



September 30, 2013

Leon Rodriguez, Director
Office for Civil Rights
U.S. Department of Health and Human Services
Hubert H. Humphrey Building, Room 509F
200 Independence Ave. SW
Washington, DC 20201

VIA ELECTRONIC SUBMISSION: www.regulations.gov

RE: RIN 0945-ZA01
Request for Information Regarding Nondiscrimination in Certain Health Programs or Activities

Dear Mr. Rodriguez:

Asian Americans Advancing Justice | AAJC (Advancing Justice | AAJC), Asian Americans Advancing Justice | Los Angeles (Advancing Justice | LA), the Asian & Pacific Islander American Health Forum (APIAHF), and the Association of Asian Pacific Community Health Organizations (AAPCHO) thank the Office for Civil Rights (OCR) at the Department of Health and Human Services (HHS) for the opportunity to respond to the *Request for Information (RFI) Regarding Nondiscrimination in Certain Health Programs or Activities* to inform your rulemaking for Section 1557 of the Patient Protection and Affordable Care Act (ACA).¹ Our comments below focus on ensuring access to health programs and activities for individuals with limited English proficiency (LEP) and for individuals living in families with different immigration statuses (“mixed-status families”). In August 2013, our organizations started a major national outreach initiative to maximize health insurance enrollment for Asian Americans, Native Hawaiians, and Pacific Islanders (AAs and NHPIs) and build capacity to empower community-based organizations to serve and advocate for AA and NHPI health. One of our key objectives is to track barriers to enrollment and monitor the civil rights enforcement of language

¹ 78 Fed. Reg. 46,558 (Aug. 1, 2013).

access and access of eligible immigrants to ensure that national and state agencies implementing health reform are accountable to AA and NHPI communities.² Toward this end of ensuring access, we provide recommendations on compliance and enforcement approaches to address discrimination on the basis of national origin under Title VI.

Advancing Justice | AAJC and Advancing Justice | LA are dedicated to promoting a fair and equitable society for all by working for civil and human rights and empowering AAs and NHPIs and other underserved communities. We provide the growing AA and NHPI communities with multilingual support and culturally sensitive legal services, community education, and public policy and civil rights advocacy. Advancing Justice | LA also leads the Health Justice Network (HJN), a statewide collaborative of over 30 community-based organizations, health care providers, and small business associations working in California's AA and NHPI communities to conduct outreach, education, enrollment and advocacy efforts to ensure the fair and equitable implementation of health care reform in the state for our communities.

APIAHF is a national health justice organization that influences policy, mobilizes communities, and strengthens programs and organizations to improve the health of AAs and NHPIs. For 26 years, APIAHF has dedicated itself to improving the health and well-being of AA and NHPI communities living in the United States and its jurisdictions. We work on the federal, state and local levels to advance sensible policies that decrease health disparities and promote health equity.

AAPCHO is a national not-for-profit association of 33 community-based health care organizations, mostly federally qualified health centers, dedicated to promoting advocacy, collaboration, and leadership that improves the health status and access of medically underserved AAs and NHPIs in the United States, its territories, and its freely associated states. AAPCHO advocates for policies and programs, including research, that improve the provision of health care services that are community-driven, financially affordable, linguistically accessible, and culturally appropriate.

Incorporation of Other Comments

National Language Access Advocates Network. We support the comments submitted by the National Language Access Advocates Network (N-LAAN) on ensuring access to health programs and activities and related compliance and enforcement approaches to Title VI under Section 1557. N-LAAN is a national organization of attorneys and legal services advocates whose collective expertise on language discrimination and language rights provides the most current analysis on legal mechanisms that will best protect low-income and disadvantaged individuals with LEP.

National Immigration Law Center. We support the comments submitted by the National Immigration Law Center (NILC) regarding compliance and enforcement approaches to ensure

² See Advancing Justice | AAJC, News and Email Blast, *Making Health Reform Work for AAs and NHPIs: Ensuring Meaningful Access to Health Care for Individuals with Limited English Proficiency*, Sept. 25, 2013, <http://www.advancingjustice-ajjc.org/news-media/news/making-health-reform-work-aas-and-nhpis-ensuring-meaningful-access-health-care>.

access to health programs and activities by individuals in mixed-status families. The difficulties faced by mixed-status families in applying for eligible programs and activities warrant OCR to consider clarifying its specific authority to regulate policies governing the eligibility processes for mixed-status families. NILC is the only national legal advocacy organization in the United States exclusively dedicated to defending and advancing the rights of low-income immigrants and their families.

Leadership Conference on Civil and Human Rights. We support the comments submitted by the Leadership Conference on Civil and Human Rights (“the Leadership Conference”) and its Health Care Task Force on the following issues covered by the RFI: sex discrimination (including pregnancy, gender identity, sex stereotypes, and sexual orientation); disability discrimination; types of programs and activities that should be considered health programs or activities under Section 1557; health electronic and information technology; and compliance and enforcement approaches. The Leadership Conference is a coalition charged by its diverse membership of more than 200 national organizations to promote and protect the civil and human rights of all persons in the United States.

Lambda Legal. We support the comments submitted by Lambda Legal on the application of Section 1557 to sex discrimination in health programs and activities. Lambda Legal is the oldest and largest national legal organization whose mission is to achieve full recognition of the civil rights of lesbians, gay men, bisexuals, transgender people, and those with HIV through impact litigation, education, and public policy work.

Understanding the Current Landscape

1. The Department is interested in experiences with, and examples of, discrimination in health programs and activities. Please describe experiences that you have had, or examples of which you are aware, with respect to the following types of discrimination in health programs and activities: (a) Race, color, or national origin discrimination . . . or (e) discrimination on one or more bases, where those bases intersect.

National Origin Discrimination: Limited English Proficiency

Discrimination on the basis of national origin, which encompasses discrimination on the basis of LEP, creates unequal access to health care. In the United States today, there are about 25 million individuals with LEP.³ About 9 million limited English proficient (LEP) adults are uninsured.⁴ Of these individuals, about 95% will be income-eligible for the Medicaid expansion program and subsidies to purchase affordable insurance in the Health Insurance Marketplace.⁵ Individuals

³ U.S. Census Bureau, *American Community Survey, Selected Social Characteristics in the United States: 2011 American Community Survey 1-Year Estimates* (25,303,308 speak English less than “very well”). http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_11_1YR_DP02&prodType=table.

⁴ 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>.

⁵ *Id.* at 3. This number does not account for LEP non-citizens, who are subject to additional restrictions for Medicaid eligibility.

with LEP of Mexican and Asian origin combined constitute 63% of all individuals with LEP in our country.⁶

As OCR has recognized that the “demographics of the United States have increasingly diversified,”⁷ the AA and NHPI population is perhaps the most illustrative of this growing diversity. AAs and NHPIs are the fastest growing racial group in the United States with dozens of different cultures and languages.⁸ Approximately 71% of Asian Americans speak a language other than English at home.⁹ Approximately 32% of Asian Americans are LEP and experience some difficulty communicating in English.¹⁰ Approximately 21% of Asian American households are linguistically isolated, meaning that all members 14 years old and older speak English less than “very well”¹¹ and would be considered LEP.¹²

Language assistance services are necessary for individuals with LEP to access federally funded programs and activities in the healthcare system. Without language assistance services that ensure meaningful access to the ACA’s new insurance programs, discrete communities such as those with a large number of individuals with LEP will be systematically excluded from opportunities to achieve better health. For example, in California, which has the highest AA and second highest NHPI population with over one-third (32%) of the entire AA and NHPI population in the country,¹³ AA and NHPIs stand to greatly benefit from the ACA.¹⁴ It is estimated that of the approximately 1,420,000 non-elderly adults who will be newly eligible to receive Medi-Cal, California’s Medicaid program, 2 out of 3 (67% or 950,000) are from communities of color, and over one-third (35% or 500,000) of the newly eligible will be LEP or speak English less than very well.¹⁵ However, without adequate outreach and education efforts, such as a robust

⁶ *Id.* at 1–2.

⁷ 78 Fed. Reg. at 46,559.

⁸ “Between 2000 and 2010, the Asian American population grew faster than another other racial group, at a rate of 46%.” Karthick Ramakrishnan, University of California Riverside & Taeku Lee, University of California Berkeley, *Public Opinion of a Growing Electorate: Asian Americans and Pacific Islanders in 2012*, National Asian American Survey 3 (2012), <http://naasurvey.com/resources/Home/NAAS12-sep25-election.pdf>.

⁹ Asian Americans Advancing Justice | Los Angeles & Asian Americans Advancing Justice | AAJC (formerly Asian Pacific American Legal Center & Asian American Justice Center, Members of Asian American Center for Advancing Justice), *A Community of Contrasts Asian Americans in the United States: 2011*, at 25 (2011), available at http://www.advancingjustice.org/pdf/Community_of_Contrast.pdf.

¹⁰ *Id.* at 27.

¹¹ *Id.* at 29.

¹² HHS LEP Guidance, 68 Fed. Reg. at 47,313.

¹³ In California, 72% of AAs speak a language other than English at home, 34% are LEP and 23% are linguistically isolated. Asian Americans Advancing Justice (formerly Asian American Center for Advancing Justice), *A Community of Contrasts: Asian Americans, Native Hawaiians and Pacific Islanders in California* 6, 16–17 (2013). http://advancingjustice-la.org/system/files/Communities_of_Contrast_California_2013.pdf.

¹⁴ A projected 370,000 AA and NHPI consumers are eligible for financial assistance to purchase health plans through Covered California, the state’s health care marketplace; another 220,000 can purchase plans through Covered California but without financial help; and close to 100,000 AAs and NHPIs who are eligible for the Medi-Cal expansion can enroll through Covered California. See California Health Benefit Exchange, *Outreach and Education Grant Program Application* 139–140 Appendix A (Jan. 25, 2013); http://www.healthexchange.ca.gov/Stakeholders/Documents/Outreach_and_Education_Grant_Program.pdf; California Pan-Ethnic Health Network (CPEHN), *Medi-Cal Expansion: What’s at Stake for Communities of Color*, at 1 (Jan. 2013) <http://www.cpehn.org/pdfs/Medi-CalExpansionFactSheet.pdf> [hereinafter CPEHN Medi-Cal Fact Sheet].

¹⁵ CPEHN Medi-Cal Fact Sheet, at 1.

culturally and linguistically appropriate outreach plan, 300,000 Californians, 70% of whom would be from communities of color, are expected *not* to enroll in Medi-Cal despite being eligible.¹⁶ When looking at the those eligible to receive financial assistance to purchase health coverage under Covered California, over 2.7 million non-elderly adults, 66% (or about 1.8 million individuals) will be people of color, and 40% of the adults (or roughly 1.09 million individuals) will be LEP and speak English less than very well.¹⁷ The study concluded that without proactive outreach efforts and multilingual enrollment efforts directed toward the LEP population, language barriers could reduce the number of LEP subsidy-eligible individuals enrolled in Covered California by 119,000.¹⁸

Moreover, the effects of LEP is often compounded with the “cumulative effects of race and ethnicity, citizenship status, low education, and poverty,” as well as gender, sexual orientation, disability and other cultural characteristics, resulting in many barriers to access for individuals with LEP.¹⁹ In fact, the rapidly growing population, poverty, and poor health status of AAs and NHPs contributes to the urgent need to enforce Section 1557. Medically underserved AA and NHPI communities—including communities where AAs and NHPIs lack access to health care, have high rates of poverty, and have high numbers of LEP populations—are growing across the country. As of the 2000 Census, there were 282 counties or 13.1% of counties classified as medically underserved or severely underserved AA and NHPI communities.²⁰

National Origin Discrimination: Mixed-Status Families

The Tri-Agency Guidance first issued in 2000 by HHS and Department of Agriculture provides some examples of national origin discrimination experienced by mixed-status families. Application programs and processes for government health programs may violate Title VI if they have the effect of preventing or deterring eligible applicants from enjoying equal participation in and access to benefits programs based on the applicant’s or family member’s national origin.²¹ Discriminatory actions may be in the form of asking for Social Security Numbers (SSN), citizenship, or immigration status from family members not applying for coverage or benefits for themselves. Confidentiality and limits on the collection of non-applicants’ personally identifiable information are thus important policies in ensuring that immigrants and their family members obtain the health care for which they are eligible.

The rules of the Tri-Agency Guidance have been adopted for the Health Insurance Marketplace, which may only collect information that is strictly necessary for eligibility determination and

¹⁶ *Id.*

¹⁷ Gans D, Kinane CM, Watson G, Roby DH, Graham-Squire D, Needleman J, Jacobs K, Kominski GF, Dexter D, and Wu E., *Achieving Equity by Building a Bridge from Eligible to Enrolled*, UCLA Center for Health Policy Research and California Pan-Ethnic Health Network, at 1 (updated Jan. 2013), <http://www.cpehn.org/pdfs/BuildingaBridgeFactSheet1-13.pdf>.

¹⁸ *Id.* at 2.

¹⁹ Kaiser Family Foundation, *Overview of Health Coverage for Individuals with Limited English Proficiency* 3.

²⁰ Rosy Chang Weir, Linda Tran & Winston Tseng, *Medically Underserved AAPI Communities*, Association of Asian Pacific Community Health Organizations (2005), <http://www.aapcho.org/wp/wp-content/uploads/2012/07/MUAC-Fact-Sheet.pdf>.

²¹ 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.

enrollment and may use and share this information only for eligibility purposes.²² It would be helpful for OCR and HHS to issue an explicit, official assurance and notification to applicants for the Health Insurance Marketplace that no private, identifiable information—including SSN and immigration status—will be shared between HHS and the Department of Homeland Security and that such information will only be used for eligibility and enrollment purposes. For example on the Covered California application, the following language will be included: “Applying for your eligible child won’t affect your immigration status or chances of becoming a permanent resident or citizen.” We have seen the reluctance of legal immigrants to apply for Medicaid for fear of being labeled a “public charge” when applying for Legal Permanent Residence. Similar fears may arise, especially given the current anti-immigrant sentiment, when legal immigrants apply for the Health Insurance Marketplace. Therefore, the Marketplace, as well as HHS, should address these fears in an official public document.

Discrimination may arise with eligibility workers, navigators, brokers, application assisters, and health care providers who fail to understand the eligibility differences between various immigrant visa statuses and length of residency requirements, fail to distinguish between applicants and non-applicants in requests for personally identifying information, or require such details without first explaining the use or confidentiality of this information. Additionally, an agency or Health Insurance Marketplace may erect onerous documentation requirements that disadvantage mixed-status families or deny them the opportunity to prove eligible income, identity, citizenship, or immigration status. More subtle instances of discrimination may arise when navigators or other workers make assumptions about entire families based on the actual or perceived immigration status of an individual member, or who use ethnicity or language to limit options provided to eligible individuals.

National Origin and Sex Discrimination: AA and NHPI Women with LEP

Language-based discrimination is often compounded with sex discrimination for AA and NHPI women to make access to comprehensive health care even more difficult. Sex discrimination has occurred as the exclusion of maternity coverage from the benefits provided to dependent children²³ and biased clinical decision making against female patients.²⁴ When operating within a culture that stigmatizes frank discussion about sexual and reproductive care,²⁵ AA and NHPI

²² Patient Protection and Affordable Care Act, Pub. L. 111-148, §§ 1411(g), 1414(a), 124 Stat. 119, 230 (2010); 45 CFR §§ 155.260, 155.270, 155.310, 155.315(i).

