American Cancer Society ☙ Children's Defense Fund-New York ☙ Coalition for Asian American Children and Families ☙ Community Service Society of New York ☙ Consumer's Union ☙ Empire Justice Center ☙ Make the Road New York Medicare Rights Center ☙ Metro New York Health Care for All Campaign ☙ New Yorkers for Accessible Health Coverage ☙ New York Immigration Coalition ☙ Public Policy and Education Fund of New York/Citizen Action of New York ☙ Raising Women's Voices-New York ☙ Schuyler Center for Analysis and Advocacy ☙ Small Business Majority

November 9, 2015

Department of Health and Human Services
Office for Civil Rights
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue S.W.
Washington, D.C. 20201

Re: 1557 NPRM (RIN 0945–AA02) – Proposed rule regarding nondiscrimination in health programs and activities

Dear Sir/Madam:

Health Care For All New York (HCFANY) respectfully submits the following comments to the Department of Health and Human Services (HHS) Office for Civil Rights (OCR) in response to the Notice of Proposed Rulemaking released on September 8, 2015.

HCFANY is a statewide coalition of over 170 organizations dedicated to achieving quality, affordable health coverage for all New Yorkers. We strive to bring consumer voices to the policy conversation, ensuring that the concerns of real New Yorkers are heard and reflected. For more information on HCFANY, visit us on the web at **www.hcfany.org**.

HCFANY greatly appreciates the opportunity to provide comments on the proposed regulations. The proposed regulations include many important steps forward for consumers. HCFANY applauds the Department for strengthening the rule's nondiscrimination protections in all federally funded, supported and conducted health programs and activities. Discrimination in health coverage and care prevents many individuals from getting the care they need to stay healthy and directly contributes to health disparities in our communities. HCFANY strongly supports the rule's prohibition on discrimination on the basis of race, color, national origin (including immigration status and language), sex (including sex stereotyping and gender identity), disability, and age. Our comments highlight advances for consumers, as well as areas where the regulations could still be strengthened.

Application & Exclusions (§ 92.2)

The rule states that Section 1557 applies to every health program or activity with limited exemptions. HCFANY supports the rule as written.

HCFANY strongly opposes adding any new exemption that would permit discrimination in health care delivery or coverage based on religious views. There is nothing in the legislative history or language of the Affordable Care Act itself that permits exemptions to Section 1557's prohibition on sex discrimination. Existing exemptions in other laws have enabled health providers and insurers to refuse to provide an array of health care services, resulting in a disproportionate negative impact on women and lesbian, gay, bisexual or transgender (LGBT) people. Access to reproductive health care is a matter of sex equality, and health care refusals involving reproductive health care and services constitute impermissible sex discrimination.

Religious exemptions often result in harmful health outcomes. Women in particular suffer from public policies that allow hospitals, clinics, pharmacies and health insurers to refuse to provide or pay for services to which they have an institutional religious or moral objection. Women can be left with no coverage for, or access to, basic reproductive health services, such as contraception, sterilization, infertility services or abortion care. For example, women suffering miscarriages and ectopic pregnancies have been turned away from hospital emergency rooms or sent miles away to other hospitals when a religiously-sponsored hospital refuses to provide emergency reproductive health care on religious grounds. In some areas of the country, where the only available hospitals operate under religious health care restrictions, women have no option for a post-partum tubal ligation, even when their doctors have recommended it for medical reasons.

Women are also still facing problems accessing the contraceptive method that best serves their health and needs because of religiously-based refusals by employers or insurers. For example, recently in New York, a woman was denied coverage for an IUD despite her doctor assuring her it would be covered by her employer's health plan. She needed the IUD to regulate abnormal bleeding. The IUD, its insertion, and the removal of the previous device cost her nearly $2,000. The woman, who works for a school run by the Catholic Diocese, is currently prevented from obtaining contraceptive coverage due to an ongoing court case related to the preventive services religious exemptions.[1]

Recommendation: HHS should not add any new exemptions based on religious views or moral objections to the nondiscrimination protections of the rule.

[1] *Catholic Health Care System v. Burwell*, 796 F.3d 207, 215 (2d Cir. 2015)(noting that enforcement of the contraceptive coverage mandate is enjoined).

