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Department of Health and Human Services  
Office for Civil Rights  
Attention: RIN 0945-ZA01  
Hubert H. Humphrey Building, Room 509F  
200 Independence Avenue, SW  
Washington, D.C. 20201

**RE: Request for Information Regarding Nondiscrimination  
in Certain Health Programs or Activities  
RIN 0945-AA01**

Dear Director Rodriguez:

The National Health Law Program (NHeLP) is a public interest law firm working to advance access to quality health care and protect the legal rights of low-income and underserved people. NHeLP provides technical support to direct legal services programs, community-based organizations, the private bar, providers and individuals who work to preserve a health care safety net for the millions of uninsured or underinsured low-income people. We are pleased to submit the following comments in response to the proposed rule issued on April 5, 2013 regarding standards for navigators and non-navigator personnel. NHeLP has been an ardent supporter of the Affordable Care Act's (ACA's) section 1557 on which this RFI is based and look forward to working with you and your staff on its implementation over the coming years.

## **Understanding the Current Landscape**

***Question 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; (b) Sex discrimination (including discrimination on the basis of gender identity, sex stereotyping, or pregnancy); (c) Disability discrimination; (d) Age discrimination; or (e) discrimination on one or more bases, where those bases interact***

Question (1) of the RFI requests comment on examples of discrimination and Question (3) asks about the impacts of discrimination. Because the impacts of discrimination flow from the examples discussed below, the comments in this section respond to both questions together.

### **(a) Race, color or national origin**

#### **Race and Color**

The burdens of costly health care are not distributed evenly. Rather, they fall disproportionately on communities of color, which are more likely to experience higher rates of unemployment, to have jobs that do not have health insurance, and to have lower incomes that put higher insurance premiums out of their financial reach. The following are some examples of this discrimination:

- Racial and ethnic minorities are much more likely to be uninsured than Whites. They constitute about one-third of the U.S. population, but make up more than half of the 50 million people who are uninsured.<sup>1</sup>
- One in five African Americans were uninsured in 2009, compared to one in ten non-Hispanic Whites. Findings from previous years also show the uninsured rate to be particularly high among people aged 18 to 34, those living in the South or the West, and those living in households with less than \$25,000 in income.<sup>2</sup>
- Whereas 71 percent of working-age Whites had health insurance through their workplace in 2005, only half of working age African Americans had employer-sponsored coverage.<sup>3</sup>

The uninsured have higher rates of illness and suffer the effects of lost educational, employment, and other social and civic opportunities. For example:

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<sup>1</sup> Kaiser Family Foundation. *The Uninsured: A Primer, Key Facts About Americans Without Health Insurance*. October, 2007.

<sup>2</sup> Broaddus, Matt. "The Census Bureau's Upcoming Report on Health Insurance." September 9, 2011. <http://www.cbpp.org/cms/index.cfm?fa=view&id=3575>.

<sup>3</sup> Joint Center for Political and Economic Studies. *Patient Protection and Affordable Care Act of 2010: Advancing Health Equity for Racially and Ethnically Diverse Populations*. July 2010, at 8.

- Better health status in childhood is associated with higher incomes, higher wealth, more weeks worked, and a higher growth rate in income.<sup>4</sup>
- Conversely, being uninsured correlates with poor education outcomes, such as failing to graduate from high school or to enroll in college. The uninsured often amass significant debt as a result of unforeseen medical expenses, leading to a downward, destabilizing financial spiral, including poor credit, bankruptcy, lost wages, lower annual earnings, and unemployment. These associated effects of being uninsured are more likely to affect racial minorities.
- African Americans suffer from obesity, heart disease, and diabetes at high levels.<sup>5</sup> In 2008, 44 percent of African Americans were obese, compared to 33 percent of Whites.
  - Nearly 50 percent of African-American women were obese, compared to 33 percent of White women. African-American adults are less likely to be diagnosed with coronary disease, but are more likely to die from heart disease. This may result in part from lack of timely prevention or screening.
  - High blood pressure contributes to both heart disease and strokes, and African-American adults are 1.5 times more likely to have high blood pressure and 1.7 times more likely to have a stroke than White adults.
  - Compared to whites, African Americans are twice as likely to both be diagnosed with diabetes and die from the disease.

### **National Origin Discrimination – Language**

Discrimination on the basis of national origin, which encompasses discrimination on the basis of limited English proficiency (LEP),<sup>6</sup> creates unequal access to health. LEP is often compounded with the “cumulative effects of race and ethnicity, citizenship status, low education, and poverty,” resulting in more barriers to access.<sup>7</sup> In the United States today, there are about 25 million individuals with LEP.<sup>8</sup> About 9 million LEP adults are

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<sup>4</sup> James A. Baker III Institute for Public Policy of Rice University. *The Economic Impact Of Uninsured Children On America* June 2009. <http://www.bakerinstitute.org/publications/HPF-pub-HoShortUninsuredChildren-060309.pdf>.

<sup>5</sup> U.S. Department of Health & Human Services. “Benefits for African Americans of New Affordable Care Act Rules on Expanding Prevention Coverage.” July 14, 2010. [http://www.healthcare.gov/news/factsheets/2010/07/benefits-for-african-americans\\_.html](http://www.healthcare.gov/news/factsheets/2010/07/benefits-for-african-americans_.html).

<sup>6</sup> *Lau v. Nichols*, 414 U.S. 563 (1974).

<sup>7</sup> Kaiser Family Foundation, Overview of Health Coverage for Individuals with Limited English Proficiency, at 3.

<sup>8</sup> 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](http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_11_1YR_DP02&prodType=table).

uninsured.<sup>9</sup> Of these individuals, about 95% will be income-eligible for the Medicaid expansion program and subsidies to purchase affordable insurance in the Health Insurance Marketplaces.<sup>10</sup> Individuals with LEP of Mexican and Asian origin combined constitute 63% of all individuals with LEP in our country.<sup>11</sup> Language assistance services are especially critical for individuals with LEP who are unfamiliar with our complex healthcare system.

See Question 4(c) for specific experiences and examples of discrimination based on English language proficiency. Also see the examples under (c) Disability discrimination as some demonstrate the intersection between language and disability.

### **National Origin Discrimination – Immigrants**

A unique set of circumstances result in discrimination experienced by mixed-immigration status families or families that include individuals with different immigration statuses, such as undocumented parents with citizen children. As the U.S. Department of Health and Human Services and Department of Agriculture recognized in their “Tri-Agency Guidance,” first issued in 2000, application programs and processes for government health programs affecting these mixed-status families may violate Title VI if they have the effect of preventing or deterring eligible applicants from enjoying equal participation in and access to benefits programs.<sup>12</sup> Primary examples involve requests for Social Security numbers, citizenship or immigration status, place of birth, ethnicity, or race, from family members not applying for coverage or benefits for themselves that result in deterring eligible family members from applying.

The ACA recognizes and codifies some of the agencies’ points. For example, § 1411(g) limits the collection, use and sharing of information to only that which is “strictly necessary,”<sup>13</sup> 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.<sup>14</sup> There are many ways that the ACA and health programs can produce this kind of discrimination, such as through applications, eligibility workers, navigators, or health care providers that may fail to distinguish between applicants and

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<sup>9</sup> 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>.

<sup>10</sup> *Id.* at 3. This number does not account for LEP non-citizens, who are subject to additional restrictions for Medicaid eligibility.

<sup>11</sup> *Id.* at 1–2.

<sup>12</sup> 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.

<sup>13</sup> Patient Protection and Affordable Care Act, Pub. L. 111-148, § 1411(g), 124 Stat. 119, 230 (2010).

<sup>14</sup> *Id.* § 1414(a).

non-applicants in requests for identifying and demographic information, or require such details without first explaining the use or confidentiality. Additionally, a state-run program may erect onerous documentation requirements that disadvantage immigrant families or deny them the opportunity to prove eligible income, identity, citizenship or immigration status. More subtle examples include navigators or other workers who make assumptions about entire families based on the immigration status of an individual member, or who use indicators such as ethnicity or language to limit options provided to eligible individuals.

One recent manifestation of this type of discrimination is in the extreme drop in use of services following Arizona's enactment of HB 2008, which requires state benefit agency employees to report discovered violations of federal immigration law to immigration authorities.<sup>15</sup> In the first nine months after HB 2008 was enacted, use of emergency medical services—often the only type of health services available without regard to immigration status, but which may result in a referral to Immigration and Customs Enforcement if undocumented persons “self-declare” their status—dropped 45 percent.<sup>16</sup> Additionally, the number of children in TANF dropped 15 percent in 7 months, and new enrollees to the food stamp program fell from 21,000–30,000 per month in the months leading up to the effective date to 1,334 and 195 per month in the second and third month following the law's commencement.<sup>17</sup>

In mixed-status families where eligible individuals are prevented or deterred from seeking or obtaining assistance, the impact primarily results in low participation rates in programs and decreased access of health services in general. The reach of this impact is potentially quite large: as of 2010, nearly one in four children younger than age 8 has an immigrant parent.<sup>18</sup> Of these children, the vast majority (93 percent) are U.S. citizens and 43 percent live in mixed-status families.<sup>19</sup> Significantly, under the ACA an estimated 3.2 million children with only undocumented parents will be eligible for Medicaid/CHIP or Marketplace subsidies.<sup>20</sup> Statistics of coverage rates for children bear out the possible results for these families. Citizen children with non-citizen parents are 38.5 percent more likely to be uninsured than are citizen children with citizen parents.<sup>21</sup> Within every ethnic group, children with immigrant parents were less likely to be insured than children with U.S.-born parents, with the highest rate for uninsured being Hispanic children.<sup>22</sup> In

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<sup>15</sup> Ariz. Rev. Stat. Ann. § 1-501–02 (2013).

<sup>16</sup> 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.

<sup>17</sup> *Id.*

<sup>18</sup> Karina Fortuny, et al., The Urban Institute, *Young Children of Immigrants* 1 (August 2010).

<sup>19</sup> *Id.* at 5.

<sup>20</sup> Stacey McMorro, et al., The Urban Institute, *Addressing Coverage Challenges for Children Under the Affordable Care Act* 6 (May 2011).

<sup>21</sup> 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.

<sup>22</sup> 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).

addition to the lower rates of children obtaining access to health insurance, evidence points to a chilling effect on immigrant access to health care more broadly. Although much of the difference between citizens and non-citizens in health care spending can be attributed to the younger population and immigrants' ineligibility for public health insurance programs, an analysis adjusting for health status, race/ethnicity, gender, health insurance coverage, and other factors found that the spending on immigrants' health care was still about 14–20 percent less than U.S.-born citizens.<sup>23</sup>

## **(b) Sex Discrimination**

### **Sex Discrimination**

Section 1557 prohibits discrimination on the ground protected under Title IX, which is sex.<sup>24</sup> This law marks the first time that federal law contains a broad-based prohibition of sex discrimination in health programs or activities. Sex discrimination includes discrimination based on pregnancy, gender identity, and sex stereotypes—as the RFI rightly notes.<sup>25</sup> Sex discrimination takes many forms and occurs at every step in the health care system—from obtaining insurance coverage to receiving proper diagnosis and treatment. This discrimination seriously harms women and threatens their health, causing them to pay more for health care and to risk receiving improper diagnoses and less effective treatments.

Some examples of discrimination against women in health programs and activities and their impacts include:

- Studies have found that women receive inadequate care when gender bias inappropriately influences medical decision-making. Although physical differences may account for some differences in treatment received by men and women, non-biological or non-clinical factors—including overt or unconscious gender bias—also affect clinical decision-making.<sup>26</sup> For example, although women disproportionately experience chronic pain<sup>27</sup> and certain chronic pain

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<sup>23</sup> 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).

<sup>24</sup> 20 U.S.C. § 1681(a) (2012).

<sup>25</sup> 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)”).

<sup>26</sup> Council on Ethical and Judicial Affairs of the American Medical Association, *Gender Disparities in Clinical Decision Making*, 266 JAMA 559 (1991).

<sup>27</sup> Dep't of Health & Human Servs., Ctrs. for Disease Control & Prevention, Nat'l Ctr. for Health Statistics, *Health United States*, 13, 69 (2006) (with special feature on pain), available at [http://www.cdc.gov/nchs/data/06.pdf](http://www.cdc.gov/nchs/data/hus/06.pdf).

conditions occur primarily in women,<sup>28</sup> women experience disparities in pain care that result from gender bias, “neglect, dismissal and discrimination from the health care system.”<sup>29</sup>

- Health plans continue to exclude maternity coverage from the benefits provided to certain female plan participants. Treating pregnancy differently, such as by excluding pregnancy care from an otherwise comprehensive insurance plan, is sex discrimination under civil rights laws such as Title IX and Title VII, and also sex discrimination under Section 1557.<sup>30</sup>
- Providers, hospitals, or clinics that refuse to provide reproductive health services to a woman who is not married or because she does not conform to sex stereotypes force women to seek care elsewhere or forgo it completely.<sup>31</sup>
- Female health care providers experience discrimination in employment. New research shows a gap in earnings between male and female physicians has persisted over the last 20 years.<sup>32</sup> In 1987-1990, male physicians earned \$33,840 (20%) more in annual salary than their female counterparts. By 2006-2010, the gender gap was \$56,019 (25.3%).
- While progress has been made, past and current exclusion of women in medical research continues to negatively affect advances in women’s health.<sup>33</sup>

Sex discrimination protections have consistently been interpreted to bar 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

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<sup>28</sup> Inst. of Med., *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research*, 75 (2011), available at [http://www.nap.edu/download.php?record\\_id=13172](http://www.nap.edu/download.php?record_id=13172).

<sup>29</sup> *Id.* at 77 (quoting (Campaign to End Chronic Pain in Women, *Chronic Pain in Women: Neglect, Dismissal, and Discrimination*, 4 (May 2010), available at <http://www.endwomenspain.org/resources>).

<sup>30</sup> See, e.g., Nat’l Women’s Law Ctr., *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).

<sup>31</sup> See Nat’l Women’s Law Ctr., *Health Care Refusals Harm Patients: The Threat to Reproductive Health Care* (Jan. 2013), available at <http://www.nwlc.org/resource/health-care-refusals-harm-patients-threat-reproductive-health-care>.

