September 30, 2013 **Via online submission to www.regulations.gov**

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

Re: Docket No. HHS-OCR-2013-0007 (Request for Information Regarding Nondiscrimination in Certain Health Programs or Activities)

Disability Rights Education and Defense Fund (DREDF), Access Living, Coalition for Disability Health Equity, Greater Boston Legal Services (GBLS), New York Lawyers for the Public Interest (NYLPI), and the additional undersigned organizations appreciate the opportunity to provide comments in response to U.S. Department of Health and Human Services Office for Civil Rights Request for Information Regarding Nondiscrimination in Certain Health Programs or Activities (RFI). We are all committed to eliminating barriers to effective healthcare and enforcing non-discrimination for people with disabilities, as mandated by the Americans with Disabilities Act (ADA), the Rehabilitation Act of 1973, and the Patient Protection and Affordable Care Act (ACA).

Our responses are structured according to the arrangement of questions in the RFI.

Understanding the Current Landscape

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

The Institute of Medicine (IOM) noted in 2007 that tens of millions of people in the US report some kind of disability.[1] The number of people with disabilities will likely grow even more 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, people who are likely to develop disabilities in the future, and people who

[1] National health surveys often define "disability" in terms of a limitation in function, but it is notable that with the passage of the ADA Amendments Act of 2008, PL 110-325 (S 3406), the legal definition of disability is not to be interpreted through only a medical lens. "Disability" is to be construed in favor of broad coverage under federal non-discrimination laws, does not require someone to be currently or consistently experiencing a functional limitation (i.e., a disability can be episodic or in remission), and encompasses someone who is "regarded as" having an impairment that substantially limits a major life activity.

are or 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.

However, as Georges Benjamin, Executive Director of the American Public Health Association (APHA) said in December 2012, "there are huge issues with health inequity [for people with disabilities]. Unless people recognize we have this problem, that there are important things we can do, we're never going to achieve equity [for people with disabilities] in our society."[2] As Benjamin recognized and as is well documented, people with disabilities (PWD) experience significant health disparities and barriers to health care, as compared with people who do not have disabilities.[3] In fact, PWD are 2.5 times more likely to have unmet health care needs than non-disabled peers.

Individuals with all types of disabilities report discriminatory physical, programmatic, and attitudinal barriers to accessing health care in hospitals, clinics, diagnostic facilities, and practitioners' offices of all sizes throughout the country.[4] 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 US 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).[5] Other forms of discrimination that prevent PWD from attaining appropriate and effective healthcare take the form of disability stereotypes,

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[2] Krahn, G. U.S. Department of Health and Human Services, Centers for Disease Control and Prevention. (2013). *Grand rounds: People with disabilities and public health*. Retrieved from website: http://blogs.cdc.gov/publichealthmatters/2013/01/4994/

[3] See, e.g.: The National Council on Disability, (2009). *The Current State of Health Care for People with Disabilities*. Retrieved from website: http://www.ncd.gov/publications/2009/Sept302009; Reis, J. P., Breslin, M. L., Iezzoni, L. I., & Kirschner, K. L. (2004). *It Takes More Than Ramps to Solve the Crisis of Healthcare for People with Disabilities.* Informally published manuscript, Rehabilitation Institute of Chicago, Chicago, IL, Retrieved from www.tvworldwide.com/events/hhs/041206/PPT/RIC_whitepaperfinal82704.pdf.

[4] 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."

[5] 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.

prejudicial practices, and incorrect perceptions. Finally, the failure to provide needed policy modifications and reasonable accommodations affects healthcare treatment decisions and outcomes.

Physical Barriers

With respect to physical barriers, research indicates that more than 3 million adults residing in the United States require a wheelchair for mobility.[6] The Americans with Disabilities Act requires full and equal access to healthcare services and facilities for PWD, yet patients with mobility impairments are frequently denied services, receive less preventive care and fewer examinations, and report longer waits to see subspecialists despite this mandate. A study recently published in the Annals of Internal Medicine reports the results of telephone interviews with specialty practices concerning their willingness to accept and capacity to accommodate patients with disabilities. Medical residents at a hospital in Springfield, Massachusetts telephoned 256 specialty practices in locations across the country and asked if the practice could accommodate a patient who was described as a large individual who used a wheelchair and who was unable to independently transfer. Fifty-six practices (22%) reported that they could not accommodate the patient. Nine practices (4%) reported that the building was inaccessible. Forty-seven (18%) reported that they were unable to transfer a patient from their wheelchair to an examination table. Only twenty-two (9%) reported the use of height adjustable tables or a lift for a transfer director. Finally, the study reported that gynecology is the subspecialty with the highest rate of inaccessible practices (44%).[7]

Something as fundamental to health management as weight measurement remains elusive for PWD. A California study reported, for example, that among over 2300 primary care practices, only 3.6 percent had accessible weight scales.[8] Related research reveals that wheelchair users report almost never being weighed even though weight measurement is a crucial metric for many types of health care including determining anesthesia and prescription dosages, and ongoing health and fitness monitoring.

Attitudinal Barriers

According to the Alliance for Disability in Healthcare Education, “Without training, healthcare providers tend to:

- Underestimate the abilities of patients with disabilities
- Grossly underestimate the quality of life of patients with disabilities
- Minimize the patient’s capacity to contribute to their own care

[6] Brault M. Americans with Disabilities: 2005. Current Population Reports, P70-117. Washington, DC: U.S. Census Bureau; 2008. Accessed at www.census.gov/prod/2008pubs/p70-117.pdf on 14 December 2012.

[7] Tara Lagu et al. Access to Subspecialty Care for Patients With Mobility Impairment, Annals of Internal Medicine. 2013; 158:441 – 446.

[8] Mudrick, Breslin, Liang, 2012.

- Minimize the extent and importance of the patient's expertise in [their] own condition.[9]

In addition, stereotypes and biases have led providers to believe, for example, "[T]hat PWD do not have a good quality of life; that people with developmental disabilities do not feel pain and, therefore do not require anesthesia; that people who are deaf have cognitive deficits because they may not be fluent in standard English; and that women with disabilities do not require reproductive counseling and care because they are not sexually active."[10]

Lack of Programmatic Access

The failure to provide needed policy modifications and reasonable accommodations as required by current disability rights laws, affects healthcare treatment decisions and outcomes. For example, lack of effective communication when Sign Language interpreters are not provided for Deaf patients or print materials are not available in alternative, accessible formats for people with visual impairments can lead to ineffective communication about medical problems and treatment. Accommodations such as alternative formats are not offered or available even when their necessity is clinically obvious and predictable. For example, there is a high correlation between diabetes and vision loss, but printed self-care and treatment instructions in alternative formats such as Braille, large font type, CD, or audio recording, and accessible glucometers, are rarely available although the Americans With Disabilities Act of 1990 and Section 504 of the 1973 Rehabilitation Act requires the provision of auxiliary aids and services when required for effective medication. Other common problems include provider failure to modify routine diagnostic procedures in order to accommodate an individual's disability or to establish policies that allow for extended or flexible exam times. Some patients require additional time to communicate effectively, dress and undress, or transfer from their wheelchair or scooter to a diagnostic device or exam table or be positioned for an exam. When such accommodations are not available, providers may make incorrect diagnosis and treatment decisions and serious health problems sometimes are not properly diagnosed or treated. The result can be unequal healthcare that affects the quality and length of life for many.[11]

Moreover, insufficient knowledge of how to provide accommodations or ignorance about the critical need for accommodations can result in people being injured in the very process of seeking care. For example, patients with disabilities have been injured when they are transferred to exam tables by untrained staff, given improper dosages of medication or anesthesia due to lack of proper weight measurement, and when

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[9] Havercamp, S. M. (Ohio State University Nisonger Center); Robey, K. (Matheny Medical and Educational Center and UMDNJ – New Jersey Medical School); & Smeltzer, S. (Villanova University College of Nursing); *Approaches to training healthcare providers on working with patients with disabilities*. Webinar at AUCD. Retrieved from http://www.aucd.org/docs/Approaches to Training Healthcare Providers.pdf
(Accessed on July 18, 2013)

[10] See supra note 1, at 49.