Definitions (§ 92.4)

The proposed rule defines "on the basis of sex" to include pregnancy, false pregnancy, termination of pregnancy, or recovery therefrom, childbirth or related medical conditions, sex stereotyping, or gender identity.

HCFANY supports the rule's prohibitions on discrimination on the basis of sex and its definition. We strongly support the proposed regulation's definition of "on the basis of sex" to include discrimination on the basis of "pregnancy, false pregnancy, termination of pregnancy, or recovery therefrom, childbirth or related medical conditions." HCFANY also supports the rule's inclusion of sex stereotyping and gender identity in the definition of sex discrimination.

Recommendation: HCFANY strongly urges HHS to add sexual orientation to the definition of "on the basis of sex."

Assurances required (§ 92.5)

The notice of proposed rulemaking (NPRM) requires covered entities to submit an assurance that their health program or activity will be operated in accordance with Section 1557 (i.e. will uphold the nondiscrimination statute).

HCFANY strongly supports the rule's requirement that institutions receiving federal funds comply with Section 1557. In addition, HCFANY recommends that HHS add a specific data collection requirement in §92.5 (or create a separate regulatory section governing data collection). Covered entities should be required to collect data on race, ethnicity, language, sex, gender, gender identity, sexual orientation, disability status, and age. In New York State, HCFANY is advocating to the New York State of Health Marketplace to collect sexual orientation and gender identity data to ensure that our Marketplace is adequately serving the needs of LGBT people as they enroll in coverage and seek care. Demographic data collection will be especially important as we move towards a health care payment system that rewards quality rather than quantity.

Recommendation: HCFANY recommends that HHS add a specific data collection requirement in §92.5, or create a separate regulatory section governing data collection.

Notice Requirement (§ 92.8)

This section requires entities to notify the people they serve and the general public about a number of provisions, including but not limited to: (1) that the covered entity does not

discriminate on the basis of sex; (2) that auxiliary aids such as interpreters and language assistance services are available; and (3) that aids and services for those with visual and auditory impairments are available.

HCFANY supports the Department's requirement that covered entities notify beneficiaries, enrollees, applicants, and members of the public that the covered entity does not discriminate on the basis of sex and disability.

However, HCFANY urges the Department to add a requirement related to religious accommodations and exemptions currently in law. As noted above, religiously-based exemptions based on other statutes are already in effect and these exemptions result in numerous barriers for women accessing reproductive health care.

While covered entities are required by § 92.8 to notify beneficiaries, enrollees, applicants, and members of the public that they provide auxiliary aids and services for communication for people who have vision or hearing impairments, the regulation does not go beyond these two impairments to provide notice of how a person would obtain other accommodations such as modifications to policies, practices or procedures required by §92.205 that people with cognitive impairments, mental health disabilities, learning disabilities or intellectual disabilities might require. For example, programmatic access could include flexibility in scheduling as an accommodation. The notices should mention other types of accommodations, and indicate that the accommodations listed are nonexclusive.

Recommendations: HCFANY urges the Department to add requirements to notify beneficiaries, enrollees, applicants, and members of the public that (1) the covered entity has obtained a religious accommodation or exemption to Section 1557; and (2) a person may obtain other accommodations such as modifications to policies, practices or procedures required by §92.205 that people with cognitive impairments, psychiatric learning disabilities or intellectual disabilities might require.

Discrimination Prohibited (§ 92.101)

This section prohibits discrimination "on the basis of race, color, national origin, sex, age, or disability" in health programs and activities. It enumerates some specific instances in which discrimination is prohibited, such as State-based Marketplaces and Federally-facilitated Marketplaces, but also emphasizes that it is not an exhaustive list of situations. HCFANY supports the prohibition of discrimination in health programs and activities as outlined in this section.

