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September 30, 2013
U.S. Department of Health and Human Services
Office for Civil Rights
Attention: 1557 RFI (RIN 0945-AA02)
Hubert H. Humphrey Building
Room 509F
200 Independence Ave. SW
Washington, DC 20201

Re: RIN 0945-ZA01
Comments on the HHS Office for Civil Rights' Request For
Information Regarding Nondiscrimination in Certain Health Programs
or Activities

Dear Director Rodriguez,

The National Immigration Law Center (NILC) specializes in the intersection of health care and immigration laws and policies, offering technical assistance, training, and publications to government agencies, labor unions, non-profit organizations, and health care providers across the country. For over 30 years, NILC has worked to promote and ensure access to health services for low-income immigrants and their family members. NILC submits the following comments in response to the request for information (RFI) concerning § 1557 of the Patient Protection and Affordable Care Act. The goal of these comments is to identify situations that implicate discrimination in health programs and activities that are experienced by families where individuals have different immigration statuses. We also provide comments suggesting ways in which HHS can develop the scope and enforcement procedures for § 1557.

UNDERSTANDING THE CURRENT LANDSCAPE

Issue 1: Experiences with, and Examples of, Discrimination in Health Programs and Activities

I. Experiences of Mixed-Status Families Subject to Title VI Oversight

The Department of Health and Human Services (HHS) has made significant progress in the past fifteen years to recognize the unique experiences of discrimination within families that include individuals with different immigration statuses, such as an undocumented parent with U.S. citizen children, commonly referred to as “mixed-status families.” As a result of a

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settlement agreement reached with the state of Georgia, the department developed a set of principles specifically focused on these families. The Office for Civil Rights (OCR) in HHS initiated the investigation concerning Georgia’s Medicaid application, which required applicants to certify under penalty of perjury that every household member—not just the applicant—were legal residents. Because the effect of this application was to deter eligible applicants from enrolling in the program due to fear that family members would be reported to immigration authorities, OCR reached a settlement with the state and resulted in a redesign of the form. The individual case led OCR to initiate a review of all states’ eligibility applications and, after finding consistent inappropriate questions that implicated similar deterrent effects, OCR worked with the U.S. Department of Agriculture to issue what is known as the Tri-Agency Guidance¹ in September 2000. The Guidance established policy guidelines for drafting eligibility applications for public benefit programs in a manner that does not deter eligible applicants and implicate civil rights violations.² On a broader scale, the Guidance’s creation and its principles provide an important template for understanding the challenges for mixed-status families and the importance of civil rights law in addressing them.

The Tri-Agency Guidance confirmed the application of Title VI of the Civil Rights Act of 1964³ to the context of mixed-status families. In the Guidance, the agencies set forth the policy that 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 government programs and access to the benefits they provide based on the applicant’s or a family member’s national origin. This position is consistent with regulations enforcing Title VI, which provide that in addition to situations of intentional discrimination, the civil rights protections—which cover any federally funded program—apply to programs and services that have the “effect of subjecting individuals to discrimination,” or have “the effect of defeating or substantially impairing accomplishment of the objectives of the program”⁴ The Guidance responds to two significant types of fear with immigrant communities for which inappropriate eligibility questions may affect participation: (1) fear that using these programs will hinder immigrants’ pending applications for citizenship, and (2) fear that applying for these services or benefits will force disclosure that a household member is undocumented.⁵ Primary examples of disparate, effect-based discrimination in this context involve

¹ DEPT. HEALTH AND HUMAN SERVICES AND DEPARTMENT OF AGRICULTURE, POLICY GUIDELINES REGARDING INQUIRIES INTO CITIZENSHIP, IMMIGRATION STATUS AND SOCIAL SECURITY NUMBERS IN STATE APPLICATION FOR MEDICAID, STATE CHILDREN’S INSURANCE PROGRAM (SCHIP), TEMPORARY ASSISTANCE FOR NEEDY FAMILIES (TANF), AND FOOD STAMP BENEFITS.

² Thomas E. Perez, *The Civil Rights Dimension of Racial and Ethnic Disparities in Health Status*, in *UNEQUAL TREATMENT*, ed. Brian D. Smedley, et al., 626, 648–49 (2003).

³ Pub. L. 88-352, 70 Stat. 241, 252–53 *codified at* 42 U.S.C. §§ 2000d *et seq.* (2012); *see also* 42 C.F.R. §§ 80.1–80.13 (2012).

