COMMENTS to the Department of Health and Human Services
Office for Civil Rights (OCR), Office of the Secretary

RE: 1557 NPRM - Nondiscrimination in Health Programs and Activities

by OHIO CONSUMERS FOR HEALTH COVERAGE
NOVEMBER 9, 2015

OHIO CONSUMERS FOR HEALTH COVERAGE respectfully submits the following comments to the Department of Health and Human Services (HHS), Office of Civil Rights (OCR), in response to Nondiscrimination in Health Programs and Activities, released on September 9th, 2015.

Ohio Consumers for Health Coverage (OCHC) is a coalition of 20+ organizations, both statewide and local, that has worked since 2007 to unite the consumer voice with the goal of achieving affordable, high quality health care for all. OCHC combines the forces of tens of thousands of health care consumers. Our organizational membership is diverse, representing both those with illness and those in good health, both insured and uninsured, those with resources, and those of limited means.

OCHC greatly appreciates the opportunity to provide comments on the proposed rule on Nondiscrimination in Health Programs and Activities. This rule is a very important step toward strengthening protections for people who have often been subject to discrimination in our health care system.

We commend OCR and HHS for the proposed rule on nondiscrimination that will support a broader health disparities reduction agenda to protect the most vulnerable Americans from discrimination in our health care system. As such, we have focused our comments and recommendations on strengthening the application and scope of the proposed rule in terms of language access; disability and sex discrimination; non-discrimination in health insurance and compliance and enforcement.

Application and Scope

BACKGROUND: The Affordable Care Act (ACA) gives HHS the authority to issue government-wide regulations to implement Section 1557 of the ACA. However, the proposed rule only applies to health programs and activities that receive financial assistance through HHS, are administered by HHS or are administered by entities established under Title I of the ACA.

Additionally, the preamble to the proposed rule seeks comment on whether additional exemptions to the proposed rule should be considered. The following recommendations seek to broaden the scope and application of the proposed rule drawing from existing authority, as well as limit exemptions that would weaken the impact of the proposed rule.

1. **We urge HHS to explicitly apply the final rule to *all* federally-administered health programs and activities, and health programs and activities any part of which receive federally funding – not just those administered by HHS and Title I of the ACA (§ 92.2)**. Such broad application is permitted by the text of Section 1557 of the ACA. This will centralize oversight for this rule in the OCR within HHS, which specializes in discrimination in health, rather than require separate enforcement offices across disparate agencies.

2. **We urge HHS to make the scope of the application of Section 1557 clearer by defining the term "health."** HHS can use the widely referred to World Health Organization (WHO) definition, in which "health" is not just the absence of disease, but also as an individual's or a population's physical, mental or social well-being.[1]

3. **We ask HHS to strengthen nondiscrimination protections for immigrants by clarifying that it has explicit authority under Section 1557 to enforce the principles found in the Tri-Agency Guidance.**[2] These principles include protecting confidentiality and limiting the collection, use and disclosure of personally identifiable information**—** such as Social Security numbers, citizenship or immigration status information—for non-eligible/non-applicant family members in families whose members are of mixed-immigration status.[3]

4. **We urge HHS not to use this regulation to add any additional religiously-based exemptions to those already in effect through the protections afforded by provider conscience laws,**[4] **the Religious Freedom Restoration Act,**[5] **or provisions in the ACA related to abortion services**[6] **or regulations issued related to preventive health services.**[7] We believe these existing federal protections are sufficient for health care refusals based on religious exemptions. Religious exemptions authorize health care

[1] 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.
[2] The Tri-Agency Guidance limits inquiries regarding citizenship, immigration status and Social Security numbers from family members who are not applying for assistance. 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.
[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] See, e.g., 42 U.S.C. 300a–7; 42 U.S.C. 238n; Consolidated and Continuing Appropriations Act 2015, Pub. L. 113–235, 507(d) (Dec. 16, 2014).
[5] 42 U.S.C. 2000bb–1.
[6] See, e.g., 42 U.S.C. 18023.
[7] See 45 CFR 147.131.

refusals that have very real and devastating consequences, especially for women. We strongly oppose any new exemption that would permit discrimination based on religious views against any person, especially women, people with disabilities, or LGBT people.