<sup>32</sup> Seth A. Seabury, et al., *Trends in the Earnings of Male and Female Health Care Professionals in the United States, 1987 to 2010* JAMA Intern Med. (Online First) (Sept. 2013).

<sup>33</sup> See, e.g., K. Coleman-Phox, et al., *Recruitment and Retention of Pregnant Women for a Behavioral Intervention: Lessons from the Maternal Adiposity, Metabolism, and Stress (MAMAS) Study*, 10 Prev. Chronic Dis. (Mar. 2013), [http://www.cdc.gov/pcd/issues/2013/12\\_0096.htm](http://www.cdc.gov/pcd/issues/2013/12_0096.htm); Mary A. Foulkes, et. al., *Clinical Research Enrolling Pregnant Women: A Workshop Summary*, 20(10) J. Women’s Health 1429 (2011).

such discrimination.<sup>34</sup> Discrimination based on gender identity, gender expression, and sexual orientation is a persistent problem in our health care system. LGBT individuals consistently face health care discrimination, including verbal abuse, physical abuse, and outright refusals of treatment. This is especially true for transgender and gender nonconforming individuals.<sup>35</sup> The National Transgender Discrimination Survey, the largest survey to date of transgender people in the United States, revealed that transgender and gender nonconforming people seeking health care were denied equal treatment in doctors' offices and hospitals (24%), emergency rooms (13%), mental health clinics (11%), by EMTs (5%) and in drug treatment programs (3%). Moreover, Latino/a respondents reported the highest rate of unequal treatment of any racial category (32% by a doctor or hospital and 19% in both emergency rooms and mental health clinics). Such discrimination in treatment can lead to death,<sup>36</sup> prolong painful conditions,<sup>37</sup> and exacerbate underlying conditions.<sup>38</sup>

### **Sexual Orientation and Gender Identity Discrimination**

Lesbian, gay, bisexual, and transgender Americans have too often faced health care and coverage systems that have provided inequitable and sometimes hostile treatment on the basis of their sexual orientation or gender identity. Discrimination has touched the lives of many LGBT people at all points in the health care system – from being unable to access insurance coverage, to outright refusals to provide care, to verbal and physical abuse at the hands of medical professionals. We support the comments submitted by CAP and NCLR with regards to gender identity discrimination and provide only short comments herein.

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<sup>34</sup> See, e.g., *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).

<sup>35</sup> Jaime M. Grant et al., *Injustice at Every Turn: A Report of the National Transgender Discrimination Survey 73 (2011)* available at [http://transequality.org/PDFs/NTDS\\_Report.pdf](http://transequality.org/PDFs/NTDS_Report.pdf).

<sup>36</sup> In 1995, a transgender woman bled to death after paramedics halted emergency treatment for her serious injuries resulting from an automobile accident when they discovered she was transgender. Anne C. DeCleene, Note, *The Reality of Gender Ambiguity: A Road Toward Transgender Health Care Inclusion*, 16 *Law & Sex*. 123, 137 (2007).

<sup>37</sup> According to a recent report, one transgender patient was forced to wait two hours in pain in the emergency room without treatment for injuries sustained from a fall on ice after the health care provider discovered she was transgender. Jaime M. Grant et al., *Injustice at Every Turn: A Report of the National Transgender Discrimination Survey 73 (2011)* available at [http://transequality.org/PDFs/NTDS\\_Report.pdf](http://transequality.org/PDFs/NTDS_Report.pdf).

<sup>38</sup> Patients with HIV are particularly susceptible to sudden declines in health, and denial of or substandard treatment puts them at increased risk. For patients with HIV, missing as few as two doses of medication can have a significant impact on maintenance of proper medication levels. See generally R.J. Smith, *Adherence to Antiretroviral HIV Drugs: How Many Doses Can You Miss Before Resistance Emerges?*, 273 *Proc. Royal Soc'y B* 617, 621 (2006).

## Discrimination in Insurance Coverage

Prior to passage of the Affordable Care Act, few nondiscrimination protections applied to insurance, and these laws and regulations had only a limited effect in ensuring fair coverage for all consumers.<sup>39</sup> Exclusions on the basis of preexisting conditions, variations in rates and charges based on personal characteristics, and arbitrary revocation of coverage were among the discriminatory practices that persisted in private insurance markets, but are being ended by the reforms introduced by the Affordable Care Act.

However, discrimination in benefits design has also been pervasive in both public and private systems of health coverage, and eradicating such discrimination has historically been a challenging process for both consumers and regulators.<sup>40</sup> For example, in the private insurance market, breast reconstruction following mastectomy was widely considered cosmetic and routinely excluded from coverage until the passage of the Women's Cancer Recovery Act of 1998. Similarly, private market carriers continue to argue that exclusions for services or drugs commonly provided for the treatment of conditions such as HIV/AIDS are not discriminatory because they apply to all plan enrollees, regardless of their specific negative effect on people with these conditions. As a result, these discriminatory exclusions persist – and an estimated 30 percent of individuals living with HIV are unable to access coverage – despite nondiscrimination laws such as the Americans with Disabilities Act (ADA) and the Health Insurance Portability and Accountability Act (HIPAA).<sup>41</sup> These exclusions have disproportionately impacted the LGBT community, in that lesbian and bisexual women have higher rates of breast cancer than heterosexual women, and HIV infection rates are elevated among gay and bisexual men, as well as transgender women.<sup>42</sup>

Transgender people have also experienced discrimination in the form of exclusions for otherwise-covered services when provided for the purpose of treating Gender Identity Disorder, gender dysphoria, or related conditions. Like anyone else, transgender people need acute care when they are sick and preventive care to keep from becoming sick, including services that are traditionally considered to be gender-specific, such as pap smears, prostate exams, and mammograms. In addition, transgender people need access to medically necessary care related to gender transition, and access to these transition-related services is integral to the meaning of gender identity non-discrimination. For transgender people, their identity – the essence of who they are – is

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<sup>39</sup> See e.g. Katie Keith and others, “Nondiscrimination Under the Affordable Care Act” (Washington DC: Georgetown University Health Policy Institute 2013) available at [http://chir.georgetown.edu/pdfs/NondiscriminationUndertheACA\\_GeorgetownCHIR.pdf](http://chir.georgetown.edu/pdfs/NondiscriminationUndertheACA_GeorgetownCHIR.pdf).

<sup>40</sup> *Id.*

<sup>41</sup> AIDS.gov. 2012. “The Affordable Care Act Helps People Living with HIV/AIDS.” Available from <http://aids.gov/federal-resources/policies/health-care-reform/>.

<sup>42</sup> Institute of Medicine. *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*.

closely connected with a medical condition.<sup>43</sup> The medical diagnosis that correlates with a transgender identity is most frequently referred to as gender identity disorder, or GID, which the American Medical Association,<sup>44</sup> the American Psychiatric Association,<sup>45</sup> and the World Health Organization<sup>46</sup> all recognize as a serious medical condition. To fail to provide equal coverage for services when provided to transgender people for the purpose of gender transition is to engage in discrimination on the basis of gender identity.

People living with HIV, a population that disproportionately includes gay and bisexual men and transgender women, also face significant barriers in accessing health care and treatment due to discriminatory benefits designs in public and private health insurance plans. Examples of these designs include: monthly limits on prescription drugs or the exclusion of drugs recognized as the standard of care for HIV and utilization management techniques used primarily to deny or restrict access to care for people with chronic and complex health conditions. In addition to discriminatory plan designs, people living with HIV are also more likely to experience adverse coverage decisions, including service denials and rescission of coverage.

### Discrimination in the provision of health care

For LGBT people who have been able to access health care despite barriers in coverage and benefits programs, many experiences have been colored by discriminatory experiences in the provision of that care.

In addition, stigma associated both with the LGBT community and HIV status serves as a significant barrier to care for people living with HIV or AIDS. People living with HIV report provider refusal to treat them as well as excessive provider precautions with regard to treatment of people living with HIV that do not comport with federal HIV treatment or health professional safety guidelines.<sup>47</sup> HIV providers also report

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<sup>43</sup> See, e.g., *South v. Gomez*, 211 F.3d 1275, \*1 (9th Cir. 2000) (noting that “gender dysphoria [is] more commonly known as transsexualism”); *Schwenk v. Hartford*, 204 F.3d 1187, 1193 (9th Cir. WA 2000) (referring to “gender dysphoria [as] the technical diagnosis for transsexuality.”); *Farmer v. Haas*, 990 F.2d 319, 320 (7th Cir. 1993) (using “transsexualism” and “gender dysphoria” as interchangeable); *Glenn v. Brumby*, 724 F. Supp. 2d 1284, 1304, n.5 (N.D. Ga. 2010) *aff’d*, 663 F.3d 1312 (11th Cir. 2011) (stating that “GID and transsexualism are closely related and are sometimes used as synonyms, with transsexuals characterized by an intention to undergo medical treatments to align their bodies with their gender identities”).

<sup>44</sup> American Medical Association House of Delegates, “Removing Financial Barriers to Care for Transgender Patients” (2008), available at [http://www.tgender.net/taw/ama\\_resolutions.pdf](http://www.tgender.net/taw/ama_resolutions.pdf).

<sup>45</sup> American Psychiatric Association, “Transgender, Gender Identity, & Gender Expression Non-Discrimination” (2008), available at <http://www.apa.org/about/policy/transgender.aspx>.

<sup>46</sup> The World Health Organization’s International Statistical Classification of Diseases and Related Health Problems, version 10 (ICD-10) includes “gender identity disorder.” See <http://apps.who.int/classifications/icd10/browse/2010/en#/F64>.

<sup>47</sup> National Women’s Law Center, *Health Care Refusals Harm Patients: The Threat to LGBT People and Individuals Living with HIV/AIDS* (2013), available at [http://www.nwlc.org/sites/default/files/pdfs/lgbt\\_refusals\\_factsheet\\_8-6-13.pdf](http://www.nwlc.org/sites/default/files/pdfs/lgbt_refusals_factsheet_8-6-13.pdf).

challenges with linking their patients to other specialty services.<sup>48</sup> Provider refusal to treat as well as excessive precautions when treating people living with HIV has occurred across provider types, including private physicians, dentists, and community health centers.<sup>49</sup> Some services providers have gone so far as to put in place blanket policies refusing to provide services to people living with HIV.<sup>50</sup> Black gay men and other men who have sex with men (MSM) also report high rates of stigma when accessing health care. In 2011, the National Alliance of State and Territorial AIDS Directors (NASTAD) and the National Coalition of STD Directors (NCSD) designed and implemented a survey to explore how community- and institution-level stigma within public health practice negatively affects HIV- and STD-related outcomes.<sup>51</sup> The survey was completed by more than 1,300 health department and community-based organization (CBO) staff, health providers, and community members representing 54 different states and territories.<sup>52</sup> Survey results showed high levels of perceived community-level and institutional stigma directed at Black and Latino gay men and other MSM.<sup>53</sup> Individual stories of health care discrimination lay bare the results of these extraordinarily high rates of discrimination against LGBT patients – and transgender patients in particular. The tragic reality is that discrimination against LGBT people and people living with HIV, solely because of their sexual orientation, gender identity, and/or HIV status, has resulted in deaths and undue hardships that were likely preventable.

### **(c) Disability Discrimination**

The Institute of Medicine (IOM) noted in 2007 that between 40 million and 50 million people in the US report some kind of disability. That number will likely grow significantly in the next 30 years as the baby boom generation enters late life, when the risk of disability is the highest. If one considers people who now have disabilities (one in six adult Americans live with a disability when defined by a limitation in function), people who are likely to develop disabilities in the future, and people who are will be affected by disabilities of family members and others close to them, then disability affects today or will affect tomorrow the lives of most Americans. We support the comments submitted by DREDF and provide brief comments herein.

Individuals with all types of disabilities report discriminatory physical, programmatic, and attitudinal barriers to accessing health care in hospitals, clinics, diagnostic facilities, and

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<sup>48</sup> *Id.*

<sup>49</sup> *Id.*

<sup>50</sup> Brad Sears and Deborah Ho, The Williams Institute, UCLA School of Law, HIV Discrimination in Health Care Services in Los Angeles County: The Results of Three Testing Studies (2006), available at <http://williamsinstitute.law.ucla.edu/wp-content/uploads/Sears-Ho-Discrimination-Health-Care-LA-County-Dec-2006.pdf>.

<sup>51</sup> NASTAD/NCSD Stigma Survey Findings Presentation, United States Conference on AIDS (2012), available at [http://www.nastad.org/Docs/042244\\_Slides-NASTAD-Stigma%20Seminar-and-Public-Health-USCA-2012-09-24-12-FINAL.pdf](http://www.nastad.org/Docs/042244_Slides-NASTAD-Stigma%20Seminar-and-Public-Health-USCA-2012-09-24-12-FINAL.pdf).

<sup>52</sup> *Id.*

<sup>53</sup> *Id.*

practitioners' offices of all sizes throughout the country.<sup>54</sup> Moreover, lifetime and annual limits on essential health benefits such as durable medical equipment can lead to health problems that reduce productivity and can even lead to unnecessary, costly institutionalization. Responsibility for addressing discriminatory barriers resides with every level of the healthcare delivery system including the Department of Health and Human Services and other federal agencies concerned with health and healthcare, insurers and commercial health plans, institutions that train, educate and license practitioners, states and managed care organizations, and clinical and administrative units within healthcare facilities. Such barriers are also likely to be present in the newly formed Health Insurance Marketplace.

### **Barriers to Care**

Some of the barriers to comprehensive, quality health care are present in the physical environment—for example, cramped waiting and exam rooms, inaccessible bathrooms, and inaccessible equipment (such as exam tables, weight scales, and imaging and other diagnostic equipment).<sup>55</sup> Other forms of discrimination that prevent PWD from attaining appropriate and effective healthcare take the form of disability stereotypes, prejudicial practices, and incorrect perceptions. Finally, the failure to provide needed policy modifications and reasonable accommodations affects healthcare treatment decisions and outcomes. We support the comments of DREDF with regards to these barriers to care.