²³ See, e.g., National Women’s Law Center, *NWLC Section 1557 Complaint: Sex Discrimination Complaints Against Five Institutions*, <http://www.nwlc.org/resource/nwlc-section-1557-complaint-sex-discrimination-complaints-against-five-institutions> (last visited Sept. 17, 2013) (Section 1557 complaints filed against five institutions that exclude pregnancy coverage for plan beneficiaries who are dependent children of employees at institutions).

²⁴ Council on Ethical and Judicial Affairs of the American Medical Association, *Gender Disparities in Clinical Decision Making*, 266 JAMA 559 (1991).

²⁵ For example, Asian American and NHPI women are the least likely to have a Pap test when compared to other women. U.S. Department of Health and Human Services, Fact Sheet, *The Affordable Care Act and Asian Americans and Pacific Islanders*, Jul. 29, 2013, <http://www.hhs.gov/healthcare/facts/factsheets/2012/05/asian-americans05012012a.html>. Asian American and NHPI women have the lowest use of birth control pills at a rate of 56% , as compared to 68% of Hispanic or Latina women, 78% of black women, and 89% of white women. National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human

women with face communication barriers that have severe consequences on their sexual and reproductive health. Already, individuals who require interpreters are less likely to be insured and to receive mammograms and other preventive services.²⁶

2. There are different types of health programs and activities. These include health insurance coverage, medical care in a physician’s office or hospital, or home health care, for example. What are examples of the types of programs and activities that should be considered health programs or activities under Section 1557 and why?

Section 1557 protects individuals from discrimination “on the ground[s] prohibited under title VI of the Civil Rights Act of 1964, title IX of the Education Amendments of 1972, the Age Discrimination Act of 1975, or section 504 of the Rehabilitation Act of 1973” in health programs or activities, any part of which receives federal financial assistance; programs or activities administered by an executive agency; and entities established under Title I of the ACA. As is discussed more fully below, these health programs include public and private entities and activities in virtually all aspects of the health care system such as:

- Any health program or activity of a recipient of federal financial assistance. “Program or activity” has the same meaning in Section 1557 as it does under the Civil Rights Restoration Act of 1987 (CRRA) so that broad institutions, such as public or private entities that receive federal funds, are covered. For example, state health departments, hospitals and hospital systems, clinics, or insurance companies that receive federal funds are covered. Section 1557 specifically extends its discrimination prohibition to entities that receive federal financial assistance including credits, subsidies, or contracts of insurance.
- Any program or activity administered by an executive agency, including federal health programs like the Federal Employee Health Benefits Program (FEHBP) and Medicare as well as programs jointly administered by federal and state governments, such as Medicaid and the Children’s Health Insurance Program.
- Any entity established under Title I of the ACA, such as the health insurance marketplaces.

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

Services, *Use of Contraception in the United States: 1982–2008*, at 5 (2010), http://www.cdc.gov/nchs/data/series/sr_23/sr23_029.pdf.

²⁶ Asian & Pacific Islander American Health Forum, *Diverse Communities, Diverse Experiences: The Status of Asian Americans and Pacific Islanders in the U.S., A Review of Six Socioeconomic Indicators and Their Impact on Health* 15 (2004), available at <http://www.aapcho.org/wp/wp-content/uploads/2012/02/APIAHF-DiverseCommunitiesDiverseExperiences.pdf>.

Health programs and activities that are covered under Section 1557 are those that receive federal financial assistance in the form of credits, subsidies, and contracts of insurance. All operations of a covered entity that has health as its primary purpose must be in compliance with Section 1557. Specifically, entities with health as its primary purpose include, but are not limited to, state and local health departments; hospitals and hospital systems; community health centers; nursing homes; home care agencies; health insurance companies; health or medical research centers; medical, dental, or other schools that focus on training individuals to enter careers in the health field; pharmacies; public and private contractors, subcontractors and vendors, and physicians and other providers who receive federal financial assistance from HHS.²⁷ An entity that does not have health as its primary purpose but has a health program or activity receiving federal financial assistance must comply with Section 1557 in regards to that health program or activity. Section 1557 also applies to programs or activities administered by an executive agency, such as Medicare, Medicaid, and the CHIP and their related managed care plans, as well as federal agencies themselves that are implementing programs of the ACA. Title I programs established under the ACA, which are expressly subject to Section 1557, include the Health Insurance Marketplace,²⁸ Qualified Health Plans (QHPs), and Consumer-Oriented and Operated Plans (CO-OPs).

See the Leadership Conference's comments for detailed analysis explaining why these programs and activities should be covered under Section 1557.

See N-LAAN's comments for detailed analysis explaining why managed care plans and pharmacies should be covered under Section 1557.

Clarification of Section 1557 Protection for Mixed-Status Families

In addition to the ACA and Tri-Agency Guidance's existing protections for limited collection and confidentiality of information in the Health Insurance Marketplace, Medicaid, and CHIP, we believe it is critical to clarify that these programs fall under the jurisdiction of Section 1557. The reach of Title VI should extend to eligible applicants who are a part of mixed-status families that may be subject to discriminatory state policies. Already, nearly half of the 33 states with federally facilitated exchanges have enacted laws that will circumscribe the activities of organizations providing outreach, including prohibiting navigators from advising applicants concerning plan details, creating stringent standards that may have the effect of deterring the

²⁷ Under the list of entities that are covered by Title VI are subcontractors, vendors and physicians and other health care providers. Guidance to Federal Financial Assistance Recipients Regarding Title VI Prohibition against National Origin Discrimination Affecting Limited English Proficient Persons, 68 Fed. Reg. 47,311, 47313 (Aug. 8, 2003) [hereinafter HHS LEP Guidance].

²⁸ For a more detailed analysis about application of Section 1557 to the Health Insurance Marketplace, see Mara Youdelman., *The ACA and Application of § 1557 and Title VI of the Civil Rights Act of 1964 to the Health Insurance Exchange*, National Health Law Program (2011), http://www.healthlaw.org/images/stories/Short_Paper_6_The_ACA_and_Application_of_Section_1557_and_Title_VI.pdf.

participation of organizations focused on underserved communities, and requiring further regulation that result in delays in the navigator program.²⁹

3. What are the impacts of discrimination? What studies or other evidence documents the costs of discrimination and/or the benefits of equal access to health programs and activities for various populations? For example, what information is available regarding possible consequences to health programs and services, such as delays in diagnosis or treatment, or receipt of an incorrect diagnosis or treatment? We are particularly interested in information relevant to areas in which Section 1557 confers new jurisdiction.

National Origin Discrimination: Limited English Proficiency

There are numerous studies that have documented the problems associated with a lack of language services, including one by the Institute of Medicine, which stated that:

Language barriers may affect the delivery of adequate care through poor exchange of information, loss of important cultural information, misunderstanding of physician instruction, poor shared decision-making, or ethical compromises (e.g., difficulty obtaining informed consent). Linguistic difficulties may also result in decreased adherence with medication regimes, poor appointment attendance, and decreased satisfaction with services.³⁰

Lack of language services limits the amount and quality of care that LEP individuals receive.³¹ One study showed that language problems were among the leading barriers to child health services cited by Latino parents and could increase medical errors because of misdiagnosis and misunderstanding of physicians' orders.³² Another study found that

many immigrants and residents with limited English proficiency face special challenges in obtaining adequate health care and paying for it. The results show[ed] dramatic differences in the health care experiences of those with limited English proficiency who had interpreters available and those who did not. On most measures, the uninsured who needed an interpreter and had access to one

²⁹ 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>.

³⁰ Institute of Medicine, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health* 17 (2002) (citations omitted); see also Jane Perkins, Mara Youdelman & Doreena Wong, National Health Law Program, *Ensuring Linguistic Access in Health Care Settings: Legal Rights and Responsibilities* (2003). http://www.healthlaw.org/index.php?option=com_content&view=article&id=326:ensuring-linguistic-access-in-health-care-settings-legal-rights-and-responsibilities&catid=45; E. Jacobs, et al., *Language Barriers in Health Care Settings: An Annotated Bibliography of the Research Literature*, The California Endowment (2003), http://www.calendow.org/uploadedFiles/language_barriers_health_care.pdf.

³¹ See, e.g., G. Flores et al., *Errors in Medical Interpretation and Their Potential Clinical Consequences in Pediatric Encounters*, 111 PEDIATRICS 6–14 (2003); T.K. Ghandi et al. *Drug Complications in Outpatients*, 15 J. OF GEN. INTERNAL MED. 149–54 (2000); D. K Pitkin et al., *Limited English Proficiency and Latinos' Use of Physician Services*, 57 MEDICAL CARE RESEARCH AND REVIEW 76–91 (2000).

³² G. Flores et al., *Access Barriers to Health Care for Latino Children*, 152 ARCHIVES OF PEDIATRIC AND ADOLESCENT MEDICINE 1119–112 (1998).

had experiences similar to or more positive than the uninsured without language barriers.³³

In explaining how the lack of adequate communication can pose health risks for patients with LEP, the report revealed that over one-quarter (27%) of patients who needed, but did not get, an interpreter reported they did not understand their medication instructions (another 7% did receive an instructions), compared with only 2% of those who did not need an interpreter and those who needed and received one.³⁴ Even more importantly, it concluded the following:

Consistently offering the same information about financial assistance programs to LEP and English-speaking patients may also simply be good for business. Improving LEP patients' access to financial assistance information may increase the likelihood that hospitals can obtain at least some payment for services provided, rather than none, when patients cannot afford to pay for care. Without an interpreter to facilitate communication between patients and billing staff or social workers, hospitals may also be missing opportunities to enroll eligible patients with LEP into public or private sector insurance or payment program.

At the same time, offering interpreter services may be a valuable strategy for attracting and retaining future insured patients with LEP. More than 9 of 10 LEP patients who did get interpreters said they would return to their present facility if they became insured. These survey findings suggest that patients needing interpreter services, if given a broader choice of providers, would seek out health care facilities that provide them. Offering interpreter services may improve patient revenues of safety net hospitals in the long term, in addition to improving patient care in the short- and long-term.³⁵

Health care providers also recognize the need to provide language assistance services for LEP patients. One study surveyed four major metropolitan areas where physicians identified language difficulties as a major barrier to immigrants' access to health care and a serious threat to medical care quality. These providers also expressed concern that they could not get information to make good diagnoses and that patients might not understand prescribed treatment.³⁶

With national attention focused on the ACA's emphasis on quality of care and patient safety, improving communication between health care providers and LEP patients becomes increasingly important. At the actual point of service, providers will have communication issues with patients who cannot explain their medical history and symptoms or readily understand questions or

³³ D. Andrulis, N. Goodman & C. Pryor, The Access Project, *What a Difference an Interpreter Can Make* 9 (2002). http://www.accessproject.org/adobe/what_a_difference_an_interpreter_can_make.pdf.

³⁴ *Id.* at 7.

³⁵ *Id.* at 10.

³⁶ L. Ku & A. Freilich, Urban Institute, *Caring for Immigrants: Health Care Safety Nets in Los Angeles, New York, Miami, and Houston* at ii-iii (2001), available at <http://aspe.hhs.gov/hsp/immigration/caring01/execsum.htm>; see also Jennifer Cho & Beatriz M. Solis, L.A. Care Health Plan, *Healthy Families Culture & Linguistic Resources Survey: A Physician Perspective on their Diverse Member Population* (2001) (51% of doctors reported their patients do not adhere to treatments because of culture and language barriers).

instructions. This increases barriers to care, and often creates dangerous delays and unnecessary and risky procedures, ultimately increasing the chances of negative outcomes. In turn, bad outcomes and delayed access increase health care system costs. In a report released by the National Health Law Program, a survey of one malpractice carrier's closed claims found 2.5% of the cases involved language issues and cost the carrier over \$5 million in damages, settlements and legal fees.³⁷ Thus, medical malpractice claims involving significant language barriers and resulting in patient injuries provide insight as to the impacts and costs of discrimination against individuals with LEP. As the study of 35 medical malpractice claims concluded,

[t]hose costs include damages paid to patients, legal fees, the time lost when defending a lawsuit, the loss of reputation and patients, the fear of possible monetary loss, and the stress and distraction of litigation. . . . [T]he heightened risk of patient harm from poor medical care is the ultimate critical and unacceptable cost.³⁸

In one lawsuit, the husband of a deceased Spanish-speaking pregnant woman alleged that his wife was denied competent interpretation which led to a neurologist's failure to determine that she had pork tapeworms. The lawsuit claimed \$3.25 million in damages. Although the lawsuit was dismissed, the medical malpractice carrier paid over \$40,000 in legal fees.³⁹ In another case involving a Cantonese-speaking female patient who was not provided a competent interpreter or translated consent form prior to her Cesarean section, the medical malpractice carrier paid \$22,000 in legal fees.⁴⁰ We refer OCR to the report for more detailed accounts of other medical malpractice claims involving the "failure to provide competent oral interpretation; failure to provide written translations of important documents . . . ; inadequate documentation; and allegations of discrimination."⁴¹

Therefore it is clear that language barriers can also increase the cost of care by creating what has been called a "language-barrier premium."⁴² Such barriers are a primary reason why LEP populations disproportionately underutilize less expensive and quality-enhancing preventive care.⁴³ In addition, an inability to comprehend the patient, mixed with a fear of liability, can lead some providers to avoid LEP patients altogether or, in the alternative, to order expensive,

³⁷ K. Quan & J. Lynch, *The High Costs of Language Barriers in Medical Malpractice* 15, National Health Law Program (2010) [hereinafter Medical Malpractice Report], http://www.healthlaw.org/images/stories/High_Costs_of_Language_Barriers_in_Malpractice.pdf.

³⁸ *Id.* at 15.

³⁹ *Id.* at 14.

⁴⁰ *Id.* at 11.

⁴¹ *Id.* at 4.

⁴² See, e.g., Judith Bernstein et al., *Trained Interpreters in the Emergency Department: Effects on Services, Subsequent Charges, and Follow-Up*, 4 J. IMMIG. HEALTH 171 (2002) (finding interpreters improved clinic follow-up and reduced post emergency room visits and charges); L.C. Hampers, *Language Barriers and Resources Utilization in a Pediatric Emergency Department*, 103 PEDIATRICS 1253 (1999) (finding patients with a language barrier had higher charges and longer stays).

⁴³ See, e.g., Michelle M. Doty, The Commonwealth Fund, *Hispanic Patients' Double Burden: Lack of Health Insurance and Limited English*, at vii–viii, 8, 11–14 & 21 (2003); D. Andrulis et al., The Access Project, *What a Difference an Interpreter Can Make* 1–2 (2002).

otherwise avoidable tests.⁴⁴ Another study, while confirming problems with informed consent, concluded that the failure to appreciate the importance of language and culture in pediatric emergencies is also associated with inadequate understanding of diagnoses and treatment by families, dissatisfaction with care, preventable morbidity and mortality, and lower quality of care, as well as with disparities in prescriptions, analgesia, test ordering, and diagnostic evaluations.⁴⁵ Research determined that asthmatic patients who did not speak the same language as their physicians were less likely to keep scheduled office appointments and more likely to use the emergency room and to miss follow up medications.⁴⁶

While the failure to address language barriers can lead to much harm, LEP individuals who through the use of competent language services *can* communicate effectively with their health care providers reap the benefits of accessing preventive care, understanding their diagnosis and condition, making informed decisions about treatment options, and following through with recommended treatments. This in turn leads to better health outcomes. In a survey by PALS for Health, 96% of those surveyed reported that the PALS interpretation service directly improved their health and well-being.⁴⁷ Positive outcomes included a better understanding of health conditions (46%) and an ability to ask questions and get clearer answers (19%).⁴⁸ These additional costs and strains on the system, must also be factored into any cost benefit analysis of providing language services.