In particular, HCFANY supports the requirement that covered entities provide equal access to its health programs or activities without discrimination on the basis of sex and that they treat individuals consistently with their gender identity. The final rule should add that access without discrimination on the basis of sex includes equal access without discrimination on the basis of pregnancy. Pregnant women have experienced considerable discrimination in accessing certain health care services such as mental health care and drug treatment services.[2]

HCFANY supports this section's prohibition of discrimination based on national origin. To be effective, HHS should clarify in regulations implementing Section 1557 that it has the explicit authority to enforce the statutory and regulatory provisions that are based on the principles articulated in the Tri-Agency Guidance.[3] The Guidance, which limits inquiries regarding immigration status and Social Security numbers from family members not applying for assistance (i.e. Medicaid, CHIP, TANF and SNAP), invokes the federal civil rights laws when it notes, "[t]o 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." In Section 1557, the authority to address disparate, effect-based discrimination resides in the invocation of Title VI and other civil rights statutes.[4] HCFANY supports HHS's authority to do so.

To prevent discrimination on the basis of national origin, the final rule should provide explicit oversight for protecting confidentiality and limiting the inappropriate collection, use, and disclosure of personally identifiable information from non-applicants, such as Social Security numbers or citizenship or immigration status information, that deter ineligible immigrants from applying on behalf of eligible family members. What's more, HCFANY believes it is critical that

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[2] *See e.g.*, J. Marsh et al., *Increasing Access and Providing Social Services to Improve Drug Abuse Treatment for Women with Children*, 95 ADDICTION 237 (2000). In 2011, only 12.7% of substance abuse treatment facilities in the U.S. included programs for pregnant or postpartum women. U.S. DEPT. OF HEALTH AND HUMAN SERV., 2011 NATIONAL SURVEY OF SUBSTANCE ABUSE TREATMENT SERVICES 4 (2011), *available at* http://wwwdasis.samhsa.gov/webt/state_data/US11.pdf. In addition, only 19 states have drug treatment programs specifically targeted to women. *State Policies in Brief: Substance Abuse During Pregnancy*, GUTTMACHER INST. (OCT. 1, 2015), http://www.guttmacher.org/statecenter/spibs/spib_SADP.pdf. *See also* Andrew Solomon, *The Secret Sadness of Pregnancy with Depression*, N.Y. TIMES (May 28, 2015), http://www.nytimes.com/2015/05/31/magazine/the-secret-sadness-of-pregnancy-with-depression.html?_r=0 (discussing doctors' reluctance to treat pregnant women suffering from depression).

[3] 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.

[4] Dept. 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))).

Marketplaces, Medicaid, and the Children's Health Insurance Program (CHIP) be brought under the rubric of Section 1557 rulemaking to make available to these families the accountability and enforceability mechanisms of the HHS Office for Civil Rights. OCR must have the authority to use civil rights mechanisms to prohibit states from enacting or otherwise enforcing policies or practices that frustrate the ACA's purpose or its ability to reach eligible applicants.

Recommendations: HCFANY recommends that (1) the final rule adds that access without discrimination on the basis of sex includes equal access without discrimination on the basis of pregnancy; (2) the final rule amends § 92.101(a)(1) to include the following language: "Except as provided in Title I of the ACA, an individual shall not, on the basis of race, color, national origin, sex, age, or disability, be excluded *or deterred* from participation in, be denied the benefits of, or otherwise be subjected to discrimination under any health program or activity to which this part applies"; and (3) the final rule amends § 92.101(b)(1) to include the following language: "Each covered entity must comply with the regulation implementing Title VI, at § 80.3(b)(1) through (6) of this subchapter, *as well as 42 USC 18081(g) and 45 C.F.R. § 155.260(a)(1), § 155.260(a)(2), § 155.305(f)(6), § 155.310(a)(2), and § 435.907(e).*"

Meaningful access for individuals with limited English proficiency (§ 92.201)

This section requires that covered entities "take reasonable steps to provide meaningful access to each individual with limited English proficiency." This includes providing language assistance services free of charge, and excluding some individuals as interpreters, such as a companion of the individual with limited English proficiency.