### **Intersectional Bases of Discrimination**

While disability affects people of all races, ethnicities, genders, languages, sexual orientations, and gender identities, this does not mean that impairment occurs uniformly among racial and ethnic groups. Disability is identified in differing ways among surveys, but national sources indicate that disability prevalence is highest among African Americans who report disability at 20.5 percent compared to 19.7 percent for non-Hispanic whites, 13.1 percent for Hispanics/Latinos and 12.4 percent of Asian Americans.<sup>56</sup> Disability prevalence among American Indians and Alaskan Natives is

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<sup>54</sup> Disabilities are diverse. As the Surgeon General said in his 2005 Call to Action to Improve the Health and Wellness of Persons with Disabilities stated: "Some disabilities are visible; others are not. Some are physical, some visual or auditory, some developmental or cognitive, and some mental or behavioral. Some persons are born with one or more disabilities; others acquire a disability during the course of a lifetime . . . . No single disabling condition necessarily affects one person in exactly the same way as it does another."

<sup>55</sup> Mudrick, N.R.; Breslin, M.L.; Liang, M.; and Yee, S. (2012) "Physical Accessibility in Primary Health Care Settings: Results from California On-site Reviews," *Disability and Health Journal*, October, Vol. 3, Issue 4, Pages 253-261.

<sup>56</sup> Brault, Matthew, *Americans With Disabilities: 2005*, Current Population Reports, P70117, U.S. Census Bureau, Washington, DC, 2008. Many of the differences between the disability rates by race and Hispanic origin can be attributed to differences in the age distributions of their populations. For example, Hispanics are predominantly younger than non-Hispanic whites.

16.3 percent.<sup>57</sup> In raw numbers, over 10.8 million non-institutionalized PWD aged 5 and over are estimated to be members of ethnic minorities.<sup>58</sup> An Institute of Medicine report has already observed that there are “clear racial differences in medical service utilization rates of PWD that were not explained by socioeconomic variables,” and “persistent effects of race/ethnicity [in medical service utilization] could be the result of culture, class, and/or discrimination.”<sup>59</sup> Therefore, the relationship between race and disability is a complex one that needs to be freshly viewed as race and disability together may have a previously unaccounted cumulative impact on creating health disparities. We support the comments submitted by DREDF both with regards to this section.

#### **(d) Age Discrimination**

Older adults are consistently the victims of age discrimination in federally supported and administered health care programs. The National Health Law Program (and other advocacy groups) regularly represents these older adults, and supports state advocates representing older adults, who suffer from reduced access to care as a result of their age and related characteristics. Below we provide five examples of such discrimination.

#### **Olmstead Discrimination**

Many older adults suffer from disabling conditions and require supports to live safely and maximize their independence in their home environments. Federal law requires that reasonable accommodations be made to prevent segregation of such older adults in institutional settings when they want to live in a home or community based setting.<sup>60</sup> Despite this clear legal protection, in place since 1999, older adults have nonetheless been the victims of countless cases of discrimination in the Medicaid program, with virtually all states implementing too few supports for too few seniors, and many states implementing severe *reductions* to supports, including home attendant care and medical equipment such as incontinence supplies. As a result, countless older adults have been forced into institutions, or in the best case, reduced to living at home with some combination of pain, reduced function, unsafe conditions, and reduced independence and dignity. Section 1557 could and should be an important tool to protect older adults from this discrimination.

#### **Accessible Eligibility and Enrollment Systems**

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<sup>57</sup> U.S. Census Bureau, *2009 American Community Survey*, S1810. Disability Characteristics 1 year estimates, available at [http://factfinder.census.gov/servlet/STTable?\\_bm=y&qz\\_name=ACS\\_2009\\_1YR\\_G00\\_S1810&-geo\\_id=01000US&ds\\_name=ACS\\_2009\\_1YR\\_G00\\_-lang=en&-format=&-CONTEXT=st](http://factfinder.census.gov/servlet/STTable?_bm=y&qz_name=ACS_2009_1YR_G00_S1810&-geo_id=01000US&ds_name=ACS_2009_1YR_G00_-lang=en&-format=&-CONTEXT=st).

<sup>58</sup> *Id.* The 10.8 million figure is derived from subtracting the total number of PWD who identify as non-Hispanic or Latino white from the total number of those with a disability aged 5 and over.

<sup>59</sup> Institute of Medicine (IOM). 2007. *The Future of Disability in America*. Washington, DC: The National Academies Press, p. 92.

<sup>60</sup> See *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 (1999) and Title II of the Americans with Disabilities Act.

The health care system consistently discriminates against seniors because entry into the system is inaccessible for many seniors. Many seniors with hearing impairments, visual impairments, cognitive limitations, or other disabling conditions, are unable to take the many steps often required to apply for options in programs such as Medicaid and Medicare – including contacting offices to apply, completing paperwork, collecting verifications, etc. Throughout these steps, they also face severely limited access to consumer assistance resources which can help them make sense of incredibly complex program features such as four “Parts” of Medicare, Medicare Part D cost-sharing (including initial coverage limits, “doughnut holes,” and catastrophic coverage limits), Medicare Savings Programs where one government program pays another program’s costs. State Health Insurance Assistance Programs, though a step in the right direction, are underfunded and consistently unable to meet the needs of seniors. Section 1557 must be a vehicle to ensure that enrollment and eligibility systems have the capability and resources needed to effectively enroll seniors in the care they need.

### **Historic Failure to Enroll Seniors in Health Programs**

Even when senior do successfully navigate the system and apply for health care assistance, they are persistently under-enrolled in programs they are eligible for. In the case of the Medicare Savings Programs, for example, this is a decades old problem, with countless seniors paying for Medicare services from their limited fixed incomes, in some cases going hungry to make their Part B payment, when the costs should be fully covered by Medicaid. As another example, many seniors in desperate need of support in states with HCBS programs remain unenrolled simply because the state makes no outreach efforts or has poorly designed systemic connections between programs. Section 1557 must be a vehicle to ensure that seniors are not discriminated against in the enrollment and eligibility system.

### **Provider Accessibility**

Once seniors are enrolled in health care programs, they often face challenges finding providers who they can actually visit. Many seniors need providers who can accommodate their physical needs (disabling conditions, functional limitations, etc.) and communication impairments (visual impairments, hearing impairments, etc.). However, many recipients of federal program funding lack this capacity and seniors are thus victims of discrimination at the provider and system level. We have grown particularly concerned that this discrimination will accelerate with the rapid expansion of managed care (and other experimental delivery system redesign) into the coverage of older adults, a population which managed care has less history with. Section 1557 must be used to ensure that older adults can access medical providers paid through federal programs.

## **Network Adequacy/Provider Specialization**

In addition to accessible providers, older adults need the right kinds of providers. Older adults need primary care with geriatric specialization, specialty care for high-prevalence conditions, rehabilitative care, and infrastructure to address functional needs and home support services. However, most health care programs discriminate against older adults by failing to have enough capacity for the services they need. Again, this problem is especially acute with managed care expansions that will subsume senior populations that have not traditionally been cared for in managed care networks. Section 1557 must be used to require network adequacy to meet the needs of seniors in all federally funded programs.

***Question 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?***

In addition to large federal programs such as Medicaid and Medicare, section 1557 should be used to reduce age discrimination in the large matrix of state-federal programs providing health care and related social services to older adults. In many cases these may be nominally state programs which are conducted with significant federal support, whether through financing or administrative support, or in coordination with federally established infrastructure (such as Area Agencies on Aging). We urge HHS to take a broad view of the reach of federal programs and resources, and not allow state programs to be shielded from section 1557 nondiscrimination protections when they are part of or dependent on the federal system.

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 (CRRRA) 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.

**Section 1557 applies to any health program or activity, any part of which receives federal financial assistance, which for purposes of Section 1557 specifically includes credits, subsidies, and contracts of insurance.** Congress, in drafting Section 1557, used the same language – “program or activity” – as used in the four civil rights statutes Section 1557 references to indicate the entities covered by it.<sup>61</sup> “Program or activity” under Section 1557 thus has the same meaning as it does under those statutes, as defined by the CRRA. A covered “program or activity” therefore includes public or private entities, as well as departments or agencies of a state or local government that receive federal financial assistance.

Congress structured Section 1557 similarly to the way it structured Title IX. Like Title IX, Section 1557 is written with a term that modifies the phrase “program or activity” (“education” in Title IX, “health” in Section 1557). The term “education” in Title IX does not limit the range of recipients of federal financial assistance that fall under Title IX’s jurisdiction; rather, the term indicates which portions of a covered program or activity cannot discriminate. This interpretation was confirmed by Congress when it enacted the CRRA.<sup>62</sup> Because Section 1557 is structured like Title IX, the analysis used to determine coverage under Title IX should be used to determine coverage under Section 1557.

In the Title IX context, if the entity has education as its primary purpose, like a public or private university, Title IX prohibits sex discrimination in all of its programs or activities.<sup>63</sup>

<sup>61</sup> Civil Rights Restoration Act of 1987, Pub. L. 100-259, 102 Stat. 28 (1988), (codified as amended in scattered sections of 20, 29, and 42 U.S.C.).

<sup>62</sup> See, e.g., *O’Connor v. Davis*, 126 F.3d 112, 118 (2d Cir. 1997); Dep’t of Justice, *Title IX Legal Manual* (2001), available at <http://www.justice.gov/crt/about/cor/coord/ixlegal.php> (stating that the scope of Title coverage “will depend upon which portions of a covered program or activity are educational in nature.”).

<sup>63</sup> 20 U.S.C. § 1687(2) (2012). See also *O’Connor v. Davis*, 126 F.3d 112, 117 (2d Cir. 1997) (“[C]ourts have consistently interpreted Title IX to mean that if one arm of a university or state

If the entity does not have education as its primary purpose, Title IX bars discrimination in the education portions of the entity, any part of which receives federal financial assistance for any purpose.<sup>64</sup>

Likewise, Section 1557 prohibits discrimination in all the operations of a covered entity that has health as its primary purpose.<sup>65</sup> These include entities such as state and local health departments, hospitals and hospital systems, health clinics, nursing homes, home care agencies, health insurance companies, health or medical research centers, and medical, dental, or other schools that focus on training individuals to enter careers in the health field.

For a covered entity that does not have health as its primary purpose, Section 1557 prohibits discrimination in that entity's health programs or activities, regardless of whether those health programs or activities receive federal financial assistance as long as the entity itself does. This includes, for example, health insurance plans offered by institutions that receive federal financial assistance and health education programs at schools or other entities that receive such assistance.<sup>66</sup>

Whether a particular entity or program should be considered "health" related for purposes of Section 1557, like the question of whether a program is educational under Title IX, is a fact-specific question. To effectuate Section 1557's nondiscrimination principle, the determination of whether a program is a "health" program or activity should be consistent with existing interpretations of the term "health" offered by the World Health Organization (WHO). WHO defines health to include not just the absence of disease but also "physical, mental, and social well-being."<sup>67</sup> Based on this widely accepted definition of health, a health program or activity includes any program or activity that is designed to promote, maintain, or prevent the decline of the health of the physical, mental, or social well-being of an individual or population's health.

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agency receives federal funds, the entire entity is subject to Title IX's proscription against sex discrimination.").

<sup>64</sup> See, e.g., *Jeldness v. Pearce*, 30 F.3d 1220, 1226 (9th Cir. 1994) (recognizing that the recipient of federal financial assistance need not be educational in nature for an education program or activity operated by the non-educational entity to be covered by Title IX); Dep't of Justice, *Title IX Legal Manual* (2001), available at <http://www.justice.gov/crt/about/cor/coord/ixlegal.php>.

<sup>65</sup> See Civil Rights Restoration Act of 1987, § 3 (codified as amended at 20 U.S.C. 1687(2)). See also *id.* at § 3 (codified as amended at 20 U.S.C. 1687(3)(A)(ii)).

<sup>66</sup> Some entities are directly bound by Section 1557 in addition to other antidiscrimination laws, such as Title IX or Title VII. Section 1557, however, may provide additional protections to individuals not covered by those laws. See, e.g., Nat'l Women's Law Ctr., *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>.

<sup>67</sup> Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 8 April 1948.

**Section 1557 includes credits, subsidies, and contracts of insurance as federal financial assistance.** Section 1557 differs from the civil rights laws to which it refers by expressly identifying “credits, subsidies, [and] contracts of insurance” as federal financial assistance to make clear that each trigger its application. For example, Section 1557’s inclusion of “contracts of insurance” as federal financial assistance means that it has broader application than some of the other civil rights laws it references. Unlike Section 1557, Title VI, Title IX, and the Rehabilitation Act either explicitly exclude or have been interpreted in some circumstances to exclude contracts of insurance as a form of federal financial assistance.<sup>68</sup> A contract of insurance that is federal financial assistance is any contract of insurance that is funded, entered into, administered, or guaranteed by the federal government. Thus, for example, an insurance company in a Marketplace that receives federally-subsidized payments such as through premium tax credits is covered by Section 1557. In addition, contracts for health insurance entered into by the federal government to provide coverage for federal employees are also federal financial assistance to the contracting insurance company. Because contracts of insurance are explicitly included in Section 1557, its regulations must recognize this fact and ensure that these federal funds are not used to finance discrimination.

**Section 1557 applies to programs or activities administered by an executive agency.** Section 1557 protects individuals from discrimination “under any program or activity that is administered by an Executive Agency.” Section 504, too, applies to any program or activity, “conducted by any Executive agency.”<sup>69</sup> The phrases “administered by” and “conducted by” are generally synonymous.<sup>70</sup> Federally-conducted programs or activities have typically been defined to include “anything a federal agency does.”<sup>71</sup>

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<sup>68</sup> Because “contracts of insurance” are not excluded in the statutory text of Section 504 but in its regulations, there are conflicting decisions about whether the regulations properly exclude it. *Compare Moore v. Sun Bank of North Florida*, 923 F.2d 1423, 1429-32 (11th Cir. 1991) (finding that because Section 504 did not expressly exclude contracts of insurance or guaranty, the regulations containing the exclusion were invalid as inconsistent with congressional intent and that the contract at issue did in fact constitute federal financial assistance) *with Gallagher v. Croghan Colonial Bank*, 89 F.3d 275 (6th Cir. 1996) (holding that based on the Section 504 regulation’s exclusion of contracts of insurance or guaranty as federal financial assistance, a bank’s receipt of reimbursement for default loans was not federal financial assistance and thus the bank was not subject to the Rehabilitation Act).