⁴ 45 C.F.R. § 80.3(b)(2).

⁵ Perez, *supra* note 2, at 648.

inappropriate requests for Social Security numbers, or for citizenship or immigration status from family members not applying for coverage or benefits for themselves. Such actions implicate Title VI because of the chilling effect on eligible family members who do not seek to enroll in the programs based on concerns about immigration enforcement.

The Patient Protection and Affordable Care Act (ACA) statute⁶ recognizes the importance of these principles and includes statutory language addressing confidentiality and personally identifiable information. Section 1411(g) limits the collection, use and sharing of information to only that which is “strictly necessary”⁷ for determining eligibility, and §1414(a) similarly amends the Internal Revenue Code and the Social Security Act to clarify that tax return information and Social Security numbers may be collected, used, and shared only for eligibility determination purposes.⁸ The implementation of the ACA and other health programs can heighten the risk of discrimination in a number of contexts. The examples of ACA-related actions that could implicate discrimination pertinent to Title VI include eligibility applications, marketplace and eligibility workers, navigators, brokers, application assisters, and health care providers that may 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 exchange 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 examples include navigators or other workers who make assumptions about entire families based on the immigration status, or perceived immigration status, of an individual member, or who use indicators such as ethnicity or language to limit options provided to eligible individuals.

II. Specific Examples of Discrimination Implicating Title VI for Mixed-Status Families

In addition to disparate, effect-based discrimination in benefit applications that are discussed by the Tri-Agency Guidance, such situations may also arise from both registration workers and state programs that result in deterring eligible members of mixed-status families from participating in programs and services.

A. Florida Department of Children and Families

OCR reached a Voluntary Compliance Agreement in 2002 with Florida’s Department of Children and Families concerning eligibility determinations for federally funded programs including Medicaid, Temporary Assistance for Needy Families (TANF), and

⁶ Pub. L. 111-148, § 1411(g), 124 Stat. 119, 230 (2010) [hereinafter ACA].

⁷ ACA § 1411(g).

⁸ *Id.* § 1414(a).

the Children's Health Insurance Program (CHIP).⁹ This agreement stemmed from the practices of state employees administering benefits programs. An investigation by OCR followed a complaint by Farmworkers Health Services, Inc., alleging that state employees requested extra documents from Hispanic applicants, asked questions about the citizenship status of non-applicant household members, threatened to report Hispanic household members to immigration officials, and systematically denied benefits to households containing any members who were unwilling or unable to provide Social Security numbers. The OCR investigation confirmed civil rights violations within the system and set up guidelines to ensure that the federally funded programs were administered without discrimination and intimidation.¹⁰ As part of the resolution of the complaint, Florida agreed not to deny benefits or services because an applicant did not provide information regarding non-applicants, to allow family members to designate themselves as non-applicants, and to subject itself to two years' oversight concerning any changes to the program.¹¹ The Agreement goes into extensive detail on further stipulations that Florida change its application language, improve outreach programs, and establish new written guidance and trainings for its employees.¹²

B. Arizona HB 2008

A complaint filed by Valle del Sol, Inc., a nonprofit behavior health and social services organization in Maricopa County, Arizona, has alleged civil rights violations based on the state's enactment of HB 2008, which took effect October 2009 and requires state benefit agency employees to report discovered violations of federal immigration law to immigration authorities.¹³ The law imposes criminal sanctions on state employees and supervisors who do not meet these reporting guidelines. The complainants assert that the law has resulted in the effect-based discrimination discussed in the Tri-Agency Guidance and enforcing regulations of Title VI.

The impact of the law was swift. Regardless of whether an individual was seeking a benefit for herself or a family member, agency employees who believed they had discovered an immigration violation reported the individual or household member to federal immigration officials. Shortly after the law took effect, in a period from mid-November to mid-December 2009, the Arizona Department of Economic Security reported 772 names to Immigration and Customs Enforcement (ICE).¹⁴ Anecdotal

⁹ Voluntary Compliance Agreement between The Office for Civil Rights, U.S. Dept. of Health & Hum. Servs, and Fla. Dept. Children and Families Pertaining to Immigrant Access to Public Benefits, OCR No. 04-02-7004 and 02-00612 (2002), § I(A)–(B).