The availability of language services is vitally important to immigrants and their families as they try to access health care services, and HCFANY supports the rule's specific requirements to ensure meaningful access for individuals with limited English proficiency. In particular, we support the definition of qualified interpreter, and we suggest adding a definition of a qualified translator. Further, HCFANY strongly supports including specific thresholds for translating written documents to ensure minimum standards exist that would directly aid in evaluating compliance and enforcement. Finally, HCFANY supports the requirement to use taglines, but recommends that covered entities include taglines in the top 15 languages in their state/service area rather than the proposal to only include the top 15 languages nationally. In many states, the top 15 languages nationally will not be useful for informing local limited English proficient communities.

Recommendations: HCFANY recommends that the final rule: (1) add a definition of a qualified translator; (2) add quantitative thresholds for translating written documents; and (3)

require that covered entities include taglines in the top 15 languages in their state or service area, rather than nationally.

Accessibility Standards for Buildings and Facilities (§ 92.203)

This section requires that buildings and facilities meet standards of physical accessibility for people with disabilities, "so as to be readily accessible to and usable by individuals with disabilities."

While the proposed regulation does have accessibility standards for buildings and facilities which adopt the 1991 and 2010 Standards for Accessible Design, it does not have any standards for accessible medical and diagnostic equipment. HCFANY urges HHS to add requirements for accessibility to equipment in addition to facilities.

The Access Board[5] is developing accessibility standards for medical diagnostic equipment, including examination tables and chairs, weight scales, radiological equipment, and mammography equipment, which should be incorporated into these regulations. Inaccessible exam tables and weight scales prevent participation by people with disabilities, deny them the benefits of health programs and activities, and result in discrimination as the following examples illustrate:

- A wheelchair user was asked if she would be able to get on the exam table herself because staff were not allowed to lift. She actually has crutches in addition to her motorized wheelchair and was able to transfer, but when an adjustable height exam table has been available the experience of her medical appointment has been much less stressful.

- "My daughter has cerebral palsy. She uses a wheelchair and can't walk or transfer out of her chair by herself. She is overweight and needs a diet and treatment for diabetes. When we went to the hospital clinic, they wanted me to lift her out of her chair and onto the regular scale to be weighed. I can't do it and they don't have a scale that can take her chair on it. So they just didn't weigh her."

Recommendations: HCFANY recommends that the final rule add the Access Board's standards for equipment accessibility into this section.

Accessibility of Electronic and Information Technology (§ 92.204)

[5] The Access Board is an independent federal agency that promotes equality for people with disabilities through leadership in accessible design and the development of accessibility guidelines and standards.

This section directs entities to ensure "their health programs or activities provided through electronic and information technology are accessible to individuals with disabilities."

HCFANY is concerned that, as proposed, the rule on electronic and information technology would focus on nondiscrimination and accessibility for individuals with disabilities at the expense of other protected groups.[6] Section 1557 is not limited to discrimination on the basis of disability alone; accordingly, the rule on electronic and information technology should cover and prohibit discrimination on the basis of *all* enumerated grounds, including discrimination based on sex and age, as well as disability. HCFANY urges the Department to require covered entities to implement privacy safeguards to comply with Section 1557 in their use of electronic and information technology.

While all individuals who engage in the health care system have an interest in the privacy and confidentiality of their health information, these concerns can be particularly salient for women, young adults, individuals affected by domestic violence and those who are LGBT. People with behavioral health and substance use disorders are also often concerned about their health information being shared, and additional legal protections are needed for information related to these diagnoses and treatments. Sensitive health information can be used by employers and others to discriminate against women, LGBT people, and others. Privacy concerns can therefore lead individuals to avoid care or delay seeking care, which can be particularly damaging for women who need time-sensitive reproductive health services.

Specific examples that are important for women include health insurance billing and claims processing procedures widely used today—notably the practice of sending "explanation of benefits" forms (EOBs) to a policy holder whenever care is provided under his or her policy. These practices unintentionally but routinely violate confidentiality for anyone enrolled as a dependent on someone else's policy. This is a very big concern for women who are seeking services like family planning and reproductive health care. Women may not want their partners to know about their contraceptive use or request for a sexually-transmitted infection test. A woman's safety may even be threatened if an abusive partner finds out that she is receiving care that he/she does not know about.