[11] Kirschner, K.L., Breslin, M.L., Iezzoni, L.I., & Sandel, E. (2009) "Attending to Inclusion: People with Disabilities and Health-Care Reform," *PM&R*, Oct 1, Vol. 10, Pages 957-63.

pressure sores develop because providers waive physical exams for wheelchair users who cannot transfer to exam tables.[12]

Finally, PWD report putting off needed care due to the significant distress associated with seeking and receiving care and therefore frequently must rely on emergency department treatment as a last resort when a treatable condition has become acute.[13]

Documented Health Disparities Experienced By People With Disabilities

Research shows that along with social determinants of health (such as income insecurity and lack of healthcare insurance), the aforementioned barriers contribute to significant health and healthcare disparities for PWD as compared to the general population. For example, PWD are more likely to:

- Experience difficulties or delays in getting the health care they need
- Not have had an annual dental visit
- Not have had a mammogram in the past 2 years
- Not have had a Pap test within the past 3 years
- Not engage in fitness activities
- Have high blood pressure[14]

Moreover:

- Women with disabilities have higher death rates from breast cancer than women without disabilities
- PWD die from lung cancer at higher rates than people who do not have disabilities[15]
- Adults with disabilities have a 400 percent elevated risk of developing Type II diabetes.[16]
- Three out of five people with serious mental illness die 25 years earlier than other individuals, from preventable, co-occurring chronic diseases[17]

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[12] J. M. Glionna, "Suit Faults Kaiser's Care for Disabled; Courts, Advocates Say Provider Fails to Give Equal and Adequate Treatment to the Handicapped. Chain Says It Complies with Disabilities Act," Los Angeles Times (record edition), July 27 2000, p. 3.

[13] A recent study by National Institutes of Health researchers found that working-age adults with disabilities account for a disproportionately high amount of annual emergency department visitors. Rasch, E. K., Gulley, S. P., & Chan, L. (2012). Use of emergency departments among working age adults with disabilities: A problem of access and service needs. *Health Services Research*, *48*(4), 1334-1358. Retrieved from http://onlinelibrary.wiley.com/doi/10.1111/1475-6773.12025/references

[14] Altman, B., & Bernstein, A. U.S. Department of Health and Human Services, CDC National Center for Health Statistics. (2008). *Disability and Health in the United States, 2001–2005*. Retrieved from website: http://www.cdc.gov/nchs/data/misc/disability2001-2005.pdf

[15] Iezzoni, L. I. (2011). Eliminating health and health care disparities among the growing population of people with disabilities. *Health Affairs, 30*(10), 1947-54.

[16] U.S. Department of Health and Human Services, Healthy People 2020. (2013). *Disability and health*. Retrieved from website: http://www.healthypeople.gov/2020/topicsobjectives2020/nationalsnapshot.aspx?topicId=9

[17] Assoc. of University Centers on Disabilities, "Letter to Kathleen Sebelius" http://www.aucd.org/docs/policy/health_care/CLAS_StandardsDisabilityLetter%2012011.pdf. Citing (Colton & Manderscheid, 2006; Manderscheid, Druss, & Freeman, 2007.

- Adults with disabilities are three times more likely to commit suicide than peers without disabilities[18]

Adding to this picture of healthcare inequality, scientific evidence is lacking about effective treatments for PWD, especially those who develop common conditions of aging (e.g., cancer, heart disease, diabetes) because they are routinely excluded from clinical trials and creating comparative effectiveness research aimed at PWD presents complex challenges.[19] Healthcare professionals therefore have access to limited comparative treatment information and evidence about therapeutic options. It also becomes very difficult to discuss or refute the often unexpressed bias that poorer health, shorter lifespans, and a lesser quality of life are inherent features of living with a disability, regardless of the functional impairment or clinical condition in question, and without respect to whether or not healthcare facilities are accessible and legally required accommodations have been provided.

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.[20] Disability prevalence among American Indians and Alaskan Natives is 16.3 percent.[21] In raw numbers, over 10.8 million non-institutionalized PWD aged 5 and over are estimated to be members of ethnic minorities.[22] 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.'"[23] Therefore, the relationship between race and disability is a complex one that needs to be freshly viewed as race and disability

[18] Seth Curtis and Dennis Heaphy, Disability Policy Consortium: Disabilities and Disparities: Executive Summary (March 2009), p. 3.
[19] *Identifying effective health care services for adults with disabilities: Why study designs and outcome measures matter*. (2011). Presentation at the Mathematica Policy Research Center on Health Care Effectiveness (CHCE) Issue Forum. Retrieved from http://www.mathematica-mpr.com/CHCE/forum_archives/July_2011/powerpoint.pdf
[20] 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.
[21] U.S. Census Bureau, *2009 American Community Survey*, S1810. Disability Characteristics 1 year estimates, *available at* http://factfinder.census.gov/servlet/STTable?_bm=y&qr_name=ACS_2009_1YR_G00_S1810&-geo_id=01000US&ds_name=ACS_2009_1YR_G00_&-_lang=en&-format=&-CONTEXT=st.
[22] *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.
[23] Institute of Medicine (IOM). 2007. The Future of Disability in America. Washington, DC: The National Academies Press, p. 92.

together may have a previously unaccounted cumulative impact on creating health disparities. For example:

- 31 percent of PWD report fair or poor health in comparison to 6 percent of the general population.[24] Among adults with a disability, 55.2 percent of Hispanic persons, and 46.6 percent of African Americans, report fair or poor health, as compared with 36.9 percent of whites.[25]
- Adults with disabilities have a 400 percent elevated risk of developing Type II diabetes.[26] Diabetes is also a rapidly growing health challenge among Asian Americans and Pacific Islanders who have immigrated to the United States, affecting about 10 percent of Asian Americans, with 90-95 percent of these having type 2 diabetes.[27] Despite the high correlation between diabetes and vision loss, printed self-care and treatment instructions in alternative formats such as Braille, large font type, CD, or audio recording, and accessible glucometers, are rarely available.
- 4.6 percent of Deaf people are infected with HIV/AIDS, four times the rate for the African-American population,[28] the most at-risk racial group in the U.S. that "accounted for half of all new HIV diagnoses and just under half of new AIDS diagnoses in 2009."[29] Gay and bisexual men, another group heavily impacted by HIV/AIDS, have a 19 percent rate of infection, and 44 percent of those infected were unaware of their HIV status.[30] Measures to target HIV/AIDS outreach and information to LGBT people of color who experience multiple health barriers must also consider the factor of hearing impairments on effective communication of health information.
- Adults with disabilities are three times more likely to commit suicide than peers without disabilities.[31] Three out of five people with serious mental illness die 25 years earlier than other individuals, from preventable, co-occurring chronic diseases.[32] At the same time, African Americans with severe mental health disabilities are less likely than whites to access mental health services, more likely to drop out of treatment, more likely to receive poor-quality care, and more

[24] Seth Curtis and Dennis Heaphy, Disability Policy Consortium: *Disabilities and Disparities: Executive Summary* (March 2009), p. 3.
[25] Center for Disease Control Website, http://www.cdc.gov/ncbddd/disabilityandhealth/data.html [Accessed July 14, 2011].
[26] Curtis and Heaphy, p. 3.
[27] Asian American Diabetes Initiative, Joslin Diabetes Center, http://aadi.joslin.org/content/asian/why-are-asians-higher-risk-diabetes] (2010).
[28] Curtis & Heaphy, p. 8.
[29] Avert, United States Statistics by Race and Age, http://www.avert.org/usa-race-age.htm] (2009).
[30] Centers for Disease Control and Prevention. (CDC) HIV and AIDS among gay and bisexual men, September 2010, *available at*: http://www.cdc.gov/nchhstp/newsroom/docs/FastFacts-MSM-FINAL508COMP.pdf.
[31] Curtis & Heaphy, p. 3.
[32] Assoc. of University Centers on Disabilities, "Letter to Kathleen Sebelius" http://www.aucd.org/docs/policy/health_care/CLAS_StandardsDisabilityLetter%2012011.pdf. Citing (Colton & Manderscheid, 2006; Manderscheid, Druss, & Freeman, 2007.

likely to be dissatisfied with care.[33] Asian Americans and Hispanics are less than half as likely as whites to receive mental health treatment.[34]

- People with significant vision loss experience a greater prevalence of obesity, hypertension and heart disease, and cigarette use than the general public.[35] People who are Hispanic have higher rates of visual impairments than people who are African American, and both groups have higher rates of vision impairment than people who are white.[36]
- 15 percent of PWD report not seeing a doctor due to cost in comparison to 6 percent of the general population.[37] At the same time, adults with annual household incomes of less than $25,000 are more likely to report having a disability than adults with an annual household income equal to or greater than $25,000.[38] PWD and members of racial minorities often share socio-economic characteristics and related health access barriers due to the expense of maintaining health with a disability. PWD are much more likely to experience various forms of material hardship— including food insecurity, not getting needed medical or dental care, and not being able to pay rent, mortgage, and utility bills—than people without disabilities, even after controlling for income and other characteristics.[39]
- Among people who are deaf, women of color appear to experience the greatest health disparities and difficulty accessing appropriate health care. They tend to have lower incomes and poorer health, and to be less educated compared with white women. Among women of color, African American Deaf women appear to experience the greatest health disadvantages.[40]

Please note that we have also included additional information relating to sub-part (e) on intersectional bases of healthcare discrimination in our responses to other questions. Most notably, information concerning the experiences of women with disabilities comprises our response to Question 5. Our response to Question 4 includes the experiences of Deaf persons of a particular race or ethnicity, and/or whose first written language is not English.