<sup>69</sup> 29 U.S.C § 794 (2012). See also Exec. Order 13,160 3 C.F.R. 279 (2000).

<sup>70</sup> “Conduct” means “to direct or take part in the operation or management of.” Conduct - Definition from the Merriam-Webster Dictionary, <http://www.merriam-webster.com/dictionary/conduct>. “Administer” means “to manage or supervise the execution, use, or conduct of.” Administer - Definition from the Merriam-Webster Dictionary, <http://www.merriam-webster.com/dictionary/administer>.

<sup>71</sup> *E.g.*, Enforcement of Nondiscrimination on the Basis of Handicap in Programs or Activities Conducted by the Central Intelligence Agency, 57 Fed. Reg. 39,605 (Sept. 1, 1992); Gen. Servs. Admin., Office of Civil Rights, The Key To Accessing Federally Conducted Programs and Activities 4, available at

[http://www.gsa.gov/graphics/staffoffices/Interim\\_Key\\_to\\_Accessing\\_FCPA\\_Handbook\\_R2-](http://www.gsa.gov/graphics/staffoffices/Interim_Key_to_Accessing_FCPA_Handbook_R2-)

Simply put, “any program or activity that is administered by an Executive Agency” means that “anything a federal agency does” is subject to the nondiscrimination requirements of Section 1557.

More specifically, Section 1557 applies to HHS-administered health programs such as Medicare as well as jointly-administered federal and state programs such as Medicaid and the Children’s Health Insurance Program (CHIP).<sup>72</sup> HHS is not the only federal agency that must comply with Section 1557; indeed, all federal agencies must conduct their programs and activities in a nondiscriminatory way to comply with Section 1557. This includes, for example, the agencies involved in implementing the ACA such as the Department of Labor and the Department of the Treasury. Likewise, Section 1557 applies to the Federal Employee Health Benefits Program (FEHBP) which is administered by the Office of Personnel Management, an executive agency.

**Section 1557 applies to entities established under Title I of the ACA.** The third category of entities in which Section 1557 protects individuals from discrimination are entities established under Title I of the ACA. The health insurance Marketplaces and Consumer-Oriented and Operated Plans (CO-OPs) are examples of entities that were or will be created pursuant to Title I of the ACA and that are, therefore, subject to Section 1557.<sup>73</sup>

In short, it is essential that Section 1557 apply to the full range of health care entities operating in the health care system. And, as under other civil rights laws, a covered entity itself can neither discriminate, nor can it provide assistance—monetary or otherwise—to entities that discriminate.<sup>74</sup> The complexity of the health care enterprise makes it impossible for discrimination to be addressed without every facet of the system bearing responsibility for implementing nondiscrimination policies and procedures, and reporting on and self-monitoring on adherence to policies and procedures. Disability nondiscrimination, for instance, not only requires entities to refrain from engaging in prohibited activities, but also requires entities to actively engage to ensure physical accessibility and provide reasonable accommodations and policy modifications. Section

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<sup>72</sup> Medicaid and CHIP are jointly administered by HHS and state agencies; nonetheless, because HHS participates in the administration of these programs, Section 1557 applies to them. Section 1557 also applies to the state agencies that receive and distribute federal funds to operate these programs, as “health programs or activities, any part of which receive federal financial assistance.”

<sup>73</sup> The Pre-existing Condition Insurance Program and the Early Retiree Reinsurance Program are also examples of entities that were brought into existence pursuant to Title I of the ACA that are subject to Section 1557. These programs expire January 1, 2014. 42 U.S.C. §§ 18001, 18002 (2012).

<sup>74</sup> See, e.g., 34 C.F.R. § 106.31(b)(6) (2012) (prohibiting covered programs or activities from aiding or perpetuating discrimination on the basis of sex by providing aid or assistance to any entity that discriminates on the basis of sex).

1557 must be understood to apply affirmative obligations to covered entities in addition to prohibiting discriminatory practices.

**Section 1557 applies to Managed Care Plans.** We see that increasing numbers of those we serve are enrolled in managed care plans. Today, approximately 28 percent of Medicare beneficiaries are enrolled in Medicare Advantage plans.<sup>75</sup> Well over three quarters of the Medicaid population is enrolled in managed care.<sup>76</sup> The increasing reliance on managed care plans to organize and deliver federally-funded or subsidized health care offers both opportunities and challenges for language access.

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. 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 (CRRRA) 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.

Managed care plans, federally administered by Medicare and federally funded by Medicaid, are programs providing health care. As such, they are subject to the non-discrimination regulations, promulgated under Title VI. All interactions the managed care plans have with members, whether or not those activities involve health care providers directly, affect the ability of plan members to access their health care.

To access care, plan members need quality language assistance at call centers, during plan appeals, on nurse help lines, in medication therapy management programs and at every point where they interact with the plan. In addition to the documents discussed in

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<sup>75</sup> Kaiser Family Foundation, Medicare Advantage 2012 Spotlight: Enrollment Market Update (June 2013), <http://kff.org/medicare/issue-brief/medicare-advantage-2013-spotlight-enrollment-market-update/>.

<sup>76</sup> See Medicaid Managed Care Enrollment Report at <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Data-and-Systems/Downloads/2011-Medicaid-MC-Enrollment-Report.pdf>.

4(f) below, in the managed care context, 'vital documents' need to be defined to include not just the Evidence of Coverage, Explanations of Benefits, provider lists and other standard member materials, but also particularized notices about coverage and care plans, service denial and reduction notices, appeals correspondence and other notices that affect rights to or access to services. Section 1557 regulations should address these requirements.

We also support the comments of DREDF in response to this question.

***Question 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 of unequal access 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.***

Please refer to the response to Question 1, above, for the impacts of discrimination in health care. We also support the comment submitted by NWLC, AAJC, CAP, NCLR and DREDF in regard to this section.

### **Ensuring Access to Health Programs and Activities**

***Question 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 or 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; (2) oral interpretation services, including in-person and telephonic communications, as well as interpretation services provided via telemedicine or telehealth communications; and (3) competence (including certification and skill levels) of oral interpretation and written translation providers and bilingual staff?***
- (b) What are examples of effective and cost-efficient practices for providing language assistance services, including translation, oral interpretation, and taglines? What cost-benefit data are available on providing language assistance services?***
- (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?***
- (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?**

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

**(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?**

## **I. Limited English Proficiency Due to Language**

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 (“CLAS”) in Health and Health Care (“enhanced National CLAS Standards”)<sup>77</sup> and HHS’ Guidance to Federal Financial Assistance Recipients Regarding Title VI Prohibition Against National Origin Discrimination Affecting LEP Persons (“HHS LEP Guidance”).<sup>78</sup> We also offer additional recommendations for compliance with both Title VI and Section 1557 below.

Current HHS LEP Guidance employs a four-factor balancing test to determine the “mix” of language assistance services that should be provided.<sup>79</sup> 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. 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 limited English proficient individuals that information is available to be interpreted in their primary language.

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<sup>77</sup> 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), available at <https://www.thinkculturalhealth.hhs.gov/Content/clas.asp>.

<sup>78</sup> Office for Civil Rights, U.S. Dept. of Health and Human Services, Guidance to Federal Financial Assistance Recipients Regarding Title VI Prohibition Against National Origin Discrimination Affecting Limited English Proficient Persons, 69 Fed. Reg. 47,311 (Aug. 8, 2003) [hereinafter HHS LEP Guidance].

<sup>79</sup> 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.”).

## Thresholds

Translation services should be subject to thresholds that operate as mandatory minimum requirements rather than “safe harbors.”<sup>80</sup> We strongly recommend HHS adopt new policy setting forth that the failure to translate documents when languages meet the percentage or numeric threshold is evidence of non-compliance with Title VI and Section 1557. Documents should be translated for each language group that makes up 5 percent or 500 persons, whichever is less, of the population of persons eligible to be served or likely to be affected by the program or recipient in a service area. This percentage and numeric threshold is already employed in other federal agency policy guidance, with some programs and agencies employing even lower thresholds.<sup>81</sup> HHS LEP Guidance currently uses a 5% and 1,000 person “safe harbor” threshold,<sup>82</sup> which leaves out millions of limited English proficient individuals. When applying the 500 threshold to service areas measured by counties, **1,324 counties** in the United States have populations of 500 or more limited English proficient individuals speaking at least one single language, as compared to only **987 counties** with populations of 1,000 or more limited English proficient individuals.<sup>83</sup> A 5 percent 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. Service areas should be approved by HHS. Where no service area has previously been approved, a recipient itself may self-identify the service area, subject to showing that the service area does not discriminatorily exclude certain populations. Documentation of how the self-identifying determination was made and what data was used. 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.<sup>84</sup> HHS should consider equipping

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<sup>80</sup> 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.” HHS LEP Guidance, 68 Fed. Reg. at 47,319.

<sup>81</sup> U.S. Dep’t of Labor, Style and Format of Summary Plan Description, 29 C.F.R. § 2520.102-2(c)(2) (2012); Supplemental Nutrition Assistance Program (SNAP), 7 C.F.R. § 272.4(b)(2)(i); U.S. Housing and Urban Development, Final Guidance to Receiving Federal Assistance Recipients Regarding Title VI Prohibition Against National Origin Discrimination Affecting Limited English Proficient Persons, 72 Fed. Reg. 2732, at 2753.

<sup>82</sup> HHS LEP Guidance, 68 Fed. Reg. at 47,319.

<sup>83</sup> Migration Policy Institute analysis of American Community Survey Data, 2007–2011 (on file with NHeLP). It is noted that some language populations not comprising of 1,000 LEP individuals may still comprise 5% of the population.

<sup>84</sup> HHS LEP Guidance, 68 Fed. Reg. at 47,314.

recipients with data driven maps that show estimates of eligible individuals with LEP for each service area as well as their approximate location.

### **Services by Trained Interpreters and Funding of Interpretation Services**

The correlation between oral interpretation by trained professional interpreters and improved access to quality of care is well-documented.<sup>85</sup> The number and kinds of interpretation service are shaped by the way the medical service itself is managed and delivered. Best practices for funding interpretation services should *disincentivize* the use of bilingual staff that is untrained in medical terminology and interpretation.

We support the comments submitted by APIAHF, AAJC, and AFSCME, which provide more details on this topic.

### **Telemedicine or Telehealth Communications**

Some providers may want to rely on telephonic interpretation as a best practice. Among the many types of in-person and video remote interpretation services available, telephonic services should be used as a last resort.<sup>86</sup> In general, telephonic interpretation may be a useful practice when communication needed is short and straightforward. The use of remote interpretation such as telephonic services is also less preferred by patients with LEP, medical providers, advocates, and interpreters.<sup>87</sup>

### **Competence of Oral Interpretation Providers and Bilingual Staff**

Best practices for ensuring competent oral interpretation may be taken from the

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<sup>85</sup> 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. Bell, T.S. et al., *Interventions to Improve Uptake of Breast Screening in Inner City Cardiff General Practices with Ethnic Minority Lists*, 4 *Ethnic Health* 277 (1999); Tocher, T.M. & Larson, E., *Quality of Diabetes Care for Non-English-Speaking Patients: A Comparative Study*, 168 *Western J. of Medicine* 504 (1998); Kuo, D. & Fagan, M. J., *Satisfaction with Methods of Spanish Interpretation in an Ambulatory Care Clinic*, 14 *J. of General Internal Medicine* 547 (1999); Marcos, L.R., *Effects of Interpreters on the Evaluation of Psychopathology in Non-English-Speaking Patients*, 136 *American J. of Psychiatry* 171 (1979).

<sup>86</sup> See Torres, B., Office of Minority Health, Massachusetts Dep't of Public Health, *Best Practice Recommendations for Hospital-Based Interpreter Services* 16, [www.mass.gov/eohhs/docs/dph/health-equity/best-practices.doc](http://www.mass.gov/eohhs/docs/dph/health-equity/best-practices.doc).

<sup>87</sup> In a 2011 survey, 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. Available from American Federation of State, County and Municipal Employees (AFSCME).

Certification Commission for Healthcare Interpreters (CCHI)<sup>88</sup> and the National Board of Certification for Medical Interpreters,<sup>89</sup> both of which use standards established by the National Council on Interpreting in Health Care.<sup>90</sup> Additional guidance and best practices are provided in Standards 5 and 7 of the enhanced National CLAS Standards,<sup>91</sup> as well as the HHS LEP Guidance.

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. Timely services 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.

### **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.

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."<sup>92</sup>

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<sup>88</sup> Certification Commission for Healthcare Interpreters,  
<http://www.healthcareinterpretercertification.org>.

<sup>89</sup> 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> (last accessed Sept. 17, 2013).

<sup>90</sup> National Council on Interpreting in Health Care, *National Standards of Practice for Interpreters in Health Care*,  
<http://www.ncihc.org/assets/documents/NCIHC%20National%20Standards%20of%20Practice.pdf>.

<sup>91</sup> 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).

<sup>92</sup> HHS LEP Guidance, 68 Fed. Reg. at 47,317.

## **Examples of Efficient and Cost-Effective Language Assistance Practices**

Data analyzing the costs and benefits of providing language assistance services supports a business case for integrating interpreters into the clinical setting. We support the comments submitted by APIAHF and AAJC which provide more details on this topic.

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 and Section 1557. 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.”<sup>93</sup> Section 1557 policies must do the same. Cost-benefit analyses fail to evaluate how professional and industry culture contribute to racial disparities in health care.<sup>94</sup>

## **Experiences of Individuals with LEP**

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.”<sup>95</sup> Unfamiliarity with the health care system often results in inaction that could compromise a basic standard of living for individuals and families. 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.<sup>96</sup>

Patient experiences that have resulted in malpractice claims are documented in *The High Costs of Language Barriers in Medical Malpractice*, a joint publication by the National Health Law Program and University of California, Berkeley, School of Public Health.<sup>97</sup>

These examples—and others submitted separately by APIAHF and AAJC which we support—demonstrate time and time again that lack of language assistance services have detrimental and often fatal consequences for both patients and providers. The affirmative obligation to provide language assistance services under Section 1557 is as important now as it was decades ago when Title VI was passed, as increased

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<sup>93</sup> 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.