¹⁰ *Id.* § I(B)–(C).

¹¹ *Id.* §§ II(E)–(G), IV(E).

¹² *Id.* § V(A)–(J).

¹³ Ariz. Rev. Stat. Ann. § 1-501–02 (2013).

¹⁴ Casey Newton, *Benefits Law Nets Illegal Immigrant Suspects*, ARIZ. REPUBLIC (Dec. 18, 2009, 12:00 AM), http://www.azcentral.com/news/election/azelections/articles/2009/12/18/20091218desrep_orts1218.html.

evidence reported in the media raised concerns that undocumented immigrants were deterred by fear from obtaining services to which they were legally entitled, such as hospital care for childbirth.¹⁵ Analysis by Valle del Sol of the data made publicly available by the state exemplifies the fears that the law would exacerbate the kind of deterrence from securing critical services that the Tri-Agency Guidance is intended to prevent. In the first nine months after HB 2008 was enacted, use of emergency medical services—often the only type of health services available without regard to immigration status, but which may result in a referral to Immigration and Customs Enforcement if individuals “self-declare” their status—dropped 45 percent.¹⁶ Additionally, the number of children in TANF dropped 15 percent in 7 months, and new enrollees to the food stamp program fell from 21,000–30,000 per month in the months leading up to the entry into force to 1,334 and 195 per month in the second and third month following the law’s commencement.¹⁷ The challenge to the implementation of this law in specific federal programs is still pending at OCR.

Issue 2: The Scope of Health Programs and Activities That Should Be Subject to § 1557

It is essential to the effectiveness of § 1557 in addressing health disparities for immigrants and their families that regulations promote the principles of the Tri-Agency Guidance prohibiting processes and requirements that have the effect of deterring or preventing eligible individuals in mixed-status families from securing access to programs and services. We appreciate that the statute and promulgated regulations have built protections for limited collection and confidentiality of information into the exchange, Medicaid, and Children’s Health Insurance Program (CHIP), but we believe it is critical that all of these programs be brought under the rubric of §1557 rulemaking to make available to these families the accountability and enforceability mechanisms of the HHS Office for Civil Rights. OCR must have the authority to use civil rights mechanisms to prohibit states from enacting or otherwise enforcing policies or practices that frustrate the ACA’s purpose or its ability to reach eligible applicants.

These regulations must cover all programs that perform ACA-related functions, including partnerships such as navigators and other consumer assistance programs that will play a crucial role in reaching mixed-status families, who because of fear of immigration enforcement, limited English proficiency, or other immigration-related concerns are more difficult to reach. Particularly important to mixed-status families is outreach, which can assuage fears that eligibility determinations could be used for immigration enforcement, and can address limited English proficiency or other immigration-related concerns. Individuals who are eligible for Medicaid and CHIP, but who do not enroll, are expected

¹⁵ *Id.*

¹⁶ This analysis was done through use of statistics from the Arizona Department of Economic Security and included in an attachment to the Civil Rights Complaint filed by Valle del Sol, Inc., concerning HB 2008.

¹⁷ *Id.*

to constitute the largest group of people uninsured after implementation of the ACA.¹⁸ The disparity is strongest in Hispanic communities, and especially those with large immigrant communities. Researchers addressing this disparity suggest that targeted outreach strategies to address immigration-related fears accurately and clearly will be crucial in reaching these individuals.¹⁹ OCR's role in oversight of these organizations is particularly relevant because in many cases they are private organizations that have been hired as navigators. A private right of action may be more difficult to enforce for immigrant families, particularly against private actors²⁰ (although we support regulations strengthening this option, see issue 7), and thus administrative civil rights mechanisms are an important tool for ensuring compliance from these actors.

There are indications already within the navigator programs that clear regulations for § 1557 are needed for states to know what is necessary for compliance with civil rights standards. Nearly half of the 33 states with federally facilitated exchanges have enacted laws that will circumscribe the activities of organizations providing outreach, including by prohibiting navigators from advising applicants concerning plan details, creating stringent standards that may have the effect of deterring the participation of organizations focused on underserved communities, and requiring further regulation that result in delays in the navigator program.²¹ Although there is no available evidence that these create conditions implicating Title VI, they are the types of programs and activities that must be within the scope of § 1557 to make clear to the states their responsibilities and to ensure a mechanism to address outreach programs that deter mixed-status families from securing health care.

