In fact, exceptions to general rules like Section 1557's antidiscrimination provision must be read strictly and narrowly.[lxxxvi]

Nothing in Section 1557, its language or legislative history, allows for any other limitations or exceptions regarding its application. Question (5) of the RFI notes that Title IX[lxxxvii] contains limited exceptions to its

protection in certain circumstances. These exceptions, however, are not incorporated into Section 1557. First, because those limited exceptions are not explicitly stated in Section 1557, they cannot be read to apply to it. Second, Section 1557 does not import any exceptions from Title IX. Section 1557 references Title IX solely for the ground on which it prohibits discrimination, which is sex.

Sex-specific health programs or activities do not violate Section 1557 when they are necessary to accomplish an essential health purpose.

Because the RFI specifically asks how Section 1557 should apply to health programs and activities that serve only one sex, we address that issue here. Like Title IX and other civil rights laws, the circumstances under which sex-specific programs and activities are permissible and thus nondiscriminatory must be narrow. Consistent with Section 1557's broad nondiscrimination purpose, sex-specific health programs or activities should be permissible under Section 1557 when they are necessary to serve the disadvantaged sex – most usually women – or to comply with constitutionally protected rights to privacy. At heart, single-sex programs must be narrowly tailored and *necessary to accomplish an essential health purpose.* For example, clinical trials that aim to determine whether sex differences exist in certain diseases or responses to treatment do not violate Section 1557 when they establish sex-specific studies because the very purpose of the study is about sex difference and its impact on medical treatments. Further, Section 1557's protection against sex discrimination still applies in single-sex environments. So, where sex-specific programs or activities exist, they must be nondiscriminatory for each sex.

To the extent that Section 1557 makes narrow allowances for single-sex programs or activities, participation in these programs is determined by an individual's self-identified gender. As noted above, Section 1557 protects against gender identity discrimination, which means that the law protects an individual's ability to live in his or her community *as* a man or a woman.[lxxxviii] So too Section 1557 protects an individual's access to health programs and activities in accordance with their self-identified gender and free from sex stereotypes.

Question 7: Enforcement mechanisms provided by Section 1557

Section 1557 Includes the Enforcement Mechanisms Provided For and Available Under Title VI, Title IX, Section 504, and the Age Discrimination Act.

It is critical that OCR create and administer a strong enforcement system for this new statute. The success of Title IX in combatting sex discrimination demonstrates the importance of strong agency enforcement.

The compliance and enforcement procedures used under Title IX and the three other civil rights laws referenced by Section 1557 provide a starting point for establishing procedures under Section 1557. The regulations adopted for Section 1557 must reflect the entire wide range of equitable relief and enforcement mechanisms established and available under those statutes, including agency enforcement as well as the private right of action for monetary damages.

Because the statutes listed in Section 1557 contain a private right of action for a full range of relief, including equitable relief and monetary damages, Section 1557 does as well.[lxxxix] Likewise, Section 1557 provides for the full range of agency enforcement and Department of Justice enforcement in court.

The enforcement procedures provided under the laws referenced by Section 1557 are a starting point for developing procedures under Section 1557. Like those laws, Section 1557 must be interpreted to provide for complaints brought on behalf of an individual, a class, or by a third party. Each of these vehicles for agency enforcement is crucial and a hallmark of civil rights enforcement under the laws Section 1557 references. Class complaints and third party complaints in particular allow OCR to resolve systemic problems of discrimination, rather than proceeding piecemeal only on behalf of individual complainants. They are especially important in the health care area because of the consequences of allowing system-wide patterns of discrimination to continue. Individual victims of discrimination may be hesitant to file complaints themselves because, for example, they fear retaliation from individuals or entities on which they rely for health care or insurance coverage. This creates a strong disincentive for some to file complaints and reinforces the importance of class and third party complaints.

Compliance reviews, outreach, and education will assist in enforcement of the protections provided by Section 1557

Section 1557 is a powerful proactive tool in OCR's work to combat discrimination in health programs and activities. OCR's authority is not limited to responding to complaints under Section 1557. It can—and should—also address discriminatory policies and practices at covered entities through technical assistance, systemic investigations, and compliance reviews of selected entities. OCR has conducted these reviews pursuant to its authority under other civil rights laws.[xc] Because Section 1557 is a new law, it is especially important that OCR complete compliance reviews to both identify discrimination and set precedents under this new law. Without knowledge of Section 1557's protection or how to file a complaint, individuals remain vulnerable to discrimination in health care settings and covered entities may well continue discriminatory practices.[xci] The results of compliance reviews should also be made public. The reports from such reviews can serve as guidance for other covered entities as to what it means to comply with Section 1557.

The communities protected by Section 1557 will also require education as to their rights and the enforcement mechanisms available to them under the statute and implementing regulations. Previous experience dictates that those who have gone without nondiscrimination protections previously may be uncertain regarding their rights when these protections are introduced. In a survey conducted by the Transgender Law Center on the impact of the California's LGBT nondiscrimination laws on the transgender community, research showed that 30 percent of survey respondents did not know about the law, and 27 percent did not know how to file a complaint.[xcii] Therefore, when promulgating rules regarding enforcement processes and mechanisms for Section 1557, HHS should craft effective measures to encourage minorities, including the LGBT community, to seek out resources that are created to assist them. HHS must proactively (1) educate communities about new protections, (2) require information about Section 1557 patient rights to be posted in health care facilities, (3) provide clear information, resources, and assistance for people to file complaints, and (4) provide training for health administrators, legal professionals, and Marketplace consumer assistance entities about new duties under Section 1557.

We commend HHS for taking the important step of issuing this RFI and urge the Department to move forward with the rulemaking necessary to implement this crucial new civil rights protection. We urge HHS to administer this statute through robust implementation and enforcement mechanisms, and this must be reflected in the final regulations that HHS promulgates. This is essential if Section 1557's guarantee of protection from discrimination in health care is to be fulfilled.

Sincerely,

Andrew Cray
Policy Analyst, Center for American Progress

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[i] Institute of Medicine. 2011. *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*. Available from http://www.iom.edu/Reports/2011/The-Health-of-Lesbian-Gay-Bisexual-and-Transgender-People.aspx

[ii] Department of Health and Human Services. 2010. "Lesbian, Gay, Bisexual, and Transgender Health." Available from http://www.healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=25

[iii] Substance Abuse and Mental Health Services Administration. 2012. "Top Health Issues for LGBT Populations." Available from http://store.samhsa.gov/product/Top-Health-Issues-for-LGBT-Populations/SMA12-4684

[iv] Agency for Healthcare Research and Quality. 2012. *National Healthcare Disparities Report*. Available from http://www.ahrq.gov/qual/nhdr11/nhdr11.pdf

[v] The Joint Commission. 2011. "Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care for the LGBT Community: A Field Guide." Available from http://www.jointcommission.org/assets/1/18/LGBTFieldGuide.pdf

[vi] Institute of Medicine. *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*.

[vii] Ibid.

[viii] Ibid.

[ix] Substance Abuse and Mental Health Services Administration. "Top Health Issues for LGBT Populations."

[x] *See e.g.* Centers for Disease Control and Prevention. 20005. "HIV/AIDS and Transgender Persons." Available from http://www.cdc.gov/lgbthealth/transgender.htm.

[xi] *See e.g.* Katie Keith and others, "Nondiscrimination Under the Affordable Care Act" (Washington DC: Georgetown University Health Policy Institute 2013) available at http://chir.georgetown.edu/pdfs/NondiscriminationUndertheACA_GeorgetownCHIR.pdf

[xii] Ibid.

[xiii] AIDS.gov. 2012. "The Affordable Care Act Helps People Living with HIV/AIDS." Available from http://aids.gov/federal-resources/policies/health-care-reform/

[xiv] Institute of Medicine. *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*.

[xv] See, e.g., South v. Gomez, 211 F.3d 1275, *1 (9th Cir. 2000) (noting that "gender dysphoria [is] more commonly known as transsexualism"); Schwenk v. Hartford, 204 F.3d 1187, 1193 (9th Cir. WA 2000) (referring to "gender dysphoria [as] the technical diagnosis for transsexuality."); Farmer v. Haas, 990 F.2d 319, 320 (7th Cir. 1993) (using "transsexualism" and "gender dysphoria" as interchangeable); Glenn v. Brumby, 724 F. Supp. 2d 1284, 1304, n.5 (N.D. Ga. 2010) aff'd, 663 F.3d 1312 (11th Cir. 2011) (stating that "GID and transsexualism are closely related and are sometimes used as synonyms, with transsexuals characterized by an intention to undergo medical treatments to align their bodies with their gender identities").

[xvi] American Medical Association House of Delegates, "Removing Financial Barriers to Care for Transgender Patients" (2008), available at http://www.tgender.net/taw/ama_resolutions.pdf

[xvii] American Psychiatric Association, "Transgender, Gender Identity, & Gender Expression Non-Discrimination" (2008), available at http://www.apa.org/about/policy/transgender.aspx

[xviii] The World Health Organization's International Statistical Classification of Diseases and Related Health Problems, version 10 (ICD-10) includes "gender identity disorder." *See* http://apps.who.int/classifications/icd10/browse/2010/en#/F64

[xix] Kellan Baker and Andrew Cray "Ensuring Benefits Parity and Gender Idnentity Nondiscrimination in Essential Health Benefits" (Washington: Center for American Progress, 2013) available at http://www.americanprogress.org/wp-content/uploads/2012/11/BakerHealthBenefits-2.pdf

[xx] Ariz. Admin Code § R9-27-203
[xxi] *See e.g.* Government Employees Health Association, Inc. Benefit Plan (2013) Available from: http://www.opm.gov/healthcare-insurance/healthcare/plan-information/plan-codes/2013/brochures/71-006.pdf (excluding coverage for "Services, drugs, or supplies related to sex transformations").
[xxii] *See* 38 C.F.R. § 17.38(c)(4) (Excluding coverage for "gender alterations").
[xxiii] National Center for Transgender Equality, "Medicare Benefits and Transgender People (2011) available at http://transequality.org/Resources/MedicareBenefitsAndTransPeople_Aug2011_FINAL.pdf
[xxiv] American Medical Association House of Delegates, "Removing Financial Barriers to Care for Transgender Patients" (2008), available at http://www.tgender.net/taw/ama_resolutions.pdf
[xxv] Lambda Legal, "When Healthcare Isn't Caring" (2010) available at http://data.lambdalegal.org/publications/downloads/whcic-report_when-health-care-isnt-caring.pdf at 9-10.
[xxvi] Lambda Legal, "When Healthcare Isn't Caring."
[xxvii] Ibid.
[xxviii] Ibid.
[xxix] Jaime M. Grant et al., Injustice at Every Turn: A Report of the National Transgender Discrimination Survey 73 (2011), *available at* http://transequality.org/PDFs/NTDS_Report.pdf.
[xxx] Ibid.
[xxxi] Ibid.
[xxxii] Ibid.
[xxxiii] National Women's Law Center, Health Care Refusals Harm Patients: The Threat to LGBT People and Individuals Living with HIV/AIDS (2013), available at http://www.nwlc.org/sites/default/files/pdfs/lgbt_refusals_factsheet_8-6-13.pdf.
[xxxiv] Ibid.
[xxxv] Ibid.
[xxxvi] Brad Sears and Deborah Ho, The Williams Institute, UCLA School of Law, HIV Discrimination in Health Care Services in Los Angeles County: The Results of Three Testing Studies (2006), available at http://williamsinstitute.law.ucla.edu/wp-content/uploads/Sears-Ho-Discrimination-Health-Care-LA-County-Dec-2006.pdf.
[xxxvii] NASTAD/NCSD Stigma Survey Findings Presentation, United States Conference on AIDS (2012), available at http://www.nastad.org/Docs/042244_Slides-NASTAD-Stigma%20Seminar-and-Public-Health-USCA-2012-09-24-12-FINAL.pdf.
[xxxviii] Ibid.
[xxxix] Ibid.
[xl] http://www.glaa.org/archive/1998/margiehunter1211.shtml
[xli] http://www.glaa.org/archive/1999/silber0325.shtml
[xlii] http://www.ghjournal.org/jgh-online/the-story-about-robert-eads/
[xliii] http://www.queerty.com/in-the-face-of-discrimination-transgendered-man-denied-care-for-breast-cancer-20120809/
[xliv] http://www.hivlawandpolicy.org/resources/view/297
[xlv] *N. Coast Women's Care Med. Grp., Inc. v. San Diego Cnty.* Superior Court, 44 Cal. 4th 1145 (2008).
[xlvi] Civil Rights Restoration Act of 1987, Pub. L. 100-259, 102 Stat. 28 (1988), (codified as amended in scattered sections of 20, 29, and 42 U.S.C.).
[xlvii] *See, e.g., O'Connor v. Davis*, 126 F.3d 112, 118 (2d Cir. 1997); Dep't of Justice, *Title IX Legal Manual* (2001), *available at* http://www.justice.gov/crt/about/cor/coord/ixlegal.php (stating that the scope of Title coverage "will depend upon which portions of a covered program or activity are educational in nature.").
[xlviii] 20 U.S.C. § 1687(2) (2012). *See also O'Connor v. Davis*, 126 F.3d 112, 117 (2d Cir. 1997) ("[C]ourts have consistently interpreted Title IX to mean that if one arm of a university or state agency receives federal funds, the entire entity is subject to Title IX's proscription against sex discrimination.").
[xlix] *See, e.g., Jeldness v. Pearce*, 30 F.3d 1220, 1226 (9th Cir. 1994) (recognizing that the recipient of federal financial assistance need not be educational in nature for an education program or activity operated by the non-educational entity to be covered by Title IX); Dep't of Justice, *Title IX Legal Manual* (2001), *available at* http://www.justice.gov/crt/about/cor/coord/ixlegal.php.
[l] *See* Civil Rights Restoration Act of 1987, § 3 (codified as amended at 20 U.S.C. 1687(2)). *See also id*. at § 3 (codified as amended at 20 U.S.C. 1687(3(A)(ii)).

[li] Some entities are directly bound by Section 1557 in addition to other antidiscrimination laws, such as Title IX or Title VII. Section 1557, however, may provide additional protections to individuals not covered by those laws. *See, e.g.,* Nat'l Women's Law Ctr., *NWLC Section 1557 Complaint: Sex Discrimination Complaints Against Five Institutions*, http://www.nwlc.org/resource/nwlc-section-1557-complaint-sex-discrimination-complaints-against-five-institutions (last visited Sept. 17, 2013).
[lii] Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 8 April 1948.
[liii] Because "contracts of insurance" are not excluded in the statutory text of Section 504 but in its regulations, there are conflicting decisions about whether the regulations properly exclude it. *Compare Moore v. Sun Bank of North Florida*, 923 F.2d 1423, 1429-32 (11th Cir. 1991) (finding that because Section 504 did not expressly exclude contracts of insurance or guaranty, the regulations containing the exclusion were invalid as inconsistent with congressional intent and that the contract at issue did in fact constitute federal financial assistance) *with Gallagher v. Croghan Colonial Bank*, 89 F.3d 275 (6th Cir. 1996) (holding that based on the Section 504 regulation's exclusion of contracts of insurance or guaranty as federal financial assistance, a bank's receipt of reimbursement for default loans was not federal financial assistance and thus the bank was not subject to the Rehabilitation Act).
[liv] *See e.g.* http://chir.georgetown.edu/pdfs/NondiscriminationUndertheACA_GeorgetownCHIR.pdf
[lv] Ibid.
[lvi] http://www.americanprogress.org/wp-content/uploads/2012/11/BakerHealthBenefits-2.pdf
[lvii] http://www.lambdalegal.org/sites/default/files/publications/downloads/fs_professional-org-statements-supporting-trans-health_1.pdf
[lviii] 29 U.S.C § 794 (2012). *See also* Exec. Order 13,160 3 C.F.R. 279 (2000).
[lix] "Conduct" means "to direct or take part in the operation or management of." Conduct - Definition from the Merriam-Webster Dictionary, http://www.merriam-webster.com/dictionary/conduct (last visited Sept. 17, 2013). "Administer" means "to manage or supervise the execution, use, or conduct of." Administer - Definition from the Merriam-Webster Dictionary, http://www.merriam-webster.com/dictionary/administer (last visited Sept. 17, 2013).
[lx] *E.g.*, Enforcement of Nondiscrimination on the Basis of Handicap in Programs or Activities Conducted by the Central Intelligence Agency, 57 Fed. Reg. 39,605 (Sept. 1, 1992); Gen. Servs. Admin., Office of Civil Rights, The Key To Accessing Federally Conducted Programs and Activities 4, *available at* http://www.gsa.gov/graphics/staffoffices/Interim_Key_to_Accessing_FCPA_Handbook__R2-yY5K_0Z5RDZ-i34K-pR.pdf; *Commonly Asked Questions and Answers Regarding Executive Order 13166*, http://www.lep.gov/13166/lepqa.htm (last visited Sept. 17, 2013).
[lxi] Medicaid and CHIP are jointly administered by HHS and state agencies; nonetheless, because HHS participates in the administration of these programs, Section 1557 applies to them. Section 1557 also applies to the state agencies that receive and distribute federal funds to operate these programs, as "health programs or activities, any part of which receive federal financial assistance."
[lxii] The Pre-existing Condition Insurance Program and the Early Retiree Reinsurance Program are also examples of entities that were brought into existence pursuant to Title I of the ACA that are subject to Section 1557. These programs expire January 1, 2014. 42 U.S.C. §§ 18001, 18002 (2012).
[lxiii] *See, e.g.*, 34 C.F.R. § 106.31(b)(6) (2012) (prohibiting covered programs or activities from aiding or perpetuating discrimination on the basis of sex by providing aid or assistance to any entity that discriminates on the basis of sex).
[lxiv] Institute of Medicine. *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*.
[lxv] Ibid.
[lxvi] Ilan Meyer, *et al., Minority Stress and Physical Health Among Sexual Minorities* (2011).
[lxvii] M. Bazargan, & F. Galvan, *Perceived Discrimination and Depression among Low-Income Latina Male-to-Female Transgender Women* 12 BMC Public Health 663 (2012).
[lxviii] Grant et al., "Injustice at Every Turn"
[lxix] K.I. Fredriksen-Goldsen et al., *Physical and Mental Health of Transgender Older Adults: An At-Risk and Underserved Population*, Epub ahead of print, Gerontologist (2013).
[lxx] See section one above.
[lxxi] Institute of Medicine. *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*.

[lxxii] *See*, *e.g.*, A.B. Bindman, K. Grumback, D. Osmond, et al., *Preventable Hospitalization and Access to Care*, 274 Journal of the American Medical Association 305 (1995).
[lxxiii] State of California Department of Insurance, "Economic Impact Assessment: Gender Nondiscrimination in Health Insurance."
[lxxiv] 20 U.S.C. § 1681(a) (2012).
[lxxv] Dep't of Health & Human Servs., Request for Information Regarding Nondiscrimination in Certain Health Programs or Activities,78 Fed. Reg. 46,558, 46,559 (proposed Aug. 1, 2013) ("Sex discrimination (including discrimination on the basis of gender identity, sex stereotyping, or pregnancy)").
[lxxvi] *E.g.* 34 C.F.R. § 106.40(a) (2012); 34 C.F.R. § 106.57(a).
[lxxvii] *E.g.* 34 C.F.R. § 106.57(a) (2012).
[lxxviii] *See* Dep't of Educ., Office of Civil Rights, *Revised Sexual Harassment Guidance: Harassment of Students by School Employees, Other Students, or Third Parties: Title IX* (January 19, 2001), *available at* http://www2.ed.gov/about/offices/list/ocr/docs/shguide.html; Dep't of Educ., "Dear Colleague," 7-8 (October 26, 2010), *available at* http://www2.ed.gov/about/offices/list/ocr/letters/ colleague-201010_pg8.html.. *See also Price Waterhouse v. Hopkins*, 490 U.S. 228 (1989); *Lewis v. Heartland Inns of America, L.L.C.*, 591 F.3d 1033 (8th Cir. 2010); *Bibby v. Phila Coca Cola Bottling Co.*, 260 F.3d 257, 2652-63 (3rd Cir. 2001); *Smith v. City of Salem*, 378 F.3d 566 (6th Cir. 2004). *See also Doe v. Brimfield Grade School,* 552 F. Supp. 2d 816, 823 (C.D. Ill. 2008); *Theno v. Tonganoxi Unified School District*, 377 F. Supp. 3d 952 (D. Kansas 2005); *Schroeder v. Maumee Bd. Of Educ.*, 296 F. Supp. 2d 869, 880 (N.D. Ohio 2003); *Montgomery v. Indep. Sch. Dist. No.* 709, 109 F. Supp. 2d 1081, 1090-91 (D. Minn. 2000).
[lxxix] *Macy v. Holder*, E.E.O.C. Appeal No. 0120120821, *7 (Apr. 23, 2012) (interpreting Title VII's prohibition against sex discrimination to include discrimination based on a person's transgender status).
[lxxx] Memorandum from John Trasviña to FHEO Regional Directors, *Assessing Complaints that Involve Sexual Orientation, Gender Identity, and Gender Expression* (June 2010), *available at* http://www.fairhousingnc.org/wp-content/uploads/2012/03/HUD-Memo-re-Sexual-Orientation-Discrimination-6-15-2010.pdf (announcing that the Department would treat "gender identity discrimination most often faced by transgender persons as gender discrimination under the Fair Housing Act").
[lxxxi] *See, e.g.,* 45 C.F.R. §§ 155.120(c) (nondiscrimination rule for Exchanges); 156.200(e) (for QHPs); Health Insurance Market Rules; Rate Review, 78 Fed. Reg. 13,406, 13,438 (Feb. 27, 2013) (to be codified at 45 C.F.R. § 147.104(e)) (for marketing and benefit design); Standards Related to Essential Health Benefits, Actuarial Value, and Accreditation, 78 Fed. Reg. 12,834, 12,867 (Feb. 25, 2013) (to be codified at 45 C.F.R. § 156.125) (for the EHB).
[lxxxii] "[Studies] have consistently found correlations between conventional expectations about gender roles and hostility toward homosexuals." Andrew Koppelman, Why Discrimination Against Lesbians and Gay Men is Sex Discrimination, 69 N.Y.U. L. REV. 197, 238 (citations omitted).
[lxxxiii] *See e.g.* Zachary Kramer, Heterosexuality and Title VII, 103 NW. U. L. REV. 205, 232 (2009).
[lxxxiv] *See, e.g., Simonton v. Runyon*, 232 F.3d 33, 38 (2d Cir. 2000). *See also,* Zachary Kramer, Heterosexuality and Title VII, 103 NW. U. L. REV. 205, 232 (2009).
[lxxxv] Patient Protection and Affordable Care Act § 1557, codified at 42 U.S.C. § 18116 (2012).
[lxxxvi] *Nussle v. Willette*, 224 F.3d 95, 99 (2d Cir. 2000) (quoting *Commissioner v. Clark*, 489 U.S. 726, 739 (1989), *overruled on other grounds by Porter v. Nussle*, 534 U.S. 516 (2002)); *Detroit Edison Co. V. SEC,* 119 F.2d 730, 739 (6th Cir. 1941) (holding that "[e]xceptions in statutes must be strictly construed and limited to objects fairly within their terms, since they are intended to restrain or except that which would otherwise be within the scope of the general language."). *See also McNely v. Ocala Star-Banner Corp*., 99 F.3d 1068, 1074 (11th Cir. 1996) (limiting language of "except as otherwise provided" precluded the ADA from importing more restrictive language from the Rehabilitation Act); *New York v. Bloomberg*, 524 F.3d 384, 402 (2d Cir. 2008).
[lxxxvii] 20 U.S.C. 1681(a)(1)-(9) (2012).
[lxxxviii] *See, e.g.*, *Macy v. Holder,* E.E.O.C. Appeal No. 0120120821 (Apr. 23, 2012) (employer violated Title VII when job offer revoked because plaintiff sought to work as a woman); *Schroer v. Billington*, 577 F. Supp. 2d 293 (D.C.C. 2008) (same).
[lxxxix] In *Cannon v. University of Chicago*, the Supreme Court emphasized the importance of the private right of action to enforcing antidiscrimination statutes. 441 U.S. 677, 704-05 (1979). The Court later determined that money damages are available for intentional discrimination, relying on the longstanding principle that all remedies are presumed to be available to accompany a federal right of action "unless Congress has expressly indicated otherwise." *Franklin v. Gwinnett County Public Schs.*, 503 U.S. 60, 66 (1992). There, the Court stated "Congress surely did not intend for federal monies to be expended to support the intentional actions it sought by statute to

proscribe." *Id.* at 74. *See also Guardians Assn. v. Civil Service Comm'n of New York City,* 463 U.S. 582 (1983) (damages available under Title VI for intentional violations); *Consolidated Rail Corporation v. Darrone,* 465 U.S. 624 (1984) (awarding backpay for violation of Section 504 of Rehabilitation Act).

[xc] *See, e.g.*, Dep't of Health & Human Servs., Office for Civ. Rts., *Compliance Review Initiative: Advancing Effective Communication in Critical Access Hospitals* (Apr. 2013), *available at* http://www.hhs.gov/ocr/civilrights/activities/agreements/compliancereview_initiative.pdf

[xci] For instance, staff for the California Health and Human Services Agency, which oversees California's Medicaid program, indicated a lack of complaints to the agency on language access issues in 2011 and 2012. Linda Bennett interview with Amanda Ream, Organizing Director, Interpreting for California (August 2013). The absence of complaints, however, is not an indication that discrimination does not exist; to the contrary, it suggests that individuals may not know their rights or about the complaint process.

[xcii] Masen Davis & Kristina Wertz, When Laws Are Not Enough: A Study of the Economic Health of Transgender People and the Need for A Multidisciplinary Approach to Economic Justice, 8 Seattle J. for Soc. Just. 467, 479 (2010).

Lambda Legal
making the case for equality

September 30, 2013

U.S. Department of Health and Human Services
Office for Civil Rights
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue SW
Washington, DC 20201
Attn: 1557 RFI (RIN 0945-AA02 & 0945-ZA01)

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

Lambda Legal appreciates the opportunity to respond to the request of the Department of Health and Human Services (HHS) for information regarding discrimination in health programs, services, and activities and implementation of Section 1557 of the Patient Protection and Affordable Care Act (ACA). We thank HHS for its commitment to ensuring that all people receive affordable and high quality health care and are especially grateful for the work HHS has done to increase access to care for lesbian, gay, bisexual, and transgender (LGBT) people and those living with HIV. Lambda Legal is the oldest and largest national legal organization dedicated to achieving full recognition of the civil rights of LGBT people and those living with HIV through impact litigation, policy advocacy, and public education. We are especially eager to comment on Section 1557 because discrimination based on gender identity, gender expression, sexual orientation, and HIV status are serious problems in our health care system. Lambda Legal has made these problems a primary focus of its work spanning the last four decades and believes enforcement of Section 1557 can reduce this discrimination significantly, with important corresponding improvements in health quality for these populations.

Section 1557 of the ACA provides that an individual shall not be excluded from participation in, denied the benefits of, or be subject to discrimination under any health program or activity, any part of which is receiving federal financial assistance, or under any program or activity established by the ACA on the basis of race, sex (including gender identity and non-conformity with sex stereotypes), disability, or age. The ACA will expand access to quality care for many thousands of currently uninsured and underinsured LGBT and HIV-positive people (1) by creating access to insurance for individuals who have been precluded due to lack of recognition of their family relationships, (2) by eliminating insurance practices that have limited or precluded access to care for people living with chronic conditions, and (3) by forbidding other discriminatory practices and helping to reduce stigma that limit access and reduce quality of care for these vulnerable populations. Because the health disparities affecting LGBT and HIV-positive people are pervasive and long-standing, it is essential that HHS issue guidance making clear that the protections and remedies provided for by Section 1557 are broad, meaningful, and enforceable.

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With Section 1557's mandate in mind, we ask that HHS consider the following key points in response to the issue areas identified in the RFI, which are addressed more fully in the following pages:

(1) LGBT people experience persistent health disparities due to discrimination based on gender identity and sexual orientation, which often are compounded by discrimination based on race, age, disability including HIV, immigration status, limited English proficiency, poverty, and other factors.

(2) LGBT persons perceived as more gender non-conforming tend to experience more discrimination, with transgender individuals facing the most extreme disrespect, refusals of insurance and medical care, and even physical abuse in medical settings. It is time to treat gender dysphoria like other medical conditions and end the discriminatory exclusion of medically indicated care.

(3) The prohibition against sex discrimination in covered health programs, activities and facilities necessarily includes discrimination based on sexual orientation both because sexual orientation is a relational term based on one's sex and because the stigmatizing of same-sex relationships is a function of gender stereotypes.

(4) Health professionals engage in improper discrimination when they provide or refer LGBT persons for aversion therapy to "cure" gender non-conforming behavior, including same-sex attraction. These practices have damaging effects and are repudiated by settled medical consensus and the laws of some states. For health professionals providing care to youth and their families, non-discriminatory practice requires support for acceptance of LGBT youth by other family members, not pressure on LGBT youth to change, because rejection and pressure to change undermine the health of LGBT youth and the relationships on which they depend.

(5) People living with HIV need effective enforcement of Section 1557 to challenge discriminatory insurance plans, discriminatory application of benefit plan rules, and persistent HIV-related stigma and discrimination by providers and health care facilities.

(6) The quality of medical care provided to patients who are, or are perceived to be, LGBT and/or HIV-positive must not be compromised due to the anti-LGBT religious views of either individual health professionals or religiously affiliated organizations providing health services pursuant to state medical licensure and any amount of federal funding.

(7) Harms of discrimination include delay and outright denials of care by insurers and medical providers, as well as lack of care due to avoidance of medical settings prompted by past discrimination. The harms of discrimination also include the mental and physical harms of stigma perpetuated by health professionals and others in health care settings who make those environments hostile for LGBT people and those with HIV.

(8) Appropriate language support is essential for limited English proficient (LEP) LGBT and HIV-positive patients because reliance on either family members or others lacking in cultural competence causes withholding of information essential for quality health care. LEP patients who are socially and/or financially dependent upon family members may be even more fearful than others that disclosure of their HIV or LGBT status, or any health needs related to such status, may cause family rejection.

(9) Where legitimate health needs justify limiting or segregating programs, activities or facilities by sex, individuals must be permitted to participate according to their gender identity.

(10) Information technology can permit increased consistency of health care for LGBT and HIV-positive individuals who are homeless or in transient living situations such as foster care. Confidentiality protections within electronic health records remain important due to persistent stigma concerning a minority sexual orientation and status as transgender or HIV positive.

(11) The established correlation between stigma and longstanding health disparities affecting LGBT people and those with HIV underscore the need for effective enforcement of the anti-discrimination mandate of Section 1557 through the full range of remedies including a private right of action. The fact that protections against discrimination on these grounds remains incomplete and confusing in related federal and state civil rights laws further reinforces this need.

UNDERSTANDING THE CURRENT LANDSCAPE

1. Examples of Discrimination

In 2010, Lambda Legal conducted the first-ever national survey to examine the refusals of care and other barriers to health care confronting LGBT people and those living with HIV: WHEN HEALTH CARE ISN'T CARING.[1] Of the nearly 5,000 respondents, more than half reported that they have experienced at least one of the following types of discrimination in care:

- Health care providers refusing to touch them or using excessive precautions;
- Health care providers using harsh or abusive language;
- Health care providers being physically rough or abusive;
- Health care providers blaming them for their health status.[2]

Almost 56 percent of lesbian, gay, or bisexual (LGB) respondents had at least one of these experiences; 70 percent of transgender and gender-nonconforming respondents had one or more of these experiences; and almost 63 percent of respondents living with HIV experienced one or more of these types of discrimination in health care. [3] Almost 8 percent of LGB respondents reporting having been denied needed care because of their sexual orientation,[4] and 19 percent of respondents living with HIV

[1] LAMBDA LEGAL, WHEN HEALTH CARE ISN'T CARING: SURVEY ON DISCRIMINATION AGAINST LGBT PEOPLE AND PEOPLE LIVING WITH HIV (2010), http://data.lambdalegal.org/publications/downloads/whcic-report_when-health-care-isnt-caring.pdf.

[2] *Id.* at 5, 9-10.

[3] *Id.*

[4] *Id.* at 5, 10.

reported being denied care because of their HIV status.[5] The picture was even more disturbing for transgender and gender-nonconforming respondents, who reported the highest rates of being refused care (nearly 27 percent), being subjected to harsh language (nearly 21 percent), and even being abused physically (nearly 8 percent).[6]

Respondents of color and low-income respondents reported much higher rates of hostile treatment and denials of care. Nearly half of low-income respondents living with HIV reported that medical personnel refused to touch them, while the overall rate among those with HIV was nearly 36 percent.[7] And while transgender respondents as a whole reported a care-refusal rate of almost 27 percent, low-income transgender respondents reported a rate of nearly 33 percent.[8] People of color living with HIV and LGB people of color were at least twice as likely as whites to report experiencing physically rough or abusive treatment by medical professionals.[9]

The WHEN HEALTH CARE ISN'T CARING report explains the context of this study and its recommendations. Accompanying the report are eight supplements providing excerpts of the personal testimonies submitted by study participants and presenting findings about particular subgroups; these supplements are:

- Lesbian, Gay, Bisexual and Transgender (LGBT) People and People Living with HIV Speak Out[10]
- LGBT People of Color and People of Color Living with HIV[11]
- LGBT Women[12]
- LGBT Older Adults and Older Adults Living with HIV[13]
- LGBT Immigrants and Immigrants Living with HIV[14]
- Transgender and Gender-nonconforming People[15]

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[5] *Id.*

[6] *Id.* at 10-11.

[7] *Id.* at 11.

[8] *Id.*

[9] *Id.* at 12.

[10] http://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-insert_lgbt-people-and-people-living-with-hiv-speak-out.pdf. Examples from these testimonies are provided in the following sections.

[11] http://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-insert_lgbt-people-of-color.pdf.

[12] http://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-insert_lgbt-women.pdf.

[13] http://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-insert_lgbt-older-adults-and-older-adults-living-with-hiv.pdf.

[14] http://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-insert_lgbt-immigrants-and-immigrants-living-with-hiv.pdf.

[15] http://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-insert_transgender-and-gender-

- People Living with HIV[16]
- Low-Income or Uninsured LGBT People and People Living with HIV[17]

The study results showing that LGBT and HIV-positive people who also are people of color, older, immigrants and/or low income experience much more discrimination in health care settings, with correspondingly compromised health outcomes, than people who do not experience such compounding of vulnerabilities reinforce that Section 1557 must be implemented and enforced effectively. What follows to assist HHS in pursuing those goals is information responding to the issue areas listed in the RFI drawn from Lambda Legal's survey, from years of experience litigating discrimination cases and developing health policy recommendations, and from other sources. First is information about discrimination based on gender identity, then sex discrimination against LGB people, and then discrimination against people living with HIV.

A. Examples of Discrimination Based On Gender Identity, Gender Stereotypes and Sexual Orientation That Should Be Prevented By Enforcement Of Section 1557

1. Gender Identity Discrimination In Health Insurance and Services Undermines the Health of Many Transgender Americans

While LGBT people as a whole are insured at lower percentages than the overall American population,[18] transgender individuals are uninsured and underinsured to an ever greater extent and frequently are denied coverage and access to quality care specifically because of their transgender status.[19] This section addresses three problem areas for transgender patients: (a) biased treatment and discriminatory refusals of care unrelated to the person's gender and transition; (b) refusals of sex-specific care; and (c) refusals of transition-related care.

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nonconforming-people.pdf.

[16] http://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-insert_people-living-with-hiv.pdf.

[17] http://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-insert_low-income-or-uninsured.pdf.

[18] *See* Laura F. Redman, *Outing the Invisible Poor: Why Economic Justice and Access to Health Care is an LGBT Issue*, 17 GEO. J. POVERTY L. & POL'Y 451, 453-54 (2010) (compiling statistics). *See also* THE INST. OF MED., THE HEALTH OF LESBIAN, GAY, BISEXUAL AND TRANSGENDER PEOPLE: BUILDING A FOUNDATION FOR BETTER UNDERSTANDING 25-88 (2011) (IOM Report), http://www.iom.edu/Reports/2011/The-Health-of-Lesbian-Gay-Bisexual-and-Transgender-People.aspx.

[19] Redman, *Outing the Invisible Poor*, *supra* note 18, at 453-54; TRANSGENDER LAW CENTER, *Transgender Health and the Law: Identifying and Fighting Health Care Discrimination* (July 2004) ("Many transgender people have their applications for health insurance denied when they disclose their transgender status or transition-related medical history (such as hormone level tests) to a potential insurer."), http://transgenderlawcenter.org/pdf/Health%20Law%20fact%20sheet.pdf.

(a) Discriminatory treatment of transgender people needing care unrelated to their gender identity

It now is well-established that transgender people face very significant barriers to appropriate, high-quality health care. From verbal abuse and humiliation to refusals of care, our health care system presents a minefield of discrimination for transgender people. The end result is a broad disengagement from the health care system that results in dire health outcomes for transgender people as a group. Rather than enduring degradation and poor treatment, a great many transgender people simply do without care. As a result of this disengagement, treatable medical conditions routinely become emergency problems with compromised outcomes, a common situation in communities with suboptimal access to care.[20]

Following Lambda Legal's 2009 survey, the National Transgender Discrimination Survey (the NTDS) of 2011 again revealed widespread disparities in transgender health care. Of over 6,000 transgender individuals who responded, 19 percent reported having been refused health care due to their transgender or gender non-conforming status. In addition, 28 percent had postponed necessary health care when sick or injured and 33 percent had delayed or not sought preventive care because of prior health care discrimination based on their transgender status.[21]

Even when health care is not refused, the biased behavior toward transgender people by hospital staff – including physicians, nurses, allied health professionals, admitting and registration personnel, and security officers – creates a negative experience that discourages future care seeking. As reported in the community surveys, such behavior too often has included:

- Laughter, pointing, joking, taunting, mockery, slurs, and a wide variety of negative comments;
- Violations of confidentiality, regardless of HIPAA;
- Use of improper names and/or pronouns for patients;
- Exceptionally long waits for care;
- Inappropriate questions and/or exams, including needless viewing of genitals;
- Prohibitions of restroom use;
- Inappropriate room assignments;
- Malpractice and even physical assault.[22]

Discrimination by individual practitioners is more than a matter of requesting different care providers; it can be a matter of life and death. For example:

- Emergency medical services workers in the District of Columbia were called to the scene of a car accident in which Tyra Hunter, a transgender woman, had been seriously injured.

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[20] *See* IOM REPORT, *supra* note 18, at 25-88.

[21] JAIME M. GRANT, PH.D., ET. AL., INJUSTICE AT EVERY TURN: A REPORT OF THE NATIONAL TRANSGENDER DISCRIMINATION SURVEY, 76 (2011) (Grant, NTDS), http://transequality.org/PDFs/NTDS_Report.pdf.

[22] *Id*. at 74 (finding that 28% of survey participants reported having been subjected to verbal harassment in medical settings and 2% were victims of violence in doctors' offices).

As Tyra lay unconscious, the EMS professionals discovered she had male genitalia and stopped providing emergency treatment to her, instead starting to laugh and make derogatory comments. Tyra died as a result of their withholding of medical care.[23]

- Author Leslie Feinberg was denied treatment for endocarditis, a heart condition, at an emergency room when sie was revealed to be transgendered.[24]
- Nakoa Nelson, a transgender man in Hawaii, had a near-fatal allergic reaction to eating a cookie after church. His partner drove him to the closest fire station for help, but when the EMS workers realized he was transgender they refused to treat him. Although Nakoa did find a doctor nearby who gave him steroid shots to help him breathe, the doctor said Nakoa could have died because of the delay.[25]

The three trangender individuals just described have a medical condition classified in the current edition of the Diagnostic and Statistical Manual (DSMV) as "gender dysphoria," previously having been classified as "gender identity disorder."[26] As is discussed in (c) below, it remains common for health insurance policies categorically to exclude coverage for gender dysphoria and for some medical care providers to refuse to treat gender dysphoria.[27] Separate from the propriety of these exclusions and refusals to treat, however, is the fact that such exclusions and refusals often are used to deny all treatment to transgender individuals, improperly correlating an individual's GD diagnosis with unrelated care needed on a routine or even emergency basis.[28] One assessment of the field concluded that "[s]ome

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[23] *See* Sue Anne Pressley, *Realizing, Fulfilling 'Who They Are': D.C. Slayings Help Galvanize Transgender Community's Push for Acceptance*, WASHINGTON POST (Nov. 29, 2003); Gay & Lesbian Activists Alliance of Washington D.C., *District Settles Hunter Lawsuit for $1.75 Million* (Aug. 10, 2000), http://www.glaa.org/archive/2000/tyrasettlement0810.shtml.

[24] *See* Leslie Feinberg, TRANS LIBERATION 2 (1998) (recounting the experience) (sie is hir preferred gender pronoun).

[25] LAMBDA LEGAL, TRANSGENDER RIGHTS TOOLKIT: TRANSITION-RELATED HEALTH CARE (Feb. 7, 2013 (Transition-Related Health Care), http://www.lambdalegal.org/publications/trt_overcoming-health-care-discrimination.

[26] American Psychiatric Association, *Gender Dysphoria* (2013), http://www.dsm5.org/Documents/Gender%20Dysphoria%20Fact%20Sheet.pdf.

[27] Transgender Law Center, *Transgender Health and the Law*, *supra* note 19, at 2-3. *See also* Lambda Legal, TRANSITION-RELATED HEALTH CARE, *supra* note 25.

[28] *See* Kari E. Hong, *Categorical Exclusions: Exploring Legal Responses to Health Care Discrimination Against Transsexuals*, 11 COLUM. J. GENDER & L. 88, 92 (2002) ("[M]any insurers liberally apply the SRS exclusion clauses to deny transsexuals coverage for non-transition related, medically necessary conditions such as back pain, intestinal cysts, and even cancer, under the rationale that any medical care a transsexual needs is an excludable transsexual-related condition."); Transgender Law Center, *Transgender Health and the Law: Identifying and Fighting Health Care Discrimination*, at 2 (July 2004) ("Insurers justify these exclusions by stating that your current medical problem is somehow related to your transition. For example, the insurer might argue (often times without any proof) that liver damage or blood clotting results from hormone therapy."), http://transgenderlawcenter.org/issues/health/transgender-health-and-the-law-identifying-and-fighting-health-care-discrimination.

insurance companies maintain a broad definition of 'transition-related' [issues] and create false connections between illness and transition," stretching to categorize any possible medical need as transition related.[29] For example, in one documented case, an insurance company refused to pay the costs of treating a transgender man's broken arm, wrongfully asserting that even that medical need was related to his transgender status.[30]

The physical and emotional harms of such discrimination are significant for transgender people and those who do not conform to gender stereotypes. Consequently, many simply avoid medical care, even when they are sick or injured, sometimes with severe health consequences.[31]

(b) Denial of sex-specific medical care

Transgender people are regularly denied sex-specific healthcare. This includes preventative care such as prostate cancer screenings and gynecological exams, as well as treatment for sex-specific illness. This is partly a function of health insurance coding according to which sex-specific care is coded with a specific gender marker.[32] When an individual needs care associated with a sex different from the gender coding of that person's records, the coding does not match and often neither the insurer nor the care provider adjusts and responds appropriately to the patient's needs. Insurers frequently claim that their systems simply cannot recognize two genders for one client, even though trans people commonly require health care needed by both sexes. As one commentator explains, "The law assumes that sex is binary: an individual can be a man or a woman, but not both or neither."[33] As a result, transgender people are routinely denied insurance coverage for medically necessary care that does not correspond with the gender recorded in their documents.

Discrimination in accessing sex-specific care extends beyond preventative care. Transgender people are also routinely denied health insurance coverage for treatment of sex-specific cancers and other diseases. [34] Health insurers have used even a *suspicion* of transgender status to deny coverage of medical

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[29] J. Denise Diskin, *Taking it the Bank: Actualizing Health Care Equality for San Francisco's Transgender City and County Employees*, 5 HASTINGS RACE & POVERTY L.J. 129, 137 (2008).

[30] Transgender Law Center, *Recommendations for Transgender Health Care*, http://www.transgenderlaw.org/resources/tlchealth.htm#_ftnref2.

[31] *See* Grant, NTDS, *supra* note 21, at 76 (reporting that 28% of transgender and gender non-conforming respondents, and 42% of transgender men, postpone or avoid medical treatment when they are sick or injured because they anticipate disrespect and discrimination).

[32] See KELLAN BAKER & JEFF KREHELY, CHANGING THE GAME: WHAT HEALTH CARE REFORM MEANS FOR LESBIAN, GAY, BISEXUAL, AND TRANSGENDER AMERICANS 19 (2011) (hereinafter CHANGING THE GAME) at 18-19 ("Some health services, such as gynecological exams and certain cancer screenings, are traditionally 'gendered,' meaning that health insurers routinely refuse to cover these services for anyone whose gender marker on their insurance documents does not match their physical anatomy."), http://www.americanprogress.org/issues/lgbt/report/2011/03/29/9200/changing-the-game/.

[33] Liza Khan, Note: *Transgender Health at the Crossroads: Legal Norms, Insurance Markets, and the Threat of Healthcare Reform*, 11 YALE J. HEALTH POL'Y L. & ETHICS 375, 377 (2011).

[34] *See* TRANSGENDER LAW CENTER, *Transgender Health*, *supra* note 19, at 2-3 ("Female-to-male transgender people, in particular, may have difficulty obtaining gynecological services or treatment for gynecological

care. In one documented example, a lesbian who had breast cancer in one breast decided, along with her physician, to have both breasts removed to protect against recurrence. Her insurance company "worried that the second breast was 'elective surgery' and that, if they paid for that, it would be setting a precedent for covering elective transsexual surgery."[35] Another sadly famous example is the refusal by twenty-seven physicians to treat Robert Eads, a transgender man, for his ovarian cancer, a disease which initially was treatable but from which he eventually died.[36]

Given the role of gender markers for securing coverage for sex-specific care, and the frequency with which transgender people cannot secure insurance at all once their transgender status is known, some who are insured are apprehensive about changing the gender marker on their insurance policy after they have transitioned.[37] Others have attempted to change the gender marker on their health insurance records after fully transitioning but have been denied the ability to do so by their insurer.[38] Still others have discovered that their gender marker has been changed without their knowledge by doctors or nurses acting on their own.[39]

This problem is solvable. For example, the Centers for Medicare and Medicaid Services (CMS) has created additional billing codes to prevent transgender patients from being inappropriately denied coverage when the gender marker on the insurance record is not the gender typically associated with a certain medical treatment.[40] To accomplish this adjustment broadly, it may simply require direction from HHS, pursuant to Section 1557, that programs, activities and services receiving federal funding must take the same step.

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cancers.").

[35] Khan, *supra* note 33, at 388 n.67, quoting Judith Butler, *Undiagnosing Gender*, TRANSGENDER RIGHTS 283 (Paisley Currah et al. eds., 2006) (internal quotation marks omitted).

[36] SOUTHERN COMFORT (Kate Davis, director and producer, 2001), as discussed in Elvis Mitchell, FILM REVIEW; *Genders That Shift, but Friends Firm as Bedrock*, NY TIMES (Feb. 21, 2001), *available at* http://movies.nytimes.com/movie/review?res=9B01E5DC1639F932A15751C0A9679C8B63. *See also* Kari E. Hong, *Categorical Exclusions: Exploring Legal Responses to Health Care Discrimination Against Transsexuals*, 11 COLUM. J. GENDER & L. 88, 98-99 (2002) ("Female-to-male transsexuals report doctors who will not administer gynecological care.").

[37] *See* Grant, NTDS, *supra* note 19, at 151 (only 39% of people who are fully transitioned have changed the gender marker on their health insurance records).