Moreover, in calculating the costs of language assistance services, cost savings are more difficult to calculate to offset the costs of providing interpreter and translation services, to arrive at the actual cost of these services. However, cost savings can be incurred by avoiding costly chronic diseases by providing language assistance services and encouraging the use of preventive care, as well as treating individuals currently suffering from chronic conditions or conditions more effectively through primary and preventive care. If routine access is effectively denied, these conditions are exacerbated and require more expensive emergency interventions and treatment. One study found that LEP Latinos with hypertension and diabetes were significantly more likely to experience improved physical functioning, better psychological well-being, better health outcomes, and less pain if their primary care physician could communicate with them effectively. A comparison of LEP Spanish- and Portuguese-speaking patients with non-LEP patients found that the use of interpreters significantly increased the LEP groups' utilization of preventive services, office visits, and written prescriptions.⁴⁹

The literature thus clearly demonstrates the benefits to be derived from competent language

⁴⁴ See, e.g., Barry Newman, *Doctors' Orders Can Get Lost in Translation for Immigrants*, WALL STREET J., Jan. 9, 2003.

⁴⁵ G. Flores et al., *The Importance of Cultural and Linguistic Issues in the Emergency Care of Children*, 18 PEDIATRIC EMERGENCY CARE 271 (2002).

⁴⁶ A. Manson, *Language Concordance as a Determinant of Patient Compliance and Emergency Room Use in Patients with Asthma*, 26 MED. CARE at 1119 (Dec. 1988).

⁴⁷ S. Tanjasiri, PALS For Health, *Client Evaluation of Interpretation Services* at 6 (Apr. 30, 2001).

⁴⁸ E.J. Perez-Stable et al., *The Effects of Ethnicity and Language on Medical Outcomes of Patients with Hypertension or Diabetes*, 35 MED. CARE 1212 (1997).

⁴⁹ Alyssa Sampson, National Health Law Program, *Language Services Resource Guide for Health Care Providers*(2006), <http://www.healthlaw.org/images/pubs/ResourceGuideFinal.pdf>.

services. Ineffective communication will sometimes result in substantial additional medical procedures or otherwise avoidable human suffering. There is no figure that can be calculated to measure the benefits of reducing patient suffering and deaths that result from ensuring that LEP patients can fully communicate with their health care provider and have access to culturally and linguistically competent health care.

See Question 4.(c) for additional examples of individuals with LEP in accessing health care.

See Question 4.(b) for more information about cost-benefit data on providing language assistance services.

National Origin Discrimination: Mixed-Status Families

Immigration status is an important component of racial and ethnic disparities in insurance coverage and access to care.⁵⁰ In mixed-status families where eligible individuals are prevented or deterred from securing programs, the primary result is low participation rates in programs and decreased access to health services in general. The reach of this impact is potentially quite large. Among Asian Americans, there are about 1.3 million undocumented individuals.⁵¹ As of 2010, nearly one in four children younger than eight years has an immigrant parent.⁵² Of these children, the vast majority (93%) are U.S. citizens.⁵³ In 2008, there were four million children with undocumented immigrant parents.⁵⁴ Significantly, under the ACA an estimated 3.2 million citizen or lawful permanent resident children with only undocumented parents will be eligible for Medicaid, CHIP, or subsidies.⁵⁵

Citizen children in mixed-status families are impacted by the insurance status of their non-citizen parents. A child's insurance status is largely correlated with his or her parent's status.⁵⁶ Even when insured, noncitizens and their children (even U.S.-born) have less access to regular ambulatory and emergency care than insured American citizens have.⁵⁷ In addition to the lower rates of health insurance among children with non-citizen parents than with citizen parents, evidence points to a chilling effect on immigrant access to health care more broadly. Spending on immigrants' health care was still about 14% to 20% less than for U.S.-born citizens.⁵⁸

⁵⁰ L. Ku & S. Matani, *Left Out: Immigrants' Access to Health Care and Insurance*, HEALTH AFFAIRS at 147 (2001) [hereinafter Immigrant Access Report].

⁵¹ Jeffery S. Passel & Vera Cohn, *Unauthorized Immigrant Population: National and State Trends, 2010*, Pew Research Hispanic Trends Project, Feb. 1, 2011, <http://www.pewhispanic.org/2011/02/01/ii-current-estimates-and-trends/>.

⁵² Karina Fortuny, et al., The Urban Institute, *Young Children of Immigrants* 1 (2010).

⁵³ *Id.* at 5.

⁵⁴ *Id.* at 9, n.5.

⁵⁵ These numbers are based on population estimates from 2009. There are 1.2 million children with one undocumented parent and one citizen or lawful permanent resident parent. Stacey McMorrow, et al., The Urban Institute, *Addressing Coverage Challenges for Children Under the Affordable Care Act* 6 (2011).

⁵⁶ Government Accountability Office, GAO 11-24, *Medicaid and CHIP: Given the Association Between Parent and Child Insurance Status, New Expansions May Benefit Families* 8–10 (2011).

⁵⁷ Immigrant Access Report at 147.

⁵⁸ 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, but this analysis adjusted for health status, race/ethnicity, gender, health insurance coverage, and other factors. Leighton Ku, *Health Insurance Coverage*

Already, undocumented immigrants are ineligible for the ACA’s insurance programs and most lawfully present immigrants are barred from federal, non-emergency Medicaid and CHIP programs until they have had a specific status, such as lawful permanent residence (LPR or green card) for five years. Thus, eligible children of these individuals are less likely to enroll in health insurance unless the civil rights protections of the ACA are fully and vigorously enforced.

Ensuring Access to Health Programs and Activities

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

(a) What are examples of recommended best practice standards for the following topics:

(1) Translation services, including thresholds for the translation of documents into non-English languages and the determination of the service area relevant for the application of the thresholds;

Best practice standards for translation services, oral interpretation services, and competence of oral interpretation and written translation providers and bilingual staff are found in the enhanced National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care (“enhanced National CLAS Standards”)⁵⁹ and HHS’ Guidance to Federal Financial Assistance Recipients Regarding Title VI Prohibition Against National Origin Discrimination Affecting LEP Persons (“HHS LEP Guidance”).⁶⁰ We also offer additional recommendations below.

Current HHS LEP Guidance employs a four-factor balancing test to determine the “mix” of language assistance services that should be provided.⁶¹ This “mix” of services should distinguish when oral interpreter and written translation services are required. Oral interpreter services should not be subject to the four-factor test but rather be available “on demand” and free of charge—from enrollment in the Health Insurance Marketplace to clinical encounters to consumer assistance services. On the other hand, it may be more reasonable to subject the availability of translated documents to the four-factor test. In all circumstances when information cannot be translated into multiple languages, taglines should be used to notify LEP individuals that information is available to be interpreted in their primary language.

In addition, notices about the availability of language assistance services, such as oral or interpreter services, should be available in as many languages as possible. Many hospitals, such

and Medical Expenditures of Immigrants and Native-Born Citizens in the United States, 99 AM. J. PUB. HEALTH 1322, 1326–27 (2009).

⁵⁹ Office of Minority Health, U.S. Dep’t of Health & Human Servs., *National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care: A Blueprint for Advancing and Sustaining CLAS Policy and Practice* (2013).

⁶⁰ HHS LEP Guidance, 68 Fed. Reg. 47,311.

⁶¹ HHS LEP Guidance, 68 Fed. Reg. at 47,314–15 (“(1) The number or proportion of LEP persons eligible to be served or likely to be encountered by the program or grantee; (2) the frequency with which LEP individuals come in contact with the program; (3) the nature and importance of the program, activity, or service provided by the program to people’s lives; and (4) the resources available to the grantee/recipient and costs.”).

as the public hospitals in Los Angeles County, and community clinics have signs offering interpreter services in up to 24 languages.

Thresholds

Translation services should be subject to thresholds that operate as mandatory minimum requirements rather than “safe harbors.” Thresholds, as currently used in HHS LEP Guidance, are part of safe harbors which provide “strong evidence of compliance with the recipient’s written-translation obligations” and “a guide for recipients that would like greater certainty of compliance than can be provided by a fact-intensive, four-factor analysis.”⁶² We strongly recommend HHS adopt new policy setting forth that the failure to translate documents when languages meet the percentage or numeric threshold, as outlined below, is evidence of non-compliance with Title VI.

We recommend that documents should be translated for each language group that makes up 5% or 500 persons, whichever is less, of the population of persons eligible to be served or likely to be affected by the program or recipient in a service area. This percentage and numeric threshold is in existing federal agency policy guidance. HHS’ LEP Guidance currently uses a 5% or 1000-person “safe harbor” threshold,⁶³ which leaves out millions of LEP individuals. For example, in El Paso County, Texas, there are 900 individuals with LEP who speak Korean as their primary language, and 900 individuals who speak Chinese. In York County, Pennsylvania, there are 600 individuals with LEP who speak Chinese and 500 individuals who speak Vietnamese. In Henry County, Georgia, there are 800 individuals with LEP who speak Vietnamese and 600 who speak Gujarati.⁶⁴ When applying the 500 threshold to service areas measured by counties, 1324 counties in the United States have populations of 500 or more LEP individuals speaking at least one single language, as compared to only 987 counties with populations of 1000 or more LEP individuals.⁶⁵ A 5% and 500-numeric threshold better ensures that the intent and statutory requirements to provide linguistically appropriate services will be met.

Service Areas

Service areas relevant for the application of thresholds should be program-specific, encompassing the geographic area where persons *eligible to be served or likely to be directly or significantly affected* by the recipient’s program are located. Under Section 1557, the service area for Title VI compliance should be approved by HHS. Where no service area has previously been approved by HHS, a recipient itself may designate the service area, subject to showing that the service area does not discriminatorily exclude certain populations. OCR should provide guidelines for recipients to self-identify service areas by requiring documentation of how the

⁶² HHS LEP Guidance, 68 Fed. Reg. at 47,319.

⁶³ HHS LEP Guidance, 68 Fed. Reg. at 47,319.

⁶⁴ Migration Policy Institute analysis of American Community Survey data from 2007 to 2011 (on file with Asian Americans Advancing Justice | AAJC).

⁶⁵ *Id.* It is noted that some language populations not comprising of 1000 LEP individuals may still comprise 5% of the population and thus fall under the threshold.

determination was made and what data that was used, including the percentage of LEP population within the service area.

As discussed in the HHS LEP Guidance, recipients should determine their service areas based on their actual experiences with LEP encounters as well as demographic data on the languages spoken by those who are not proficient in English.⁶⁶ For some entities created under the ACA, such as the Health Insurance Marketplace, it may be clear that the state is the appropriate service area. However, some states, including California, has divided the state into regions, where the service areas are much smaller, and in some cases, they may be counties where some of the QHPs operate. Covered California has determined that it would translate its paper application and materials into 11 Medi-Cal non-English threshold languages, covering all of the required Medi-Cal languages in each county.

HHS should consider equipping recipients with data driven maps that show estimates of eligible individuals with LEP for each service area as well as their approximate location. Population estimates for service areas that HHS has not previously approved can likely be extrapolated from existing data. For example, in the Supplemental Nutrition Assistance Program (SNAP), state agencies are required to “develop estimates of the number of low-income single-language minority households . . . for each project area and certification office by using Census data . . . and knowledge of project areas and areas served by certification offices.”⁶⁷ SNAP regulations also allow state agencies to collect data in other ways, such as through community action agencies and school officials.⁶⁸

Limiting the latitude for health insurance companies to identify their own service areas is important because of the industry’s history of redlining—or “medlining”—resulting from a “deeply embedded” notion that race is a proxy for poor health and high cost.⁶⁹ Notably, in 2001, Medicare+Choice organizations were allowed to identify their own service areas, which, “while clearly linked to an effort to hold on to a declining market, also appear[ed] to explicitly sanction redlining of racially identifiable portions of a community in favor of healthier and more affluent residents.”⁷⁰ The inextricable relation between LEP and race, poverty, and poor health makes

⁶⁶ HHS LEP Guidance, 68 Fed. Reg. at 47,314.

⁶⁷ 7 C.F.R. § 272.4(b)(6).

⁶⁸ 7 C.F.R. § 272.4(b)(6).

⁶⁹ Sara Rosenbaum & Joel Teitelbaum, *Civil Rights Enforcement in the Modern Healthcare System: Reinvigorating the Role of the Federal Government in the Aftermath of Alexander v. Sandoval*, 3 YALE J. HEALTH POLICY, LAW & ETHICS 215, 235 (2003).

⁷⁰ *Id.*; see also Charles Ornstein, *HMOs' Cuts in Medicare Benefits, Availability of Coverage Draw Fire; Insurance: Legislator calls exclusion of some areas 'cherry-picking,'* L.A. TIMES, Dec. 13, 2001, at 9 (“A key state senator accused health maintenance organizations . . . of eliminating crucial benefits for Medicare enrollees and ‘redlining to avoid certain areas where patient expenses are too high. Using maps and graphics, Sen. Jackie Speier, chairwoman of the Senate Committee on Insurance, showed how in some cases HMOs have sliced up counties to avoid patients in certain ZIP codes.”); David S. Hilzenrath, *The Life Savers' Dilemma: 'Medlining' of Riskier Patients is Focus of HMO Reform*, WASHINGTON POST, Jan. 17, 1998, at D01 (“There are many subtle ways in which health plans can attract the healthy and repel the sick, either intentionally or unintentionally, experts say. One example is “medlining”—health care's version of redlining, the practice in lending and insurance of avoiding certain neighborhoods considered to be deteriorating. To avoid patients with severe conditions, the simplest strategy may be to avoid doctors who excel in treating those conditions. Patients with chronic heart disease, for example, might think twice about joining a health plan if it doesn't offer access to leading cardiologists in their area.”).

LEP communities likely targets of redlining within a free market framework. Costs associated with providing language assistance services should not obviate the obligation that health insurance companies now have under Section 1557 to ensure meaningful access to their health plans, especially when they have opted to receive federal funding.

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

Trained Interpreters

The correlation between oral interpretation by trained professional interpreters and improved access to quality of care is well-documented.⁷¹ Since health care providers depend on receiving accurate information from a patient, *ad hoc* interpretation can sometimes be as harmful as no interpretation at all. Interpretation is a learned skill and requires training as well as bilingual ability in both English and target language.⁷² While it is true that every interpreter can speak at least two languages, it does not follow that every person who can speak two languages is an effective interpreter.⁷³ The ability of a provider to diagnose accurately a patient's condition can be jeopardized by untrained interpreters, such as family and friends, especially minor children, who are prone to omissions, additions, substitutions, volunteered opinions, semantic errors, and other problematic practices.⁷⁴ *Ad hoc* interpreters may themselves be limited in their English language abilities or lack knowledge with medical terminology or confidentiality issues, and be unfamiliar with their roles as an interpreter.⁷⁵

While the above problems pertain to the use of any family member, friend or other untrained person as an interpreter, it is particularly problematic when children are used as interpreters.⁷⁶

⁷¹ Leah S. Karliner et al., *Do Professional Interpreters Improve Clinical Care for Patients with Limited English Proficiency? A Systematic review of the Literature*, 42 HEALTH SERVICES RESEARCH 727 (2007). For example, patients with LEP who are provided with such interpreters make more outpatient visits, receive and fill more prescriptions, and report a high level of satisfaction with their care. Additionally, these patients do not differ from their English proficient counterparts in test costs or receipt of intravenous hydration and have outcomes among those with diabetes that are superior or comparable to those of English proficient patients. Truda S. Bell et al., *Interventions to Improve Uptake of Breast Screening in Inner City Cardiff General Practices with Ethnic Minority Lists*, 4 ETHNIC HEALTH 277 (1999); Thomas M. Tocher & Eric Larson, *Quality of Diabetes Care for Non-English-Speaking Patients: A Comparative Study*, 168 WESTERN JOURNAL OF MEDICINE 504 (1998); David Kuo & Mark J. Fagan, *Satisfaction with Methods of Spanish Interpretation in an Ambulatory Care Clinic*, 14 J. OF GENERAL INTERNAL MEDICINE 547 (1999); L.R. Marcos, *Effects of Interpreters on the Evaluation of Psychopathology in Non-English-Speaking Patients*, 136 AMERICAN J. OF PSYCHIATRY 171 (1979).