RECOMMENDATION: The scope of programs and activities covered by § 1557 should include applications covered by the Tri-Agency Guidance as well as outreach programs. A key to addressing health disparities among mixed-status families is ensuring that eligible individuals have access to available programs. Reaching these individuals to inform them of their options and providing a workable application process will be key to addressing the disparate discrimination affecting these families.

Issue 3: Studies and Other Evidence Documenting Impacts of Discrimination

The impact of discrimination in mixed-status families is largely in deterring individuals from gaining access to the programs for which they are eligible. Thus the main research

¹⁸ Lisa Clemens-Cope, et al., *The Affordable Care Act's Coverage Expansion Will Reduce Differences in Uninsurance by Race and Ethnicity*, 31 *Health Affairs* 920, 924–25 (2012).

¹⁹ *Id.* at 927–28.

²⁰ See *Alexander v. Sandoval*, 532 U.S. 275, 293 (2001). See generally Perez, *supra* note 2, at 630.

²¹ 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>.

on this issue focuses on the size of the affected population, the low participation rates in programs, and the expected role that the ACA may play in addressing these disparities in health care. Additional research indicates that these disparities promote the perception of discrimination among minority groups—especially immigrants, and further reduces their use of health care programs. Taken together, this research indicates that discrimination experienced by immigrants in the health care system will lead to significant adverse health effects on those individuals and their families.

I. The Demographic Impact of Mixed-Status Families

Families that include individuals with different immigrant statuses are a growing demographic: as of 2010, nearly one in four children younger than age 8 have an immigrant parent.²² Of the total group of children, the vast majority (93 percent) are U.S. citizens.²³ Two significant trends in the rates of health insurance affect mixed-status families. First is the high rate of uninsured noncitizens. Although there is a 30 percent difference in the uninsured rate for native-born and foreign-born citizens, the distinction is most acute when comparing those who have not naturalized. Noncitizens are uninsured at nearly four times the rate of native-born citizens and three times of the overall population.²⁴ The second trend in insurance data is the particularly high rate for uninsured Hispanics, which is relevant to the situation of mixed-status families because Hispanic children constitute the largest group of children in mixed-status families, with 62 percent living in families with at least one immigrant parent as of 2008.²⁵ The uninsured rates of Hispanics was 30.1 percent in 2011, according to Census data, which is nearly three-times the rate for white, non-Hispanics and the largest of any racial or ethnic classification.²⁶ Thus mixed-status families are commonly at the intersection of two groups with the highest insured rates.

II. Mixed-Status Families and the ACA

The ACA affects mixed-status families significantly in the exchange marketplaces and subsidies for purchasing those plans, and in the context of expanded Medicaid, which opens the program to individuals with slightly higher incomes and to single, childless individuals. The largest group of people expected to remain uninsured after ACA implementation are those who would be eligible for Medicaid but have not enrolled. Within mixed-status families, those individuals would be citizens or “qualified” immigrants. Most lawfully present immigrants are barred from federal, non-emergency

²² KARINA FORTUNY, ET AL., THE URBAN INSTITUTE, *YOUNG CHILDREN OF IMMIGRANTS* 1 (August 2010).

²³ *Id.* at 5.

²⁴ The numbers are 12.7 percent for native-born citizens, 47.4 percent for non-citizens, and 15.4 percent for the population as a whole. PEW HISPANIC CENTER, *STATISTICAL PORTRAIT OF THE FOREIGN-BORN POPULATION IN THE UNITED STATES, 2001*, Table 38.

²⁵ RICHARD FRY AND JEFFREY S. PASSEL,

²⁶ U.S. CENSUS BUREAU, *INCOME, POVERTY, AND HEALTH INSURANCE IN THE UNITED STATES: 2011* 22 (2012).

Medicaid and CHIP programs until they have had a specific status, such as lawful permanent residence (LPR or green card) for at least 5 years.²⁷ A broader group of lawfully present immigrants is eligible to purchase health care through the exchange marketplaces and to qualify for income-based subsidies. Undocumented immigrants cannot qualify for any ACA or non-emergency federal health insurance program.