[38] *Id.*

[39] *Id.* ("Once the nurses or doctor find out I have a penis, they start referring to me as a male and often change my [recorded] gender status to male, which messes up Medicare and Medicaid paying for my hospitalization.").

[40] *See* Medicare Claims Processing Manual, *Billing Requirements for Special Services*, §240 (Special Instructions for Services with a Gender/Procedure Conflict), http://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/downloads/clm104c32.pdf; *Instructions Regarding Processing Claims Rejecting for Gender/Procedure Conflict*, http://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNMattersArticles/downloads/MM6638.pdf. *See also* National Center for Transgender Equality, *Medicare Benefits and Transgender People* (Aug. 2011), http://transequality.org/Resources/MedicareBenefitsAndTransPeople_Aug2011_FINAL.pdf.

In addition to gender-related insurance problems, many transgender individuals are especially uneasy about having their bodies examined in the context of sex-specific care.[41] Most doctors are not trained about the needs of transgender individuals, including how to address patients' anxieties about how they will be received.[42] Combining the uneasiness of both doctors and patients with the propensity of insurance companies to deny coverage for sex-specific care, many transgender individuals forego basic, preventative health care. This contributes to worsened health outcomes, including higher HIV and other sexually transmitted infection rates among transgender and gender non-conforming populations.[43]

(c) Denial of coverage for gender transition-related health care

Leading authorities in the medical and policy communities, including the American Medical Association and American Psychological Association, have recognized the medical necessity of hormone therapy and sex reassignment surgery (SRS) for some patients with gender dysphoria.[44] Yet, the historical exclusions of transition-related medical care such as hormone therapy and SRS remain in the health insurance contracts of the majority of public and private insurance companies – preventing

[41] Harvey J. Makadon et al., THE FENWAY GUIDE TO LESBIAN, GAY, BISEXUAL AND TRANSGENDER HEALTH 354 (2007) ("It is common for transgender men to refuse breast and pelvic exams, and for transgender women to refuse testicular and prostate exams.").

[42] The ACA does promote cultural competency standards for health care providers that have the potential to alleviate the problem. *See* CHANGING THE GAME, *supra* note 32, at 12.

[43] *See* NTDS, *supra* note 19, at 80 (reporting HIV infection rate among respondents four times greater than the infection rate of the general population). An additional 8% of respondents reported not knowing their HIV status. *Id.*

[44] For a full compilation of professional organizations' statements in support of access to care for transgender patients, *see* LAMBDA LEGAL, PROFESSIONAL ORGANIZATION STATEMENTS SUPPORTING TRANSGENDER PEOPLE IN HEALTH CARE, http://www.lambdalegal.org/publications/fs_professional-org-statements-supporting-trans-health. *See also, e.g.*, AM. PSYCHOLOGICAL ASS'N, COUNCIL OF REPRESENTATIVES, TRANSGENDER, GENDER IDENTITY, & GENDER EXPRESSION NON-DISCRIMINATION (Aug. 2008), http://www.apa.org/about/policy/transgender.aspx ("APA recognizes the efficacy, benefit and medical necessity of gender transition treatments for appropriately evaluated individuals and calls upon public and private insurers to cover these medically necessary treatments"); AM. MED. ASS'N, RESOLUTION 122: REMOVING FINANCIAL BARRIERS TO CARE FOR TRANSGENDER PATIENTS (June 2008), http://www.ama-assn.org/resources/doc/hod/a08resolutions.pdf ("Resolved, That our American Medical Association support public and private health insurance coverage for treatment of gender identity disorder as recommended by the patient's physician."); AM. MED. ASS'N H.D., RESOLUTION 122 (A-08): REMOVING FINANCIAL BARRIERS TO CARE FOR TRANSGENDER PATIENTS (June 2008), http://www.tgender.net/taw/ama_resolutions.pdf ("Whereas, An established body of medical research demonstrates the effectiveness and medical necessity of mental health care, hormone therapy and sex reassignment surgery as forms of therapeutic treatment for many people diagnosed with GID; and . . . Health experts in GID . . . have rejected the myth that such treatments are 'cosmetic' or 'experimental' and have recognized that these treatments can provide safe and effective treatment for a serious health condition . . . therefore be it . . . Resolved, That the AMA oppose categorical exclusions of coverage for treatment of gender identity disorder when prescribed by a physician . . . .").

coverage even when a doctor confirms the treatment is medically necessary for a patient.[45] Such exclusions sometimes also deny coverage for visits to monitor hormone replacement therapy, to receive ongoing transition assistance, and for psychological counseling. These exclusions generally were based on the now-outdated misconception that the treatments are experimental or cosmetic. Despite today's settled medical consensus that this care is medically necessary for some patients, the exclusions remain common.[46]

The unjust harms of such exclusions have been recognized in an ever lengthening list of court decisions addressing the medical needs of prisoners and recognizing that it is wrongful discrimination to treat the medical needs of this minority differently from the needs of others.[47] Although this is not a new

[45] *See* LAMBDA LEGAL, TRANSGENDER RIGHTS TOOLKIT: TRANSITION-RELATED HEALTH CARE, *supra* note 25; Kari E. Hong, *Categorical Exclusions*, *supra* note 28, at p. 92 ("Despite the DSM-IV diagnosis, the medical community's internationally endorsed treatment, and the documented side effects of leaving gender dysphoria untreated, most public and private insurers explicitly exclude coverage for sex-reassignment surgery [SRS]."); Pooja Gehi & Gabriel Arkles, *Unraveling Injustice: Race and Class Impact of Medicaid Exclusions of Transition-Related Health Care for Transgender People*, 4 SEXUALITY RESEARCH & SOC. POL'Y: J. OF NSRC 7, 9 (2007) ("Twenty-four states explicitly exclude coverage for transition-related health care by [state Medicaid] regulation. . . . In those states that do not have an explicit exclusion, coverage for transition-related care may still be denied based on interpretation and application of a more general exclusion, such as for so-called experimental or cosmetic treatments.").

[46] *See* THE WORLD PROFESSIONAL ASSOCIATION FOR TRANSGENDER HEALTH, STANDARDS OF CARE FOR THE HEALTH OF TRANSSEXUAL, TRANSGENDER, AND GENDER NONCONFORMING PEOPLE (7th ed.), http://www.wpath.org/documents/Standards%20of%20Care%20V7%20-%202011%20WPATH.pdf (providing clinical guidance for health professionals to assist transgender patients with primary care, gynecologic and urologic care, reproductive options, voice and communication therapy, mental health services, and hormonal and surgical treatments); THE ENDOCRINE SOCIETY, ENDOCRINE TREATMENT OF TRANSSEXUAL PERSONS: AN ENDOCRINE SOCIETY CLINICAL PRACTICE GUIDELINE (2009), https://www.endocrine.org/~/media/endosociety/Files/Publications/Clinical%20Practice%20Guidelines/Endocrine-Treatment-of-Transsexual-Persons.pdf.

[47] In harmony with the medical consensus, there now is a consensus among federal courts that gender dysphoria constitutes a serious medical condition and that failures to provide prisoners adequate treatment can violate the Eighth Amendment. *See De'lonta v. Johnson*, 708 F.3d 520, 523 & 525 (4th Cir. 2013) (reversing dismissal of Eighth Amendment claim where non-surgical treatment failed to address gender dysphoria and plaintiff sought SRS, "an accepted, effective, medically indicated treatment for GID"); *Battista v. Clarke*, 645 F.3d 449, 451-52 (1st Cir. 2011) (affirming finding of Eighth Amendment violation where evidence showed plaintiff would likely engage in genital self-surgery and requiring provision of hormone therapy); *Fields v. Smith*, 653 F.3d 550, 555-56 (7th Cir. 2011) (holding that a state law barring hormone therapy and SRS for transgender prisoners violated the Eighth Amendment); *White v. Farrier*, 849 F.2d 322, 325 (8th Cir. 1988) (recognizing that gender dysphoria presents a serious medical need); *O'Donnabhain v. Comm'r of Internal Revenue*, 134 T.C. 34, 62 (U.S. Tax Ct. 2010) ("Seven of the U.S. Courts of Appeals that have considered the question have concluded that severe GID or transsexualism constitutes a 'serious medical need' for purposes of the Eighth Amendment"). In fact, even the U.S. Supreme Court has recognized gender dysphoria as a serious medical condition, noting its inclusion (as "transsexualism") in the Diagnostic and Statistical Manual and the AMA's Encyclopedia of Medicine. *See Farmer v. Brennan*, 511 U.S. 825, 829 (1994). For more information about why it can be unconstitutional for prisons to categorically deny medically necessary care for gender dysphoria, see discussion of Lambda Legal's litigation of *Fields v. Smith* at http://www.lambdalegal.org/in-court/cases/fields-v-smith.

view among those attentive to the issue,[48] public discussion about the medical needs of transgender people has only recently become amplified. As a result, many more people understand not only that SRS is not cosmetic but also that gender dysphoria does not abate spontaneously and cannot be treated by changing the person's gender identity through psychotherapy.

Although public support is growing rapidly, individuals with gender dysphoria who lack access to appropriate medical care may become desperate and engage in harmful self-treatment, as the following examples illustrate:

- Emilie of Boise, Idaho reported to Lambda Legal's health care survey: "I am a post-operative trans woman who began my gender transition in 2004. After talking about transitioning with my family MD, she agreed to continue her medical relationship with me. … she referred me to a local endocrinologist who could perform blood work and recommend a hormone replacement regime. When I called the endocrinologist to set up an appointment, I was told by the secretary, "We don't treat people like you." I called the two other local endocrinologists and was told the exact same thing. My psychologist told me that some of her clients experienced the same … She told me that they just don't want trans people in their waiting rooms because they might make other customers feel uncomfortable, or they simply have a moral objection to trans people. Endocrinologists like this relegate people like me to self-medicate, which can be dangerous to our health. Hormones are easily available over the Internet without a prescription."[49]
- Mia Rosati, a transgender prisoner in state custody in California, is appealing the dismissal of her complaint against the California Department of Corrections. Her request for an individualized assessment of whether genital surgery is medically necessary in her case to address her extreme gender dysphoria has been refused based on the prison's policy, followed by the physician's assistant who processed her request, that SRS is cosmetic. In desperation, Rosati has attempted self-surgery on three occasions. Lambda Legal represents Rosati in her appeal to the Ninth Circuit.[50]

[48] *See, e.g., J.D. v. Lackner*, 80 Cal. App. 3d 90, 95 (1978) ("We do not believe, by the wildest stretch of the imagination, that [sex reassignment] surgery can reasonably and logically be characterized as cosmetic.").

[49] Lambda Legal, Lesbian, Gay, Bisexual and Transgender (LGBT) People and People Living with HIV Speak Out, *supra* note 10.

[50] *Rosati v. Igbinoso*, Case No. 1:12-cv-01213-RRB , 2013 U.S. Dist. LEXIS 60247, at * 4 fn. 14, *5 (E.D. Cal. April 26, 2013) **(**"Prior to being imprisoned Rosati partially emasculated himself by surgically removing his testicles" and he "reported a history of prior self-mutilation attempts and … felt having male genitalia while having other physical characteristics of a woman, had led to significant psychological distress"), *on appeal*, Ninth Circuit Court of Appeals Case No. 13-15984. *Compare Battista v. Clarke*, 645 F.3d 449, 451-52 (1st Cir. 2011) (evidence showed plaintiff Battista needed hormone therapy and likely would engage in genital self-surgery if denied proper medical treatment).

2. LGB People Experience Improper Sex Discrimination In Health Care

(a) Sex discrimination against LGB people includes bias based on same-sex attraction and relationships as well as bias based on non-conformity with gender stereotypes

Director of the Office of Civil Rights, Leon Rodriguez, confirmed last year that Section 1557's sex discrimination prohibition includes discrimination based on gender identity or failure to conform to stereotypical notions of masculinity or femininity, as well as to sexual harassment and other forms of sex discrimination regardless of the actual or perceived sexual orientation or gender identity of the individuals involved. [51] Some uncertainty has remained about whether the sex discrimination prohibition covers the particular subset of sex discrimination that is based on sexual orientation. HHS already has included explicit prohibitions against sexual orientation discrimination in final rules for health insurance Exchanges, QHPs, and the EHB.[52] The present RFI does not, however, explicitly enumerate sexual orientation discrimination among the forms of sex discrimination identified for illustration purposes. It thus will be helpful to have this form of protection made explicit in the implementing regulations for Section 1557.

There should be little doubt, however, that the sex discrimination prohibition necessarily includes discrimination based on sexual orientation, for at least two reasons. First, sexual orientation is a relational term based expressly on one's sex; it cannot be understood without sex-based references and distinctions. Second, the stigmatizing of same-sex relationships is a function of gender stereotypes and perceptions that persons who engage in such relationships are improperly disregarding their proper, gender-based roles.

Concerning the first framing of the point, many scholars and numerous courts, in contexts concerning both family relationships and discrimination against individuals, have considered this a straightforward analysis.[53] A person's sexual orientation is a function of the person's own sex in relation

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[51] Letter of Leon Rodriguez to Maya Rupert dated July 12, 2012 (OCR Transaction Number: 12-000800).

[52] *See, e.g.*, 45 C.F.R. §§ 155.120(c) (nondiscrimination rule for Exchanges); 156.200(e) (for QHPs); Health Insurance Market Rules; Rate Review, 78 Fed. Reg. 13,406, 13,438 (Feb. 27, 2013) (to be codified at 45 C.F.R. § 147.104(e)) (for marketing and benefit design); Standards Related to Essential Health Benefits, Actuarial Value, and Accreditation, 78 Fed. Reg. 12,834, 12,867 (Feb. 25, 2013) (to be codified at 45 C.F.R. § 156.125) (for the EHB). See also Letter of Leon Rodriguez to Maya Rupert dated July 12, 2012 (OCR Transaction Number: 12-000800), confirming that Section 1557's sex discrimination prohibition includes discrimination based on gender identity or failure to conform to stereotypical notions of masculinity or femininity, as well as sexual harassment and other forms of sex discrimination regardless of the actual or perceived sexual orientation or gender identity of the individuals involved.

[53] *See, e.g., Goodridge v. Dep't of Pub. Health*, 798 N.E.2d 941, 971 (Mass. 2003) (Greaney, J., concurring); *Baehr v. Lewin*, 852 P.2d 44, 61-63 (Haw. 1993) (plurality opinion); Victoria Schwartz, *Title VII: A Shift From Sex to Relationships*, 35 HARVARD J. L. & GENDER 209 (2012); Anthony E. Varona & Jeffrey M. Monks, *En/Gendering Equality: Seeking Relief Under Title VII Against Employment Discrimination Based on Sexual*

to the sex of others, and the person either is eligible to receive a benefit or not depending on whether their sex is "correct" given the sex of the other person.[54] This conclusion follows directly from the cases recognizing that it is race discrimination to base one's eligibility to maintain a relationship with another person upon one's race in relation to the other person's race[55] and the fact that constitutional rights belong to individuals and not to classes or groups.[56]

In addition to the formal analysis, it long has been recognized by scholars and others that sexual orientation discrimination is a form of sex discrimination because it is bias based on a person's failure to conform to the central gender stereotypes that women *should* seek relationships with men, and men *should* seek relationships with women.[57] In the context of marriage, for example, sex-based restrictions reflect stereotyped expectations about the roles each spouse shall perform.[58] And yet, the Supreme Court

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Orientation, WM. & MARY J. OF WOMEN & L. 67 (Fall, 2000); Andrew Koppelman, *Why Discrimination Against Lesbians and Gay Men is Sex Discrimination*, 69 N.Y.U. L. REV. 197 (1994); Andrew Koppelman, *The Miscegenation Analogy: Sodomy Law as Sex Discrimination*, 98 YALE L.J. 145 (1988). *See also Golinski v. U.S. Office of Pers. Mgmt*., 824 F. Supp. 2d 968, 982 n.4 (N.D. Cal. 2012) (agreeing that refusal to recognize same-sex couples' marriages was discrimination based on sex); *In re Balas*, 449 B.R. 567, 577–78 (Bankr. C.D. Cal. 2011) (concluding federal Defense of Marriage Act was "gender-biased" because it deprived same-sex couples of benefits based on their gender).

[54] *See Goodridge v. Dep't of Pub. Health*, 798 N.E.2d 941, 971 (Mass. 2003) (Greaney, J., concurring)("That the classification is sex based is self-evident. The marriage statutes prohibit some applicants . . . from obtaining a marriage license . . . based solely on the applicants' gender.").

[55] *Loving v. Virginia*, 388 U.S. 1, 11–12 (1967) (invalidating Virginia's anti-miscegenation); *McLaughlin v. Florida*, 379 U.S. 184, 188–96 (1964) (invalidating Florida law banning interracial cohabitation). *See also, e.g.*, Koppelman, *Why Discrimination Against Lesbians and Gay Men is Sex Discrimination*, *supra* note 53, 69 N.Y.U. L. REV. at 211 ("*McLaughlin* thus stands for the proposition (which should be obvious even without judicial support) that if prohibited conduct is defined by reference to a characteristic, the prohibition is not neutral with reference to that characteristic."); Koppelman, *Defending the Sex Discrimination Argument for Lesbian and Gay Rights*, *supra* note 53, 49 UCLA L. REV. at 519. *See also Baker v. State*, 744 A.2d 864, 906 (Vt. 1999) (Johnson, J., concurring in part and dissenting in part) (citing *Loving*).

[56] *Goodridge*, 798 N.E.2d at 970 (Greaney, J., concurring) (discussing cases and observing "[a] classification may be gender based whether or not the challenged government action apportions benefits or burdens uniformly along gender lines. This is so because constitutional protections extend to individuals and not to categories of people.").

[57] *See, e.g.*, Deborah A. Widiss, et al., *Exposing Sex Stereotypes in Recent Same-Sex Marriage Jurisprudence*, 30 HARV. J. L. & GENDER 461, 463–64 (2007); Koppelman, *Why Discrimination Against Lesbians and Gay Men is Sex Discrimination*, 69 N.Y.U. L. REV. at 238 ("[Studies] have consistently found correlations between conventional expectations about gender roles and hostility toward homosexuals.") (citations omitted); Ann C. McGinley, *Erasing Boundaries: Masculinities, Sexual Minorities, and Employment Discrimination*, 43 U. MICH. J.L. REFORM 713 (Spring, 2010); Olivia Szwalbnest, *Discriminating Because of "Pizzazz": Why Discrimination Based on Sexual Orientation Evidences Sexual Discrimination Under the Sex-Stereotyping Doctrine of Title VII*, 20 TEX. J. WOMEN & L. 75 (Fall, 2010); Zachary Kramer, *Heterosexuality and Title VII*, 103 NW. U. L. REV. 205, 232 (2009); Sylvia A. Law, *Homosexuality and the Social Meaning of Gender*, 1988 WIS. L. REV. 187 (1988).

[58] Widiss, *Exposing Sex Stereotypes in Recent Same-Sex Marriage Jurisprudence*, *supra* note 57, at 469 (restrictive marriage statutes discriminate because they rely upon and perpetuate "a system under which men and women occupy different marriage and family roles: men must 'act like husbands' and women must 'act like wives.'").

has taught that our laws "must be applied free of fixed notions concerning the roles and abilities of males and females." [59] In fact, the Court has emphasized that "care must be taken in ascertaining whether the statutory objective itself reflects archaic and stereotypic notions."[60] More recent decisions have confirmed and even strengthened this principle.[61]

(b) Examples of Discrimination against LGB People

As explained below, three common forms of discrimination against LGB people are (1) refusal to respect the family relationships of same-sex couples and their children; (2) discriminatory insurance coverage and services relating to infertility and assisted reproduction; and (3) lack of respect and cultural competence concerning the non-heterosexual orientation of LGB people.

i. Refusal to recognize same-sex family relationships in health care settings

Because this has been a pervasive problem, Lambda Legal has brought claims on behalf of surviving partners against multiple hospitals that had prevented the survivor from being at the bedside of the dying same-sex partner. Here are two examples:

- Washington State residents Janice Langbehn and her three children were kept from the bedside of Janice's dying partner, Lisa Pond, as Lisa lay dying following a brain aneurism during the family's vacation in Florida. Although Langbehn held Lisa's power of attorney, hospital staff refused information from her regarding Pond's medical history. And although a physician admitted there was no medical reason to deny visitation, staff refused her and the children access to Lisa's room for nearly 8 hours, saying they were in an "antigay city and state" and could expect no acknowledgment as family. Lambda Legal sued Jackson Memorial Hospital on behalf of Janice and the couple's children. The case inspired President Obama to issue new visitation guidelines requiring respect for same-sex couples in health care facilities receiving federal funding.[62]
- Robert Daniel and Bill Flanigan were traveling from California to visit family in Maryland when Robert suddenly needed emergency care. Although Robert and Bill were registered domestic partners in California and Bill had Robert's power of attorney, hospital personnel kept Bill from Robert's side, telling him only family was permitted to

[59] *Miss. Univ. for Women v. Hogan*, 458 U.S. 718, 724–25 (1982).

[60] *Id.* at 725.

[61] *See, e.g., Nev. Dep't of Human Res. v. Hibbs*, 538 U.S. 721 (2003); *United States v. Virginia*, 518 U.S. 515, 533 (1996) (forbidding reliance on "overbroad generalizations about the different talents, capacities, or preferences of males and females").

[62] Information about *Langbehn v. Jackson Memorial Hospital*, including the complaint, is at http://www.lambdalegal.org/in-court/cases/langbehn-v-jackson-memorial. The memorandum issued by President Obama requiring equal treatment of same-sex partners for visitation purposes in medical facilities receiving federal funds is here http://www.lambdalegal.org/in-court/cases/langbehn-v-jackson-memorial.

visit and partners did not qualify. Bill could not inform doctors that Daniel wanted to forego life-prolonging measures. By the time Bill was allowed to visit hours later, Daniel had lost consciousness and doctors had inserted a breathing tube. Daniel never regained consciousness and the couple never had a chance to say goodbye. Lambda Legal represented Bill in litigation against the hospital, which spurred policy reform.[63]

ii. Unequal access to family health insurance for same-sex couples and discriminatory insurance plan terms

Over the years, a great many same-sex couples and their children have experienced discrimination when attempting to access insurance, such as when plans have refused to offer coverage for family members absent a valid marriage, or even with one if it is not recognized in-state. The ACA reduces these problems by making it easier for individuals to obtain insurance, although inequalities may remain as coverage may not be equivalent to what is offered by the plan offered by the employer of one's same-sex spouse or partner. The Supreme Court's decision in *United States v. Windsor*, 133 S. Ct. 2675 (2013), striking down Section 3 of the Defense of Marriage Act (DOMA) means same-sex married couples are to be treated the same under federal law as different-sex married couples in the administration of premium tax credits and cost-sharing reductions as well as Qualified Health Plan spousal coverage. This is a great improvement, although it does not provide equality for married couples living in states that do not honor their marriages for purposes of income taxation of the value of spousal health coverage and other matters.

Separate from the ability to acquire insurance are issues concerning policy terms. With respect to health coverage and provision of medical services concerning infertility and assisted reproduction, LGBT people frequently encounter discrimination. Here are two examples illustrating distinct concerns of women and men, respectively:

- In many health insurance policies that cover infertility treatment, infertility in a woman is defined as the inability to achieve pregnancy through unprotected sexual intercourse with a man for at least one year. This eligibility rule discriminates against lesbians who suffer from the same medical problem as heterosexual women but are not pursuing pregnancy through intercourse with a male partner.[64]
- Dennis Barros and his partner planned to have a child with the assistance of a surrogate mother who would carry an egg fertilized by Barros's sperm. But the clinic they enlisted refused to provide services to Barros, citing an FDA guideline recommending against insemination using anonymous donations from men who have had sex with men in the

[63] Information about *Flanigan v. University of Maryland Hospital System*, including the complaint, is at http://www.lambdalegal.org/in-court/cases/flanigan-v-university-of-maryland.

[64] Lambda Legal consulted with the Illinois Department of Insurance on a revision of the state administrative regulation that applies to this issue, obtaining a change that permits equal treatment not only of women with a same-sex partner but also those for whom this method of demonstrating infertility is neither feasible nor fair. Information is at http://www.lambdalegal.org/news/il_20100420_illinois-department-of.

past five years. Lambda Legal has been representing Barros, explaining that the FDA guideline does not apply to known donors such as Barros. The clinic still refuses to provide care to Barros. The Orlando, Florida Human Rights Board has ruled that discrimination occurred; the case is now pending before the Circuit Court.[65]

iii. Lack of "cultural competence" – or even basic understanding and respect – for the health needs of LGB people

The following testimonies from Lambda Legal's WHEN HEALTH CARE ISN'T CARING report show that many providers lack even basic understanding of lesbian, gay and bisexual people and what constitutes an appropriately respectful professional interaction, let along the "cultural competence" that enables health providers to address their health needs effectively.

- Michelle of San Jose, California reported: "When I left the U.S. Army in 1993, I moved to Georgia to go to college. As I had a disability from my active duty service, I tried to sign up for the Vocational Rehabilitation and Employment program to pay for my college tuition. In order to qualify for the program, I had to attend an evaluation with the local VA clinic psychiatrist. … [T]he psychiatrist asked me why I had left the Army. I explained that I had come to accept that I was gay … The psychiatrist proceeded to spend the entire rest of our hour convincing me that I was not a lesbian, just 'misguided by some other gals' and that he could 'cure me of my deviancy.' By the end of the hour, I knew my chances of signing up for the program were gone. The psychiatrist even went so far as to offer me free counseling at his 'camp for girls like you to get better.'" [66]
- Gregory of Brooklyn, New York recalled: "I had prostate cancer six years ago. The urologist was fully aware of my sexual orientation. A few years ago I went to the urologist who took over his practice when he retired, for erectile dysfunction. He asked me how hard I'd get on a scale of one to ten, if I saw a beautiful woman. I told him 'I'm gay.' His reaction? 'Very funny.' I didn't find this particularly funny." [67]
- Torrey of Portland, Oregon explained: "I went to visit my school's health clinic for an annual checkup. While I was filling out my health history information sheet, I was pleasantly surprised to find that there was space to indicate whether I was sexually active with male or female partners, the number of partners I'd had, and the type of birth control I used. I thought that this was a great example for LGBT-friendly medical facilities. Unfortunately, when I was called into the exam room, the nurse didn't read the form and proceeded to ask me if I was sexually active and used condoms. When I replied no, and

[65] Information about *Barros v. Riggall* including the complaint is available at http://www.lambdalegal.org/in-court/cases/barros-v-riggall.

[66] Lambda Legal, Lesbian, Gay, Bisexual and Transgender (LGBT) People and People Living with HIV Speak Out, http://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-insert_lgbt-people-and-people-living-with-hiv-speak-out.pdf.

[67] *Id.*

told the nurse that I was a lesbian, she was shocked. After that, the appointment was awkward and I felt as though the nurse was not willing to touch me because of my sexual orientation. It just goes to show you that having a LGBT-friendly form does not make a clinic LGBT-friendly." [68]

- John, a doctor in East Stroudsburg, Pennsylvania, described his treatment of an 18-year-old high school student: "He [had] moved from the West Coast … because of trouble in school. He was having attacks of sudden shaking and weakness. His mom took him to her primary care provider, who referred him to a neurologist, suspecting temporal lobe epilepsy (a very rare condition). He underwent thousands of dollars' worth of tests—all of which turned out normal. I saw him professionally at the request of his boyfriend. Turns out he had been gay bashed in the bathroom at his old high school. He received death threats … None of his new physicians had asked him about his sexual orientation. It quickly became apparent to me that he was having anxiety or panic attacks …. I treated him with small doses of Lorazepam …. This completely eliminated the attacks. The presumption of heterosexuality and failure of his primary care provider and consulting neurologist led to many costly and unnecessary tests and failure to correctly diagnose and treat his problem." [69]

B. Intersectional Discrimination

1. Discrimination against LGBT youth generally

Under the ACA, mental health care now is among the essential covered health benefits. What constitutes appropriate mental health care for LGBT people was a matter of dispute in past generations when homosexuality was considered a mental illness and transgender identity also was not well understood. The overwhelming consensus of contemporary mental health professions now is that there is no illness in homosexuality or bisexuality per se, and that efforts to change a same-sex orientation through aversion or "conversion" therapy are likely to be ineffective and damaging.[70] Similarly, while medical care may be indicated for those with gender dysphoria, the treatment is to align the body with the brain's internal sense of gender rather than to attempt to change the brain's awareness of its gender or to train the person to display the behavior society expects based on the person's external appearance.

Due to continuing social stigma, however, LGBT people continue to seek or be subjected to mental health counseling represented as having the potential to cure same-sex attraction or gender-variant behavior, despite the evidence that such aversion counseling often is damaging. Consequently, two states

[68] *Id.*

[69] *Id.*

[70] See APA Task Force on Appropriate Therapeutic Responses to Sexual Orientation, *Report of the Task Force on Appropriate Therapeutic Responses to Sexual Orientation,* at 121 (2009), *available at* www.apa.org/pi/lgbt/resources/therapeutic-response.pdf; Joy S. Whitman, *et al. Ethical Issues Related to Conversion or Reparative Therapy* (2006), *available at* http://www.counseling.org/news/updates/2013/01/16/ethical-issues-related-to-conversion-or-reparative-therapy.

have prohibited subjecting minors to these practices, deeming it "unprofessional conduct" warranting discipline from the state licensing board,[71] and other states are considering similar legislation.

California's law was challenged and recently upheld by the Ninth Circuit Court of Appeals. [72] Lambda Legal submitted an amicus brief in the litigation on behalf of organizations that serve LGBT youth. The brief presents numerous examples of the harms to young people of being subjected to counseling based on the false and discriminatory premise that they should and can change these innate personal characteristics.[73] In its decision upholding the statute, the Ninth Circuit noted that the legislature had relied on the "well-documented, prevailing opinion" amongst the country's major medical and psychological authorities that these practices are ineffective and pose a risk of "serious harm to those who experience it." [74]

The harms of anti-LGBT aversion counseling are discussed here because, for purposes of Section 1557 implementation***, they should be recognized as a prohibited form of sex discrimination***. The only persons targeted for such aversion counseling are those who exhibit or claim a same-sex sexual orientation or other gender-nonconforming behavior. Persons who present with a different-sex sexual orientation and other gender-conforming behavior are not counseled that there is something wrong with them that they should attempt to change through an unpleasant, at best, course of medical intervention.

In addition to the personal accounts in Lambda Legal's amicus brief of the adverse effects for many young people of aversion counseling, an established body of research shows a link between parental reactions to a child's sexual orientation or gender non-conforming behavior and that child's subsequent health outcomes. This research on family rejection or acceptance shows:

- There is a predictive link between specific, negative family reactions to a child's minority sexual orientation and serious health problems for these adolescents in young adulthood – such as depression, illegal drug use, risk for HIV infection, and suicide attempts.[75]
- LGB young adults who reported higher levels of family rejection during adolescence were 8.4 times more likely to report having attempted suicide, 5.9 times more likely to report high levels of depression, 3.4 times more likely to use illegal drugs, and 3.4 times more likely to report having

[71] California' Senate Bill 1172, 2012 Cal. Stat. 835; New Jersey's A3371, P.L.2013, c.150.

[72] *Pickup v. Brown*, 2013 U.S. App. LEXIS 18068, 2013 WL 4564249 (9th Cir. Cal., Aug. 29, 2013).

[73] Brief of *Amicus Curiae* Children's Law Center of California, *et al*., *available at* http://www.lambdalegal.org/in-court/cases/pickup-v-brown-and-welch-v-brown.

[74] *Id*. at *13-*14, citing the legislature's reliance on position statements and reports by, among others, the American Psychological Association, the American Psychiatric Association, The American School Counselor Association, the American Academy of Pediatrics, the American Medical Association, the National Association of Social Workers, the American Counseling Association, the American Psychoanalytic Association, the American Academy of Child and Adolescent Psychiatry, and the Pan American Health Organization.

[75] Caitlin Ryan, PhD, ACSW, *et al*., *Family Rejection as a Predictor of Negative Health Outcomes in White and Latino Lesbian, Gay and Bisexual Young Adults*, PEDIATRICS, Vol. 123, No. 1, pp. 346 -352 (Jan. 1, 2009) (doi: 10.1542/peds.2007-3524), *available at* http://pediatrics.aappublications.org/content/123/1/346.full.

engaged in unprotected sexual intercourse, compared with peers that reported no or low levels of rejection by their families.[76]

- Accepting behaviors of parents and caregivers towards LGBT children are protective against mental health risks, including depression, substance abuse, and suicide.[77]

According to this leading research in this field, Latino male youth report the highest number of negative family reactions to disclosure of a youth's minority sexual orientation in adolescence.[78] A subsequent survey similarly found that Latino LGBT youth identified the need for family acceptance as their top problem and personal priority.[79] A separate study of transgender adults showed a similar correlation between family rejection and increased rates of suicidal attempt; 32 percent of transgender respondents who had experienced acceptance from their families reported that they had attempted suicide, compared with 51 percent of respondents who reported family rejection.[80]

Enforcement of Section 1557 to decrease discriminatory counseling and other biased health services provided to LGBT youth and their families, and to increase medically sound services, is needed urgently because LGBT youth are over-represented in youth homeless populations[81] and in foster care systems[82] with all the adverse health consequences those living situations entail. Numerous studies have determined that family rejection due to a young person's minority sexual orientation and/or gender identity is a main cause of the disproportionate numbers of LGBT youth in these situations.[83] In fact, one study found that 42 percent of LGBT youth in out-of-home care were there due to family rejection or

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[76] *Id.*

[77] Caitlin Ryan, PhD, ACSW, *et al., Family Acceptance in Adolescence and the Health of LGBT Young Adults*, J. Child & Adolescent Psych. Nursing, Vol. 23, No. 4, pp. 205–213 (Nov. 2010) (doi: 10.1111/j.1744-6171.2010.00246.x), *available at* http://familyproject.sfsu.edu/files/FAP_Family%20Acceptance_JCAPN.pdf.

[78] Ryan, *et al., Family Rejection, supra* note 75.

[79] Human Rights Campaign Foundation & League of United Latin American Citizens, *Supporting and Caring for our Latino LGBT Youth* (2013), *available at* http://www.hrc.org/files/assets/resources/LatinoYouthReport-FINAL.pdf (last accessed September 2013)

[80] Grant, NTDS, *supra* note 19.

[81] Andrew Cray, et al., *Seeking Shelter: The Experiences and Unmet Needs of LGBT Homeless Youth*, at p. ___ (Sept. 2013) *available at* http://www.americanprogress.org/wp-content/uploads/2013/09/LGBTHomelessYouth.pdf.

[82] Mark E. Courtney, *et al., Midwest evaluation of the adult functioning of former foster youth: Outcomes at Ages 23 and 24* (2009), *available at* http://www.chapinhall.org/sites/default/files/Midwest_Study_Age_23_24.pdf.

[83] Shahera Hyatt, *Struggling to Survive: Lesbian, Gay, Bisexual, Transgender, and Queer/Questioning Homeless Youth on the Streets of California* (2011), *available at* http://cahomelessyouth.library.ca.gov/docs/pdf/StrugglingToSurviveFinal.pdf; Laura E. Durso & Gary J. Gates, *Serving Our Youth: Findings from a National Survey of Service Providers Working with Lesbian, Gay, Bisexual, and Transgender Youth who are Homeless or At Risk of Becoming Homeless* (2012), *available at* http://fortytonone.org/wp-content/uploads/2012/06/LGBT-Homeless-Youth-Survey-Final-Report-7-11-12.pdf.

because they had been removed from their families because of conflict over their sexual orientation and/or gender identity.[84]

One root of the problem is that, "Unlike children and adolescents, in general, who receive services and care in the context of their families, LGB adolescents are typically served as adults as if they have no families, across a wide range of settings."[85] This is particularly misguided – and causes missed opportunities to facilitate family coping and to reduce likelihood of destructive behaviors within the family – because many "parents consider pediatricians and other health providers to be important sources of guidance in childrearing."[86] Indeed, many parents of LGBT children turn to a range of health care providers for support when trying to come to terms with their child's minority sexual orientation and/or non-conforming gender identity. The American Academy of Family Physicians instructs that, "Family physicians are in an ideal position to be aware that their adolescent patients may be dealing with issues of sexual identity or orientation that impact their psychosocial and physical health. Asking open questions about sexual identity and orientation can open a dialogue on family relationships, safe sexual practices, suicide risks and other issues confronting gay, lesbian, bisexual, transgendered and questioning adolescents in a sensitive and accepting atmosphere."[87] This is especially true for LGBT youth, for whom it is essential that health care be supportive and free from sex discrimination. The services they receive should not only support their own wellness but also nurture the accepting family relationships that will influence their long-term health prospects. [88]

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[84] Nico Sifra Quintana, *et al*., *On the Streets: The Federal Response to Gay and Transgender Homeless Youth* (June 2010), http://www.americanprogress.org/issues/2010/06/pdf/lgbtyouthhomelessness.pdf. *See also* Shannan Wilber, *et al., Child Welfare League of America (CWLA) Best practice guidelines: Serving LGBT youth in out-of-home care* (2009).

[85] Ryan, *et al., Family Rejection, supra* note 75.

[86] *Id*.

[87] Am. Acad. of Family Physicians, *AAFP Policy Statements: Adolescent Healthcare, Sexuality and Contraception* (1987, 2011 COD), *available at* http://www.aafp.org/about/policies/all/adolescent-sexuality.html.

[88] Indeed, the American Academy of Pediatrics' Task Force on the Family highlights the importance of family support for adolescent development and recommends that pediatricians include assessment of family relationships and behaviors in their practice. Edward L. Schor, MD, *et al*., *American Academy of Pediatrics, Report of the Task Force on the Family*, PEDIATRICS, Vol. 111, No. Suppl. 2, pages 1541– 1571 (June 1, 2003), *available at* http://pediatrics.aappublications.org/content/111/Supplement_2/1541.full.html. *See also* Caitlyn Ryan & Donna Futterman, *Lesbian and gay youth: Care and counseling*, J. ADOLESC. MED., Vol. 8, No. 2, pages 207– 374 (June 1997) (abstract available at http://www.ncbi.nlm.nih.gov/pubmed/10360017) (asking LGB adolescents about their family relationships and experiences with rejection can help providers assess the adolescent's risk profile and how to guide their parents to support the child's health and development).

2. Discrimination against LGBT youth in foster care, juvenile justice and homeless systems

(a) The landscape for LGBT youth in out-of-home care

As discussed above, LGBT youth are over-represented in foster care, juvenile justice, and homeless systems. Many enter out- of-home care due to rejection by parents or kinship caregivers and are, therefore, already statistically more likely to have poor health outcomes.[89] Due to the rejection and discrimination that led to placement in out-of-home care settings, LGBT youth are more likely to need behavioral health services in addition to basic medical care.[90]

Although some jurisdictions have nondiscrimination policies and regulations in place to protect LGBT youth in care, many still face harassment and discrimination by child welfare workers, congregate care staff, and others.[91] As a result, LGBT youth are forced out of homes and facilities or flee for their own safety and are less likely to have stable placements while in care. In child welfare cases, LGBT are less likely to return home or to be adopted and as result remain in impermanent situations. For youth involved with the juvenile justice system, moves from detention to home to congregate care can result in multiple medical and behavioral health care providers and inconsistent treatment. Each move to a new foster home, a different homeless shelter, or, in the worst cases, to living on the street, can mean a disruption in health care or a failure to establish a primary physician at all.

Youth of color are over-represented in child welfare, juvenile justice, and homeless systems and LGBT youth of color often experience multiple forms of discrimination while in care. In a Massachusetts study, LGBT youth of color stated they access health care from LGBT-focused facilities because they feel providers in these settings are more knowledgeable about their needs.[92] Youth in the study expressed reluctance to engage in behavioral health care services because of the lack of health care providers' personal knowledge of LGBT people of color.[93]

Transgender and gender non-conforming (TGNC) youth in out-of-home care systems face particular challenges. In group care facilities, transgender youth are often denied supportive counseling,

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[89] Caitlin Ryan, et al., *Family Rejection as a Predictor of Negative Health Outcomes in White and Latino Lesbian, Gay, and Bisexual Young Adults*, 123 Pediatrics 346 (2009); Heather M. Berberet, *Putting the Pieces Together for Queer Youth*, 85 Child Welfare 261 (2006).

[90] National Alliance on Mental Illness, *Mental Health Risk Factors Among GLBT Youth* (2007), *available at* http://www.nami.org/texttemplate.cfm?section=fact_sheets1&template=/contentmanagement/contentdisplay.cfm&contentID=48112.

[91] http://www.nrcyd.ou.edu/lgbtq-youth

[92] http://www.bostonalliance.org/wprs/wp-content/uploads/2012/02/GLBT-Youth-of-Color-Community-Health-Assessment.pdf

[93] http://www.bostonalliance.org/wprs/wp-content/uploads/2012/02/GLBT-Youth-of-Color-Community-Health-Assessment.pdf

appropriate evaluations, and other medically necessary transgender-related treatments.[94] In some cases, facilities have refused to fill prescriptions from a transgender youth's treating physician. Transgender youth who are denied appropriate treatment are at risk for serious negative health and social consequences, including depression, suicide attempts, and self-treatment (using street hormones and engaging in other medically unsupervised activities for gender transition).[95]

Currently, health care for transgender youth in out-of-home care is a patchwork across the country because youth in care are eligible for Medicaid, but coverage varies widely from state to state. The Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit provides comprehensive and preventive health care services for children under age 21 who are enrolled in Medicaid. EPSDT is key to ensuring that children and adolescents receive appropriate preventive, dental, mental health, and developmental, and specialty services.[96] States are required to provide any additional health care services that are coverable under the Federal Medicaid program and found to be medically necessary to treat, correct or reduce illnesses and conditions discovered regardless of whether the service is covered in a state's Medicaid plan. It is the responsibility of states to determine medical necessity on a case-by-case basis.[97] This case-by-case basis approach to coverage is a breeding ground for discrimination against transgender youth where so much stigma and misunderstanding persists around their experiences and needs. When procedures that have been recommended by a physician as medically necessary are not covered by the child welfare agency, it puts transgender health care in a unique class as the only type of medically necessary treatment not covered for youth in care.

Because of broader societal changes more youth are now openly identifying as LGBT.[98] Medical and behavior health care providers and the out-of-home care systems serving youth across the country must improve their competency in working with these young people or they will continue to face discrimination and have significant unmet health needs.

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[94] http://whttp://www.bostonalliance.org/wprs/wp-content/uploads/2012/02/GLBT-Youth-of-Color-Community-Health-Assessment.pdfww.villagecounselingcenter.net/A_GUIDE_FOR_GROUP_CARE_FACILITIES.pdf

[95] http://whttp://www.bostonalliance.org/wprs/wp-content/uploads/2012/02/GLBT-Youth-of-Color-Community-Health-Assessment.pdfww.villagecounselingcenter.net/A_GUIDE_FOR_GROUP_CARE_FACILITIES.pdf

[96] http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-Periodic-Screening-Diagnosis-and-Treatment.html

[97] http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-Periodic-Screening-Diagnosis-and-Treatment.html

[98] http://www.americanprogress.org/issues/lgbt/news/2013/05/02/62087/improving-the-lives-of-lgbt-americans-beginning-with-our-youth/

(b) Examples of discrimination in health services experienced by LGBT youth in out-of-home care

The following two stories, drawn from Lambda Legal's work with these youth, illustrate all-too-common forms of health care discrimination faced by transgender youth, particularly those being raised in foster care systems.

- S.T., a transgender youth of color in foster care, was diagnosed with gender identity disorder. Following WPATH standards, her doctor recommended breast augmentation in addition to a social transition. S.T.'s foster care agency supported her in her social transition and also paid for hormone treatment. However, breast augmentation was not covered by state Medicaid and, therefore, the procedure could only be paid out of discretionary agency funds. S.T. waited nine months for the agency to decide whether to pay for the procedure. Her request ultimately was denied. The agency cited S.T.'s instability and a concern that she might be ill-suited to make such an important decision. S.T.'s attorney asked the family court to require payment and the agency is fighting her request. The agency is now requiring a second opinion by a doctor of its choice and will not allow S.T. or her attorney to provide collateral information or even to speak with the doctor outside of S.T.'s consultation. The agency says S.T. must comply with the second doctor's recommendation even though it has not questioned the qualifications of S.T.'s primary doctor. The agency's decision makers have neither met S.T. nor spoken to her doctor. S.T. is now waiting for a second opinion and the outcome of the family court litigation. Meanwhile, her transition has stopped, exacerbating the symptoms which resulted in the original gender identity disorder diagnosis and contributing to the instability the agency now uses against her.

- P.F., a transgender girl living in the northeast, went into foster care and then later returned home to her mother where problems persisted. Months later, she entered the juvenile justice system and, ultimately, was placed in a group home. Individuals involved in her care from child welfare and juvenile justice systems were not aware of her transgender-related health needs. As a result, every time she was moved her treatment was disrupted and prior treatment recommendations were questioned. P.F. ultimately aged out the system, Medicaid coverage ended when she did, and no health coverage plan was put in place. Her treatment again was compromised.

3. Sex Discrimination against Children with Intersex Conditions/Disorders of Sexual Development

One in every 2000 children is born with some form of a disorder of sexual development (DSD), also known as intersex conditions.[99] Misinformation about treatment and inconsistency in treatment are prevalent.[100] Parents are left with a confusing patchwork of policies and recommendations from medical professionals and often are ill-equipped to make fully-informed decisions regarding procedures. As a

[99] *See* Advocates for Informed Choice, *What is intersex/DSD?*, http://aiclegal.org/who-we-are/faqs/. *See also* Intersex Society of North America, *How common is intersex?*, http://www.isna.org/faq/frequency.

[100] Intersex Society of North America, *What do doctors do now when they encounter a patient with intersex?*, http://www.isna.org/faq/concealment.

result, many children with DSD have medically unnecessary gender reassignment surgery performed at a very early age before gender identity develops.

These unnecessary procedures may have life-long and profound negative health implications. Residual effects of surgery or resulting scar tissue from surgery can leave individuals incapable of reproducing or experiencing sexual pleasure.[101] In addition, by unnecessarily deciding gender identity for a child at an age when a child cannot consent, uninformed parents and physicians are inadvertently creating the potential for gender dysphoria and other behavioral health conditions.[102]

The following two examples illustrate the types of health care discrimination faced by children with DSDs, particularly those being raised in foster care systems:

- M.C. was born with an intersex condition – a reproductive or sexual anatomy that does not fit typical definitions of male or female. Children with M.C.'s condition have bodies that are not easily labeled as either male or female. Doctors referred to M.C. as a "true hermaphrodite." M.C. was in the care of the South Carolina Department of Social Services (SCDSS) when doctors, in cooperation with social services employees, decided to perform gender reassignment surgery. Typically, children with these conditions develop as a boy or girl as they grow. Despite not knowing whether 16-month-old M.C. would develop into a man or woman, SCDSS consented to sex-assignment surgery and M.C.'s healthy phallus was removed in an attempt to make M.C. a girl. M.C., now 8, has shown signs of developing a male gender and now identifies as a boy. M.C.'s adoptive parents have filed a lawsuit on his behalf in an attempt to end this practice.[103]

- R.T., a child diagnosed with a rare form of DSD, is in foster care in the northeast. His foster mother is accepting and supportive. R.T. needed extensive testing to determine the proper course of treatment, but child welfare caseworkers were uninformed about DSDs and have large caseloads. As a result of the caseworkers' lack of knowledge and excessive workloads, R.T. and his foster mother waited months for treatment referrals, test results, and recommendations on R.T.'s needs. When the tests finally were ordered they were referred to out-of-state providers due to the limitations of state resources. Administrative hurdles regarding payment for the out-of-state testing caused further complications and delays. In the meantime, R.T.'s foster mother has been forced to assign a gender to R.T. without proper information and recommendations.