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

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[33] Whitley, R., & Lawson, W.. (2010). The Psychiatric Rehabilitation of African Americans With Severe Mental Illness. *Psychiatric Services, 61*(5), 508-11.
[34] 2008 National Healthcare Disparities Report. Table 15_3_1.1a & 15_3_1.1b http://www.ahrq.gov/qual/qrdr08/index.html
[35] Michele Capella-McDonnall, "The Need for Health Promotion for Adults Who Are Visually Impaired," *Journal of Visual Impairment and Blindness* 101, no. 3 (March 2007).
[36] *Id.* Note that a vision impairment is a visual disability not correctable by glasses or other modifications.
[37] Curtis & Heaphy, p. 3.
[38] Curtis & Heaphy, p. 3.
[39] Shawn Fremsted, "Half in Ten: Why Taking Disability into Account is Essential to Reducing Income Poverty and Expanding Economic Inclusion," Center for Economic and Policy Research, (2009), p. 2.
[40] National Council on Disability, 2009.

It is vitally important for 1557 to cover the full and complex range of health care entities operating in the American health care system, from individual providers to hospitals, from MCOs to insurers, from HIT support to state and federal agencies. The complexity of the healthcare enterprise makes it impossible for discrimination to be addressed without every facet of the system bearing at least some specific level of responsibility for implementing non-discrimination policies and procedures, as well as reporting on and monitoring adherence to policies and procedures among increasing layers of sub-contracted responsibility. Disability discrimination, in particular, does not only require entities to refrain from engaging in bad activities, but requires entities to actively engage in ensuring physical accessibility and reasonable accommodations and policy modifications. The very nature of effective communication necessarily involves meeting the discrete elements of providing notice to the public, determining the communication method needed, and actually following through with effective communication methods, which include having alternative formats and translations prepared beforehand. Section 1557 health programs and activities should include, but not be limited to, provider offices and clinics, provider groups, specialty treatment centers, hospitals, managed care organizations, qualified health plans participating in the exchange, and exchanges themselves. These are all entities that receive federal funds under existing streams of Medicaid or Medicare money, or expanded or new funds made available under the ACA or through the Exchanges, which in themselves are also authorized under the ACA and federally funded. The same rationale applies to the myriad medical and long-term services and supports sub-contractors that are going to be needed as state Medicaid agencies increasingly turn to MCOs for the delivery of some or all Medicaid services.

We would like to highlight two additional points. Sufficient medications, durable medical equipment, and Long-Term Services and Supports (LTSS), especially Home and Community-Based Services (HCBS), are key components that enable PWD to remain in their homes and communities instead of institutions in accordance with the Supreme Court's *Olmstead*[41] decision. Many MCOs and subcontracting entities have primarily provided medical services to children and healthy families. These MCOs do not understand the degree to which PWD rely on these components to maintain health and functional capacity, and they also lack familiarity with the tenets of *Olmstead*. As entities that administer and deliver Medicaid and Medicare they clearly operate a program or activity that falls under Section 1557, and must understand the implications of *Olmstead* for every aspect of their operations, from risk assessment to treatment approvals to care coordination.

The second point is that as state agencies devolve the delivery of public program services to private entities, the non-discrimination standards applicable to and expected of those services should remain the same. For example, a state Medicaid agency is subject to Title II of the ADA and to Sections 504, 508, and state disability rights laws. If the state chooses to contract with MCOs and other entities to administer and deliver Medicaid services, Medicaid beneficiaries with disabilities must be able to rely on the same standards of accessibility and non-discrimination that previously applied. Even if the state itself did not always deliver on those standards, it must contractually ensure

[41] Olmstead v. L. C., 527 U.S. 581 (1999), 138 F.3d 893.

that all contracting standards adopt and manifest the concepts of accessibility, undue burden, reasonable accommodation and policy modification, and fundamental alteration. States also must continue to monitor and ensure enforcement of those disability rights laws since they must ultimately ensure that *Olmstead* rights are honored.

The interaction of these two points in the context of *Olmstead* merits closer attention, and we will use factual examples to further illustrate our argument that Section 1557 regulations must directly address non-discrimination in the managed care administration and delivery of Medicaid and Medicare services. In 1999, the United States Supreme Court in *Olmstead* ruled that segregation and institutionalization of PWD who are able to live independently in the community with supports and services is prohibited by the ADA. In addition, Title II of the ADA Act mandates that public entities (e.g., state Medicaid agencies) provide services, programs, and activities "in the most integrated setting appropriate to the needs of qualified individuals with disabilities."[42] Title II also provides a broad array of prohibitions of any direct or indirect administrative actions that create a discriminatory impact on qualified individuals with disabilities.[43]
Both the letter and the spirit of the *Olmstead* mandate and the ADA regulations are violated when states, as well as federal agencies:

- Require higher and higher Medicaid copayments and cost sharing for medications and services.
- Require prior approval of medications despite their prescription for Medicaid recipients by licensed physicians in good standing.
- Refuse (both Medicaid and Medicare) to provide and/or repair durable medical equipment.
- Arbitrarily set determination of need scores so as to render individuals with disabilities ineligible to receive HCBS regardless of their functional status.
- Arbitrarily impose permanent cuts in critical HCBS services.
- Fail to develop and maintain a provider network that is physically and programmatically accessible to PWD or to provide PWD with the information they need to choose accessible and appropriate care providers.
- Design a particular benefit – such as personal care services – so that it is offered in greater amounts to individuals in segregated settings.
- Make coverage decisions that result in people with disabilities being served needlessly in segregated settings.
- Set reimbursement rates for coverage in a way that results in individuals with disabilities being served needlessly in segregated settings.

All of these practices, singly and collectively, put PWD who currently live successfully in the community at risk for institutionalization in violation of *Olmstead* and ADA regulatory precepts. They also make it more difficult for PWD who are currently in institutions to return to the community as desired and appropriate.

[42] 28 CFR 35.130(d).
[43] 28 CFR 35.130(b)(1) and (3).

Prescription Medication Caps and Prior Authorization; Raised Copays and Cost-Sharing

People with serious mental illness and people with multiple chronic conditions are likely, if not almost certain, to require multiple medications in order to maintain their ability to live successfully outside of institutional settings. In states resorting to prior authorization, copayments, and other limitations to control the number of prescriptions filled for Medicaid recipients, these individuals are placed at serious risk of a need for emergency care and, in some cases, institutionalization or reinstitutionalization.

A just-published study of twenty-two states demonstrated that medication utilization management practices, including prior authorization, copayment amounts, and limits on quantities and refills, had measurable impact on medication continuity among Medicaid beneficiaries with serious mental illness.[44] Another study showed that medication discontinuity and access problems raised the number of emergency department visits nearly 74% and the number of inpatient hospital stay days nearly 72%.[45] A third study showed that persons with mental illness who experienced medication discontinuity and medication access problems had a 3.6 *times* greater likelihood of adverse events including emergency room visits, hospitalizations, homelessness, suicidal ideation or behavior, or incarceration.[46] Particularly in the context of people with mental health issues, these barriers can result in rapid decompensation and double the risk for hospitalization.[47]

Here is what an Access Living consumer has to say about medication discontinuity in Illinois:

> *I don't think there should be a limit on how many medications a person needs to take. Because this year is going to cost me a bundle. You can only have four. They do a utilization review, and they can either deny you or accept it, and maybe they'll pay for it all except for the co-pay. After you get your four max, then you have to have a doctor write a prescription for you and you have to go through the chain of command to get help with medication. My doctors prescribed certain medication, and Medicaid said no, we won't pay for it, you have to take a different medication, which really didn't cover the problem as well. And this has been a routine thing that they do to me very often. So it either slows down my recovery or gives me side effects that don't make it compatible with my other medicines.*

[44] Brown, J., Barrett, A., Caffery, E., Hourihan, K., Ireys, H., "Medication Continuity Among Medicaid Beneficiaries with Schizophrenia and Bipolar Disorder," Psychiatr Serv. 2013 Sep 1;64(9):878-85. doi: 10.1176/appi.ps.201200349.
[45] West, J., Rae, D., Huskamp, H., Rubio-Stipec, M., Regier, D., "Medicaid medication access problems and increased psychiatric hospital and emergency care," General hospital psychiatry, 2010, 32(6):615-622.
[46] West, J., Wilk, J., Rae, D., Muszynski, I., Rubio Stiped, M., Alter, C., Sanders, K., Crystal, S., Regier, D., "Medicaid prescription drug policies and medication access and continuity: Findings from ten states," Psychiatric Services, 2009, 60(5):601-610.
[47] Law, et al., Journal of Clinical Psychiatry Vol. 69, No. 1, January 2008. Weiden, Et. Al., Partial Compliance and Risk of Rehospitalization Among California Medicaid Patients with Schizophrenia, Psychiatric Services, Vol. 55, 2004.