In 2008, there were 4 million U.S.-born children with undocumented immigrant parents.²⁸ Under the ACA, an estimated 3.2 million children with only undocumented parents will be eligible for Medicaid/CHIP or Exchange subsidies.²⁹ The significance of these statistics on access to health insurance and quality care cannot be overstated. A 2011 study by the Government Accounting Office documented the strong association between a child's health insurance status and that of his or her parent, finding that a child was eight times more likely to have public insurance if his or her parent is insured, and 87 times more likely to have private insurance if his or her parent is insured.³⁰ Citizen children with non-citizen parents are 38.5 percent more likely to be uninsured than are citizen children with citizen parents.³¹

Coverage rates for children bear out the possible results for these families. U.S. citizen children with non-citizen parents are 38.5 percent more likely to be uninsured than are citizen children with citizen parents.³² This trend is consistent in every ethnic group; Hispanic children were the most likely to be uninsured.³³ In addition to the lower rates of children obtaining access to health insurance, evidence points to a chilling effect on immigrant access to health care more broadly—a reality that has the previously mentioned trickle-down effect on citizen children. Although much of the difference between citizens and non-citizens in health care spending can be attributed to the younger population and immigrants' ineligibility for public health insurance programs, an analysis

²⁷ There are exceptions to this general rule for certain classes of humanitarian and other categories.

²⁸ Fortuny, *supra* note 22, at 9 n.5.

²⁹ 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 (May 2011).

³⁰ GOVERNMENT ACCOUNTING OFFICE, GAO-11-24, MEDICAID AND CHIP: GIVEN THE ASSOCIATION BETWEEN PARENT AND CHILD INSURANCE STATUS, NEW EXPANSIONS MAY BENEFIT FAMILIES 8–10 (February 2011).

³¹ GOVERNMENT ACCOUNTING OFFICE, GAO-11-24, MEDICAID AND CHIP: GIVEN THE ASSOCIATION BETWEEN PARENT AND CHILD INSURANCE STATUS, NEW EXPANSIONS MAY BENEFIT FAMILIES 8–10 (February 2011).

³² Leighton Ku and Brian Bruen, *Poor Immigrants Use Public Benefits at a Lower Rate than Poor Native-Born Citizens*, CATO INSTITUTE: ECONOMIC DEVELOPMENT BULLETIN, May 4, 2013, 1, 3.

³³ DONALD J. HERNANDEZ, ET AL., FOUNDATION FOR CHILD DEVELOPMENT, DIVERSE CHILDREN: RACE, ETHNICITY, AND IMMIGRATION IN AMERICA'S NEW NON-MAJORITY GENERATION 10 (July 2013).

adjusting for health status, race/ethnicity, gender, health insurance coverage, and other factors found that the spending on immigrants' health care was still about 14–20 percent less than for U.S.-born citizens.³⁴ The impact is magnified with the ACA's effect on areas with smaller Latino populations because the smaller infrastructure, lower number of doctors, and language barriers are more acute, leading to increased reliance on emergency services.³⁵ Considering that undocumented immigrants are ineligible for the affordable insurance programs under the Affordable Care Act 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 5 years, the 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.

III. Perceptions of Discrimination and Effects on Levels of Care

In a far-reaching report by the Institute of Medicine of the National Academies in 2003, researchers noted that hundreds of studies have documented health disparities in minority communities, confirming that minorities often receive lower levels of treatment compared to whites, facts that are borne out in diminished treatments following certain procedures and fewer diagnostic tests, the latter of which has been shown to result in higher death rates for minority cancer patients.³⁶ Significantly, the Institute of Medicine report found that “radical changes in the financing and delivery of health care services” had a greater risk of creating barriers to care for minorities than non-minorities, and that Hispanic Americans—the most likely to be members of mixed-status families—face greater barriers to insurance than all other racial and ethnic groups in the U.S., although disparate access was also widely reported among Asian and black Americans.³⁷

A number of studies have indicated that a significant factor in creating these barriers is discrimination and the perception it creates in minority communities, especially for immigrants. One study concerning patient experiences found that minorities were much more likely to report being looked down upon or treated unfairly because of their race, but the largest disparity involved the question of whether the individuals believed they would have received better care if they were a different race. In this measurement 1.4 percent of whites responded affirmatively compared to 12.2 to 15.2 percent for various minority groups.³⁸ The researchers found that respondents who reported disparate treatment were less likely to have received an exam in the previous year, to have received

³⁴ Leighton Ku, *Health Insurance Coverage and Medical Expenditures of Immigrants and Native-Born Citizens in the United States*, 99 AM. J. PUB. HEALTH 1322, 1326–27 (2009).

