Georgetown University
Health Policy Institute
CENTER FOR CHILDREN
AND FAMILIES

Your Comment Tracking Number: **1jx-87wh-kem9**

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 Georgetown University Center for Children and Families appreciates the opportunity to provide comment on the Request for Information regarding nondiscrimination in health programs and activities. The Center for Children and Families is an independent, nonpartisan policy and research center whose mission is to expand and improve health coverage for America's children and families.

Understanding the Current Landscape

Question 1 – Experience and Examples of Discrimination

Racial, Ethnic, and/or National Origin Discrimination – Immigrants

A unique set of circumstances result in discrimination experienced by mixed-immigration status families or families that include individuals with different immigration statuses, such as undocumented parents with citizen children. As the U.S. Department of Health and Human Services and Department of Agriculture recognized in their "Tri-Agency Guidance," first issued in 2000, application programs and processes for government health programs affecting these mixed-status families 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.[1] Primary examples involve requests for Social Security numbers, citizenship or immigration status, place of birth, ethnicity, or race, from family members

[1] 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.

not applying for coverage or benefits for themselves that result in deterring eligible family members from applying.

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,"[2] 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.[3] 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, citizenship or immigration status. 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.[4] 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 referral to Immigration and Customs Enforcement if undocumented persons "self-declare" their status—dropped 45 percent.[5] Additionally, the number of children in TANF dropped 15 percent in 7 months, and new enrollees to the food stamp program fell from 21,000–30,000 per month in the months leading up to the effective date to 1,334 and 195 per month in the second and third month following the law's commencement.[6]

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.[7] Of these children, the vast majority (93 percent) are U.S. citizens and 43 percent

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[2] Patient Protection and Affordable Care Act, Pub. L. 111-148, § 1411(g), 124 Stat. 119, 230 (2010).
[3] *Id.* § 1414(a).
[4] Ariz. Rev. Stat. Ann. § 1-501–02 (2013).
[5] 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.
[6] *Id.*
[7] Karina Fortuny, et al., The Urban Institute, Young Children of Immigrants 1 (August 2010).

live in mixed-status families.[8] Significantly, under the ACA an estimated 3.2 million children with only undocumented parents will be eligible for Medicaid/CHIP or exchange subsidies.[9] 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.[10] 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 Hispanic children.[11] 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. Although much of the difference between citizens and non-citizens in health care spending can be attributed to the younger population and immigrants' ineligibility for public health insurance programs, an analysis adjusting for health status, race/ethnicity, gender, health insurance coverage, and other factors found that the spending on immigrants' health care was still about 14–20 percent less than U.S.-born citizens.[12]

Question 2 – Covered Programs and Activities

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. 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.

[8] Id. at 5.
[9] Stacey McMorrow, et al., The Urban Institute, Addressing Coverage Challenges for Children Under the Affordable Care Act 6 (May 2011).
[10] 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.
[11] 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).
[12] Leighton Ku, *Health Insurance Coverage and Medical Expenditures of Immigrants and Native-Born Citizens in the United States*, 99 Am. J. Pub. Health 1322, 1326–27 (2009).

- Any entity established under Title I of the ACA, such as the health insurance marketplaces.

Because of this broad applicability, the Department should read 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. Under 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. All of these entities will receive federal funds under the ACA or through Medicaid, Medicare, or the Marketplaces.

The same rationale applies to the myriad medical and long-term services and supports sub-contractors that state Medicaid agencies increasingly turn to for the delivery of Medicaid services. As state agencies devolve the delivery of health services to private entities, the non-discrimination standards applicable to and expected of those services should remain the same. For example, a state Medicaid agency is subject to Title II of the ADA and to Sections 504, 508, and state disability rights laws. If the state chooses to contract with MCOs and other entities to deliver Medicaid in the state, Medicaid beneficiaries must have the same standards of accessibility and non-discrimination that previously applied. Even if the state itself did not always *deliver* on those standards, it must ensure that contracting entities adopt and understand the concepts of accessibility, reasonable accommodation and policy modification, undue burden, fundamental alteration, and community integration.