⁷² HHS LEP Guidance, 68 Fed. Reg. at 47,316.

⁷³ *Id.*

⁷⁴ See D. W. Baker et al., *Use and Effectiveness of Interpreters in an Emergency Department*, 275 JAMA 783–788 (1996); Bruce T. Downing, *Quality in Interlingual Provider-Patient Communication and Quality of Care* 7–9 (1995) (available from Kaiser Family Foundation Forum, *Responding to Language Barriers to Health Care*) (finding 28% of words incorrectly translated by a son for his Russian speaking father); Steven Woloshin et al., *Language Barriers in Medicine in the United States*, 273 JAMA 724 (1995).

⁷⁵ See generally, J. McQuillan & L.Tse, *Child Language Brokering in Linguistic Minority Communities: Effects on Cultural Interaction, Cognition, and Literacy*, 9 LANGUAGE AND EDUCATION 195–215 (1995).

⁷⁶ See, e.g., D. W. Baker et al., *Interpreter Use and Satisfaction with Interpersonal Aspects of Care for Spanish-speaking Patients*, 36 MED. CARE 1461 (1998); Gold, *Small Voice for Her Immigrant Parents*, L.A. TIMES, May 24, 1999, at A1; Thomas Ginsberg, *Shouldering a Language Burden*, THE PHIL. INQUIRER,

The use of minors to interpret will frequently require children to take on burdens, decision-making and responsibilities beyond their years or authority; cause friction and a role reversal within the family structure; call on the child to convey information that is technical and educationally advanced; and undermine patient confidentiality.⁷⁷ In short, using minors to interpret in the health care context should never be the norm, but only a last resort and in cases of emergencies until a trained, competent interpreter arrives.

Most importantly, the lack of adequately trained health care interpreters can result in an increased risk of medical errors. One study revealed a greatly increased incidence of interpreter errors of potential clinical consequence when untrained interpreters were used instead of those with training.⁷⁸ Additional research determined that while interpretation errors of potential clinical consequence occurred in 12% of encounters using trained interpreters, they occurred in 22% of encounters in which *ad hoc* interpreters were employed.⁷⁹ Interestingly, the latter figure was higher than the percentage of encounters in which such errors occurred (20%) when there was no interpreter present at all. The HHS Office of Minority Health has specifically recognized this phenomenon and offers an explanation for why bad interpretation can be as harmful as no interpretation:

The research . . . makes clear that the error rate of untrained ‘interpreters’ (including family and friends) is sufficiently high as to make their use more dangerous in some circumstances than no interpreter at all. Using untrained interpreters lends a false sense of security to both provider and client that accurate communication is actually taking place.⁸⁰

The value of competent interpretation, both to the quality of the care offered by the provider and the health of the patient, is well accepted. However, the cost of competent language services is frequently cited as a reason why language assistance services are not provided to those who need them. Costs are certainly an important factor, and as noted above, we must find a way to ensure that the costs of providing language services do not compromise their availability and use, especially given the opportunity under the ACA to expand access to needed health care.

Mar. 3, 2003; Q. Lu, *Children: Voices for Their Parents*, Asian Week, May 17–23, 2001, at 6 (describing a young woman’s traumatic experience of telling her mother she had cancer and trying to explain treatment options with her limited vocabulary).

⁷⁷ See also *infra* text accompanying notes 133 & 134 (interviews with children who interpret for their parents) (citing Vikki Katz, *Children as Brokers of their Immigrant Families’ Healthcare Connections*, at 24 (2013) (under review)).

⁷⁸ G. Flores *et al.*, *Errors in Medical Interpretation and Their Potential Consequences in Pediatric Encounters*, 111 PEDIATRICS 4 (2003). Of 165 total errors committed by nonprofessional interpreters, 77% had potentially serious clinical consequences. See also Garret Condon, *Translation Errors Take Toll on Medical Care*, CLEVELAND PLAIN DEALER, at C3, Jan. 20, 2003.

⁷⁹ G. Flores, Abstract, 53 PEDIATRIC RESEARCH (2003) (For hospital interpreters with at least 100 hours of training, the rate of errors of potential clinical consequence was only 2%).

⁸⁰ Office of Minority Health, U.S. Dept. of Health and Human Services, *National Standards for Culturally and Linguistically Appropriate Services in Health Care* 73 (2001), <http://www.omhrc.gov/clas>.

Example: Washington State’s ‘Shared Supports’ for Oral Interpretation Services

Washington State provides a best practice model that avoids misaligned incentives in providing interpretation services. It does this by providing interpretation *services* rather than interpretation *funding* to providers. The state makes an interpreter available only when a medical provider requests one—removing funding from the encounter equation. This program provides trained medical interpretation for over 228,000 patient encounters a year. The model’s centralized scheduling of interpretation gives the State direct access to information about service usage, beneficiaries with LEP, quality control, and risk management.

Washington State follows a “shared supports” model. This is a model that is advanced by the Commonwealth Fund, which has two detailed publications on the potential of shared support networks to improve the health of vulnerable populations and deliver value in Medicaid primary care.⁸¹ A shared interpretation service is a best practice because it emphasizes ease of use and is cost-free to the provider. As a best practice, it prioritizes in-person interpretation, particularly for family meetings regarding medical care, medical encounters involving difficult or agitated patients, psychiatric encounters, medical encounters to make treatment decisions, obtaining informed consent involving review of documents, and end-of-life discussions. At the same time, it permits other means of interpretation, such as remote interpretation that are more appropriate for encounters already taking place over the phone (like making appointments), in rural areas, and with languages of lesser diffusion.

In Washington State, scheduling an interpreter is made easy through an online system that providers can access simply by having an internet connection; no additional software is needed to request and schedule an interpreter. Centralized scheduling for in-person interpretation allows for block scheduling where all speakers of a certain language have the option of appointments during a specific period when an interpreter is scheduled. Ease of use for the provider and interpreter also allows for easy data collection. This model provides control mechanisms and oversight to ensure quality interpretation services with shared costs, ultimately lowering costs overall. One improvement to this model would be allowing an LEP patient to request an interpreter and a medical provider, who may not be aware of the patient’s language need or forget to arrange for an interpreter.

⁸¹ Edward Schor et al., The Commonwealth Fund, *Ensuring Equity: A Post-Reform Framework to Achieve High Performance Health Care for Vulnerable Populations* 41 (2011), http://www.commonwealthfund.org/~media/Files/Publications/Fund%20Report/2011/Oct/1547_Schor_ensuring_equality_postreform_vulnerable_populations_v2.pdf (“Because of the non-health services that many vulnerable individuals require to fully access and benefit from the health care system, all providers serving these populations should be able to link their practices with community-based services, including transportation, language interpretation, social services, housing assistance, nutritional support, and legal services.”); Nikki Highsmith & Julia Berenson, The Commonwealth Fund, *Driving Value in Medicaid Primary Care: The Role of Shared Support Networks for Physician Practices* (2011), http://www.commonwealthfund.org/~media/Files/Publications/Fund%20Report/2011/Mar/1484_Highsmith_driving_value_Medicaid_primary_care.pdf (“Medicaid can connect physician practices and deliver shared practice supports in a number of ways. As a significant insurer in most states, Medicaid could use its market power and influence to drive changes in primary care delivery in general and the provision of practice supports in particular. By viewing practice supports as publicly financed-shared utilities, Medicaid could lead in efforts to organize virtual or real networks of physician practices through such trusted entities.”).

Bilingual and Multilingual Staff

Some health care providers may call upon employed staff whose work responsibilities may not include direct patient contact, but who have been formally identified as speaking languages other than English, to interpret on an *ad hoc* basis, and to translate informed consent documents. Self-identification as bilingual is not adequate to identify an employee as trained and qualified for medical interpretation. HHS should limit the use of employee language banks as secondary to the use of formal interpreters, who often have more training and skills.⁸² These cautions are supported by research that looked at dual-role staff interpreters. One in five dual-role staff interpreters had insufficient bilingual skills to serve as interpreters in medical encounters.⁸³ For example these staff members lacked the necessary grasp of medical terminology and were unable to interpret such terms as gall bladder, stroke, uterus, and contractions. The study found that serious mistakes occurred in confusing words with similar sounds but different meanings, such as interpreting the Spanish word for “diabetic” to the English “diabolic” and “measles” to “lice.”⁸⁴ Assessment of bilingual staff, additional interpreter training, and further research are needed to ensure that use of dual-role staff is an appropriate practice.⁸⁵

We have also heard from staff interpreters whose supervisors have not allowed them to interpret, especially when it would take them away from their other job responsibilities for a period of time. Even when their supervisor may allow the on-call bilingual staff to interpret for LEP patients, the bilingual staff may be reluctant if she/he has to perform the interpretation in addition to their existing work load. The *ad hoc* use of a bilingual staff roster often results in long waits or re-scheduled appointments if no provider staff member is available.

With regard to the Health Insurance Marketplace and QHPs, we hope that adequate numbers of bilingual staff for Service Centers and Help Lines are hired to avoid using a third party telephone interpreter. Telephone interpreters often take longer to assist LEP applicant/enrollees when they are not trained and do not understand technical terminology and health care options.

Telemedicine and Telehealth Communications

Among the many types of in-person and video remote interpretation services available, telephonic services should be used as a last resort.⁸⁶ In general, telephonic interpretation may be a useful practice when communication needed is short and straightforward. These instances may be when a care team is trying to find out what a patient wants or needs or triage a patient’s needs, given that the patient is clear-minded and capable. Researchers and interpreter organizations recommend that telephonic interpretation and video technology be limited to situations where patient safety is not at risk. Because of the unique needs involved, it is recommended that telephonic or remote consecutive interpretation should not be used for hard of hearing patients,

⁸² Brunilda Torress, Massachusetts Department of Public Health, *Best Practice Recommendations for Hospital-Based Interpreter Services* 15, <http://www.mass.gov/eohhs/docs/dph/health-equity/best-practices.pdf> (last accessed Sept. 16, 2013).

⁸³ Maria R. Moreno, Regina Otero-Sabogal & Jeffrey Newman, *Assessing Dual-Role Staff-Interpreter Linguistic Competency in an Integrated Healthcare System*, 22 J. OF GENERAL INTERNAL MEDICINE 331 (2007).

⁸⁴ *Id.*

⁸⁵ *Id.*

⁸⁶ See Torres, *Best Practice Recommendations for Hospital-Based Interpreter Services* 16.

trauma mental health appointments, end-of-life scenarios, procedures needing demonstration or a consent signature, or labor and delivery or surgery appointments. The use of remote interpretation such as telephonic services is also less preferred by patients with LEP, medical providers, advocates, and interpreters.⁸⁷

Several studies confirm that providers, interpreters, and patients prefer in-person medical interpretation and video-medical interpretation (VMI) over telephonic interpretation.⁸⁸ During VMI, the interpreter is at a remote location but can see the provider and patient via a computer screen. VMI allows the interpreter to capture visual cues in addition to audio discussion. In contrast, telephonic interpretation can only capture audio.

We also recommend that organizations or agencies using an automated telephonic system be required to use dedicated language lines or, at a minimum, add voice prompts in multiple languages. Currently, many voice prompts are only available in English and, if any additional language, Spanish. Ideally, dedicated numbers should be added for frequently encountered languages so that LEP individuals can quickly access competent bilingual customer service representatives or English-speaking representatives who communicate with LEP individuals using interpreters. Further, HHS should ensure that the staff providing information is trained to respond appropriately to LEP callers and know how to access bilingual staff or interpreters.

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

Competence of Oral Interpretation Providers and Bilingual Staff

Best practices for ensuring competent oral interpretation may be taken from the leading from the leading accreditation entity for Health Care Interpreters, the Certification Commission for Healthcare Interpreters (CCHI).⁸⁹ CCHI, established in 2009, was the first certifying organization for health care interpreter to receive accreditation from the National Commission for Certifying Agencies. Its mission is to develop and direct a comprehensive credentialing program for healthcare interpreters and brings together representatives from national and regional non-profit interpreting associations, language companies, community-based organizations, educational institutions, healthcare providers, and advocates for LEP individuals. Interpreters can take examinations to become a Certified Health Care Interpreter in Spanish, Arabic, and Mandarin or an Associate Health Care Interpreter in other languages.⁹⁰

⁸⁷ In a 2011 survey of over 500 interpreters, patients with LEP, advocates, medical providers, and state employees, about 90% of respondents selected in-person interpreting as the most appropriate form of interpreting when compared to other types of interpreting across a wide array of services, such as mental health appointments, pharmacy encounters, and surgeries. For more information on the results, contact Linda Bennett, Federal Government Affairs Department, American Federation of State, County and Municipal Employees (AFSCME), lbennett@afscme.org.

⁸⁸ See C. Locatis et al., *Comparing In-Person, Video and Telephonic Medical Interpretation*, Abstract., 25 J. GEN. INTERNAL MED. 345–50 (2010); see also L. Saint-Louis et al., *Testing New Technologies in Medical Interpreting*, Cambridge Health Alliance (2003); M. Paras et al., *Videoconferencing Medical Interpretation: the Results of Clinical Trials*, Health Access Foundation (2002).

⁸⁹ Certification Commission for Healthcare Interpreters, <http://www.healthcareinterpretercertification.org>.

⁹⁰ *Id.*

There is another accreditation entity, the National Board of Certification for Medical Interpreters, which offers a certification examination in Spanish, Russian, Mandarin and Cantonese.⁹¹

Both accreditation bodies use standards established by the National Council on Interpreting in Health Care, which is a multidisciplinary organization whose mission is to promote and enhance language access in health care in the United States. It has also published guidance on a Code of Ethics, Standards of Practice, and Standards for Training, and National Certification for health care interpreters.⁹²

Moreover, additional guidance is provided in Standards 5 and 7 of the enhanced National CLAS Standards⁹³, as well as the HHS LEP Guidance, which also set forth best practices.

Two points should be noted as particularly important for providing competent interpretation: (1) having minimum training standards; and (2) making oral language assistance timely and readily available. Recipients should ensure that interpreters are trained and demonstrate competency as interpreters by requiring a minimum of 40 hours of formal training and assessing competency in specific subject areas in which they will be interpreting. The accuracy of interpretation services is likely to fall short without formal training requirements. Despite HHS' discouragement of the use of *ad hoc* interpreters, many providers and most pediatricians still use family members to communicate with LEP patients.⁹⁴ As for services being timely, this should mean that consumers and patients should not wait for more than 30 minutes to receive interpreter services, since at a minimum, a telephone interpreter should be available until an in-person interpreter can be located.⁹⁵

See Question 4.(a)(2) for the importance of having trained interpreters.

Competence of Written Translation Providers and Bilingual Staff

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

It is not only critical that back translations are used to ensure accurate translations but community-based organizations that work with LEP populations must be consulted before finalizing any consumer-facing translated materials. An example of the need for community

⁹¹ The National Board of Certification for Medical Interpreters, *Certified Medical Interpreter Candidate Handbook 2013–2014*, <https://www.certifiedmedicalinterpreters.org/sites/default/files/national-board-candidate-handbook-2013.pdf> (also using National Council on Interpreting in Health Care's *National Standards of Practice of Interpreters in Health Care* as model standards of practice) (last accessed Sept. 17, 2013).