4. Discrimination against LGBT seniors

For LGBT older adults, the experience of being denied the care they need is prevalent, with research showing that 13 percent of LGBT older adults report having been denied health care or provided

[101] Consortium on the Management of Disorders of Sex Development, *Clinical Guidelines for the Management of Disorders of Sex Development in Childhood* at 28, http://www.accordalliance.org/dsdguidelines/clinical.pdf.

[102] Intersex Society of North America, *What's wrong with the way intersex has traditionally been treated?*, http://www.isna.org/faq/concealment.

[103] http://aiclegal.org/

inferior care because they are LGBT.[104] Fear of discrimination in accessing care is widespread. For example, in a large-scale study from 2006, 19 percent of gay and lesbian baby boomers had little or no confidence that the health care system would treat them respectfully.[105] Another study showed that, because of concerns about how they will be treated, almost 25 percent of LGBT older adults have not revealed their LGBT status to their primary care physicians. This lack of disclosure often means that LGBT seniors do not sufficiently discuss their sexual health, risks of breast or prostate cancer, hepatitis, HIV risk, hormone therapy, or other risk factors with their doctors.[106] As noted by the American Medical Association, "Unrecognized homosexuality by the physician or the patient's reluctance to report his or her sexual orientation can lead to failure to screen, diagnose or treat important medical problems."[107] These barriers to accessing health care and the negative consequences from not being able to do so are even more pronounced for transgender seniors than for LGB seniors.[108]

Specifically with regard to home-based health care, LGBT elders who fear harassment will often attempt to "de-gay" their home before a caregiver arrives, including hiding photographs or books, or asking a same-sex partner to leave temporarily. This process can have significant negative impacts on the emotional and physical health of a person who already has serious health care needs.[109]

Finally, LGBT seniors experience a range of discrimination in long term care facilities, including verbal and physical harassment from both staff and other residents, refused admission or attempted discharge, refusal to accept medical powers of attorney from a patient's same-sex spouse or partner, restrictions on visitors, refusals by staff to use the correct name or pronoun for transgender patients, and failure to provide appropriate medical care or treatment.[110]

A study conducted by the National Senior Citizens Law Center, Lambda Legal and others captured many stories of inadequate health care caused by anti-LGBT bias and lack of cultural competence concerning the needs of LGBT elders. Responding to the survey, Jean-Luc D. from Maybee, Michigan told the following story about his partner, Johnny Jones, who was in a skilled nursing facility for four days in 2007:

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[104] K. Fredriksen-Goldsen, *et al., The Aging and Health Report: Disparities and Resilience among Lesbian, Gay, Bisexual, and Transgender Older Adults* (2011).

[105] MetLife Mature Market Institute, *Out and Aging: The MetLife Study of Lesbian and Gay Baby Boomers*, at 14 (2006).

[106] K. Fredriksen-Goldsen, *et al., The Aging and Health Report: Disparities and Resilience among Lesbian, Gay, Bisexual, and Transgender Older Adults* (2011)*;* R. Klitzman and J. Greenberg, *Patterns of Communication between Gay and Lesbian Patients and their Health Care Providers*, J. of Homosexuality 42(4) (2002).

[107] American Medical Association, Policy H-160.991, *Health care needs of the homosexual population*.

[108] K. Fredriksen-Goldsen, *et al., The Aging and Health Report: Disparities and Resilience among Lesbian, Gay, Bisexual, and Transgender Older Adults* (2011).

[109] Services & Advocacy for GLBT Elders (SAGE) & Movement Advancement Project, *Improving the Lives of LGBT Older Adults*, at 34 (Mar. 2010).

[110] Nat'l Senior Citizens Law Center, *et al., Stories from the Field: LGBT Older Adults in Long Term Care Facilities*, at 9 (2011).

> The first day the nursing staff "accidentally" pulled out his feeding tube. The second day they "accidentally" injured his urethra after pulling out the catheter or inserting it too forcefully. Johnny had to go to the ER twice in the four days: the first time to treat his damaged urethra and the second time after he was found unresponsive following the trip back from the ER. After that, Johnny's family and I moved him to a bigger hospital in Ann Arbor. I don't know whether the poor care Johnny received was because he is black, or because we are a gay couple. I was at his side all day every day, only leaving to sleep. The bad things happened at night, when I couldn't see what was going on.[111]

Another respondent, C. from Columbia, SC, reported:

> I went for nine days without heart medication during a rehabilitation stay in a nursing home. For 17 days I received another, inappropriate, medication. Even though I had been out for many years, I was so dependent on the nurses that I became afraid. It took all the courage I could muster up to keep pushing the staff to solve the problem.[112]

C. Discrimination Against People Living With HIV

The ACA will expand access to care for many thousands of currently uninsured and underinsured people living with HIV by prohibiting pre-existing condition exclusions, lifetime and annual benefits limits, and premium rating based on health status. Section 1557 also will help to reduce the more subtle discriminatory practices in health programs and activities that limit access to care for people living with HIV will help to reduce HIV-related stigma and its adverse health effects.[113]

1. Discriminatory Insurance Benefit Designs

People living with HIV have reported significant barriers to accessing treatment even when they have public or private insurance due to discriminatory plan designs including:

(a) Monthly limits on prescription drugs or the exclusion of drugs recognized as the standard of care for HIV

Drug formularies should meet the federal HIV treatment guidelines, which are widely recognized as setting the standard of care for keeping people living with HIV healthy.[114] Several Medicaid programs

[111] Nat'l Senior Citizens Law Center, *et al., Stories from the Field: LGBT Older Adults in Long Term Care Facilities*, at 15 (2011)

[112] *Id.*

[113] HIV Health Care Access Working Group 2012 Policy Priorities, http://66.147.244.246/~aidsconn/hivhealthreformorg/wp-content/uploads/2012/02/HHCAWG_priorities.pdf.

[114] See federal guidelines, including for antiretroviral treatment and prevention and treatment of opportunistic

utilize either monthly limits or brand-name only requirements, and these restrictions are a significant barrier to care and treatment for people living with HIV. Private insurers also have utilized limited drug formularies to foreclose access to medications needed by people living with HIV. For chronic and complex conditions like HIV, where the standard of care is evolving rapidly, reference to clinical guidelines is important to ensure that coverage decisions are based on established medical guidelines.

(b) High cost-sharing on the medications and services that are considered standard of care for people with HIV

Higher costs – particularly in the form of co-pays, deductibles, and coinsurance – can serve as a discriminatory barrier to care for people living with HIV and other chronic conditions. For instance, even with out-of-pocket caps, placing lifesaving HIV or viral hepatitis medications on specialty tiers that require 25 or 30 percent coinsurance acts as an insurmountable barrier to that treatment by making it unaffordable. When cost-sharing features prohibit access to care, HHS should delineate medical override provisions or exception processes that can be initiated by the enrollee, an authorized representative, or the medical provider (similar to the process in Medicare Part D). Cost sharing – in the form of co-payments, deductibles, and coinsurance – must be evaluated closely to ensure that it is not used improperly to limit access to essential care and treatment.

(c) Utilization management techniques used to deny or restrict access to care for people with chronic and complex conditions

Requiring step therapy for HIV treatment without a medical override provision or imposing burdensome prior authorization requirements on HIV medications are examples of discriminatory utilization management techniques. Also of concern are requirements that patients buy HIV and other designated medications only through mail-order pharmacies and/or imposition of significant costs for not doing so.[115] In addition to impeding timely access and adherence to medications, this utilization management technique eliminates the opportunity for consultation with one's pharmacist, interferes with management of drug interactions and side effects, and creates confidentiality concerns, particularly for those who must have medications delivered to a place of employment to ensure receipt.

(d) Insurers refusing to recognize Ryan White Programs as third-party payers

Because insurance coverage provides people living with HIV access to regular and comprehensive medical care, Ryan White Program funds may be used to purchase private insurance for eligible clients. Many states use their Ryan White/AIDS Drug Assistance Program (ADAP) funds to

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infections at http://aidsinfo.nih.gov/guidelines.

[115] *See, e.g.*, "Blue Cross to Allow HIV/AIDS Patients to 'Opt-Out' of Mandatory Mail-Order Rx Program—Blue Cross Settles Lawsuit Alleging Discrimination, Threats to Health & Privacy," http://www.consumerwatchdog.org/case/blue-cross-allow-hivaids-patients-%E2%80%9Copt-out%E2%80%9D-mandatory-mail-order-rx-drug-program-blue-cross-set.

cover client premium, co-pay, and deductible obligations. However, several state Ryan White/ADAP programs have encountered insurers who refuse to recognize Ryan White/ADAP as a third-party payer. Administrative barriers – such as refusals to accept bulk premium payments or pharmacy refusals to invoice Ryan White/ADAP for co-pay amounts – significantly limit Ryan White clients' meaningful access to comprehensive insurance.

(e) Barriers to accessing substance use and mental health services

Access to behavioral health care, including substance use disorder and mental health services is also critical for individuals living with HIV and many others. Yet insurance plans often create barriers for individuals trying to access these needed services. For example, the American Society of Addiction Medicine (ASAM) recently reported that many Medicaid and commercial insurance programs impose significant barriers for individuals seeking Medication Assisted Treatment for opioid dependence, including exclusion of medications such as methadone and buprenorphine, as well as imposing burdensome prior -authorization requirements and step therapy. [116] The ASAM also found that needlessly complex coverage rules limit access similarly. It will be crucial for HHS to scrutinize plans for practices such as these that discriminate against individuals with behavioral health needs, and to enforce the Mental Health Parity and Addiction Equity Act.

(f) Medical necessity definitions not based on physician recommendations and supported with medical justifications

Plans can use medical necessity definitions to limit access to essential treatment for people living with HIV and other chronic and complex conditions. For example, medical necessity definitions that deny access to otherwise covered treatment when a person's health cannot be restored, but where the treatment will help maintain health or prevent deterioration, may exclude people from necessary care. Any medical necessity definition must ensure that treatment decisions are based on physician recommendations and medical justification. Because the application of medical necessity to insurance coverage determinations varies greatly within private insurance coverage, HHS should include analysis of medical necessity definitions and provide examples of impermissible definitions in non-discrimination compliance tools.

(g) Provider networks that exclude HIV providers or do not identify HIV providers in their directories transparently for prospective enrollees.

Inadequate physician network size and composition also exclude people living with HIV and other chronic conditions from accessing insurance by excluding providers that can deliver the quality care they need. A plan network that systematically excludes HIV providers violates both network

[116] The American Society of Addiction Medicine, *Advancing Access to Addiction Medications, Implications for Opioid Addiction Treatment* (2013), *available at* http://www.asam.org/docs/advocacy/Implications-for-Opioid-Addiction-Treatment.

adequacy standards outlined in Qualified Health Plan certification requirements and is a discriminatory plan design practice that forecloses meaningful access to care.

2. Discriminatory Enforcement of Insurance Rules

In addition to discriminatory plan designs, people living with HIV also are more likely to experience adverse coverage decisions, including service denials and rescission of coverage. For instance, plans have systematically dropped people living with HIV from coverage for failure to pay premiums timely, while allowing healthier populations to remain in coverage. Because of the potential for irregular enforcement of insurance rules in ways that disproportionately impact people living with HIV, it is essential that HHS monitor the amount and types of adverse coverage decisions to ensure that people living with HIV are not systematically denied coverage.

3. Stigma and Discrimination in Health Care Settings

Despite significant social and political equality advances for LGBT people as well as advances in HIV care and treatment, the stigmas associated with a same-sex sexual orientation, a non-conforming gender identity, or HIV-positive status still create significant barriers to care, with the following consequences:

(a) Individual refusals to treat and excessive precautions during treatment

People living with HIV report provider refusals to treat them as well as excessive provider precautions during treatment that do not comport with federal HIV treatment or health professional safety guidelines.[117] For instance, in 2009, Lambda Legal brought suit on behalf of a Wisconsin woman who had been denied necessary gall bladder surgery because the surgeon she consulted mistakenly believed her HIV presented an undue risk to the surgical team.[118] That same year, Lambda Legal also represented Dr. Robert Franke, a 75-year-old retired university provost and minister, against the assisted living in Little Rock, Arkansas from which he was evicted abruptly when the facility learned he was living with HIV.[119] Earlier, Lambda Legal had represented Cecil Little, who needed nursing home care during his recovery from two strokes and brain aneurysms.[120] Six different Louisiana facilities refused him upon learning of his HIV status, prompting Lambda Legal to pursue care for little via discrimination

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[117] Lambda Legal, *HIV Stigma and Discrimination in the U.S.: An Evidence-Based Report* (2010), http://data.lambdalegal.org/publications/downloads/fs_hiv-stigma-and-discrimination-in-the-us.pdf.

[118] *See Lambda Legal and ARCW Resolve Discrimination Case on Behalf of HIV-Positive Woman Denied Surgery*, http://www.lambdalegal.org/news/wi_20101228_discrimination-case-resolved. Additional information about the case, *Rose v. Cahee*, is at http://www.lambdalegal.org/in-court/cases/rose-v-cahee-et-al.

[119] Like *Rose v. Cahee*, this case, *Franke v. Parkstone Living Center, Inc*., also settled after the federal district court denied defendants' motion to dismiss, http://www.lambdalegal.org/in-court/cases/franke-v-parkstone-living. The complaint is available at http://www.lambdalegal.org/in-court/legal-docs/franke_ar_20090508_complaint.

[120] Details of the case are at http://www.lambdalegal.org/in-court/cases/in-re-cecil-little.

complaints with HHS.[121] HIV care providers report similar difficulties when trying to link their patients to other specialty services. Provider refusals to treat as well as excessive precautions when treating people with HIV have been encountered across provider types, including private physicians, dentists, and community health centers.[122]

(b) Blanket refusal to treat policies

Some service providers have adopted blanket policies refusing care to people living with HIV. For instance, researchers surveyed 131 skilled nursing facilities, 98 plastic and cosmetic surgeons, and 102 obstetricians in Los Angeles County to determine how many of these institutions had blanket policies of refusing to provide services to people living with HIV. Of the providers surveyed, 46 percent of the skilled nursing facilities, 26 percent of the cosmetic and plastic surgeons, and 55 percent of the obstetricians refused to accept any patients with HIV — and did not have any lawful explanation for their discriminatory practice.[123]

(c) Men of color who have sex with men report higher rates of stigma

Black gay men and other men of color who have sex with men (MSM) report high rates of stigma when accessing health care. In 2011, the National Alliance of State and Territorial AIDS Directors (NASTAD) and the National Coalition of STD Directors (NCSD) designed and implemented a survey to explore how community- and institution-level stigma within public health practice negatively affects HIV- and STD-related outcomes.[124] The survey was completed by more than 1,300 health department and community-based organization (CBO) staff, health providers, and community members representing 54 different states and territories. Survey results showed high levels of perceived community-level and institutional stigma directed at Black and Latino gay men and other MSM.

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[121] This matter resolved through the complaint process. http://www.lambdalegal.org/news/la_20031008_la-nursing-home-reverses-course-agrees-to-take-man.

[122] National Women's Law Center, *Health Care Refusals Harm Patients: The Threat to LGBT People and Individuals Living with HIV/AIDS* (2013), http://www.nwlc.org/sites/default/files/pdfs/lgbt_refusals_factsheet_8-6-13.pdf.

[123] Brad Sears and Deborah Ho, The Williams Institute, UCLA School of Law, HIV Discrimination in Health Care Services in Los Angeles County: The Results of Three Testing Studies (2006), available at http://williamsinstitute.law.ucla.edu/wp-content/uploads/Sears-Ho-Discrimination-Health-Care-LA-County-Dec-2006.pdf.

[124] NASTAD/NCSD Stigma Survey Findings Presentation, United States Conference on AIDS (2012), available at http://www.nastad.org/Docs/042244_Slides-NASTAD-Stigma%20Seminar-and-Public-Health-USCA-2012-09-24-12-FINAL.pdf.

D. Religion Used To Discriminate Against LGBT Patients

1. Discrimination by individual health professionals in secular health care contexts based on the professional's personal religious views about LGBT people and same-sex relationships

Here is a selection of cases in which health professionals invoked protections for their religious liberty as grounds for providing unequal treatment to LGBT patients. The first two concern refusal of routine services to address reproductive and sexual health care needs.

- Guadalupe "Lupita" Benitez was referred for infertility care to North Coast Women's Care Medical Group, a for-profit clinic that had an exclusive contract with Benitez's insurance plan. After eleven months of preparatory treatments, including medication and unwarranted surgery, Lupita's doctors finally admitted they would not perform donor insemination for her because she is a lesbian. The doctors claimed a right not to comply with California's public accommodations law due to their fundamentalist Christian views against treating lesbian patients as they treat others. In a unanimous decision, the California Supreme Court held that religion liberty protections do not authorize doctors to violate the civil rights of lesbian patients, enforcing. [125]
- Washington resident Jonathan Shuffield was denied a medical prescription when his doctor in a secular medical practice claimed a personal religious right to refuse to provide care based on Jonathan's sexual orientation. Lambda Legal negotiated a settlement on Jonathan's behalf in which the doctor and employing medical center agreed to take steps to protect other LGBT patients, including LGBT cultural competence for training physicians and staff and amending the center's antidiscrimination policies.[126]

The following cases illustrate the range of situations in which individual health professionals have asserted claims of a right to discriminate against LGBT people or people living with HIV in a health care setting based on the provider's religious views about LGBT people.

- Counseling student's objections to providing relationship counseling to same-sex couples. *Keeton v. Anderson-Wiley*, 664 F.3d 865 (11th Cir. 2011) (finding student unlikely to prevail on free speech and religious liberty claims challenging her expulsion from counseling program due to her religiously based refusal to counsel same-sex couples, contrary to professional standards requiring nonjudgmental, nondiscriminatory treatment of all patients).
- Physician's objection to working with an LGB person. *Hyman v. City of Louisville*, 132 F. Supp. 2d 528, 539-540 (W.D. Ky. 2001) (physician's religious beliefs did not exempt him from law prohibiting employment discrimination based on sexual orientation or gender identity), *vacated on other grounds by* 53 Fed. Appx. 740 (6th Cir. 2002).
- Proselytizing to patients concerning religious condemnation of homosexuality. *Knight v.*

[125] *North Coast Women's Care Med. Grp., Inc. v. San Diego Cnty. Superior Court (Benitez)*, 189 P.3d 959 (Cal. 2008) (physicians' free exercise rights did not exempt them from law's prohibition against sexual orientation discrimination).

[126] *In re Shuffield*: http://www.lambdalegal.org/in-court/cases/in-re-shuffield.

Connecticut Dep't of Pub. Health, 275 F.3d 156 (2d Cir. 2001) (rejecting free exercise wrongful termination claim of visiting nurse fired for antigay proselytizing to home-bound AIDS patient).

- Refusal to process lab specimens from persons with HIV. *Stepp v. Review Bd. of Indiana Emp. Sec. Div.*, 521 N.E.2d 350, 352 (Ind. 1988) (rejecting religious discrimination claim of lab technician fired for refusing to do tests on specimens labeled with HIV warning because he believed "AIDS is God's plague on man and performing the tests would go against God's will").

Testimonies received in Lambda Legal's health survey describe similar encounters with health professionals who felt free to express their religiously grounded bias toward LGBT patients:

- Kara in Philadelphia, PA: "Since coming out, I have avoided seeing my primary physician because when she asked me my sexual history, I responded that I slept with women and that I was a lesbian. Her response was, 'Do you know that's against the Bible, against God?'"
- Joe in Minneapolis, MN: "I was 36 years old at the time of this story, an out gay man, and was depressed after the breakup of an eight-year relationship. The doctor I went to see told me that it was not medicine I needed but to leave my 'dirty lifestyle.' He recalled having put other patients in touch with ministers who could help gay men repent and heal from sin, and he even suggested that I simply needed to 'date the right woman' to get over my depression. The doctor even went so far as to suggest that his daughter might be a good fit for me."

Similar examples of discrimination are all too common. Such treatment demonstrably leads to a distressing encounter for the patient, inadequate care, and future medical care avoidance, with potentially dangerous health consequences. It therefore is essential that the courts continue to rule as they have in the cases cited above that protections for religious liberty do not exempt health professionals from legal duties not to discriminate against patients, any more than is true under the American Medical Association's ethical rules.[127]

Lambda Legal has submitted amicus briefs in challenges to the ACA's contraception coverage requirement brought by proprietors of for-profit businesses.[128] Lambda Legal strongly supports the coverage requirement that includes contraception as an essential preventive care benefit for women. The

[127] *See, e.g.,* American Medical Association Policies E-9.12, *Patient-Physician Relationship: Respect for Law and Human Rights* ("physicians who offer their services to the public may not decline to accept patients because of race, color, religion, national origin, sexual orientation, or any other basis that would constitute invidious discrimination."); E-10.05, *Potential Patients* ((2) The following instances identify the limits on physicians' prerogative: … (b) Physicians cannot refuse to care for patients based on race, gender, sexual orientation, or any other criteria that would constitute invidious discrimination. … (3) In situations not covered above, it may be ethically permissible for physicians to decline a potential patient when: … (c) A specific treatment sought by an individual is incompatible with the physician's personal, religious, or moral beliefs.") (emphasis added).

[128] *See, e.g.*, Brief of Amicus Curiae Lambda Legal Defense and Education Fund, Inc. In Support of Appellants and For Reversal of the District Court, *Domino's Farms Corporation, et al. v. Sebelius, et al.*, Sixth Circuit Court of Appeals Case No. 13-1654, pages 35-39 (filed Aug 12, 2013) (copy submitted electronically with these comments).

Lambda Legal brief explains why for-profit enterprises do not have religious freedom rights and, even if they did, the connection between an employer's exercise of religion and its employees' access to contraception through third party plans is too tenuous to constitute a cognizable burden on religious liberty. Were such a religious liberty right to be recognized, it would leave a devastatingly small step from the unduly expansive religion claims employers make in these cases to employer power to impose their religious beliefs even more oppressively on their employees. For example, employers might object to employees' use of HIV medications, to infertility care for lesbians or unmarried non-lesbian women, to treatment of gender dysphoria, to pain management and other end-of-life care, and many more basic health care options individuals should be free to consider with guidance from their physicians rather than coercion from their employers.

2. Discrimination against LGBT people by religiously affiliated service providers

When LGBT people receive medical care in religiously affiliated facilities, they may have limited recourse against discrimination under applicable nondiscrimination laws. Accordingly, it is that much more important that institutions that accept public funding be held to the same nondiscrimination standards as others offering services to patients. Here are two examples of situations in which patients had little notice or opportunity to select a secular provider to ensure protection against discrimination.

- Melody Rose in Wisconin required gall bladder surgery but was refused when the surgeon expressed medically baseless concerns that her HIV posed a threat to him and his surgical team. Lambda Legal represented Melody against the physician and health facility that refused her. The physician and clinic were responsible to Melody under the nondiscrimination laws. However, the court determined that Agnesian HealthCare, Inc., the religiously affiliated corporation that did business with the clinic, was exempt from any liability under the civil rights law.[129]
- Jennifer in Folsom, CA: "I am transgender, a registered nurse and married to my same-sex spouse of 6 years. … [W]e were involved in a car crash and taken by trauma alert ambulance to a hospital … My spouse was more seriously hurt and we were separated at the hospital. I was denied any information about her condition despite identifying myself as her spouse and producing a certified copy of our marriage certificate. This Catholic hospital didn't recognize my status as next of kin so they would provide no information. I had to wait several hours until I was discharged from the ER to visit her and see how she was doing for myself. … No one at the hospital ever apologized for adding to our suffering by denying us what would be usual courtesy if we had fit their standards. Until this happened I had never experienced discrimination in health care—I just couldn't believe it happened to us."

2. Health Programs and Activities That Should Be Considered Covered By Section 1557

One of the most significant shortcomings of current federal non-discrimination laws as they apply to health care is that they offer a patchwork of protections applicable only to certain programs, products,

[129] Information about *Rose v. Cahee* is at http://www.lambdalegal.org/in-court/cases/rose-v-cahee-et-al.

and activities. This has left wide swaths of the health care arena outside of any meaningful federal non-discrimination regulation. The language of § 1557 of the ACA – prohibiting discrimination in "health programs and activities" – is broad and should be construed to cover a wide range of activities, including outreach and enrollment activities, Qualified Health Plan certification procedures and approval, Qualified Health Plan activities and procedures, private insurance companies, physicians, and other providers who receive payment from subsidized Qualified Health Plans, programs administered by the Executive branch (including the multi-state Qualified Health Plans and Federal Employees Health Benefits Program (FEHB)); ACA grant and demonstration projects, Medicaid and Medicare, and community health centers.

For LGBT and HIV-positive seniors, it is critical to be clear that this mandate applies not only to doctors' offices and hospitals, but to urgent care centers and "minute clinics," home health care services, and long-term care, assisted living, and skilled nursing facilities. Given both the barriers to health care experienced by LGBT seniors and the generally increased need to access health care as we age, LGBT seniors are more likely to need to take advantage of acute care settings.[130] As well, in light of the increased health disparities and decreased social support experienced by LGBT seniors, this population is more likely to need to access home health care services or long term care settings.[131]

3. Impact, costs and benefits of ending discrimination in health care for people living with HIV.

HIV-related stigma and discrimination have significant implications for individual health and public health generally, such as:

- **Decreased access to testing**
  Fears of discrimination and stigma lead to delayed testing and late diagnosis of HIV, as well as reluctance to disclose HIV status.[132] Stigma and discrimination-related delays in testing (and consequently delays in identification of HIV infection and delayed access to care and treatment) are particularly troubling given that access to treatment is not only essential for individual health, but is also essential to prevent new infections.

[130] K. Fredriksen-Goldsen, et. al, *The Aging and Health Report: Disparities and Resilience among Lesbian, Gay, Bisexual, and Transgender Older Adults* (2011).

[131] Services & Advocacy for GLBT Elders (SAGE) & Movement Advancement Project, *Improving the Lives of LGBT Older Adults*, at 30-34 (Mar. 2010); Nat'l Senior Citizens Law Center, et al., *Stories from the Field: LGBT Older Adults in Long Term Care Facilities*, at 4 (2011).

[132] Margaret Chesney and Ashley Smith, Critical Delays in HIV Testing and Care: The Potential Role of Stigma, 42(7) American Behavioral Scientist (1999).

- **Decreased access to care and treatment**
  Stigma and discrimination also negatively impact access to essential care and treatment. Studies have shown that people who report a high level of stigma are more likely to report poor access to care, a regular source of HIV care, and adherence to anti retroviral therapy. [133]

- **Adverse health outcomes**
  Discriminatory refusals to provide health services and denials of coverage result in adverse health outcomes for people living with HIV. Refusals to provide care may result in harmful disruptions in treatment, making medication ineffective. This is true for both provider refusals and insurance denials of necessary HIV medications and treatment.[134] Barriers to accessing medically necessary care are particularly significant for low-income people living with HIV and those living in rural areas, where finding an alternative provider is often impossible.

- **Disproportionate burden of HIV and other STDs on stigmatized populations**
  Stigmatized populations are disproportionately impacted by HIV/AIDS and other STDs.[135] HIV/AIDS disproportionately impacts gay men and other men who have sex with men (MSM), particularly gay men/MSM of color – in the form of higher infection rates, less likelihood of timely linkage to care, and less likelihood of viral suppression.[136] In 2010, black men accounted for 36% of new HIV infections among MSM. The number of new infections among young MSM aged 13-24 increased 22% from 2008 to 2010, with young black gay and other MSM accounting for more than half of new HIV infections among young MSM.

To make headway against the epidemic and to meet the goals of the National HIV/AIDS Strategy, tools and strategies are needed that are aimed at improving prevention, access to care, and retention in care for gay men/MSM, including addressing stigma and discrimination associated with this population.

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[133] Jennifer Sayles, et al., The Association of Stigma with Self-Reported Access to Medical Care and Antiretroviral Therapy Adherence in Persons Living with HIV/AIDS, 24(10) Journal of General Internal Medicine (2008).

[134] Kelsey Rounds, et al., Perspectives on Provider Behaviors: A Qualitative Study of Sexual and Gender Minorities Regarding Quality of Care, 44 Contemporary Nurse (2013); National Women's Law Center, Health Care Refusals Harm Patients: The Threat to LGBT People and Individuals Living with HIV/AIDS (2013), available at http://www.nwlc.org/sites/default/files/pdfs/lgbt_refusals_factsheet_8-6-13.pdf.

[135] NASTAD/NCSD Stigma Survey Findings Presentation, United States Conference on AIDS (2012), available at http://www.nastad.org/Docs/042244_Slides-NASTAD-Stigma%20Seminar-and-Public-Health-USCA-2012-09-24-12-FINAL.pdf.

[136] Centers for Disease Control and Prevention (CDC), HIV Among Black/African American Gay, Bisexual, and Other Men Who Have Sex With Men, available at http://www.cdc.gov/hiv/risk/racialethnic/bmsm/facts/index.html.

Ensuring Access to Health Programs and Activities

4. **Ensuring access for those with limited English proficiency.**

We strongly support the many ACA provisions requiring consumer assistance, outreach, education, and Marketplace and Medicaid information resources to be available in plain language and to accessible for individuals who have limited English proficiency (LEP), including meeting the Culturally and Linguistically Appropriate Services (CLAS) standards. The CLAS standards as well as the Title VI requirements with respect to services for limited LEP individuals should be applied to services received through ACA outreach and enrollment programs (including Navigators and in-person assisters) as well as Marketplace web portals, written materials, and call centers.

Standards should include both translation of important documents into multiple languages as well as inclusion of a "tagline" in multiple languages that informs recipients that the notice or document is important and how to obtain the document in a different language. Similarly, programs that utilize a call center must ensure adequate voice prompts in different languages alerting callers to availability of translation services. We urge HHS to look to the Social Security Administration's practice of translating materials into fifteen languages and to consider adopting the fifteen-language threshold for all HHS and Marketplace-developed materials.

Navigators and other assister personnel in particular must be able to meet the needs of the communities in which they are working and to provide services in a way that is culturally and linguistically competent. Ensuring provision of culturally and linguistically competent assistance, outreach, and education activities is particularly important to ensure that stigmatized and vulnerable populations – for instance, the LGBT community, people living with HIV, and people with mental health or substance use disorder needs – have meaningful access to insurance assistance.

5. **Particular Needs of LGBT People With Respect To Ending Sex Discrimination**

HHS should require that child welfare, juvenile justice, and homeless systems providers are informed about the specific health care needs of LGBT youth of color and knowledgeable regarding LGBT specific health care providers in their communities. HHS should provide information and training on these topics. In addition, the federal government should require that child welfare, juvenile justice, and homeless service providers be knowledgeable about LGBT-focused providers within communities of color and offer those services to youth. Further, the federal government should require that all providers, including behavioral health providers, have specific training regarding the specific experiences and needs of LGBTQ youth of color. Staff at all group homes, psychiatric hospitals, and juvenile detention facilities should be familiar with transgender medical care to ensure that a youth's treatment is not interrupted and should look to a youth treating clinician for treatment planning.[137] HHS should

[137] http://whttp://www.bostonalliance.org/wprs/wp-content/uploads/2012/02/GLBT-Youth-of-Color-Community-Health-Assessment.pdfww.villagecounselingcenter.net/A_GUIDE_FOR_GROUP_CARE_FACILITIES.pdf

require that child welfare, juvenile justice, and homeless systems providers utilize health care providers that are LGBT competent. Providers make referrals to health care providers in their community and, often, have specific contracts with local providers. HHS should require that all providers used are LGBT competent and affirming.

6. Issues Posed for LGBT and HIV-Positive People By New Information Technologies in Health Care Delivery

HHS should prioritize the use of electronic medical records for youth involved in child welfare, juvenile justice, and homeless systems. The federal government should acknowledge that while all youth in care may experience disruption in medical care due to placement changes, LGBT youth are at a higher risk for poor health outcomes due to higher incidences of placement disruption than their heterosexual peers. HHS should provide guidance that all children in care are to maintain a principal medical provider. Such a directive would be of particular benefit to LGBT youth. In addition, remote access to electronic medical records would give all youth in care, their caregivers, and their caseworkers the ability o obtain needed information if providers were to change and guarantee some baseline consistency in treatment. Again, such access would be of enormous benefit LGBT youth who are at disproportionate risk of bouncing from placement to placement and clinician to clinician.

In addition, while better continuity of care is possible through increased access to medical records for vulnerable populations, continuing social stigma causes many LGBT people to value confidentiality of personal information such as a history of having transitioned, HIV status, and even a minority sexual orientation. As information is more readily retained and accessed by a broad range of health care providers, it will be important to secure appropriate privacy protections and to ensure cultural competence training about the needs of LGBT and HIV-positive individuals.

Compliance and Enforcement Approaches

7. Section 1557 Includes the Enforcement Mechanisms Provided For and Available Under Title VI, Title IX, Section 504, and the Age Discrimination Act.

It is critical that OCR create and administer a strong enforcement system for this new statute. The success of Title IX in combating sex discrimination demonstrates the importance of strong agency enforcement. The compliance and enforcement procedures used under Title IX and the three other civil rights laws referenced by Section 1557 provide a starting point for establishing procedures under Section 1557. The regulations adopted for Section 1557 must reflect the entire wide range of equitable relief and enforcement mechanisms established and available under those statutes, including agency enforcement as well as the private right of action for monetary damages.

Because the statutes listed in Section 1557 contain a private right of action for a full range of relief, including equitable relief and monetary damages, Section 1557 does as well.[138] Likewise, Section 1557 provides for the full range of agency enforcement and Department of Justice enforcement in court.

The enforcement procedures provided under the laws referenced by Section 1557 are a starting point for developing procedures under Section 1557. Like those laws, Section 1557 must be interpreted to provide for complaints brought on behalf of an individual, a class, or by a third party. Each of these vehicles for agency enforcement is crucial for enforcement under the laws Section 1557 references. Class complaints and third party complaints in particular allow OCR to resolve systemic problems of discrimination, rather than proceeding piecemeal only on behalf of individual complainants. They are especially important in the health care area because of the consequences of allowing system-wide patterns of discrimination to continue. Individual victims of discrimination may be hesitant to file complaints themselves because, for example, they fear retaliation from individuals or entities on which they rely for health care or insurance coverage. This creates a strong disincentive for some to file complaints and reinforces the importance of class and third party complaints.

Section 1557 is a powerful proactive tool in OCR's work to combat discrimination in health care. OCR's authority is not limited to responding to complaints under Section 1557. It can—and should—also address discriminatory policies and practices at covered entities through technical assistance, systemic investigations, and compliance reviews of selected entities. OCR has conducted these reviews pursuant to its authority under other civil rights laws.[139] Because Section 1557 is a new law, it is especially important that OCR complete compliance reviews to both identify discrimination and set precedents under this new law. Without knowledge of Section 1557's protection or how to file a complaint, individuals remain vulnerable to discrimination in health care settings and covered entities may well continue discriminatory practices.[140] The results of compliance reviews should also be made public. The reports from such reviews can serve as guidance for other covered entities as to what it means to comply with Section 1557.

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[138] In *Cannon v. University of Chicago*, the Supreme Court emphasized the importance of the private right of action to enforcing antidiscrimination statutes. 441 U.S. 677, 704-05 (1979). The Court later determined that money damages are available for intentional discrimination, relying on the longstanding principle that all remedies are presumed to be available to accompany a federal right of action "unless Congress has expressly indicated otherwise." *Franklin v. Gwinnett County Public Schs.*, 503 U.S. 60, 66 (1992). There, the Court stated "Congress surely did not intend for federal monies to be expended to support the intentional actions it sought by statute to proscribe." *Id.* at 74. *See also Guardians Assn. v. Civil Service Comm'n of New York City*, 463 U.S. 582 (1983) (damages available under Title VI for intentional violations); *Consolidated Rail Corporation v. Darrone*, 465 U.S. 624 (1984) (awarding backpay for violation of Section 504 of Rehabilitation Act).

[139] *See, e.g.*, Dep't of Health & Human Servs., Office for Civ. Rts., *Compliance Review Initiative: Advancing Effective Communication in Critical Access Hospitals* (Apr. 2013), *available at* http://www.hhs.gov/ocr/civilrights/activities/agreements/compliancereview_initiative.pdf

[140] For instance, staff for the California Health and Human Services Agency, which oversees California's Medicaid program, indicated a lack of complaints to the agency on language access issues in 2011 and 2012. Linda Bennett (AFSCME) interview with Amanda Ream, Organizing Director, Interpreting for California (August 2013). The absence of complaints, however, is not an indication that discrimination does not exist; to the contrary, it suggests that individuals may not know their rights or about the complaint process.

Concerning the needs of people living with HIV, the ability of § 1557 to eliminate HIV and LGBT-related discrimination in health programs and activities and to advance the health equity goals of the National HIV/AIDS Strategy rests on the extent to which the law's protections are enforced. Section 1557 greatly expands existing civil rights protections and is unprecedented in the scope of providers, activities, and programs it reaches. It is therefore, again, essential that HHS develop regulatory and sub-regulatory guidance that is provider, activity, and program-specific and that provides the necessary details of what constitutes discriminatory activity. For instance, the guidance for healthcare providers should make clear that the definition of disability under the Americans with Disabilities Act Amendments Act of 2009 will be employed in enforcement of § 1557 (as it is has been under Section 504 of the Rehabilitation Act), that any individual living with HIV falls within the scope of § 1557's protections, and that a "direct threat" defense to discriminatory conduct based on actual or perceived HIV status will rarely, if ever, absolve an individual or entity from liability.[141]

In addition, HHS should convene a cross-agency task force to ensure federal alignment as regulations are promulgate and also to ensure that regulations are sufficiently detailed and targeted to provide insurance issuers and new ACA programs and providers the specific guidance they need. For instance, in the Health Insurance Portability and Accountability Act (HIPAA) enforcement realm, identification of practices that violated the non-discrimination provisions in the group insurance market through regulations, sub-regulatory guidance, and "insurance standards bulletins" was helpful in identifying what constituted prohibited discriminatory insurance practices. This is particularly important given that recent research has indicated that state regulators as well as insurance issuers are still unclear as to how to develop products and procedures that comply with the ACA's new non-discrimination requirements.[142]

Given the barriers to access to the courts, HHS should create a mechanism for robust administrative enforcement of § 1557, together with a private right of action in federal court after exhaustion of administrative remedies (the process used in enforcement of the Age Discrimination Act). Creating meaningful administrative redress mechanisms, backed by the option to proceed with litigation in court, will increase the likelihood that discrimination of various dimensions and degrees may be appropriately addressed through § 1557.

Moreover, many states have passed rules or regulations specifically prohibiting state enforcement of federal provisions of the ACA. There must be clear procedures in place for individuals living in these states to report instances of discrimination directly to the federal government and to facilitate swift review and enforcement. HHS should develop robust monitoring mechanisms to ensure that facially

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[141] *See* U.S. Department of Justice, Civil Rights Division, Disability Rights Section, "Questions and Answers: The Americans with Disabilities Act and Persons with HIV/AIDS," http://www.ada.gov/aids/ada_q&a_aids.htm ("Can a public accommodation exclude a person with HIV or AIDS because that person allegedly poses a direct threat to the health and safety of others? In almost every instance, the answer to this question is no. Persons with HIV or AIDS will rarely, if ever, pose a direct threat in the public accommodations context.")

[142] Katie Keith, et al., *Nondiscrimination under the Affordable Care Act, The Center on Health Insurance Reforms, Georgetown University Health Policy Institute* (2013), http://chir.georgetown.edu/pdfs/NondiscriminationUndertheACA_GeorgetownCHIR.pdf.

neutral insurance practices and other health care activities are not used to discriminate against people living with HIV and other people living with complex and expensive conditions. To this end, we suggest that probing but not overly burdensome data collection requirements be used, including data collected from consumer surveys and plan data involving denials of coverage, to monitor compliance at the state and federal levels.

8. Other issues important to the implementation of Section 1557

A. HHS should specify that under 1557 medically necessary transgender health care services for transgender youth receiving Medicaid are covered by EPSDT as "additional health care services."

By clarifying this point at the federal level, HHS can help alleviate the patchwork approach that has developed across the country due to each state's interpretation of this provision of EPSDT (in the absence of clear federal guidance), as it relates to health care for transgender youth.

B. HHS should clarify that individuals with intersex/DSD conditions are covered under 1557 and provide protections for children who are not of age to consent to reassignment surgeries.

In addition to clarifying that individuals with intersex/DSD conditions are covered, HHS recognition would bring much needed attention to this population. While it is not possible to recommend a uniform treatment for individuals with DSDs because every situation is unique, guidance from the federal government summarizing current recommended treatment standards, articulating uniform procedures to follow, and directing that accurate, comprehensive information be provide to parents would do a great deal to address a complicated area with profound health implications. In particular, HHS should provide guidance and education for staff in child welfare systems that are responsible for

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making health care decisions for children with DSD conditions and advocate for legal oversight over non-voluntary gender reassignment surgeries.

Thank you for considering the information submitted in response to your inquiry.

Most respectfully,

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All private health insurance plans offered in the Marketplace will offer the same set of essential health benefits. These are services all plans must cover.

The essential health benefits include at least the following items and services:

- Ambulatory patient services (outpatient care you get without being admitted to a hospital)
- Emergency services
- Hospitalization (such as surgery)
- Maternity and newborn care (care before and after your baby is born)
- Mental health and substance use disorder services, including behavioral health treatment (this includes counseling and psychotherapy)
- Prescription drugs
- Rehabilitative and habilitative services and devices (services and devices to help people with injuries, disabilities, or chronic conditions gain or recover mental and physical skills)
- Laboratory services
- Preventive and wellness services and chronic disease management
- Pediatric services
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NATIONAL LATINA INSTITUTE FOR REPRODUCTIVE HEALTH

September 30, 2013

Department of Health and Human Services
Office for Civil Rights
Attention: RIN 0945-ZA01
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 Latina Institute for Reproductive Health (NLIRH) is pleased to have the opportunity to respond to the Office for Civil Rights' (OCR) Request for Information (RFI) Regarding Nondiscrimination In Certain Health Programs or Activities. NLIRH is the only national organization working on behalf of the reproductive health and justice of the 24 million Latinas, their families and communities in the United States through public education, community mobilization and policy advocacy. We join the Administration in strongly supporting efforts to successfully implement the Affordable Care Act (ACA), in particular Section 1557, with the eventual goal of ensuring that all individuals in the United States can access affordable, quality health care that meets their individual needs.

We are glad to provide responses to Questions 1, 2, 3, 4, 5, and 7.

Understanding the Current Landscape

Question 1: ***The Department is interested in experiences with, and examples of, discrimination in health programs and activities. 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 interact.***

Recently, we conducted a survey of the Latino/a community in Texas with the help of our field staff. The survey, written in Spanish, asked respondents if they have received health care in the United States, including a visit to the pharmacy. It also asked respondents if they thought that their race/ethnicity, sex, their primary language, and/or sexual orientation have impacted their

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health. A majority of the respondents were Spanish-speaking Latinas. Sixty-three out of one-hundred respondents stated that they had received healthcare in the United States. **Overwhelmingly, seventy-four respondents out of eighty-seven thought that their race/ethnicity, sex, and/or primary language have impacted their health.** Our field staff told us that respondents were reluctant to tell them their health care stories because of fear of discrimination and repercussions to them and their families.

Latinas have faced discrimination due to limited English proficiency and national origin in health programs and activities.

(a) National origin and limited English proficiency

Discrimination on the basis of national origin, which encompasses discrimination on the basis of limited English proficiency (LEP),[1] creates unequal access to health, particularly for LEP Latinas. LEP is often compounded with the "cumulative effects of race and ethnicity, citizenship status, low education, and poverty," resulting in more barriers to access.[2] In the United States today, there are about 25 million individuals with LEP.[3] Individuals with LEP of Mexican and Asian origin combined constitute 63% of all individuals with LEP in our country.[4] Language assistance services are especially critical for individuals with LEP who are unfamiliar with our complex healthcare system.

In 1996, Executive Order 13166 reaffirmed this principle of meaningful access for individuals with LEP, which was further implemented by Health and Human Services' (HHS) Guidance to Federal Financial Assistance Recipients Regarding Title VI Prohibition Against National Origin Discrimination Affecting Limited English Proficient Persons (HHS LEP Guidance) released in 2000 and revised in 2003.[5] Today, Title VI remains an important tool to help patients and consumers who do not understand English achieve better health.

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[1] Lau v. Nichols, 414 U.S. 563 (1974).
[2] Kaiser Family Foundation, Overview of Health Coverage for Individuals with Limited English Proficiency, at 3.
[3] U.S. Census Bureau, *American Community Survey*, *Selected Social Characteristics in the United States: 2011 American Community Survey 1-Year Estimates* (25,303,308 speak English less than "very well"). http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_11_1YR_DP02&prodType=table
[4] *Id.* at 1–2.
[5] Guidance to Federal Financial Assistance Recipients Regarding Title VI Prohibition Against National Origin Discrimination Affecting Limited English Proficient Persons, 68 Fed. Reg. 47,311 (Aug. 8, 2003) [hereinafter HHS LEP Guidance].

Without adequate language assistance services, limited English proficient individuals face difficulty enrolling in and navigating health programs and activities. Unfamiliarity with the health care system arises from unfamiliarity with its cultural norms, vocabulary, and procedures. The stories we have heard and seen tell us that individuals with LEP often forgo primary care altogether, as a result of not understanding how to fill out enrollment applications in English or inaccurately translated non-English languages, not understanding the benefits and costs of services in a health plan, or not having the appropriate cultural and language brokers to communicate with English-speaking physicians and pharmacists. In one study by Professor Nápoles, who is at the University of California, San Francisco, she found that Latina breast cancer survivors needed simple information in Spanish about breast cancer, treatment, management of side effects, and community resources because they often felt confusion regarding terminology, expressed myths about cancer, and did not know how to pay for treatment, especially if they were undocumented.[6]

In fact, one Latina who spoke to our promotoras in Willacy County, Texas, told her that she couldn't express or tell the doctor of what she was feeling. She suffers from arthritis and couldn't tell the doctor how much pain she was in and that it affected her the most at night. In fact, the doctor just looked at her and gave her some medication. However, the medication doesn't do anything for her. She has visited the same doctor multiple times and is continually given the same medication.

(i) National origin discrimination and Latina immigrants

Latinas may also face discrimination in health programs and activities because of their immigration status. The Tri-Agency Guidance first issued in 2000 by HHS and Department of Agriculture provides some examples of national origin discrimination experienced by mixed-status families. Application programs and processes for government health programs may violate Title VI if they have the effect of preventing or deterring eligible applicants from enjoying equal participation in and access to benefits programs based on the applicant's or family member's national origin.[7] Discriminatory actions may be in the form of asking for Social Security

[6] Anna Nápoles, University of California San Francisco, Improving Inequities in Diagnosis, Treatment, and Survival among Latinas. Komen SF Bay Area Many Faces-One Voice Conference. June 17, 2013. Available at: www.komensf.org/files/Office_Documents/2013_MFOV_DR_NAPOLES_presentation.pdf (last visited May 29, 2013).

[7] Dept. Health and Human Services and Department of Agriculture, Policy Guidelines Regarding Inquiries into Citizenship, Immigration Status and Social Security Numbers in State Application for Medicaid, State Children's Insurance Program (SCHIP), Temporary Assistance for Needy Families (TANF), and Food Stamp Benefits.

numbers, citizenship, place of birth, ethnicity or race, or immigration status from family members not applying for coverage or benefits for themselves. Confidentiality and limits on the collection of non-applicants' personally identifiable information are thus important policies in ensuring that immigrants and their family members obtain the health care for which they are eligible.