The regulations also must cover all programs that perform ACA-related functions, including partnerships such as navigators and other consumer assistance programs that will play a crucial role in reaching mixed-status families, who because of fear of immigration enforcement, limited English proficiency, or other immigration-related concerns are more difficult to reach. Already nearly half of the 33 states with federally facilitated exchanges have enacted laws that will circumscribe the activities of organizations providing outreach, including by 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.[13] This is just one of the myriad ways that states can either address or perpetuate health disparities among mixed-status families; robust civil rights protection are necessary to reduce these disparities.

Question 3 – Impacts of Discrimination

Age

[13] 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.

Prohibitions on age discrimination apply not only to discrimination on the basis of old age but also of youth. Children are often excluded from coverage determinations because of lack of clinical evidence, but more often because they are simply assumed to be similar to adults. As an example of these problems, we note that coverage determinations are often made in the Medicare program and note Medicare's decision to provide coverage for intensive behavioral therapy to treat overweight and obesity.[14] Because so few children are covered by Medicare, it is understandable that the program would not approve these services for children below the age of 19. But considering the epidemic problem of obesity in children, this decision is an example of what can happen when children are not explicitly considered in coverage determinations.

Children may also face discrimination on the basis of age in health programs and activities due to other benefit limits. For example, a benefit plan may limit covered services to those that restore function. Continuing this practice would inherently preclude those services to help a child attain a function that the child did not previously possess (and which could not therefore be restored) because it was not yet age-appropriate.

Section 1557 should be used to ensure that health benefits plans in general and the essential health benefits package in particular do not include pediatric benefits with arbitrary age-based limits. For example, Connecticut statute mandates insurer coverage of hearing aids for children up to age 12 and of neonate formula for children with cystic fibrosis up to age 8. Utah's essential health benefits benchmark limits dental services based on the age of the recipient. Such limits are not related to the medical necessity of these treatments and would seem to violate both Section 1557 and the requirement of ACA §1302(b)(4)(B) that prohibits a definition of essential health benefits that discriminates against individuals because of their age.

Question 4 – Ensuring Access to Health Programs and Activities for Individuals with Limited-English Proficiency

In the United States today, there are about 25 million individuals with limited-English proficiency (LEP).[15] About 9 million LEP adults are uninsured.[16] Of these individuals, about 95% will be income-eligible for the Medicaid expansion program and subsidies to purchase affordable insurance in the Health Insurance Marketplaces.[17] Individuals with LEP of

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[14] Proposed Decision Memo for Intensive Behavioral Therapy for Obesity (CAG-00423N), This document states the following: "Intensive behavioral therapy for obesity consists of the following: 1. Screening for obesity *in adults. . .*"

[15] 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

[16] Kaiser Family Foundation, *Overview of Health Coverage for Individuals with Limited English Proficiency*, at 2 (Figure 5) (2012),
http://kaiserfamilyfoundation.files.wordpress.com/2013/01/8343.pdf.

[17] *Id.* at 3. This number does not account for LEP non-citizens, who are subject to additional restrictions for Medicaid eligibility.

Mexican and Asian origin combined constitute 63% of all individuals with LEP in our country.[18] Language assistance services are especially critical for individuals with LEP, including immigrants, who are unfamiliar with our complex healthcare system.

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.

For HHS OCR to address the lack of meaningful access by LEP persons to health programs and activities in implementing § 1557, we recommend adoption of the following best practice standards:

- In all circumstances when information cannot be translated into multiple languages, taglines will be used to notify LEP individuals that information is available to be interpreted in their primary language.
- Failure to translate documents when languages meet percentage or numeric thresholds constitutes evidence of non-compliance with Title VI; documents will be translated for each language group that makes up 5 percent 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.
- Service areas relevant for the application of thresholds will 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, must be approved by HHS or, in the alternative, must be demonstrated to be non-discriminatory toward certain populations.
- Funding of interpretation services will disincentivize the use of bilingual staff who are untrained in medical terminology and interpretation.
- Among the many types of in-person and video remote interpretation services available, telephonic services should be used as a last resort.
- Competent interpretation requires: (1) having minimum training standards; and (2) making oral language assistance timely and readily available.
- The competency standards for oral interpretation and written translation providers and bilingual staff include cultural competence as a critical component to addressing ethnic and national origin discrimination.