Higher copays and cost sharing caused at least two consumers to reenter nursing homes voluntarily as a way of managing unaffordable costs.

> *The reason why I moved into a nursing home is because I couldn't keep up with the copays. I'm diabetic and to get the test strips for diabetes is $60.00 a month or whatever it is. Then you have to keep testing yourself to get the insulin. They want you to turn the insulin level in. You need the test strips to get the insulin. The insulin was paid for, and then what happened was there was a tier system within my health plan. I got switched to a medication that was in a higher tier than what I had been in. That was like a $60.00 copay to do that. I get paid $893.00 and I get a $96.00 Medicare copay with that. On top of that I've got to pay about $150.00 to get my medications. When you are living off of $600.00 without a job… When I lost my job, I wasn't able to pay. It was either food or medication. I remember just eating oatmeal every day. I decided just take me to the nursing home. At the nursing home I don't have to fool with any copays.*
>
> *I used to see a good doctor, but she had a $60.00 copay every time I saw her. So if I'm having problems where I need to see her every week that could really add up. At the time I've usually had jobs where they help me pay some of the copays, but I have to deal with what I have to deal with now because of the money situation, and I can't afford quality health care. I've been trying to locate a psychotherapist that will take Medicaid, and I've been having a hard time locating a therapist because they are so expensive. If they don't take Medicaid, then they want money, $100.00 an hour or whatever. If they do take Medicaid then they want a copay. I'm living off of below poverty level, and I have to pay on top of that, I've got thousands of dollars of hospital bills on top of what Medicaid or Medicare should have picked up. They only pick up a certain percentage. If I paid my hospital bills, all my disability money would go there. It's ridiculous to me, and that's why I moved into a nursing home. It's very stressful when I'm living on my own.*

Delayed or Rejected Repairs of Durable Medical Equipment

In 2012, the Illinois legislature enacted a bill entitled the SMART Act, SB 2840. One of the numerous provisions in that bill that cut Medicaid services and supports required preauthorization of even routine repair of wheelchairs and scooters – a requirement that caused consumers to wait and to miss work, school, appointments and other essential activities for weeks and even months for minor as well as major repairs. A notable example of the extreme limitations that can result from such a requirement concerns a consumer who missed two months of physical therapy in addition to his other activities of daily living because his wheelchair required repairs. Confined to bed, he acquired three pressure sores. He was finally given an ill-fitting loaner chair that worsened his pressure sores.

In Access Living's focus groups, numerous consumers commented on the problems they experience attempting to have their essential equipment repaired and the impact these problems create for their independence and quality of life.

The first wheelchair I got was a power chair. I had it for 10 years. The thing was falling apart, motor, gears, tires, everything. They did not want me to get a new chair. The parts, they wouldn't pay for the parts. They fight you tooth and nail, Medicare and Medicaid, both.

My wheelchair stopped in the middle of the street. Here come cars everywhere, and if it wasn't for a young man who helped push me across the street, I probably got hit or something. It just stopped. I've been trying to get Medicare to give me a new chair for the last six months to a year, now.

You can only change your tires every year. So if something goes wrong with your tires, they're worn so bad… You have to buy them yourself. The time thing, limiting, putting restrictions on when a person can get a part for their wheelchair, affects the quality of life, because if your chair is wobbling or it's not working, you're not going to want to take a chance going out doing your everyday activities.

They don't give loaners anymore; they have to take your chair and repair it right then and there. They send a guy out instead of giving a loaner. And sometimes you might have to stay at home just until the parts come in.

Arbitrary Setting of Determination of Need Score or Imposition of Permanent Block Cuts

With respect to home- and community-based services, some states have redefined eligibility by increasing the point scores that applicants must meet in order to be considered "in need" of such services. In Kentucky in 2003, the Commonwealth responded to budgetary concerns by adopting what it termed an "emergency regulation" that redefined eligibility for Medicaid long-term care, causing persons who had been receiving such services to become ineligible. The United States District Court for the Eastern District of Kentucky held that arbitrarily reducing benefits to otherwise qualified recipients by the simple expedient of manipulating eligibility standards is "unreasonable and inconsistent with Medicaid objectives." The District Court further held that the claims arising out of such state action were likely in further litigation to be found to violate due process.[48]

Consistent with the *Kerr* opinion, CMS rejected an attempt by the State of Illinois in 2012 to raise its "DON" (determination of need) score from 29 to 37. CMS informed the Medicaid Director of the Illinois Department of Healthcare and Family Services that changes in eligibility rules that would cause persons to be required to reside in nursing facilities would be unacceptable. Each individual enrolled in a waiver is required to have a service plan inclusive of all services and supports necessary to meet assessed

[48] *Kerr v. Holsinger*, No. 03-68-JMH (U.S. Dist. Ct., E.D., 2004), http://scholar.google.com/scholar_case?case=2490084190791530 34&hl=en&as_sdt=2&as_vis=1&oi=scholarr.

needs. "[E]nrolling individuals in the waiver in order to keep their Medicaid eligibility status, but not providing them services under the waiver would not be permitted."[49]

Other states have made budget decisions that attempted to unambiguously cut or deeply reduce critical HBCS services. In *Darling. V. Douglas*,[50] advocates brought a class action lawsuit to prevent the elimination of Adult Day Health Care, which at the time served 35,000 Medi-Cal eligible adults with disabilities in 300 ADHC community centers. The case was successfully settled in 2012 when the state agreed to continue providing community center care for low-income PWD. Similarly in a long-running battle over California's "In Home Supportive Services" (IHSS) program which provides approximately 130,000 low-income Californians with chore and personal assistance services, advocates fought first a 2009 proposed reduction in IHSS services based on a recipient's Functional Index Ranking, and then a massive 20% permanent reduction in IHSS hours for recipients. The federal judge in *Oster et al. v. Lightbourne*[51] found in 2009 that the state's Functional Index rankings were clearly not based on need, and stated that "people could lose something irreplaceable – the ability to remain safely in their homes." *Oster* was recently settled, with the 20% block cut replaced by a series of incremental small cuts that could be restored as early as 2015. IHSS consumers will also be able to request a reassessment upon a change in circumstances, including non-medical circumstances.

States are unambiguously precluded from such practices under the regulations implementing Title II of the Americans with Disabilities Act. 28 CFR 35.130(b)(8) whereby a public entity shall not impose or apply eligibility criteria that screen out or tend to screen out an individual with a disability, or any class of individuals with disabilities, from fully and equally enjoying any service, program, or activity, unless such criteria can be shown to be necessary for the provision of the service, program, or activity being offered. Despite the clarity of this mandate, states have nevertheless engaged in precisely that kind of manipulation of eligibility criteria for reasons unrelated to Medicaid objectives and standards. We therefore recommend that any regulation implementing Section 1557 include a categorical prohibition of such practices and a mandate that eligibility determinations reflect standards clearly enunciated in the regulation that are based on medical and functional need and certainly not on state budgetary constraints.

Our final example of a Section 1557 health care program or activity is the health care and health services research that the ACA authorizes, mandates, and funds. These research activities must be included amongst the critical programs and activities that are considered health programs or activities under Section 1557, especially when much of this research in intended, implicitly or explicitly, to help establish standards for evidence-based treatment and prescription standards. The development of clinical research that does not involve PWD will lead to treatment standards that will ignore the needs of

[49] Letter from Verlon Johnson, Associate Regional Administrator, Division of Medicaid and Children's Health Operations, to Theresa Eagleson, Medicaid Director, Division of Medical Programs, Illinois Department of Healthcare and Family Services, October 26, 2012.
[50] *Darling et al. v. Douglas et al.*, C09-03798 SBA.
[51] No. C 09-04668 CW.

PWD.[52] As federally conducted or federally funded health programs or activities, *all* government supported research activity must encourage addressing disability-related issues and health disparities research in funded studies. Similarly all government support research activity, whether initiated under the ACA or not, must require including PWD within the study populations in the same way that members of other medically vulnerable or underserved groups, such as women or racial minorities, are required for inclusion. Research proposals that explicitly, or by design, fail to address the recruitment of PWD must explain the rationale or medical value of such an exclusion.[53] Scholarships, grants, and tuition waivers/reimbursement incentives must be provided to researchers and scholars who pursue disability-related research topics in the same way, for example, that the National Institutes of Health provide such incentives to minority researchers. In the current landscape, researchers with disabilities that seek to perform disability-related health research face an unequal playing field when they pursue funding opportunities.