The rules of the Tri-Agency Guidance have been adopted for the Health Insurance Marketplaces, which may only collect information that is strictly necessary for eligibility determination and enrollment and may use and share this information only for eligibility purposes.[8]

The ACA recognizes and codifies some of the agencies' points. For example, § 1411(g) limits the collection, use and sharing of information to only that which is "strictly necessary,"[9] for determining eligibility and § 1414(a) similarly amends the Internal Revenue Code and the Social Security Act to clarify that tax return information and Social Security numbers may be collected, used and shared only for eligibility determination purposes.[10] There are many ways that the ACA and health programs can produce this kind of discrimination, such as through applications, eligibility workers, navigators, or health care providers that may fail to distinguish between applicants and non-applicants in requests for identifying and demographic information, or require such details without first explaining the use or confidentiality. Additionally, a state-run program may erect onerous documentation requirements that disadvantage immigrant families or deny them the opportunity to prove eligible income, identity, and citizenship or immigration status. **Some Latinas in Texas have commented in our survey that they have been asked for some form of identification in order to access healthcare services.** Unfortunately, they are barred from these services due to lack of identification and other factors. More subtle examples include navigators or other workers who make assumptions about entire families based on the immigration status of an individual member, or who use indicators such as ethnicity or language to limit options provided to eligible individuals.

One recent manifestation of this type of discrimination is in the extreme drop in use of services following Arizona's enactment of HB 2008, which requires state benefit agency employees to report discovered violations of federal immigration law to immigration authorities.[11] In the first nine months after HB 2008 was enacted, use of emergency medical services—often the only type of health services available without regard to immigration status, but which may result in a

[8] Patient Protection and Affordable Care Act, Pub. L. 111-148, §§ 1411(g), 1414(a), 124 Stat. 119, 230 (2010); 45 CFR §§ 155.260, 155.270, 155.310, 155.315(i).
[9] Patient Protection and Affordable Care Act, Pub. L. 111-148, § 1411(g), 124 Stat. 119, 230 (2010).
[10] *Id.* § 1414(a).
[11] Ariz. Rev. Stat. Ann. § 1-501–02 (2013).

referral to Immigration and Customs Enforcement if undocumented persons "self-declare" their status—dropped 45 percent.[12]

In mixed-status families where eligible individuals are prevented or deterred from seeking or obtaining assistance, the impact primarily results in low participation rates in programs and decreased access of health services in general. The reach of this impact is potentially quite large: as of 2010, nearly one in four children younger than age 8 has an immigrant parent.[13] Of these children, the vast majority (93 percent) is U.S. citizens and 43 percent live in mixed-status families.[14] Significantly, under the ACA an estimated 3.2 million children with only undocumented parents will be eligible for Medicaid/CHIP or exchange subsidies.[15] Statistics of coverage rates for children bear out the possible results for these families. Citizen children with non-citizen parents are 38.5 percent more likely to be uninsured than are citizen children with citizen parents.[16] Within every ethnic group, children with immigrant parents were less likely to be insured than children with U.S.-born parents, with the highest rate for uninsured being Latino children.[17] In addition to the lower rates of children obtaining access to health insurance, evidence points to a chilling effect on immigrant access to health care more broadly. Many undocumented Latinas fear taking their citizen children to health care facilities because of increased immigration enforcement.

(b) Sex Discrimination

Latinas have faced discrimination on the basis of sex in health programs and activities.

Section 1557 prohibits discrimination on the ground protected under Title IX, which is sex.[18] This law marks the first time that federal law contains a broad-based prohibition of sex discrimination in health programs or activities. Sex discrimination includes discrimination

[12] This analysis was done through use of statistics from the Arizona Department of Economic Security and included in an attachment to the Civil Rights Complaint filed by Valle del Sol, Inc., concerning HB 2008.
[13] Karina Fortuny, et al., The Urban Institute, Young Children of Immigrants 1 (August 2010).
[14] Id. at 5.
[15] Stacey McMorrow, et al., The Urban Institute, Addressing Coverage Challenges for Children Under the Affordable Care Act 6 (May 2011).
[16] Leighton Ku and Brian Bruen, *Poor Immigrants Use Public Benefits at a Lower Rate than Poor Native-Born Citizens*, Cato Institute: Economic Development Bulletin, May 4, 2013, 1, 3.
[17] Donald J. Hernandez, et al., Foundation for Child Development, Diverse Children: Race, Ethnicity, and Immigration in America's New Non-Majority Generation 10 (July 2013).
[18] 20 U.S.C. § 1681(a) (2012).

based on pregnancy, gender identity, and sex stereotypes—as the RFI rightly notes.[19] Sex discrimination takes many forms and occurs at every step in the health care system—from obtaining insurance coverage to receiving proper diagnosis and treatment. This discrimination has serious adverse impacts on the lives of women, causing them to pay more for health care and to risk receiving improper diagnoses and less effective treatments. The effects of sex discrimination for Latinas may be compounded by other forms of discrimination they face, including racial discrimination.

Some examples of discrimination against women, including Latinas, in health programs and activities and their impacts include:

- Health plans continue to exclude maternity coverage from the benefits provided to certain female plan participants. Treating pregnancy differently, such as by excluding pregnancy care from an otherwise comprehensive insurance plan, is sex discrimination under civil rights laws such as Title IX and Title VII, and also sex discrimination under Section 1557.[20]
- Providers, hospitals, or clinics that refuse to provide reproductive health services to a woman who is not married or because she does not conform to sex stereotypes force women to seek care elsewhere or forgo it completely.[21] This may become more prevalent as states continue to pass religious refusal clauses, which allow health care providers to deny health care services to clients solely on the basis of their moral beliefs.[22] For many

[19] Dep't of Health & Human Servs., Request for Information Regarding Nondiscrimination in Certain Health Programs or Activities,78 Fed. Reg. 46,558, 46,559 (proposed Aug. 1, 2013) ("Sex discrimination (including discrimination on the basis of gender identity, sex stereotyping, or pregnancy)").

[20] *See, e.g.*, Nat'l Women's Law Ctr., *NWLC Section 1557 Complaint: Sex Discrimination Complaints Against Five Institutions*, http://www.nwlc.org/resource/nwlc-section-1557-complaint-sex-discrimination-complaints-against-five-institutions (last visited Sept. 17, 2013) (Section 1557 complaints filed against five institutions that exclude pregnancy coverage for plan beneficiaries who are dependent children of employees at institutions).

[21] *See* Nat'l Women's Law Ctr., *Health Care Refusals Harm Patients: The Threat to Reproductive Health Care* (Jan. 2013), *available at* http://www.nwlc.org/resource/health-care-refusals-harm-patients-threat-reproductive-health-care.

[22] Forty-six states allow some health care providers to refuse to provide abortion care and thirteen states allow some providers to refuse to provide services related to contraception. Guttmacher Institute. State Policies in Brief: Refusing to Provide Health Services. September 1st, 2013. Available at: www.guttmacher.org/statecenter/spibs/spib_RPHS.pdf (last visited September 29, 2013).

Latinas, access to affordable contraception is often non-existent but is necessary to ensure that they can make the best decisions for them and their families. Latinas are twice as likely to suffer from unintended pregnancies in comparison to their white peers.[23] Women of color, including Latinas, have said that cost has kept them from regularly using contraception. A recent survey conducted by Hart Research Associates and commissioned by Planned Parenthood Action Fund found that fifty-seven percent of young Latina women 18–34 have struggled with the cost of prescription birth control.[24] It is imperative that all Latinas have access to the reproductive health services they need.

(e) Discrimination on one or more bases

Latino/a LGBTQ community members have faced discrimination in healthcare programs and activities.

Another population of concern to us is the Latino/a, lesbian, gay, bisexual, and transgender (LGBT) population. Sources such as the Institute of Medicine,[25] Healthy People 2020,[26] the Substance Abuse and Mental Health Services Administration,[27] and the *National Healthcare Disparities Report*[28] indicate that LGBT individuals and their families are disproportionately likely to live in poverty, to be uninsured, and to face substantial barriers to quality health care,

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[23] Cohen SA. Guttmacher Institute. *Abortion and Women of Color: The Bigger Picture*; 2008. Available at: http://www.guttmacher.org/pubs/gpr/11/3/gpr110302.html. [Accessed April 8, 2013].

[24] Planned Parenthood. *Survey: Nearly Three in Four Voters in America Support Fully Covering Prescription Birth Control*. Available at: http://www.plannedparenthood.org/about-us/newsroom/press-releases/survey-nearly-three-four-voters-america-support-fully-covering-prescription-birth-control-33863.htm. [Accessed April 8, 2013].

[25] Institute of Medicine. 2011. *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*. Available from http://www.iom.edu/Reports/2011/The-Health-of-Lesbian-Gay-Bisexual-and-Transgender-People.aspx

[26] Department of Health and Human Services. 2010. "Lesbian, Gay, Bisexual, and Transgender Health." Available from http://www.healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=25

[27] Substance Abuse and Mental Health Services Administration. 2012. "Top Health Issues for LGBT Populations." Available from http://store.samhsa.gov/product/Top-Health-Issues-for-LGBT-Populations/SMA12-4684

[28] Agency for Healthcare Research and Quality. 2012. *National Healthcare Disparities Report*. Available from http://www.ahrq.gov/qual/nhdr11/nhdr11.pdf

including refusals of care, substandard care, inequitable policies and practices, and exclusion from health outreach or education efforts.[29] These inequities may be even more pronounced for LGBT people who are also members of other groups that are disadvantaged on the basis of factors such as race, ethnicity, geography, or disability. For instance, the National Transgender Discrimination Survey found that 23% of Latino transgender respondents had been refused medical care due to bias, and 36% reported having postponed care when they were sick or injured due to fear of discrimination.[30]

Discrimination in Insurance Coverage

Prior to passage of the ACA, few nondiscrimination protections applied to insurance, and these laws and regulations had only a limited effect in ensuring fair coverage for all consumers.[31] Exclusions on the basis of preexisting conditions, variations in rates and charges based on personal characteristics, and arbitrary revocation of coverage were among the discriminatory practices that persisted in private insurance markets, but are ending now due to the ACA.

However, discrimination in benefits design has also been pervasive in both public and private systems of health coverage, and eradicating such discrimination has historically been a challenging process for both consumers and regulators.[32] Private market carriers continue to argue that exclusions for services or drugs commonly provided for the treatment of conditions such as HIV/AIDS are not discriminatory because they apply to all plan enrollees, regardless of their specific negative effect on people with these conditions. As a result, these discriminatory exclusions persist – and an estimated 30 percent of Americans living with HIV are unable to access coverage – despite nondiscrimination laws such as the Americans with Disabilities Act

[29] The Joint Commission. 2011. "Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care for the LGBT Community: A Field Guide." Available from http://www.jointcommission.org/assets/1/18/LGBTFieldGuide.pdf

[30] *Injustice at every turn: a look at Latino/a respondents in the National Transgender Discrimination Survey*. National Center for Transgender Equality, National Gay and Lesbian Taskforce and LULAC. Available at: http://www.transequality.org/Resources/Injustice_Latino_englishversion.pdf. [Accessed December 10, 2012].

[31] *See e.g.* Katie Keith and others, "Nondiscrimination Under the Affordable Care Act" (Washington DC: Georgetown University Health Policy Institute 2013) available at http://chir.georgetown.edu/pdfs/NondiscriminationUndertheACA_GeorgetownCHIR.pdf

[32] Ibid.

(ADA) and the Health Insurance Portability and Accountability Act (HIPAA).[33] These exclusions have disproportionately impacted the LGBT community, in that lesbian and bisexual women have higher rates of breast cancer than heterosexual women, and HIV infection rates are elevated among gay and bisexual men, as well as transgender women.[34]

Latina/o transgender people have also experienced discrimination in the form of exclusions for otherwise-covered services when provided for the purpose of treating Gender Identity Disorder, gender dysphoria, or related conditions. Like anyone else, transgender people need acute care when they are sick and preventive care to keep from becoming sick, including services that are traditionally considered to be gender-specific, such as pap smears, prostate exams, and mammograms. Preventive health services may be a particular concern for Latino/a transgender persons who have intact cervixes. In general, Latinas have the highest rate of cervical cancer incidence,[35] meaning that Latino/a transgender persons are also at high risk for cervical cancer. In addition, transgender people need access to medically necessary care related to gender transition, and access to these transition-related services is integral to the meaning of gender identity nondiscrimination. The medical diagnosis that correlates with a transgender identity is most frequently referred to as gender identity disorder, or GID, which the American Medical Association,[36] the American Psychiatric Association,[37] and the World Health Organization[38] all recognize as a serious medical condition. To fail to provide equal coverage for services when provided to transgender people for the purpose of gender transition is to engage in discrimination on the basis of gender identity.

In the private market, carriers have often excluded benefits from coverage in a manner that discriminates on the basis of gender identity. Examples of such discriminatory designs include

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[33] AIDS.gov. 2012. "The Affordable Care Act Helps People Living with HIV/AIDS." Available from http://aids.gov/federal-resources/policies/health-care-reform/

[34] Institute of Medicine. *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding.*

[35] Centers for Disease Control and Prevention. Cervical Cancer Rates by Race and Ethnicity. Available at: http://www.cdc.gov/cancer/cervical/statistics/race.htm (last visited September 30, 2013).

[36] American Medical Association House of Delegates, "Removing Financial Barriers to Care for Transgender Patients" (2008), available at http://www.tgender.net/taw/ama_resolutions.pdf

[37] American Psychiatric Association, "Transgender, Gender Identity, & Gender Expression Non-Discrimination" (2008), available at http://www.apa.org/about/policy/transgender.aspx

[38] The World Health Organization's International Statistical Classification of Diseases and Related Health Problems, version 10 (ICD-10) includes "gender identity disorder." *See* http://apps.who.int/classifications/icd10/browse/2010/en#/F64

exclusions for "any procedure or treatment, including hormone therapy, designed to change your physical characteristics from your biologically determined sex to those of the opposite sex," or for "all services related to gender dysphoria or gender identity disorder."[39] In public or government-provided health benefits programs, these discriminatory exclusions also frequently block coverage for medically necessary care provided to transgender people. For example, Medicaid programs have adopted exclusions for "treatment of gender dysphoria including gender reassignment surgeries"[40] among others. Health plans offered to federal government employees through the FEHB program have contained exclusions targeting transgender enrollees,[41] as have benefits offered through the VA[42] and Medicare.[43]

These exclusions arbitrarily target transgender people for discrimination by forcing them to pay out-of-pocket for the same medically necessary services provided to non-transgender people. Moreover, coverage determinations based on these exclusions are sometimes used in practice to deny transgender people coverage for basic services that are unrelated to gender transition.

These transgender-specific exclusions contradict the consensus of leading professional medical associations regarding the medical necessity of these treatments for many patients, and they unacceptably limit access to otherwise covered benefits on the basis of gender identity. Major expert associations also agree that transition-related medical services, including mental health services, hormone therapy, and surgery, are medically necessary for many transgender people. The American Medical Association; the American Psychological Association; the American Psychiatric Association; the American Academy of Family Physicians; the American Congress of Obstetricians and Gynecologists; the Endocrine Society; the National Association of Social

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[39] Kellan Baker and Andrew Cray "Ensuring Benefits Parity and Gender Identity Nondiscrimination in Essential Health Benefits" (Washington: Center for American Progress, 2013) available at http://www.americanprogress.org/wp-content/uploads/2012/11/BakerHealthBenefits-2.pdf

[40] Ariz. Admin Code § R9-27-203

[41] *See e.g.* Government Employees Health Association, Inc. Benefit Plan (2013) Available from: http://www.opm.gov/healthcare-insurance/healthcare/plan-information/plan-codes/2013/brochures/71-006.pdf (excluding coverage for "Services, drugs, or supplies related to sex transformations").

[42] *See* 38 C.F.R. § 17.38(c)(4) (Excluding coverage for "gender alterations").

[43] National Center for Transgender Equality, "Medicare Benefits and Transgender People (2011) available at http://transequality.org/Resources/MedicareBenefitsAndTransPeople_Aug2011_FINAL.pdf

Workers; and the World Professional Association for Transgender Health have all issued public statements to this effect. According to these expert associations, determination of the medical necessity of any particular transition-related service for an individual patient properly rests with medical providers, not insurance companies.

People living with HIV, a population that disproportionately includes gay and bisexual men and transgender women, also face significant barriers in accessing health care and treatment due to discriminatory benefits designs in public and private health insurance plans. Examples of these designs include: monthly limits on prescription drugs or the exclusion of drugs recognized as the standard of care for HIV and utilization management techniques used primarily to deny or restrict access to care for people with chronic and complex health conditions. In addition to discriminatory plan designs, people living with HIV are also more likely to experience adverse coverage decisions, including service denials and rescission of coverage.

Discrimination in the provision of health care

A national survey of transgender people conducted by the National Gay and Lesbian Task Force and National Center for Transgender Equality details the experiences of discrimination among transgender Americans to an even greater degree. Discrimination reported among transgender people of color is especially high. Nearly one in five African American respondents reported being refused treatment, and 6 percent reported being physically attacked in a doctor's office.[44] Nearly one in three Latino/a respondents reported unequal treatment by a doctor or hospital.[45] 36 percent American Indian respondents were refused medical care.[46] These figures are only some of the findings regarding discrimination in health care settings reported in the survey.

In addition, stigma associated both with the LGBT community and HIV status serves as a significant barrier to care for people living with HIV or AIDS. People living with HIV report provider refusal to treat them as well as excessive provider precautions with regard to treatment of people living with HIV that do not comport with federal HIV treatment or health professional safety guidelines.[47] HIV providers also report challenges with linking their patients to other

[44] Ibid.
[45] Ibid.
[46] Ibid.
[47] National Women's Law Center, Health Care Refusals Harm Patients: The Threat to LGBT People and Individuals Living with HIV/AIDS (2013), available at http://www.nwlc.org/sites/default/files/pdfs/lgbt_refusals_factsheet_8-6-13.pdf.

specialty services.[48] Provider refusal to treat as well as excessive precautions when treating people living with HIV has occurred across provider types, including private physicians, dentists, and community health centers.[49] Some services providers have gone so far as to put in place blanket policies refusing to provide services to people living with HIV.[50] Black gay men and other men who have sex with men (MSM) also report high rates of stigma when accessing health care. In 2011, the National Alliance of State and Territorial AIDS Directors (NASTAD) and the National Coalition of STD Directors (NCSD) designed and implemented a survey to explore how community- and institution-level stigma within public health practice negatively affects HIV- and STD-related outcomes.[51] The survey was completed by more than 1,300 health department and community-based organization (CBO) staff, health providers, and community members representing 54 different states and territories.[52] Survey results showed high levels of perceived community-level and institutional stigma directed at Black and Latino gay men and other MSM.[53]

Individual stories of health care discrimination lay bare the results of these extraordinarily high rates of discrimination against LGBTQ patients – and transgender patients in particular. The tragic reality is that discrimination against LGBTQ people and people living with HIV, solely because of their sexual orientation, gender identity, and/or HIV status, has resulted in deaths and undue hardships that were likely preventable.

> For instance, Lupita Benitez, a lesbian who wanted to have a child, was denied access to the full range of infertility treatment by her medical doctor because of her sexual orientation. Her doctors were conservative Christians who claimed their religious beliefs gave them a right to withhold routine care from Benitez. Benitez was denied effective treatment for nearly a year. She subsequently was forced to abandon her course of

[48] Ibid.
[49] Ibid.
[50] Brad Sears and Deborah Ho, The Williams Institute, UCLA School of Law, HIV Discrimination in Health Care Services in Los Angeles County: The Results of Three Testing Studies (2006), available at http://williamsinstitute.law.ucla.edu/wp-content/uploads/Sears-Ho-Discrimination-Health-Care-LA-County-Dec-2006.pdf.
[51] NASTAD/NCSD Stigma Survey Findings Presentation, United States Conference on AIDS (2012), available at http://www.nastad.org/Docs/042244_Slides-NASTAD-Stigma%20Seminar-and-Public-Health-USCA-2012-09-24-12-FINAL.pdf.
[52] Ibid.
[53] Ibid.

treatment and seek out a doctor who would provide her with the treatment she needed.[54]

***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?*

Section 1557 protects individuals from discrimination "on the ground[s] 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" in health programs or activities, any part of which receives federal financial assistance; programs or activities administered by an executive agency; and entities established under Title I of the ACA. As is discussed more fully below, these health programs include public and private entities and activities in virtually all aspects of the health care system such as:

- Any health program or activity of a recipient of 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) so that broad institutions, such as public or private entities that receive federal funds are covered. For example, state health departments, hospitals and hospital systems, clinics, or insurance companies that receive federal funds are covered. Section 1557 specifically extends its discrimination prohibition to entities that receive federal financial assistance including credits, subsidies, or contracts of insurance.
- Any program or activity administered by an executive agency, including federal health programs like the Federal Employee Health Benefits Program (FEHBP) and Medicare as well as programs jointly administered by federal and state governments, such as Medicaid and the Children's Health Insurance Program.
- Any entity established under Title I of the ACA, such as the health insurance marketplaces.

Prior to the enactment of Section 1557, the four laws that it references (Title VI, Title IX, Section 504 of the Rehabilitation Act ("Section 504"), and the Age Discrimination Act ("the Age Act")) provided some protection against discrimination in health care. It is essential that Section 1557 be interpreted consistent with these existing protections in health programs as generally described under the CRRA. In addition, Section 1557's nondiscrimination mandate may overlap

[54] *N. Coast Women's Care Med. Grp., Inc. v. San Diego Cnty.* Superior Court, 44 Cal. 4th 1145 (2008).

with existing protections under Title VI, Title IX, Section 504, and the Age Act. Other federal antidiscrimination laws, like Title VII, apply to aspects of health programs as well.

Section 1557 applies to any health program or activity, any part of which receives federal financial assistance, which for purposes of Section 1557 specifically includes credits, subsidies, and contracts of insurance. Congress, in drafting Section 1557, used the same language – "program or activity" – as used in the four civil rights statutes Section 1557 references to indicate the entities covered by it.[55] "Program or activity" under Section 1557 thus has the same meaning as it does under those statutes, as defined by the CRRA. A covered "program or activity" thus includes public or private entities, as well as departments or agencies of a state or local government that receive federal financial assistance.

Congress structured Section 1557 similarly to the way it structured Title IX. Like Title IX, Section 1557 is written with a term that modifies the phrase "program or activity" ("education" in Title IX, "health" in Section 1557). The term "education" in Title IX does not limit the range of recipients of federal financial assistance that fall under Title IX's jurisdiction; rather, the term indicates which portions of a covered program or activity cannot discriminate. This interpretation was confirmed by Congress when it enacted the CRRA.[56] Because Section 1557 is structured like Title IX, the analysis used to determine jurisdiction under Title IX should be used to determine jurisdiction under Section 1557.

In the Title IX context, if the entity has education as its primary purpose, like a public or private university, Title IX prohibits sex discrimination in all of its programs or activities.[57] If the entity does not have education as its primary purpose, Title IX bars discrimination in the education portions of the entity, any part of which receives federal financial assistance for any purpose.[58]

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[55] Civil Rights Restoration Act of 1987, Pub. L. 100-259, 102 Stat. 28 (1988), (codified as amended in scattered sections of 20, 29, and 42 U.S.C.).

[56] *See, e.g., O'Connor v. Davis*, 126 F.3d 112, 118 (2d Cir. 1997); Dep't of Justice, *Title IX Legal Manual* (2001), *available at* http://www.justice.gov/crt/about/cor/coord/ixlegal.php (stating that the scope of Title coverage "will depend upon which portions of a covered program or activity are educational in nature.").

[57] 20 U.S.C. § 1687(2) (2012). *See also O'Connor v. Davis*, 126 F.3d 112, 117 (2d Cir. 1997) ("[C]ourts have consistently interpreted Title IX to mean that if one arm of a university or state agency receives federal funds, the entire entity is subject to Title IX's proscription against sex discrimination.").

[58] *See, e.g., Jeldness v. Pearce*, 30 F.3d 1220, 1226 (9th Cir. 1994) (recognizing that the recipient of federal financial assistance need not be educational in nature for an education program or

Likewise, Section 1557 prohibits discrimination in all the operations of a covered entity that has health as its primary purpose.[59] These include entities such as state and local health departments, hospitals and hospital systems, health clinics, nursing homes, home care agencies, health insurance companies, health or medical research centers, and medical, dental, or other schools that focus on training individuals to enter careers in the health field.

For a covered entity that does not have health as its primary purpose, Section 1557 prohibits discrimination in that entity's health programs or activities, regardless of whether those health programs or activities receive federal financial assistance as long as the entity itself does. This includes, for example, health insurance plans offered by institutions that receive federal financial assistance and health education programs at schools or other entities.[60]

Whether a particular entity or program should be considered "health" related for purposes of Section 1557, like the question of whether a program is educational under Title IX, is a fact-specific question. To effectuate Section 1557's nondiscrimination principle, the determination of whether a program is a "health" program or activity should be consistent with existing interpretations of the term "health" offered by the World Health Organization (WHO). WHO defines health to include not just the absence of disease but also "physical, mental, and social well-being."[61] 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 health of the physical, mental, or social well-being of an individual or population's health.

Section 1557 includes credits, subsidies, and contracts of insurance as federal financial assistance. Section 1557 differs from the civil rights laws to which it refers by expressly

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activity operated by the non-educational entity to be covered by Title IX); Dep't of Justice, *Title IX Legal Manual* (2001), *available at* http://www.justice.gov/crt/about/cor/coord/ixlegal.php.

[59] *See* Civil Rights Restoration Act of 1987, § 3 (codified as amended at 20 U.S.C. 1687(2)). *See also id.* at § 3 (codified as amended at 20 U.S.C. 1687(3(A)(ii)).

[60] Some entities are directly bound by Section 1557 in addition to other antidiscrimination laws, such as Title IX or Title VII. Section 1557, however, may provide additional protections to individuals not covered by those laws. *See, e.g.*, Nat'l Women's Law Ctr., *NWLC Section 1557 Complaint: Sex Discrimination Complaints Against Five Institutions*, http://www.nwlc.org/resource/nwlc-section-1557-complaint-sex-discrimination-complaints-against-five-institutions (last visited Sept. 17, 2013).

[61] Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 8 April 1948.

identifying "credits, subsidies, [and] contracts of insurance" as federal financial assistance to make clear that each trigger its application. For example, Section 1557's inclusion of "contracts of insurance" as federal financial assistance means that it could have broader application than the other civil rights laws it references. Unlike Section 1557, Title VI, Title IX, and the Rehabilitation Act either explicitly exclude or have been interpreted in some circumstances to exclude contracts of insurance as a form of federal financial assistance.[62] A contract of insurance that is federal financial assistance is any contract of insurance that is funded, entered into, administered, or guaranteed by the federal government. Thus, for example, an insurance company in a Marketplace that receives federally-subsidized payments such as through premium tax credits is covered by Section 1557. In addition, contracts for health insurance entered into by the federal government to provide coverage for federal employees are also federal financial assistance to the contracting insurance company. Because contracts of insurance are explicitly included in Section 1557, its regulations must recognize this fact and ensure that these federal funds are not used to finance discrimination.

Section 1557 applies to programs or activities administered by an executive agency. Section 1557 protects individuals from discrimination "under any program or activity that is administered by an Executive Agency." Section 504, too, applies to any program or activity, "conducted by any Executive agency."[63] The phrases "administered by" and "conducted by" are generally synonymous.[64] Federally-conducted programs or activities have typically been defined

[62] Because "contracts of insurance" are not excluded in the statutory text of Section 504 but in its regulations, there are conflicting decisions about whether the regulations properly exclude it. *Compare Moore v. Sun Bank of North Florida*, 923 F.2d 1423, 1429-32 (11th Cir. 1991) (finding that because Section 504 did not expressly exclude contracts of insurance or guaranty, the regulations containing the exclusion were invalid as inconsistent with congressional intent and that the contract at issue did in fact constitute federal financial assistance) *with Gallagher v. Croghan Colonial Bank*, 89 F.3d 275 (6th Cir. 1996) (holding that based on the Section 504 regulation's exclusion of contracts of insurance or guaranty as federal financial assistance, a bank's receipt of reimbursement for default loans was not federal financial assistance and thus the bank was not subject to the Rehabilitation Act).

[63] 29 U.S.C § 794 (2012). *See also* Exec. Order 13,160 3 C.F.R. 279 (2000).

[64] "Conduct" means "to direct or take part in the operation or management of." Conduct - Definition from the Merriam-Webster Dictionary, http://www.merriam-webster.com/dictionary/conduct (last visited Sept. 17, 2013). "Administer" means "to manage or supervise the execution, use, or conduct of." Administer - Definition from the Merriam-Webster Dictionary, http://www.merriam-webster.com/dictionary/administer (last visited Sept. 17, 2013).

to include "anything a federal agency does."[65] Simply put, "any program or activity that is administered by an Executive Agency" means that "anything a federal agency does" is subject to the nondiscrimination requirements of Section 1557.

More specifically, Section 1557 applies to HHS-administered health programs such as Medicare as well as jointly-administered federal and state programs such as Medicaid and the Children's Health Insurance Program (CHIP).[66] HHS is not the only federal agency that must comply with Section 1557; indeed, all federal agencies must conduct their programs and activities in a nondiscriminatory way to comply with Section 1557. This includes, for example, the agencies involved in implementing the ACA such as the Department of Labor and the Department of the Treasury. Likewise, Section 1557 applies to the Federal Employee Health Benefits Program (FEHBP) which is administered by the Office of Personnel Management, an executive agency.

In addition, the reach of Title VI should extend to eligible applicants who are a part of mixed-status families that may be subject to discriminatory state policies. Already nearly half of the 33 states with federally facilitated exchanges have enacted laws that will circumscribe the activities of organizations providing outreach, including prohibiting navigators from advising applicants concerning plan details, creating stringent standards that may have the effect of deterring the participation of organizations focused on underserved communities, and requiring further regulation that result in delays in the navigator program.[67]

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[65] *E.g.*, Enforcement of Nondiscrimination on the Basis of Handicap in Programs or Activities Conducted by the Central Intelligence Agency, 57 Fed. Reg. 39,605 (Sept. 1, 1992); Gen. Servs. Admin., Office of Civil Rights, The Key To Accessing Federally Conducted Programs and Activities 4, *available at* http://www.gsa.gov/graphics/staffoffices/Interim_Key_to_Accessing_FCPA_Handbook_R2-yY5K_0Z5RDZ-i34K-pR.pdf; *Commonly Asked Questions and Answers Regarding Executive Order 13166*, http://www.lep.gov/13166/lepqa.htm (last visited Sept. 17, 2013).

[66] Medicaid and CHIP are jointly administered by HHS and state agencies; nonetheless, because HHS participates in the administration of these programs, Section 1557 applies to them. Section 1557 also applies to the state agencies that receive and distribute federal funds to operate these programs, as "health programs or activities, any part of which receive federal financial assistance."

[67] Katie Keith, et al., *Will New Laws in States with Federally Run Health Insurance Marketplaces Hinder Outreach?*, Commonwealth Fund, July 1, 2013, http://www.commonwealthfund.org/Blog/2013/Jul/Will-State-Laws-Hinder-Federal-Marketplaces-Outreach.aspx.

Section 1557 applies to entities established under Title I of the ACA. The third category of entities in which Section 1557 protects individuals from discrimination are entities established under Title I of the ACA. The health insurance Exchanges and Consumer-Oriented and Operated Plans (CO-OPs) are examples of entities that were or will be created pursuant to Title I of the ACA and that are, therefore, subject to Section 1557.[68] As under other civil rights laws, a covered entity itself can neither discriminate, nor can it provide assistance—monetary or otherwise—to entities that discriminate.[69]

Further, it is vitally important for 1557 to cover the full and complex range of health care entities operating in the American health care system, from individual providers to hospitals, from MCOs to insurers, from HIT support to state and federal agencies. The complexity of the healthcare enterprise makes it impossible for discrimination to be addressed without every facet of the system bearing at least some specific level of responsibility for implementing non-discrimination policies and procedures, and reporting on and self-monitoring on adherence to policies and procedures. The very nature of effective communication necessarily involves meeting the discrete elements of providing notice to the public, determining the communication method needed, and actually following through with effective communication methods, which include having alternate formats and translations prepared beforehand.

Section 1557 health programs and activities should include, but not be limited to, provider offices and clinics, provider groups, specialty treatment centers, hospitals, managed care organizations, provider education and licensing entities, qualified health plans participating in the exchange, exchanges themselves, and county and state governments. These are all entities that receive federal funds under existing streams of Medicaid or Medicare money, or expanded or new funds made available under the ACA or through the Marketplaces which are also authorized under the ACA and federally funded. The second point is that as state agencies devolve the delivery of public program services to private entities, the non-discrimination standards applicable to and expected of those services should remain the same. Even if the state itself did not always **deliver** on those standards, it must contractually ensure that contracting entities adopt and understand the concepts of accessibility, reasonable accommodation and policy modification, undue burden, fundamental alteration, and community integration.

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[68] The Pre-existing Condition Insurance Program and the Early Retiree Reinsurance Program are also examples of entities that were brought into existence pursuant to Title I of the ACA that are subject to Section 1557. These programs expire January 1, 2014. 42 U.S.C. §§ 18001, 18002 (2012).

[69] *See, e.g.*, 34 C.F.R. § 106.31(b)(6) (2012) (prohibiting covered programs or activities from aiding or perpetuating discrimination on the basis of sex by providing aid or assistance to any entity that discriminates on the basis of sex).

***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.*

Latinas suffer severe health disparities. Latinos are uninsured at higher rates than any other racial or ethnic group: one in three is uninsured.[70] For the Latina population, lack of access to comprehensive, affordable insurance coverage means sporadic, if not non-existent access to desperately needed treatment and services. Due to this and other factors, Latinas experience disproportionately high rates of unintended pregnancy,[71] sexually transmitted infections including HIV,[72] diabetes,[73] asthma,[74] and other health issues. Latinas have the highest incidence of cervical cancer;[75] and Latinas are diagnosed with cervical cancer at nearly twice the rate of non-Latina white women.[76] Due to lack of quality, affordable insurance coverage, Latinos

[70] U.S. Centers for Medicaid and Medicare Services. *Latinos: The Top Five Things You Need to Know about the Affordable Care Act*. Available at: http://www.hhs.gov/iea/acaresources/brochures/latinos-top5.pdf [Accessed on August 19, 2013].
[71] Cohen SA. *Abortion and Women of Color: The Bigger Picture*. The Guttmacher Institute; 2008: 3. Available at: http://www.guttmacher.org/pubs/gpr/11/3/gpr110302.pdf. [Accessed on August 19, 2013].
[72] Centers for Disease Control and Prevention. HIV/AIDS. HIV Among Latinos. http://www.cdc.gov/hiv/risk/racialethnic/hispaniclatinos/facts/index.html [Accessed on August 19, 2013].
[73] U.S. Department of Health and Human Services. Office of Minority Health. Diabetes and Hispanic Americans. http://minorityhealth.hhs.gov/templates/content.aspx?lvl=2&lvlID=54&ID=3324 [Accessed on August 19, 2013].
[74] U.S. Department of Health and Human Services. Office of Minority Health. Asthma and Hispanic Americans. http://minorityhealth.hhs.gov/templates/content.aspx?ID=6173 [Accessed on August 19, 2013].
[75] Centers for Disease Control and Prevention. Gynecologic Cancers. Cervical Cancer Rates by Race and Ethnicity. http://www.cdc.gov/cancer/cervical/statistics/race.htm [Accessed on August 19, 2013].
[76] Latinas contract cervical cancer at 1.6 times the rate of white women. U.S. Department of Health and Human Services. The Affordable Care Act and Latinos.

must use community health centers to meet their health care needs. Latinos represent one-third of all community health center patients.[77] Immigrant Latinas also experience these inequities because they lack employment opportunities that provide insurance coverage, face extreme poverty, and lack culturally and linguistically competent health care providers and services.

Recently, researchers found that discrimination against young, pregnant, urban women of color contributed to symptoms of depression and consequently, lower birth weight, an indicator of poor future health.[78] Additionally, in a study conducted from 2009 to 2012, 64% of LEP Latina mothers of infants and toddlers were found to have clinically significant symptoms of depression.[79] Two of the contributing factors may have been economic hardship and the stress of immigration status. Discrimination on the basis of race, ethnicity, sex, or other identities compound the grave health disparities that Latinas already experience.

Latinas also face negative impacts of discrimination due to immigration status. In mixed-status families where eligible individuals are prevented or deterred from securing programs, the primary result is low participation rates in programs and decreased access to health services in general. The reach of this impact is potentially quite large. As of 2010, nearly one in four children younger than eight years has an immigrant parent.[80] Of these children, the vast majority (93%) are U.S. citizens.[81] In 2008, there were four million children with undocumented immigrant parents.[82]

Latina, citizen children in mixed-status families are impacted by the insurance status of their non-citizen parents. A child's insurance status is largely correlated with his or her parent's

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http://www.hhs.gov/healthcare/facts/factsheets/2012/04/aca-and-latinos04102012a.html [Accessed on August 19, 2013].

[77] U.S. Department of Health and Human Services. The Affordable Care Act and Latinos. http://www.hhs.gov/healthcare/facts/factsheets/2012/04/aca-and-latinos04102012a.html [Accessed on August 19, 2013].

[78] Latinas were 62% of the study participants. Earnshaw V.A. et al. *Maternal experiences with everyday discrimination and infant birth weight: a test of mediators and moderators among young, urban women of color*. Ann. Behav. Med. 2013 Feb;45(1):13-23. *Available at*: http://www.ncbi.nlm.nih.gov/pubmed/2292701.

[79] Beeber L., Schwartz T., & Smith L. The "Wings" Depressive Symptom Intervention for Latina Mothers. Available at: sonapps.unc.edu/research/current/?studyid=3001-The "Wings" Depressive Symptom Intervention for Latina Mothers (last visited September 29, 2013).

[80] Karina Fortuny, et al., The Urban Institute, *Young Children of Immigrants* 1 (2010).

[81] *Id.* at 5.

[82] *Id.* at 9, n.5.

status.[83] In addition to the lower rates of health insurance among children with non-citizen parents than with citizen parents, evidence points to a chilling effect on immigrant access to health care more broadly. Already, undocumented immigrants are ineligible for the ACA's insurance programs and most lawfully present immigrants are barred from federal, non-emergency Medicaid and CHIP programs until they have had a specific status, such as lawful permanent residence (LPR or green card) for five years.

For instance, Latinas granted deferred action under the new Deferred Action for Childhood Arrivals (DACA) will be ineligible for expanded coverage options under the ACA, Medicaid, and CHIP. This decision will restrict access to vital reproductive and sexual health services for immigrant women, who already face numerous barriers to health insurance and the health care they need. According to recent estimates, 48% of the 1.78 million anticipated to be eligible for DACA are women, 72% are 15 years and older, over half are enrolled in K-12 education or college, and 58% were engaged in the labor force.[84] This particular population is one that needs expanded, not restricted, access to sexual and reproductive health care. These young people, like all Americans, need access to quality and affordable preventive sexual and reproductive health care services in order to plan and space pregnancies, prevent sexually transmitted infection (STI) and gynecological cancers, obtain information and counseling about family planning, among other health needs.

LGBTQ Latinos/as also face negative health outcomes because of discrimination on the basis of race/ethnicity, sexual orientation, gender identity and other factors. Systemic issues in healthcare programs and activities further compound the effects of discrimination that LGBTQ Latinos/as experience. The Institute of Medicine has recognized that the stigma and discrimination experienced by LGBT people contributes to minority stress, which in turn can cause negative mental health outcomes.[85] Studies have documented such disparities among subpopulations of the LGBT community, including elevated rates of depression, anxiety, and

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[83] Government Accountability Office, GAO 11-24, *Medicaid and CHIP: Given the Association Between Parent and Child Insurance Status, New Expansions May Benefit Families* 8–10 (2011).

[84] Batalova J, Mittelstadt M. Relief from Deportation: Demographic Profile of the DREAMers Potentially Eligible Under the Deferred Action Policy. Migration Policy Institute. August 2012. Available at http://www.migrationpolicy.org/pubs/FS24_deferredaction.pdf. Accessed on October 9, 2012.

[85] Institute of Medicine. *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding.*

substance use.[86] For example, in a 2011 report presented to the American Psychology Association, researchers found that lesbian, gay, and bisexual people who had experienced prejudice-related events were three times more likely to have suffered a serious physical health problem over a one-year follow-up period than those who had not experienced such events.[87] Also, in a recent study of Latina transgender women, respondents reported high levels of discrimination in various aspects of everyday life, and those who reported higher levels of discrimination were more likely to be identified with moderately severe to severe levels of depression.[88] And while data from the National Transgender Discrimination Survey, conducted by the National Gay and Lesbian Task Force and National Center For Transgender Equality, on the relationship between discrimination in health care and suicidality was not reported, the high lifetime suicide attempt rate among the sample (41 percent) was dramatically higher among those who had experienced bias-motivated victimization in other forms, such as bullying in school (51 percent), loss of a job (55 percent), and physical assault in any setting (61 percent).[89] Ultimately, internalized stigma, experiences of victimization, and fear of accessing health services were all significantly associated with poorer physical health, higher likelihood of disability, and higher degrees of depressive symptoms and perceived stress. [90] As a result, Latino LGBT individuals are more likely to experience significant disparities in health indicators such as smoking, obesity, experiences of abuse and violence, mental and behavioral health concerns, and HIV infection.

In addition to the institutional drivers of health disparities among the LGBT population, discrimination in the health care context can result in more direct negative health outcomes. While in severe instances, acts of discrimination by healthcare providers have resulted in serious injury, disease progression, and death,[91] denial of care and delivery of inadequate care can also lead to mistrust and reluctance to seek care on the part of LGBT patients.[92] For example,

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[86] Ibid.
[87] Ilan Meyer, *et al.*, *Minority Stress and Physical Health Among Sexual Minorities* (2011).
[88] M. Bazargan, & F. Galvan, *Perceived Discrimination and Depression among Low-Income Latina Male-to-Female Transgender Women* 12 BMC Public Health 663 (2012).
[89] Grant et al., "Injustice at Every Turn"
[90] K.I. Fredriksen-Goldsen et al., *Physical and Mental Health of Transgender Older Adults: An At-Risk and Underserved Population*, Epub ahead of print, Gerontologist (2013).
[91] See section one above.
[92] Institute of Medicine. *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding.*

according to a national survey of transgender adults, 28 percent of respondents reported postponing or not seeking care when sick or injured and 33 percent reported postponing or not seeking preventive care out of fear of discrimination or disrespect from providers. Failure to obtain preventative health care screenings out of fear of discrimination can lead to a delay in diagnosing and treating general health issues and to higher rates of hospitalization.[93]

Ensuring Access to Health Programs and Activities

Question 4: ***In the interest of ensuring access to health programs and activities for individuals with limited English proficiency:***

(a) What are examples of recommended or best practice standards for the following topics: (1) Translation services, including thresholds for the translation of documents into non-English languages and the determination of the service area relevant for the application of the thresholds; (2) oral interpretation services, including in-person and telephonic communications, as well as interpretation services provided via telemedicine or telehealth communications; and (3) competence (including certification and skill levels) of oral interpretation and written translation providers and bilingual staff?

(f) What documents used in health programs and activities are particularly important to provide in the primary language of an individual with LEP and why? What factors should we consider in determining whether a document should be translated? Are there common health care forms or health-related documents that lend themselves to shared translations?

(1) Translation Services, including thresholds?

It is particularly important for women with limited English proficiency (LEP) that HHS promulgate robust regulations ensuring access to health care that meets their unique needs. Women with LEP face linguistic, cultural barriers that limit their access to comprehensive health care. As a result of these barriers, women with LEP confront significant challenges accessing culturally and linguistically appropriate care as well as information about accessing services and health insurance. In particular, discussions about sexual and reproductive care can be sensitive and raise issues of privacy and confidentiality. Without adequate interpretation or translation services, women may be forced to seek language assistance from individuals with whom they do not want to share sensitive health information—such as their child. It is

[93] *See, e.g.*, A.B. Bindman, K. Grumback, D. Osmond, et al., *Preventable Hospitalization and Access to Care*, 274 Journal of the American Medical Association 305 (1995).

therefore essential that that information about and access to sexual and reproductive health care is made available is a culturally and linguistically competent manner.

Best practice standards for translation services, oral interpretation services, and competence of oral interpretation and written translation providers and bilingual staff, are found in the enhanced National Standards for Culturally and Linguistically Appropriate Services ("CLAS") in Health and Health Care ("enhanced National CLAS Standards")[94] and HHS' Guidance to Federal Financial Assistance Recipients Regarding Title VI Prohibition Against National Origin Discrimination Affecting LEP Persons ("HHS LEP Guidance"). [95] We also offer additional recommendations below.

Current HHS LEP Guidance employs a four-factor balancing test to determine the "mix" of language assistance services that should be provided.[96] This "mix" of services should distinguish when oral interpreter and written translation services are required. Oral interpreter services should not be subject to the four-factor test but rather be available "on demand" and free of charge. In all circumstances when information cannot be translated into multiple languages, taglines should be used to notify limited English proficient individuals that information is available to be interpreted in their primary language.

Thresholds

Translation services should be subject to thresholds that operate as mandatory minimum requirements rather than "safe harbors.[97] We strongly recommend HHS adopt new policy

[94] Office of Minority Health, U.S. Dep't of Health & Human Servs., *National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care: A Blueprint for Advancing and Sustaining CLAS Policy and Practice* (2013).

[95] Office of Civil Rights, U.S. Dept. of Health and Human Services, Guidance to Federal Financial Assistance Recipients Regarding Title VI Prohibition Against National Origin Discrimination Affecting Limited English Proficient Persons, 69 Fed. Reg. 47,311 (Aug. 8, 2003) [hereinafter HHS LEP Guidance].

[96] HHS LEP Guidance, 68 Fed. Reg. at 47,314–15 ("(1) The number or proportion of LEP persons eligible to be served or likely to be encountered by the program or grantee; (2) the frequency with which LEP individuals come in contact with the program; (3) the nature and importance of the program, activity, or service provided by the program to people's lives; and (4) the resources available to the grantee/recipient and costs.").

[97] Thresholds, as currently used in HHS LEP Guidance, are part of safe harbors which provide "strong evidence of compliance with the recipient's written-translation obligations" and "a guide

setting forth that the failure to translate documents when languages meet the percentage or numeric threshold is evidence of non-compliance with Title VI. Documents should be translated for each language group that makes up 5% or 500 persons, whichever is less, of the population of persons eligible to be served or likely to be affected by the program or recipient in a service area. This percentage and numeric threshold is in already employed in other federal agency policy guidance, with some programs and agencies employing even lower thresholds.[98] HHS LEP Guidance currently uses a 5% and 1,000 person "safe harbor" threshold,[99] which leaves out millions of limited English proficient individuals. When applying the 500 threshold to service areas measured by counties, **1324 counties** in the United States have populations of 500 or more limited English proficient individuals speaking at least one single language, as compared to only **987 counties** with populations of 1,000 or more limited English proficient individuals.[100] A 5% and 500-numeric threshold better ensures that the intent and statutory requirements to provide linguistically appropriate services will be met.

Service Areas

Service areas relevant for the application of thresholds should be program-specific, encompassing the geographic area where persons **eligible to be served or likely to be directly or significantly affected** by the recipient's program are located. Service areas should be approved by HHS. Where no service area has previously been approved, a recipient itself may self-identify the service area, subject to showing that the service area does not discriminatorily exclude certain populations. As discussed in the HHS LEP Guidance, recipients should determine their service areas based on their actual experiences with LEP encounters as well as demographic data on the languages spoken by those who are not proficient in English.[101] HHS should consider equipping recipients with data driven maps that show estimates of eligible individuals with LEP for each service area as well as their approximate location.