Further, the perception of lack of confidentiality in reproductive health care can lead to considerable harm. For example, someone who forgoes or even just delays testing and treatment for STIs out of fear of disclosure puts not only himself or herself at risk, but his or her partners as well. In addition, a pregnant woman who is concerned that her partner will learn that she is

[6] Nondiscrimination in Health Programs and Activities NPRM, proposed § 92.204 (Sept. 8, 2015); Nondiscrimination in Health Programs and Activities NPRM, 80 Fed. Reg. 54172, 54187-88 (Sept. 8, 2015).

pregnant may delay entry into prenatal care, with potentially serious consequences for her health and for that of a future child.

Fear of disclosure may prevent young women who are insured as dependents on a parent's policy from using their insurance to pay for an abortion or other services, leaving them without the resources to pay for needed care. In those circumstances, lack of confidentiality is the equivalent to a de facto parental notification requirement, a provision that has been shown to create serious impediments for many teens (and young adults, in this scenario). Some teens who are denied confidential abortion services delay having the procedure, which threatens their health and results in later, more costly abortions. Others may seek help outside the formal health care system, leaving them vulnerable to unsafe services.

Recommendation: HCFANY urges the Department to require covered entities to implement privacy safeguards to comply with Section 1557 in their use of electronic and information technology.

Equal Program Access on the Basis of Sex (§ 92.206)

Section §92.206 of the proposed rule requires covered entities to treat all individuals equally, regardless of gender, gender identity or gender expression, and to provide them with equal access to health programs and activities. HCFANY strong supports this section.

We strongly support the recognition that health services ordinarily associated with one gender such as cervical pap smears or prostate exams may not be denied or limited based on the fact that an individual's sex assigned at birth may differ from the individual's current gender identity or current gender expression. But HCFANY urges HHS to clarify that the circumstances under which sex-specific programs and activities are nondiscriminatory and thus permissible under Section 1557 are narrow. Consistent with Section 1557's broad nondiscrimination purpose, sex-specific programs may be permissible only when they are narrowly tailored and *necessary to accomplish an essential health purpose*. HCFANY recommends that HHS adds this language to the final rule.

In New York, the Department of Financial Services, the state's insurance regulator, issued guidance in December 2014 requiring insurers under its authority to cover all medically necessary health services for the treatment of gender dysphoria.[7] The guidance further requires

[7] New York Dep't Financial Servs., Insurance Circular Letter No. 7 (2014), available at http://www.dfs.ny.gov/insurance/circltr/2014/cl2014_07.pdf.

that all categorical exclusions be removed from insurer's plans.[8] Despite this guidance, transgender New Yorkers continue to face a number of barriers to accessing care that should be covered by their health insurance as a result of the DFS letter. On October 22, 2015, Health Care For All New York led a listening session in collaboration with the Department of Financial Services to document these continuing barriers. The following selection of stories shared during that session illustrate the need for strong federal regulations to prevent discrimination against transgender and gender nonconforming people, even in states that are have adopted transgender coverage requirements:

- Female-to-male transgender individuals are regularly denied access to double mastectomies on the basis that this medically-necessary treatment is considered cosmetic by their insurance companies. By contrast, non-transgender female individuals with breast cancer are regularly entitled to mastectomies and breast reconstruction for both the treatment of active breast cancer *and* prophylactic care. Male-to-female transgender individuals are denied access to breast implants, while non-transgender female individuals are covered for reconstructive breast services. For example, a transgender woman residing in Queens explained that she was denied access to breast augmentation because she was unable to prove medical necessity under her health plan, even though the policy did not include an explicit exclusion of coverage for transgender health care. Using the same criteria as a breast cancer survivor, she was denied exclusively on the fact that her breast reconstruction was for the purposes of gender reassignment surgery.
- Obtaining coverage for transgender medical services is arduous, time consuming and prohibitively expensive, often resulting in a series of denials requiring multiple appeals. A transgender man living in New York explained that he had attempted to obtain pre-certification for a double mastectomy and nipple reconstruction through his insurance policy and was denied on the basis that nipple reconstruction constituted a cosmetic procedure. This was despite the fact that the enrollee's plan did not include a categorical exclusion for transgender health services. Because this medical procedure was financially prohibitive to obtain without insurance coverage, this individual filed internal and external appeals and consulted with a lawyer who specializes in transgender issues. He finally won approval for treatment after 10 months of appeals.
- Non-binary identified transgender individuals are regularly denied access to gender affirming health benefits because insurance policy statements often refer to requirements to live in either a strictly male or female role. A genderqueer-identified New Yorker described being denied hormones and surgery because the individual's gender did not fit into the confines of male or female, according to the issuer issuing the policy (purchased through the New York State of Health Marketplace).