³⁵ Kathryn Pitkin Derose, Jose J. Escarece, & Nicole Lurie, *Immigrants and Health Care: Sources of Vulnerability*, 1258 HEALTH AFFAIRS 1258, 1262 (2007).

³⁶ INSTITUTE OF MEDICINE, *UNEQUAL TREATMENT* 5, 39 (ed. Brian D. Smedley et al. 2003)

³⁷ *Id.* at 87, 140.

³⁸ Janice Blanchard & Nicole Lurie, *R-E-S-P-E-C-T: Patient reports of disrespect in health care setting and its impact on care*, 53 J. FAMILY PRACTICE 721, 726 (2004).

optimal care for certain diseases, and to have followed doctors' advice.³⁹ This research is consistent with other work that has indicated disparities in health care utilization such as fulfilling prescriptions.⁴⁰ For individuals with limited English proficiency, these perceptions of disparate treatment resulted in less use of preventative care⁴¹ and an increase in seeking informal alternatives.⁴² At least one study, based on California Health Interview Study data, indicated that immigration status itself is a significant factor, finding that among foreign-born Asians and Latinos, not only did respondents report higher levels of discrimination than their white counterparts, but their status as foreign-born was more likely a source of discrimination than race/ethnicity.⁴³

Taken together, the data suggest that minorities, especially immigrants, perceive higher experiences of discrimination in the health care system, and this perception leads to negative health effects in these communities. Because of the strong correlation of health care among family members, these health disparities have significant impact among both entirely immigrant families and mixed-status families.

ENSURING ACCESS TO HEALTH PROGRAMS AND ACTIVITIES

Issue 4: Access to Health Programs and Activities for Individuals with Limited English Proficiency

Barriers posed by limited English proficiency (LEP) are significant in preventing eligible members of mixed-status families from accessing health care programs and activities. Both in obtaining health care insurance and receiving health care under these programs, robust regulations for translation, oral interpretation, and other practices are crucial factors in overcoming health disparities. We support and endorse the comments submitted by the Leadership Conference on Civil and Human Rights and its Health Care Task Force that address this issue.

COMPLIANCE AND ENFORCEMENT APPROACHES

³⁹ *Id.* at 727–28.

⁴⁰ Courtney Harold Van Houtven et al., *Perceived Discrimination and Reported Delay of Pharmacy Prescriptions and Medical Test*, 20 J. GEN. INTERN MED. 578, 580–81 (2005).

⁴¹ Ke Tom Xu & Tyrone F. Borders, 19 J. HEALTH CARE FOR POOR & UNDERSERVED 380, 388 (2008) (reporting that individuals who reported unfair or bad treatment based on their language abilities or accent were 2.2 times more likely to seek out informal services than those who did not report such treatment).

⁴² Michael S. Spencer & Juan Chen, *Effect of Discrimination on Mental Health Service Utilization on Mental Health Service Among Chinese Americans*, 94 AM. J. PUB. HEALTH 809, 812 (2004).

⁴³ Diane S. Lauderdale et al., *Immigrant Perceptions of Discrimination in Health Care*, 44 MEDICAL CARE 914, 918–19 (2006). The data used controlled for language, socioeconomic status, and access to care.

Issue 7(a): The Effectiveness of Civil Rights Mechanisms & Strengthening Enforcement Processes

Within its responsibility to standardize enforcement of statutes and regulations, HHS OCR is uniquely positioned to combat discrimination that results from different application across states. Historically this was part of the reasoning behind the Civil Rights Act of 1964, and fulfilling this responsibility is an important tool for confronting health disparities between immigrant and all-citizen families. Title VI mechanisms can be an effective tool because they are generally broad enough to encompass the types of disparate, effect-based discrimination that impacts this group. Existing HHS regulations provide that Title VI prohibits recipients of federal funds from utilizing procedures that “have the effect of subjecting individuals to discrimination”⁴⁴ This principle must be strengthened and the agency should provide explicit parameters for what constitutes discrimination in health care programs and activities if OCR is to have the necessary authority to address discrimination in ACA programs and activities. The following comments address ways HHS should strengthen enforcement processes.