⁹² National Council on Interpreting in Health Care, <http://www.ncihc.org>.

⁹³ Office of Minority Health, U.S. Dep't of Health & Human Servs., *National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care: A Blueprint for Advancing and Sustaining CLAS Policy and Practice* (2013).

⁹⁴ Lisa Ross DeCamp et al., *Changes in Language Services Use by U.S. Pediatricians*, 132 PEDIATRICS 396 (2013), <http://pediatrics.aappublications.org/content/132/2/e396.abstract>.

⁹⁵ See e.g., N.Y. Comp. Code R. & Regs. tit. 10, § 405.7(a)(7) (Interpreters must be available in inpatient and outpatient settings within 20 minutes and in emergency rooms within 10 minutes of a request by the patient, the patient's family or representative, or a health care provider.)

feedback was recently illustrated by Covered California’s unfortunate mis-translation on its “lead” generator form. The form is being used to obtain the name and contact information, as well as the language spoken by the potential applicant in order for the person to be contacted when the Open Enrollment period begins on October 1, 2013. The word for “contact” on the Vietnamese card was wrongly translated into “relationship,” implying a sexual connotation to the request. Thousands of copies of the card were printed before it could be corrected—a correction that has yet to be made. Such a mistake could easily have been avoided had Covered California shared the translation with Advancing Justice | LA’s Health Justice Network partners, who have been funded to collaborate with Covered California to conduct outreach and education efforts.

HHS should not encourage the use of less-skilled translators to translate non-vital documents. Because all documents provided by providers and program administrators tend to have some consequence on the perceptions and actions of people who receive them, it is important to ensure that individuals do not receive erroneous information about available services. We echo HHS’ acknowledgment that “[t]he permanent nature of written translations . . . imposes additional responsibility on the recipient to take reasonable steps to determine that the quality and accuracy of the translations permit meaningful access by LEP persons.”⁹⁶

Cultural Competence

In establishing standards for competence of oral interpretation and written translation providers and bilingual staff, we recommend that cultural competence be included in both categories as critical components to addressing ethnic and national origin discrimination. Standard 1 of the enhanced National CLAS Standards explains how providing “effective, equitable, understandable, and respectful quality care and services” requires incorporating cultural health beliefs into the delivery of medical care. Language assistance services are more effective when delivered within cultural context, since communities have different perceptions of health, wellness, illness, disease, and health care.⁹⁷

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

The only government study on the potential costs of language assistance services was done by the Office of Management and Budget, which estimated it would only add on average only \$0.50 to the cost of a \$100 health care visit to provide language assistance services.⁹⁸ An HMO-based study found that, for an average cost of \$2.40 per person per year, language services could be provided to those who needed them. It also noted that the health plans would be able to fund the increase from savings realized in other areas.⁹⁹

⁹⁶ HHS LEP Guidance, 68 Fed. Reg. at 47,317.

⁹⁷ Lisa C. Ikemoto, *Symposium: Racial Disparities in Health Care and Cultural Competency*, 48 ST. LOUIS L.J. 75, 86 (2003).

⁹⁸ Office of Management and Budget, *Report to Congress, Assessment of the Total Benefits and Costs of Implementing Executive Order No. 13166: Improving Access to Services for Persons With Limited English Proficiency* 43–52, 55 (2002) (based on total and average cost of emergency room, inpatient hospital, outpatient physician, and dental visits).

⁹⁹ E. Jacobs et al., Abstract, *Overcoming Language Barriers in Health Care: Costs and Benefits of Interpreter*

Data analyzing the costs and benefits of providing language assistance services supports a business case for integrating interpreters into the clinical setting. Using professional interpreters has been shown to be more cost-effective than using bilingual staff, to reduce test charges by \$38 per patient with LEP in pediatric emergency rooms, and to improve both patient and provider satisfaction.¹⁰⁰ Spanish language training programs for residents have been implemented in a pediatric emergency room for a small cost of about \$1500 to \$2000.¹⁰¹ These studies, however, were context and culture specific, and gaps in more comprehensive data on the costs of language barriers and language assistance services demand further research.

A 2004 comprehensive review of research about language barriers in health care identified 35 articles in response to the study's initial inquiry of whether there are "effective interventions to language barriers in health care settings, and if so, how . . . they benefit patients and providers."¹⁰² This study concluded that there are indeed effective interventions to improve outcomes for LEP patients. Yet, little guidance has been proposed on various aspects of using interpreters: the types of interventions that are the most effective in reducing language barriers; the qualifications that should be required of interpreters; and the establishment and use of interpreter services.¹⁰³ At the time of this publication about gaps in research, there were only three studies that directly measured the cost of language barriers.¹⁰⁴

Our current search of articles published between January 1, 2005, and September 15, 2013, resulted in 26 additional articles about the cost of interpreter services.¹⁰⁵ One study found that the cost of integrating formal interpreters into a hospital's internal medicine services for Spanish-speaking patients represented just a mere 1.5% of the overall cost of patient care.¹⁰⁶ The study also suggested that having bilingual physicians may result in cost-savings due to reduced emergency department visits.¹⁰⁷ Interpreter services may be implemented at low costs when used as a shared network among health care organizations through videoconference and telephones. In a study of California hospitals, each interpreter encounter through a shared network lasted an

Services, 16 SUPP. J. GEN. INTERNAL MED. 201 (2001).

¹⁰⁰ Elizabeth Jacobs, et al., *Language Barriers in Health Care Settings: An Annotated Bibliography of the Research Literature* (2003), http://www.calendow.org/uploadedFiles/language_barriers_health_care.pdf; Elizabeth Jacobs, Alice Hm Chen, Leah Karliner, Niels Agger-Gupta & Sunita Mutha, *The Need for More Research on Language Barriers in Health Care: A Proposed Research Agenda*, 84 MILBANK QUARTERLY 111, 122 (2006), <http://www.ncbi.nlm.nih.gov/pubmed/16529570>.

¹⁰¹ Jacobs et al., *An Annotated Bibliography*, at 10, 46 (2003),

http://www.calendow.org/uploadedFiles/language_barriers_health_care.pdf

¹⁰² Jacobs et al., *A Proposed Research Agenda*, at 118.

¹⁰³ *Id.* at 121–22.

¹⁰⁴ *Id.*

¹⁰⁵ PubMed.gov (last accessed Sept. 16, 2013) (using search terms "interpreter services" and "cost," filtering for publication dates between January 1, 2005, and September 16, 2013).

¹⁰⁶ Elizabeth Jacobs, Laura Sadowski & Paul Rathouz, *The Impact of an Enhanced Interpreter Service Intervention on Hospital Costs and Patient Satisfaction*, 22 J. GENERAL INTERNAL MEDICINE 306, 310 (2007). Overall, the researchers concluded that "[w]hereas the study did not demonstrate that providing enhanced interpreter services results in cost-savings, it provides information on the cost of enhanced interpreter services in the context of a hospital stay." *Id.* at 310.

¹⁰⁷ *Id.* at 310.

average of 10.6 minutes at an average cost of only \$24.86.¹⁰⁸ More cost-benefit data are available in the reports *Making the Business Case for Culturally and Linguistically Appropriate Services in Health Care: Case Studies from the Field*,¹⁰⁹ *The Evidence Base for Cultural and Linguistic Competency in Health Care*,¹¹⁰ and *The High Costs of Language Barriers in Medical Malpractice*.¹¹¹

There are also a number of cost-effective ways to provide language assistance services, including some activities designed to decrease cost of providing language services. Numerous translated materials are readily available¹¹² and some hospitals and managed care plans are assembling libraries of translated forms for participating providers to use.¹¹³ As noted above, other approaches include medical interpretation through the use of videoconferencing, remote simultaneous medical interpretation by means of wireless technology, centralized language support offices, language banks (including interpreter and translation pools) and incremental compensation programs for bilingual staff. In addition, there are an ever-increasing number of agencies and community-based organizations that provide language assistance services either on a volunteer basis or at reasonable rates.¹¹⁴

When discussing the cost of language services, it is critical to remind states that they have potential resources to defray the costs with help from the federal government. The Centers for Medicare & Medicaid Services within HHS has made clear that federal matching payments are available for interpretation and translation services provided to Medicaid and State CHIP applicants and enrollees.¹¹⁵ Unfortunately, only 13 states and D.C. have chosen to seek provider reimbursement to pay for language assistance services for their Medicaid and CHIP beneficiaries.¹¹⁶

¹⁰⁸ Elizabeth Jacobs et al., *Shared Networks of Interpreter Services, at Relatively Low Cost, Can Help Providers Serve Patients with Limited English Skills*, 30 *Health Affairs* 101,930 (2011).

¹⁰⁹ Alliance of Community Health Plans Foundation, *Making the Case for Culturally and Linguistically Appropriate Services in Health Care: Case Studies from the Field* (2007), <http://minorityhealth.hhs.gov/Assets/pdf/Checked/CLAS.pdf>.

¹¹⁰ Tawara D. Goode, M. Clare Dunne & Suzanne M. Bronheim, *The Evidence Base for Cultural and Linguistic Competency in Health Care*, The Commonwealth Fund (2006), http://www.commonwealthfund.org/usr_doc/Goode_evidencebasecultlinguisticcomp_962.pdf.

¹¹¹ Medical Malpractice Report.

¹¹² These include “I Speak” cards, examples of which are available at <http://www.lep.gov> and <http://www.palsforhealth.org>.

¹¹³ Kaiser Permanente maintains a library of translated clinical materials for its physicians and another of translated nonclinical materials, including consent forms and health education materials. For California’s Medicaid and SCHIP programs, L.A. Care Health Plan has translated forms and member materials and is developing a web-based translation service that will identify and translate forms into appropriate threshold languages.

¹¹⁴ See Cindy E. Roat, *The California Endowment, How to Choose and Use a Language Agency: A Guide For Health and Social Service Providers Who Wish to Contract With Language Agencies* (2002).

¹¹⁵ See Centers for Medicare & Medicaid Services, U.S. Department of Health And Human Services, *Dear State Medicaid Director Letter*, Aug. 31, 2000, http://www.cms.hhs.gov/states/letter/smd83_100.asp.

¹¹⁶ They are the District of Columbia, Hawaii, Idaho, Kansas, Massachusetts, Maine, Minnesota, Montana, New Hampshire, Utah, Texas (pilot), Vermont, and Washington. See *Medicaid/SCHIP Reimbursement Models for Language Services* (updated 2009), http://www.healthlaw.org/images/stories/Medicaid_and_SCHIP_Reimbursement_Models_for_Language_Services_2009_update.pdf.

As made clear by OCR’s posit of this question, having robust data on the costs and benefits of language assistance services is important for stakeholders throughout the healthcare system, particularly for employers, providers, insurers, and policymakers. We encourage OCR to partner with federal research agencies to take greater leadership in funding these studies.

Finally, in discussions of costs and benefits, we caution against using these factors as dispositive of when federally funded entities must—or are recommended to—provide language assistance services pursuant to Title VI. As OCR has reiterated from the Department of Justice’s LEP Guidance, Title VI policies advance the longstanding principle that “federally assisted programs aimed at the American public do not leave some behind simply because they face challenges communicating in English.”¹¹⁷ Cost-benefit analyses fail to evaluate how professional and industry culture contribute to racial disparities in health care.¹¹⁸

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

Visiting health care facilities and agencies that administer health programs and activities are often uncomfortable for individuals with LEP who are “unfamiliar with [the system’s] cultural norms, vocabulary, and procedures.”¹¹⁹ In preparing for ACA outreach and enrollment efforts, Jing Zhang, Director of Community Health Programs at Asian Health Services in Chicago, said, “In person counseling can be challenging for our community . . . not only because they are limited English speaking but also unfamiliar with healthcare and insurance systems.”¹²⁰ Describing parents in a clinical setting, Ms. Jaramillo, a community outreach worker in South Los Angeles, said, “You know, I don’t even know if [parents with LEP] are empowered to ask questions. A lot of it is that they don’t know the system. It’s really complicated, you know.”¹²¹ Similarly, a social service worker from the Immigrant and Refugee Community Organization-Asian Family Center, located in Oregon, shared that Vietnamese applications are “so poorly translated [that] people are not able to fill out the form[s] on their own.”¹²² Despite the mandate of Title VI to mitigate these difficult interactions, many LEP individuals are unaware of their right to language assistance services.¹²³

¹¹⁷ Guidance to Federal Financial Assistance Recipients Regarding Title VI Prohibition Against National Origin Discrimination Affecting Limited English Proficient Persons, 67 Fed. Reg. 41,455, at 41,45; HHS LEP Guidance, 68 Fed. Reg. at 47,312.

¹¹⁸ Lisa C. Ikemoto, *Symposium: Racial Disparities in Health Care and Cultural Competency*, 48 ST. LOUIS L.J. 75, 119 (2003).

¹¹⁹ Vikki Katz, *Children as Brokers of their Immigrant Families’ Healthcare Connections*, at 24 (2013) (under review).

¹²⁰ Email from Jing Zhang, Director, Community Health Programs, Asian Human Services, to Asian Americans Advancing Justice | AAJC, Sept. 3, 2013 (on file with Advancing Justice | AAJC).

¹²¹ *Id.*

¹²² Email from Nga-My Vuong, Community Organizer, Immigrant and Refugee Community Organization-Asian Family Center, to Asian Americans Advancing Justice | AAJC, Sept. 5, 2013 (on file with Advancing Justice | AAJC).

¹²³ *E.g.*, Email from Nga-My Vuong, Immigrant and Refugee Community Organization-Asian Family Center (“The health care system in the [U.S.] is a brand new experience to newcomers because they don’t have something similar to it in Vietnam. Many Vietnamese who have recently arrived don’t understand how their benefits work including

Unfamiliarity with the health care system often results in inaction that could compromise a basic standard of living for individuals and families. The social service worker from the Immigrant and Refugee Community Organization-Asian Family Center recounted a situation of a Vietnamese-speaking family whose children, despite being fully covered by a state health plan, did not visit a doctor or dentist for three years because of perceived costs.¹²⁴ Similarly, patients face end-of-life care without adequate linguistic, cultural, or medical support. In Orange County, California, a Marshallese community leader who had end-stage renal failure was in the care of a medical center that did not have Marshallese language services to accurately ask for the patient's informed consent, explain the terms of an advanced health care directive, or convey other critical medical information.¹²⁵ Often times, LEP residents, have to travel long distances to seek care at medical centers that provide adequate interpreter services. In Cleveland, Ohio, a group of ethnic minority Chinese residents chartered a bus every weekend to drive over 500 miles to New York City's Chinatown to the Charles B. Wang community health center to receive health care from culturally and linguistically competent staff who spoke their dialect.¹²⁶ A Vietnamese-speaking man from Eastern New Orleans shared, "If there were no interpreters, I would not understand anything the doctor is telling me, things like when to take medication and when my next visit is."¹²⁷

Furthermore, the lack of language assistance services negatively impacts communities at large—not just LEP individuals. When interpreter services are inadequate, children often serve as language brokers for their parents with health insurance plans and providers.¹²⁸ "One imagines that for immigrants from less demographically dominant groups, language access issues and dependence on their children may be even more acute."¹²⁹

For Thanh who grew up in a predominately black and Hispanic community where health information was often not available in Vietnamese, he served as a broker—and advocate—for his parents when interacting with Medi-Cal caseworkers. This continued after he left for college, returning home during semester breaks to renew applications for his parents who sometimes had their benefits terminated.¹³⁰ Thanh's story may be found throughout the United States in communities with both large and small numbers of immigrant families. About 20% of children in the United States have immigrant parents, and 61% of these children have at least one parent who has difficulty speaking English.¹³¹ In families where there is one Mexican-born parent, about 82% of children have at least one parent who has difficulty speaking English.¹³²

their right to request an interpreter. Most are too shy to complain about services they receive at a clinic thinking: 'I am lucky enough to get government insurance, I should not complain.'").