In addition, at least half of the stories we have collected via statewide survey do not fall under the jurisdiction of New York state insurance regulators because the transgender individual

[8] *Id.*

is enrolled in a self-insured plan. As result, HCFANY recommends that HHS require federally regulated insurance policies to render categorical exclusions of transgender services[9] and/or treatment of gender dysphoria illegal, as these exclusions constitute sex discrimination against transgender and gender nonconforming individuals. With the removal of these exclusions, we recommend that HSS clarify that federally regulated insurance policies must cover all medically necessary treatment for gender dysphoria, a mental health diagnosis covered under the required essential health benefits of the Affordable Care Act.

Recommendations: HCFANY recommends revising § 92.206 as follows:

> A covered entity shall provide individuals equal access to its health programs or activities without discrimination on the basis of sex, *including pregnancy, false pregnancy, termination of pregnancy, or recovery therefrom, childbirth, or related medical conditions* and shall treat individuals consistent with their gender identity, except that any health services that are ordinarily or exclusively available to individuals of one gender may not be denied or limited based on the fact that an individual's sex assigned at birth, gender identity, or gender otherwise recorded in a medical record is different from the one to which such health services are ordinarily or exclusively available. *Sex-specific health programs and activities are permissible when necessary to accomplish an essential health purpose*.

In addition, HCFANY recommends that HHS define categorical exclusions of transgender services and/or treatment of gender dysphoria as discrimination on the basis of sex.

Nondiscrimination in health-related insurance and other health-related coverage (§ 92.207)

This section states that covered entities shall not discriminate in the provision of health-related insurance and other health-related coverage on the basis of race, color, national origin, sex, age, or disability. This includes denying or limiting insurance policies, plans and claims to the protected groups mentioned above.

HCFANY strongly supports the application of nondiscrimination requirements to benefit design and marketing practices. We recommend HHS define "benefit design" to include, at a minimum, cost-sharing, formulary tiers, provider networks, limits on coverage of certain services by age or condition, prior authorization and other utilization management.

[9] This includes access to cross-sex hormone treatment, procedures to alter secondary sex characteristics (hair removal), gender affirming surgery (mastectomy, breast augmentation, genital surgeries, body contouring and removal of reproductive organs as necessary).

Although women disproportionately experience chronic pain[10] and certain chronic pain conditions occur primarily in women,[11] women experience disparities in pain care.[12] Additionally, insurers sometimes exclude coverage for chronic pain.[13] These exclusions discourage women with chronic pain conditions from enrolling in plans offered by insurers because the services to treat their pain are specifically excluded or medications are placed on higher cost-sharing tiers. Health plans should not be permitted to limit coverage of certain services by condition or put all the medications required to treat a condition or ailment on the highest formulary tier. If they do, they should be subject to Section 1557's enforcement provisions. Accordingly, HCFANY supports the language of section § 92.207(b)(3).

Beneficiaries have experienced benefit and network designs that amount to discrimination against people with serious illnesses and chronic conditions, such as not covering certain medications or not following treatment guidelines, imposing excessive medication management tools such as unreasonable prior authorizations and/or step therapy, charging patients high cost-sharing, and having narrow provider networks that don't include the specialists or subspecialists that an enrollee with a particular illness might require. Therefore, in the final rule, HCFANY recommends that employing these types of practices be clearly defined as discrimination. Standards and parameters for benefit and plan design should be detailed in the final rule, along with acceptable practices.