[18] *Id.* at 1–2.

Question 5 – Unique Issues regarding Sex Discrimination

Section 1557 prohibits discrimination on the ground protected under Title IX, which is sex. Excluding maternity care from an otherwise comprehensive insurance plan is treating pregnancy differently. This qualifies as sex discrimination under civil rights statutes such as Title IX and Title VII, and also sex discrimination under Section 1557. Courts have consistently upheld Title IX regulations that include discrimination based on pregnancy as discrimination based on sex.[19] Thus, consistent with Title IX regulatory and judicial interpretations of sex-based discrimination under Title IX, discrimination prohibited by Section 1557 includes discrimination "on the basis of…pregnancy, childbirth, false pregnancy, termination of pregnancy or recovery therefrom."[20] Section 1557 regulations should reflect this definition and ban plans from excluding maternity care in their coverage.

Question 7 – Compliance and Enforcement Approaches

Racial, Ethnic, and/or National Origin Discrimination – Immigrants

The complaint procedures under Title VI are applicable to mixed-status families because, 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."[21] Thus the civil rights mechanisms within HHS can be invoked for those explicit situations where applications require 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, and also those more subtle forms of effect-based discrimination such as creating onerous requirements for navigators that discourage participation of organizations serving immigrant communities, or onerous documentation requirements for proving eligibility.

Within its responsibility to standardize enforcement of statutes and regulations, HHS OCR is uniquely positioned to combat discrimination that results from different application across states. Historically this was part of the reasoning behind the Civil Rights Act of 1964, and fulfilling this responsibility is an important tool for confronting health disparities between immigrant and all-citizen families. To be effective, we recommend that HHS clarify in regulations implementing § 1557 that it has the explicit authority to enforce the statutory and regulatory provisions that implement the Tri-Agency Guidance. In addition, we believe that HHS must ensure that OCR is funded and staffed sufficiently to respond to

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[19] See*, e.g.*, *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).

[20] *E.g.* 34 C.F.R. § 106.40(b)(1) ("A recipient shall not discriminate against any student, or exclude any student from its education program or activity … on the basis of such student's pregnancy, childbirth, false pregnancy, termination of pregnancy or recovery therefrom ….").

[21] *Op. cit.(1).*

complaints in a timely manner, and that OCR prioritize complaints related to application procedures to ensure that all eligible individuals have access to affordable health insurance under the ACA.

We recommend that regulations implementing § 1557 expressly provide that a household member not applying for coverage for him or herself is not required to provide his or her citizenship or immigration status as part of the application process, is not required to provide an SSN if he or she does not have one, that appropriate notice is provided explaining why an SSN is requested and what it will be used for, and that 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. It is vital for HHS to encourage affected individuals and community-based groups to file meritorious complaints, especially on behalf of individuals or classes of individuals who may be afraid to identify themselves. In addition, we strongly recommend that the implementing regulations allow and promote OCR's ability to provide its own outreach and proactive compliance reviews and other implementation of § 1557, instead of relying only on a complaint system, and that HHS provide the resources to make this OCR function robust. Members of mixed-status families who fear immigration enforcement may be reluctant to put their name on a complaint, and therefore authorization and encouragement of informal information gathering in targeted areas will help ensure that § 1557 implementation does not result in a lack of participation in the health care system.

Thank you for your consideration. Any questions about these comments may be directed to Joe Touschner at jdt38@georgetown.edu or Dinah Wiley at dw688@georgetown.edu.

Sincerely,

Georgetown University Center for Children and Families