¹²⁴ Email from Nga-My Vuong, Immigrant and Refugee Community Organization-Asian Family Center.

¹²⁵ Record on file with Asian & Pacific Islander American Health Forum.

¹²⁶ Asian Services in Action, *June and LIns: A Long Journey*, Dec. 17, 2012,

<http://www.asiaohio.org/2012/12/17/make-a-year-end-donation-to-asia-for-equal-access-to-healthcare-to-all/>.

¹²⁷ Record on file with Asian & Pacific Islander American Health Forum.

¹²⁸ Katz, *Children as Brokers of their Immigrant Families' Healthcare Connections*, at 31.

¹²⁹ *Id.* at 36.

¹³⁰ Record on file with Asian & Pacific Islander American Health Forum.

¹³¹ Katz, *Children as Brokers of their Immigrant Families' Healthcare Connections*, at 9.

¹³² *Id.*

A study conducted in South Los Angeles, where residents had convenient access to only local clinics and private providers, found that children’s brokering compromised providers’ ability to provide quality care.¹³³ Not only would adequate language assistance services help providers, they would help entire families. Although children voluntarily interpret for their parents, they are also “most likely to recall brokering in healthcare settings as times when they had experienced feelings of anxiety, helplessness, or fear of failure.”¹³⁴ Aurora, age 16 at the time she was interviewed in South Los Angeles, said,

Sometimes . . . I’m just like, “I don’t understand what you’re saying. . . . Can you explain better or say it in other words, describe it to me so I can better translate it to my parents.” They try to, but sometimes I just don’t get it. . . . I feel sad ‘cus I can’t help my parents. I try to understand the doctors, but I can’t [sometimes].¹³⁵

One union, the American Federation of State, County, and Municipal Employees (AFSCME), has collected many patient stories in California to illustrate the need for LEP patients to obtain interpreter services when seeking health care. One story involved a 59-year old Hmong woman who had to stay overnight in a hospital for stomach pains. She did not understand what the nurses were doing when they began to take off her clothes. She finally found a Hmong-speaking doctor who told her that blood clots were causing her pain and to go to the hospital when her pain returned but she was too afraid to go back to the hospital and opted to take pain medication instead.¹³⁶ Many community-based organizations and community clinics have heard of similar problems with their LEP clients when undertaking outreach and education efforts across the country. One community clinic brought a Vietnamese-speaking patient before the Board of California’s Health Benefit Exchange (also known as Covered California) to testify about having to wait three hours for an during an ophthalmology appointment at a local hospital. He also told the Board that he had witnessed other patients waiting hours or all day for an interpreter.

See Question (1) for experiences of AA and NHPI women with LEP in accessing comprehensive sexual and reproductive health care.

These examples are not exhaustive of the daily experiences of individuals who speak English less than very well and who need access to basic health care. They show that linguistically appropriate services—that are also culturally appropriate—are important to help many AAs and NHPIs break through existing communication and information barriers.

¹³³ Dr. Garber recalled having an adolescent son broker a cancer diagnosis to his mother:
You don’t really want a kid to know all those serious things. I had a lady . . . [who] was in deep, deep, deep denial about her breast cancer . . . [and] I had to use her son to say the word “cancer” to her, and she was horrified and in tears. . . . He was close to grown up, but I’m sure he felt very uncomfortable. . . . I think he really didn’t want to be in that position, because it was like him telling the bad news, not be me telling the bad news.

Id. at 19.

¹³⁴ *Id.* at 21.

¹³⁵ *Id.* at 25.

¹³⁶ See, Anderson, B., *A Need for More Interpreters in the Valley*, FRESNO BEE, March 23, 2013.

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

Health centers that provide free services or low-cost services often encounter patients with LEP on a daily basis and confront the expense of providing adequate interpreter services. AAPCHO's member health centers served over 390,000 patients in 2011. Over 50% were best served in languages other than English and in some centers, LEP patients represented up to 99% of the patient population.¹³⁷ While many health centers hire bilingual staff, one women's health center, which treats patients whose primary languages are Spanish, Nepalese, Bhutanese, and Hindi, shared, "The cost [of using a language line for telephonic interpreters] is very high, and we are constantly looking for grants to help cover this expense. Approximately averaging \$1.00/minute (but varies with language), the cost of the interpreter service often supersedes the reimbursement rate/cost of the actual visit itself."¹³⁸ The health center suggested that provider services could be improved for patients with LEP

if there was a tool that would provide written translations as well as verbal translations, as we know adult learners require various methods to learn and intake information. . . . [H]aving a tablet/laptop with written translations would be a nice adjunct, something a patient could read and review after the phone call ends. Also, a screen showing the interpreter would allow us to use American Sign Language.¹³⁹

In addition, the rapid growth and diversity of the immigrant population creates unique challenges for communities that are unfamiliar with providing health services for newly emerging immigrant populations. On average, about half of the patients served at AAPCHO member health centers require language services, compared to 23% of patients served at other health centers. Unfortunately, only 29% of health centers provide bilingual staff with additional incentives (e.g., compensation) to provide interpretation services.¹⁴⁰ As a result, most health centers find it challenging to recruit bilingual staff. Furthermore, in a national survey of health centers, only 5% responded that they receive direct reimbursement for language services.¹⁴¹ Instead, health centers often finance their language service provision through a combination of general staffing funds, fees, and private financing.

Advancing Justice | LA operates an Asian Language Legal Intake Project (ALLIP), which provides toll-free hotlines in Cambodian (Khmer), Chinese (Mandarin and Cantonese),

¹³⁷ *An Analysis of AAPCHO Community Health Centers: UDS 2011*, Association of Asian Pacific Community Health Organizations (2013), http://www.aapcho.org/wp/wp-content/uploads/2013/05/2013-UDS-Fact-Sheet_2011-Data_FINAL.pdf.

¹³⁸ Record on file with Asian & Pacific Islander American Health Forum.

¹³⁹ Record on file with Asian & Pacific Islander American Health Forum.

¹⁴⁰ *Serving Patients with Limited English Proficiency*, National Association of Community Health Centers (2008), <http://www.nachc.com/client/LEPReport.pdf>.

¹⁴¹ "Serving Patients with Limited English Proficiency", National Association of Community Health Centers, 2008. <http://www.nachc.com/client/LEPReport.pdf>.

Korean, Thai, and Vietnamese. We have found that it is necessary to have dedicated telephone lines for each language so the caller receives an immediate response in her or his language. We recommend the use of dedicated language lines to ensure that callers do not simply hang up when they hear an English-speaker answer the call or when they wait too long for someone to respond in their language. It is not adequate to have callers leave messages, especially if the prompt is in English and the callers do not understand English or wade through too many options before they can finally understand the message in their language.

The intake staff also provides help in English, Tagalog, and other languages. Callers receive resources, counseling, or referral to an Advancing Justice | LA attorney or another legal aid organization on issues such as housing, domestic violence, family law, immigration, citizenship, consumer fraud, employment, discrimination, and will soon receive assistance to enroll into Covered California. We have funded the project through grants from foundations because we recognize the need in AA communities for language assistance to improve access to legal service and to provide a service for our communities. If a small non-profit agency such as Advancing Justice | LA can provide such services, it should be possible for larger entities, such as health plans, provider groups and state marketplaces to provide bilingual staff to respond to caller's in their language.

Three “promising practices” reports from The Commonwealth Fund outlines ways that health care providers,¹⁴² health benefit offices,¹⁴³ and small healthcare providers¹⁴⁴ can effectively and cost-efficiently provide language services.

See Question 4.(b) for cost-benefit data on providing language assistance services.

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

Contrary to the mandate of Title VI and Executive Order 13166 for all recipients of federal funding to ensure meaningful access to their health programs and activities, the brunt of providing language assistance services often falls on a few community-based organizations. Often times, these organizations are not covered entities under Title VI and do not receive federal funding to provide interpreter services and translate documents. When compared to the costs associated with developing language access plans, the resulting benefits are many and far-reaching.

As discussed above in Question 4.(d), Advancing Justice | LA provides interpreter and limited translation services in at least eight languages and has developed an informal language access

¹⁴² M. Youdelman and J. Perkins, *Providing Language Interpretation Services in Health Care Settings: Examples from the Field*, The Commonwealth Fund (2002), available at <http://www.commonwealthfund.org>.

¹⁴³ M. Youdelman, J. Perkins, J. D. Brooks, and D. Reid, *Providing Language Services in State and Local Health-Related Benefits Offices: Examples From the Field*, The Commonwealth Fund (2007), available at <http://www.commonwealthfund.org>.

¹⁴⁴ M. Youdelman, J. Perkins, *Providing Language Services in Small Health Care Provider Settings: Examples from the Field*, The Commonwealth Fund (2005), available at <http://www.commonwealthfund.org>.

plan similar to the model described in the HHS LEP Guidance: (1) identified the languages needed by our communities; (2) developed language assistance measures, including dedicated, toll-free hotlines; (3) trained our ALLIP staff; (4) provide notice about our hotlines, i.e., on our website, printed cards, etc.; and (5) monitor and update our protocols. Given our size and resources, we believe that most entities, including physician's offices, should be able to develop a simple, effective language access plan using the HHS LEP Guidance model.

See Question 4.(b) for cost-benefit data on providing language assistance services.

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

A federal recipient may fulfill its obligation of providing “meaningful access” under Title VI by translating all “vital documents.” While the federal interagency website LEP.gov says that “[a] document *will be* considered vital if it contains information that is *critical* for obtaining federal services and/or benefits, or is required by law,”¹⁴⁵ the HHS LEP Guidance says that “[w]hether a document . . . is ‘vital’ *may depend* upon the *importance* of the program, information, encounter, or service involved, and the *consequence* to the LEP person if the information is not provided accurately or in a timely manner.”¹⁴⁶ Examples of vital documents are listed by LEP.gov and in the HHS LEP Guidance.¹⁴⁷ On the other hand, “[n]on-vital information includes documents that are *not critical* to access such benefits and services.”¹⁴⁸

We interpret the current definition of vital documents in the HHS LEP Guidance to mean that the “importance” and “consequences” of information are a few—and not definitive—factors in determining whether information is “critical” and, therefore, “vital.” Consistently, HHS also recognizes that vital documents include not just those used during the receipt of medical care but also materials that raise “[a]wareness of rights or services” such that “where a recipient is engaged in community outreach activities, it should regularly assess the needs of the populations frequently encountered or affected by the program or activity to determine whether certain critical outreach materials may be the most useful to translate.”¹⁴⁹ When the consequence of information is a person’s access to a program or activity, whether through awareness or actual application, these materials should be considered vital documents.

¹⁴⁵ LEP.gov, Frequently Asked Questions, <http://www.lep.gov/faqs/faqs.html> (emphasis added) (last accessed Sept. 16, 2013).

¹⁴⁶ HHS LEP Guidance, 68 Fed. Reg. at 47,318 (emphasis added).

¹⁴⁷ LEP.gov, Frequently Asked Questions (listing as vital documents: “applications, consent and complaint forms; notices of rights and disciplinary action; notices advising LEP persons of the availability of free language assistance; prison rulebooks; written tests that do not assess English language competency, but rather competency for a particular license, job, or skill for which English competency is not required; and letters or notices that require a response from the beneficiary or client”); HHS LEP Guidance, 68 Fed. Reg. at 47,319 (listing as possible vital written materials: consent and complaint forms; intake forms; notices, written tests that do not assess English language competency; applications to participate in a recipient’s programs or activities; hospital menus; third party documents, forms, or pamphlets; government documents and forms; and general information)

¹⁴⁸ *Id.* (emphasis added).

¹⁴⁹ HHS LEP Guidance, 68 Fed. Reg. at 47,318.

Outreach, education, and enrollment materials to be used by the new Health Insurance Marketplace, QHPs, and other federally funded entities participating in the new Health Insurance Marketplace are vital documents that fall under the purview of Title VI. In particular, HHS should address the current translation shortcomings of the both the single, streamlined online and paper application for insurance affordability programs. As a document that is required to participate in the Health Insurance Marketplace and other programs, the single streamlined application falls squarely within the definition of a vital document. This application provides the initial entry point to apply for health insurance and is a vital component of the ACA’s “no wrong door” approach to enrollment. Based on the current number of translated languages present in other federal programs, we recommend the single streamlined application to be translated in full into at least 15 of the most commonly spoken non-English languages.¹⁵⁰ While we appreciate the Centers for Medicare & Medicaid Services’ current efforts to create translated application “job aids” in 34 languages, we believe the single streamlined online and paper application must be operational as a form that can be completed by LEP consumers and processed by the agency.

Since it may be too late to translate the online applications for the Federally-facilitated Marketplaces, at a minimum, the paper applications should be translated with the eventual translation of the web portal into at least the most commonly spoken 15 languages. In recognition of the cultural and linguistic diversity of the state, Covered California will be translating its paper application into the 11 non-English Medi-Cal threshold languages, which includes six Asian languages. It has also translated many of its fact sheets into 12 non-English languages. Building upon California’s practices, we recommend that OCR consider outreach, education and enrollment materials to be “vital” documents and translated into the top 15 languages spoken by the LEP population.

We understand the balance of interests at play in the current definition of “vital documents” and, to this end, we recommend that all entities subject to the ACA, at a minimum, include in-language “taglines” in at least 15 languages when vital documents cannot be translated. These taglines should be included at the top of a notice or as a prominent insert in the same mailing, informing recipients that the notice is important and how to obtain information about the document in the individual’s language. Similarly, if the single, streamlined application cannot be translated into all of the 15 languages, taglines should be provided on each page of the application with a number for applicants to call for assistance in completing the form.

For example, private health plans that serve California—which amounts to approximately 12% of the nation’s population—are already required to provide such notice. As an example, California’s Department of Managed Healthcare offers a sample language access notice with taglines in 12 languages. The tagline states:

¹⁵⁰ The Social Security Administration, through its Multilanguage Gateway, translates many of its documents into 15 languages. See Multilanguage Gateway, U.S. Social Security Administration (Oct. 2012), <http://www.ssa.gov/multilanguage/>. Additionally, the Centers for Medicare & Medicaid Services translates Medicare forms, including notices, into 15 languages in addition to Spanish. See *CMS Strategic Language Access Plan (LAP)*, Centers for Medicare & Medicaid Services (2010), <http://www.cms.gov/About-CMS/AgencyInformation/EEOInfo/downloads/AnnualLanguageAccessAssessmentOutcomeReport.pdf>.

IMPORTANT: You can get an interpreter at no cost to talk to your doctor or health plan. To get an interpreter or to ask about written information in (your language), first call your health plan's phone number at 1-XXX-XXX-XXXX. Someone who speaks (your language) can help you. If you need more help, call the HMO Help Center at XXX-XXX-XXXX.