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.

See Question 1 for examples and impacts of discrimination on individual PWD and their families. These impacts include increased pain and expense, humiliation, delayed or missed diagnoses, a general reluctance on the part of many PWD to use the healthcare system and services except in an emergency, and a failure to be engaged in preventive health. These impacts exacerbate individual and household financial and health costs, and systemic costs and inefficiencies. The institutional bias and unrealized Olmstead rights in LTSS leads to PWD, as well as many family members, being unable to partake more fully in the jobs economy and taxpayer base. Some of these consequences are

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[52] *See* Zulman D.M. *et al*. (2011) Examining the Evidence: A Systematic Review of the Inclusion and Analysis of Older Adults in Randomized Controlled Trials, *Journal of General Internal Medicine*, 26(7), 783-790; Chronic Disease Prevention and Control Research Center at Baylor College of Medicine. Major Deficiencies in the Design and Funding of Clinical Trials: A Report to the Nation Improving on How Human Studies Are Conducted (April 2008).

[53] *Developing Quality of Care Measures for People with Disabilities: Summary of Expert Meeting*. AHRQ Publication No. 10-0103, September 2010. Rockville, MD: Agency for Healthcare Research and Quality, *available online* at: http://www.ahrq.gov/populations/devqmdis/ ("In recent years, the National Institutes of Health (NIH) and AHRQ have required investigators submitting grant applications to explicitly address the inclusion of persons by sex and race and ethnicity. Both NIH and AHRQ grant applicants must justify the exclusion of people by sex, race, and ethnicity. NIH applicants must also address the inclusion of children and justify their exclusion. Beyond women and racial and ethnic minorities, AHRQ requires grant applicants to consider including the following "priority populations": inner-city residents; rural residents; low income persons; children; elderly people; and those with special health care needs, including individuals with disabilities and those who need chronic care or end-of-life health care.")

illustrated in the chart below.[54] The chart in our response to Question 4 also illustrates a number of these consequences.

Location	Disability	First-person account of communication discrimination in healthcare
Hospital	Cerebral Palsy/Wheelchair User	*When I go to my doctor's offices I can't get a full physical examination because I can't get on the table. So there might be stuff wrong with me that my doctor can't see or can't examine me because there's barriers in the way.*
Diagnostic facility	Polio Quadriplegic/Wheelchair User	*When I lay down, because of breathing difficulties I use a ventilator. And after, I guess, even a few more weeks, she [the nurse] said, well, I did find a place where we can schedule your MRI. But when I went there, we found out that there was no way that physically they could get me -- as a wheelchair user and a vent user -- onto the exam, you know, table that they use for the MRI. And they didn't have a Hoyer lift or any kind of other ways of giving me access to that equipment. So, after going down there, we were essentially -- said, sorry, we can't help you, go back home. So, finally, we did get a call from the nurse that she had found an accessible facility. This took about nine months in total. And when the scan was done -- the MRI was done -- they found that what had originally been a much smaller growth that they detected had become almost double the size, during the course of the time it took to scan -- to set up the imaging.*
Doctors office	Osteogenesis Imperfecta/Wheelchair User	*My doctor's office, unfortunately, is not that wheelchair accessible. The exam tables, forget it. So either the doctor or the nurse or both, they end up picking me up and putting me on the table. ..if they don't do it right or listen to me so I can tell them how to do it, I will end up breaking a bone. A matter of fact, there have been times when I have broken a bone because they didn't pick me up the right way and put me down the right way. So I have broken a leg a couple of times when I've been picked up by a nurse. I have broken my arm I'd say*

[54] These examples are primarily drawn from transcripts of *Healthcare Stories*, a video advocacy tool that captures the healthcare experiences of individuals with various disabilities, relayed in their own words. Available online at: http://dredf.org/healthcare-stories/. Examples of discrimination experienced by PWD in the Boston, Massachusetts area have been collected by Greater Boston Legal Services.

		maybe twice by having the nurse pick me up and put me in my wheelchair. If they got the right equipment, like a table that goes up and down, I wouldn't have to worry about getting a broken bone because I would be able to transfer myself.
Hospital	Anxiety/Depression	*I had a tumor that was found when I was in college. Over time I felt it growing on my head. I was seeing a resident at a health care facility and the resident knew I had anxiety and depression problems. When I approached him and said I'm convinced this tumor is growing, I can feel it on my head -- it's getting larger; he didn't take me very seriously. He started to say, 'Well, don't you really think this is your anxiety Louise? Perhaps it's really your attitude; perhaps it's really, you know, your own mind and it's really in your own head that it's growing but it's not growing at all.' And he didn't end up pursuing it. We didn't end up getting any tests done; we didn't do any follow up. A year later, I blacked out, which I thought was extremely fortunate because at the same medical facility I was seen by the Emergency Department and then they pursued getting old records on the tumor and found out that the tumor was alive and well and growing. I'm showing how if you say that you have an anxiety issue or a depression issue, a lot of medical practitioners will respond to your medical complaints with the idea .. that you are a little hysterical; the worries are out of control and they won't necessarily send you for the medical test and take you seriously. So I find that very concerning. I would've eventually started having epileptic seizures and the tumor would've moved on into my brain. I just got lucky and I blacked out, and we caught it.*
Doctor's office	Polio Quadriplegic/Wheelchair User	*I have to always guess at my weight. I've not been weighed, let's say, for 20 years. So I've--I've not been weighed and they--they don't--they don't--there's not even any attempt to weigh me. There is something they just gloss over, just you know, don't even mention so, because there is no way to weigh me there at my offi--at my doctor's office.* *I went five years without a Pap smear because I could no longer get up on the table. You know, I was the brave crip, the strong crip, and would climb up on tables. It came to a point where I could*

		not do that anymore. I just--I, you know, I just couldn't do it. And so I went five years without a Pap smear and again, my doctor just didn't ask about it and I didn't bring it up. So I told my doctor, I need a Pap smear. She said, 'Oh, you know, you do need a Pap smear.' And then--and then she said--I said, 'I need--I need one with a table that's lower so I can--I can scoot over there.' She said, 'That's a great idea. Find one.'
Hospital	Cerebral Palsy/Wheelchair User	*…when the doctors told me they wanted me to go to a nursing home I felt like my life as I knew it was over. Nobody was listening to me. I didn't know if I was ever going to be able to be the independent person that basically, that I am. But I knew I didn't want to go to the nursing home. I wanted to go back to my apartment. But like I said the surgeon wasn't listening to me, and it took my nurse practitioner to really fight for me...she's an advocate for people with disabilities.[She said] You're going to take her life away if you put her in the nursing home.*
Diagnostic facility	Wheelchair User	*Recently, I went for a bone density scan. However, when I showed up for the appointment, the technician asked if I could get up and onto the table. When I said no, he said that he had to cancel the appointment because he did not realize that I was not ambulatory. The table did not lower, and I think he did not want to go through the trouble of trying to find a lift.*
Hospital	Neuromuscular Disability/Wheelchair and Ventilator User	*When I cannot have my PCA [personal-care assistant] with me, I experience anxiety and terror due to the staff's ignorance about how to care for me properly. Some nurses understand that and tell me it's okay to have my PCA or my wife do the suctioning or provide other assistance. But they also say not to let anyone know. This puts us in the position of having to hide what we are doing, which only increases my anxiety level. As I said earlier, I was very lucky that my PCA was there to use the Ambu bag to keep me breathing when the ventilator stopped, because the nurse did not think to do it.*
Diagnostic facility	Wheelchair User	*However, the last time I went for my MRI, the technicians refused to lift me because, they said, of the liability. I had to wait for about half an hour until two middle-aged overweight men—security guards, I think—lifted me onto the gurney. The*

		worst of it is that they did not know what they were doing. One of the security guards looked horrified that he had to enter an exam room to lift a woman in a johnnie.