We agree with comments filed by OCHC member Stonewall Columbus who point out that "…we have seen our transgender community suffer the most in regard to religious objections as we have had many reports of transgender individuals being refused proper care or being treated cruelly or unfairly in hospitals and healthcare facilities that were owned/operated by organized religious communities and/or churches. Similar stories arise from our same-sex couples in hospitals who are giving birth. No one should be turned away or discriminated against when it comes to their vital healthcare. There is no place for that in ours laws or our policies."

In order to reflect the ACA's clear intent and its overriding purpose of ensuring that no one should face discrimination in health care on any protected basis, including sex, the Section 1557 regulations should not contain a religious exemption.

5. **We oppose continuing the exclusion of Medicare Part B providers from coverage under Section 1557.**

Language Access

BACKGROUND: The proposed regulations specifically address some of the communication issues facing people with disabilities and people with limited English proficiency (LEP). As they are currently drafted, they codify long-standing principles that require covered entities to take "reasonable steps to provide meaningful access" to individuals with LEP. This includes requiring covered entities to 1) post an English-language notice of consumers' rights to free, appropriately tailored language assistance services; and to 2) post taglines in the top 15 languages spoken nationally by people with LEP. To assist covered entities in meeting this burden, HHS proposes to provide translated versions of the required notice and taglines in the top 15 languages. The following recommendations would strengthen the proposed regulations in several ways, including requiring covered entities to translate certain documents into languages other than English.

1. We support the codification of the definition in § 94.2 of "qualified interpreter," which requires interpreters to meet both competency and ethical standards. **We recommend that HHS also require knowledge of specialized terminology and concepts, as outlined in the LEP guidance, in addition to requiring the ability to "[use] any necessary specialized vocabulary."[8]**

2. **We also recommend the inclusion of a definition of "qualified translator" that mirrors the competency requirements for qualified interpreters.**

[8] *Guidance to Federal Financial Assistance Recipients Regarding Title VI Prohibition Against National Origin Discrimination Affecting Limited English Proficient Persons*, (hereinafter HHS LEP Guidance), 68 Fed. Reg. at 47316, http://www.gpo.gov/fdsys/pkg/FR-2003-08-08/pdf/03-20179.pdf.

We recommend that the notice required by § 92.8(a)(1) be revised to include the added categories in bold: *The covered entity does not discriminate on the basis of race; color; national origin, including* ***primary language*** *and* ***immigration status****; sex,* ***including pregnancy, gender identity, sex stereotypes, or sexual orientation****; age; or disability.* Similarly, the Appendix to Part 92 ("Sample Notice Informing Individuals about Nondiscrimination and Accessibility Requirements") should be revised to include the abovementioned bolded categories that the covered entity does not discriminate against.

3. We applaud HHS for taking steps to ease translation burdens for covered entities by providing notices in the top 15 languages used nationally. Yet, we are concerned that this national threshold will fall short of meeting the needs of local demographics, which may be more complex and prone to change over time.

   Ohio is home to a robust multiplicity of communities. There are over 265,000 persons in the Asian Community, including those from India, China, Vietnam, the Philippines, Korea, Japan, Nepal and Burma. Roughly three-quarters of Asian Americans speak a language other than English at home. Ohio Asian Americans, Ohio Dept. of Development, report based on 2013 American Community Survey, https://development.ohio.gov/files/research/P7004.pdf

   Ohio is also home to a multiplicity of African nationalities including those from Somali, Ethiopia, Sudan, Ghana, Cameroon, Nigeria, Congo, Liberia, Gambia, Senegal and Siera Leone. Ohio's Hispanic community exceeded 380,000 in the 2013 American Community Survey. They come from Mexico, Puerto Rico, Cuba, Spain, Gautemala and Columbia. The top 15 languages in the U.S. are Spanish, Chinese, Vietnamese, Korean, Tagalog, Russian, Arabic, French Creole, French, Portuguese, Polish, Japanese, Italian, German, and Persian (Farsi). These 15 languages exclude most of the languages spoken by African immigrants in Ohio, including those from Ethiopia, Sudan, Gambia, Congo, Senegal, and Sierra Leone. They also exclude sizeable Ohio Asian populations including India, the Philippines, Nepal and Burma.