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for recipients that would like greater certainty of compliance than can be provided by a fact-intensive, four-factor analysis." HHS LEP Guidance, 68 Fed. Reg. at 47,319.

[98] U.S. Dep't of Labor, Style and Format of Summary Plan Description, 29 C.F.R. § 2520.102-2(c)(2) (2012); Supplemental Nutrition Assistance Program (SNAP), 7 C.F.R. § 272.4(b)(2)(i); U.S. Housing and Urban Development, Final Guidance to Receiving Federal Assistance Recipients Regarding Title VI Prohibition Against National Origin Discrimination Affecting Limited English Proficient Persons, 72 Fed. Reg. 2732, at 2753.

[99] HHS LEP Guidance, 68 Fed. Reg. at 47,319.

[100] Migration Policy Institute analysis of American Community Survey Data, 2007–2011 (on file with Asian Americans Advancing Justice | AAJC). It is noted that some language populations not comprising of 1,000 LEP individuals may still comprise 5% of the population.

[101] HHS LEP Guidance, 68 Fed. Reg. at 47,314.

(2) *oral interpretation services, including in-person and telephonic communications, as well as interpretation services provided via telemedicine or telehealth communications?*

Oral interpretation services should be available in the Health Insurance Marketplaces to help individuals enroll in health plans, during patient-physician clinical encounters, and in consumer assistance services associated with the ACA's programs and activities. The availability of oral interpretation services should be displayed by all health programs and activities in as many languages as possible.

Services by Trained Interpreters and Funding of Interpretation Services

The correlation between oral interpretation by trained professional interpreters and improved access to quality of care is well-documented.[102] The number and kinds of interpretation service are shaped by the way the medical service itself is managed and delivered. Best practices for funding interpretation services should **disincentivize** the use of bilingual staff that is untrained in medical terminology and interpretation.

(3) *competence (including certification and skill levels) of oral interpretation and written translation providers and bilingual staff?*

Competence of Oral Interpretation Providers and Bilingual Staff

Best practices for ensuring competent oral interpretation may be taken from the leading certification entity for health care interpreters, the Certification Commission for Healthcare Interpreters (CCHI).[103] CCHI and the National Board of Certification for Medical

[102] For example, patients with LEP who are provided with such interpreters make more outpatient visits, receive and fill more prescriptions, and report a high level of satisfaction with their care. Additionally, these patients do not differ from their English proficient counterparts in test costs or receipt of intravenous hydration and have outcomes among those with diabetes that are superior or comparable to those of English proficient patients. Truda S. Bell et al., *Interventions to Improve Uptake of Breast Screening in Inner City Cardiff General Practices with Ethnic Minority Lists*, 4 Ethnic Health 277 (1999); Thomas M. Tocher & Eric Larson, *Quality of Diabetes Care for Non-English-Speaking Patients: A Comparative Study*, 168 WESTERN J. OF MEDICINE 504 (1998); David Kuo & Mark J. Fagan, *Satisfaction with Methods of Spanish Interpretation in an Ambulatory Care Clinic*, 14 J. of General Internal Medicine 547 (1999); L.R. Marcos, *Effects of Interpreters on the Evaluation of Psychopathology in Non-English-Speaking Patients*,136 American J. of Psychiatry 171 (1979).

[103] Certification Commission for Healthcare Interpreters, http://www.healthcareinterpretercertification.org.

Interpreters,[104] another certification entity, both use standards established by the National Council on Interpreting in Health Care.[105] Additional guidance and best practices are provided in Standards 5 and 7 of the enhanced National CLAS Standards,[106] as well as the HHS LEP Guidance.

We also emphasize the importance of **cultural competency** to address ethnic and national origin discrimination. Standard 1 of the enhanced National CLAS Standards explains how providing "effective, equitable, understandable, and respectful quality care and services" requires incorporating cultural health beliefs into the delivery of medical care. Language assistance services are more effective when delivered within cultural context, since communities have different perceptions of health, wellness, illness, disease, and health care.[107] This is especially important for LGBTQ communities as well.

One Latina from Brownsville, Texas, told our field staff that language impacts access to help for urgent care. Another Latina, also from Brownsville, Texas, commented that, "In this area, there were no satisfactory healthcare providers at her clinic."

Competence of Written Translation Providers and Bilingual Staff

Best practices for ensuring competent written translation may be taken from Standards 5 and 7 of the enhanced National CLAS Standards and the HHS LEP Guidance.

HHS should not encourage the use of less-skilled translators to translate non-vital documents. Because all documents provided by providers and program administrators tend to have some consequence on the perceptions and actions of people who receive them, it is important to

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[104] The National Board of Certification for Medical Interpreters, *Certified Medical Interpreter Candidate Handbook 2013–2014*, https://www.certifiedmedicalinterpreters.org/sites/default/files/national-board-candidate-handbook-2013.pdf (last accessed Sept. 17, 2013).

[105] National Council on Interpreting in Health Care, *National Standards of Practice for Interpreters in Health Care*, http://www.ncihc.org/assets/documents/NCIHC%20National%20Standards%20of%20Practice.pdf.

[106] Office of Minority Health, U.S. Dep't of Health & Human Servs., *National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care: A Blueprint for Advancing and Sustaining CLAS Policy and Practice* (2013).

[107] Lisa C. Ikemoto, *Symposium: Racial Disparities in Health Care and Cultural Competency*, 48 ST. LOUIS L.J. 75, 86 (2003).

ensure that individuals do not receive erroneous information about available services. We echo HHS' acknowledgment that "[t]he permanent nature of written translations . . . imposes additional responsibility on the recipient to take reasonable steps to determine that the quality and accuracy of the translations permit meaningful access by LEP persons."[108]

(f) Health Care Forms and Related Documents that Should be Translated?

In addition to the "vital documents" listed by LEP.gov and the HHS LEP Guidance,[109] outreach, education, and enrollment materials used by health plans and other entities in the new Health Insurance Marketplaces are important to provide in the primary language of an individual with LEP. In particular, HHS should address the current translation shortcomings of the single streamlined application. As a document that is required to obtain health insurance through the Health Insurance Marketplaces and other programs, this application falls squarely within the definition of a vital document.[110] It is the initial entry point to apply for health insurance and a vital component of the ACA's "no wrong door" approach to enrollment. Based on the current number of translated languages present in other federal programs, we recommend the single streamlined application to be translated in full into at least 15 of the most commonly spoken non-English languages.[111] While we appreciate the Centers for Medicaid and Medicare

[108] HHS LEP Guidance, 68 Fed. Reg. at 47,317.
[109] LEP.gov, Frequently Asked Questions, Question 9, http://www.lep.gov/faqs/faqs.html (last accessed Sept. 19, 2013); HHS LEP Guidance, 68 Fed. Reg. at 47,319.
[110] "Vital documents" have been defined as documents that are "critical for obtaining federal services and/or benefits" and "may depend upon the importance of the program, information, encounter or service involved, and the consequence to the LEP person if the information is not provided accurately or in a timely manner." LEP.gov, Frequently Asked Questions, http://www.lep.gov/faqs/faqs.html (last accessed Sept. 16, 2013); HHS LEP Guidance, 68 Fed. Reg. at 47,318. Vital documents include materials that raise "[a]wareness of rights or services" such that where a recipient is engaged in community outreach activities, it should regularly assess the needs of the populations frequently encountered or affected by the program or activity to determine whether certain critical outreach materials may be the most useful to translate." HHS LEP Guidance, 68 Fed. Reg. at 47,318.
[111] The Social Security Administration, through its Multilanguage Gateway, translates many of its documents into 15 languages. See Multilanguage Gateway, U.S. Social Security Administration (Oct. 2012), http://www.ssa.gov/multilanguage/. Additionally, the Centers for Medicare and Medicaid Services translates Medicare forms, including notices, into 15 languages in addition to Spanish. *See CMS Strategic Language Access Plan (LAP)*, Centers for Medicare and Medicaid Services (2010), http://www.cms.gov/About-CMS/AgencyInformation/EEOInfo/downloads/AnnualLanguageAccessAssessmentOutcomeReport.pdf.

Services' current efforts to create translated application "job aids" in 34 languages, we believe the single streamlined application must be operational as a form that can be completed by limited English proficient consumers and processed by the agency.

We understand the balance of interests at play in the current definition of "vital documents" and, to this end, support the inclusion of in-language "taglines" in at least 15 languages when vital documents cannot be translated. Taglines are a low-cost way to inform enrollees of the availability of language services.

Furthermore, In discussions of costs and benefits, we caution against using these factors as dispositive of when federally funded entities must—or are recommended to—provide language assistance services pursuant to Title VI. As OCR has reiterated from the Department of Justice's LEP Guidance, Title VI policies advance the longstanding principle that "federally assisted programs aimed at the American public do not leave some behind simply because they face challenges communicating in English."[112] Cost-benefit analyses fail to evaluate how professional and industry culture contribute to racial disparities in health care.[113]

***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?*

Section 1557 bars discrimination "on the ground prohibited under . . . title IX of the Education Amendments of 1972," which is sex.[114] It is the first federal law to broadly prohibit sex discrimination in health care. Any interpretation of what it means to discriminate "on the ground prohibited under" should be informed by the regulations and case law that interpret the

[112] Guidance to Federal Financial Assistance Recipients Regarding Title VI Prohibition Against National Origin Discrimination Affecting Limited English Proficient Persons, 67 Fed. Reg. 41,455, at 41,45; HHS LEP Guidance, 68 Fed. Reg. at 47,312.
[113] Lisa C. Ikemoto, *Symposium: Racial Disparities in Health Care and Cultural Competency*, 48 ST. LOUIS L.J. 75, 119 (2003).
[114] 20 U.S.C. § 1681(a) (2012).

listed statutes. In addition, Section 1557 may not be misinterpreted to narrow existing interpretations of and protections against sex discrimination.

It is critical that regulations issued pursuant to this new statute reflect the long-established jurisprudence of strong protections against sex discrimination in federal law. Regulations, guidance, and case law under Title VII of the Civil Rights Act of 1964, the Pregnancy Discrimination Act (PDA), and Title IX of the Education Amendments of 1972 should inform what constitutes sex discrimination in health care under Section 1557. More specifically:

Section 1557's prohibition of sex discrimination necessarily includes discrimination based on pregnancy, gender identity, and sex stereotypes—as the RFI rightly notes. [115]

Pregnancy discrimination constitutes sex discrimination under Title IX[116] and other civil rights statutes such as Title VII[117] and thus also constitutes sex discrimination under Section 1557. These laws prohibit discrimination based on pregnancy itself, as well as pregnancy-related conditions.[118] Section 1557 regulations should expressly recognize this basic principle.

Discrimination on the basis of actual or potential parental, family or marital status also violates Section 1557 if this behavior treats women and men differently or is based on sex stereotypes. Title IX's prohibition on sex discrimination encompasses these grounds.[119] Title IX further prohibits actions based on head of household or principal wage earner status.[120] Section 1557 regulations should likewise prohibit discrimination on these bases.

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[115] Dep't of Health & Human Servs., Request for Information Regarding Nondiscrimination in Certain Health Programs or Activities,78 Fed. Reg. 46,558, 46,559 (proposed Aug. 1, 2013) ("Sex discrimination (including discrimination on the basis of gender identity, sex stereotyping, or pregnancy)").

[116] 34 C.F.R. § 106.40(b)(1) (2012). *See also Pfeiffer v. Marion Ctr. Area Sch. Dist.*, 917 F.2d 779, 784 (3d Cir. 1990); *Hogan v. Ogden*, No. CV-06-5078-EFS, 2008 U.S. Dist. LEXIS 58359, at *26 (E.D. Wash. July 30, 2008); *Chipman v. Grant County Sch. Dist.*, 30 F. Supp. 2d 975, 977-78 (E.D. Ky. 1998); *Hall v. Lee Coll.*, 932 F. Supp. 1027, 1033 n.1 (E.D. Tenn. 1996); *Cazares v. Barber*, Case No. CIV-90-0128-TUC-ACM, slip op. (D. Ariz. May 31, 1990); *Wort v. Vierling*, Case No. 82-3169, slip op. (C.D. Ill. Sept. 4, 1984), *aff'd*, 778 F.2d 1233 (7th Cir. 1985).

[117] 42 U.S.C. § 2000e(k) (2012). *See also* 29 C.F.R. pt. 1604 app.; *Newport News Shipbuilding & Dry Dock v. EEOC*, 462 U.S. 669 (1983).

[118] *See, e.g.*, 42 USC § 2000e(k) (2012).

[119] *E.g.* 34 C.F.R. § 106.40(a) (2012); 34 C.F.R. § 106.57(a).

[120] *E.g.* 34 C.F.R. § 106.57(a) (2012).

Further, Title IX has consistently been interpreted to bar discrimination based on sex stereotyping—including discrimination based on the assumption that someone conforms to a sex stereotype and discrimination against an individual because he or she departs from a sex stereotype—and Section 1557 must be understood to ban such discrimination.[121] Similarly, the E.E.O.C. has also concluded that discrimination based on gender identity or transgender status is a form of sex discrimination under Title VII,[122] as has the Department of Housing and Urban Development with regard to the Fair Housing Act.[123] Indeed, HHS has already recognized the importance of addressing discrimination against LGBT people in health care when it included explicit prohibitions against sex, gender identity, and sexual orientation discrimination in final rules for health insurance Exchanges, QHPs, and the EHB.[124]

The only exceptions to Section 1557's broad nondiscrimination mandate are specifically and explicitly contained in Title I of the ACA. The Section 1557 ban against discrimination in health programs includes a single exception – that it applies "[e]xcept as otherwise provided" in

[121] *See* Dep't of Educ., Office of Civil Rights, *Revised Sexual Harassment Guidance: Harassment of Students by School Employees, Other Students, or Third Parties: Title IX* (January 19, 2001), *available at* http://www2.ed.gov/ about/offices/list/ocr/docs/shguide.html; Dep't of Educ., "Dear Colleague," 7-8 (October 26, 2010), *available at* http://www2.ed.gov/about/offices/list/ocr/letters/ colleague-201010_pg8.html.. *See also Price Waterhouse v. Hopkins*, 490 U.S. 228 (1989); *Lewis v. Heartland Inns of America, L.L.C.*, 591 F.3d 1033 (8th Cir. 2010); *Bibby v. Phila Coca Cola Bottling Co.*, 260 F.3d 257, 2652-63 (3rd Cir. 2001); *Smith v. City of Salem*, 378 F.3d 566 (6th Cir. 2004). *See also Doe v. Brimfield Grade School*, 552 F. Supp. 2d 816, 823 (C.D. Ill. 2008); *Theno v. Tonganoxi Unified School District*, 377 F. Supp. 3d 952 (D. Kansas 2005); *Schroeder v. Maumee Bd. Of Educ.*, 296 F. Supp. 2d 869, 880 (N.D. Ohio 2003); *Montgomery v. Indep. Sch. Dist. No.* 709, 109 F. Supp. 2d 1081, 1090-91 (D. Minn. 2000).

[122] *Macy v. Holder*, E.E.O.C. Appeal No. 0120120821, *7 (Apr. 23, 2012) (interpreting Title VII's prohibition against sex discrimination to include discrimination based on a person's transgender status).

[123] Memorandum from John Trasviña to FHEO Regional Directors, *Assessing Complaints that Involve Sexual Orientation, Gender Identity, and Gender Expression* (June 2010), *available at* http://www.fairhousingnc.org/wp-content/uploads/2012/03/HUD-Memo-re-Sexual-Orientation-Discrimination-6-15-2010.pdf (announcing that the Department would treat "gender identity discrimination most often faced by transgender persons as gender discrimination under the Fair Housing Act").

[124] *See, e.g.*, 45 C.F.R. §§ 155.120(c) (nondiscrimination rule for Exchanges); 156.200(e) (for QHPs); Health Insurance Market Rules; Rate Review, 78 Fed. Reg. 13,406, 13,438 (Feb. 27, 2013) (to be codified at 45 C.F.R. § 147.104(e)) (for marketing and benefit design); Standards Related to Essential Health Benefits, Actuarial Value, and Accreditation, 78 Fed. Reg. 12,834, 12,867 (Feb. 25, 2013) (to be codified at 45 C.F.R. § 156.125) (for the EHB).

Title I of the ACA.[125] Thus, the only exceptions to Section 1557 are those expressly stated in that title. The plain language of the statute bars any interpretation that would suggest any other exceptions apply. In fact, exceptions to general rules like Section 1557's antidiscrimination provision must be read strictly and narrowly. Courts have strictly construed such exceptions to give the fullest force to the primary operation of the general rule.[126] Indeed, in considering "[e]xcept as otherwise provided" language in the Americans with Disabilities Act (ADA), the Eleventh Circuit limited the exceptions to only those expressly mentioned in the statute.[127] The same principles apply here.

Nothing in Section 1557, its language or legislative history, allows for any other limitations or exceptions regarding its application. Question 5 of the RFI notes that Title IX[128] contains limited exceptions to its protection in certain circumstances. These exceptions, however, are not incorporated into Section 1557. First, because those limited exceptions are not explicitly stated in Section 1557, they cannot be read to apply to it. Second, Section 1557, does not import any exceptions from Title IX. Section 1557 references Title IX solely for the ground on which it prohibits discrimination, which is sex.[129]

Sex-specific health programs or activities do not violate Section 1557 when they are necessary to accomplish an essential health purpose. Because the RFI specifically asks how Section 1557 should apply to health programs and activities that serve only one sex, NLIRH addresses that issue here. Like Title IX and other civil rights laws, the circumstances under

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[125] Patient Protection and Affordable Care Act § 1557, codified at 42 U.S.C. § 18116 (2012).
[126] *Nussle v. Willette*, 224 F.3d 95, 99 (2d Cir. 2000) (quoting *Commissioner v. Clark*, 489 U.S. 726, 739 (1989), *overruled on other grounds by Porter v. Nussle*, 534 U.S. 516 (2002)). *See also New York v. Bloomberg*, 524 F.3d 384, 402 (2d Cir. 2008). *See also Detroit Edison Co. V. SEC*, 119 F.2d 730, 739 (6th Cir. 1941) (holding that "[e]xceptions in statutes must be strictly construed and limited to objects fairly within their terms, since they are intended to restrain or except that which would otherwise be within the scope of the general language.")
[127] *See McNely v. Ocala Star-Banner Corp.*, 99 F.3d 1068, 1074 (11th Cir. 1996) (limiting language of "except as otherwise provided" precluded the ADA from importing more restrictive language from the Rehabilitation Act).
[128] 20 U.S.C. § 1681(a)(1)-(9) (2012).
[129] As is discussed in more depth in response to Question (7), the Supreme Court held in similar context that the incorporation by reference of protections from one civil rights statute into another does not mean that the limitations of the first apply to the second. *See Consolidated Rail Corp. v. Darrone*, 465 U.S. 624 (1984) (holding that Section 504's reference to Title VI's remedies, procedures, and rights did not import limitations from Title VI not expressly provided in Section 504).

which sex-specific programs and activities are permissible and thus nondiscriminatory must be narrow. Consistent with Section 1557's broad nondiscrimination purpose, sex-specific health programs or activities should be permissible under Section 1557 when they are necessary to serve the disadvantaged sex—most usually women—or to comply with constitutionally protected rights to privacy. At heart, single-sex programs must be narrowly tailored and **necessary to accomplish an essential health purpose**. Further, Section 1557's protection against sex discrimination still applies in single-sex environments. So, where sex-specific programs or activities exist, they must be nondiscriminatory for each sex.

To the extent that Section 1557 makes narrow allowances for single-sex programs or activities, participation in these programs is determined by an individual's self-identified gender. As noted above, Section 1557 protects against gender identity discrimination, which means that the law protects an individual's ability to live in his or her community **as** a man or a woman.[130] So too, Section 1557 protects an individual's access to health programs and activities in accordance with their self-identified gender and free from sex stereotypes.

Compliance and Enforcement Approaches

Question 7: ***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 set of administrative procedures 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 of these laws, parties also may file private litigation in federal court, subject to some restrictions.***

(a) How effective have these different processes been in addressing discrimination? What are ways in which we could strengthen these enforcement processes?

(b) The regulations that implement Section 504, Title IX, and the Age Act also require that covered entities conduct a self-evaluation of their compliance with the regulation. What experience, if any, do you have with self-evaluations? What are the benefits and burdens of conducting them?

(c) What lessons or experiences may be gleaned from complaint and grievance procedures already in place at many hospitals, clinics, and other covered entities?

[130] *See, e.g.*, *Macy v. Holder*, E.E.O.C. Appeal No. 0120120821 (Apr. 23, 2012) (employer violated Title VII when job offer revoked because plaintiff sought to work as a woman); *Schroer v. Billington*, 577 F. Supp. 2d 293 (D.C.C. 2008) (same).

It is critical that OCR create and administer a strong enforcement system for this new statute. Section 1557 specifically references the enforcement mechanisms "provided for" and "available under" Title VI, Title IX, Section 504, and the Age Act. Therefore, the regulations adopted for Section 1557 must reflect the entire wide range of equitable relief and enforcement mechanisms established and available under the statutes, including agency enforcement as well as the private right of action for monetary damages.[131] And, although HHS has primary oversight over Section 1557, the Department of Justice (DOJ) has coordinating responsibility pursuant to Executive Order 12250.[132] In addition, each agency must have implementing regulations for Section 1557.

It is essential that Section 1557 regulations recognize both discriminatory intent and disparate impact claims. Disparate impact claims are allowed under the civil rights statutes referenced by Section 1557.[133] Section 1557 thus imports this important antidiscrimination principle. The disparate impact standard is crucial for smoking out discrimination in an era in which discrimination takes ever more subtle forms—as documented in the examples described throughout these comments—and is often hidden in the very structures of our society. Section 1557 regulations should protect against disparate impact discrimination in the strongest possible terms.

Section 1557 provides for a private right of action. Because the statutes listed in Section 1557 contain a private right of action for a full range of relief, including equitable relief and monetary damages, Section 1557 does as well.[134] While agency enforcement is critical to securing the

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[131] Some of these enforcement mechanisms are expressly or implicitly provided for in statutory text. Others are established by the implementing regulations (e.g., administrative complaints, agency compliance reviews, and formal investigations).

[132] Exec. Order No. 12,250, 3 C.F.R. 298 (1980).

[133] Dep't of Justice, *Title VI Legal Manual* (2001), *available at* http://www.justice.gov/crt/about/cor/coord/vimanual.php#B (stating that Title VI regulations "may validly prohibit practices having a disparate impact on protected groups, even if the actions or practices are not intentionally discriminatory." (citing *Guardians Ass'n v. Civil Serv. Comm'n*, 463 U.S. 582, 582 (1983) and *Alexander v. Choate*, 469 U.S. 287, 293 (1985); Dep't of Justice, *Title IX Legal Manual* (2001), *available at* http://www.justice.gov/crt/about/cor/coord/ixlegal.php#2 (stating "[i]n furtherance of [Congress'] broad delegation of authority [to implement Title IX's prohibition of sex discrimination], federal agencies have uniformly implemented Title IX in a manner that incorporates and applies the disparate impact theory of discrimination." (citing cases).

[134] In *Cannon v. University of Chicago*, the Supreme Court emphasized the importance of the private right of action to enforcing antidiscrimination statutes. 441 U.S. 677, 704-05 (1979). The Court later determined that money damages are available for intentional discrimination, relying on the

protections provided under Section 1557, a private right of action is also crucial for ensuring individuals the robust protection Section 1557 affords them. As the Supreme Court articulated in *Cannon v. University of Chicago*, a private right of action is essential to achieving Congress' intent "to provide individual citizens effective protection against [discriminatory] practices."[135] Section 1557's explicit language thus requires that Section 1557 include a private right of action and it is important that OCR acknowledge this avenue for relief.

Section 1557 provides for the full range of agency enforcement and Department of Justice enforcement in court. Title VI, Title IX, Section 504, and the Age Discrimination Act expressly provide for a similar administrative enforcement scheme. Each statute provides for the availability of periodic compliance reviews and establishes procedures for processing and investigating administrative complaints. Under each statute, an agency may terminate or refuse to grant or continue assistance to a recipient.[136] Agencies may also refer to the DOJ for enforcement in court. In addition, agencies enforce disparate impact obligations through any of the available enforcement procedures.[137] Section 1557, too, includes this full range of enforcement mechanisms.

Limitations on agency or individual enforcement from the Age Discrimination Act should not apply to claims under Section 1557. Section 1557 does not incorporate the Age Discrimination Act's ("the Age Act") two procedural requirements–mediation and exhaustion of administrative remedies–that differ from those in Title IX, Title IX and Section 504. A plain reading of Section 1557 makes clear that it cannot be interpreted to include these limitations simply because one of the four laws it references does. Title VI, Title IX and the Rehabilitation

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longstanding principle that all remedies are presumed to be available to accompany a federal right of action "unless Congress has expressly indicated otherwise." *Franklin v. Gwinnett County Public Schs.*, 503 U.S. 60, 66 (1992). There, the Court stated "Congress surely did not intend for federal monies to be expended to support the intentional actions it sought by statute to proscribe." *Id.* at 74. *See also Guardians Assn. v. Civil Service Comm'n of New York City*, 463 U.S. 582 (1983) (damages available under Title VI for intentional violations); *Consolidated Rail Corporation v. Darrone*, 465 U.S. 624 (1984) (awarding backpay for violation of Section 504 of Rehabilitation Act).

[135] 441 U.S. at 704-05.

[136] *See, e.g.*, 29 C.F.R. § 31.8(b) (2012).

[137] *See, e.g.*, Dep't of Justice, *Title VI Legal Manual* (2001), *available at* http://www.justice.gov/crt/about/cor/coord/vimanual.php#B (discussing disparate impact obligations under Title VI); Dep't of Justice, *Title IX Legal Manual* (2001), *available at* http://www.justice.gov/crt/about/cor/coord /ixlegal.php#2 (discussing disparate impact obligations under Title IX).

Act require neither mandatory mediation nor an exhaustion of claims.[138] Thus, to interpret Section 1557 as including the limitations under the Age Act would either mean that enforcement mechanisms available under Section 1557 pursuant to the other three statutes are limited in a way that the drafters did not express or that Section 1557 is internally inconsistent and that some of its enforcement mechanisms are limited and some are not. Neither of these readings can be correct. Moreover, Supreme Court precedent supports reading Section 1557 as not importing the limitations of the Age Act.[139] Any other interpretation would conflict with Section 1557's language and broad remedial goals.

Enforcement procedures provided under the laws referenced by Section 1557 are a starting point for developing procedures under Section 1557. Like investigations under other civil rights laws, Section 1557 investigations must be fair, efficient, and prompt. A 2012 report by the Department of Education's Office of Civil Rights demonstrates its efforts to investigate and resolve complaints in a range of areas under its jurisdiction.[140] The report highlights OCR's interest in and the importance of resolving complaints promptly and in proactively addressing complaints of discrimination.[141] HHS-OCR's own case resolution manual, too, emphasizes the importance of fair, efficient, and prompt investigations and resolutions.[142] These priorities are

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[138] *See, e.g.*, *Neighborhood Action Coalition v. City of Canton*, 882 F.2d 1012, 1015 (6th Cir. 1989) (Title VI); *Cannon*, 441 U.S. at 706 n.41 (Title IX); *Gean v. Hattaway*, 330 F.3d 758, 775 (6th Cir. 2003) (Rehabilitation Act).

[139] Importantly, the Supreme Court has held that when one of the Spending Clause antidiscrimination statutes references the enforcement provisions of another, it adopts its enforcement mechanisms but not its limitations. For example, Section 504 expressly makes available to victims of discrimination the "remedies, procedures, and rights set forth in Title VI." 29 U.S.C. § 794a(a)(2) (2012). In *Consolidated Rail Corp. v. Darrone*, the Court considered whether the Section 504 reference to Title VI limited the Rehabilitation Act's broad application. 465 U.S. 624 (1984). Although the Court held that the Rehabilitation Act's reference to the remedies, procedures, and rights set forth in Title VI allowed for enforcement similar to Title VI, it did not import limitations from Title VI not expressly provided in the Rehabilitation Act. 465 U.S. at 635 (1984). In so doing, the Court emphasized the broad purpose behind the Rehabilitation Act to support its conclusion that a limitation contrary to that broad purpose (that was not expressly set forth in the statute) should not be read into the statute. *Id.* at 632 n.13.

[140] Dep't of Educ., Office for Civ. Rts., *Title IX Enforcement Highlights* (June 2012), *available at* http://www2.ed.gov/documents/press-releases/title-ix-enforcement.pdf

[141] *Id.* at 2, 4-12.

[142] Dep't of Health & Human Servs., Office for Civ. Rts., *Case Resolution Manual for Civil Rights Investigations*, 1, 30 (2009), *available at*

especially important in the health care area. Delaying investigations of alleged discrimination in the health care area can have serious physical, emotional, and financial consequences for individuals seeking care or health coverage. OCR must not exacerbate harm by allowing complaints to remain unresolved.

Section 1557 provides for individual, class, and third party complaints. Title IX, Title VI, Section 504, and the Age Act provide for individual, class, and third party complaints. Because Section 1557 incorporates the enforcement mechanisms in those statutes, it too must be interpreted to provide for complaints brought on behalf of an individual, a class, or by a third party. Each of these vehicles for agency enforcement is crucial and a hallmark of civil rights enforcement under the laws Section 1557 references. The ability to file an administrative complaint can make it easier for victims of discrimination to seek a resolution of their claim than going to court, which can be more costly and more public than administrative complaints.

Class complaints and third party complaints also allow OCR to resolve systemic problems of discrimination. They are particularly important in the health care area because of the consequences of allowing system-wide patterns of discrimination to continue. Individual victims of discrimination may be hesitant to file complaints themselves because, for example, they fear retaliation from individuals or entities on which they rely for health care or insurance coverage. This creates a strong disincentive for some to file complaints and reinforces the importance of class and third party complaints.

Moreover, because Section 1557, like the civil rights statutes to which it refers, prevents federal funds from being used to finance discrimination all complaint mechanisms are crucial to ensuring that the government neither operates its programs in a discriminatory manner nor fosters discrimination by providing federal funds to discriminatory entities.

It is essential that OCR conduct Section 1557 compliance reviews of covered entities and provide technical assistance regarding compliance with Section 1557. Section 1557 is a powerful proactive tool in OCR's work to combat discrimination in health care. OCR's authority is not limited to responding to complaints under Section 1557. It can—and should—also address discriminatory policies and practices at covered entities through technical assistance, systemic investigations, and compliance reviews of selected entities. OCR already

http://www.hhs.gov/ocr/civilrights/complaints/crm2009.pdf.

conducts these reviews pursuant to its authority under other civil rights laws[143] as do other agencies.[144]

Because Section 1557 is a new law, it is especially important that OCR complete compliance reviews to both identify discrimination and set precedents under this new law. Without knowledge of Section 1557's protection or how to file a complaint, individuals remain vulnerable to discrimination in health care settings and covered entities may well continue discriminatory practices.[145] The results of any compliance reviews should also be made public. The reports from such reviews can serve as guidance for other covered entities as to what it means to comply with Section 1557.

OCR must establish procedures for enforcement against discrimination by programs or activities administered by an executive agency and by entities established under Title I of the ACA. Section 1557 protects individuals from being excluded from participation in, being denied the benefits of, or being subjected to discrimination under any program or activity administered by an executive Agency. Section 504's protections apply to programs or activities conducted by executive agencies and HHS has adopted regulations outlining procedures for enforcing nondiscrimination protections in these programs.[146] Other federal agencies have adopted their own regulations to govern the programs and activities they administer. HHS should use these as a starting point for developing Section 1557 procedures. DOJ should also use its coordinating authority to ensure that federal agencies administer their programs and activities in compliance with the nondiscrimination protections of Section 1557.

Section 1557 also applies to entities established under Title I of the ACA. Most notably, this includes the health insurance Marketplaces. It is critical that these new entities establish robust and clear standards for compliance with Section 1557. This includes training individuals that

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[143] *See, e.g.*, Dep't of Health & Human Servs., Office for Civ. Rts., *Compliance Review Initiative: Advancing Effective Communication in Critical Access Hospitals* (Apr. 2013), *available at* http://www.hhs.gov/ocr/civilrights/activities/agreements/compliancereview_initiative.pdf

[144] For example, agencies including the Department of Justice, the Office of Federal Contract Compliance Programs (OFCCP), the Department of Housing and Urban Development, and the Department of Education, among others, regularly conduct compliance reviews.

[145] For instance, staff for the California Health and Human Services Agency, which oversees California's Medicaid program, indicated a lack of complaints to the agency on language access issues in 2011 and 2012. Linda Bennett interview with Amanda Ream, Organizing Director, Interpreting for California (August 2013). The absence of complaints, however, is not an indication that discrimination does not exist; to the contrary, it suggests that individuals may not know their rights or about the complaint process.

[146] 45 C.F.R. pt. 85 (2012).

operate Marketplaces and those performing consumer assistance, about the requirements of Section 1557. In addition, consumer assisters should also be able to inform consumers who believe they have been subjected to discrimination where they can file a complaint.

Self-evaluations by covered entities can be useful to ensuring compliance with Section 1557. Section 1557 regulations should require covered entities to complete self-evaluations.[147] A self-evaluation aims to identify discriminatory policies or practices and prompt a covered entity to correct those noncompliant policies or practices. Because Section 1557 applies to newly-created entities and expands the application of existing antidiscrimination protections, self-evaluations may be particularly useful. Covered entities should be required to review their current policies and practices for compliance with Section 1557 and modify any policies or practices that do not meet its requirements. Further, covered entities should take the appropriate remedial steps to eliminate the effects of discrimination that resulted or may have resulted from adherence to those policies and practices. Self-evaluations should remain on file with the covered entity and available for review by OCR or other interested parties.

Compliance procedures at covered entities should be made widely available and be fair, efficient, and prompt. The communities protected by Section 1557 will also require education as to their rights and the enforcement mechanisms available to them under the statute and implementing regulations. Previous experience dictates that those who have gone without nondiscrimination protections previously may be uncertain regarding their rights when these protections are introduced. Therefore, when promulgating rules regarding enforcement processes and mechanisms for Section 1557, HHS should craft effective measures to encourage minorities, including the Latino/a community and LGBTQ Latino/a community, to seek out resources that are created to assist them. HHS must proactively (1) educate communities about new protections, (2) require information about Section 1557 patient rights to be posted in health care facilities, (3) provide clear information, resources, and assistance for people to file complaints, and (4) provide training for health administrators, legal professionals, and Marketplace consumer assistance entities about new duties under Section 1557.
Also, we recommend that OCR increase its outreach and education efforts regarding the right of limited English proficient individuals to have meaningful access to health programs and activities, with an emphasis on how to file a complaint with OCR. As to OCR's Online Complaint Portal, we recommend that HHS provide limited English proficient individuals the same ease of access in filing a complaint as it provides English speakers by updating its

[147] Title IX and Section 504 regulations require covered entities to complete self-evaluations to evaluate their policies and practices—and their effects—to determine if they are complying with the law. 34 C.F.R § 106.3(c) (2012) (Title IX); 45 C.F.R. § 84.6(c) (Section 504). The Age Act states that covered entities employing 15 or more employees may be required to complete a self-evaluation as part of a compliance review or complaint investigation. 45 C.F.R. § 91.33 (2012).

Complaint Portal to include more commonly spoken languages by limited English proficient individuals. Similarly, we strongly recommend that HHS use an automated telephone system for OCR's call center that adds voice prompts in multiple languages. Voice prompts should be added, at the very least, for the seven non-English languages in which OCR has translated its webpages.

In addition, we recommend that HHS strengthen Title VI enforcement processes. To strengthen HHS' current practice to encourage voluntary compliance with Title VI obligations, we recommend that HHS adopt a policy setting forth clearer guidance as to the reasonable time when intermediate steps should be taken and when full access to limited English proficient individuals should be achieved. Clearer time frames will promote speedier compliance by recipients and institutions serving limited English proficient populations. Similarly, we recommend that HHS provide clearer guidance as to when investigations should be initiated once a complaint is received, as well as when a case should be closed. This will ensure that the administrative complaint procedure is effectively administered as to avoid a complaint backlog. We also recommend that HHS adopt a policy that favors a private remedy under Section 1557. Individual causes of actions, along with the range of enforcement mechanisms available through HHS and the Department of Justice, are necessary to effectuate Congress's intent to prevent discrimination in access to health care.

Furthermore, we note that the complaint procedures under Title VI are also applicable to mixed-status families. As the Tri-Agency Guidance noted: "To the extent that states' application requirements and processes have the effect of deterring eligible applicants and recipients who live in immigrant families from enjoying equal participation in and access to those benefit programs based on their national origin, states inadvertently may be violating Title VI."[148] The enforcement mechanisms under Title VI may be used to prohibit applications requiring personally identifiable information from non-applicants, such as Social Security numbers or proof of citizenship or immigration status, that deter ineligible immigrants from applying on behalf of eligible family members. As discussed above, effect-based discrimination is also prohibited, such as creating onerous requirements for navigators that discourage participation of organizations serving immigrant communities and onerous documentation requirements for proving eligibility.

We encourage OCR to clarify in Section 1557 regulations that it has the authority to enforce provisions set forth in the Tri-Agency Guidance. Promulgated rules on Section 1557

[148] Dept. Health and Human Services and Department of Agriculture, Policy Guidelines Regarding Inquiries into Citizenship, Immigration Status and Social Security Numbers in State Application for Medicaid, State Children's Insurance Program (SCHIP), Temporary Assistance for Needy Families (TANF), and Food Stamp Benefits.

should expressly provide that household members *not* applying for coverage for themselves are subject to the following rules and protections:

- They are *not* required to provide their citizenship or immigration status as part of the application process;
- They are *not* required to provide a Social Security number if they do not have one;
- They *must* be provided appropriate notice explaining why a Social Security number is requested and what it will be used for; and
- *Only* information strictly necessary for determining an applicant's eligibility may be collected, used or shared with other entities, and not for any other purposes.

Affected individuals and community-based groups should be encouraged to file complaints, including on behalf of individuals or classes of individuals who may be afraid to identify themselves. In addition, implementing regulations should allow and promote OCR's ability to provide its own outreach and proactive implementation of Section 1557 instead of relying only on a complaint system. Because limited English proficient individuals and members of mixed-status families who lack clear information or fear immigration enforcement may be reluctant to put their name on a complaint, informal information gathering in targeted areas would help ensure that mixed-status families are not subject to discriminatory rules.

Conclusion

In conclusion, we commend OCR for taking the important step of issuing this RFI and urge OCR to move forward with the rulemaking necessary to implement this crucial new civil rights protection. It is critical that OCR administers this new law through robust implementation and enforcement mechanisms, and this must be reflected in the final regulations that OCR promulgates. This is essential if Section 1557's guarantee of protection from discrimination in health care is to be fulfilled and the statute's mandate reflected.

We believe Section 1557 has the potential to improve the health and lives of Latinas and LGBT Latinos/as, including the health of their families and communities if rigorously implemented.

If you have any questions regarding our comments, please contact Candace Gibson at 202-621-1435 or at Candace@latinainstitute.org.

Thank you for your time and consideration.

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BEFORE THE UNITED STATES DEPARTMENT OF
HEALTH AND HUMAN SERVICES
OFFICE FOR CIVIL RIGHTS

Request for Information Regarding Nondiscrimination in Certain Health Programs or Activities	))	RIN 0945–ZA01

RESPONSE OF WHITMAN-WALKER HEALTH TO REQUEST FOR INFORMATION ON REGULATIONS TO IMPLEMENT THE NONDISCRIMINATION REQUIRMENTS IN SECTION 1557 OF THE AFFORDABLE CARE ACT

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Pursuant to the Request for Information (RFI) issued by the Department of Health and Human Services Office for Civil Rights (OCR) on August 1, 2013, 78 Fed. Reg. 46,560, Whitman-Walker Clinic, Inc., d/b/a Whitman-Walker Health (WWH or Whitman-Walker), hereby submits these comments in response to the questions posed in the RFI.

EXPERTISE AND INTEREST OF WHITMAN-WALKER HEALTH

Whitman-Walker Health is a community-based, nonprofit clinic offering primary medical care and HIV specialty care, mental health and addiction treatment services, dental care, medical adherence case management, and legal services to residents of the greater Washington metropolitan area. WWH has a special mission to the lesbian, gay, bisexual and transgender (LGBT) members of the community, and to all Washington-area residents with HIV regardless of race, gender or sexual orientation. At its two sites – the Elizabeth Taylor Medical Center in Northwest and Max Robinson Center in Southeast – WWH is the medical home for approximately 20% of DC residents diagnosed with HIV. In calendar year, 2012, WWH provided health services to more than 13,600 unique persons. Approximately 6,000 of those individuals are our medical patients – WWH is their medical home.

Whitman-Walker's Legal Services Program was established in 1986 to provide *pro bono* legal assistance to people living with HIV on matters related to their diagnosis. In more recent years our work has expanded to include legal counsel and representation to LGBT individuals and families in the Washington, DC metropolitan area. Over the past 27 years, Whitman-Walker Legal Services has

provided *pro bono* assistance to tens of thousands of individuals and families on a wide range of issues including: access to health care (Medicaid, Medicare, AIDS Drug Assistance programs, private and employer-sponsored health insurance, and DC, Maryland and Virginia programs); HIV and LGBT discrimination in health care, employment and public accommodations; disability income options for those too sick to work; immigration; wills, advance healthcare directives and powers of attorney; and medical privacy. We also assist transgender individuals with name and gender marker changes in their identity documents and other legal records, and with discrimination in employment and in health insurance. In the most recent 12 months our legal staff and volunteers assisted 2,770 new clients on 3,662 new legal matters. This fall, we have launched a new initiative to address the specific legal needs of LGBT seniors and seniors living with HIV.

WWH Legal Services has been very involved in the implementation of the Affordable Care Act in the District of Columbia. Since 2007 our Public Benefits Unit, which has been recognized as a model for other DC community health clinics, has screened all uninsured WWH patients for public medical program eligibility, including Medicaid, DC Healthcare Alliance and the AIDS Drug Assistance Program; enrolled eligible clients; and assisted with timely recertification to avoid any lapse in coverage. That unit has now been expanded to a Public Benefits and Insurance Navigation Unit, and additional staff have been hired, to help uninsured and under-insured DC residents understand their options under the new DC Health Benefit Exchange Authority. Whitman-Walker Legal Services was selected by the DC Health Benefit Exchange to provide the training for all of the new In-Person Assisters in the District.

Whitman-Walker's patient populations, and our legal clients, reflect the diversity of the Washington, DC metropolitan area, and our special commitment to the LGBT and HIV-affected communities. Of the more than 13,600 persons receiving health services in 2012, 47% of those who reported their sexual orientation identified as gay, lesbian or bisexual; 5% identified as transgender,

27% as female and 68% as male; 47% identified as black and 38% as white; 13% identified their ethnicity as Hispanic; and 47% were HIV-positive. In Legal Services, approximately 50% identified as gay, lesbian or bisexual; 10% identified as transgender, 25% as female and 65% as male; 55% identified as black and 21% as white; 18% listed their ethnicity as Hispanic; and almost 70% were living with HIV or AIDS.

As one of the oldest medical-legal partnerships in the country, WWH has substantial experience with the interrelationships between health care and the law. For many years, Whitman-Walker medical and mental health providers, and lawyers, have worked with persons living with HIV/AIDS and with the LGBT community, which continue to experience barriers to adequate health care due to under-insurance and discrimination, and which suffer continuing health disparities. We welcome this opportunity to provide information to OCR to assist in the formulation of regulations to fully implement the promise of Section 1557 the Patient Protection and Affordable Care Act (ACA), 42 U.S.C. § 18116(a).

SUMMARY OF COMMENTS

1. LGBT discrimination in health care and Section 1557's prohibition of sex discrimination. Widespread discrimination against LGBT individuals by health care providers and institutions of every kind has been documented in national surveys. Whitman-Walker providers and attorneys hear reports of such discrimination regularly. Health insurance companies and employer-sponsored health plans also discriminate against LGBT persons in two ways: by restricting and often completely excluding coverage of health care related to gender transitioning, and, in some instances, by denying enrollment to the same-sex spouses of plan members. (Response to Question 1.) This discrimination harms the health of LGBT individuals, and the public health, in direct and indirect ways. It directly harms persons who are in need of health care by depriving them of that care. The danger of encountering discrimination discourages many LGBT individuals from seeking health care

when they need it. It also exacerbates health inequalities in our society. LGBT people are at risk for a number of diseases and other health challenges. In order to address these risks, LGBT individuals should receive regular health care, fully disclose their sexual activities and gender identities to their health care providers, and (like everyone) involve their partners in their health care. But they often cannot do so, and even more often believe they cannot do so, because of the threat of discrimination. (Response to Question 3.)

The Department should issue regulations that expressly state that discrimination against LGBT persons by any provider or entity subject to Section 1557 is prohibited sex discrimination. This includes denial of equal visitation rights to the same-sex partners of patients in covered hospitals and residents in covered skilled nursing facilities. With regard to covered health insurance plans, the regulations should make clear that unlawful sex discrimination includes discriminatory restrictions on coverage of any medically-supported treatment or procedure related to gender transitioning, including but not limited to hormone therapy, mental health counseling, and any surgical procedure related to gender reassignment. (Response to Question 2.)

The prohibition of discrimination "on the basis of sex" in Title IX of the Education Amendments of 1972, incorporated into Section 1557 of the ACA, is sufficiently broad to encompass any discriminatory treatment of LGBT persons by health care providers or entities and by covered health insurers. Title IX, and Title VII of the Civil Rights Act of 1964, which prohibits discrimination "because of sex," have been interpreted by the courts and the federal agencies with authority to administer them, as encompassing discrimination based on an individual's failure to adhere to gender stereotypes. As further interpreted by the Equal Employment Opportunity Commission in Title VII cases, this includes discrimination against gay, lesbian or bisexual persons based on their failure to conform to the stereotype of heterosexual attraction and partnering. Moreover, discrimination against an individual because of they are a man attracted to or partnered

with another man instead of a woman , or because they are a woman attracted to or partnered with another woman instead of a man, is *per se* discrimination based on sex. And, recent court and EEOC decisions have established that discrimination against transgender persons is sex discrimination. (Response to Question 5.)

2. Ensuring access to health care for persons with limited English proficiency. Whitman-Walker agrees that health care providers and centers should prioritize efforts to ensure that their services are fully accessible to persons with limited English proficiency. Consistent with Department guidelines, Whitman-Walker's Language Access Plan (which we have included as an Appendix to these Comments) balances the needs of our patient population with our operational constraints to provide translation of vital documents into the major languages spoken by our patients, together with staff or contract interpreters for less prevalent languages. (Response to Question 4.)

3. Information technology and access to health care. Advances in health information technology hold great promise for improving the quality and containing the cost of health care, by enhancing communications between a patient's providers across health systems and facilities, and communications between providers and patients. The Department can assist health care providers by issuing regulations that provide detailed guidance on the appropriate balance between a patient's access to his or her health information, and privacy protections. In addition, it would be helpful for the Department to address significant limitations in existing electronic information systems create barriers for patients with limited English proficiency and patients who are transgender or otherwise gender nonconforming. (Response to Question 6.)

4. Ensuring compliance with Section 1557's requirements. With regard to ensuring compliance with the nondiscrimination requirements of Section 1557, the Department's regulations should provide for well-staffed and well-funded, vigorous administrative enforcement process. In

addition, the regulations should acknowledge that aggrieved persons have a private right of action under 1557 – which the Supreme Court has held applies to Title IX and to Section 504 of the Rehabilitation Act. (Response to Question 7.)