<sup>94</sup> Ikemoto, L. C., *Symposium: Racial Disparities in Health Care and Cultural Competency*, 48 St. Louis L.J. 75, 119 (2003).

<sup>95</sup> Katz, V., *Children as Brokers of their Immigrant Families’ Healthcare Connections*, at 24 (2013) (under review).

<sup>96</sup> *Id.* at 31.

<sup>97</sup> Quan, K., & Lynch, J., *The High Costs of Language Barriers in Medical Malpractice* (2010), [http://www.healthlaw.org/images/stories/High\\_Costs\\_of\\_Language\\_Barriers\\_in\\_Malpractice.pdf](http://www.healthlaw.org/images/stories/High_Costs_of_Language_Barriers_in_Malpractice.pdf).

complexity in medical information and program bureaucracy have made navigating systems for limited English proficient individuals more difficult.<sup>98</sup>

### **Experiences in Providing Language Assistance Services**

Three “promising practices” reports from The Commonwealth Fund outlined ways that health care providers,<sup>99</sup> health benefit offices,<sup>100</sup> and small health care providers<sup>101</sup> can effectively and cost-efficiently provide language services.

### **Developing a Language Access Plan and the benefits or burdens of developing such a plan**

See above for cost-benefit data on providing language assistance services.

### **Translation of Documents**

A federal recipient may fulfill its obligation of providing “meaningful access” under Title VI by translating all “vital documents.” Section 1557 should be interpreted in accordance with this requirement. 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,”<sup>102</sup> 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.”<sup>103</sup>

We interpret the current definition of vital documents in HHS LEP Guidance to mean that the “importance” and “consequences” of information are a few—and not definitive—factors to consider when determining whether information is “critical” and, therefore, “vital.” Consistently, HHS recognizes that vital documents include 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

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<sup>98</sup> Katz, *Children as Brokers of their Immigrant Families’ Healthcare Connections*, at 37.

<sup>99</sup> Youdelman, M. & Perkins, J., *Providing Language Interpretation Services in Health Care Settings: Examples from the Field*, The Commonwealth Fund, May 2002, available at <http://www.commonwealthfund.org>.

<sup>100</sup> Youdelman, M., Perkins, J., *et al. Providing Language Services in State and Local Health-Related Benefits Offices: Examples From the Field*, The Commonwealth Fund, January 2007, available at <http://www.commonwealthfund.org>.

<sup>101</sup> Youdelman, M. and Perkins, J., *Providing Language Services in Small Health Care Provider Settings: Examples from the Field*, The Commonwealth Fund, April 2005, available at <http://www.commonwealthfund.org>.

<sup>102</sup> LEP.gov, Frequently Asked Questions, <http://www.lep.gov/faqs/faqs.html> (emphasis added).

<sup>103</sup> HHS LEP Guidance, 68 Fed. Reg. at 47,318 (emphasis added). Examples of vital documents are listed by [www.LEP.gov](http://www.LEP.gov) and in the HHS LEP Guidance. [www.LEP.gov](http://www.LEP.gov), Frequently Asked Questions, Question 9, <http://www.lep.gov/faqs/faqs.html>; HHS LEP Guidance, 68 Fed. Reg. at 47,319.

encountered or affected by the program or activity to determine whether certain critical outreach materials may be the most useful to translate.”<sup>104</sup>

We understand the balance of interests at play in the current definition of “vital documents” and, to this end, support the inclusion of in-language “taglines” in at least 15 languages when vital documents cannot be translated. Taglines are a low-cost way to inform enrollees of the availability of language services.

## **II. Limited English Proficiency Due to Disability**

We unambiguously support the need to ensure access to health programs and activities for individuals who have limited English proficiency (LEP), and appreciate that this question solicits information concerning the barriers and best practices experienced by that group. In addition, we also want to emphasize the communication needs and experiences of PWD, which we believe strongly evoke many of the same discrimination and enforcement issues that are raised in Question 4 with respect to people with LEP. For example, individuals whose primary language is American Sign Language (ASL) use a manually communicated language with a different sentence structure, grammar and syntax than English. The effective communication of healthcare concepts in ASL is best-served by an on-site qualified interpreter with training in medical terminology, and healthcare entities need to have prior policies, procedures and a budget in place to meet this need.

One of the best practices for ASL translation is the Metropolitan Hospital Consortium, established in November 2005 to ensure emergency ASL interpreter services for the 26 member health facilities located in Minnesota, Minneapolis.<sup>105</sup> The Consortium has an operation contract under which ASL interpreters, who must meet certain qualification standards, are listed on a reserved 24/7 on-call schedule and can respond immediately in a need arises in a member facility. The Consortium provides for 3 shifts every 24 hours, with 3 translators available per shift. A translator is able to arrive within 1 hour 95% of the time, and is guaranteed to arrive within 2 hours. In 2008, the Consortium reported monthly operating costs of approximately \$22,500, and each of the 26 member hospitals pays a \$433/month “subscription fee,” with the rest of the costs divided according to actual usage by member hospitals in a given month.

This model of establishing a common pool of translators that will be available to more than one healthcare delivery entity is also highly appropriate in the managed care context, where an MCO’s greater resources and administrative capacity can help ensure that interpreters and alternative formats for written materials are available at smaller clinics and provider offices who may not commonly recognize or implement their own obligations to provide effective communication. The MCO’s engagement with such a model necessarily includes telling their network providers that they cannot simply turn

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<sup>104</sup> HHS LEP Guidance, 68 Fed. Reg. at 47,318.

<sup>105</sup> The National Council on Disability, (2009) at 288, available online at: <http://www.ncd.gov/publications/2009/Sept302009>.

away Deaf/HOH individuals, that they must provide effective communication, and how to schedule use of the interpreter service or obtain alternative formats. Use of a common interpreter/translation pool should be available to MCO members as part of their membership, but we would also highly recommend that interpretation and translation be made available, possibly at a reasonable fee, to providers within the MCO network when they see patients who are *not* members. This could be an incentive for providers to join the network.

The Deaf and Hard-of-Hearing Program at Advocate Illinois Masonic Medical Center in Chicago has been operating for almost 30 years and specializes in providing mental health services and prevention education to Deaf and HOH persons.<sup>106</sup> The program combines telepsychiatry services and interactive videoconferencing to enable Deaf patients in geographically dispersed locations to have access to mental health services. In light of the fact that many Deaf persons are not fluent in written English, the program has also developed a library of ASL pamphlets that feature Deaf actors who present signed narration, vignettes, and graphics that is available in both video and streaming video formats. The health education pamphlets feature common preventive topics such as HIV/AIDS, sexually transmitted diseases, breast health, diabetes, smoking cessation, and depression management. Interactive screenings for depression, anxiety, and health attack risk are also available.

In the area of wellness and prevention, the Lighthouse for the Blind and Visually Impaired in San Francisco operates a Vision Loss Resource Center (VLRC) that offers an adaptive technology and health seminar.<sup>107</sup> VLRC offers participants an audio transcript, and information handouts of presentations on such adoptive equipment as accessible tools for glucose monitoring, weight management, healthy food preparation, and exercise equipment that does not require the visual intake of data. The technology to include people who are blind and visually impaired has existed for decades, and electronic formats such as email and accessible websites and documents make it even easier to communicate effectively. Nonetheless, many healthcare providers and practitioners ignore the general healthcare needs of blind and visually impaired people, assume that the practice cannot afford expenses incurred to provide alternative formats, and know next to nothing about adoptive equipment.

In terms of primary documents, the health education pamphlet topics mentioned in the prior paragraphs are all good candidates for prior translation. Common outpatient healthcare examinations and procedures need be available in ASL and alternative formats, including what is needed for prior preparation and after-procedure care. Medical and legal considerations should be among the criteria that should be used to decide whether a particular healthcare document needs to be translated. Some standards could include: (1) information that a consumer needs to adequately prepare before and take care after a medical procedure, treatment or drug; (2) information that explains why common procedure are needed and the risks and benefits of undergoing

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<sup>106</sup> *Id.* at 287.

<sup>107</sup> *Id.* at 286.

or not undergoing a procedure, and (3) general and individualized notices and information that have consequences for the scope and length of a patient's coverage and resulting out-of-pocket consequences for a patient. Much of this information, as well as common treatment and drug side effect information, can be very complex, and it cannot be assumed that Deaf persons in particular are able to read and comprehend this information in written English.

It also cannot be assumed that blind or low-vision persons have someone available to read healthcare information to them, or that people with developmental disabilities or speech impairments cannot independently understand this information. Important best practices include making written information available in a range of alternative formats such as Braille, large font print and electronic discs, including information that is translated into other languages, and communicating directly with an individual with a disability (or his or her chosen representative) to ask for his or her preferred communication methods. The public must also be clearly given notice that PWD have a right to effective communication, and where a patient or family member of a minor has an evident disability or chooses to disclose a disability that implicates a need for a reasonable accommodation concerning effective communication, staff must be trained to proactively offer a range of appropriate accommodations. The inclusion of a tagline in a brochure or putting up a poster on the wall will only be helpful to those blind or visually impaired individuals who have a sighted person to assist them.

***Question 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?***

Section 1557 bars discrimination “on the ground prohibited under . . . title IX of the Education Amendments of 1972,” which is sex.<sup>108</sup> It is the first federal law to broadly prohibit sex discrimination in health care. In addition, Section 1557 may not be misinterpreted to narrow existing interpretations of and protections against sex discrimination.

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 (most importantly, given Section 1557's

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<sup>108</sup> 20 U.S.C. § 1681(a) (2012).

statutory language) Title IX of the Education Amendments of 1972 must inform the interpretation of 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—as the RFI rightly notes.<sup>109</sup>

Pregnancy discrimination constitutes sex discrimination under Title IX<sup>110</sup> and other civil rights statutes such as Title VII<sup>111</sup> and thus also constitutes sex discrimination under Section 1557. These laws prohibit discrimination based on pregnancy itself, as well as pregnancy-related conditions.<sup>112</sup> 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.<sup>113</sup> Title IX further prohibits actions based on head of household or principal wage earner status.<sup>114</sup> Section 1557 regulations should likewise prohibit discrimination on these bases.

Further, Title IX has consistently been interpreted to bar 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.<sup>115</sup> Similarly, the E.E.O.C. has also concluded that discrimination based

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<sup>109</sup> 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”).

<sup>110</sup> 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).

<sup>111</sup> 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).

<sup>112</sup> See, e.g., 42 USC § 2000e(k) (2012).

<sup>113</sup> E.g. 34 C.F.R. § 106.40(a) (2012); 34 C.F.R. § 106.57(a).

<sup>114</sup> E.g. 34 C.F.R. § 106.57(a) (2012).

<sup>115</sup> 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](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

on gender identity or transgender status is a form of sex discrimination under Title VII,<sup>116</sup> as has the Department of Housing and Urban Development with regard to the Fair Housing Act.<sup>117</sup> The E.E.O.C. has also concluded that a claim of discrimination based on perceived sexual orientation can also constitute a claim of sex discrimination based on a failure to conform to gender-based expectations.<sup>118</sup> Indeed, 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 Marketplaces, QHPs, and the EHB.<sup>119</sup> As these precedents make clear, sex discrimination protections, including protection against discrimination based on sex stereotypes, apply to all individuals regardless of their sexual orientation. As such, section 1557 regulations should affirm the availability of sex discrimination claims, including sex stereotyping claims, to individuals who may also have lesbian, gay, or bisexual sexual orientations.

**The only exceptions to Section 1557’s broad nondiscrimination mandate are specifically and explicitly contained in Title I of the ACA.** The Section 1557 ban against discrimination in health programs includes a single exception – that it applies “[e]xcept as otherwise provided” in Title I of the ACA.<sup>120</sup> Thus, the only exceptions to Section 1557 are those expressly stated in that title. The plain language of the statute bars any interpretation that would suggest any other exceptions apply. In fact, exceptions to general rules like Section 1557’s antidiscrimination provision must be read strictly and narrowly. Courts have strictly construed such exceptions to give the fullest force to the primary operation of the general rule.<sup>121</sup> Indeed, in considering “[e]xcept as

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F.3d 1033 (8th Cir. 2010); *Bibby v. Phila Coca Cola Bottling Co.*, 260 F.3d 257, 2652-63 (3<sup>rd</sup> 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).

<sup>116</sup> *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).

<sup>117</sup> 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”).

<sup>118</sup> *Couch v. Chu*, E.E.O.C. Appeal No. 0120131136, \* 7 (Aug. 13, 2013).

<sup>119</sup> See, e.g., 45 C.F.R. §§ 155.120(c) (nondiscrimination rule for Marketplaces); 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).

<sup>120</sup> Patient Protection and Affordable Care Act § 1557, codified at 42 U.S.C. § 18116 (2012).

<sup>121</sup> *Nussle v. Willette*, 224 F.3d 95, 99 (2d Cir. 2000) (quoting *Commissioner v. Clark*, 489 U.S. 726, 739 (1989), *overruled on other grounds by Porter v. Nussle*, 534 U.S. 516 (2002)). See

otherwise provided” language in the Americans with Disabilities Act (ADA), the Eleventh Circuit limited the exceptions to only those expressly mentioned in the statute.<sup>122</sup> The same principles apply here.

Nothing in Section 1557, its language or legislative history, allows for any other limitations or exceptions regarding its application. Question 5 of the RFI notes that Title IX<sup>123</sup> contains limited exceptions to its protection in certain circumstances. These exceptions, however, are not incorporated into Section 1557. First, because those limited exceptions are not explicitly stated in Section 1557, they cannot be read to apply to it. Second, Section 1557, does not import any exceptions from Title IX. Section 1557 references Title IX solely for the ground on which it prohibits discrimination, which is sex.<sup>124</sup>

**Sex-specific health programs or activities do not violate Section 1557 when they are necessary to accomplish an essential health purpose.** Because the RFI specifically asks how Section 1557 should apply to health programs and activities that serve only one sex, we address that issue here. Like Title IX and other civil rights laws, the circumstances under which sex-specific programs and activities are permissible and thus nondiscriminatory must be narrow. Consistent with Section 1557’s broad nondiscrimination purpose, sex-specific health programs or activities should be permissible under Section 1557 when they are necessary to serve the disadvantaged sex—most usually women—or to comply with constitutionally protected rights to privacy. At heart, single-sex programs must be narrowly tailored and *necessary to accomplish an essential health purpose*. Further, Section 1557’s protection against sex discrimination still applies in single-sex environments. So, where a sex-specific program or activity exists, an equivalent sex-specific program or activity must be available on a nondiscriminatory basis for the other sex.