Additional impacts result from disability not being included in the funding of larger scientific studies on the effectiveness of public health education programs or a project is not funded because the principle investigator is a person with a disability. Similarly, many studies on specific medical research exclude people with any form of disability as participants or when research is done on general health topics such as sex or aging or the impact of certain treatments. PWD may in fact take part in a study, but since identifying demographic questions are not asked, the data cannot be analyzed with an understanding of disability as a treatment or health factor. The failure to include or even identify PWD when providers and health care delivery systems are increasingly held to "evidence-based medicine" standards means that individuals with disabilities face procedural delays and barriers because there are few scientifically validated or administratively "pre-authorized" treatments for PWD. More broadly, PWD simply disappear from the national health agenda. There is a dearth of scientifically validated information about how people with various disabilities respond to common, leading, or cutting edge treatments, whether they are medical, mental or behavioral health, or preventive programs for smoking cessation or weight loss. The costs of this will become increasingly clear as the American population ages and the prevalence of different types of disabilities increases. The latter fact will also come to cost the public health care system dearly as the dearth of provider training in disability competence and general lack of accessibility comes to directly affect more and more members of the public.

Ensuring Access to Health Programs and Activities

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

(a) What are examples of recommended 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?

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.[55] Our answer below focuses not on individuals with LEP, but on 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.

Our response does not hew strictly to the structure of Question 4 since some of its sub-parts are specific to LEP non-discrimination laws. We do not, for example, address the "threshold" questions as PWD have a right to effective communication regardless of how many individuals in a given area have the same diagnosis or functional limitation. First, we provide some examples in the chart below[56] of traumatic healthcare experiences undergone by individuals who have disabilities that affect communication in spoken or written English (subsection (c)). Then there are a few examples of

[55] We have read the comments of the Leadership Conference on Civil Rights (LCCR) on Question 4 of the Section 1557 RFI, and support LCCR's recommendations for populations with LEP, which we know also include PWD.

[56] These examples are primarily drawn from two sources. The first is a document that summarizes the findings from 10 focus groups that were conducted by Access Living in Chicago and an academic researcher in 2012 to discover the barriers faced by PWD when seeking healthcare. Available online at: http://www.accessliving.org/index.php?tray=content&tid=118gatop15&cid=118ga419 The second source is excerpts of transcripts from *Healthcare Stories*, a video advocacy tool that captures the healthcare experiences of individuals with various disabilities, relayed in their own words. Available online at: http://dredf.org/healthcare-stories/.

documented best practices for ASL interpretation and translation in the healthcare context (subsection (a)). Finally we provide some thoughts on priority healthcare documents that must be translated (subsection (f)) for PWD.

Location	Disability	First-person account of communication discrimination in healthcare
Hospital	Deaf	*I had a heart attack. I was in the clinic when it happened. I had requested an interpreter, but they had not provided one . . . There was no interpreter that showed up there and that's where I had the heart attack, so I went straight to the emergency room from there. My father brought me to the emergency room, but they didn't know that I was deaf. I ended up having open-heart surgery, but they didn't know I was deaf. I was in the hospital all week and I didn't have an interpreter. At the end of the week an interpreter finally showed up, the last day.*
Hospital	Deaf	*I went to the doctor with stomach pains and I had to wait for an interpreter to show up to the emergency room and I couldn't communicate with the doctor or nurses. You'd think they would have just had an interpreter there or gotten one as soon as possible, but I was in agonizing pain. I couldn't think through the pain to be able to write back and forth. The waiting got to the point where I was vomiting. It was impossible to even write to communicate back and forth. I'd see people coming and going and looking at me like, what are we going to do with this guy, but I'm just waiting for an interpreter. I'm just waiting for access to the system. They're trying to ask me about my pain and I can't answer them because I have no idea what they're actually saying. It's usually hours before I even am able to have a conversation with the doctor or the nurse, to be able to tell them what is wrong.*
Hospital	Deaf	*I had gotten up at 5:00 in the morning to go to the hospital. I was supposed to have surgery. The interpreter arrived and when I went into surgery the interpreter left and they were replaced by another interpreter. My surgery kept getting pushed back and pushed back. I told everyone at the hospital they needed to provide me another interpreter, because the second interpreter had to*

		go soon, and they looked at me and assumed that I spoke Spanish, that I needed a Spanish-speaking interpreter instead of a sign language interpreter. I didn't understand this confusion. I'm deaf; I'm not hearing. Why would I need a Spanish-speaking interpreter? Finally, 12 hours later, at like 5:00 in the evening, they found a replacement interpreter, but the surgery had gotten pushed back 12 hours. In that time they still couldn't figure out if I needed a Spanish interpreter or a sign language interpreter. The fact that they couldn't figure out to provide me an ASL interpreter instead of a Spanish interpreter, that's what caused the delay. That's what pushed my surgery back 12 hours. After the surgery was completed, they still brought in a notepad and pen to communicate with me in a written form of communication, not with an interpreter Please note: This is also an example of discrimination on the dual basis of race and ethnicity, since stereotypes presumably based on race/ethnic appearance interfered with the hospital's capacity to meet disability-related language needs.
Dentist and optometrist	Deaf	*At the dentist's office it seems to be a problem. They don't have interpreters. We are required to write back and forth and I don't write English, the written language very well. I'm Arabic, so that's my language, my first language, so it's kind of hard for the communication at the dentist's office. I do my best at the front desk with the secretary and then I'll go in to see the dentist and kind of just gesture and show him what's giving me pain, but they do not have interpreters there.* *I need to go to an optometrist to have an eye test performed, but I don't have an interpreter. I've been asking them. I've been trying to write back and forth, but it seems their habit is to just write back and forth when they have deaf customers.* Please note: This example also illustrates the needs of both individuals who are Deaf or hard-of-hearing (HOH) but literate in a non-English language, as well as the similar situation of individuals who are Deaf and *not* literate (in any

		language). They both encounter the common assumption that hastily written English notes are an adequate compensation for the failure to provide qualified on-site interpreters/translators.
Doctor's office	Deaf	*I had another primary doctor; it was my mother's family practitioner. With that doctor, we really struggled to communicate. I would always have to go with my mother to facilitate communication. Sometimes my mother couldn't go with me, so I was stuck by myself, having a difficult time trying to communicate with the doctor. Writing back and forth didn't really work for me.*
Doctor's office	Deaf	*We'd show up for our appointments again and again, or we'd postpone them again and again, to try and call for an interpreter and there would still be no interpreter provided. I had a very serious problem, a urinary problem. That's a sensitive issue and I had to sit there and wait for hours to get somebody to come. I was in pain the whole time.*
Doctor's office	Deaf	*I tried to get an interpreter for an appointment. My sister came to help me and we were struggling to communicate. She was confused, the doctor was confused and communication was flying all over the place, but nothing was making sense. Once in a while we could pick out words and concepts from each other, but I eventually was frustrated. Then we realized that there were mistakes being made and miscommunications happening. I was going in because there was fluid buildup in my ear. When I tried to meet with the doctor, the doctor got angry with me and was screaming at me. They thought I was mentally ill. They thought that I had a developmental disability, that I had vision issues, and the problem was in my ear. When they finally got me on the examination table and started giving me the exam, I had to again struggle to get their attention, to get them to listen to me. I was so frustrated and angry the whole time. We tried written forms of communication. I was in so much pain I thought I was going to die. I didn't know if they were proposing surgery. There was so much going on and I couldn't make sense of it. That experience, for me, was absolutely terrible. I never want to do that again. I felt like I was shunned because I was deaf.*
Hospital	Deaf	*I've had an experience where I've arrived at a*

		hospital and they've provided an interpreter via VRI [video remote interpreter] and I kept getting distracted. I had the interpreter on the screen there and often the doctors would not look at me; they'd look at the screen. I feel like even where they position the screen in the room, depending on the appointment I'm having, to be able to see the screen is difficult. Also, the way I was positioned on the table did not allow me to see the screen, so I wasn't able to utilize the video relay for remote interpreting because I couldn't see the screen and they couldn't position it in a way that would allow me to. Please note: This example illustrates how easily people who are Deaf/HOH will be cut out of the benefits of telemedicine, telehealth, and any kind of remote health service unless there are clear standards concerning how systems are set up, and training for providers who must use the systems.[57]
Doctor's office	Blind	*The major problem I have when I go to an office is the privacy issue. They give me a stack of papers and say okay, take this home and have someone help you with it. I say I don't have anyone to help me with this, so then they'll say okay, we'll have someone help you with this, so I'm sitting in the waiting room with twenty other people, and they're asking me questions like have you ever had venereal disease. There are like twenty other people, there's like no confidentiality, and I say no, I don't want to answer these questions.*
Hospital	Blind	*I was visiting my grandmother in the hospital when she had pneumonia. I go up there and I say can you direct me to the room of Mrs._____, I'm her grandson. So they sent a security guard with a wheelchair. I said, Sir, with all due respect, I can just take your arm, thank you.*
Doctor's office	Blind	*Since 2004, I've only been weighed twice, one time in the last year, and then one time before that. It's like I don't know if they're scared I'm going to trip over it or what. I tell them I can see pretty good to*