   We recommend HHS strengthen the regulation by:

   - **Requiring that sample notices by HHS and tagline translation requirements of covered entities must include the top 15 languages in the State,** rather than the proposal to only include the top 15 languages nationally (§ 92.8(c) through (e)).
   - **Requiring, instead of merely encouraging, covered entities to post one or more of their notices in the most prevalent non-English languages frequently encountered by covered entities in their State or service area (**§ 92.8(b))**.** Covered entities should be required to post taglines in the top 15 languages in the State of this section in a conspicuously visible font and size (§ 92.8 (f)).
   - **Requiring covered entities to translate vital documents for each language group that makes up 5 percent or 1,000 persons, whichever is less, of the population eligible to be served, or likely to be affected by the program, or recipient in the service area.** This numeric threshold is already employed in

other federal agency policy guidance, with some programs and agencies employing even lower thresholds.

Disability Issues

BACKGROUND: The proposed rule applies existing Title II standards to require effective communication for individuals with disabilities and accessibility standards, including the requirements for websites and electronic and information technology. The following recommendations aim to strengthen these protections as well as explicitly cover individuals with health conditions who have historically been the victims of some of the worst forms of discrimination in health care. [9, 10, 11]

1. We strongly support the provisions requiring effective communication for individuals with disabilities and accessibility standards, including the requirements for websites and electronic and information technology (**§** 92.202) and the requirement that covered entities must give "primary consideration" to the person with a disability's choice of auxiliary aid or service. Auxiliary aids and services can include, as appropriate, qualified interpreters, a variety of assistive technology devices, and the provision of materials in alternative formats . In addition, because disability does not occur uniformly among racial and ethnic groups,[12,13] **we recommend ensuring that cultural competency standards, such as the CLAS standards,[14] are also applied to entities serving people with disabilities.**

2. **We strongly recommend that the definition of "disability" in § 92.4 should explicitly include the *non-exhaustive* list of health conditions that qualify as disabilities under the Americans with Disabilities Act (ADA) Amendments Act of 2008,** [15] **because**

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[9] Patient Protection and Affordable Care Act; HHS Notice of Benefit and

Payment Parameters for 2016; Final Rule. 45 CFR Parts 144, 147, 153, et al. *Federal Registrar*. Available from: http://www.gpo.gov/fdsys/pkg/FR-2015-02-27/pdf/2015-03751.pdf

[10] Avalere Health. "An Analysis of Exchange Plan Benefits for Certain Medicines." http://www.phrma.org/media-releases/many-exchange-plans-burden-the-most-vulnerable-patients-with-high-outofpocket-costs-for-vital-medicines

[11] Avalere Health. "Exchange Benefit Designs Increasingly Place All Medications for Some Conditions on Specialty Tier." Available from: http://avalere.com/expertise/life-sciences/insights/avalere-analysis-exchange-benefit-designs-increasingly-place-all-medication

[12] Brault, Matthew, *Americans With Disabilities: 2005*, Current Population Reports, P70117, U.S. Census Bureau, Washington, DC, 2008. Many of the differences between the disability rates by race and Hispanic origin can be attributed to differences in the age distributions of their populations. For example, Hispanics are predominantly younger than non-Hispanic whites.

[13] Institute of Medicine (IOM). 2007. The Future of Disability in America. Washington, DC: The National Academies Press, p. 92.

[14] National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care, https://www.thinkculturalhealth.hhs.gov/pdfs/EnhancedNationalCLASStandards.pdf

[15] 29 CFR Part 1630 implementing these amendments made any condition a "disability" that substantially limits major bodily functions, such as functions of the immune system, special sense organs, and skin; normal cell growth; and digestive, genitourinary, bowel, bladder, neurological, brain, respiratory, circulatory, cardiovascular, endocrine, hemic, lymphatic, musculoskeletal, and reproductive functions.

these conditions significantly limit major life activities (including major bodily functions): Deafness, blindness, intellectual disabilities, missing limbs, autism, cancer, cerebral palsy, diabetes, epilepsy, HIV, multiple sclerosis, muscular dystrophy, major depressive disorder, bipolar disorder, post-traumatic stress disorder, obsessive compulsive disorder, and schizophrenia.