In addition, HCFANY believes that the Department should clarify that the definition of who is protected under Section 1557 is not only limited to beneficiaries who are "disabled" under the definition in the Americans with Disabilities Act (ADA), but to all beneficiaries with chronic health conditions or serious illness. Using the definition under the ADA will include only some individuals or health conditions and overlooks many beneficiaries who may be exposed to discrimination in their health care coverage – particularly in these areas of benefit and network design. These individuals should enjoy the same patient protections. In addition, HCFANY urges HHS to specify that plans must have an adequate network of ADA-compliant providers to ensure people with disabilities have full and equal access to choice in health services without discrimination.

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[10] Dep't of Health & Human Servs., Ctrs. for Disease Control & Prevention, Nat'l Ctr. for Health Statistics, *Health United States*, 13, 69 (2006) (with special feature on pain), *available at* http://www.cdc.gov/nchs/data/hus/hus06.pdf
[11] Instit. of Med., *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research*, 75 (2011), *available at* http://www.nap.edu/download.php?record_id=13172.
[12] *Id.* at 77 (quoting (Campaign to End Chronic Pain in Women, *Chronic Pain in Women: Neglect, Dismissal, and Discrimination*, 4 (May 2010), *available at* http://www.endwomenspain.org/resources).
[13] State of Women's Coverage: Health Plan Violations of the Affordable Care Act at 19-20 (http://www.nwlc.org/sites/default/files/pdfs/stateofcoverage2015final_0.pdf).

HCFANY also strongly supports the enumeration of some prohibited forms of discrimination against transgender individuals. In particular, we support the enumeration of the practice of categorically excluding gender reassignment surgeries and cross-sex hormone therapy from covered services, when covering the same services for purposes other than gender reassignment. In addition, HCFANY urges HHS to enumerate and prohibit a range of insurance carrier and coverage program practices that discriminate against transgender individuals by arbitrarily singling them out for categorical denials of coverage for benefits provided to non-transgender people. Such practices include and are not limited to:

- Denial of primary care services required for all qualifying health care plans in accordance with the Affordable Care Act on the basis of the individual having a discordant documented gender marker. Commonly, transgender individuals are denied primary care when their documented gender marker differs from the gender for which the care usually is associated. For example, a female-to-male transgender individual may be denied cervical pap smears and access to contraceptive services because he no longer has a female gender marker. Such denials should be considered a form of sex discrimination.
- Under insurance policies that do not carry categorical transgender care exclusions, arbitrary gender dysphoria clinical protocols describe the requirements to get access to medically necessary hormones and surgery. While most insurance companies recognize the World Professional Association for Transgender Health (WPATH) Standards of Care within their medical protocols, these protocols are often outdated, cumbersome and have clauses written-in with the exclusive intention of denying coverage. These arbitrary, unregulated requirements constitute sex discrimination, as non-transgender individuals seeking the same services are not so heavily scrutinized. Examples of such burdens are that for some plans, transgender individuals may not have coverage for hormones administered outside of a medical provider's office, where as non-transgender individuals receiving hormones for the purposes of hormone replacement therapy can administer their hormone treatments at home.
- Requirements for psychological assessment prior to administering gender affirmative treatment constitute a form of sex discrimination, as patients who receive reconstructive surgeries and hormone treatment do so without any gatekeeping process to determine psychological wellness to receive these treatments. While these requirements often follow WPATH's Standards of Care, the Standards are merely recommendations, and should not be treated as requirements that, in effect, impede access to medical services.

Recommendations: HCFANY recommends that the final rule: (1) define "benefit design" to include, at a minimum, cost-sharing, formulary tiers, provider networks, limits on coverage of certain services by age or condition, prior authorization and other utilization management; (2) define as discrimination benefit and network designs that hurt people with serious illnesses and chronic conditions, such as not covering certain medications or including certain specialists or subspecialists in their networks; (3) clarify the definition of "disabled" to include all beneficiaries with chronic health conditions or serious illness; (4) specify that plans must have an adequate network of ADA-compliant providers; and (5) enumerate and prohibit a

range of practices beyond gender reassignment surgeries that discriminate against transgender individuals.

Nondiscrimination on the Basis of Association (§ 92.209)

This section prohibits discrimination in health programs against a beneficiary based upon the race, color, national origin, age, disability, or sex of an individual who associates with that beneficiary.