To the extent that Section 1557 makes narrow allowances for single-sex programs or activities, participation in these programs is determined by an individual’s self-identified gender. As noted above, Section 1557 protects against gender identity discrimination, which means that the law protects an individual’s ability to live in his or her community

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*also New York v. Bloomberg*, 524 F.3d 384, 402 (2d Cir. 2008). *See also Detroit Edison Co. V. SEC*, 119 F.2d 730, 739 (6th Cir. 1941) (holding that “[e]xceptions in statutes must be strictly construed and limited to objects fairly within their terms, since they are intended to restrain or except that which would otherwise be within the scope of the general language.”)

<sup>122</sup> *See McNely v. Ocala Star-Banner Corp.*, 99 F.3d 1068, 1074 (11th Cir. 1996) (limiting language of “except as otherwise provided” precluded the ADA from importing more restrictive language from the Rehabilitation Act).

<sup>123</sup> 20 U.S.C. § 1681(a)(1)-(9) (2012).

<sup>124</sup> As is discussed in more depth in response to Question (7), the Supreme Court held in similar context that the incorporation by reference of protections from one civil rights statute into another does not mean that the limitations of the first apply to the second. *See Consolidated Rail Corp. v. Darrone*, 465 U.S. 624 (1984) (holding that Section 504’s reference to Title VI’s remedies, procedures, and rights did not import limitations from Title VI not expressly provided in Section 504).

as a man or a woman.<sup>125</sup> So too Section 1557 protects an individual's access to health programs and activities in accordance with his or her self-identified gender and free from sex stereotypes.

We also want to address the question of the unique issues, burdens, and barriers encountered by women with disabilities in seeking quality health care since “[d]isability and gender are predictive of lack of access to health care.”<sup>126</sup>

The following are some examples of this issue:

- Regardless of disability type, women with disabilities are provided poorer health care in the area of cervical and breast cancer screenings and reproductive health generally.<sup>127</sup>
- Women with mobility disabilities rarely get weighed and are often examined while seated in their wheelchairs because examination tables are not accessible. A study of women veterans with spinal cord injury found that they were less likely to receive recommended mammograms and Pap smears than women veterans with no disabilities.<sup>128</sup>
- Women with disabilities, particularly older women and those with multiple disabilities, are less likely to receive a physician recommendation for screening mammography.<sup>129</sup>
- The absence of height-adjustable examination tables and the common use of mammography equipment designed only for women in a standing position pose serious barriers for women with physical disabilities who seek breast and cervical cancer screening.<sup>130</sup>

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<sup>125</sup> See, e.g., *Macy v. Holder*, E.E.O.C. Appeal No. 0120120821 (Apr. 23, 2012) (employer violated Title VII when job offer revoked because plaintiff sought to work as a woman); *Schroer v. Billington*, 577 F. Supp. 2d 293 (D.C.C. 2008) (same).

<sup>126</sup> Smith, D.L., *Disabil Health J. Disparities in health care access for women with disabilities in the United States from the 2006 National Health Interview Survey*, 2008 Apr;1(2):79-88. doi: 10.1016/j.dhjo.2008.01.001. Source: Kinesiology and Community Health, University of Illinois at Urbana-Champaign, Champaign, IL 61820, USA. smithdl@uiuc.edu.

<sup>127</sup> Drainoni, M., Lee-Hood, E., Tobias, C., Bachman, S., Andrew, J., Maisels, L., “Cross-Disability Experiences of Barriers to Health-Care Access: Consumer Perspectives,” *Journal of Disability Policy Studies* Fall 2006 vol. 17 no. 2 101-115.

<sup>128</sup> Lavela, S. L., Weaver, F. M., Smith, B., & Chen, K. (2006). Disease prevalence and use of preventive services: comparison of female veterans in general and those with spinal cord injuries and disorders. *Journal of Women's Health*, 15, 301-311.).

<sup>129</sup> Yankaskas, B., Dickens, P., Bowling, J. Michael, Jarman, M., Luken, K., Salisbury, K., Halladay, J., Lorenz, C., “Barriers to Adherence to Screening Mammography Among Women With Disabilities,” *Am J Public Health*. 2010 May; 100(5): 947–953, doi: [10.2105/AJPH.2008.150318](https://doi.org/10.2105/AJPH.2008.150318).

<sup>130</sup> Centers for Disease Control and Prevention. (1998). Use of cervical and breast cancer screening among women with and without functional limitations-United States, 1994-1995. *Morbidity and Mortality Weekly Report*, 47, 853-856.; Nosek & Howland, 1997; Nosek, M. A., & Howland, C. A. (1997). Breast and cervical cancer screening among women with physical disabilities. *Archives of Physical Medicine and Rehabilitation*, 78(12, Suppl. 5), S39-S44.

- Women who are deaf or hard of hearing have difficulty finding reproductive health care options that provide sign language interpreters and captioned audio-visual information, and women who are blind or have low vision have difficulty obtaining information in Braille or large print or in non-print formats, resulting in inadequate communication with medical personnel.
- Women with intellectual and cognitive disabilities do not receive explanations of medical information in language they can understand, because medical staff is not trained in effective communication techniques and extra time is not provided. A study of working-age women with cognitive disabilities showed that they had significantly lower rates of receiving cervical cancer and breast cancer screenings.<sup>131</sup> A study of African-American women with intellectual disabilities showed striking disparities in receipt of mammography screenings.<sup>132</sup>
- Women with severe mental illness are far less likely to receive mammograms, with women with schizophrenia or severe depression being the least likely to be screened.<sup>133</sup>
- When verbal information is provided to women who are blind or have low vision and to women who need additional explanations, that information is often conveyed in crowded waiting rooms at the expense of patient privacy and dignity.
- In the area of reproductive health care, women with all types of disabilities encounter some providers who assume they are sexually inactive.<sup>134</sup> Such false assumptions mean that those women are not examined for sexually transmitted diseases, are not provided comprehensive data on contraception alternatives and family planning, and are not educated on protecting their sexual and reproductive health.
- Despite the wish of many women with disabilities to discuss prevention, health promotion, and wellness, many primary care providers concentrate solely on underlying disabling conditions or make unwarranted assumptions about quality of life to the exclusion of preventive health measures.<sup>135</sup>

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<sup>131</sup> Parish, S. L., & Saville, A. W., Women with cognitive limitations living in the community: evidence of disability-based disparities in health care. *Mental Retardation*, (2006), 44(4), 249-259.

<sup>132</sup> Parish, S., Swaine, J., Son, E., Luken, K., "Receipt of mammography among women with intellectual disabilities: Medical record data indicate substantial disparities for African American women," *Disability and Health Journal* 6 (2013) 36-42.

<sup>133</sup> South Bend Tribune, "Mentally Ill May Skip Cancer Screenings, November 8, 2006, [http://articles.southbendtribune.com/2006-11-08/news/26933555\\_1\\_mental-illness-cancer-screenings-annual-mammograms](http://articles.southbendtribune.com/2006-11-08/news/26933555_1_mental-illness-cancer-screenings-annual-mammograms).

<sup>134</sup> Anderson, P., & Kitchin, R. (2000). Disability, space and sexuality: access to family planning services. *Social Science & Medicine*, 51, 1163-1173.; Welner, S., Hammond, C., "Gynecologic and Obstetric Issues Confronting Women with Disabilities," *Glob. Libr. Women's med.* August 2009, p. 4.

<sup>135</sup> Lisa I. Iezzoni, L., McCarthy, E., Davis, R., Siebens, H., "Mobility Impairments and Use of Screening and Preventive Services," *American Journal of Public Health*, June 2000, Vol. 90, No. 6, 955-961.

All of these barriers are compounded by the natural reluctance of women who encounter them to avoid such situations in the future, thus resulting in poor adherence to regularly scheduled screenings and exacerbating their lack of access to medical screening and treatment in the first place.<sup>136</sup> And late or no cancer screenings result in diagnosis at later stages and higher mortality rates compared to women without disabilities.<sup>137</sup>

In light of the U.S. Access Board's new standards for accessible weight scales, examination tables, and mammography equipment, we recommend that any regulation designed to enforce Section 1557 mandate that medical practitioners provide access to such tables, scales, and equipment to women with disabilities. *To make this recommendation meaningful, we further request a requirement that health plans that advertise on the state Marketplaces not be considered qualified unless they can demonstrate that such access can be provided.*

***Question 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.***

We support the comments submitted by the National Partnership for Women & Families on this question. We provide brief comments herein. The federal mandate to build a national infrastructure of electronic health information technology and exchange under the Health Information Technology Economic and Clinical Health (HITECH) Act of 2009<sup>138</sup> entails both health programs and activities receiving Federal financial assistance, and programs or activities administered by an Executive Agency.

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<sup>136</sup> Liu S, Clark M. Breast and cervical cancer screening practices among disabled women aged 40–75: Does quality of experience matter? *J Women's Health (Larchmt)* 2008;17(8):1321–9.

<sup>137</sup> Caban, M. E., Nosek, M. A., Graves, D., Esteva, F., & McNeese, M. (2002). Breast carcinoma treatment received by women with disabilities compared with women without disabilities. *Cancer*, 94, 1391-1396.

<sup>138</sup> Health Information Technology for Economic and Clinical Health (HITECH) Act, Title XIII of Division A and Title IV of Division B of the American Recovery and Reinvestment Act of 2009, Pub. L. No. 111-5, §§ 13001-13424 (February 17, 2009), codified at 42 U.S.C. §§ 201 note, 300jj-300jj-51, 17901-17953.

First, the HITECH Act provides substantial Federal financial assistance, totaling approximately \$27 billion, to private and public health programs and activities across the nation. The majority of this Federal financial assistance takes the form of incentive payments to eligible professionals and eligible hospitals serving Medicare and Medicaid beneficiaries, to encourage them to adopt certified electronic health record technology and use it meaningfully to improve patient and population health and health care.<sup>139</sup> As of July 2013, approximately 375,000 eligible professionals and eligible hospitals in all 50 states had received more than \$15.5 billion in Federal financial assistance.<sup>140</sup> Under section 13301 of the HITECH Act, Federal financial assistance increases approximately \$2 billion more.<sup>141</sup> Overall, “the Secretary [of Health and Human Services] shall . . . invest in the infrastructure necessary to allow for and promote the electronic exchange and use of health information for each individual in the United States consistent with the goals outlined in the strategic plan developed by the National Coordinator . . . .”<sup>142</sup>

Separately, the Department of Health and Human Services administers programs for “electronic exchange and use of health information and the enterprise integration of such information,” “utilization of an electronic health record for each person in the United States by 2014,” “a framework of coordination and flow of recommendations and policies under this subtitle,” and “a governance mechanism for the nationwide health information network.”<sup>143</sup>

Under Section 1557, no individual shall “be excluded from participation in, be denied the benefits of, or be subjected to discrimination under” these program and activities on any of the prohibited grounds. But such discrimination, denial or exclusion will occur if these HITECH programs and activities are not designed and used correctly.

A few examples will illustrate the magnitude of the problem and the importance of a solution now. According to the 2010 Census, approximately 60.5 million people ages five and older speak a language other than English at home.<sup>144</sup> But the current proposals would require each of the Medicare and Medicaid providers receiving Federal financial assistance to deliver only one patient-specific educational resource to *only one patient* in that patient's preferred language other than English.<sup>145</sup> ATM machines, by

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<sup>139</sup> 42 U.S.C. § 1395ww(n) (Medicare, eligible hospitals); id. § 1396b(t) (Medicaid, States for eligible professional and hospitals); id. § 1848(o) (Medicare, eligible professionals),

<sup>140</sup> Centers for Medicare & Medicaid Services, Combined Medicare and Medicaid Payments by State, January 2011-July 2013.

<sup>141</sup> 42 U.S.C. §§ 300jj-31 - 300jj-38.

<sup>142</sup> 42 U.S.C. § 300jj-31(a).

<sup>143</sup> 42 U.S.C. § 300jj-11(c)(3)(A), (c)(8).

<sup>144</sup> United States Census Bureau, Language Use in the United States: 2011, p. 3 (Aug. 2013), available at <http://www.census.gov/prod/2013pubs/acs-22.pdf>.

<sup>145</sup> E.g., Meaningful Use Work Group, "Draft Recommendations: Meaningful Use Stage 3," p. 43, Health Information Technology Policy Committee, August 7, 2013, available at [http://www.healthit.gov/facas/sites/faca/files/muwg\\_stage3\\_draft\\_rec\\_07\\_aug\\_13\\_v3.pdf](http://www.healthit.gov/facas/sites/faca/files/muwg_stage3_draft_rec_07_aug_13_v3.pdf).

contrast, are necessarily accessible in multiple languages other than English for all daily transactions.

Health disparities illustrate the problem, but they also present an extraordinary opportunity to implement Section 1557 and use health information technology now to reduce health disparities. The Consumer Partnership for eHealth, led by the National Partnership for Women & Families, recently developed and submitted to the HIT Policy Committee a Disparities Action Plan setting forth strategic changes that the Department of Health and Human Services should make to programs and activities under development. The Action Plan identifies minimum changes to certified EHR technology and meaningful use of EHR technology 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.<sup>146</sup>

These changes are essential to meet the requirements of Section 1557. As the HIT Policy Committee (the public advisory body to the Secretary on implementing the HITECH Act) has acknowledged and discussed repeatedly, reducing health disparities is essential yet remains a "key gap" in EHR functionality that the market will not drive alone<sup>147</sup>--and a key gap in current policy.

