

November 6, 2015

Office for Civil Rights
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue S.W.
Washington DC 20201

ATTN: 1557 NPRM (RIN 0945-AA02)

The New York Lawyers for the Public Interest (NYLPI) is a nonprofit civil rights law firm dedicated to advancing health, environmental and disability justice through community lawyering and partnerships with the private bar. NYLPI exercises strategies such as community organizing, policy work, community education, capacity building and litigation to confront the systemic and institutional barriers to quality healthcare. NYLPI recognizes that discrimination in health care and coverage results in health disparities. In this way, NYLPI advocates with and for underrepresented New York communities: immigrant communities, individuals with limited English proficiencies (LEP), people with disabilities and individuals that experience gender identity and/or sex based discrimination for access to quality health care.

We write to submit comments to the proposed section 1557 rulemaking (NPRM) of the Patient Protection and Affordable Care Act. As NYLPI works closely with community groups and community partners, our comments are based on our advocacy and relationships with the clients and communities that we serve. We support the Office for Civil Rights (OCR) for seeking these comments. We strongly support the proposed rule's nondiscrimination protections in all federally funded, supported and conducted health programs and activities. We support the rule's prohibition on discrimination on the basis of race, color, national origin (including immigration status and language) and sex (including sex stereotyping and gender identity, disability and age.

Language Access

The following recommendations focus on the need to protect immigrants from various forms of discrimination that may arise when attempting to receive care from medical professionals. It is critical that HHS finalize the language prohibiting minors from interpreting in emergencies and prohibiting other adults accompanying an individual to interpret only if the individual specifically requests it.

Recommendation:

Where an individual requests that an adult accompanying an individual serve as an interpreter, we suggest that HHS should describe the steps that should occur in order to confirm that this manner of interpretation is the individual's choice. HHS should inform the covered entity that if it knows or has reason to know the accompanying adult does not meet the qualified interpreter

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requirements, the covered entity could be found out of compliance with this section. Our recommended steps are as follows:

1. The covered entity should again inform the individual that language services are available free of charge;
2. The covered entity should inform the individual that the accompanying adult may accompany the individual even if the adult is not serving as an interpreter and that the accompanying adult may be better suited to serve as an advocate for the patient rather than interpreter;
3. If the individual still wishes to use the accompanying adult as an interpreter, the covered entity shall:
 - a. Use a qualified interpreter to obtain a signed waiver of language services from the individual;
 - b. Have a qualified interpreter monitor the interaction of the individual, accompanying adult and covered entity staff to assess if the accompanying adult is a qualified interpreter. If the accompanying adult is not able to provide qualified interpreting, the qualified interpreter will step in to ensure effective communication.

Recommendation:

LEP individuals are often deterred from using interpretation services that are available to them because they experience a delay in receiving interpreting services, which in turn delays receipt of medical care or other services from covered entities. This underscores the need for swift, accessible, and efficient interpreting services. Several NYLPI clients expressed that the long wait for an interpreter while seeing a doctor or while receiving other services by covered entities causes them to decline interpretation services that they have a right to access. Furthermore, when an individual declines interpretation services, covered entity staff should be required to explain that the interpreter will be available shortly and that the interpretation services will not delay the individual. Staff at covered entities should be required to explain to individuals the importance of interpretation.

Discrimination on the Basis of Sex and Sexual Orientation

NYLPI works across the spectrums of immigrant and disability rights. We see that immigrants and individuals with disabilities are at high risk of facing discrimination when they identify as LGBTQ or gender non-conforming. We support the rule's inclusion of sex stereotyping and interpretation of discrimination on the basis of sex. NYLPI supports the rule's protection requiring that individuals must be treated consistent with their gender identity including access to facilities. Failing to provide coverage and facility access for transitioning individuals is a discriminatory practice.

Discrimination for individuals who do not identify as heterosexual, particularly in the fields of reproductive health care, exists and leads to health disparities. For these reasons, NYLPI strongly encourages HHS to include specific protections for varying sexual orientations. We also strongly oppose any new exemption that would permit discrimination based on religious views against

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any person, especially women, people with disabilities or LGBTQ and gender non-conforming people.

In reference to HHS's definition of gender identity, NYLPI proposes the following comment be amended. This comment is made in effort to provide further descriptions of varying gender identities so as to avoid sex based discrimination for individuals in health care settings who do not identify as cis-gendered or transgendered—but as gender non-conforming.

Recommendation: We recommend amending Definitions (§ 92.4) as follows:

Gender identity. The term “gender identity” means an individual’s internal sense of gender, which may be different from an individual’s sex assigned at birth. The way an individual expresses gender identity is frequently called “gender expression,” and may or may not conform to social stereotypes associated with a particular gender. Gender may be expressed through, for example, dress, grooming, mannerisms, speech patterns, and social interactions. For purposes of this part, an individual has a transgender identity when the individual's gender identity is different from the sex assigned to that person at birth; an individual with a transgender identity is referred to in this part as a transgender individual. ***Additionally, an individual has a gender non-conforming identity when their gender identity does not exist within the social understandings and/or conceptions of gender. A gender non-conforming individual’s identity is different from the sex assigned to that person at birth and the individual informs others of how they identify.***

Regulatory Impact Analysis I, B. Training

NYLPI understands that health entities that receive federal financial assistance are required to complete a one-time staff familiarization training after the regulation is issued. HHS categorizes health care staff into five different health related professional categories. The “health related activities and program employees” should also include outreach workers, community health workers, program managers and other health related program staff employed by these entities.

Recommendation: NYLPI recommends that outreach workers, community health workers, program managers staff be moved into an additional and separate category, or be added to one of the existing categories.

Disability Issues

NYLPI strongly supports the provision requiring effective communication for individuals with disabilities and accessibility standards, including requirements for websites and electronic and information technology.

Recommendation: However, we are concerned that these requirements do not have to be implemented for 18 months after publication of the final rule when the ADA has required such accessibility for over 20 years. We also recommend that the rule require basic accessibility for medical equipment now while recognizing that more specific standards from The Access Board will be provided at a later date.

Data Collection

One tenet of ensuring compliance with nondiscrimination requirements is to ensure strong data collection. Having accurate data ensures that covered entities have the needed information to determine how to provide language services and auxiliary aids and services.

Recommendation: We urge HHS to add specific demographic data collection requirements to the rule for all covered entities. Covered entities should be required to collect data on race, ethnicity, language, sex, gender, gender identity, sexual orientation, disability status, and age. Further, covered entities should be required to assess (and update their assessments) the population they serve and whom are eligible to be served so that they can appropriately plan how to meet the needs of their clients/patients. HHS should provide guidelines as to how to conduct an assessment and what data may be readily available to covered entities.

Benefit Design and Marketing

NYLPI also strongly supports nondiscrimination requirements to benefit design and marketing practices.

Recommendation: We recommend that 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. As an example, health plans should not be permitted to 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.

Enforcement

We strongly support Section 1557’s inclusion of both administrative and judicial remedies for discrimination.

Recommendation: In particular, we recommend 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 that the proposed rule apply to all federally funded, supported, and conducted activities and not just those of HHS.

Thank you for your consideration of these comments,

Laura Redman

A handwritten signature in black ink, appearing to read 'Laura Redman', with a stylized, cursive script.