HCFANY supports the inclusion of the explicit prohibition against nondiscrimination on the basis of association. For these purposes, the rule should state that unlawful discrimination based on association occurs when a provider is subject to adverse treatment because they are known or believed to furnish services that are medically appropriate for, ordinarily available to, or otherwise associated with a patient population protected by Section 1557. This interpretation would, for instance, prohibit covered entities from using the provision of sex-specific services, such as abortion, as a disqualifying factor in recruiting otherwise eligible and qualified providers for participation in health programs supported by HHS. Providers should not be discriminated against for offering to competently care for a class of individuals with particular medical needs.

The rule should also address discrimination on the basis of association faced by lesbian, gay and bisexual people. There are numerous examples of discrimination based on an individual's family relationships; one troublesome area has been coverage for and provision of infertility services. Some insurance companies prohibit the use of donor sperm for artificial insemination, thus discriminating against women with same-sex partners or without partners. Other insurance companies require women to demonstrate that they have tried to become pregnant for one year through intercourse with their spouse and have not succeeded. Again, such a requirement discriminates against women with same-sex partners or without spouses.

Physicians should not deny infertility services to people who are unmarried, gay or lesbian, according to the American Society for Reproductive Medicine.[14] Yet, such discrimination does occur, as was demonstrated by the case of *Benitez v. North Coast Women's Care Medical Group*. In August of 2008, the California Supreme Court unanimously ruled that North Coast Women's Care Medical Group had violated state anti-discrimination rules when it denied infertility services to Guadalupe "Lupita" Benitez because she is a lesbian and North Coast's physicians are conservative Christians who object to lesbians having children.[15]

[14] Fertility Rights and Responsibilities, American Society for Reproductive Medicine, access on October 13, 2015, at: https://www.asrm.org/FACTSHEET_Fertility_Rights_and_Responsibilities/.
[15] Case summary of the Benitez lawsuit accessed on October 13, 2015, at: http://www.lambdalegal.org/in-court/cases/benitez-v-north-coast-womens-care-medical-group

Unfortunately, many lesbians live in states without the kind of anti-discrimination laws that aided Ms. Benitez.

Recommendations: HCFANY recommends amending § 92.209 to include the following language: "A covered entity shall not exclude ***or deter*** from participation in, deny the benefits of, or otherwise discriminate against an individual or entity in its health programs or activities on the basis of the race, color, national origin, age, disability, or sex of an individual with whom the individual or entity is known or believed to have a relationship or association."

HCFANY also recommends that the final rule enumerate that the following are forms of discrimination on the basis of association: (1) when a provider is subject to adverse treatment because they are known or believed to furnish services that are medically appropriate for, ordinarily available to, or otherwise associated with a patient population protected by Section 1557; and (2) when infertility services are denied to people who are unmarried, gay or lesbian.

Enforcement Mechanisms (§ 92.301)

HCFANY supports the NPRM's inclusion of both administrative and judicial remedies for discrimination. In particular, HCFANY recommends that the rule better reflect the statutory language by clarifying and strengthening the judicial enforcement opportunities and by directly recognizing that Section 1557 permits judicial claims for disparate impact discrimination. Further, as the statutory language of Section 1557 authorized the Secretary of HHS to promulgate regulations, we recommend the proposed rule apply to **all** federally funded, supported and conducted activities and not just those of HHS.

Finally, any law or regulation is useless if it is not enforced. Serious deficiencies result when there is no auditing or oversight**.** HCFANY urges the Office of Civil Rights to properly enforce the law now and act on any discrimination complaints that have been filed in order to ensure beneficiary rights are protected, but also to develop and audit an oversight program to systematically review compliance.

Recommendations: HCFANY recommends that the final rule: (1) clarify and strengthen the judicial enforcement opportunities; (2) state that Section 1557 permits judicial claims for disparate impact discrimination; (3) apply to **all** federally funded, supported and conducted activities and not just those of HHS; and (4) direct the OCR to develop and audit an oversight program to systematically review compliance.

Thank you for the opportunity to provide comments on the HHS Nondiscrimination in Health Programs proposed rule. If you have any questions about our comments, please contact Hannah Lupien at hlupien@cssny.org or at (212) 614-5541.

Very truly yours,

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