Prescription Drug Labels as Vital Documents

One area which has been overlooked has been the inclusion of prescription drug labels as vital documents. In prior sections, we have identified the serious consequences when an LEP patient does not understand medication instructions. Although people depend on prescription medications to treat a variety of health conditions, about 90 million adults in the United States misunderstand at least some of the instructions provided on prescription drug labels.¹⁵¹ For LEP individuals, this problem is exacerbated simply because they may not read or understand the written instructions. The implications of being unable to correctly understand and use medication information can be costly and dangerous.¹⁵² In addition, treating people for illnesses caused by taking medicine incorrectly or in the wrong doses can bear a heavy toll on the economy with increased visits to the emergency room or repeat visits for untreated illness.¹⁵³

There have been several successful language access campaigns in the pharmacy setting. We recommend that HHS adopt policies for pharmacies reflecting the progress made by campaigns launched in New York and California. In 2009, based on a campaign co-led by Make the Road New York and New York Lawyers for the Public Interest, the New York legislature passed the Language Access in Pharmacies Act, which mandated that pharmacies in New York provide language access services, including translating prescription labels, signage, and interpretation services. HHS can adopt a policy requiring pharmacies that receive federal funds provide similar language access services.

In California, the state legislature passed S.B. 472, a bill to standardize prescription drug labels to make them more patient-centered and accessible to LEP patients.¹⁵⁴ The statute required the Board of Pharmacy (Board) to specifically consider the needs of patients with LEP in designing the new standardized drug label. Advocates provided input into the regulatory process, which resulted in requiring pharmacies, at a minimum, to provide interpreting services to all LEP patients, either by pharmacy staff members or through telephone interpreting for all hours that the pharmacy is open.¹⁵⁵ Pharmacies must also post a notice that informs LEP patients about their rights to an interpreter free of charge in 12 languages. The Board has created a model notice, and if a pharmacy opts to use its own sign, it must be approved by the Board.¹⁵⁶ The Board also translated 15 standard instructions for medicine use into the top five languages and

¹⁵¹ Consumer Reports, *Consumer Reports: Pharmacies Don't Always Provide Required Drug Warnings*, WASHINGTON POST, Aug. 29, 2011, http://articles.washingtonpost.com/2011-08-29/national/35269840_1_drug-labels-drug-warnings-prescription-drug.

¹⁵² See *Prescription for Inequity: The Struggles of Limited English Proficient Patrons at D.C. Pharmacies* (2013) (on file with Sapna Pandya, Executive Director, Many Voices One Love www.mlovdc.org).

¹⁵³ *Id.*

¹⁵⁴ Cal. Bus. & Prof. Code § 4076.5.

¹⁵⁵ 16 Cal. Code of Regs. § 1707.2.

¹⁵⁶ 16 Cal. Code of Regs. § 1707.6.

posted it on their website as a resource to pharmacies serving LEP communities. HHS can adopt a policy requiring that pharmacies receiving federal funding translate standard instructions into various threshold languages by specifically defining prescription drug labels and instructions as “vital” documents.

5. Title IX, which is referenced in Section 1557, prohibits sex discrimination in federally assisted education programs and activities, with certain exceptions. Section 1557 prohibits sex discrimination in health programs and activities of covered entities. What unique issues, burdens, or barriers for individuals or covered entities should we consider and address in developing a regulation that applies a prohibition of sex discrimination in the context of health programs and activities? What exceptions, if any, should apply in the context of sex discrimination in health programs and activities? What are the implications and considerations for individuals and covered entities with respect to health programs and activities that serve individuals of only one sex? What other issues should be considered in this area?

It is critical that regulations issued pursuant to this new statute reflect the long-established jurisprudence of strong protections against sex discrimination in federal law. Regulations, guidance, and case law under Title VII of the Civil Rights Act of 1964, the Pregnancy Discrimination Act (PDA), and Title IX of the Education Amendments of 1972 should inform what constitutes sex discrimination in health care under Section 1557. More specifically, Section 1557’s prohibition of sex discrimination necessarily includes discrimination based on pregnancy, gender identity, and sex stereotypes, and sexual orientation.¹⁵⁷

Pregnancy discrimination constitutes sex discrimination under Title IX¹⁵⁸ and other civil rights statutes such as Title VII¹⁵⁹ and thus also constitutes sex discrimination under Section 1557. These laws prohibit discrimination based on pregnancy itself, as well as pregnancy-related conditions.¹⁶⁰ Section 1557 regulations should expressly recognize this basic principle.

Discrimination on the basis of actual or potential parental, family or marital status also violates Section 1557 if this behavior treats women and men differently or is based on sex stereotypes. Title IX’s prohibition on sex discrimination encompasses these grounds.¹⁶¹ Title IX further prohibits actions based on head of household or principal wage earner status.¹⁶² Section 1557 regulations should likewise prohibit discrimination on these bases.

¹⁵⁷ Dep’t of Health & Human Servs., Request for Information Regarding Nondiscrimination in Certain Health Programs or Activities, 78 Fed. Reg. 46,558, 46,559 (proposed Aug. 1, 2013) (“Sex discrimination (including discrimination on the basis of gender identity, sex stereotyping, or pregnancy)”).

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

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

¹⁶⁰ See, e.g., 42 USC § 2000e(k) (2012).

¹⁶¹ E.g., 34 C.F.R. § 106.40(a) (2012); 34 C.F.R. § 106.57(a).

¹⁶² E.g. 34 C.F.R. § 106.57(a) (2012).

Further, Title IX has consistently been interpreted to include prohibitions against discrimination based on sex stereotyping—including discrimination based on the assumption that someone conforms to a sex stereotype and discrimination against an individual because he or she departs from a sex stereotype—and Section 1557 must be understood to ban such discrimination.¹⁶³ Similarly, the E.E.O.C. has also concluded that discrimination based on gender identity or transgender status is a form of sex discrimination under Title VII,¹⁶⁴ as has the Department of Housing and Urban Development with regard to the Fair Housing Act.¹⁶⁵ Indeed, the HHS has already recognized the importance of addressing discrimination against LGBT people in health care when it included explicit prohibitions against sex, gender identity, and sexual orientation discrimination in final rules for health insurance Exchanges, QHPs, and the EHB.¹⁶⁶

6. The Department has been engaged in an unprecedented effort to expand access to information technology to improve health care and health coverage. As we consider Section 1557's requirement for nondiscrimination in health programs and activities, what are the benefits and barriers encountered by people with disabilities in accessing electronic and information technology in health programs and activities? What are examples of innovative or effective and efficient methods of making electronic and information technology accessible? What specific standards, if any, should the Department consider applying as it considers access to electronic and information technology in these programs? What, if any, burden or barriers would be encountered by covered entities in implementing accessible electronic and information technology in areas such as web-based health coverage applications, electronic health records, pharmacy kiosks, and others? If specific accessibility standards were to be applied, should there be a phased-in implementation schedule, and if so, please describe it.

Health information technology has the potential to provide new opportunities for health providers to track and eliminate health disparities that disproportionately impact LEP and AA

¹⁶³ See Dep't of Educ., Office of Civil Rights, *Revised Sexual Harassment Guidance: Harassment of Students by School Employees, Other Students, or Third Parties: Title IX* (January 19, 2001), available at <http://www2.ed.gov/about/offices/list/ocr/docs/shguide.html>; Dep't of Educ., "Dear Colleague," 7-8 (October 26, 2010), available at http://www2.ed.gov/about/offices/list/ocr/letters/colleague-201010_pg8.html. See also *Price Waterhouse v. Hopkins*, 490 U.S. 228 (1989); *Lewis v. Heartland Inns of America, L.L.C.*, 591 F.3d 1033 (8th Cir. 2010); *Bibby v. Phila Coca Cola Bottling Co.*, 260 F.3d 257, 2652-63 (3rd Cir. 2001); *Smith v. City of Salem*, 378 F.3d 566 (6th Cir. 2004). See also *Doe v. Brimfield Grade School*, 552 F. Supp. 2d 816, 823 (C.D. Ill. 2008); *Theno v. Tonganoxi Unified School District*, 377 F. Supp. 3d 952 (D. Kansas 2005); *Schroeder v. Maumee Bd. Of Educ.*, 296 F. Supp. 2d 869, 880 (N.D. Ohio 2003); *Montgomery v. Indep. Sch. Dist. No. 709*, 109 F. Supp. 2d 1081, 1090-91 (D. Minn. 2000).

¹⁶⁴ *Macy v. Holder*, E.E.O.C. Appeal No. 0120120821, *7 (Apr. 23, 2012) (interpreting Title VII's prohibition against sex discrimination to include discrimination based on a person's transgender status).

¹⁶⁵ Memorandum from John Trasviña to FHEO Regional Directors, *Assessing Complaints that Involve Sexual Orientation, Gender Identity, and Gender Expression* (June 2010), available at <http://www.fairhousingnc.org/wp-content/uploads/2012/03/HUD-Memo-re-Sexual-Orientation-Discrimination-6-15-2010.pdf> (announcing that the Department would treat "gender identity discrimination most often faced by transgender persons as gender discrimination under the Fair Housing Act").

¹⁶⁶ See, e.g., 45 C.F.R. §§ 155.120(c) (nondiscrimination rule for Exchanges); § 156.200(e) (for QHPs); Health Insurance Market Rules; Rate Review, 78 Fed. Reg. 13,406, 13,438 (Feb. 27, 2013) (to be codified at 45 C.F.R. § 147.104(e)) (for marketing and benefit design); Standards Related to Essential Health Benefits, Actuarial Value, and Accreditation, 78 Fed. Reg. 12,834, 12,867 (Feb. 25, 2013) (to be codified at 45 C.F.R. § 156.125) (for the EHB).

and NHPI communities. For example, AAPCHO member health centers are currently utilizing electronically collected patient health information to monitor non-clinical services such as translation, and determine if these services improve the health of patients with chronic disease. Through an electronic patient monitoring system and newly developed decision support tool, health center staff can readily access patients' medical records, as well as review the overall steps and processes required in helping patients manage their illness. Prior to this electronic patient monitoring system, providers often maintained hardcopy files that were not centralized or easily monitored. However, in order to maximize the effectiveness of these systems, electronic medical records must be linguistically accessible for LEP patients.

In ensuring that individuals with LEP have access to these electronic and information technology programs, OCR should consider the oral interpretation and written translation standards that it will be employing in other health programs and activities. Educational resources aimed to help patients should be available in multiple non-English languages. OCR may also consider the potential of technology to help identify and prevent discrimination in health programs and activities with the goal of reducing health disparities. As stated in the Leadership Conference's comments, meaningful use of electronic health records may be used in three areas:

(1) data collection and use to identify disparities; (2) barriers regarding language, literacy, and communication that exclude protected classes from participation, deny them the benefits of, or discriminate against them in health IT programs or activities receiving Federal financial assistance; and (3) barriers in care coordination and planning which do the same.

With regard to data collection used to identify health disparities and access to care, it is critically important that disaggregated data be collected among racial groups, especially AA and NHPI populations given the diverse experiences each sub-population faces. Although the data collection categories in ACA Section 4302 allow for seven different AA racial groups and four NHPI groups, it falls short of capturing the range of health disparities experienced by each sub-population in the AA and NHPI communities. Given the availability of technology to handle large amounts of data, the limitation is due to the collection of such data by providers, plans, and the Health Insurance Marketplace. HHS could provide useful guidance for collection and reporting of data collected from health records.

In developing standards for technology programs, OCR should build upon existing privacy standards of the Health Insurance Portability and Accountability Act (HIPAAA) to protect patient health data. Members of protected classes that are most often subject to discrimination may also be subjected to disproportionate abuses of privacy rights or misuses of their private health data.

As mentioned above, we refer OCR to the detailed comments submitted by the Leadership Conference on this question.

Compliance and Enforcement Approaches

7. Section 1557 incorporates the enforcement mechanisms of Title VI, Title IX, Section 504 and the Age Act. These civil rights laws may be enforced in different ways. Title VI, Title IX, and Section 504 have one set of established administrative procedures for investigation of entities that receive Federal financial assistance from the Department. Under all these laws, parties may file private litigation in Federal court, subject to some restrictions.

In addition to the comments below, we support the more detailed comments provided by the Leadership Conference on compliance and enforcement approaches.

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

Voluntary Compliance

An individual choosing to use Title VI's administrative enforcement procedures begins by filing an administrative complaint with OCR.¹⁶⁷ Federal rules provide that an agency "will make a prompt investigation whenever a compliance review, report, complaint or any other information indicates a possible failure to comply with [Title VI requirements]."¹⁶⁸ According to the HHS LEP Guidance, "the goal for Title VI and Title VI regulatory enforcement is to achieve voluntary compliance."¹⁶⁹

Currently, federal law does not provide a proscribed time period for resolution of the noncompliance by voluntary means before an agency can refuse to grant or continue the federal financial assistance. However, it is worth emphasizing that "efforts to obtain voluntary compliance . . . should not be allowed to become a device to avoid compliance."¹⁷⁰ Further, the Department of Justice's Title VI Legal Manual for Federal Coordination and Compliance states that "although Title VI does not provide a specific time limit within which voluntary compliance may be sought, it is clear that a request for voluntary compliance, if not followed by responsive action on the part of the institution within a reasonable time, does not relieve the agency of the responsibility to enforce the Title VI by [other means contemplated by federal laws]."¹⁷¹

Current HHS LEP Guidance provides that HHS "will look favorably on intermediate steps recipients take . . . as part of a broader implementation plan or schedule [to move their] service delivery system toward providing full access to LEP persons."¹⁷² Although we commend HHS

¹⁶⁷ 28 C.F.R. § 42.107(b) (2001) ("(b) Complaints. Any person who believes himself or any specific class of individuals to be subjected to discrimination prohibited by this subpart may by himself or by a representative file with the responsible Department official or his designee a written complaint. A complaint must be filed not later than 180 days from the date of the alleged discrimination, unless the time for filing is extended by the responsible Department official or his designee").

¹⁶⁸ *Id.* §42.107(c).

¹⁶⁹ HHS LEP Guidance, 68 Fed. Reg. 47,321.

¹⁷⁰ U.S. Department of Justice, *Federal Funding Agency Methods to Enforce Compliance*, Title VI Legal Manual, (Sept. 20, 2013 at 5:30 PM), <http://www.justice.gov/crt/about/cor/coord/vimannual.php>.

¹⁷¹ *Id.*

¹⁷² HHS LEP Guidance, 68 Fed. Reg. 47,321.

for recognizing that recipients with limited resources may not have the same compliance responsibilities as recipients with greater resources, we recommend that HHS adopt a policy setting forth clearer guidance as to the reasonable time when intermediate steps should be taken by and when full access to LEP persons should be achieved by Advancing Justice | LA has been involved in filing administrative complaints in the past and is aware of many others that have taken a very long time to resolve. In fact, the length of time it has taken to negotiate a resolution agreement often has discouraged potential complainants from stepping forward and seeking this remedy. Clearer time frames will promote speedier compliance by recipients and institutions serving LEP populations, enabling LEP persons to receive the meaningful access they are entitled to under Title VI.

We also recommend that OCR specifically direct its Regional Office staff to work more closely with the complainant and/or the complainant's representative, which is often a community-based organization or legal services provider who is assisting the complainant, on the investigation and resolution agreement. In the past, Advancing Justice | LA has worked with the Region IX office on successful resolution agreements but such cooperation varies with the specific region and administration.

Investigation

Once OCR receives an administrative complaint, federal rules require prompt investigation. The HHS LEP Guidance provides that "OCR will investigate whenever it receives a complaint, report, or other information that alleges or indicates possible noncompliance with Title VI or its regulations."¹⁷³ Although we recognize OCR is investigating complaints as promptly as they can given budget and resource restraints, we recommend that HHS provide clearer guidance or time frame as to when investigations should be initiated once a complaint is received, as well as when a case should be closed. This will ensure that the administrative complaint procedure is effectively administered as to avoid a complaint backlog. We would like echo a comment made by the United States Commission on Civil Rights in their 1999 study of discrimination in health care:

Unlike the civil rights enforcement agencies that address discrimination in education and employment, OCR is responsible for uncovering discrimination that may affect not just one's life opportunities but on something far more profound—individuals' health and physical well-being. In some cases, prompt investigation could be a matter of life and death.¹⁷⁴

Monitoring

CMS' monitoring plan must place the burden on the agency, and not the LEP individual, to identify and rapidly resolve violations. An effective language access enforcement program must include proactive approaches by HHS, such as secret shopper surveys, to test whether

¹⁷³ HHS LEP Guidance, 68 Fed. Reg. 47,323.