Sex Discrimination

BACKGROUND: The proposed rule expands the definition of sex discrimination by stating that discrimination based on sex stereotypes or gender identity constitutes discrimination on the basis of sex. However, lesbian, gay, and bisexual people continue to face discrimination in many areas of their lives, including health care, on the basis of their sexual orientation, which is not covered by the proposed rule. Additionally, women continue to face barriers to reproductive services by religiously affiliated hospitals and providers, which the proposed rule does not address. The following recommendations aim to effectively address the full scope of discrimination against LGBT individuals and protect women's access to necessary care.

1. We support the rule's new prohibitions on discrimination on the basis of sex and the definition included (92.206 and 92.207(b)). We support the rule's inclusion of sex stereotyping and gender identity in the definition of sex discrimination. **We strongly urge HHS to include sexual orientation – which means homosexuality, heterosexuality or bisexuality-- into this definition "on the basis of sex" in § 92.4.**

2. The final rule should contain a provision that follows American Medical Association and American College of Obstetricians and Gynecologists guidelines on informed consent, in which a clinician must provide adequate disclosure and explanation of the full range of medically appropriate treatment options before the patient and clinician settle on a course of treatment. [16, 17] **The final rule should make clear that religiously-affiliated institutions and providers are not shielded from the obligation to provide information concerning either the status of the patient or the limited number of treatment options that the institution or provider is willing to furnish.** Such a requirement would also enable women to seek care in a nonsectarian hospital or from a provider who does not have objections.

3. We also incorporate the comments of Stonewall Columbus that strongly

> supports the recognition in § 92.206 that health services ordinarily associated with 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 that gender. This section should also include specific language addressing how

[16] 42 C.F.R. § 482.55 (2011) (setting forth the conditions of hospital participation in Centers for Medicare and Medicaid Services)

[17] Am. Med. Assoc., *Opinion* 8.082 *Withholding Information from Patient*s (Nov. 2006), http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion8082.page?; Committee on Ethics, Am. Coll. of Obstetricians and Gynecologists, *Informed Consent, Committee Opinion* (Aug. 2009), http://www.acog.org/Resources-And-Publications/Committee-Opinions/Committee-on-Ethics/Informed-Consent.

non-binary transgender people should be treated consistent with their gender identity. The final rule should state that, "*in the case of an otherwise lawful gender-specific or gender-segregated facility or program,* [a covered entity] *shall not deny an individual whose gender identity is not male or female access to the gender-specific health facility or program that the individual determines is most appropriate for them.*"

Non-discrimination in Health Insurance

BACKGROUND: The proposed rule recognizes and prohibits discriminatory benefit designs and marketing practices (§ 92.207). *This is an important step toward ensuring that health insurers cannot circumvent the nondiscrimination protections in the ACA by using discriminatory benefit designs or marketing practices when providing or administering health insurance. The following recommendations seek to clarify and strengthen this section.*

1. **Add language for the definition of "benefit design"** as the coverage and benefits offered by a covered program or entity, including, but not limited to: prescription drug formularies; tiering structures; wellness programs; cost sharing, including co-payments and co-insurance; utilization management; quantitative treatment limits; non-quantitative treatment limits including prior authorization and step therapy; provider networks, including access to specialists; and pharmacy access.

2. **Define "marketing practices"** as the activities of any covered entity or program designed to encourage individuals to enroll in or seek services from a covered entity.

3. **Add language that plans that do not include all or nearly all of a certain specialist provider type in the plan network or network tier are discriminatory.** Plans have been shown to completely exclude certain providers at alarming rates, which discriminates against those with disabilities or other classes requiring access to these providers.[18]

4. **Include as regulatory language the following examples of insurance practices that are discriminatory on the basis of disability:**
   - Placing all or nearly all medications or services that treat a certain condition on the highest cost-sharing tiers.[19, 20]
   - Not covering certain medications that are recommended in treatment guidelines.
   - Imposing arbitrary or unreasonable medication management tools such as requiring prior authorizations and/or step therapy for all or nearly all medications that treat a certain condition.[21]

[18] Dorner SC, Jacobs DB, Sommers BD. Adequacy of outpatient specialty care access in marketplace plans under the Affordable Care Act. *JAMA*. 2015;314(16):1749-1750.