Lastly, protecting privacy is especially important in health care, and the Privacy and Security rules implementing the Health Insurance Portability and Accountability Act (HIPAA) provide national minimums to protect patient health data in both paper records and electronic health records. Other provisions of law provide additional privacy protections, some of special importance to members of protected classes, such as reproductive health for women. Members of protected classes who are traditionally denied benefits, excluded from participation, or subjected to discrimination, may also be subjected to disproportionate abuses of privacy rights or misuses of their private health data. While the shift from paper to electronic records can present new challenges to protecting the privacy and security of a patient's health information, health information technology also presents powerful new ways to improve the privacy and security of patients' data, including encryption of the patient's private data, electronic authentication and authorization controls to prevent unauthorized access, and electronic audit trails. Regulations implementing Section 1557 should harness these new tools and provide

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<sup>146</sup> Consumer Partnership for eHealth, Leveraging Meaningful Use to Reduce Health Disparities: An Action Plan (Aug. 2013), available at <http://www.nationalpartnership.org/research-library/health-care/HIT/leveraging-meaningful-use-t-o.pdf>.

<sup>147</sup> E.g., Meaningful Use Work Group, "Draft Recommendations: Meaningful Use Stage 3," p. 6, Health Information Technology Policy Committee, August 7, 2013, available at [http://www.healthit.gov/facas/sites/faca/files/muwg\\_stage3\\_draft\\_rec\\_07\\_aug\\_13\\_v3.pdf](http://www.healthit.gov/facas/sites/faca/files/muwg_stage3_draft_rec_07_aug_13_v3.pdf).

guidance to protect the privacy rights of members of protected classes and protect against misuse of their health data.

In summary, the RFI's question regarding health information technology is applicable to the entire range of classes covered by Section 1557. The Office for Civil Rights should consider the benefits and barriers all protected classes might encounter in accessing electronic information technology in health programs and activities. If designed, built, and used correctly, health information technology introduces important new solutions and can reduce the disparities in access and outcomes covered by Section 1557; but if these programs and activities fail to anticipate and accommodate such needs, then millions of people will continue to be denied the benefits of, or even be excluded from participation in, these programs and activities. Regulations implementing Section 1557 should require covered programs and activities to incorporate and use these important new electronic tools and policies, such as those explained above, to identify and reduce health disparities so that members of protected classes receive full and equal benefits. Likewise, they should enforce Section 1557 where such disparities continue to occur in violation of its provisions. Lastly, the regulations must harness these new tools and provide guidance to protect the privacy rights of members of protected classes and protect against misuse of their health data.

Any HIT records or plans must be displayed to individual consumers and medical professionals in non-medical language and have fully accessible and consumer-friendly interfaces. Specifically, individual patients and authorized providers with disabilities who use screen reading software, speech recognition software and other technological interfaces must be able to use those devices to read, correct and enter information on the record. Required HIT information must include granular information about a consumer's specific functional limitation and the corresponding reasonable accommodations (e.g., large font print, height adjustable examination equipment or lift, extended appointment time, ASL interpreter). This simple requirement would save patients literally hundreds of hours repeatedly requesting the same accommodations for every single appointment, even at the same office.

The ACA recognizes that the recruitment and development of health care providers from within a population that is subject to health disparities is one key strategy for reducing health disparities, but if underlying HIT that supports the U.S. health care system is allowed to be inaccessible to providers with disabilities, this is one key strategy that has been taken away from the disability community. As one example, a mental health professional with vision impairments encountered numerous limitations in work because the large state-wide clinic that employed her use a HIT record system that was incompatible with screen readers. The employer provided a human reader/data recorder, but that limited the professional in her scheduling of appointments, her time (the human reader could be on leave or sick), and her exercise of professional judgment (the professional could not always linger over certain notes and look up related questions).<sup>148</sup> It is a constraint that should absolutely not be necessary when HIT rather

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<sup>148</sup> Information on file with the National Partnership for Women and Families.

than hand-written notes come online, and it would be wastefully ironic for the new system to be just as inaccessible as the old. There are a limited number of companies that make large records systems for providers, and they cannot traditionally be reached under the ADA which does not generally apply to “manufacturers” but Section 1557 provides a new opportunity to insist that companies that assist health care providers, hospitals, clinics, and MCOs to come into compliance with new HIT regulations must provide fully accessible HIT systems in accordance with W3 (World Wide Web) principles of accessibility.

We are strongly supportive of HHS’ focus on the importance of health information technology. For many seniors with complex medical conditions necessitating the interaction of numerous medical providers, such technology may radically improve care. Information technology may also help address the longstanding failures around eligibility and enrollment (for example, under-enrollment of seniors in Medicare Savings Programs). At the same time, we urge HHS to ensure that the adoption of information technology does not discriminate against seniors who may have less experience with such technology or less capacity for using it.

We also wish to address the impact on people with disabilities. According to the 2010 census, 56.6 million people had a disability in America, or 18.7 percent of the population. Over 14.9 million people (29.0% of people with a disability aged 15 years and older) had a disability related to seeing, hearing, or speaking. Approximately 15.1 million (29.4%) had a mental disability. Nearly 15.8 million people (30.7%) had disabilities in *two* domains, not just one.<sup>149</sup> Yet current proposals would only require the certified electronic health record technology to record disability status, with no requirement to accommodate those disabilities in the ways that the electronic health records share personal health information with the individual.<sup>150</sup> We also support the comments on Health IT submitted by DREDF.

### **Compliance and Enforcement Approaches**

***Question 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. The Age Act has a separate set of administrative procedures that is similar, but requires mediation before an investigation. There is also a separate administrative procedure under Section 504 that applies to programs conducted by the Department. Under all of these laws, parties also may file private litigation in federal court, subject to some restrictions.***

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<sup>149</sup> United States Census Bureau, Americans With Disabilities: 2010, pp. 4, 8-9, 17-19 (July 2012), available at <http://www.census.gov/prod/2012pubs/p70-131.pdf>.

<sup>150</sup> E.g., Meaningful Use Work Group, "Draft Recommendations: Meaningful Use Stage 3," p. 43, Health Information Technology Policy Committee, August 7, 2013, available at [http://www.healthit.gov/facas/sites/faca/files/muwg\\_stage3\\_draft\\_rec\\_07\\_aug\\_13\\_v3.pdf](http://www.healthit.gov/facas/sites/faca/files/muwg_stage3_draft_rec_07_aug_13_v3.pdf).

- (a) How effective have these different processes been in addressing discrimination? What are ways in which we could strengthen these enforcement processes?**
- (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 the regulation. What experience, if any, do you have with self-evaluations? What are the benefits and burdens of conducting them?**
- (c) What lessons or experiences may be gleaned from complaint and grievance procedures already in place at many hospitals, clinics, and other covered entities?**

It is critical that OCR create and administer a strong enforcement system for this new statute. Section 1557 specifically references the enforcement mechanisms “provided for” and “available under” Title VI, Title IX, Section 504, and the Age Discrimination Act (“the Age Act”). Therefore, the regulations adopted for Section 1557 must 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.<sup>151</sup> And, although HHS has primary oversight over Section 1557, the Department of Justice (DOJ) has coordinating responsibility pursuant to Executive Order 12250.<sup>152</sup> In addition, each agency must have implementing regulations for Section 1557.

**It is essential that Section 1557 regulations recognize that the statute authorizes both discriminatory intent and disparate impact claims.** Disparate impact claims are allowed under the civil rights statutes referenced by Section 1557.<sup>153</sup> Section 1557 thus imports this important antidiscrimination principle. The disparate impact standard is crucial for addressing 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.

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<sup>151</sup> Some of these enforcement mechanisms are expressly or implicitly provided for in statutory text. Others are established by the implementing regulations (e.g., administrative complaints, agency compliance reviews, and formal investigations).

<sup>152</sup> Exec. Order No. 12,250, 3 C.F.R. 298 (1980).

<sup>153</sup> Dep’t of Justice, *Title VI Legal Manual* (2001), available at <http://www.justice.gov/crt/about/cor/coord/vimannual.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)); 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).

**Section 1557 provides for a private right of action.** Because the statutes listed in Section 1557 contain a private right of action for a full range of relief, including equitable relief and monetary damages, Section 1557 does as well.<sup>154</sup> While agency enforcement is critical to securing the protections provided under Section 1557, a private right of action is also crucial for ensuring individuals the robust protection Section 1557 affords them. 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."<sup>155</sup> Section 1557's explicit language thus requires that Section 1557 include a private right of action and it is important that OCR acknowledge this avenue for relief.

**Section 1557 provides for the full range of agency enforcement and Department of Justice enforcement in court.** Title VI, Title IX, Section 504, and the Age Act expressly provide for periodic compliance reviews and establish procedures for processing and investigating administrative complaints. Under each statute, an agency may terminate or refuse to grant or continue assistance to a recipient.<sup>156</sup> Agencies may also refer cases to the DOJ for enforcement in court. In addition, agencies enforce disparate impact obligations through any of the available enforcement procedures.<sup>157</sup> Section 1557, too, includes this full range of enforcement mechanisms.

**Limitations on agency or individual enforcement of the Age Discrimination Act should not apply to claims under Section 1557.** The Age Act requires that complainants engage in mediation and exhaust administrative remedies, while Title IX, Title IX and Section 504 do not<sup>158</sup>. Accordingly, Section 1557 cannot be interpreted to include these limitations simply because one of the four laws it references does.. To interpret Section 1557 as including these limitations that apply to the Age Act would

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<sup>154</sup> 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). The Court later determined that money damages are available for intentional discrimination, relying on the longstanding principle that all remedies are presumed to be available to accompany a federal right of action "unless Congress has expressly indicated otherwise." *Franklin v. Gwinnett County Public Schs.*, 503 U.S. 60, 66 (1992). There, the Court stated "Congress surely did not intend for federal monies to be expended to support the intentional actions it sought by statute to proscribe." *Id.* at 74. See also *Guardians Assn. v. Civil Service Comm'n of New York City*, 463 U.S. 582 (1983) (damages available under Title VI for intentional violations); *Consolidated Rail Corporation v. Darrone*, 465 U.S. 624 (1984) (awarding backpay for violation of Section 504 of Rehabilitation Act).

<sup>155</sup> 441 U.S. at 704-05.

<sup>156</sup> See, e.g., 29 C.F.R. § 31.8(b) (2012).

<sup>157</sup> See, e.g., Dep't of Justice, *Title VI Legal Manual* (2001), available at <http://www.justice.gov/crt/about/cor/coord/vimannual.php#B> (discussing disparate impact obligations under Title VI); Dep't of Justice, *Title IX Legal Manual* (2001), available at <http://www.justice.gov/crt/about/cor/coord/ixlegal.php#2> (discussing disparate impact obligations under Title IX).

<sup>158</sup> See, e.g., *Neighborhood Action Coalition v. City of Canton*, 882 F.2d 1012, 1015 (6th Cir. 1989) (Title VI); *Cannon*, 441 U.S. at 706 n.41 (Title IX); *Gean v. Hattaway*, 330 F.3d 758, 775 (6th Cir. 2003) (Rehabilitation Act).

either mean that enforcement mechanisms available under Section 1557 pursuant to the other three statutes are limited in a way that the drafters did not express or that Section 1557 is internally inconsistent and that some of its enforcement mechanisms are limited and some are not. Neither of these readings can be correct. Moreover, Supreme Court precedent supports reading Section 1557 as not importing the limitations of the Age Act.<sup>159</sup> Any other interpretation would conflict with Section 1557's language and broad remedial goals.

**Enforcement procedures provided under the laws referenced by Section 1557 are a starting point for developing procedures under Section 1557.** Like investigations under other civil rights laws, Section 1557 investigations must be fair, efficient, and prompt. A 2012 report by the Department of Education's Office of Civil Rights demonstrates its efforts to investigate and resolve complaints in a range of areas under its jurisdiction.<sup>160</sup> The report highlights OCR's interest in and the importance of resolving complaints promptly and in proactively addressing complaints of discrimination.<sup>161</sup> HHS-OCR's own case resolution manual, too, emphasizes the importance of fair, efficient, and prompt investigations and resolutions.<sup>162</sup> These priorities are especially important in the health care area. Delaying investigations of alleged discrimination in the health care area can have serious physical, emotional, and financial consequences for individuals seeking care or health coverage. OCR must not exacerbate harm by allowing complaints to remain unresolved.

**Section 1557 provides for 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 crucial and a hallmark of civil rights enforcement under the laws Section 1557 references. The ability to file an administrative complaint can make it easier for victims

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<sup>159</sup> Importantly, the Supreme Court has held that when one of the Spending Clause antidiscrimination statutes references the enforcement provisions of another, it adopts its enforcement mechanisms but not its limitations. For example, Section 504 expressly makes available to victims of discrimination the "remedies, procedures, and rights set forth in Title VI." 29 U.S.C. § 794a(a)(2) (2012). In *Consolidated Rail Corp. v. Darrone*, the Court considered whether the Section 504 reference to Title VI limited the Rehabilitation Act's broad application. 465 U.S. 624 (1984). Although the Court held that the Rehabilitation Act's reference to the remedies, procedures, and rights set forth in Title VI allowed for enforcement similar to Title VI, it did not import limitations from Title VI not expressly provided in the Rehabilitation Act. 465 U.S. at 635 (1984). In so doing, the Court emphasized the broad purpose behind the Rehabilitation Act to support its conclusion that a limitation contrary to that broad purpose (that was not expressly set forth in the statute) should not be read into the statute. *Id.* at 632 n.13.

<sup>160</sup> Dep't of Educ., Office for Civ. Rts., *Title IX Enforcement Highlights* (June 2012), available at <http://www2.ed.gov/documents/press-releases/title-ix-enforcement.pdf>.

<sup>161</sup> *Id.* at 2, 4-12.

<sup>162</sup> Dep't of Health & Human Servs., Office for Civ. Rts., *Case Resolution Manual for Civil Rights Investigations*, 1, 30 (2009), available at <http://www.hhs.gov/ocr/civilrights/complaints/crm2009.pdf>.

of discrimination to seek a resolution of their claim than going to court, which can be more costly and more public than administrative complaints.

Class complaints and third party complaints also allow OCR to resolve systemic problems of discrimination. They are particularly important in the health care area 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.