[57] The National Association of the Deaf (NAD) has *Position Statement: VRI Services in Hospitals*, available at: http://www.nad.org/issues/technology/vri/position-statement-hospitals, that provides an excellent list of Minimum Requirements for VRI Technology and Equipment. NAD also makes it clear that "on-site interpreter services are not subject to many of the limitations experienced by VRI services. NAD strongly believes that VRI services should be provided only if on-site interpreter services are unavailable."

		get on it.
Doctor's office	Cerebral Palsy/Wheelchair User	*My experience with a lot of people in the medical profession is I freak them out as soon as I roll in the door because here I am a grown woman with cerebral palsy with a speech impairment and they seem to look at me and think, "Oh, why isn't this woman in an institution?" You know, or "Why is nobody with her?" I used to go alone to my appointments but now that I'm older and I don't have the energy, um, to deal with all their misperceptions*
Doctor's office	Cerebral Palsy/Wheelchair User (speech impairment)	*Here's the letter that accompanied the lab results that went to my doctor from the specialist of endocrinology and metabolism. Okay.* *"We saw this unfortunate 57 year old woman in our office. My impression is she is far more intelligent than she looks."*
Hospital	Cerebral Palsy/Wheelchair User (speech impairment)	*I needed to go to x-ray and stuff and have other tests done but in the midst of being transferred from the bed to the gurney -- it was a two person lift but nobody would listen to me about how you have to hold on to my legs because my legs are very sensitive and if you pull on them a certain way without talking to me and letting me tell you you can really do some damage some bodily harm. So that being said they came in just pulled back the covers and started lifting and I was like no way you can't grab me like that. …and when they went up to lift me you heard this loud pop in my knee. It's like my knee went one way and the rest of my body spread over onto the gurney and they were just, they kept trying to pull the rest of me onto the gurney and I was in such excruciating pain that again I'm not a cryer usually but all I could do was cry. I felt so like I was being treated less than a human being.*
Hospital	Developmental Disabilities/Seizure Disorder	*Charlie is mismedicated three times, not on any other drugs but on his own medications. As the -- as the nursing staff is about to give Charlie his drugs, my staff looks and says, "Wait a minute, that's not right." the staff was wholly unprepared to deal with a severely disabled young man. They were not used to having a young man with seizures. They were not used to having someone who could not himself articulate what his issues were. …they allowed themselves to do something that was absolutely*

		unprofessional and unethical -- to mismedicate a patient more than once. Fortunately, if my staff had not been there, you cannot imagine what would have happened if Charlie had not gotten enough of or too much of the multitude of anti-convulsant drugs and behavior meds that he was on. I immediately pulled him from that hospital.

One of the best practices that we have encountered 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 Minneapolis, Minnesota.[58] 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 if 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 which may not commonly recognize or implement their own obligations to provide effective communication. The MCO's engagement with such a model necessarily includes telling its network providers that they cannot simply turn 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.[59] 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

[58] The National Council on Disability, (2009) at 288, available online at: http://www.ncd.gov/publications/2009/Sept302009.
[59] The National Council on Disability, (2009) at 287, available online at: http://www.ncd.gov/publications/2009/Sept302009.

has also developed a library of ASL pamphlets, featuring Deaf actors who present signed narration, vignettes, and graphics, that are 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 heath 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.[60] VLRC offers participants an audio transcript, and information handouts on such adaptive equipment as accessible non-visual tools for glucose monitoring, weight management, healthy food preparation, and exercise equipment. 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 adaptive 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 to 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 procedures are needed and the risks and benefits of undergoing 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 have limited mental capacity to independently understand healthcare 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

[60] The National Council on Disability, (2009) at 286, available online at: http://www.ncd.gov/publications/2009/Sept302009.

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.

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?

We address the question of the unique issues, burdens, and barriers encountered by women with disabilities in seeking quality health care.

"Disability and gender are predictive of lack of access to health care."[61]

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.[62]

- 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.[63]

- Women with disabilities, particularly older women and those with multiple disabilities, are less likely to receive a physician recommendation for screening mammography.[64]

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[61] 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.

[62] 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.

[63] 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.).

[64] 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.

- 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.[65]

- 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 are 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.[66] A study of African-American women with intellectual disabilities showed striking disparities in receipt of mammography screenings.[67]
- 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.[68]
- 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.[69] 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

[65] 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.
[66] 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.
[67] 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.
[68] 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.
[69] 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.

underlying disabling conditions or make unwarranted assumptions about quality of life to the exclusion of preventive health measures.[70]

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.[71] And late or no cancer screenings result in diagnosis at later stages and higher mortality rates compared to women without disabilities.[72]

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 and sell products through the state Marketplaces not be considered qualified unless they can demonstrate that such access can be provided.

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.

Benefits and Barriers for PWD

The benefits of electronic healthcare and information technology (HIT) for PWD are the same as those expected for the general public. That is, uniform HIT will greatly improve the capacity of care coordination across multiple providers and services, while also preserving the core principles of patient direction and patient centeredness that are vital to the independent living movement and disability communities. HIT is a key factor in improving the quality of care provided and in particular, tracking quality measures, some

[70] 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.
[71] 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.
[72] 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.

of which are crucial to the health of PWD and necessary to track health disparities. It can give consumers a window into their own health and treatment, and enable patients to interact with providers more efficiently, provide feedback on care, and correct their own records. HIT also offers the potential for gathering granular information about functional limitations, mandating health record inclusion of a patient's accommodation needs, requiring a real-time recording of when/how accommodations were provided, and the potential for further analysis about the effectiveness of particular treatments as they interact with specific functional limitations and chronic conditions. Finally, HIT offers providers with disabilities the opportunity to participate as independently as possible within a care team since other provider and treatment notes will be entered and maintained electronically. Clearly all these opportunities are lost if HIT is inaccessible or only partially accessible to people with various disabilities who use screen readers and other software programs and hardware to access electronic documents.

HIT offers PWD a unique and, given the pace of technological development, ephemeral opportunity to have the same access to health information and input that is available to every other health care consumer. For example, Health Affairs recently devoted an entire issue to "The New Era of Patient Engagement."[73] Many authors, including the HHS Assistant Secretary for Health quoted Leonard Kish's profound statement: "Patient engagement is the blockbuster drug of the 21st century."[74] In other words, patient engagement is patient-centered care on steroids. Patient engagement has been shown to improve health outcomes, lower costs, lead to fewer hospital readmissions, and improve patient care.[75] Engaged patients are more likely to seek preventative care, and engage in healthy behaviors such as eating healthy and regular exercise.[76] Engaged patients with chronic conditions are more likely to adhere to treatment regimens.[77] Patient engagement relies on, among other things, patients and providers sharing information. The evidence-based OpenNotes program[78] found that merely by having shared access to office visit notes, patients reported feeling more in control of their care, better understanding of their health and conditions, improved recall of their care plans, and a greater likelihood of taking their medications as prescribed.[79] As OpenNotes use spreads to healthcare facilities nationwide and becomes the standard of care among elite hospitals and providers, PWD must be able to benefit from having access to the outcomes of their individual office visits in the same manner as people without disabilities. PWD must have equal access to HIT so they can benefit, as equally as people without disabilities, from becoming and being engaged patients.

Another example is found in the Blue Button program, a government–endorsed major step forward to promote patient engagement through the use of HIT, but there is little or no information on whether the program is available, accessible, and useable, by people

[73] Health Affairs 32:2 (2013).
[74] See, e.g. Koh, H., Brach, C., Harris, L.M., & Parchman, M.L., (2013) "A proposed 'health literate care model' would constitute a systems approach to improving patient' engagement in care." 32:2 357-367.
[75] James, J. (2013, February 14). Health Policy Brief: Patient Engagement," Health Affairs, http://www.healthaffairs.org/healthpolicybriefs/brief.php?brief_id=86.
[76] Id.
[77] Id.
[78] See Unknown, (2013) OpenNotes. http://www.myopennotes.org/, a program funded by the Robert Woods Johnson Foundation.
[79] Unknown, (2013) OpenNotes. http://www.myopennotes.org.

with various functional impairments. When the Office of Consumer eHealth announces a program where a "literal button" will appear "on many websites that lets consumers get their health information online,"[80] the disability community and advocates are left to wonder whether all PWD will have access to the program's benefits. For example, is the visual button visible to, and functional for, blind and low-vision individuals who use screen-reading software? Can the button be "pushed" by individuals with mobility impairments who use both software programs and specific hardware to interact with their computer? Will any instructional or illustrative videos accompanying the device be close-captioned for those who are Deaf or hearing impaired? How much time are individuals given to interface with the program, and is there any online security function, such as a CAPTCHA, that requires consumers to have functional above-average vision and/or hearing? PWD must have equal access to these programs or the discriminatory barriers that they already face in the current landscape of health care will be compounded in future.