I. Strengthening the Principles of the Tri-Agency Guidance

To be effective, HHS should clarify in regulations implementing § 1557 that it has the explicit authority to enforce the statutory and regulatory provisions that implement the Tri-Agency Guidance. The Guidance itself invokes civil rights enforcement when it notes, “[t]o the extent that states’ application requirements and processes have the effect of deterring eligible applicants and recipients who live in immigrant families from enjoying equal participation in and access to those benefit programs based on their national origin, states inadvertently may be violating Title VI.”⁴⁵ In § 1557, the authority to address disparate, effect-base discrimination resides in the invocation of Title VI and other civil rights statutes.⁴⁶

The regulations should provide explicit oversight for ensuring confidentiality and limiting the inappropriate use of 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. Also included

⁴⁴ 45 C.F.R. § 80.3(b)(2) (2013).

⁴⁵ 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.

⁴⁶ 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*, 469 U.S. 287, 293 (1985))).

should be regulations covering onerous requirements for navigators, which may deter their participation. The examples cited in issue 1 of this comment describe the situations that regulations should address.

RECOMMENDATION: Regulations implementing § 1557 should use the Tri-Agency Guidance to address effect-based, disparate impact civil rights claims.

Principles that guard against collection of unnecessary personally identifiable information and confidentiality should address programs and activities that deter use by eligible individuals. These principles should consider both eligibility applications and outreach efforts.

II. Provide A Range of Effective and Efficient Enforcement Options

The effectiveness of nondiscrimination mechanisms relies heavily on providing a clear set of regulations so that OCR has available tools, and so that covered agencies are aware of expectations. As an example, the civil rights complaint challenging Arizona's HB 2008 discussed in issue 1 of this comment has been pending for three years as of this writing.⁴⁷ One of the attorneys for the complainant expressed frustration with a lack of transparency from OCR, long delays in receiving information on the status, and a lack of clear guidelines and expectations for the complaint structure. This experience was in contrast to her experience with another federal civil rights agency, leading her to believe that a swift effective response is possible. . The goal of § 1557 should be to ensure greater opportunity for the efficient responses.

It is critical that OCR creates and administers a strong enforcement system for this new statute. Therefore, the regulations adopted for Section 1557 should reflect the entire wide range of equitable relief and enforcement mechanisms established and available under the statutes, including agency enforcement as well as the private right of action for monetary damages.

RECOMMENDATIONS:

- (1) OCR should establish enforcement procedures to address discrimination by programs or activities administered by an executive agency and by entities established under Title I of the ACA.** Section 1557 protects individuals from being excluded from participation in, being denied the benefits of, or being subjected to discrimination under any program or activity administered by an executive Agency. This should encompass not only existing or expanded programs, but should address new programs specifically, most notably the exchanges and entities created or contracted to implement and promote the law. The Age Act's Section 504 protections apply to programs or activities conducted by executive agencies, and HHS has adopted regulations outlining procedures for enforcing nondiscrimination protections in these programs.⁴⁸ Other federal agencies have adopted their own regulations to govern the programs and activities

⁴⁷ Interview with Ellen Katz, attorney for the complainants, conducted Sept. 11, 2013.

⁴⁸ 45 C.F.R. pt. 85 (2012).

- they administer. HHS should use these as a starting point for developing § 1557 procedures. DOJ should also use its coordinating authority to ensure that federal agencies administer their programs and activities in compliance with the nondiscrimination protections of § 1557.
- (2) **Section 1557 regulations should provide for individual, class, and third party complaints.** Title IX, Title VI, § 504, and the Age Act provide for individual, class, and third party complaints. Because § 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 crucial and a hallmark of civil rights enforcement under the laws § 1557 references. The ability to file an administrative complaint may be easier for some families who may fear initiating court proceedings, and the ability for third-party complaints may further insulate family members who for immigration reasons may fear putting their name on any complaint procedure.
 - (3) **Complaint rules should provide robust protections for confidentiality and limits on inappropriate requirements for immigration status or other personally identifiable information.** The statute itself provides for these protections in health-related programs and activities, and the promulgated rules on § 1557 should take a similar approach in its complaint mechanisms. In this context, OCR should take into account the deterrent effects on mixed-status families and guard against inappropriate requests for personally identifiable information. Further, OCR should ensure that regulations require explanation for how such information will be shared before requiring a response.
 - (4) **Section 1557 regulations should establish procedures for a private right of action.** Because the statutes listed in § 1557 contain a private right of action for a full range of relief, including equitable relief and monetary damages, § 1557 does as well.⁴⁹ Although families headed by an immigrant parent or parents may be less able or willing to invoke a private right of action, regulations should ensure that option exists. As the Supreme Court articulated in *Cannon v. University of Chicago*, a private right of action is essential to achieving Congress' intent "to provide individual citizens effective protection against [discriminatory] practices."⁵⁰