[19] Patient Protection and Affordable Care Act; HHS Notice of Benefits and Payment Parameters for 2016. Available from: https://www.federalregister.gov/articles/2015/02/27/2015-03751/patient-protection-and-affordable-care-act-hhs-notice-of-benefit-and-payment-parameters-for-2016

[20] Final 2016 Letter to Issuers in the Federally-facilitated Marketplaces. Center for Consumer Information and Insurance Oversight, Centers for Medicare and Medicaid Services (CMS). February 20th, 2015. Available from: https://www.cms.gov/CCIIO/Resources/Regulations-and-Guidance/Downloads/2016-Letter-to-Issuers-2-20-2015-R.pdf

[21] Illinois governor's office warns ACA health insurance plans against HIV/AIDS discrimination

5. **Adopt a standard way of addressing cost-based discrimination in the final rule.** A cost-based discrimination standard would likely have to define unaffordability – as the Internal Revenue Service (IRS) had already done to define unaffordability for the purposes of premium assistance.[22] An "unaffordable" medication or service could become discriminatory if there was no lower-cost, but similarly efficacious drug or service available to an individual protected by Section 1557.

OCHC supports the comments of Stonewall Columbus on this issue, which appear here:

> We were particularly bothered this year by the many reports from our community members that reported their prescriptions used to treat HIV had sometimes quadrupled in cost. Some could actually no longer afford their health insurance as these new prescription costs were only partially covered now by their insurance which left them with no money to pay premiums after they paid for their medication. This is an urgent issue in our community and many have been forced to appeal to drug companies directly and apply for "patient assistance program" subsidies for this medication. Basically these rising costs have forced our community members with HIV to go begging to the very pharmaceutical companies for assistance that have increased the cost. This is not an acceptable way to cover one's healthcare costs.
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> Specifically with regard to the issue of transgender-specific exclusions, we strongly support § 92.207(b) in enumerating and prohibiting 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 procedures and services that are the same or substantially similar to those provided to non-transgender people.
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> The multifaceted nature of insurance discrimination against transgender individuals means that the provisions at § 92.207(b)(3), (4), and (5) are **all** vital to ensuring that transgender people are able to access the health coverage and care they need. We very strongly urge HHS to preserve all three of these provisions in the final rule, with the modifications below. We also very strongly support amending § 92.207(d) to ensure that carriers cannot use standards for determining medical necessity that are themselves inherently discriminatory.

Compliance and Enforcement

1. We strongly support Section 1557's inclusion of both administrative and judicial remedies for discrimination (§ 92.301-92.303) with respect to complaints and compliance reviews of health programs or activities administered by the Department. **We recommend the proposed rule apply to all federally funded, supported and conducted activities and not just those of HHS.** Also, there are currently multiple entities with overlapping responsibilities to investigate consumer complaints and initiate

[22] Internal Revenue Service, Department of the Treasury. 26 CFR Parts 1 and 602. Health Insurance Premium Tax Credit. Available from: http://www.gpo.gov/fdsys/pkg/FR-2012-05-23/pdf/2012-12421.pdf

enforcement actions. **Accordingly, we urge HHS to clarify its reporting and monitoring process for consumer complaints and appeals, with the HHS OCR as the lead agency.**

2. **We recommend that as a part of assurances in § 92.5, covered entities be required to collect data on the groups described in ACA Section 4302, a provision enacted at the same time as Section 1557.** Requiring stratified data collection on race, ethnicity, primary language, sex, and disability status has the double benefit of positioning covered entities to accurately assess the needs of the people in their geographic service areas and adjust how they are responding to those needs. It also permits the Secretary to extend this requirement to any other demographic data regarding health disparities, such as gender, gender identity, sexual orientation, and age.

Thank you for this opportunity to comment,

Sincerely,

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