RESPONSES TO SPECIFIC QUESTIONS IN THE REQUEST FOR INFORMATION

HHS/OCR QUESTION 1. The Department is interested in experiences with, and examples of, discrimination in health programs and activities. 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.

Discrimination Against LGBT Persons

The experiences of WWH, as well as other research in the field, indicate that LGBT individuals and families experience widespread, serious discrimination from health care providers and institutions, and in the health insurance industry. This widespread discrimination has made many LGBT people understandably reluctant to seek medical care – acute as well as preventative – and also discourages them from disclosing their sexual orientation and sexual activity, and their gender identity, when they do seek care. Denials of care, provision of discriminatory, suboptimal care, and the resulting disincentive to seek care, harm not only specific LGBT individuals, but the public health. They exacerbate systemic health disparities that afflict the LGBT community – disparities that, as the Department has noted, "largely relate to oppression and discrimination." U.S. DEP'T OF HEALTH & HUMAN SERVS., *Lesbian, Gay, Bisexual, and Transgender Health*, HEALTHY PEOPLE (Apr. 10, 2013), http://www.healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=25.

Discrimination by health care providers and institutions. Discrimination against lesbian, gay and bisexual individuals by physicians, nurses and other health care professionals, in doctors' offices, clinics, hospitals, urgent care centers, nursing homes and other facilities, is well

documented. A national survey by Lambda Legal Defense and Education Fund of 4,916 LGBT individuals and persons living with HIV across the Nation found that 56% of lesbian, gay, and bisexual respondents, as well as 70% of transgender and gender nonconforming respondents, had personally been discriminated against in a health care setting. LAMBDA LEGAL, WHEN HEALTH CARE ISN'T CARING 5 (2010), *available at* http://www.lambdalegal.org/publications/when-health-care-isnt-caring. This discrimination included a wide range of unequal treatment, including providers refusing to touch patients using standard procedures, being physically rough or abusive, and using harsh language, including blaming LGBT patients for creating their own health problems. *Id.* The study further found that 8% of lesbian, gay, and bisexual respondents reported that they had been denied services outright, while the same was true of 27% of transgender and gender nonconforming persons. *Id.*

Transgender people face especially harsh discrimination in the health care field. A report from the National Center for Transgender Equality and National Gay and Lesbian Task Force found that among transgender and gender nonconforming persons, 24% of the 6,450 individuals surveyed were denied equal treatment in accessing health care, 25% were harassed or disrespected, and 2% were physically assaulted in health care settings. NAT'L CTR. FOR TRANSGENDER EQUALITY & NAT'L GAY & LESBIAN TASK FORCE, INJUSTICE AT EVERY TURN 5 (2011), *available at* http://www.thetaskforce.org/reports_and_research/ntds. Furthermore, 20% of transgender men and 24% of transgender women had been outright refused care. *Id.* "Prejudice against transgendered individuals is pervasive within American medicine. Most U.S. medical providers and researchers, as well as the public at large, believe that transgendered behavior is pathological. This in itself constitutes one of the most significant barriers to care." Laura Dean et al., *Lesbian, Gay, Bisexual, and Transgender Health: Findings and Concerns,* 4 J. OF THE GAY & LESBIAN MED. ASS'N 3, 127 (2000) (*citation omitted*).

Elderly LGBT people are especially likely to experience discrimination in long-term care settings. In a survey conducted by the National Senior Citizens Law Center in collaboration with a number of other national advocacy groups,[1] 769 individuals connected with nursing homes and other long-term care facilities (including both LGBT and non-LGBT seniors, family members, and elder care providers) were asked if they had witnessed someone being discriminated against because of their sexual orientation or attractions or their gender identity. NAT'L SENIOR CITIZENS LAW CTR., LGBT OLDER ADULTS IN LONG-TERM CARE FACILITIES: STORIES FROM THE FIELD 8 (2011), *available at* http://www.nsclc.org/index.php/lgbt-older-adults-in-long-term-care-facilities-stories-from-the-field/. Remarkably, 43% responded that they had experienced or witnessed such discrimination. *Id.* These 328 respondents reported 200 instances of verbal or physical harassment from other nursing home residents, 169 cases of refused admission or attempted or abrupt discharge, 116 verbal or physical harassment from staff, 97 refusals to accept power of attorney from a spouse or partner, 93 restrictions on visitors, 80 refusals to refer to a preferred name or gender-based pronoun, 51 refusals to provide basic care, and 47 outright denials of medical treatment. *Id.*

Our experience at Whitman-Walker Health is consistent with these national reports. WWH health care providers and attorneys hear stories of discrimination on a regular basis. Recent examples include the following:

- "Marsha," a transgender woman who sought post-surgical care from a gynecologist, was treated roughly and then told by the doctor, "I don't know what to do with people like you." She has not been back to a doctor since that incident, which occurred more than a year ago.

[1] The National Gay and Lesbian Task Force, Services and Advocacy for GLBT Elders, Lambda Legal, the National Center for Lesbian Rights and the National Center for Transgender Equality.

- "Kay," an elderly lesbian woman, learned that her partner, "Ida," had been sent by her home nurse to a to a DC hospital after a fall. Kay called the hospital repeatedly to find out when Ida, who has dementia, would be released. The hospital eventually said it no longer recognized the power of attorney giving Kay decision-making authority for Ida. As a result, Kay lost all contact with Ida. The hospital opted to listen to Ida's estranged, homophobic nephew, who prevented Ida from returning home.
- "Jaime," a transgender man who had been on hormones for several years, called a local gynecologist to try to schedule a pap smear and exam and was told that they only see women at the practice. Jaime identified himself as transgender and explained that he needed a gynecological exam because he still had female reproductive organs. The staff person with whom Jaime was speaking said that the office would get back to him. They never did.
- "Edward," a gay man, went to the emergency room of a local hospital after having an accident with a sex toy involving his rectum. The ER physician chastised him for his "weird" behavior, lectured him about his "unhealthy choice of lifestyle," and treated him with hostility.
- Lesbian and gay patients at an inpatient psychiatric treatment center were repeatedly harassed by nurses and other staff members, who expressed their moral and religious disapproval of homosexuality. Some of the patients were told that they were being "prayed for." This exacerbated the acute distress of patients being treated for serious depression, anxiety and other mental health disorders, and for addiction issues.
- "Rosa," a transgender woman, was told by her new doctor that she was not welcome at her practice because her lifestyle was not compatible with the doctor's moral beliefs.
- "Jerry" and "Frank" have been living together for five years and are engaged to be married. Jerry has also executed an advance health care directive naming Jerry as his agent. Jerry has

multiple health problems, and one evening Frank took him to the ER of a DC hospital when Jerry was suffering from severe, prolonged vomiting, diarrhea, and dangerously high blood pressure. Jerry was admitted to a room on the Medical-Surgical Unit, but the unit was understaffed and Jerry was neglected by the nursing and physician staff for some hours – leaving Frank to help him to the bathroom repeatedly and to clean up after him. After repeated complaints by Frank, the attending physician and the House Supervisor came to Jerry's room. The House Supervisor demanded to know who Jerry was. When Jerry said, "I am his fiancée," the House Supervisor replied, "Then you are not a real family member and you have to leave." When Frank refused, with Jerry's support, security officers were called and Frank was forcibly escorted out of the hospital, leaving Jerry alone in severe physical and emotional distress.

- "Tom," a transgender man, went to a mental health provider who claimed to specialize in transgender health but who had never met a transgender person before. She asked Tom many inappropriate questions and refused to believe that Tom had been born a woman. Finally, she told Tom that it would be best if he gave up his transition, and refused to assist Tom in seeking out hormone therapy, thus delaying Tom's treatment.
- On a separate occasion, after an emergency developed following his mastectomy, "Ed" was refused treatment in an emergency room because the nurse demanded to know, "What are you, a man or a woman or what?" Ed was forced to explain that he was transgender, but the providers continued to refer to him as "she." He was given antibiotics that did not work, and had to be hospitalized twice more at another facility before finally receiving the right medication to address his infection.
- "Dana," a transgender woman, went to an urgent care center because she had begun to experience shortness of breath, fatigue, and lightheadedness after a recent breast

augmentation surgery. The provider on duty said that he was "not an expert" on transgender care and after determining that her lungs were fine, simply prescribed Dana with ibuprofen and valium. Dana was not told that valium is used as an anti-anxiety medication and was not warned about its side effects. Two weeks later, she went to another doctor who immediately took her off valium and put her on a muscle relaxer that was appropriate for her needs. Dana was greatly disturbed that she had been put on medication without being informed of its side effects.

Discrimination by health insurers. In addition to being discriminated against while receiving or attempting to receive health care, LGBT people also face discrimination in obtaining health insurance. The Department has noted that "legal discrimination in access to health insurance" is a major barrier to care for LGBT people. U.S. DEP'T OF HEALTH & HUMAN SERVS., *Lesbian, Gay, Bisexual, and Transgender Health, supra* page 8.

Whitman-Walker lawyers have encountered many recent examples of discrimination by health insurance plans and companies. For instance:

- "Cindy" works in Maryland for a company with offices in several states and headquarters in South Carolina. She and her long-time partner, "Hannah", were married in DC in 2011. Cindy then added Hannah to her employer's health insurance plan, which provides for coverage of and employee's "spouse" and "dependents". The plan initially enrolled Hannah. In 2012, however, the plan dropped Hannah from coverage. Cindy's employer informed her that the health insurance plan was governed by the laws of South Carolina, and that South Carolina law does not recognize same-sex marriages. Hannah was left without health insurance to cover a pending surgery.
- "Jessica" works in DC for a company headquartered in North Carolina. She and "Mary" were married in DC in 2012. When Jessica sought to enroll Mary in the company health

plan, which covers "spouses" without further definition, she was informed by letter that the company policy was to recognize only "legitimate" – in other words, different-sex – marriages. Jessica's application to enroll her wife was denied, and Jessica was forced to rely on more expensive coverage that provided significantly lower benefits.

- "Stanley," a transgender man, has a health insurance policy that excludes payment for anything related, directly or indirectly, to altering one's gender appearance. As a result, he has been forced to pay for almost everything out-of-pocket – even his yearly physical exam.
- "Paula," a transgender woman, also has a health insurance policy with an exclusion clause for all transgender-related care. She has so far spent $65,000 on care related to her gender identity, with two more surgeries coming up. When Paula informed her employer that she was conferring with Whitman-Walker lawyers, the employer reimbursed her for the cost of her recent surgery, but so far has refused to amend the health plan.
- "Jeff" is enrolled in an employer-sponsored Flexible Health Spending Plan, in which a portion of his earnings are set aside from him to use for health-related costs not covered by the company's health insurance. Because the health insurance plan excludes coverage of anything "related to sex reassignment," Jeff paid for his surgery out of pocket and then sought reimbursement from his Flexible Spending Account. The Flexible Spending Plan denied his application, claiming that the procedure was "cosmetic," until Whitman-Walker staff attorneys intervened and threatened a lawsuit.
- "Mark", a transgender man, applied for health insurance through a local broker. The policy was medically underwritten, and Mark's application was rejected because, according to the insurance company, he was on gender-reassignment-related hormone therapy that cost several hundred dollars a year.

Restrictions on and exclusions of health care needed in connection with gender transition are rooted in prejudice and historical misunderstanding, including the notion that such procedures are "cosmetic" rather than well-founded medically, and the misconception that coverage of such care would be very expensive. In fact, recent studies have revealed that inclusion of gender transition-related care in health plans has resulted in minimal increases in overall costs. JODY L. HERMAN, THE WILLIAMS INSTITUTE, COSTS AND BENEFITS OF PROVIDING TRANSITION-RELATED HEALTH CARE COVERAGE IN EMPLOYEE BENEFIT PLANS (Sept. 2013), *available at* http://williamsinstitute.law.ucla.edu/wp-content/uploads/Herman-Cost-Benefit-of-Trans-Health-Benefits-Sept-2013.pdf.

As discussed in more detail in response to Question 3, below, LGBT discrimination in health care and health insurance has harmful effects far beyond the harm to individuals who are denied the care they need in specific situations. Fear of discrimination discourages many LGBT people from seeking health care and from fully disclosing their sexual orientation and activity and gender identity when they do seek care. This harms the public health as well as the health of individuals, by exacerbating the health disparities between the LGBT community and the general population.

Discrimination Against Persons Living With HIV

Although Whitman-Walker has not, in the past several years, seen HIV discrimination in health care to the extent that we did previously, discrimination still occurs, particularly, in our experience, by dentists, weight loss clinics and pain management clinics. For instance:

- "Mario" and "Carla" are a married couple, both of whom are living with HIV. They are both obese and have a number of obesity-related health problems in addition to HIV. They were referred to a weight loss clinic in a neighboring county. They went to the clinic for an initial consultation and assessment. In the initial interview Mario disclosed

that both he and his wife were HIV-positive. The employee conducting the interview informed him that the clinic's policy was not to accept persons with HIV as patients, and terminated the interview. Mario challenged this action and subsequently called the clinic to speak to a doctor or administrator. His call was never returned.

HHS/OCR 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?

As described in our answer to the preceding question, LGBT persons experience discrimination from virtually every type of health care provider and in virtually every type of health care setting, including private physician offices, private and public health clinics, urgent care center, hospitals, home health care, skilled nursing facilities and therapist offices. Restrictions on transgender-related care, including outright exclusions, are widespread in every type of health insurance plan. Therefore, we urge the Department to issue regulations that provide for the maximum coverage consistent with the broad language of Section 1557.

With regard to covered health insurance plans, the regulations should make clear that unlawful sex discrimination includes discriminatory restrictions on coverage of any medically-supported treatment or procedure related to gender transitioning, including but not limited to hormone therapy, mental health counseling, and any surgical procedure related to gender reassignment. As noted in our response to Question 1, restrictions on medical care needed by transgender individuals is based on misconceptions about cost and simple prejudice. Health insurers and employers that have abandoned traditional exclusions and restrictions have experienced very small, if any, cost increases. HERMAN, COSTS AND BENEFITS OF PROVIDING TRANSITION-RELATED HEALTH CARE COVERAGE, *supra* page 15.

The regulations should also clearly state that unlawful sex discrimination includes any discriminatory failure of covered hospitals, other critical care facilities, rehabilitation facilities, and

skilled nursing facilities to provide full visitation rights to the same-sex partners of patients and residents. The Department previously has issued other regulations and guidance documents to emphasize the visitation rights of the partners of hospital patients[2] and nursing home residents.[3] Clarification in the Department's regulations under ACA Section 1557 that denial of equal visitation rights to same-sex partners of patients and residents is prohibited sex discrimination would substantially strengthen the rights of patients and residents and send an even stronger message to health care providers and facilities.

HHS/OCR 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.

Fear of discrimination discourages many LGBT people from seeking health care and from fully disclosing their sexual orientation and activity and gender identity when they do seek care. Widespread reports of discrimination against LGBT people seeking care have created a culture of fear in which many LGBT people either do not seek care or do not disclose important information to their providers to avoid being adversely treated. Lambda Legal's recent survey found that 29% of lesbian, gay, and bisexual persons believed that they would receive adverse treatment if they disclosed their LGBT status, while 9% thought they would be completely denied medical care. For transgender and gender nonconforming persons, those numbers were 52% and 73%, respectively. LAMBDA LEGAL, WHEN HEALTH CARE ISN'T CARING, *supra* page 9, at 12. "As a result of [general anti-transgender] prejudice, transgendered individuals underutilize medical and social services."

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[2] Changes to the Hospital and Critical Access Hospital Conditions of Participation To Ensure Visitation Rights for All Patients, 75 Fed. Reg. 70,831 (2010) (amending 42 C.F.R. §§ 482.13 & 485.635).

[3] DEP'T OF HEALTH & HUMAN SERVS., CTRS. FOR MEDICARE & MEDICAID SERVS., REMINDER: ACCESS AND VISITATION RIGHTS IN LONG TERM CARE (LTC) FACILITIES, Ref: S&C: 13-42-NH (June 28, 2013) *available at* http://www.hrc.org/files/assets/resources/CMS_Access_and_Visitation_Rights_Guidance.pdf.

Dean, *Lesbian, Gay, Bisexual, and Transgender Health, supra* page 9, at 127. The National Center for Transgender Equality and National Gay and Lesbian Task Force found that 28% of transgender and gender nonconforming people had postponed seeking care because they feared discrimination, and 33% delayed or simply refused to seek preventative care due to similar concerns. NAT'L CTR. FOR TRANSGENDER EQUALITY & NAT'L GAY & LESBIAN TASK FORCE, INJUSTICE AT EVERY TURN, *supra* page 9, at 84. Transgender men, in particular, were reluctant to seek out necessary care (42%) and preventative care (48%). *Id.* 54% of respondents had not disclosed to all or most of their doctors that they were transgender. *Id.* at 75.

Similarly, according to the recent survey by the National Senior Citizens Law Center and others of LGBT experiences with long-term care, 78% of LGBT elders feared for their safety if they were to disclose their LGBT status to the staff at the nursing home in which they lived. NAT'L SENIOR CITIZENS LAW CTR., STORIES FROM THE FIELD, *supra* page 10, at 6.

These fears extend to mental health treatment as well. Mental health providers at Whitman-Walker Health are currently unable to meet the demand for counseling or care being sought by the LGBT community, and frequently receive calls from prospective patients who are afraid to seek care elsewhere due to their fears of homo- or transphobic attitudes.

When LGBT persons avoid seeking health care, it is not only those individuals and their families who are harmed; the public health itself suffers. As HHS has acknowledged, "LGBT individuals face health disparities linked to societal stigma, discrimination, and denial of their human rights." U.S. DEP'T OF HEALTH & HUMAN SERVS., *Lesbian, Gay, Bisexual, and Transgender Health, supra* page 8. "Members of the LGBT community are at increased risk for a number of health threats" and that some "are associated with social and structural inequalities, such as the stigma and discrimination that LGBT populations experience." U.S. CTRS. FOR DISEASE CONTROL & PREVENTION, *About LGBT Health*, http://www.cdc.gov/lgbthealth/about.htm. Discrimination

against LGBT people by health care providers and institutions, and health insurers, exacerbates those disparities.

Because of the multiple stressors in their lives resulting directly or indirectly from stigmatization and discrimination, the LGBT individuals and families treated by Whitman-Walker medical and mental health providers are at greater risk than the general population for smoking, alcohol and drug abuse, eating disorders (among young gay men), obesity (among lesbians), depression and other mental health disorders, suicide, and anti-gay or anti-trans violence. Moreover, gay and bisexual men, due to sexual practices and the greater prevalence of sexually transmitted pathogens in that relatively small population, are at greater risk of HIV and other sexually transmitted infections, and of anal cancers. Studies indicate that lesbian and bisexual women are at greater risk of breast and cervical cancer than the female population in general. These risk factors and the resulting health inequities have been noted by the Department and by other medical authorities. *E.g.,* U.S. DEP'T OF HEALTH & HUMAN SERVS., *Lesbian, Gay, Bisexual, and Transgender Health, supra* page 8; Dean, *Lesbian, Gay, Bisexual, and Transgender Health, supra* page 9, at 111-25, 128-32; INSTITUTE OF HEALTH OF THE NATIONAL ACADEMIES, THE HEALTH OF LESBIAN, GAY, BISEXUAL, AND TRANSGENDER PEOPLE: BUILDING A FOUNDATION FOR BETTER UNDERSTANDING 5-6 (2011), *available at* http://www.iom.edu/Reports/2011/The-Health-of-Lesbian-Gay-Bisexual-and-Transgender-People.aspx; GAY AND LESBIAN MEDICAL ASSOCIATION, TEN THINGS GAY MEN SHOULD DISCUSS WITH THEIR HEALTHCARE PROVIDER 1 (2010), *available at* http://www.glma.org/_data/n_0001/resources/live/top%2010%20forGayMen.pdf; KAISER PERMANENTE, A PROVIDER'S HANDBOOK ON CULTURALLY COMPETENT CARE 30-38 (2004), *available at* http://kphci.org/downloads/KP.PHandbook.LGBT.2nd.2004.pdf; FENWAY INSTITUTE, HEALTH PROMOTION AND DISEASE PREVENTION 7 (2009), *available at* http://www.lgbthealtheducation.org/training/learning-modules.

The National Center for Transgender Equality and National Gay and Lesbian Task Force's recent report on the health and welfare of the transgender community found major disparities in transgender health compared to the rest of the population. As just one example, with 2.64% of transgender and gender nonconforming people reporting themselves as HIV-positive, the HIV prevalence rate among this population was four times that of the national average of 0.6% – without taking into account the 8% of transgender respondents to the study who did not know their HIV status. NAT'L CTR. FOR TRANSGENDER EQUALITY & NAT'L GAY & LESBIAN TASK FORCE, INJUSTICE AT EVERY TURN, *supra* page 9, at 80. 24.9% of transgender African Americans were HIV-positive, and a staggering 61% of transgender people who had at some point performed sex work had been diagnosed with HIV. *Id.* CDC has estimated that 27.7% of transgender women tested positive for HIV when averaging different studies that have been recently conducted. U.S. CTRS. FOR DISEASE CONTROL & PREVENTION, *HIV Among Transgender People* (APR. 23, 2013), http://www.cdc.gov/hiv/risk/transgender/index.html. They have found that the problem is mostly among transgender women; for example, transgender women rather than transgender men comprised 95% of new HIV diagnoses in New York City from 2005 to 2009. *Id.*

LGBT people face different health risks than the population as a whole. They need to seek regular medical care, and they need to be able to safely disclose their sexual orientation and activities and gender identity to their medical providers. If they cannot do so, it is impossible for them to be properly screened and given the care that they need – which in turn means that the health disparities suffered by this population will only continue or even increase.

LGBT health experts recommend that all patients be asked, in a confidential, respectful manner, about their sexual partners and the gender(s) of their sexual partners, and about the patient's own gender identity, on intake forms and during the initial medical history taken by the provider, and that patients be asked about their recent sexual partners and activities at every visit.

E.g., FENWAY INSTITUTE, KNOWING YOUR PATIENTS: TAKING A HISTORY AND PROVIDING RISK REDUCTION COUNSELING 3, 12 (2009), *available at* http://www.lgbthealtheducation.org/training/learning-modules; HUMAN RIGHTS CAMPAIGN, HEALTHCARE EQUALITY INDEX 2013 31 (2013), available at http://www.hrc.org/hei/about-the-healthcare-equality-index#.UkXl91bD9Hi (encouraging medical providers to enable their patients to identify as LGBT and share information about their sexual partners). Lesbians and bisexual women should be screened regularly for breast and cervical cancer. FENWAY INSTITUTE, HEALTH PROMOTION AND DISEASE PREVENTION, *supra* page 19, at 26-27. Gay and bisexual men who are sexually active should be screened regularly for sexually transmitted infections, *id.* at 54-55, should consider anal pap smears every 1-3 years, *id.* at 28, and should be educated about safer sex practices and about pre- and post-exposure prophylaxis to reduce the risk of becoming infected with HIV, FENWAY INSTITUTE, KNOWING YOUR PATIENTS, *supra* page 20, at 26-27. Of course, LGBT patients can only safely disclose their sexual orientation and activities, and their gender identity, if they are protected against discrimination by strong, well-publicized laws.

Moreover, just like patients in heterosexual marriages and other relationships, LGBT individuals frequently would benefit from involving their spouses and partners in discussions with their health care providers and as active participants in their treatments. KAISER PERMANENTE, A PROVIDER'S HANDBOOK ON CULTURALLY COMPETENT CARE, *supra* page 19, at 13-14. Because of fear of discrimination, however, many LGBT people avoid bringing their same-sex partners to their medical appointments, and even avoid disclosing to their providers that they have a partner. *Cf.* INSTITUTE OF HEALTH, THE HEALTH OF LESBIAN, GAY, BISEXUAL, AND TRANSGENDER PEOPLE, *supra* page 19, at 63 (noting that many LGBT patients hide that they have a same-sex partner from providers due to fear of discrimination).

Regulations under ACA Section 1557 that clearly state that LGBT discrimination by health care providers and entities, and health insurers, is prohibited sex discrimination, would encourage providers, clinics, hospitals, nursing homes and other health care facilities to train their staffs and to adopt policies and procedures to protect against the risk of discrimination. Such measures, in turn, would encourage LGBT individuals to fully disclose to their providers, and would enhance the provider-patient trust that is essential to optimal health care.

HHS/OCR QUESTION 4. In the interest of ensuring access to health programs and activities for individuals with limited English proficiency (LEP):

(a) What are examples of recommended or best practice standards for the following topics: (1) Translation services, including thresholds for the translation of documents into non-English languages and the determination of the service area relevant for the application of the thresholds; (2) oral interpretation services, including in-person and telephonic communications, as well as interpretation services provided via telemedicine or telehealth communications; and (3) competence (including certification and skill levels) of oral interpretation and written translation providers and bilingual staff?

Best practices for a particular health center will arise out of developing a Language Access Plan. Standards will be different for different types of health care providers and should balance the critical need for interpretation/translation services to LEP individuals with the practical realities of the provider's operations and patient population. Following guidelines issued by the Department, Whitman-Walker takes into account: (1) the number or proportion of LEP persons eligible to be served or likely to be encountered; (2) the frequency with which LEP individuals come in contact with WWH; (3) the nature and importance of the services provided by WWH to the lives of the persons served; and (4) the resources available to WWH.

We believe that it is reasonable for a provider to provide translation of all critical documents into any language spoken by at least 12% of patients. Of course, to the extent reasonably possible, telephonic and in-person interpretation services should be provided for smaller numbers of patients speaking other languages. WWH employs our own staff to provide oral interpretation services

where we have in-house competence; otherwise we rely on the contracted services. In cases where a patient prefers a family member to interpret, rather than using an assigned interpreter, we ensure that the patient's choice is documented in the health record.

(b) What are examples of effective and cost-efficient practices for providing language assistance services, including translation, oral interpretation, and taglines? What cost-benefit data are available on providing language assistance services?

Whitman-Walker relies on competitive bidding, and weighs quality with price whenever we consider using a new service. To the extent possible, we utilize our own staff, or competent volunteers, to translate critical documents.

(c) What are the experiences of individuals seeking access to, or participating in, health programs and activities who have LEP, especially persons who speak less common non-English languages, including languages spoken or understood by American Indians or Alaska Natives?

Our patients' language assistance needs are identified when they register for services. Subsequently, interpreters are ordered for in-person appointments as requested; the interpreters meet those patients in the lobby of the health center prior to their medical visits. Our multi-lingual staff also are available to support visits, for many of the languages spoken by our patients. Finally, telephonic support can be used, including webcam support for American Sign Language, as needed. This high level of access is critical to understand the health care needs of our patients.

(d) What are the experiences of covered entities in providing language assistance services with respect to: (1) Costs of services, (2) cost management, budgeting and planning, (3) current state of language assistance services technology, (4) providing services for individuals who speak less common non-English languages, and (5) barriers covered entities may face based on their types or sizes?

The cost and complexity of these services vary. As with all contracted providers, WWH does extensive market research including assessing the quality and costs of the translation partner on a periodic basis. We prioritize the related expenses, as they are essential to delivering health care. A

drawback is that the costs cannot be contained and so budgeting is typically based on a previous year's experience with a baseline adjustment.

(e) What experiences have you had developing a language access plan? What are the benefits or burdens of developing such a plan?

WWH has an extensive Language Access Plan and related training program. See Attachment A. It was developed as a result of a self-assessment indicating that this was an area that needed improvement. We were supported by another health care provider with special expertise in language access, especially for Spanish-speaking communities, who was funded to initiate this work with health centers by HRSA. We believe that our new system is thorough and well-thought-out – appropriately balancing the needs of the health center with the needs of our patients and our legal requirements. Developing our new Plan required extensive time and staff resources, and the Plan relies on the active participation of staff with the necessary language skills, who for the most part are involved in direct patient care and have many other demands on their time.

(f) What documents used in health programs and activities are particularly important to provide in the primary language of an individual with LEP and why? What factors should we consider in determining whether a document should be translated? Are there common health care forms or health-related documents that lend themselves to shared translations?

WWH defines a "vital documents" needing translation as a document that is essential for the effective and accurate provision of services. Vital documents at WWH include: *registration forms, consent forms, complaint forms, and notices of rights and responsibilities.* The data in these forms is essential for operations of the health center, for ensuring that patients understand that they consent to treatment, and for supporting other aspects of access for the patient. OCR should consider whether the data collected in certain forms is essential for providing services, such as a registration form. In addition, OCR should consider whether the form itself presents as a barrier to accessing care from a culturally appropriate standpoint by not being in languages other than English.

HHS/OCR 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?

Under Section 1557 of the ACA, "an individual shall not, on the ground prohibited under . . . title IX of the Education Amendments of 1972 (20 U.S.C. 1681 *et seq.*), . . . be excluded from participation in, be denied the benefits of, or be subjected to discrimination under, any health program or activity" covered by the Act. 42 U.S.C. § 18116(a) (LEXIS current through PL 113-36, approved Sept. 18, 2013). Title IX, in turn, provides that "[n]o person in the United States shall, *on the basis of sex*, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any education program or activity receiving Federal financial assistance . . . ." 20 U.S.C. § 1681(a) (*emphasis added*). Discrimination "on the basis of sex" encompasses much more than just favoring men over women, or women over men—it includes disparate or adverse treatment on any grounds that rely on sex or gender. To ensure the anti-discrimination objective of Section 1557 is achieved with respect to all people – including LGBT people – the Department should issue regulations that specifically state discrimination on the basis of same-sex attraction and sexual activity, and on the basis of gender identity or expression, constitute discrimination "on the basis of sex," and are thus prohibited by Section 1557.

In construing the prohibitions against sex discrimination in Title IX – and in Title VII of the Civil Rights Act of 1964, which prohibits discrimination "because of … sex" [4] – the courts and the federal agencies charged with interpreting and enforcing these statutes have noted that the statutory

[4] 42 U.S.C. § 2000e-2(a)(1). "Courts have generally assessed Title IX discrimination claims under the same legal analysis as Title VII claims." *Gossett v. Okla. ex rel. Bd. of Regents for Langston Univ.*, 245 F.3d 1172, 1176 (10th Cir. 2001).

language is broad. In drafting the laws prohibiting sex discrimination, Congress did not "enumerate specific discriminatory practices," but instead drafted terms that are "unconstrictive, knowing that constant change is the order of our day and that the seemingly reasonable practices of the present can easily become the injustices of the morrow." *Barnes v. Costle*, 561 F.2d 983, 994 (D.C. Cir. 1977) (*quoting Rogers v. EEOC*, 454 F.2d 234, 238 (5th Cir. 1971)). As a result, the "statutory prohibitions often go beyond the principal evil to cover reasonably comparable evils, and it is ultimately the provisions of our laws rather than the principal concerns of our legislators by which we are governed." *Oncale v. Sundowner Offshore Services*, 523 U.S. 75, 79 (1998) (Scalia, J.) (broadly construing Title VII's prohibition against work place discrimination "because of sex" to encompass male-on-male sexual harassment); *see also Meritor Sav. Bank v. Vinson*, 477 U.S. 57, 67 (1986) (holding that Title VII's bar against discrimination "because of sex" included harassment and other actions creating a gender-based hostile work environment).

Discrimination against LGBT people violates Title IX, and therefore Section 1557 of the ACA, because it constitutes discrimination "on the basis of sex." 20 U.S.C. § 1681(a). Disparate, adverse treatment of a patient or insurance plan member because he or she is attracted to, has sex with, or is in a relationship with a person of the same sex constitutes discrimination "on the basis of sex," since it arises out of the sex of that individual as well as his or her partner. Similarly, discrimination against a patient or health plan member because he or she is transgender is, by its very nature, based on the individual's gender. Consequently, discrimination on the basis of same-sex sexual attraction or activity, or gender identity, irreducibly entails discrimination "on the basis of sex." *Id.*

This kind of discrimination also violates Title IX because it is based on the individual's nonconformity with gender stereotypes. *See, e.g., Pratt v. Indian River Cent. Sch. Dist.*, 803 F. Supp. 2d 135, 151 (N.D.N.Y. 2011) (*citing Price Waterhouse v. Hopkins*, 490 U.S. 228, 251-52 (1989) (holding that

a "sex stereotyping claim . . . legally cognizable under Title VII" is also cognizable under Title IX). For example, discrimination against a transgender patient can arise from the patient's nonconformity to what a health care provider perceives as the patient's "real" sex, i.e., that the patient is a "man acting like a woman," or "trying to look like a woman." Likewise, discrimination based on a patient's attraction to, sex with, or relationship with a member of the same sex can be based on assumptions about prescriptive gender roles, e.g., that a man or woman should have sexual relations only with members of the opposite sex, not with members of the same sex. As a result, the Department of Education Office for Civil Rights has already determined that under Title IX "it can be discrimination on the basis of sex to harass a student on the basis of that victim's failure to conform to stereotyped notions of masculinity and femininity." OFFICE FOR CIVIL RIGHTS, U.S. DEP'T OF EDUC., REVISED SEXUAL HARASSMENT GUIDANCE: HARASSMENT OF STUDENTS BY SCHOOL EMPLOYEES, OTHER STUDENTS, OR THIRD PARTIES (v) (2001), *available at* http://www2.ed.gov/offices/OCR/archives/pdf/shguide.pdf.

A regulation prohibiting sex discrimination under Section 1557 should, therefore, prohibit discrimination based on an individual's sex, including nonconformity with gender stereotypes, and/or being in a same-sex rather than opposite-sex relationship. Impermissible bases for discrimination should include same-sex attraction and/or sexual activity, and gender identity and expression. As documented in the Answer to Question 1 above, discrimination based on sex can occur when, for example, a patient:

- identifies as gay, lesbian, bisexual, or homosexual;
- has changed or plans to change his or her sex, or identifies as a sex other than what the health care provider perceives or accepts;
- acts in a manner inconsistent with a gender stereotype, e.g., appears to the health care provider as too "effeminate" or too "masculine" for the patient's sex, or is otherwise gender-nonconforming in appearance or expression;

- expresses or demonstrates same-sex sexual desire;
- engages in sex with a person of the same sex;
- is in a romantic or sexual relationship with a person of the same sex; or
- is married (or in a civil union, domestic partnership, or similar relationship) with a person of the same sex.

As explained in our response to Question 3, above, gender identity, sexual attraction, and sexual activity are factors highly relevant to a patient's health and treatment. A regulation that expressly states that the ACA prohibits discrimination against gay, lesbian, bisexual, and transgender persons is needed to encourage LGBT people to seek health care, to disclose their sexual history when they do so, to include their same-sex partners in discussions with their health care providers, and to ensure that they receive appropriate treatment.

I. Title VII and Title IX broadly prohibit discrimination based on the sex of the individual, including the individual's nonconformity with a gender stereotype.

In enforcing Title IX claims, courts have incorporated the case law related to claims brought under Title VII of the Civil Rights Act of 1964, which prohibits "discriminate[ion] against any individual with respect to his compensation, terms, conditions, or privileges of employment, *because of such individual's . . . sex*." 42 U.S.C. § 2000e-2(a)(1) (*emphasis added*).[5] For example, in *Davis v. Monroe County Bd. of Educ.*, 526 U.S. 629, 651 (1999) (a Title IX case regarding sex discrimination in school), the Supreme Court applied its holdings in Title VII cases involving workplace harassment, including *Oncale* and *Meritor Savings Bank*. "[M]any . . . circuits have found Title VII cases to provide guidance in evaluating Title IX claims." *Wolfe v. Fayetteville, Ark. Sch. Dist.*, 648 F.3d at 866 n.4.[6]

[5] Though "Title VII requires a plaintiff to prove 'discriminat[ion] . . . because of . . . sex,' 42 U.S.C. § 2000e-2(a)(1), whereas Title IX requires proof of discrimination 'on the basis of sex' . . . these two phrases are treated interchangeably." *Wolfe v. Fayetteville, Ark. Sch. Dist.*, 648 F.3d 860, 866 (8th Cir. 2011) (*citing* 42 U.S.C. § 2000e(k) (providing the same definition for both "because of sex" and "on the basis of sex")).

[6] *Citing Gossett v. Okla. ex rel. Bd. of Regents for Langston Univ.*, 245 F.3d 1172, 1176 (10th Cir. 2001) ("Courts have generally assessed Title IX discrimination claims under the same legal analysis as Title VII claims.");

Title VII is violated if a protected trait such as sex "was a motivating factor for any employment practice, even though other factors also motivated the practice." 42 U.S.C. § 2000e-2(m).[7] The broad language of Title VII does not "enumerate specific discriminatory practices," nor "elucidate *in extenso* the parameter of such nefarious activities." *Barnes*, 561 F.2d at 994 (*quoting Rogers*, 454 F.2d at 238). In enacting such a broadly-worded proscription, Congress "pursued the path of wisdom by being unconstrictive, knowing that constant change is the order of our day and that the seemingly reasonable practices of the present can easily become the injustices of the morrow." *Id.* As a result, the "statute in explicit terms proscribes discrimination 'because of . . . sex,' with only narrowly defined exceptions." *Id.* For these reasons, the court in *Barnes* was one of the first to hold that Title VII's prohibition against sex discrimination was not restricted merely to disparate treatment, but also encompassed sexual harassment – even though that term does not appear explicitly in the statute itself. *See id.* at 990, 994. The Supreme Court subsequently ratified this broad construction of Title VII. *See Meritor Savings Bank*, 477 U.S. at 67.

A. Sex discrimination prohibited by Title VII includes any discrimination based on sex, including nonconformity with gender stereotypes.

"There . . . can be no question that the statutory prohibition [of Title VII] reaches all discrimination . . . which is based on gender." *Williams v. Saxbe*, 413 F. Supp. 654, 658 (D.D.C. 1976). For example, in *Oncale v. Sundowner Offshore Services*, 523 U.S. 75 (1998), where a male plaintiff "was forcibly subjected to sex-related, humiliating actions" on several occasions by other males,

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Weinstock v. Columbia Univ., 224 F.3d 33, 42 n.1 (2d Cir. 2000) (suggesting Title VII standards may also apply to discrimination claims under Title IX); *Oona R.-S.- v. McCaffrey*, 143 F.3d 473, 476 (9th Cir. 1998) (concluding it comports with leading Supreme Court precedent to apply Title VII principles to Title IX claims because the Supreme Court has "likened the duties of a school district to remedy sexual harassment under Title IX, to the Title VII duties of an employer") (*citing Franklin v. Gwinnett Cnty. Pub. Schs.*, 503 U.S. 60, 75 (1992)); *Torres v. Pisano*, 116 F.3d 625, 630 n.3 (2d Cir. 1997) ("We have held that Title VII principles apply in interpreting Title IX.").

[7] Courts have similarly held that Title IX bars discrimination "where gender is a motivating factor." *Yusuf v. Vassar College*, 35 F.3d 709, 715 (2d Cir. 1994) (*citing, inter alia,* 42 U.S.C. § 2000e-2(m)).

including name-calling "suggesting homosexuality," 523 U.S. at 77, the Supreme Court held that Title VII prohibited such harassment, even though it was male-on-male (and in an all-male environment), *id.* at 79-80. The Supreme Court clarified that discrimination under Title VII means more than simply disparate treatment in comparison to the other sex; it means any disparate treatment that is based on the *victim's* sex. *Id.; see also Rene v. MGM Grand Hotel, Inc.*, 305 F.3d 1061, 1067 (9th Cir. 2002) (holding that a plaintiff does "not need to show that he was treated worse than members of the opposite sex. It was enough to show that he suffered discrimination *in comparison to other men*," i.e., other members of the same sex). Discrimination based on the victim's sex can include disparate treatment compared to other members of the same sex – including, as demonstrated below, adverse treatment of a homosexual, bisexual or transgender woman or man compared to a heterosexual, non-transgender woman or man.

In *Price Waterhouse v. Hopkins*, 490 U.S. 228, 251 (1989), the Supreme Court held that discrimination based on a gender stereotype or norm also violates Title VII's prohibition against discrimination because of sex. "As for the legal relevance of sex stereotyping, we are beyond the day when an employer could evaluate employees by assuming or insisting that they matched the stereotype associated with their group . . . ." *Id.* The employer in *Price Waterhouse* passed over the plaintiff for promotion because it found her to be too " 'macho' "; that she needed " 'a course at charm school' "; and generally should " 'walk more femininely, talk more femininely, dress more femininely, wear make-up, have her hair styled, and wear jewelry.' " *Id.* 235 (*quoting from the record*). The Court held that "[i]n the specific context of sex stereotyping, an employer who acts on the basis of a belief that a woman cannot be aggressive, or that she must not be, has acted on the basis of gender." *Id.* at 250.

" ' "In forbidding employers to discriminate against individuals because of their sex," ' " the Court observed, " ' "Congress intended to strike at the entire spectrum of disparate treatment . . .

resulting from sex stereotypes." ' " *Id.* at 251 (*quoting Los Angeles Dept. of Water and Power v. Manhart*, 435 U.S. 702, 707 n. 13 (1978) (*quoting Sprogis v. United Air Lines, Inc.*, 444 F. 2d 1194, 1198 (7th Cir. 1971))). Thus, if the employer "relied on [the employee's] gender in making its decision," *id.*, the employer violated Title VII's prohibition against discrimination "because of sex." *See also Doe by Doe v. City of Belleville*, 119 F.3d 563, 580 (7th Cir. 1997) (*rev'd on other grounds*) (*citing Price Waterhouse*, 490 U.S. at 251) ("Title VII does not permit an employee to be treated adversely because his or her appearance or conduct does not conform to stereotypical gender roles.").

In Title VII cases, defendant employers have repeatedly sought to have courts narrowly construe the broad language of the statute – e.g., to cover only hiring, firing and compensation, not harassment, *Meritor Savings Bank*; to cover only harassment of an individual of the opposite sex, not same-sex harassment, *Oncale*; or to cover only discrimination based on biological sex, not sexual norms, *Price Waterhouse*. Each time, the Supreme Court has declined the invitation to so limit the meaning of sex discrimination, and chosen instead to broadly construe the statute to prohibit forms of sex discrimination that previously had been tolerated but now, due to growing awareness in society, were understood to be unacceptable.

Gay men, lesbians, bisexuals and transgender persons are often seen as violating fundamental gender norms and stereotypes – including, of course, the fundamental stereotype or norm of heterosexual attraction. *See, e.g.,* Andrew Koppelman, *Why Discrimination Against Lesbians and Gay Men Is Sex Discrimination*, 69 N.Y.U. L. REV. 197, 234-55 (1994) (discussing at length the stigmatization of homosexuality as fundamentally transgressing gender norms). As explained below, courts and the agencies charged with administering Title IX and Title VII have applied the teaching of *Price Waterhouse* to conclude that discrimination against LGBT people, motivated by their perceived violation of gender norms, is sex discrimination within the meaning of the statutes.

B. Adopting Title VII jurisprudence, the Department of Education and several courts have interpreted Title IX to protect LGBT persons against discriminatory harassment.

Title IX "makes clear that . . . students must not be denied access to educational benefits and opportunities on the basis of gender." *Davis*, 526 U.S. at 650. In *Davis*, the Supreme Court construed Title IX broadly as well, holding that it prohibited *any* gender-motivated discrimination if it "deprive[s] the victims of access to the educational opportunities or benefits provided . . . ." *Id.* The Department of Education (DOE) and some federal district courts have interpreted this principle to encompass discriminatory harassment against LGBT students, and students perceived as LGBT, based on their perceived nonconformity with gender stereotypes.

1. DOE has declared that harassment based on perceived nonconformity with gender stereotypes, including same-sex attraction and sexual activity, and transgender identity, violates Title IX.

DOE has the authority under 20 U.S.C. § 1221e-3 and § 1682 to "render[] administrative regulations and policy interpretations for Title IX." *Cmtys. for Equity v. Mich. High Sch. Ath. Assoc.*, 2001 U.S. Dist. LEXIS 4448, at *6 (W.D. Mich. Mar. 26, 2001). DOE's Office for Civil Rights has declared that under Title IX "it can be discrimination on the basis of sex to harass a student on the basis of that victim's failure to conform to stereotyped notions of masculinity and femininity," including "taunts based on sexual orientation." DOE OFFICE FOR CIVIL RIGHTS, REVISED SEXUAL HARASSMENT GUIDANCE, *supra* page 27.

Based on this policy, DOE investigated "nearly 700 complaints involving sexual or gender-based harassment" between 2009 and 2011, including cases in which students were harassed or otherwise discriminated against "because of their nonconformity to gender stereotypes." OFFICE FOR CIVIL RIGHTS, U.S. DEP'T OF EDUC., TITLE IX ENFORCEMENT HIGHLIGHTS 12 (2012), *available at* http://www2.ed.gov/documents/press-releases/title-ix-enforcement.pdf. These investigations included at least one case in which school staff discriminated against "students [who] were

homosexual" or perceived as such. *Id.* "These investigations led to resolution agreements in which the school districts agreed to take steps to prevent, eliminate and respond appropriately to sex-based harassment . . . ." *Id.*

2. Courts have similarly recognized a cause of action under Title IX for harassment based on sex, including gender stereotype nonconformity.

Federal courts have held that a "sex stereotyping claim . . . legally cognizable under Title VII" is also cognizable under Title IX. *Pratt v. Indian River Cent. Sch. Dist.*, 803 F. Supp. 2d 135, 151 (N.D.N.Y. 2011) (*citing Price Waterhouse*, 490 U.S. at 251-52). In *Riccio v. New Haven Bd. of Educ.*, 467 F. Supp. 2d 219 (D. Conn. 2006), a student was subjected to daily harassment that included being called "gay" and various "derogatory epitaphs for a female homosexual," *id.* at 223. The court held that such abusive language "with sexual orientation overtones, amounts to gender discrimination" under Title IX. *Id.* at 225. The court explained that the "language set forth in the [DOE] OCR Guidance and the holding in *Oncale* clearly support the conclusion that a female student, subjected to pejorative, female homosexual names by other female students, can bring a claim of sexual harassment under Title IX." *Id.* at 226. In *Kastl v. Maricopa County Cmty. College Dist.*, 2004 U.S. Dist. LEXIS 29825, at *13 (D. Ariz. June 2, 2004), the court recognized a Title IX claim for discrimination against a transgender student motivated by the student's perceived violation of gender norms.

Some courts have been hesitant to recognize a cause of action under Title IX for discrimination based on sexual orientation alone. *See, e.g., Riccio,* 803 F.Supp.2d at 225 n.6; *Montgomery v. Independent Sch. Dist. No. 709*, 109 F. Supp. 2d 1081, 1090 (D. Minn. 2000). However, those same courts have acknowledged that Title IX offers protection to students who are harassed based on their perceived violation of gender norms, which in turn was based on their real or perceived sexual orientation. For example, in *Montgomery*, the court held that Title IX prohibited "harassment based on the perception that [the student] did not fit his peers' stereotypes of

masculinity." *Id.* Yet discrimination based on "stereotypes of masculinity" is at root discrimination based on sex. Thus, the court in *Schroeder v. Maumee Bd. of Educ.*, 296 F. Supp. 2d 869, 880 (N.D. Ohio 2003), held that where the plaintiff "was repeatedly harassed based on his perceived sexual orientation," a "jury could find that this harassment, and the failure to punish it, was motivated by plaintiff's sex." *Id.* In the context of harassment, these holdings comport with the Title VII prohibition against discrimination based on nonconformity with gender stereotypes. However, they maintain an artificial distinction between gender nonconformity and sexual orientation. We respectfully submit that the regulations implementing Section 1557 of the ACA should reject this unjustified distinction and clearly state that discrimination on the basis of real or perceived homosexuality or bisexuality constitutes prohibited discrimination on the basis of sex.