**It is essential that OCR conduct Section 1557 compliance reviews of covered entities and provide technical assistance regarding compliance with Section 1557.** Section 1557 is a powerful proactive tool in OCR’s work to combat discrimination in health care. OCR’s authority is not limited to responding to complaints under Section 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 laws<sup>163</sup> as do other agencies.<sup>164</sup>

Because Section 1557 is a new law, it is especially important that OCR complete compliance reviews to both identify discrimination and set precedents under this new law. Without knowledge of Section 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.<sup>165</sup> The results of any compliance reviews should also be made public. The reports from such reviews can serve as guidance for other covered entities as to what it means to comply with Section 1557.

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<sup>163</sup> 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](http://www.hhs.gov/ocr/civilrights/activities/agreements/compliancereview_initiative.pdf).

<sup>164</sup> 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.

<sup>165</sup> 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.

This could include reviewing compliance with protections against discrimination based on sex, sex stereotypes and gender identity and antidiscrimination protections for LGBT people at hospital systems or the Marketplaces.<sup>166</sup> In general, because the Marketplaces are newly created entities under the ACA—and will be a critical point for accessing health insurance for many individuals—OCR could select Marketplaces in certain states to review for compliance with Section 1557. Specifically, given the large lower-income population that is LEP—more than half of LEP children and children with LEP parents have Medicaid or CHIP coverage and about 95% of uninsured individuals with LEP will be eligible for Medicaid or Marketplace subsidies<sup>167</sup>—both the Marketplaces and state Medicaid programs are important focuses for OCR compliance reviews regarding language access services. For the same reason, reviewing Medicaid providers as well as the state Medicaid program for compliance with language access standards is essential.

An individual, complaint-driven system of enforcement is particularly limiting in health care, where myriad factors increase an individual's reluctance to make complaints: need for ongoing relationship with health care providers (especially rare specialists), circumstances of need with financial, internal and support resources already taxed by illness, many people with functional limitations simply do not self-identify with the disability rights community (especially true of older persons who have acquired disabilities) and internalize barriers as their own problem rather than a systemic failure to comply with nondiscrimination law.

**OCR must establish procedures for enforcement against 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. Section 504's protections apply to programs or activities conducted by executive agencies and HHS has adopted regulations outlining procedures for enforcing nondiscrimination protections in these programs.<sup>168</sup> Other federal agencies have adopted their own regulations to govern the programs and activities they administer. HHS should use these as a starting point for developing Section 1557 procedures. DOJ should also use its coordinating authority to ensure that federal agencies administer

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<sup>166</sup> See, e.g., Samantha Friedman, et. al. for U.S. Dep't of Housing & Urban Dev., Office of Pol'y Dev. & Res., *An Estimate of Housing Discrimination Against Same-Sex Couples* (June 2013), available at [http://www.huduser.org/portal/publications/fairhsg/discrim\\_samesex.html](http://www.huduser.org/portal/publications/fairhsg/discrim_samesex.html) (describing study using testers that demonstrates evidence of discriminatory treatment of same-sex couples in rental housing advertised over the internet).

<sup>167</sup> See Kaiser Commission on Medicaid & the Uninsured, *Overview of Health Coverage for Individuals with Limited English Proficiency*, (Aug. 2012) available at <http://kff.org/disparities-policy/fact-sheet/overview-of-health-coverage-for-individuals-with/> (About 95% of uninsured individuals with LEP have incomes below 400% of poverty meaning they will be income-eligible for Medicaid or Marketplace subsidies in 2014).

<sup>168</sup> 45 C.F.R. pt. 85 (2012).

their programs and activities in compliance with the nondiscrimination protections of Section 1557.

Section 1557 also applies to entities established under Title I of the ACA. Most notably, this includes the health insurance Marketplaces. It is critical that these new entities establish robust and clear standards for compliance with Section 1557. This includes training individuals that operate Marketplaces and those performing consumer assistance, about the requirements of Section 1557. In addition, consumer assisters should also be able to inform consumers who believe they have been subjected to discrimination where they can file a complaint.

**Self-evaluations by covered entities can be useful to ensuring compliance with Section 1557.** Section 1557 regulations should require covered entities to complete self-evaluations.<sup>169</sup> A self-evaluation aims to identify discriminatory policies or practices and prompt a covered entity to correct those noncompliant policies or practices. Because Section 1557 applies to newly-created entities and expands the application of existing antidiscrimination protections, self-evaluations may be particularly useful. Covered entities should be required to review their current policies and practices for compliance with Section 1557 and modify any policies or practices that do not meet its requirements. Further, covered entities should take the appropriate remedial steps to eliminate the effects of discrimination that resulted or may have resulted from adherence those policies and practices. Self-evaluations should remain on file with the covered entity and available for review by OCR or other interested parties. Given that self-compliance often is insufficient, however, self-evaluations should be but one part of compliance.

As one example, experience with ADA self-evaluation by the counties and monitoring by the state of California is extremely poor. On July 13, 2012 DREDF submitted an extensively documented complaint on this subject<sup>170</sup> as it affected welfare and health care eligibility and enrollment functions to HHS' OCR. While the complaint was accepted for investigation, it has been difficult to know how the investigation is progressing or whether and when it might bring upon improvements in California's mandated county self-evaluation procedures.

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<sup>169</sup> Title IX and Section 504 regulations require covered entities to complete self-evaluations to evaluate their policies and practices—and their effects—to determine if they are complying with the law. 34 C.F.R. § 106.3(c) (2012) (Title IX); 45 C.F.R. § 84.6(c) (Section 504). The Age Act states that covered entities employing 15 or more employees may be required to complete a self-evaluation as part of a compliance review or complaint investigation. 45 C.F.R. § 91.33 (2012).

<sup>170</sup> See DREDF, *Disability Civil Rights Discrimination Complaint*, available at <http://dredf.org/access-to-public-benefits/HHS-OCR-COMPLAINT-7-13-12-REDACTED.pdf>. Since the state is undergoing current and imminent and large-scale systemic changes with regard to Medicaid eligibility, enrollment and service delivery, it would be an ideal time to clarify and reinforce how enrollment and service delivery entities are responsible for ADA compliance and self-evaluation. Instead, there is little evidence that the self-evaluation tool is taken seriously by the state or the entities that are required to undergo self-evaluation.

**Compliance procedures at covered entities should be made widely available and be fair, efficient, and prompt.** Many individuals are unaware of the protection to which Section 1557 entitles them and how to proceed if they believe they have been discriminated against. It is part of the obligation of a program, activity, or entity covered by Section 1557 to make clear that it is bound by Section 1557 and how individuals can file complaints if they believe they have been discriminated against by that program, activity, or entity. Information about how to file a complaint must be made easily and widely available; further, procedures for resolving grievances must be fair, efficient, and prompt. Regulations under civil rights statutes referenced by Section 1557 have similar requirements.<sup>171</sup>

**Medicare Part B Providers are subject to Section 1557.** One of the most important benefits of Section 1557 is that it removes the exclusion of Medicare Part B providers from coverage under Title VI. For the first time, this means that many physicians and other Part B providers will face a clear obligation to provide language services to their patients. The learning curve for these providers is significant. Center for Medicare & Medicaid Services' (CMS') approach to compliance must include a major education effort with physicians. If language access rights are to become real, provider buy-in, particularly for physicians, is critical. Providers need to be educated not only about their obligations but also about why compliance is important to the health care of their patients. They also need practical guidance in how to fulfill their obligations. While HHS clearly cannot and should not do this alone, it is important that the agency devote resources to working with provider groups, managed care organizations and others. Use of the Medicare Learning Network, <http://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNGenInfo/index.html?redirect=/mlngeninfo>, is another avenue for provider education. Education combined with enforcement will be significantly more effective than enforcement alone.

**Medicare and Medicaid Managed Care plans should have contractual requirements to report on language services and Section 1557 compliance.** For Medicare and Medicaid managed care, besides the statutory enforcement mechanisms, CMS and HHS also have the ability to impose contractual obligations on plans, to require reporting on Section 1557 compliance, and to use quality withholds and other financial incentives to improve performance. We ask that the agency work aggressively to include specific translation, interpretation and cultural competency requirements in contracts with managed care providers. While these measures are a supplement and not a substitute for broader enforcement efforts, they are levers that CMS and HHS should use, particularly because they allow a more granular approach than is usually available through regulations alone. We note that CMS already does this in a limited way by requiring in the Medicare Managed Care Manual that Medicare plans to provide interpreter services at call centers. In addition, timely access to interpreters is one of the

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<sup>171</sup> See, e.g., 34 C.F.R §§ 106.8(b), **106.9 (2012) (Title IX)**; 45 C.F.R. §§ 84.7, 84.8 (Section 504); 28 C.F.R. § **42.405(c) (Title VI)**.

measures against which Medicare Advantage and Medicare Part D plans are measured when awarding star ratings. The ratings are a factor in plan renewal and low ratings can also lead to enrollment sanctions.<sup>172</sup> Much more needs to be done, particularly with respect to measuring and incentivizing language access in provider offices but the current contractual requirements are a foundation on which more robust language access requirements can be built.

*Specific Recommendations:*

1. Medicare and Medicaid managed care plans, and all other managed care plans receiving federal funds, should have obligations to provide training to their providers on cultural competency, how to access interpreters, and protocols for using interpreters effectively. HHS should be specific in its information to managed care plans about their training obligations.
2. Medicare managed care plans have an especially important role in educating their physician network.
3. HHS should hold managed care plans responsible for the acts and omissions of their network providers who do not meet their Section 1557 obligations. The plans are the direct recipients of federal funds. They can and do set standards for their contracted providers and they should be responsible for monitoring the performance of those providers.

**Section 1557 requires 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 healthcare 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)."<sup>173</sup>

It is not uncommon for an LEP individual to not know they have the right to complain when they are not provided with proper language services. In a telephone survey of 1,200 Californians in eleven non-English languages, 1,000 were LEP participants and only 371 or 37% were aware that federal law obligates health care providers receiving federal funding to ensure language access.<sup>174</sup> 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.

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<sup>172</sup> See 2014 Call Letter at pp. 79, and 81, available at [www.cms.gov/Medicare/Health-Plans/MedicareAdvtgSpecRateStats/Downloads/Announcement2013.pdf](http://www.cms.gov/Medicare/Health-Plans/MedicareAdvtgSpecRateStats/Downloads/Announcement2013.pdf).

<sup>173</sup> 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).

<sup>174</sup> Grubbs, V., Chen, A. H., *et. al.*, *Effect of Awareness of Language Law on Language Access in the Health Care Setting*, 21 J. of Gen. Internal Med., July 2006, at 683, 688.

## **Section 1557 requires a linguistically appropriate complaint and grievance procedure.**

### *Online Complaint Portal*

We commend that OCR's website is prompting 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 completely in English, making it more accessible for an English-speaker to file a complaint as opposed to a LEP individual. 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](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 [OCRAMail@hhs.gov](mailto:OCRAMail@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, and without any voice prompts for any of the seven non-English languages.<sup>175</sup> An LEP individual who calls the number is unlikely able to understand the message and will likely not stay on the phone for the completion of the message to leave a message regarding their civil rights issues.

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 for which OCR has translated webpages. These voice prompts should be added so that LEP individuals can quickly access competent

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<sup>175</sup> 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."

bilingual representatives or English-speaking representatives who can communicate with the LEP individuals using interpreters.<sup>176</sup>

We also support the comments on this questions submitted by DREDF and the National Center for Lesbian Rights on this question.

***Question 8: Are there any other issues important to the implementation of Section 1557 that we should consider? Please be as specific as possible.***

**Section 1557 should be interpreted to prohibit Transgender exclusions in the health insurance market.** Transgender individuals have historically been discriminated against in the insurance market via insurance exclusions for otherwise-covered benefits when provided for the purpose of treating gender dysphoria. The categorical exclusion of surgery as treatment for gender dysphoria is a discriminatory relic that contradicts scientific evidence and medical standards of care for the treatment of gender dysphoria. The exclusion puts patients' lives at risk and undermines the ability of medical professionals to provide medically necessary care for their patients. As such, these exclusions constitute a form of sex discrimination and should fall within the scope of section 1557 protections.

**Section 1557 must protect the rights of immigrants.** It is also 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 that prohibit processes and requirements that have the effect of deterring or preventing eligible individuals from securing access to programs and services. We appreciate that the statute and promulgated regulations have built protections for limited collection and confidentiality into the marketplaces, Medicaid, and the Children's Health Insurance Program,<sup>177</sup> but we believe it is critical that these largely state-run programs be brought under the rubric of section 1557 rulemaking to make available the accountability and enforceability mechanisms of the HHS Office for Civil Rights. OCR must have the authority to use civil rights mechanism to prohibit states from enacting or enforcing policies or practices that frustrate the ACA's purpose or its ability to reach eligible applicants through rules governing eligibility, verification, privacy, household size, or income calculations.

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<sup>176</sup> Mara Youdelman, Nat'l Health Law Program, *The ACA and Language Access* (Jan. 2011), available at [http://www.healthlaw.org/images/stories/Short\\_Paper\\_5\\_The\\_ACA\\_and\\_Language\\_Access.pdf](http://www.healthlaw.org/images/stories/Short_Paper_5_The_ACA_and_Language_Access.pdf) (describing voice prompts).

<sup>177</sup> See, e.g., Patient Protection and Affordable Care Act, Pub. L. 111-148, §§ 1411(g), 1414(a), 124 Stat. 119, 230, 236 (2010).

## **Conclusion**

In conclusion, we commend OCR for taking the important step of issuing this RFI and urge OCR to move forward with the rulemaking necessary to implement this crucial new civil rights protection. It is critical that OCR administers this new law through robust implementation and enforcement mechanisms, and this must be reflected in the final regulations that OCR promulgates. This is essential if Section 1557's guarantee of protection from discrimination in health care is to be fulfilled and statute's mandate reflected. If you have any questions, please contact Mara Youdelman, Managing Attorney of NHeLP's DC Office, [Youdelman@healthlaw.org](mailto:Youdelman@healthlaw.org) or 202-289-7661. Thank you for your consideration of our comments.

Sincerely,

A handwritten signature in black ink, appearing to read "Emily Spitzer". The signature is fluid and cursive, with the first name "Emily" and last name "Spitzer" clearly distinguishable.

Emily Spitzer  
Executive Director