III. Create Proactive Mechanisms for Confronting Discrimination

The procedures outlined above would represent important steps toward ensuring that mixed-status families have access to effective civil rights remedies. However, complaint procedures and private actions are not the only method for protecting the rights of these families. Alternative, proactive methods may be particularly important to mixed-status families, where fear of immigration enforcement may deter invoking the procedures.

⁴⁹ In *Cannon v. University of Chicago*, the Supreme Court emphasized the importance of the private right of action to enforcing antidiscrimination statutes. 441 U.S. 677, 704-05 (1979).

⁵⁰ 441 U.S. at 704-05.

Further, without knowledge of § 1557's protection or how to file a complaint, individuals remain vulnerable to discrimination in health care settings and covered entities may well continue discriminatory practices.⁵¹

An advocate in Seattle described her success in addressing the concerns of community members not only through the complaint system, but also through working with civil rights officials outside the formal structure.⁵² She described how officials can initiate their investigations, attend community meetings to become more informed of issues outside of the complaint context, provide training and guidance to the entities covered by the Title VI procedures, and prioritize particular areas of concern in responding to complaints or initiating compliance reviews. Such processes require that officials are empowered to conduct such work and that OCR has the capacity to undertake these efforts.

RECOMMENDATIONS:

- (1) **It is essential that OCR conduct § 1557 compliance reviews of covered entities and provide technical assistance regarding compliance with § 1557.** OCR's authority is not limited to responding to complaints under § 1557. It can—and should—also address discriminatory policies and practices at covered entities through technical assistance, systemic investigations, and compliance reviews of selected entities. OCR already conducts these reviews pursuant to its authority under other civil rights laws⁵³ as do other agencies.⁵⁴ This option is consistent with ensuring that an individual eligible for a health program is not also deterred from submitting a complaint because of national origin of a family member.
- (2) **Compliance review results should be made public.** With these new programs, affected families and their advocates may be unclear as to what protections exist for mixed-status families. Broader dissemination of this information will help to ensure that individuals obtain relief from discriminatory programs or activities.

⁵¹ For instance, staff for the California Health and Human Services Agency, which oversees California's Medicaid program, indicated a lack of complaints to the agency on language access issues in 2011 and 2012. Linda Bennett interview with Amanda Ream, Organizing Director, Interpreting for California (August 2013). The absence of complaints, however, is not an indication that discrimination does not exist; to the contrary, it suggests that individuals may not know their rights or about the complaint process.

⁵² Interview with Gillian Dutton, Seattle University School of Law, Sept. 13, 2013.

⁵³ See, e.g., Dep't of Health & Human Servs., Office for Civ. Rts., *Compliance Review Initiative: Advancing Effective Communication in Critical Access Hospitals* (Apr. 2013), available at

http://www.hhs.gov/ocr/civilrights/activities/agreements/compliancereview_initiative.pdf

⁵⁴ For example, agencies including the Department of Justice, the Office of Federal Contract Compliance Programs (OFCCP), the Department of Housing and Urban Development, and the Department of Education, among others, regularly conduct compliance reviews.

- (3) **Internal processes and regulations should allow for informal investigations.** In addition to formal complaints, OCR investigations should include informal information gathering within immigrant and other communities. Such processes would facilitate a better understanding of discrimination affecting those who are unwilling to come forward.
- (4) **HHS should prioritize complaints to ensure that more urgent issues are addressed.** There are proactive steps OCR can make even within the complaint structure. The initial enrollment in these programs is going to be crucial to protecting mixed-status families. Although all complaints are important, in situations where the discrimination is particularly significant or timely, HHS should ensure that those applications are addressed quickly.

Thank you for the opportunity to provide these comments. If you have any questions, you may contact Jenny Rejeske at rejeske@nilc.org or 202-683-1994.

Sincerely,

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