II. Recent Title VII case law has construed discrimination "because of sex" to encompass employment discrimination against LGBT persons.

A. Recent cases recognize that discrimination based on an individual's attraction to the same sex is sex discrimination based on the individual's failure to conform to heterosexual gender norms.

The Equal Employment Opportunity Commission (EEOC)[8] has recognized that gender-based stereotypes include heterosexual attraction, heterosexual activity, and heterosexual partnering. *See, e.g., Veretto v. Postmaster General*, Appeal No. 0120110873, 2011 EEOPUB LEXIS 1973, at *8 (July 1, 2011) (recognizing the "sexual stereotype that marrying a woman is an essential part of being a man); *Castello v. Postmaster General*, Appeal No. 0120111795, 2011 EEOPUB LEXIS 3966, at *5 (Dec. 20, 2011) (recognizing "the sexual stereotype that having relationships with men is an essential part of being a woman"). Based on *Price Waterhouse*, the EEOC has enforced Title VII's prohibition against discrimination based on failure "to conform to [such] gender-based expectations." *Baker v. Astrue*, Appeal No. 0120110008, 2013 EEOPUB LEXIS 735, at *13 (Jan. 11, 2013) (*citing Price*

[8] The "rulings, interpretations and opinions" of the EEOC in enforcing Title VII "constitute a body of experience and informed judgment to which courts and litigants may properly resort for guidance." *General Electric Co. v. Gilbert*, 429 U.S. 125, 141-42 (1976) (*quoting Skidmore v. Swift & Co.*, 323 U.S. 134, 140 (1944)).

Waterhouse v. Hopkins, 490 U.S. 228 (1989) (upholding cause of action for harassment based on employee's appearance as effeminate)). In *Veretto*, 2011 EEOPUB LEXIS 1973, at *8, the EEOC held that a male complainant had a cause of action where the defendant "was motivated by the sexual stereotype that marrying a woman is an essential part of being a man, and became enraged when Complainant did not adhere to this stereotype." *Id.* Similarly, the EEOC in *Castello*, 2011 EEOPUB LEXIS 3966, at *5, allowed a lesbian employee's action for sex discrimination to proceed because her harasser "was motivated by the sexual stereotype that having relationships with men is an essential part of being a woman." *Id.*

These holdings are based on the understanding that Title VII prohibits discrimination based on *any* gender stereotype, including failure to conform to the gender stereotype of heterosexuality. *See also Schwenk v. Hartford*, 204 F.3d 1187, 1202 (9th Cir. 2000) ("Discrimination because one fails to act in the way expected of a man or woman is forbidden under Title VII"); *Koren v. Ohio Bell Tel. Co.*, 894 F. Supp. 2d 1032, 1038 (N.D. Ohio 2012) (holding that plaintiff had a cause of action under Title VII when, after he "chose to take his [same-sex] spouse's surname," his employer took adverse action due to "that gender non-conformance"). The statue, therefore, bars discrimination based on same-sex attraction and sexual activity.

While some courts have held that discrimination based on sexual orientation alone is not actionable under Title VII, *see, e.g., Spearman v. Ford Motor Co.*, 231 F.3d 1080, 1084-85 (7th Cir. 2000), "the line between discrimination because of sexual orientation and discrimination because of sex is hardly clear," since "[s]ex stereotyping is central to all [sex] discrimination." *Centola v. Potter*, 183 F. Supp. 2d 403, 408 (D. Mass. 2002). Furthermore, any such distinction is without basis in the statutory language, or in the holding in *Price Waterhouse*.

> Sexual orientation harassment is often, if not always, motivated by a desire to enforce heterosexually defined gender norms. . . . The harasser may discriminate against an openly gay co-worker, or a co-worker that he perceives to be gay, whether effeminate or not, because he thinks, "real men don't date men." The gender stereotype at work here is that

> "real" men should date women, and not other men. Conceivably, a plaintiff who is perceived by his harassers as stereotypically masculine in every way except for his actual or perceived sexual orientation could maintain a Title VII cause of action alleging sexual harassment because of his sex due to his failure to conform with sexual stereotypes about what "real" men do or don't do.

Centola, 183 F. Supp. 2d at 410 (*footnote omitted*). It is therefore virtually impossible to distinguish between discrimination based on sexual *orientation* versus discrimination based on nonconformity to a sex *stereotype*, since "sex, gender, and sexual orientation are inextricably linked." COURTNEY WEINER, SEX EDUCATION: RECOGNIZING ANTI-GAY HARASSMENT AS SEX DISCRIMINATION UNDER TITLE VII AND TITLE IX, 37 Colum. Hum. Rts. L. Rev. 189, 193 (2005); *see also Veretto*, 2011 EEOPUB LEXIS 1973, at *8 (upholding EEOC claim of discrimination based on male same-sex sexual activity); *Castello*, 2011 EEOPUB LEXIS 3966, at *5 (upholding EEOC of discrimination based on female same-sex sexual activity). A distinction between "sex" and "sexual orientation" is incoherent precisely because discrimination based on same-sex attraction and sexual activity is irreducibly "on the basis of sex." 20 U.S.C. § 1681(a); *see Heller v. Columbia Edgewater Country Club*, 195 F. Supp. 2d 1212, 1224 (D. Or. 2002) (holding that discrimination based on same-sex sexual activity constitutes discrimination based on sex).[9]

B. Discrimination based on same-sex attraction and sexual activity also constitutes discrimination "because of sex," *per se*, because the discrimination occurs simply because of the victim's sex.

Even aside from any nonconformity to gender stereotypes, discrimination based on same-sex attraction or sexual activity is impermissible on the ground that it is based on the individual's sex. In determining whether sex discrimination has occurred, some courts have construed Title VII to ask, "would the complaining [plaintiff] have suffered the harassment [or adverse action] had he or

[9] Courts that have held that Title VII does not cover sexual orientation discrimination generally have relied on other, previous holdings to that effect; on the argument that Congress did not intend to prohibit sexual orientation discrimination in Title VII; or on the circular argument that a gender stereotype analysis should not "bootstrap" sexual orientation into Title VII since the statute does not cover it. None of those rationales are persuasive. See, e.g., the analysis in Victoria Schwartz, *Title VII: A Shift From Sex to Relationships*, 35 HARV. J. LAW & GENDER 209, 234-46 (2012).

she been of a different gender?" *Bundy v. Jackson*, 641 F.2d 934, 942 n.7 (D.C. Cir. 1981) (*citing Barnes*, 561 F.2d at 990 n.55); *see also Jennings v. Univ. of N.C.*, 482 F.3d 686, 723 (4th Cir. 2007) (observing that the same test is applied in Title IX sex discrimination cases). "So long as the plaintiff demonstrates in some manner that he would not have been treated in the same way had he been a woman, he has proven sex discrimination." *Shepherd v. Slater Steels Corp.*, 168 F.3d 998, 1009 (7th Cir. 1999). Applying this rule, discrimination by a health care provider against, e.g., a male patient engaging in sexual activity with a male is impermissible for the simple reason that the patient "would not have been treated the same way," *Bundy*, 641 F.2d at 942 n.7, had he been a female doing the same thing, *Shepherd*, 168 F.3d at 1009.

The holding in *Heller v. Columbia Edgewater Country Club*, 195 F. Supp. 2d 1212 (D. Or. 2002), illustrates these principles. In that case, the plaintiff's supervisor "allegedly became increasingly obsessed with the fact that" the plaintiff, a female employee, "was having an intimate relationship with a woman, and otherwise failing to comport with [the supervisor's] notions of how a woman ought to behave." *Id.* at 1217. The court denied the employer's motion for summary judgment, because terminating the employee on this basis violated Title VII's bar against sex discrimination. *Id.* at 1223-24. The court held that a "jury could find that [the supervisor] would not have acted as she (allegedly) did if Plaintiff were a man dating a woman, instead of a woman dating a woman. If that is so, then Plaintiff was discriminated against *because of her gender*." *Id.* at 1223 (*emphasis added*). In other words, the court held that discrimination on the basis of same-sex attraction and sexual activity, alone, constituted discrimination "because of sex." [10] *See also Carrasco v. Lenox Hill Hosp.*, 2000 U.S. Dist. LEXIS 5637, 2000 WL 520640, at *27 (S.D.N.Y. Apr. 28, 2000) ("[C]omments that imply "that [a] plaintiff [is] a homosexual . . . may have been made 'because of sex,' " both because

[10] Applying, alternatively, the *Price Waterhouse* sex stereotype test, "a jury could find that [the supervisor] repeatedly harassed (and ultimately discharged) [the employee] because [the employee] did not conform to [the supervisor's] stereotype of how a woman ought to behave," i.e., that "a woman should be attracted to and date only men." *Heller*, 195 F. Supp. 2d at 1224.

they "focus[] on the sexual conduct of plaintiff as a man," and also because they are "comments to which other similarly-situated female members of the . . . staff were likely not exposed, thereby indicating the possibility of disparate treatment.").

C. Title VII also prohibits discrimination based on the sex of the person(s) with whom the victim has a relationship.

The courts have recognized that Title VII is implicated not only when an employer discriminates based on an employee's own race, national origin or sex, but also when the employer discriminates based on the race, national origin, or sex of the person(s) with whom the employee associates. While courts have not limited the application of this "association" or "relationship" principle to relationships that are romantic or sexual in nature, its application to persons who choose same-sex romantic or sexual relationships provides an additional ground for protection against discrimination under Title VII.

Courts first used this relationship principle in interpreting Title VII in cases in which an employee was subjected to discrimination because of the race of someone with whom the employee had a relationship, with respect to the employee's own race. For example, in *Whitney v. Greater New York Corp. of Seventh-Day Adventists*, 401 F. Supp. 1363, 1366 (S.D.N.Y. 1975), the court held that an employer who fired a white employee for having an African-American friend violated Title VII's prohibition against discrimination based on race. In *Parr v. Woodmen of the World Life Ins. Co.*, 791 F.2d 888, 892 (11th Cir. 1986), the Eleventh Circuit affirmed this principle, holding that a white plaintiff had been discriminated against because of race when he was fired for having an African-American wife. Such discrimination is impermissible regardless of the "degree of association," because the test focuses on whether or not discrimination happened due to race, not the nature of the relationship between the plaintiff and the third party. *Drake v. 3M Co.,* 134 F.3d 878, 884 (7th Cir. 1997).

Courts have applied the same principle to discrimination based on an associate's national origin. *See, e.g., Reiter v. Ctr. Consol. Sch. Dist.*, 618 F. Supp. 1458, 1460 (D. Colo. 1985) (holding that discrimination based on a woman's association with Latino persons in general was prohibited by Title VII under the relational discrimination theory). Furthermore, this principle applies even if one is discriminated against because of his or her association with a broad class of people rather than with a particular individual. *See id.* People who are discriminated against because of the race of someone with whom they associate are themselves considered to be a protected class. *See Holcomb v. Iona College*, 521 F.3d 130, 138-39 (2nd Cir. 2008).

Recently, this principle, first developed in race and national origin discrimination cases, has been applied to sex discrimination. In *Ventimiglia v. Hustedt Chevrolet,* 2009 U.S. Dist. LEXIS 24834, at *32-33 (E.D.N.Y. 2009), the court held that firing a man because of his association with a female coworker – which the employer suspected was an intimate relationship – amounted to discrimination because of sex. The firing constituted discrimination under Title VII because, "but for [the employee's] sex, male, his relationship with his co-worker, female, . . . would not have been an issue." *Id.* at *33.

These cases establish that discrimination based on the sex of the plaintiff with respect to that of a third party constitutes discrimination "because of sex" under Title VII. Applying the reasoning established in the race-based cases above, the nature of the relationship (e.g., intimate versus friendly) is irrelevant, *see Drake*, 134 F.3d at 884, and the principle applies even if the discrimination is because of the party's general association with a class of people and not a specific individual, *see Reiter*, 618 F. Supp. at 1460. Therefore, if a man is discriminated against because the sex of his partner or partners is male, this would qualify as discrimination "because of sex," since "but for [his]

sex" – male – his relationship with his male partner "would not have been an issue," *Ventimiglia,* 2009 U.S. Dist. LEXIS 24834, at *33.[11]

D. Titles VII and Title IX also prohibit discrimination on the basis of gender identity and expression.

Discrimination based on transgender identity violates Title VII – and, therefore, Title IX – because it is discrimination based on gender nonconformity as well as discrimination based simply on sex.

1. Transgender discrimination is impermissible discrimination based on gender nonconformity.

Sex stereotypes include the stereotype or norm of gender immutability: e.g., a man is forever a man, and must behave "like a man." *See, e.g., Macy v. Holder*, EEOC Appeal No. 0120120821, 2012 EEOPUB LEXIS 1181, at *19 (April 20, 2012) (noting that transgender identity does not conform to gender stereotypes). The Eleventh Circuit has held that "discrimination against a transgender individual because of her gender-nonconformity is sex discrimination" under Title VII. *Glenn v. Brumby*, 663 F.3d 1312, 1317 (11th Cir. 2011) (*citing, inter alia, Smith v. City of Salem*, 378 F.3d at 569, 572 (holding "that a transsexual firefighter could not be suspended because of 'his transsexualism and its manifestations' ")). In *Glenn*, the defendant supervisor "testified at his deposition that he fired Glenn," a transgender woman, "because he considered it 'inappropriate' for her to appear at work dressed as a woman and that he found it 'unsettling' and 'unnatural' that Glenn would appear wearing women's clothing." 663 F.3d at 1320. Firing the plaintiff therefore constituted "gender

[11] For a detailed discussion of the Title VII relationship cases, and their applicability to discrimination based on sexual orientation, see Schwartz, *supra* note 9, at 246-58.

non-conformity" discrimination. *Id.* at 1321.[12] The Eleventh Circuit relied in part on *Smith v. City of Salem,* where the Sixth Circuit noted, 378 F.3d at 574 (*emphasis in original*):

> After *Price Waterhouse*, an employer who discriminates against women because, for instance, they do not wear dresses or makeup, is engaging in sex discrimination because the discrimination would not occur but for the victim's sex. It follows that employers who discriminate against men because they *do* wear dresses and makeup, or otherwise act femininely, are also engaging in sex discrimination, because the discrimination would not occur but for the victim's sex.

In *Kastl*, 2004 U.S. Dist. LEXIS 29825, at *4, *13, the district court recognized that the male-to-female transgender plaintiff stated a cause of action under both Titles VII and IX when the College she worked at and attended as a student barred her from using the women's restroom, and terminated her enrollment when she refused to use the men's restroom. "The presence or absence of anatomy typically associated with a particular sex cannot itself form the basis of a legitimate employment [or education] decision unless the possession of that anatomy (as distinct from the person's sex) is a bona fide occupational qualification (BFOQ)." *Id.* at *8-9 (*citing Price Waterhouse*, 490 U.S. at 251). The plaintiff had therefore had a valid claim under both Title VII and Title IX because "neither a woman with male genitalia nor a man with stereotypically female anatomy, such as breasts, may be deprived of a benefit or privilege of employment [or education] by reason of that nonconforming trait." *Id.* at *9; *13.

2. Transgender discrimination is also sex discrimination *per se*.

The case of *Schroer v. Billington*, 577 F. Supp. 2d 293 (D.D.C. 2008), demonstrates that discrimination on the basis of transgender identity is also simply discrimination "because of sex." In *Schroer*, the plaintiff, presenting as a man, applied for, was offered, and accepted a position at the Library of Congress. 577 F. Supp. 2d at 296. Prior to starting his job, the plaintiff informed her future supervisor that "she was transgender, that she would be transitioning from male to female,

[12] *Glenn v. Brumby* was a case against a state government entity, decided under the Equal Protection Clause, but the Eleventh Circuit relied on Title VII cases and the holding is fully applicable to Title VII – and, therefore, to Title IX.

and that she would be starting work as 'Diane.' " *Id.* The supervisor then informed the plaintiff that she "would not be a 'good fit' " after all, " 'based on our conversation,' " i.e., her transgender identity. *Id.* at 299 (*quoting the record*). Ms. Schroer then filed a claim for sex discrimination, pursuant to Title VII.

After a bench trial, the court held that, though the plaintiff was "entitled to judgment based on a *Price Waterhouse*-type claim for sex stereotyping," she also was "entitled to judgment based on the language of the statute itself." 577 F. Supp. 2d at 305-306. Under the plain language of Title VII, the employer's "refusal to hire Schroer after being advised that she planned to change her anatomical sex by undergoing sex reassignment surgery was *literally* discrimination 'because of . . . sex.' " *Id.* at 308 (*quoting* 42 U.S.C. § 2000e-2(a)(1) (*emphasis in the original*). While acknowledging that other circuits have held "that discrimination based on changing one's sex is not discrimination because of sex," the *Schroer* court observed that to reach that holding, those courts essentially had to reason " 'that a thing may be within the letter of the statute and yet not within the statute, because not within its spirit, nor within the intention of its makers.' " *Id.* at 307 (*quoting Church of the Holy Trinity v. United States*, 143 U.S. 457, 459 (1892)). Yet, as Justice Scalia observed for a unanimous Supreme Court in *Oncale*, "statutory prohibitions often go beyond the principal evil to cover reasonably comparable evils, and it is ultimately the provisions of our laws" that govern. *Id.* (*quoting Oncale*, 523 U.S. at 79).

The court in *Schroer,* therefore, began its analysis " 'with the language of the statute itself' and '[i]n this case it is also where the inquiry should end, for where, as here, the statute's language is plain, 'the sole function of the courts is to enforce it according to its terms.' " *Id.* at 306 (*quoting United States v. Ron Pair Enters.*, 489 U.S. 235, 241 (1989)). "Imagine that an employee is fired because she converts from Christianity to Judaism. Imagine too that her employer testifies that he harbors no bias toward either Christians or Jews but only 'converts.' That would be a clear case of

discrimination 'because of religion.' " *Id.* at 306. No court would seriously entertain the notion that the statute protects Christians and Jews, but not "converts." *Id.* The same is true for a plaintiff who "has changed her sex, and faces discrimination because of the decision to stop presenting as a man and to start appearing as a woman." *Id.* at 306-307. This is just as clear a case of discrimination because of sex – even though other courts have allowed the term " 'transsexual' to blind them to the statutory language itself." *Id.* at 307.

The EEOC has likewise made clear that workplace discrimination on the basis of transgender identity is simply discrimination on the basis of sex, whether it is characterized by "gender stereotyping" or not. *See Macy*, 2012 EEOPUB LEXIS at *30. "[G]ender stereotyping is simply one means of proving sex discrimination." *Id.* If a "[c]omplainant can prove that the reason that she did not get that job . . . is that the [employer] was willing to hire her when he thought she was a man, but was not willing to hire her once he found out that she was now a woman—she will have proven that the Director discriminated on the basis of sex." *Id.* at 32. The plaintiff does not have to additionally prove any gender-stereotyping, e.g., that discrimination occurred because "the employer believed that biological men should consistently present as men and wear male clothing." *Id.* at 32-33.

III. Conclusion: Regulations implementing Section 1557 of the ACA should bar discrimination based on same-sex attraction and sexual activity, and gender identity and expression.

The prevailing case law under Title VII and Title IX compels the conclusion that sex discrimination includes discrimination against a health care patient, nursing home resident, or health insurance plan member based on the individual's same-sex attraction or sexual activity, gender identity or gender expression. Discrimination on any of these bases constitutes discrimination "on the basis of sex," since it occurred irreducibly because of the individual's sex. *See, e.g., Heller*, 195 F. Supp. 2d at 1223; *Schroer*, 577 F. Supp. 2d at 306-307. Second, discrimination on any of these bases

amounts to discrimination for nonconformity with sex/gender stereotypes. *See, e.g., Heller*, 195 F. Supp. 2d at 1224; *Schroer*, 577 F. Supp. 2d at 305-306. "Sex stereotyping based on a person's gender non-conforming behavior is impermissible discrimination, irrespective of the cause of that behavior." *Smith*, 378 F.3d at 575.

Impermissible sex discrimination therefore encompasses any adverse or disparate treatment against a health care patient, nursing home resident, or health plan member because that individual:

- identifies as, or is suspected of being, gay, lesbian, homosexual or bisexual;
- displays or states an attraction to persons of the same sex, or discloses same-sex sexual activity;
- is an "effeminate-acting" man or a "masculine-acting" woman; or
- is transgender or otherwise gender non-conforming.

The distinction some courts have made between actionable discrimination based on "sex stereotyping" and not-actionable discrimination based on "sexual orientation," is illogical and unsupported by the statutory language. Regulations interpreting and implementing Section 1557 should, therefore, prohibit discrimination based on same-sex attraction and sexual activity, and gender identity and expression.

HHS/OCR 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 as 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.

The move to increase access to and the use of electronic health information is a critical improvement to the delivery of health care. Further integration of electronic health information, especially across health care delivery systems, is promises to significantly improve health care outcomes and support cost containment. Balancing the protection of patient health information with providing ready access to that information by the patient is an effort that is playing out real-time with health care providers across the country.

Electronic health record (EHR) systems are varied in nature. Many are hospital-based systems, which do not scale for smaller health care practices. Others are practice management systems, focused on the scheduling and billing aspects of health care delivery ; all other interfaces within such systems, including where a provider enters progress notes and test results and otherwise documents the patient's care, are in support of the layers of documentation required for appropriate billing. In addition to our EHR system, other information technologies that Whitman-Walker is utilizing, or has utilized, include: appointment reminder systems that text or call patients phones; web-based applications to request refills on prescriptions; smart phone applications to request refills on prescriptions and web-based applications to support adherence to medication.

- **What are the benefits and barriers encountered by people with disabilities in accessing electronic and information technology in health programs and activities?**

Electronic health information systems promise to improve communications between providers across health care offices and systems, permitting providers to access more relevant information more quickly, thereby improving coordination of care. Health care systems are able to monitor quality of care in a much more robust way, essential to community health providers such as WWH who are on the front lines of delivering primary care to the nations' most vulnerable populations.

Perhaps the greatest benefit of such systems is that they can increase a patient's access to her or his own health information, which can result in increased engagement in health outcomes. The more patients know about their health, they more they learn to manage and improve it themselves, which improves health outcomes and also helps to contain costs. The most obvious barrier to effective use of such systems by patients is that the patients need access to appropriate technology – computers and cellular phones – especially smart phones with consistent contact information. As explained below, existing systems also pose challenges particularly for transgender patients and for patients with limited English proficiency.

Electronic health information systems also enable health care providers to perform important billing functions, more quickly and securely, which increases the ability to be paid timely by insurance carriers and other third-party payors as well as to manage other billing issues which may arise.

- **What are examples of innovative or effective and efficient methods of making electronic and information technology accessible?**

Among the most efficient methods for making electronic and information technology accessible is via cellular phones and smart phones. More and more people, of all socioeconomic backgrounds have cellular phones with the ability to send and receive SMS. The largest challenge is

that the data, once transmitted to a cellular phone, is only as secure as the individual's security settings on that device. WWH has found texting technology effective for appointment reminders, medication adherence and refill requests and targeted routine screening reminders.

- **What specific standards, if any, should the Department consider applying as it considers access to electronic and information technology in these programs?**

The Department should provide detailed guidance on the appropriate balance between allowing patients access to health information in ways which are most beneficial to them and the importance of securing protected health information as indicated in the HITECH Act and HIPAA. The Department also should consider the language limitations of hard-wired systems discussed below.

- **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?**

Expensive electronic health record modules and practice management systems are "hard-wired" in many ways and do not allow for customization. With respect to "sex", health care providers need to include sex of birth, both for health reasons and for insurance related reasons. However, that information often does not reflect a person's gender identity. Further, "name" also presents similar challenges. "Name" needs to reflect a person's legal name, but often fails to reflect a person's preferred name which is so critical in providing culturally appropriate care to transgender patients. Whitman-Walker has developed several "work-arounds" which balance the need to record the same name and gender marker that is in a patient's legal and insurance records, with the need to respect the patient's own gender identity. For example, we include a patient's preferred name, in all capital letters, after their first name in the health record. We also urged our electronic health record company to provide a better way to document gender variance. The current solution, a check box to

indicate that someone is Transgender, is not ideal, but demonstrates that even small health care providers can have an impact on these issues.

Another challenge is that EHR systems with the ability to have a secure patient portal and send text messages or voicemail messages to patients are "hard-wired" in English. This presents a real challenge for patients with limited English proficiency. The systems often do not have an ability to translate data, even basic data, into other languages. Some systems have this ability, but the additional costs are high. Further, the importance of including all patient-related documentation in one place, either for Patient-Centered Medical Home or Meaningful Use needs, among a variety of other health care documentation requirements, forces providers to try and utilize modules of one system, rather than shop for a variety of systems which support communications with patients most effectively. For example, WWH previously utilized a telephonic reminder system to text or call patients with messages regarding their next appointments. However, this system, which enabled to communicate with patients in their own languages, was outside our electronic health record, and so we were forced us to utilize the modules within the EHR system, which do not have the language sophistication.

- **If specific accessibility standards were to be applied, should there be a phased-in implementation schedule, and if so, please describe it.**

Phase-in of implementation is absolutely essential, particularly for smaller health systems struggling to provide the highest quality health care to low-income and otherwise marginalized patients with limited resources. The specific phase-in schedule that would be reasonable would depend on the specific accessibility standards to be applied. If specific standards are proposed by the Department in a Notice of Proposed Rulemaking, Whitman-Walker will submit comments on an appropriate implementation schedule at that time.

HHS/OCR QUESTION 7. 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 also may file private litigation in Federal court, subject to some restrictions.

(a) How effective have these different processes been in addressing discrimination? What are ways in which we could strengthen these enforcement processes?

Whitman-Walker Legal Service's experience to date with these enforcement mechanisms is limited to actions pursued on behalf of persons living with HIV/AIDS under Section 504 of the Rehabilitation Act. Based on that experience, we offer the following observations:

- A well-staffed and well-funded, vigorous administrative enforcement process is essential. Many aggrieved persons with substantial claims, and the nonprofit legal services and advocacy organizations that represent them, simply cannot afford the cost of litigation in federal court. Moreover, as the holder of the "purse strings" when a respondent health care provider, institution, or health plan receives federal financial assistance or participates in a health insurance exchange under the ACA, the Department is in the position to exert significant influence on respondents, and impose substantial penalties, when the evidence substantiates a charge of discrimination.
- Aggrieved persons also should have a private right of action under Section 1557. We read the statute to provide such a right to persons with claims of sex discrimination or disability discrimination. Section 1557 states: "The enforcement mechanisms provided for and available under … title VI, title IX, section 504, or [the] Age Discrimination Act shall apply for purposes of violations of this subsection." 42 U.S.C. § 18116(a). The

Supreme Court has established that there is a private right of action under Title IX[13] and Section 504.[14] Nevertheless, it would be helpful for the Department to so state in the Section 1557 regulations.

(b) The regulations that implement Section 504, Title IX, and the Age Act also require that covered entities conduct a self-evaluation of their compliance with the regulation. What experience, if any, do you have with self-evaluations? What are the benefits and burdens of conducting them?

Whitman-Walker conducts self-evaluations on an ongoing basis, often based on site visit or other audit tools developed by federal oversight entities. This work falls within the umbrella of Risk Assessment at our health center and informs work plans for various departments, including policy development, and the allocation of other resources to correct deficiencies. We believe them to be important aspects of the work that we do and an opportunity for continuous improvement. However, self-evaluations often take considerable time and require the involvement of several staff. Many health care providers are burdened by administrative oversight requirements, included those mandated by law, and so prioritizing these discretionary analysis is a challenge. Best practices for WWH in conducting these assessments include ensuring that they align with other organizational priorities. For example, as WWH considered expanding our ability to communicate directly with patients via e-mail, a security assessment was logical in order to ensure that we were compliant with the HITECH Act. With limited resources, organizations and providers must prioritize. Proactively identifying risk is crucial, however, and the benefit of any self-assessment is the time to address it in a manner which benefits the provider and more opportunity to control the process.

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[13] *Franklin v. Gwinnett County Pub. Schs.*, 503 U.S. 60 (1992) ; *Cannon v. Univ. of Chicago*, 441 U.S. 677 (1979).

[14] *Barnes v. Gorman,* 536 U.S. 181 (2002); *Consolidated Rail Corp. v. Darrone,* 465 U.S. 624 (1984).

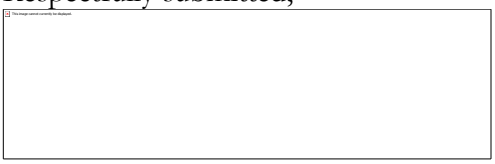
(c) What lessons or experiences may be gleaned from complaint and grievance procedures already in place at many hospitals, clinics, and other covered entities?

For an organization the size and scope of WWH, we have a robust incident report and patient compliant/grievance process in place. Most of our risk identification arises from these two reporting systems and not from self-assessments. Unusual incident reporting is encouraged by our Compliance Program, staffed by a full-time Director of Compliance. Complaints are managed by our Quality Improvement Department, and grievances are co-managed by our Director of Quality and our Director of Compliance. There are important lessons to learn both from these systems and from the data included within the reports. First, it is important to have staff trained to treat these reports as learning opportunities and to support patients and staff interesting in filing them. Staff and patients should understand that they are protected from any retaliation for reporting any complaint or concern. Second, it is important to treat each incident report, complaint and grievance as a rich learning opportunity. Qualitative data can be time-consuming for health care providers to obtain, since it is not part of regular patient care, but if sufficiently detailed it can support several improvement opportunities. Finally, these systems offer an opportunity for patients to have their concerns raised and resolved, outside of a formal legal process, which is often considerably more efficient, and can strengthen the patient-provider relationship which is critical to health care.

CONCLUSION

Whitman-Walker Health appreciates the opportunity to submit these comments. We would be happy to provide any additional information that the Department might request.

Respectfully submitted,



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September 30, 2013

APPENDIX
WHITMAN-WALKER HEALTH LANGUAGE ACCESS PLAN

1. Language Access Plan
2. Memorandum to Staff on Implementation
3. Procedures for Assessing Language Skills of Staff and Volunteers
4. PowerPoint Presentation for Staff Training

WHITMAN-WALKER HEALTH
Community. Caring. Quality.

		Policy Number	
		Effective Date	December 3, 2012
Policy Title	Language Access Plan	Statutory Authority	45 CFR 50, Subpart F
Approval(s)	Director of Compliance		

Preamble

Title VI of the Civil Rights Act of 1964 states that "No person shall, on the grounds of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or *activity* receiving Federal financial assistance."

DHHS Guidance on Interpretation Services
The Department of Health and Human Services (DHHS) has issued Guidelines to HHS grantees such as WWH. The Guidelines do not have the force of law, but provide the framework for compliance.

DHHS Guidance requires Whitman-Walker Health (WWH) to *take reasonable steps* to ensure that Limited English Proficiency (LEP) persons receive the language assistance (interpretation and translation services) necessary to *afford meaningful access* to WWH's services. WWH is required to determine the extent of its obligation to provide LEP Services by considering and balancing the following four factors:

The number or proportion of LEP persons eligible to be served or likely to be encountered.
The frequency with which LEP individuals come in contact with WWH.
The nature and importance of the services provided by the recipient to the lives of the persons served.
The resources available to the organization.

The DC Language Access Act of 2004 also affords individuals with limited or no-English proficiency greater access to and participation in public services, programs, and activities by requiring that District government programs, departments, and services to assess the need for, and offer, oral language services; and to provide written translations of documents when thresholds are met.

Policy

WWH will take reasonable steps to provide timely, meaningful access for Limited English Proficient persons (LEP) (including non-Spanish, non-English speaking and/or deaf staff or community members) to all its programs and services based on the factors set forth in DHHS Guidance. All staff members will make their best effort to facilitate free language access services to LEP individuals whom they encounter at all points of contact and whenever an LEP person requests language assistance services. Whitman-Walker will inform staff, as well as members of the public who seek to obtain care and services at the Health Center, that language access services are available free of charge.

It is also the policy of WWH to ensure that vital documents, including but not limited to consent forms, registration forms, and forms involving notice fundamental rights, are to be translated into the language of each frequently encountered LEP group based on the balancing factors and

thresholds set forth in DDH's Guidance.

Interpretation Services:

WWH will make its best effort, based on a balancing of the factors set forth in the DHHS Guidance, to provide all persons seeking information and/ or services at WWH with a method for obtaining equal linguistic access regardless of their language ability.

WWH will assess language access needs annually for every program and activity it develops.

WWH employees will be trained on how to respond to language access needs.

WWH will use a variety of methods to provide language access, including in-person, telephone interpretation, and translation. Trained bilingual staff will also act as interpreters.

WWH will seek services that meet local and national requirements as well as industry standards for the provision of language services, including training, certifications, licenses, etc.

WWH discourages the use of family members, friends or untrained individuals for interpretation. If the patient wishes to use a family member or friend, WWH will request the patient to sign the Waiver of Right to Receive Language Assistance Form attached to this Policy. See WWH Language Access Procedures.

WWH collects information about a patient's primary language preference, and the need for oral and written language services through "I speak" cards and other methods. This data is used to provide timely language access services each time a patient interacts with WWH. This data is recorded and maintained in eClinical Works (eCW) and the Legal Server.

WWH will inform the patient community that language access services are available during registration and a poster on the lobby bulletin board.

Translation of Vital Documents:

WWH will ensure that its vital documents are translated into the language of each frequently encountered group of LEP persons based on balancing factors and thresholds set forth in DHHS's Guidance.

Staff Compliance:

Each WWH department is responsible for arranging the timely provision of language services for patients and shall follow WWH procedures to request languages services.

Staff Training:

WWH has a Language Access Coordinator who educates those employees who will potentially interact with LEP individuals about how to access language services, and informs all employees about WWH's language access policies, plan and procedures at initial orientation and on an annual basis. See WWH

Language Access Procedures.

Bilingual Staff:

Standardized proficiency testing is provided to staff applying for bilingual required positions to establish the competency of those providing language services and bilingual care, including interpreters, translators and bilingual staff/clinicians. Language proficiency testing is administered during the interview and hiring process. See WWH Procedure for Assessing Limited English Proficiency Interpretation Skills of Staff and Volunteers.

Performance Measurement:

WWH's client satisfaction survey, which is administered annually, measures the effectiveness of communication between LEP individuals and providers. All translated materials are reviewed by qualified staff.

Definitions:

Bilingual staff: Any staff member that has the ability and training to effectively speak two languages. Bilingual staff provides in-language communication.

Interpreter: A person who based on ability or training or both to render a message spoken in one language into one or more other languages.

Language Access Services: Any service that helps LEP individuals or persons obtain equal access to and understanding of the health care and other services offered at WWH. Language access services include direct communication through multilingual staff, in-person interpreters, phone interpreters, and translated documents. Two primary types of language access services are available at WWH: oral and written.

Oral language access services are available in the form of "in-language" communication (provided by a qualified bilingual staff member communicating directly in the LEP person's language) or interpreting. Interpretation can take place in-person or through a telephonic interpreter. In-person interpretation is available through staff or contractors, trained and/or certified as medical interpreters.

LEP individual or person: An individual who is unable to speak, read, write or understand the English language at a level that permits him/her to interact effectively with health and social service agencies and providers.

Points of contact: Any contact, physical, electronic or telephonic, where community members might interact with WWH. Examples are: WWH's website, phone lines, email, lobbies, exam rooms, and correspondence.

Preferred language: An individual's preferred language is the language the individual prefers to use in a service or clinical encounter. The preferred language need not be the client's native or primary language if the client indicates sufficient proficiency in English and prefers to use English.

Primary language: The language a person has learned from birth.

Translation: The replacement of written text from one language into another.

Vital documents: A document that is considered essential for the effective and accurate provision of services. Vital documents at WWH include: *registration forms, consent forms, complaint forms, and notices of rights and responsibilities.*

Procedures:

WWH has written procedures governing how WWH identifies staff and volunteers who are capable of acting as interpreters and how WWH orders interpretation and translation services from other organizations or vendors when necessary. The procedures implementing this Policy are available to all employees in the public folders located in Outlook in a folder named "Language Assistance Policies and Procedures."

Approval Signature	Name, Title	Department/Committee	Date
Judy Jenkins	Director of Compliance	Compliance	November 5, 2012
Approval Signature (as needed)	Name, Title	Department/Committee	Date

Originated By:	Judy Jenkins	Director of Compliance	March, 21, 2012
Reviewed By:	Language Access Workgroup and Operations Committee	Department Program Managers	November 5, 2012

WHITMAN-WALKER HEALTH
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M E M O R A N D U M

To: WWH Staff

From: Director of Clinical Operations

Re: Procedures Implementing WWH's Language Access Policy and Policy on Provision of Auxiliary Aids and Services

Date: December 10, 2012

Whitman-Walker Health (WWH) has adopted a Language Access Policy ensuring that the organization complies with Title VI of the Civil Rights Act of 1964, Guidelines issued by the Department of Health and Human Services under Title VI, and the District of Columbia Language Access Act of 2004. The health center has also adopted a Policy on Provision of Auxiliary Aids and Services to Patients with Physical or Mental Impairments That Limit Their Ability to Communicate Effectively in order to ensure compliance with Title III of the Americans with Disabilities Act (ADA). The procedures set forth below are intended to implement both policies.

PURPOSE:

The purpose of this procedure is to explain to staff how and when to access in-person language interpretation services as well as to ensure that deaf or hearing impaired individuals are provided with access to sign language interpretation services. For purposes of this Procedure, language interpretation services and sign language services may be jointly referred to as "interpreter services."

Procedure Index:

On-site Appointments

PROCEDURE FOR LANGUAGE INTERPRETER REQUESTS:

I. **Patient Registration:** New patients who are attempting to register for services at WWH and do not speak or read English will be offered interpreting assistance. This assistance will be provided by a staff member who speaks the person's language or through an interpretation service. If the CSR does not speak the person's language and it cannot be determined what language the person speaks, then the CSR will determine this by having the person point to the language they speak on the "I Speak" card. The CSR and the new patient will then utilize the Pacific Interpreters phone interpreting service, per the instructions below, to assist in registering the patient and scheduling an appointment. New patient registration is outlined in the New Patient Registration policy, including entering of language by clicking the "Additional Info" button to enter the patient's language. Then the CSR will set a Global Alert if the patient requires an interpreter, by entering the language required in the notes of the alert.

II. **Patient Requests Family and/or Friend to Act as Interpreter:**

1. When a WWH patient with Limited English Proficiency (LEP patient) or a patient with a physical or mental impairment that limits their ability to effectively communicate requests a WWH staff member or volunteer to allow a family or friend to act as the patient's interpreter, the WWH staff member shall ask the patient to

sign the Waiver of Right to Receive Language or Interpreter Assistance Form (Waiver) attached to this Procedure. The Waiver Form is available in English and Spanish.

2. The staff member or volunteer shall scan a copy of the Waiver into the patient's medical record under "Patient Documents", title it "Year-Month-Date Language Waiver," and change the Global Alert, "Interpreter Needed" to reflect that the patient has requested that a family member or friend serve as the patient's interpreter.
    - **a.** The Waiver will be considered active for as long as the patient is in care at WWH.
    - **b.** The patient may add additional family or friends as requested. The staff member shall follow steps 1 and 2 above.
    - **c.** The patient may cease using previously identified family or friends for interpretation by either simply not bringing them to appointments or formally notifying CSR that they do not wish to use a specific person any longer. If formal notice is provided then the Waiver will be printed and the patient requested to sign and date the form to revoke use of the family or friend for interpretation purposes. The Waiver will be scanned in eCW under "Patient Documents" and titled "Year-Month-Date Interpreter Services Waiver Revoked".
    - **d.** The patient may use an interpreter scheduled by WWH on an ongoing basis by providing advance notice of this intent. If the patient provides this notice then the Global Alert will be modified to state "Interpreter: language".
    - **e.** The patient may decide to use friends/family on some occasions and a WWH scheduled interpreter on other occasions based on either the type of visit scheduled or provider. In this case, CSR will have the Waiver signed and scanned in eCW, and shall set a global alert with the note field stating "Ask Patient if Interpreter Needed".

III. Scheduled Patients: The following procedures identify interpreter services available, how they may be scheduled, and responsibility for initiating payment.

1. CSR shall normally schedule interpreters for medical, dental, and nutrition appointments. The mental health administrative assistant shall normally schedule interpreters needed for mental health, addiction counseling or psychiatry appointments.
2. Public benefits coordinators and medical adherence may schedule interpreters directly or send a Telephone Encounter to "Call Center" requesting an interpreter be scheduled for a scheduled appointment.
3. Public benefits, medical adherence, walk-in providers, and HIV testing and counseling staff should call Pacific Interpreters directly for interpreter services when needed.

The following procedures provide specific direction for obtaining an interpreter:

Pacific Interpreters Language Line

The **Pacific Interpreters Service** should be used when we are unable to order an interpreter from La Clínica del Pueblo. This service is available for staff to utilize anywhere that a phone is located. When a call is made to this number the operator will ask for the access code, language needed, name of the caller, and the patient's account number. Telephonic interpretation is available 24/7, ordering in advance is not necessary.

Medical Use at ETMC: Phone lines are installed in Exam Rooms 3, 9 and 14 if telephonic interpreting is needed for a patient. The phone that sits at the front nurse station is the phone (phone number 6104) that should be plugged in exam room 9. Phones are installed in exam rooms 3 and 14. If the provider is not assigned to the exam room to be used, please coordinate the use of one of these rooms with the Nursing Manager or ask your medical assistant if the Nursing Manager is not available.

Medical Use at MRC: All exam rooms are equipped with phone lines.

Afterhours Nurse Line: Pacific Interpreters should be called and provided the callers number and Pacific Interpreters will initiate a three-way conference call.

1. Dial: **866.421.3463**

2. When the customer service agent answers the phone, they will ask for the following information:
   Access Code: **844225**
   Language Needed
   Caller's Full Name
   Patient's (Medical Record Number) Account Number

3. You will be placed on hold while the agent connects you to an interpreter.

If you have any questions or requests, please call the Client Services Manager/Language Access Coordinator at 202-939-7677 or the Director of Clinical Operations at 202-939-7650, or you may call Susie Hubbard in the sales department at: **800.655.6380** or Mindy Dutka, Account Manager directly.

Account Manager: **Mindy Dutka**
Phone #: **800.311.1232 x5766**
Email address: mindyd@pacificinterpreters.com

UHC Community Plan

Send an email to Melanie Newkirk: melanie.newkirk@uhc.com
Include the same information that you would for an order with La Clinica del Pueblo (i.e., Name, DOB, UHC #, time of appointment, date of appointment, length of appointment, type of appointment).

Amerihealth

Call 888-656-2383 and Press 5 – Ask for the language line
Provider # 601-64-449

Medstar

Language Line

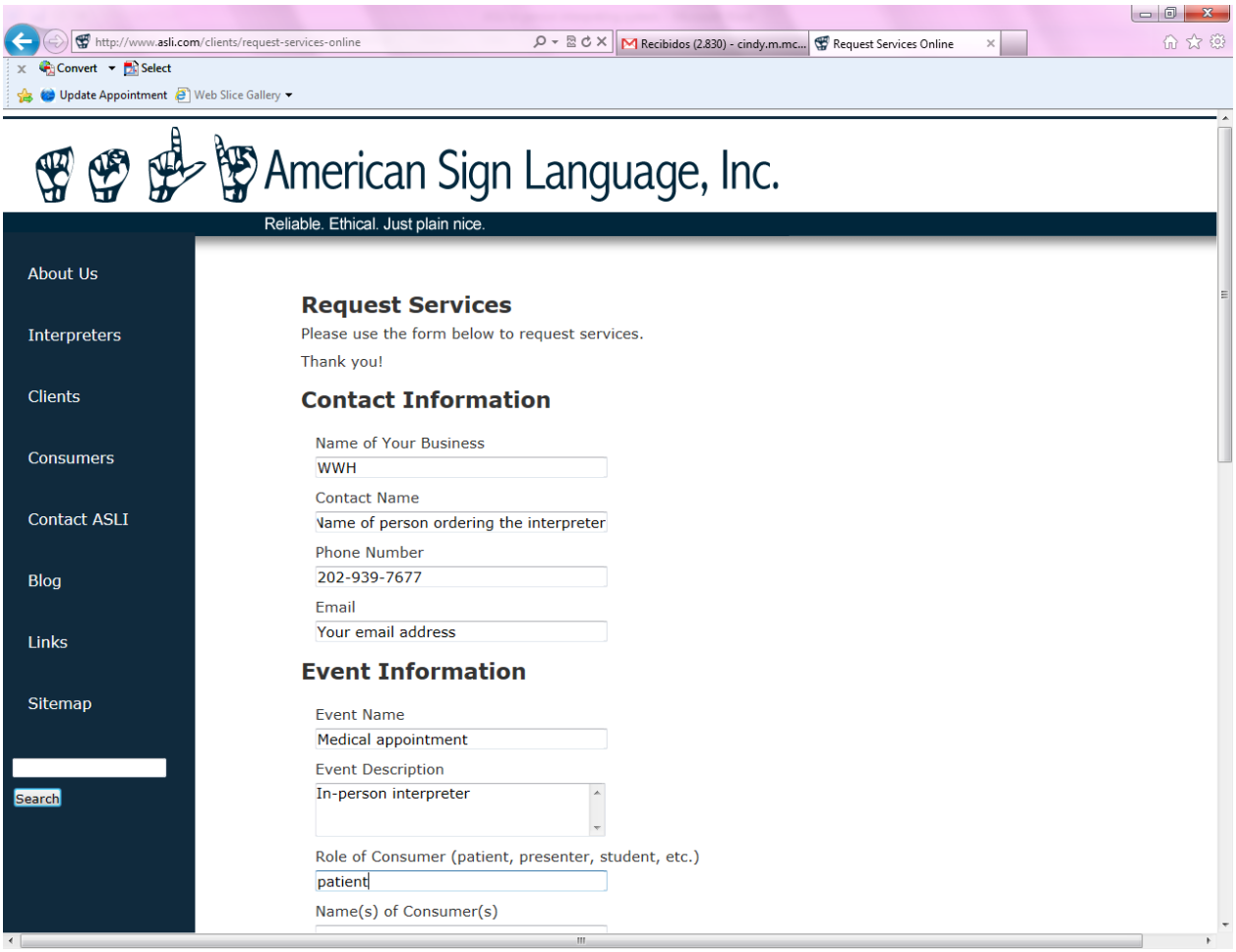
Dial 866-874-3972
Enter Client ID # 211943

- In person language & ASL Orders
  Order from La Clinica

American Sign Language, Inc.

Pre-scheduling an appointment (first choice)

1. Go to website: www.asli.com
2. Click on "Clients."
3. Click on "Request Services Online."
4. Enter requested information.