¹⁷⁴ As quoted from Sara Rosenbaum & Joel Teitelbaum, *Civil Rights Enforcement in the Modern Healthcare System: Reinvigorating the Role of the Federal Government in the Aftermath of Alexander v. Sandoval*, 3 YALE J. HEALTH POLICY, LAW & ETHICS 215, 235 (2003).

appropriate language assistance is available. HHS cannot rely exclusively on individual complaints. LEP individuals, particularly those who also are frail and poor, are reluctant to complain and many do not even know that they have the right to language assistance. They should not bear the burden of identifying violations. CMS already uses secret shopper calls to assess plan compliance with Medicare marketing rules during the Annual Election Period and to determine managed care plan compliance with call center interpreter standards.¹⁷⁵

OCR must also monitor its resolution agreement with the federal fund entity and require more than mere paperwork and reports. For example, it should conduct onsite visits to the entity's office and interview staff, as well as patients, beneficiaries and advocates working with the affected population to ensure that the entity is meeting its obligations.

Individual, Class, and Third Party Complaints

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

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

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

Discriminatory Intent and Disparate Impact Claims

Disparate impact claims are allowed under the civil rights statutes referenced by Section 1557.¹⁷⁶ Section 1557 thus imports this important antidiscrimination principle. The disparate impact

¹⁷⁵ See, e.g., CY2012 Annual Election Period Marketing Surveillance Summary Report (Sept. 2012), available at www.cms.gov/Medicare/Compliance-and-Audits/Part-C-and-Part-D-Compliance-and-Audits/Downloads/Market-Surveillance-Summary-AEP-Report-CY-2012.pdf.

¹⁷⁶ Dep't of Justice, *Title VI Legal Manual* (2001), available at <http://www.justice.gov/crt/about/cor/coord/vimanual.php#B> (stating that Title VI regulations "may validly prohibit practices having a disparate impact on protected groups, even if the actions or practices are not intentionally discriminatory." (citing *Guardians Ass'n v. Civil Serv. Comm'n*, 463 U.S. 582, 582 (1983) and *Alexander v. Choate*,

standard is crucial for smoking out discrimination in an era in which discrimination takes ever more subtle forms—as documented in the examples described throughout these comments—and is often hidden in the very structures of our society. Section 1557 regulations should protect against disparate impact discrimination in the strongest possible terms.

Private Right of Action

The operating language of Section 1557 enforcement provides that “the enforcement mechanisms provided for and available under such title VI, title IX, section 504, or such Age Discrimination Act shall apply for purpose of violations of this subsection.”¹⁷⁷ The plain language of Section 1557 requires that the implementing regulations include the range of enforcement mechanisms expressly “provided for” in Title VI, Title IX, Section 504 of the Rehabilitation Act and the Age Discrimination Act, and those “available under” the same statutes. Thus, the regulations adopted for Section 1557 should reflect the wide-range of equitable relief and enforcement mechanisms established and available under civil rights law referenced in Section 1557. This includes a private right of action for monetary damages, a full range of agency enforcement and Department of Justice enforcement in court.

The Supreme Court has established that individuals have an implied private right of action under Title VI (and Title IX and Section 504). In *Cannon v. University of Chicago*, the Court stated that it has “no doubt that Congress . . . understood Title VI as authorizing an implied private right of action for victims of illegal discrimination.”¹⁷⁸ In addition, the Supreme Court has ruled that monetary damages are an available remedy in private actions brought to enforce Title IX for alleged intentional violations.¹⁷⁹ In *Franklin v. Gwinnett*, the Court reiterated that where a federal statute provides (expressly or impliedly) for a right to bring suit, federal courts “presume the availability of all appropriate remedies until Congress has expressly indicated otherwise.”¹⁸⁰ Since Congress expressly included enforcement mechanisms provided for and available under these civil rights statutes, a private cause of action should be available under Section 1557.

We strongly recommend that HHS adopt a policy expressly providing for a private right of action for disparate impact claims under Section 1557. This will avoid the confusion arising from the Supreme Court’s *Alexander v. Sandoval*, 532 U.S. 275 (2001) decision. Individual causes of actions, along with the range of agency administrative enforcement mechanisms, are necessary to effectuate Congress’ intent to prevent discrimination in health care access.

469 U.S. 287, 293 (1985); Dep’t of Justice, *Title IX Legal Manual* (2001), available at <http://www.justice.gov/crt/about/cor/coord/ixlegal.php#2> (stating “[i]n furtherance of [Congress’] broad delegation of authority [to implement Title IX’s prohibition of sex discrimination], federal agencies have uniformly implemented Title IX in a manner that incorporates and applies the disparate impact theory of discrimination.” (citing cases).

¹⁷⁷ 42 U.S.C. § 18116 (2012).

¹⁷⁸ 441 U.S. 677 (1979).

¹⁷⁹ *Franklin v. Gwinnett County Public Schs.*, 503 U.S. 60, 72-75 (1992).

¹⁸⁰ *Id.* at 66.

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

Testing

The Department of Education’s Title IX regulations contain a “self-evaluation requirement.” Educational institutions are required to assess their current policies and procedures to determine whether they comply with Title IX and its implementing regulations within one year after the Title IX regulations apply to them.¹⁸¹ In addition to covered entities conducting self-evaluations, we recommend HHS adopt a policy where services of the covered entities are tested by independent “testers” or as stated above, “secret shoppers.”

Testing is a recognized civil rights investigative technique used to gather information about whether housing, employment opportunities or services are provided on an equal, non-discriminatory basis. HHS can contract with an outside agency to conduct a test and evaluation of the services covered entities provide to LEP individuals. Such tests will include recruiting, selecting, and training testers who then present themselves to the covered entities as seeking services. Service information provided by the testers will then be used to evaluate whether covered entities are complying with civil rights laws and LEP individuals are attaining meaningful access.

It is worth emphasizing that the complaint process by itself is an insufficient enforcement mechanism. Self-evaluations and testing, in addition to complaints, provide more accurate assessments of whether entities are complying with their Title VI obligations because many individuals including those with LEP simply do not know about their Title VI rights and associated complaint procedures.

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

Education and Outreach Efforts Regarding Complaint and Grievance Procedures

Language access services are necessary for individuals with LEP to access not only federally funded programs and activities in the health care system, but also necessary to inform LEP individuals of their rights. The Department of Justice’s Guidance to Federal Financial Assistance Recipients Regarding Title VI Prohibition Against National Origin Discrimination Affecting Limited English Proficient Persons acknowledges that “language for LEP individuals can be a barrier to accessing important benefits or services, *understanding and exercising important rights*, complying with applicable responsibilities, or understanding other information provided by Federally funded programs and activities (emphasis added).”¹⁸²

¹⁸¹ 34 C.F.R. §106.3(c).

¹⁸² Guidance to Federal Financial Assistance Recipients Regarding Title VI Prohibition Against National Origin Discrimination Affecting Limited English Proficient Persons, 67 Fed. Reg. 41, 457 (June 18, 2002).

Many LEP individuals do not know they have the right to complain when they are not provided with proper language services. As referenced earlier, in a telephone survey of 1200 Californians in 11 non-English languages, 1000 were LEP participants and only 371 or 37% were aware that federal law obligates health care providers receiving federal funding to ensure language access.¹⁸³ For this reason, we recommend that OCR increase their outreach and education efforts regarding an LEP individual's right to meaningful access, with an emphasis on a right to file a complaint with OCR.

Timely Responses to Title VI Complaints

Beyond the steps that OCR can take to ensure access to its complaint process, it must monitor access for LEP persons on the state and local levels. From our experience, attempting to ensure access for LEP patients to currently covered entities—such as state departments of health and social services, managed care plans, hospitals, clinics, and other health care providers—presents a number of challenges. We are concerned that the increased demand on the health care system may overwhelm capacity and many LEP individuals will be blocked from enrolling in the expanded Medicaid programs or the Health Insurance Marketplace. Even those who are able to enroll may have problems accessing health care services due to higher than normal patient volumes. The current complaint and grievance procedures of the state agencies and managed care plans have been inadequate and inaccessible to most LEP patients, who have not been using these mechanisms when facing Title VI problems. Title VI has been in effect since 1964, yet many individuals still do not now they have a right to an interpreter and translated materials so they do not file complaints. Many also remain unaware of available state remedies. For example, although S.B. 853 went into effect in 2009 in California, requiring all health plans and health insurers to provide interpreter and translation services to health plan enrollees, few LEP patients have filed complaints despite continuing to face language barriers. Similarly, health care providers and federally funded entities are not aware of their obligations under Title VI.

With the implementation of the ACA, there is an opportunity for OCR to play a more proactive role in requiring the Health Insurance Exchanges, the state Medicaid agencies, the QHPS and its network providers, and any other entity receiving federal funding to ensure that their services are accessible to all those covered by Section 1557 by issuing clear guidance regarding its broad jurisdiction of all the relevant civil rights statutes. If local and state complaint and grievance procedures prove to be inadequate, we hope that those who have discrimination complaints can depend on the federal complaint process under OCR. Currently, OCR defers to complaints filed with state agencies, but we recommend simultaneous investigation of complaints to ensure that they are resolved in a timely manner.

Linguistically Appropriate Complaint and Grievance Procedure

Online Complaint Portal. We commend OCR's for its website which prompts individuals to file a complaint if they feel that they have been discriminated against. However, the Complaint Portal, where an individual can electronically file a complaint is entirely in English, making it

¹⁸³ Vanessa Grubbs, Alice Hm Chen, Andrew B Bindman, Eric Vittinghoff, and Alicia Fernandez, *Effect of Awareness of Language Law on Language Access in the Health Care Setting*, 21 J. OF GENERAL INTERNAL MEDICINE 683, 688 (2006).

inaccessible to LEP individuals. We recommend that HHS provide LEP individuals the same ease of access in filing a complaint as it provides English speakers by updating its Complaint Portal to include commonly spoken LEP languages.

Call Centers. On OCR’s website (https://ocrportal.hhs.gov/ocr/cp/about_us.jsf), it states that “if you need help filing a civil rights or health information privacy complaint, please email OCR at OCRMail@hhs.gov or call 1-800-368-1019. We provide alternative formats (such as Braille and large print), auxiliary aids and services (such as a relay service), and language assistance.” The same 1-800 number is provided on the information page for the other seven non-English languages. When dialed, the caller receives an automated message, which is approximately one-minute in length, recorded entirely in English. The message fails to include voice prompts for any of the seven non-English languages,¹⁸⁴ which is clearly problematic for an LEP individual who calls the number and will be unable to understand the message. It is likely that some LEP individuals will not stay on the phone for the completion of the message and will therefore miss the opportunity to leave a message regarding their civil rights issues.¹⁸⁵

We strongly recommend that HHS use an automated telephone system that adds voice prompts in multiple languages. Voice prompts should be added, at the very least, for the seven non-English languages OCR has translated webpages for. These voice prompts should be added so that LEP individuals can quickly access competent bilingual representatives or English-speaking representatives who can communicate using interpreters.¹⁸⁶

(d) Are there any other issues important to the implementation of Section 1557 that we should consider? Please be as specific as possible.

Compliance and Enforcement Approaches for Mixed-Status Families

It is important to note that the complaint procedures under Title VI are also 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

¹⁸⁴ Automated message for 1-800-368-1019: “You have reached the call center helpline for the U.S. Department of Health and Human Services Office for Civil Rights. Your call is important to us. Our business hours are Monday through Friday from 9am to 8pm Eastern Time. We are closed Saturday and Sunday, and all federal holidays. If you are receiving this message during business hours, it means we are currently experiencing high call volume. Thank you for your patience. Here at the U.S. Department of Health and Human Services Office for Civil Rights, we handle HIPAA complaints and civil rights complaints regarding health care providers and some insurance companies. If your questions, or concerns, have to do with health care privacy or health care related civil rights issues, please leave your name, state in which you are calling from, along with a call back number. If you have an open complaint, with your region, please also leave your transaction number. Thank you for calling the U.S. Department of Health and Human Services Office for Civil Rights.”

¹⁸⁵ It should be noted that on one instance, at the completion of the automated message, the caller was told that the “mailbox was full” and disconnected. In the unlikely scenario that a LEP individual would leave a message, OCR should ensure that the means provided is actually accessible so as to not discourage the LEP individual from reporting their civil rights complaint.

¹⁸⁶ Mara Youdelman, Nat’l Health Law Program, *The ACA and Language Access* (2011), http://www.healthlaw.org/images/stories/Short_Paper_5_The_ACA_and_Language_Access.pdf (describing voice prompts).

programs based on their national origin, states inadvertently may be violating Title VI.”¹⁸⁷ The enforcement mechanisms under Title VI may be used to prohibit applications requiring personally identifiable information from non-applicants, such as Social Security numbers or proof of citizenship or immigration status, that deter ineligible immigrants from applying on behalf of eligible family members. As discussed above, effect-based discrimination is also prohibited, such as creating onerous requirements for navigators that discourage participation of organizations serving immigrant communities and onerous documentation requirements for proving eligibility.

We encourage OCR to clarify in Section 1557 regulations that it has the authority to enforce provisions set forth in the Tri-Agency Guidance. Promulgated rules on Section 1557 should expressly provide that household members *not* applying for coverage for themselves are subject to the following rules and protections:

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

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

Conclusion

We urge OCR to move forward with its rulemaking for Section 1557 with the above recommendations in mind. The civil rights protections to ensure meaningful access to health programs and activities, ones that operate free of unlawful discrimination, require robust monitoring and enforcement mechanisms that will effectuate the intent of Section 1557. Indeed, to promote health and equal access to health care, the implemented regulations must accurately reflect the realities of discrimination faced by the provision’s protected classes, such as individuals with LEP and individuals living in mixed-status families as we have underscored in our comments.

¹⁸⁷ 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.

We appreciate the opportunity to comment on this critically important issue for the AA and NHPI communities. If you have any questions regarding our comments, please contact Helen Tran, Staff Attorney and NAPABA Law Foundation Partners and In-House Counsel Community Law Fellow, Advancing Justice | AAJC, at htran@advancingjustice-aajc.org; or Priscilla Huang, Policy Director, APIAHF, at phuang@apiahf.org. Thank you for your consideration of our comments.

Sincerely,



Helen Tran
Staff Attorney & NAPABA Law Foundation Partners
and In-House Counsel Community Law Fellow
Asian Americans Advancing Justice | AAJC
1140 Connecticut Ave. NW, Suite 1200
Washington, DC 20036
htran@advancingjustice-aajc.org
(202) 296-2300 ext. 108



Doreena Wong, Esq.
Project Director, Health Access Project
Asian Americans Advancing Justice | Los Angeles
1145 Wilshire Blvd., 2nd Floor
Los Angeles, CA 90017
d Wong@advancingjustice-la.org
(213) 241-0271



Kathy Ko Chin
President & CEO
Asian & Pacific Islander American Health Forum
450 Sutter Street, Suite 600
San Francisco, CA 94108
kkochin@apiahf.org
(415) 954-9988



Jeff Caballero
Executive Director
Association of Asian Pacific Community Health Organizations
300 Frank H. Ogawa Plaza, Suite 620
Oakland, CA
jeffc@aapcho.org
(510) 272-9536 ext. 105