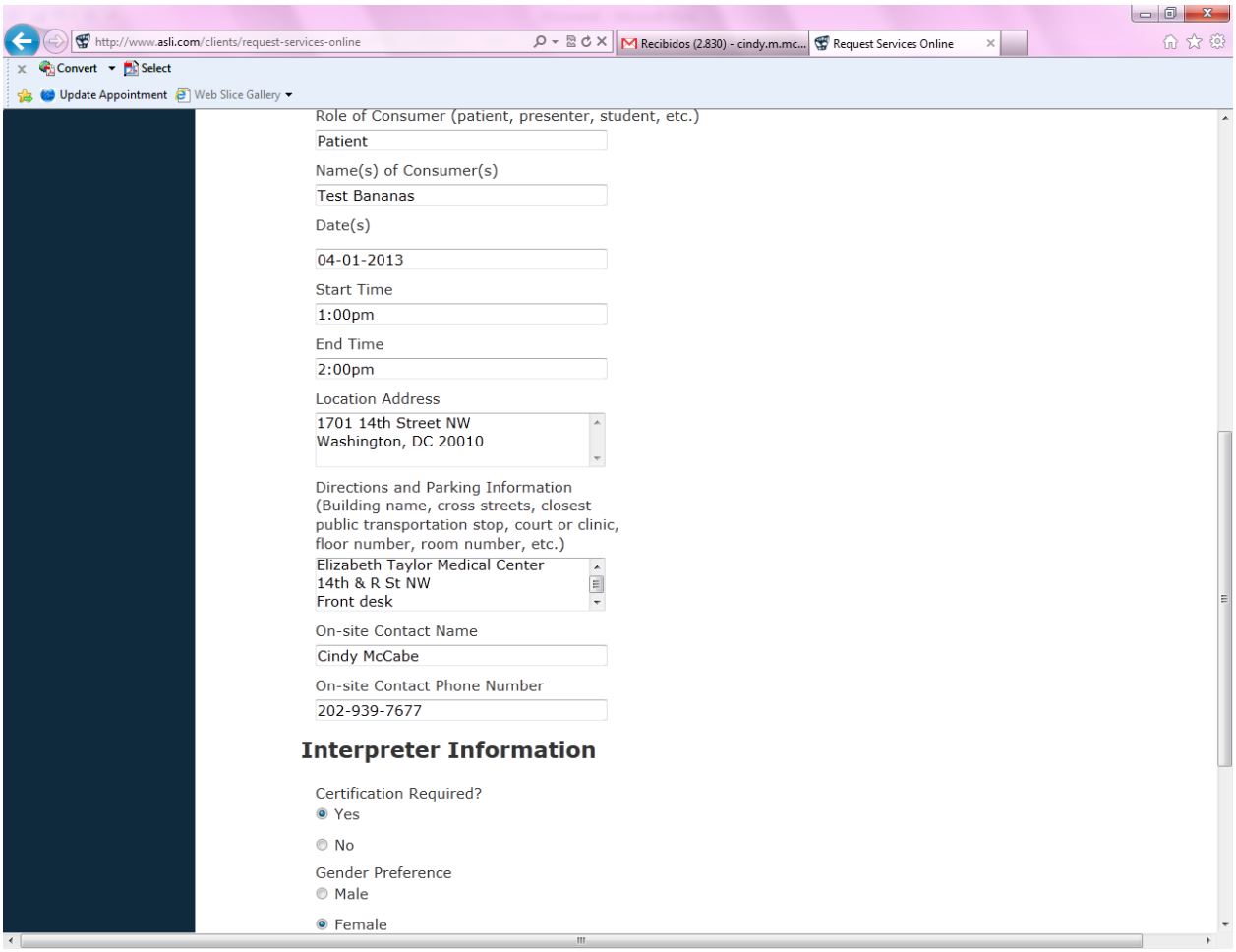


5. Enter your name, phone number, and email address in the "Contact Information" section.

6. In the "Event Information" section, enter the type of appointment (medical/dental/gyn/public benefits/medical adherence/heath screening, etc.)

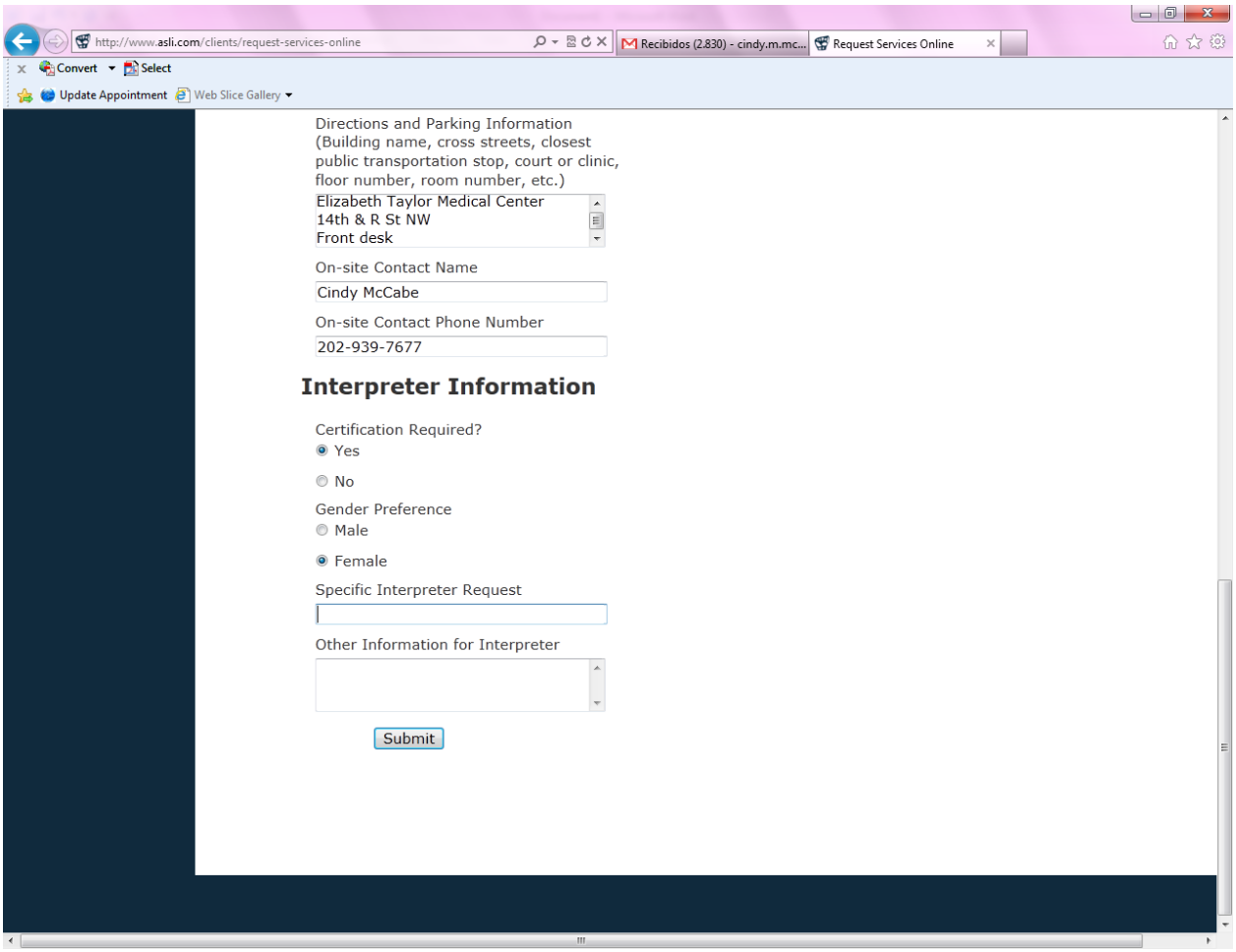
7. In the "Event Description" write either "in-person interpreter" or "video interpreter." Enter the patient's name, the date, and the address for the appointment. Remember that some appointments may be at the Max Robinson Center.

Tip: Be realistic about the end time of the appointment. We will not be charged for unused time, however, the interpreter may have another appointment schedule and may not be able to stay on the site if the appointment goes beyond the requested time.



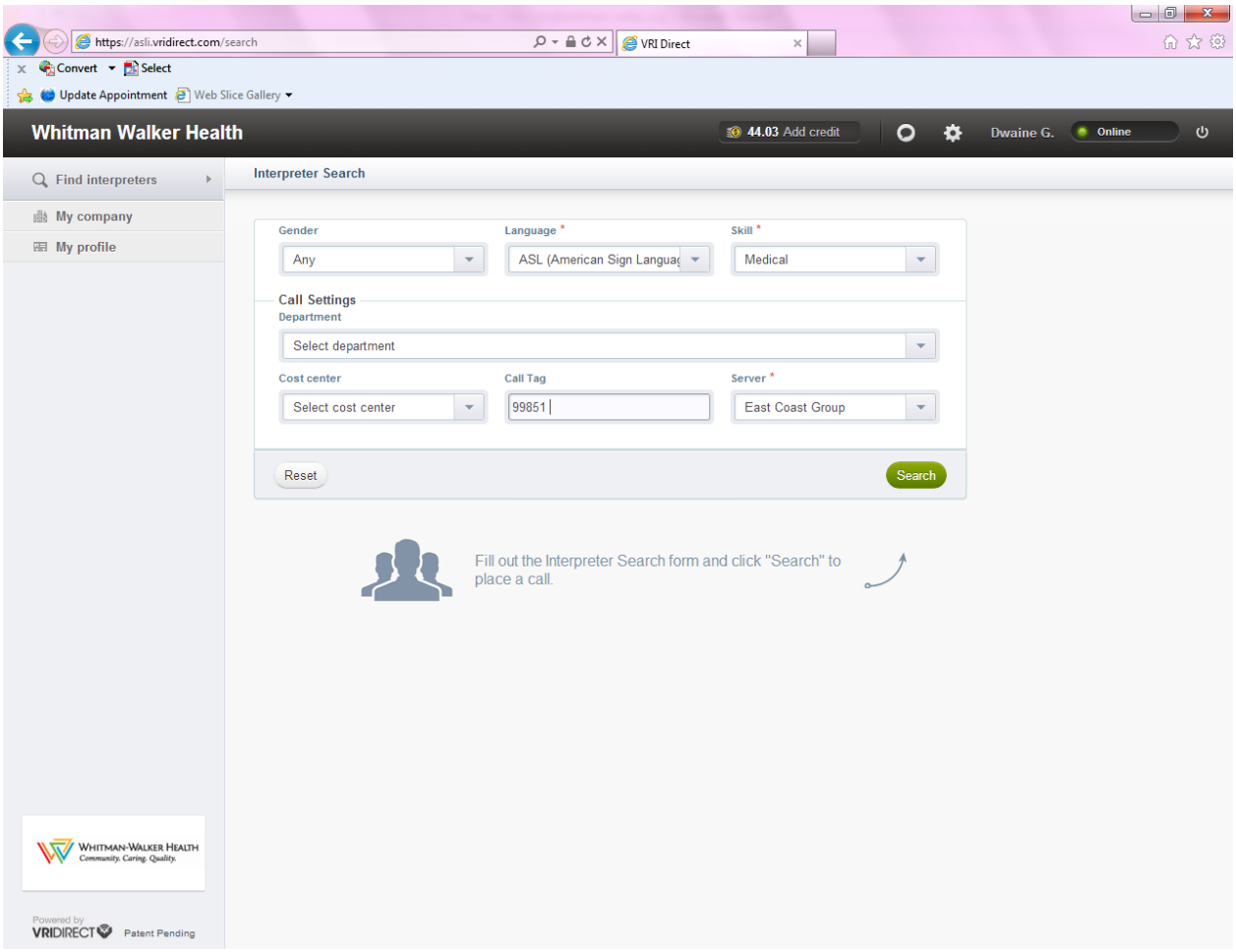
8. For the On-Site Contact Name, enter the information for the Language Access Coordinator.

9. In the Interpreter Information section, enter any specifications and then hit the submit button.



ASLI Video interpreting system

1. Go to website www.asli.vridirect.com
2. Log in: wwh@asli.com
3. Password: walker
4. Click "Login"
5. If needed or requested by patient, select the gender needed.
6. Select your department.
7. In the "Call Tag" space, enter the patient's account number.
8. Click search to see which interpreters are available.
9. If the appointment is prescheduled, the interpreter listed will be named as "WWH" and the time of the appointment.
10. Select the interpreter by clicking the green button.
11. Tip: If video skips, change settings to medium.
12. Tip: Provider should stand out of vision of the laptop to provide the interpreter with full sight of the patient, unless the interpreter cannot hear the provider.
13. Tip: Turn the laptop away from direct sunlight, but be sure the room is sufficiently lit.



La Clínica Language Interpretation Services:

Languages

Individuals who require translation in **Spanish, Amharic, Portuguese, French, Mandarin or Cantonese** require 24 hours advance notice for interpreter orders.

*Individuals who require **Arabic** translation require 1 week advanced notice for interpreter orders.

If possible, schedule appointments consecutively to best utilize interpreter's time. For example, schedule Medical Adherence immediately following or preceding a medical provider appointment, unless otherwise directed by the provider.

Insurance

WWH staff members can arrange for interpreters through La Clínica del Pueblo on behalf of patients with the following insurance coverage:

Medicaid (Chartered, MedStar Family Choice, UHC Community Health Plan)
Alliance (Chartered, MedStar Family Choice, UHC Community Health Plan)
DC Residents who are HIV + and on Ryan White

*Use the Medicaid or Alliance coverage when placing the order if the patient is HIV positive.

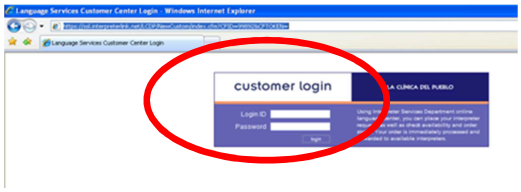
Ordering Interpreters

Orders for interpreters through La Clínica are normally placed by the CSR staff (see III page 3 above). Public benefits coordinators and medical adherence may schedule interpreters directly or send a Telephone Encounter to "Call Center" requesting an interpreter be scheduled for a scheduled appointment. Public benefits and medical adherence staff who schedule an interpreter through La Clínica themselves should enter the order number as documented in step 24 (below) in the scheduled appointment.

1. Access the following website: https://ssl.interpreterlink.net/LCDP/NewCustom/index.cfm?CFID=99892&CFTOKEN=

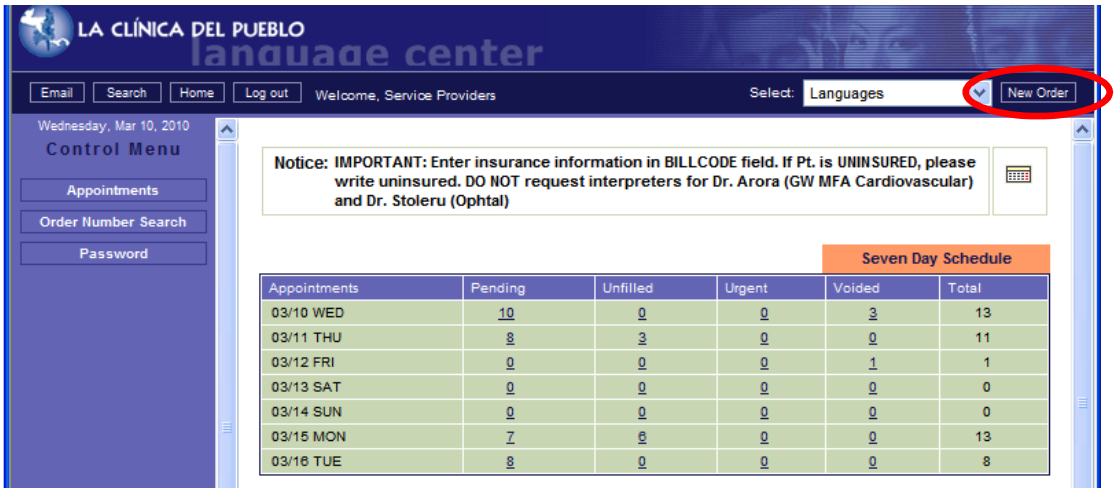
2. Enter Codeword- wwc

3. Enter Login ID – whitman Enter Password - walker



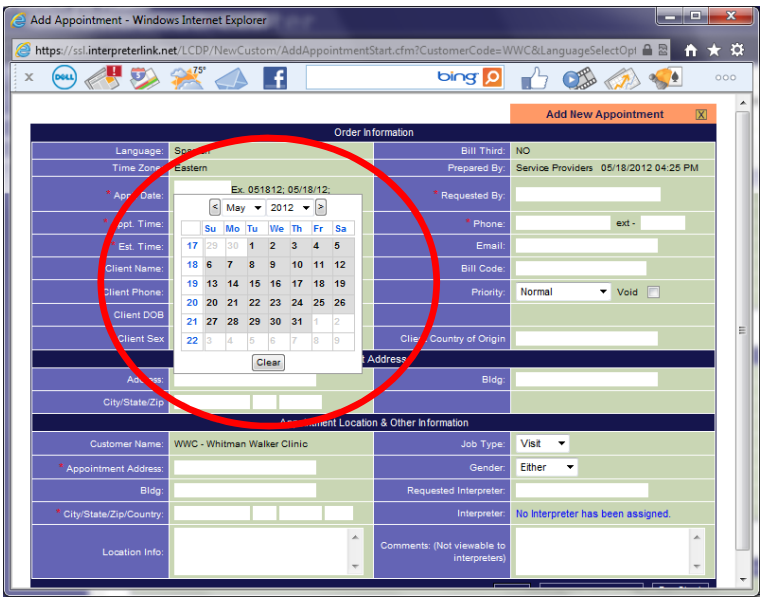
4. Select language

5. Click "New Order"



Information Entered on the LEFT Side of the Order Form:

6. Appt Date: Enter Appointment Date mm/dd/yyy or use calendar to select date:



7. Appointment time: Enter appointment time as hh:mm am or pm (01:30pm, not 1:30pm)

8. Estimated time: Enter estimated time as 1 (one hour), 1.5 (one and a half hours), or 2 (2 hours), etc.

9. Client info: Enter the client's Name, phone number, date of birth, and choose the sex.

10. If the client has MedStar Family Choice, Chartered or UHC Community Plan, you must enter the client's complete address with apartment number and zip code.

11. Appointment address: 1701 14th St NW or 2301 Martin Luther King Jr Ave SE

12. Building: Enter either medical, dental, legal, etc.

13. City/State/Zip/Country: Washington, DC 20009 or 20020

14. Location info: Enter the name of the provider here (e.g. Dr. Smith)

Information Entered on the RIGHT Side of the Order Form:

15. Requested name: Enter your name here (e.g. C McCabe)

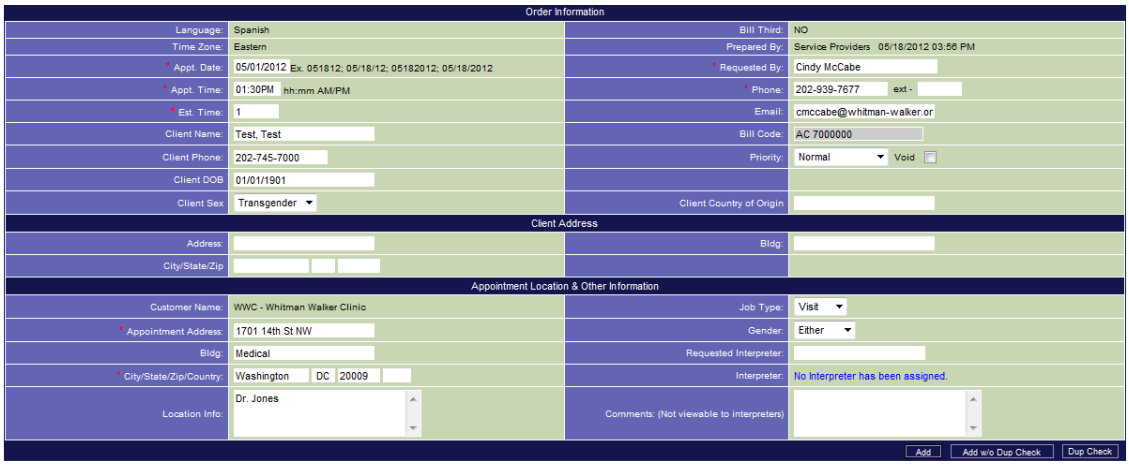
16. Phone: Enter extension for the Client Services Manager (202) 939-7677

17. Bill Code: Enter the client's insurance plan initials and Member ID here: Alliance Amerihealth (AA) Alliance UHC (AU) Alliance Medstar (AM) Medicaid Amerihealth (MA) Medicaid Medstar (MM) or Medicaid UHC (MU). For Example, "AU 7070700" or "MU 7070700."

18. For HIV + patient that do not have Medicaid MCO or Alliance, enter "Ryan White Part A."

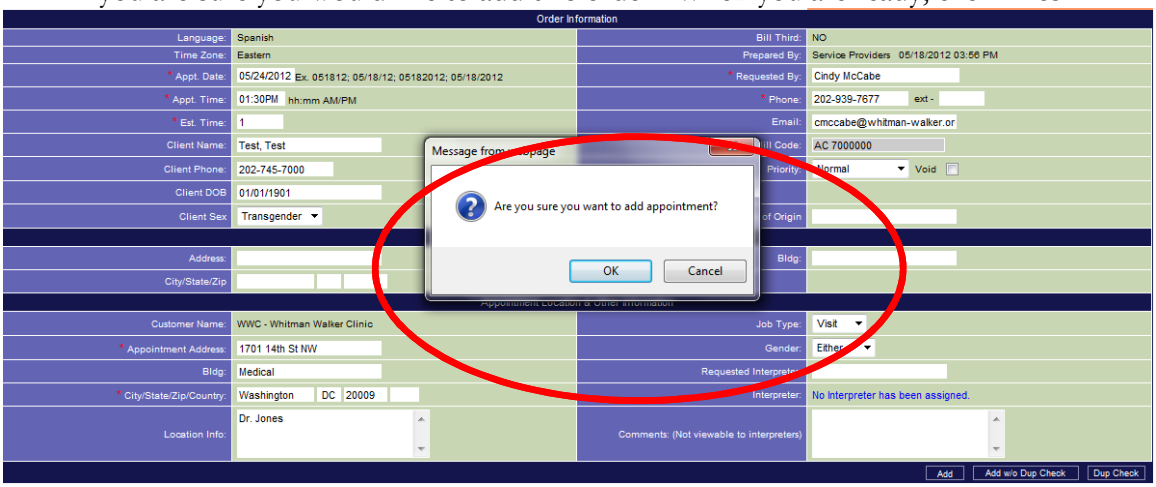
19. Gender: Select "female" ONLY if the client's appointment is for GYN.

20. Double check all information is entered correctly. See the following screen shot for an example of a completed form.

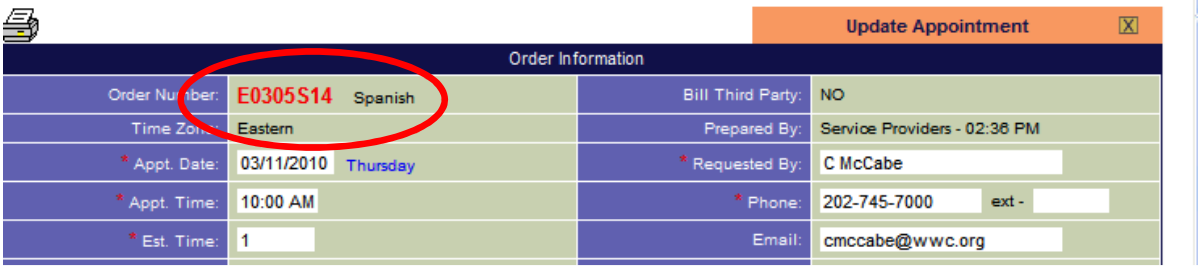


21. After double checking all information, click the button on the lower right side labeled "Add w/o Dup Check."

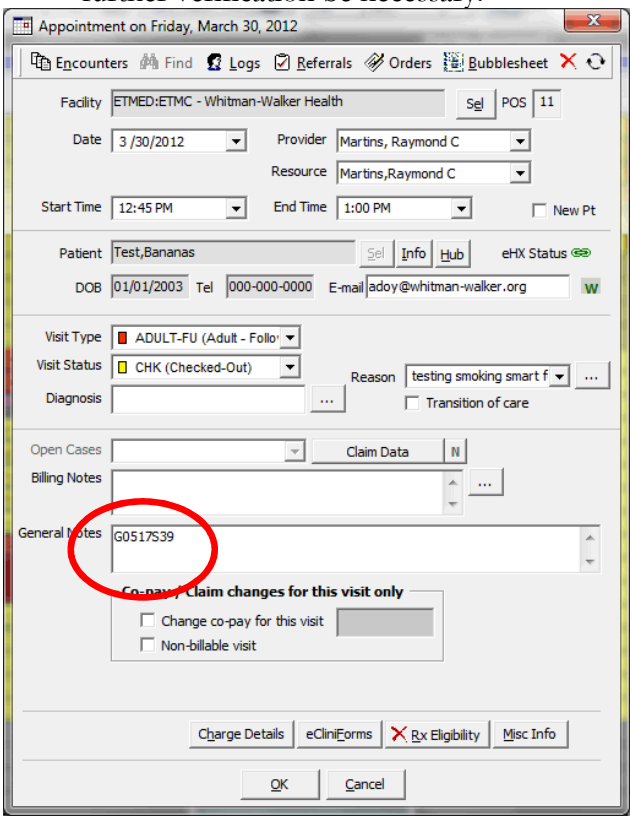
22. There will appear a prompt to ask you either if to correct information entered, or if you are sure you would like to add this order. When you are ready, click "Yes."



23. The screen will now change and the order will appear with a code in red in the upper left corner labeled "Order Number." It will always start with a letter.



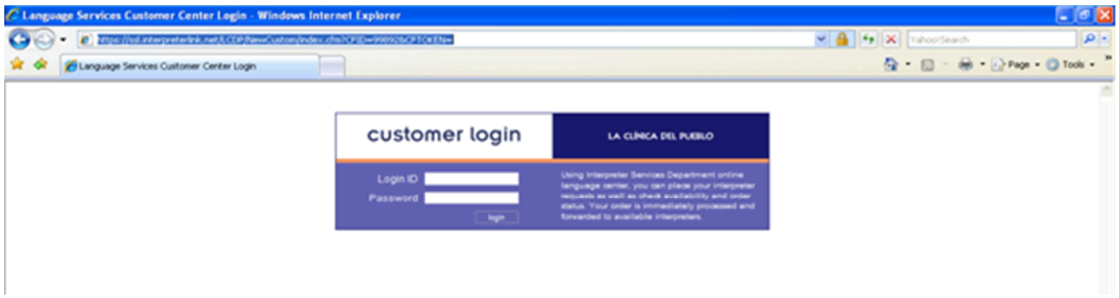
24. This code should be copied down and pasted into the client's appointment should further verification be necessary.



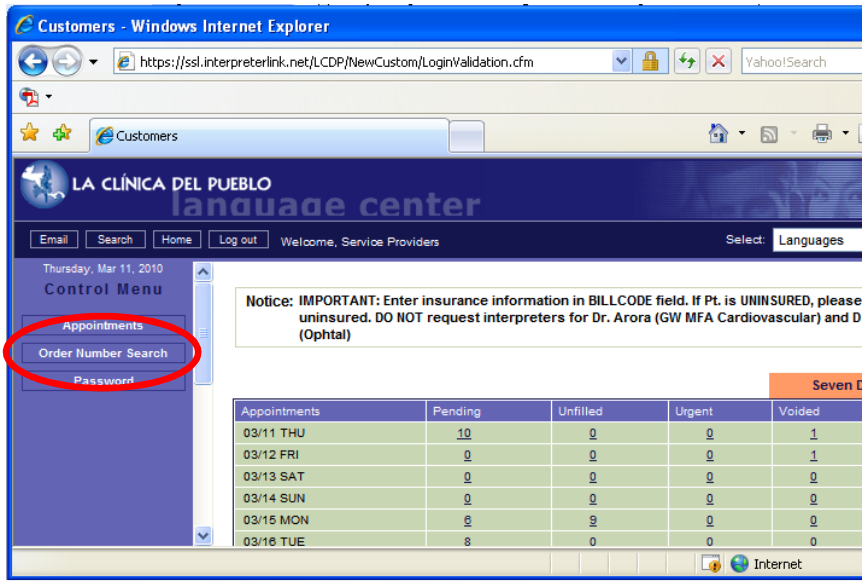
Changing an Interpreter Order:

1. Access the following website: https://ssl.interpreterlink.net/LCDP/NewCustom/index.cfm?CFID=99892&CFTOKEN=

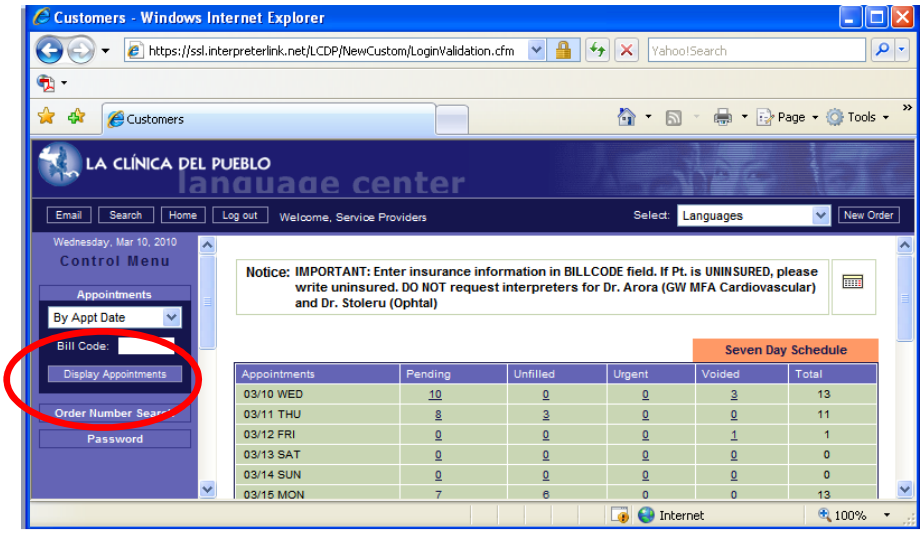
2. Login ID – whitman Password - walker



3. Click on the button labeled "Appointments," on the upper left side.



4. Click on the button labeled "Display Appointments."

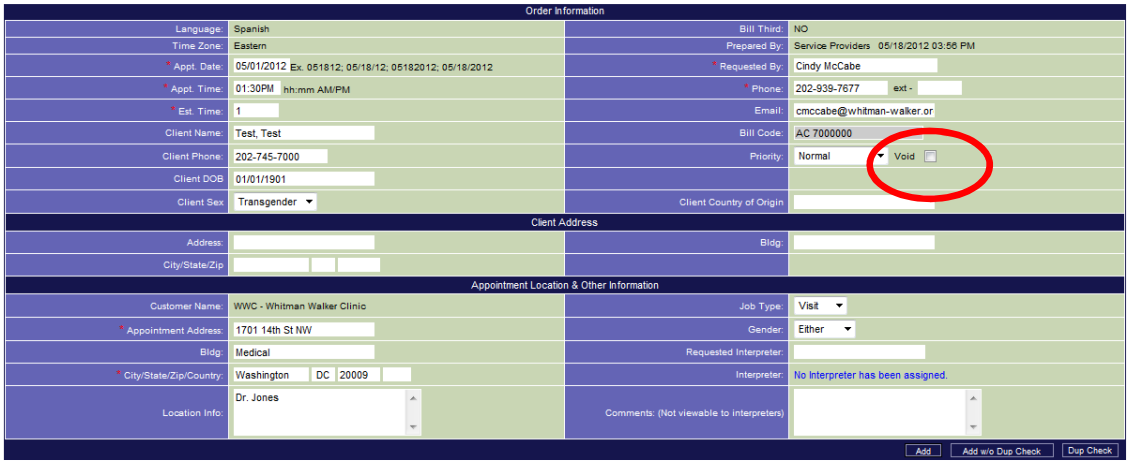


5. Scroll down the list until you find the date of the appointment in question. Click on the interpret code and update the required information. Click update.

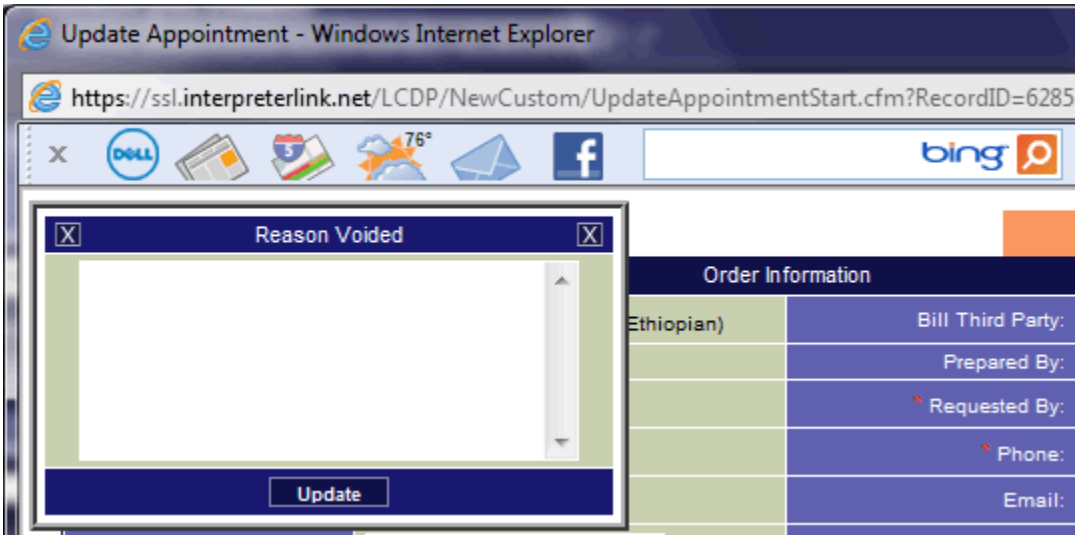
Voiding an Interpreter Order:

1. There must be 24 hours before the appointment in order to void an appointment online. If there is less than 24 hours, call or email Maria Hayaq at (202) 464-0158 mhayag@lcdp.org or Isabelle at Isabel Van Isschot at (202) 464-0157 iisschot@lcdp.org.

2. Check the box next to Void as shown below.



3. Enter in a reason for voiding the appointment, such as "Cancelled by client," in the reason box and click update. Then click "Update w/out dup check."



Off Site-Appointments

1. Referral Coordinators are to identify the need for Interpretation Services by looking in the "Patient Information", "Additional Information" screen in eCW when the referral is scheduled .
2. Referral coordinators shall notify the office where the patient is being sent for the referral that an interpreter is needed and the language the patient speaks.
   2.1. If the office provides interpretation services then it is the office responsibility to provide the interpreter.
   2.2. If the office does not provide an interpreter, then the Referral Coordinator will:
      2.2.1. Consider using a provider that can provide interpretation; or
      2.2.2. Determine if the patient meets the funding eligibility listed in the "Insurance" section above, and if they do then schedule an interpreter as described in this document through "La Clínica Language Interpretation Services". The order number generated is documented in the "notes" section of the referral and is written at the top of the printed referral as well.

Patients speaking unidentified languages

1. Use the yellow I Speak Posters located: 1) ETMC: at check-in behind the cash register or at check-out 2) MRC: under the front ledge at check-in.

2. Show the client the I Speak Cards and the patient should point to the language that they speak. Call the Language line, listed above, and ask for an interpreter in that language.

Addendum

Training

The Language Access Coordinator is available to orient all departments and new staff to the Whitman-Walker language access policy and procedure for ordering interpreters, auxiliary aids or services. New staff should be notified by their department manager and human resources staff upon hire and orientation in their department of the availability of this orientation. The Language Access Coordinator will remind managers via an e-mail to All Managers, at least once per year, of the Language Access Coordinator's availability to orient their department or new staff to the Whitman-Walker language access policy and procedure for ordering interpreters, auxiliary aids or services.

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		WWH Policy Number	
		Statutory Authority	Civil Rights Act
		Effective Date	April 14, 2013
Policy Title	Procedure for Assessing Limited English Language Interpretation And Translation Skills of Staff and Volunteers	Last Date reviewed	
Approved By	Language Access Workgroup Operations Group	Date Approved	

Preamble	
Purpose	The purpose of this procedure is to assure that staff or volunteers who will be providing language interpretation for limited English proficient (LEP) individuals are assessed to assure they are capable of communicating in the person's language.
Policy	Assessment is required for all Whitman-Walker Health (WWH) staff members, contractors and volunteers whose position comprises the following types of language assistance services: in-language communication, interpretation and translation.
Procedure	**When to Assess:** Language proficiency should be assessed/tested during the interview and hiring process. The following assessment is suggested but may be modified based on the department, position and job function of the applicant: **How to Assess:** In-Language Communication: The following is suggested to assess a bilingual person's ability to communicate directly in an LEP person's language: • Prior to interview, candidate reports bilingual experience in resume and other hiring documents • Qualified bilingual departmental staff participate to asses in-language communication skills by speaking to the candidate in the target language. Interpretation: In order to provide interpretation services, which involves rendering a message spoken in one language into another language: • Prior to the interview, the candidate reports interpretation experience in health care in their resume and other hiring documents. • A qualified bilingual staff person conducts an interpreting role play during the interview to assess the candidate's interpreting skills in the context of a setting that the candidate is likely to encounter in the job they are applying for. Translation: The following is suggested to assess qualified translators or bilingual person's ability to translate written text from one language into another: ○ Candidate reports the following credentials: higher education received in native language which attests for strong writing skills, for example: experience translating into native language and/or certification by the American Translator Association ○ Candidate presents materials previously translated ○ Candidate is asked to translate text at interview from English to the target language and also from the target language to English

Attachment A – Language Test Instructions and Questions	Communicate exclusively in the target language with the candidate to see how much they understand and can respond. Provide the second page to the candidate for the oral and written translation portion of the test. **Name of Candidate:** _____ Ask the following questions to the candidate in the language they have identified as being able to speak: • How comfortable are they speaking _____? _____ ___ _____ ___ • What if the patient could speak no English? Would they still be able to communicate? _____ ___ _____ ___ • In the position you are applying for, we collect lots of demographic information –name, address, date of birth, phone, and insurance information. You also will be scheduling appointments and talking about medical issues – do you foresee any concerns about speaking Spanish on these topics? _____ ___ _____ ___ **Oral Translation:** Have the candidate write out the following when you say it to them in Spanish – speak at a normal pace: (1) Name: YOUR NAME (you can spell it for them) (2) Address: 1467 Swann Street NW, Washington, DC 20009 (3) Phone: (202) 244-1489 (4) SSN: 577-90-8096 (5) DOB: 10/18/1967 **Interpretation Role Play: Speak the following sentences, one at a time, and have the candidate interpret them back to you in spoken Spanish.** **(1) Hello, I am Dr. Goldstein.**

	(2) How are you feeling today? **(3) Have you experienced any nausea, vomiting, dizziness, or diarrhea?** **(4) When was your last bowel movement?** **(5) What kind of work do you do?** **(6) Have you been taking your medication consistently?** **(7) Thank you, please go to the end of the hall and turn left to check out and schedule your appointments.**
Attachment B – Oral-Written Language Translation and Assessment	Translate the letter below into _____: Dear Ms. Doe: You recently called Whitman-Walker Health to find a doctor, schedule an appointment, and get help with HIV medication. We have called you several times, but have not been able to reach you. If you are still interested in receiving your medical care here, please call us. We look forward to speaking with you about the services that you need. Thank you for your interest in Whitman-Walker Health. Sincerely, Candidate Name:_____ Date: _____

REVIEWED BY Operations

_____

Team/Committee/Manager Date

APPROVED BY:

_____

Name Title Date

WHITMAN-WALKER HEALTH
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WWH Language Access

Legal Requirements

- -Whitman-Walker Health (WWH) has adopted a Language Access Policy ensuring that the organization complies with Title VI of the Civil Rights Act of 1964, Guidelines issued by the Department of Health and Human Services, and the District of Columbia Language Access Act of 2004.

Civil Rights Act

Title VI of the Civil Rights Act of 1964 states that "No person shall, on the grounds of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance."

The Supreme Court has ruled that Title VI prohibits conduct that has a disproportionate effect on Limited English Proficient (LEP) persons because that would constitute national origin discrimination.

DC Language Assistance Act

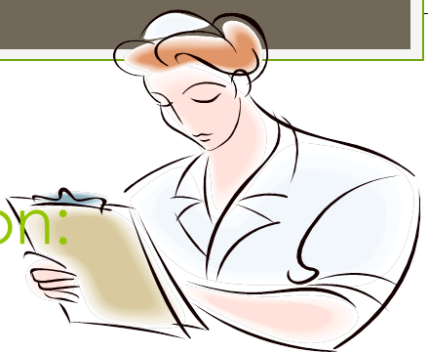
- The DC Language Access Act of 2004 also affords individuals with limited or no-English proficiency greater access and participation in public services, programs, and activities by requiring that District government programs, departments, and services to assess the need for, and offer, oral language services; and to provide written translations of documents when thresholds are met.
- WWH has adopted a Language Access Plan and written policies and procedures to ensure compliance with the Civil Rights Act and the DC Language Assistance Act.

DHHS Guidelines

- The Department of Health and Human Services (DHHS) has issued Guidelines to HHS grantees such as WWH. Under the Guidelines, WWH must take reasonable steps to ensure that LEP patients receive interpretation and translation services necessary to afford meaningful access to WWH's services.

- WWH balances the following four factors in determining the scope of services it provides to LEP patients:

(1) The number or proportion of LEP persons eligible to be served or likely to be encountered.
(2) The frequency with which LEP individuals come in contact with WWH.
(3) The nature and importance of the services provided by WWH to the lives of the persons served.
(4) The resources available to WWH.



Important Definition:

- *Limited English Proficient* (LEP) describes someone who is unable to speak, read, write or understand the English language at a level that permits him/her to interact effectively with health and social service agencies and providers. This also includes the deaf or hearing impaired community.

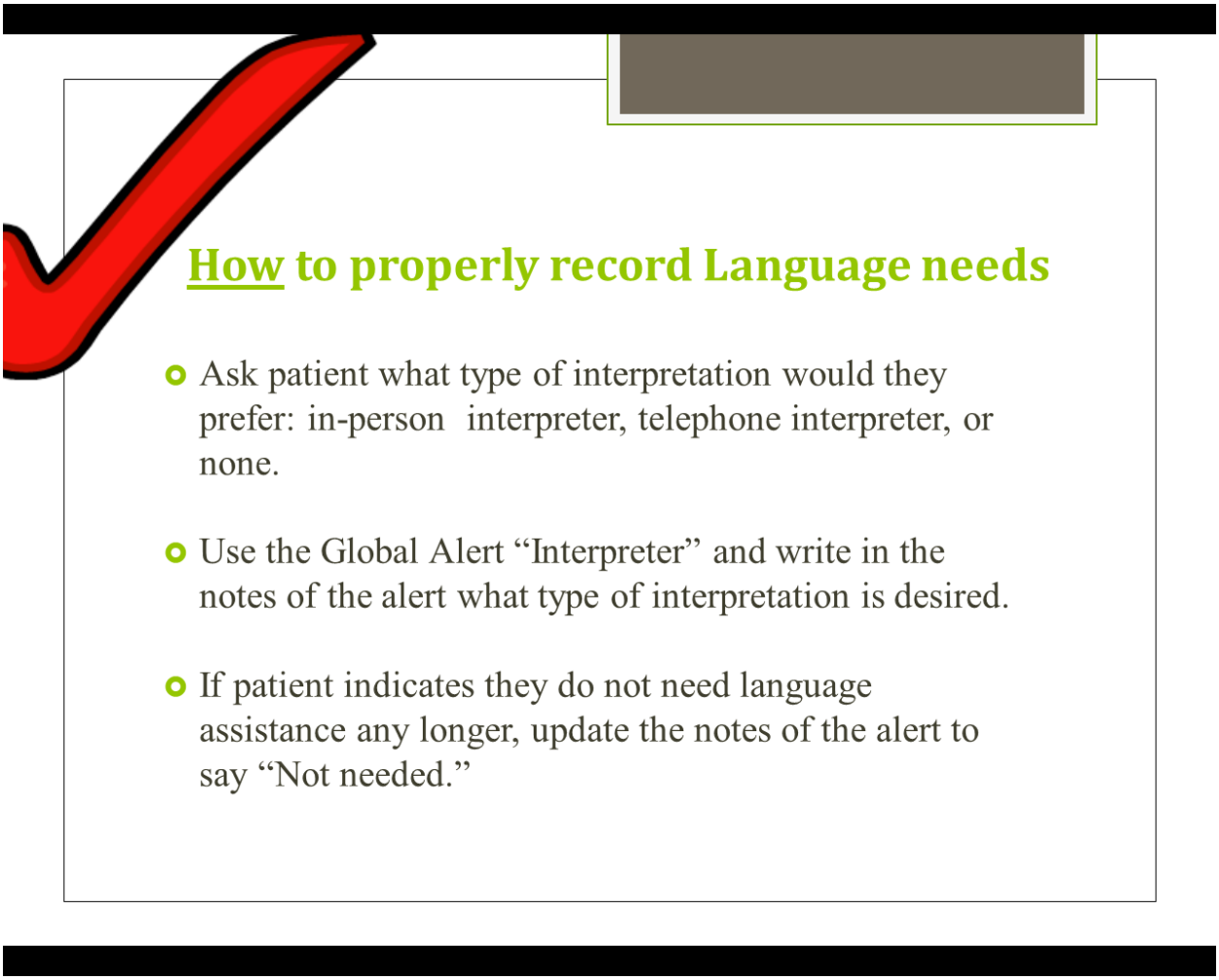
Source: Department of Justice

Who makes the change?

- Primarily ***Intake staff***, but also anyone creating new patient accounts must select Language.
- If the patient does not speak English, we will need to ask for more information. If they speak Spanish or Amharic, we have intake staff that can help find out what kind of assistance they need. If they speak another language, we will need to use our phone line to find out what they need.

When do we identify needs?

- When creating a new patient record in eCW.
- If the patient learns English proficiently.
- Anytime you notice a discrepancy.


How to properly record Language needs
Ask patient what type of interpretation would they prefer: in-person interpreter, telephone interpreter, or none.
Use the Global Alert "Interpreter" and write in the notes of the alert what type of interpretation is desired.
If patient indicates they do not need language assistance any longer, update the notes of the alert to say "Not needed."

Who do I notify if there is an error?

- *Any Staff* who become aware in the course of service delivery that the pateint's language needs are not reflected correctly should notify the Language Access Coordinator to update eCW.

Family/friend Interpreters

- Advise the patient that they are entitled to have a professional interpreter rather than using their family or friends.
- Interpreters go through intensive training, not on languages, but on how to properly interpret. Fluency in a language does not prepare you to interpret.
- Professional interpreters are bound by confidentiality requirements.
- Many WWH appointments concern serious matters. We are liable if the information is not passed accurately to the patient.

What if they insist?

- If the patient refuses professional interpretation, encourage the use of telephone interpretation.
- If the patient insists, they will need to sign a waiver releasing WWH from liability of inaccurate interpretation.
- The patient's waiver form must be scanned into the EMR/patient documents.
- Advise the patient that we will need to reschedule the appointment if their personal interpreter does not show.

What interpretation is available?

แล้วเจอกัน

- La Clínica del Pueblo: In-Person Interpretation
  - **Spanish, Amharic, Portuguese, French, Mandarin or Cantonese** require 24 hours advance notice
  - Medicaid (Amerihealth, MedStar Family Choice, Trusted)
  - Alliance (Amerihealth, MedStar Family Choice, Trusted)
  - DC Residents who are HIV + and on Ryan White

Who orders interpreters?

- Anyone can order an interpreter!
- If you need assistance, please send an open telephone encounter to the box named "Call Center"

Interpretation available

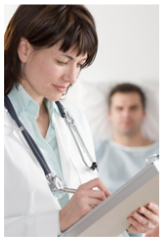
- Telephone Interpretation: Any patient in any room with a phone and phone jack.
- Sign Language: In-person and Video through ASLI
  - In-person order placed through website
  - Video service available in real time

WWH Staff interpretation

- Should only be used to gather information such as demographics in order to schedule an appointment with a professional interpreter
- If patient's language is unknown, use the "I Speak" cards at the front desk at ETMC and MRC.

Recording Interpretation

- Every time a provider communicates with a consumer through an interpreter of any type, they should document this in their progress notes.



Going Forward

- Any feedback, questions or concerns should be directed to me.
- This is a work in progress and we need your cooperation and input.