There is also a growing movement towards shared decision-making between patient and providers. Many shared decision-making tools are being developed for online use and as phone applications (apps). Apps are also being created to perform such common health care functions as keeping track of blood pressure, reminding people to take their medications on time, tracking fitness routines and sleep patterns, and so forth. Information will be provided to consumers through electronic means. In 2012, the Office of the National Coordinator for Health Information Technology announced a new "Investing in Innovations Mobile App Challenge"[81] that sought new ideas for helping PWD interact with their health records. The winner would "receive $60,000 and an opportunity to demo the solution at a future, prominent conference!"[82] We acknowledge that this kind of encouragement of public and private innovation can spark new ideas, but it also falls tremendously short of the kind of systemic standard-setting and monitoring needed to ensure that federal and state governments are not spending billions of dollars to build a discriminatory HIT system that will be practically inaccessible to PWD for years to come. Some providers already expect health care consumers to go to their office websites before an in-person visit and download or fill out online forms. Such an arrangement can actually meet the accessibility needs of some PWD who use computers, but only if the website is fully accessible, and only if the required forms can be filled out and returned online. For PWD who do not have computer access, there must be a feasible alternative that allows the individual to independently fill out forms and managed their health affairs to the greatest extent desired and appropriate.

Specific Standards, Associated Burdens, and Implementation Timeline

Any HIT records or plans must be displayed to individual consumers and medical professionals in non-medical or plain-meaning 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

[80] See, http://www.healthit.gov/buzz-blog/electronic-health-and-medical-records/blue-button-movement-kicking-national-health-week-consumer-engagement/.
[81] *See* http://www.healthit.gov/buzz-blog/health-innovation/access-to-health-records/.
[82] *Id*.

enter information on the record. Health apps must build in screen reading capacity and other technology to make them accessible. Required HIT information must include optional granular requests for 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) needed for effective healthcare. This latter requirement would save patients literally hundreds of hours of repeatedly requesting the same accommodations for every single appointment, even at the same office from the same provider.

HIT Meaningful Use Standards (MUS) must incorporate a requirement to meet existing standards of accessibility. The MUS already require significant changes in the way health care providers do business in terms of HIT. It should be straightforward to adopt electronic accessibility standards into meaningful use standards. There are several standards available or forthcoming that should be incorporated into MUS to ensure HIT access for PWD. Section 508 of the Rehabilitation Act of 1973[83] and its forthcoming 508 regulations apply to all technology purchased and used in federally conducted programs and activities including those using, managing or directing HIT. The World Wide Web Consortium (W3C)[84] and the Web Content Accessibility Guidelines (WCAG 2.0)[85] establish standards relating to accessibility for websites and electronic communication. WCAG 2.0 are voluntary standards, but the critical importance of HIT accessibility and usability justifies HHS OCR's adoption of WCAG 2.0 as a non-discrimination mandate for federally funded HIT systems. There are also relevant state regulations, such as California's incorporation of Section 508 for state entities through the following:

In order to improve accessibility of existing technology, and therefore increase the successful employment of individuals with disabilities, particularly blind and visually impaired and deaf and hard-of-hearing persons, state governmental entities, in developing, procuring, maintaining, or using electronic or information technology, either indirectly or through the use of state funds by other entities, shall comply with the accessibility requirements of Section 508 of the Rehabilitation Act of 1973, as amended (29 U.S.C. Sec. 794d), and regulations implementing that act . . ."[86]

The burden on covered entities is analogous to physical construction. It is much less expensive to make sure a building is accessible in the first place, than to raze it or retrofit it once an inaccessible building is erected. Costs are minimal if accessibility is built into HIT from the origin of those electronic applications, or if the new ACA mandate for electronic systems compatibility across healthcare entities and organizations already demands the substantial re-engineering of existing systems. The incorporation of accessibility and usability requirements within the final meaningful use standards makes sense and can lower costs over the mid- and long term. Expenses become greater and accessibility requirements more time-consuming as developed systems must be "retrofitted" for accessibility. There is the additional cost to PWD and the healthcare system of PWD being unable to reap the benefits of HIT the longer it remains

[83] 29 U.S.C. § 794(d).
[84] *See* http://www.w3.org/.
[85] Available online at: http://www.w3.org/TR/WCAG20/.
[86] Cal Gov Code § 11135(d)(2).

inaccessible. There is tremendous ferment right now in HIT prompted by different ACA provisions: the HIT mandate, the requirement for state exchange marketplaces to have a "single, streamlined application" in common with Medicaid, and many states which choose to deliver Medicaid services through managed care organizations thereby requiring state and MCO data systems to "speak" with one another. HIT systems in private and public entities are undergoing substantial changes *right now*. HIT accessibility for people with various disabilities must be understood and addressed as a fundamental requirement *right now*.

The latter point speaks against a "phased-in" implementation schedule. Any newly developed HIT since the passage of the ACA should already be accessible given the clarity of Section 508 and Section 1557, even if the latter has lacked specific regulations concerning HIT until this point. If inaccessible HIT has been developed in this period, it has occurred with a kind of "deliberate indifference" towards relevant accessibility laws and the requirements of web access standards laws and should not be rewarded with any kind of "phased-in" implementation. The physical inaccessibility of pharmacy or provider kiosks is also something that should be immediately obvious to any ADA Title III or II entity. Unlike some of the rationales for inaccessibility that have historically been given by ADA Title III entities such as commercial retail and service establishments – "we don't see any customers with disabilities so why do we have to be accessible" – it is very difficult for healthcare entities to claim that they do not think PWD will ever cross their door or website threshold so accessibility should not be required.

The ACA's purpose is to provide coverage, lower costs, and improve the quality of care for everyone. To do this, PWD must be included from the ground up. If accessibility is not a priority in a brand new and still developing HIT system, experience tells us that the inaccessible results will haunt PWD, and be problematic for systemic efficiency, for years to come. Despite this, in our collective experience no government agency, large or small healthcare provider, or technological entity has ever stepped forward and volunteered to follow best practices with regard to HIT accessibility. In California, the *Covered California* exchange entity claims that it has the capacity to provide applications, correspondence, and notices in alternative formats, yet consistently over the months leading up to the development of both its online and paper applications, has refused to include a question that would ask applicants beforehand what alternative format they need for effective communication (examples could include Braille, large font, electronic disc, ASL DVD, and so forth).[87] The exchange application rightly asks applicants for their preferred written language, and their preferred spoken language, but said they would not include the effective communication question because "they did not have the [technical] functionality to include this question." OCR"s clear inclusion of HIT requirements under Section 1557 must ensure that accessibility needs establish the agenda for technology, and not the other way around.

<u>HIT, Data Collection, and Disability Health Disparities</u>

[87] Series of stakeholder meetings and negotiations between Covered California representatives, DREDF, and other state consumer advocates occurring throughout 2013.

The costs of excluding PWD from access to HIT will have a profound effect on their health, increasing both the health disparities faced by PWD and overall health care costs. According to Healthy People 2020, "[i]f a health outcome is seen in a greater or lesser extent between populations, there is disparity." [88] Healthy People 2020 and the ACA acknowledge that PWD are a population that faces heath disparities. Data Collection is one of the ACA provisions designed to support efforts to decrease health disparities. The data collection provisions of ACA are symbiotically tied to HIT. HIT is a powerful tool to collect data that will be used to measure health disparities. If HIT does not include access for PWD, health disparities experienced by PWD, both from common factors that impact PWD and other minority sub-populations as well as from barriers that are unique to disability, cannot be adequately documented. Without evidence of disability disparities, quality measures cannot be tailored to ensure that providers and healthcare delivery systems work over time to eliminate discrimination and barriers to care. HIT must first identify PWD, and then qualitatively and quantitatively recognize healthcare disparities affecting this population as effectively as HIT identifies disparities involving racial, ethnic, gender, or other minority characteristics. This is also the only way to begin to address how people with dual or intersecting personal characteristics can experience multiple levels of disparities. PWD and disability advocates, providers, and researchers should have appropriate access to this granular information, while also protecting the individual's right to privacy of healthcare and personally identifying information.

The recruitment and development of healthcare providers from within a population that is subject to health disparities is one key strategy for reducing health disparities. Such providers bring an inherent understanding of healthcare barriers that enables them to empathize effectively with minority patients, and can advocate for greater cultural competence among their peers. However, if the underlying HIT that supports the U.S. healthcare system is inaccessible to providers with disabilities, this key recruitment key strategy is rendered meaningless to the disability community. For example, a mental health professional with vision impairments has encountered numerous limitations at work because the large clinic where she works within an integrated care team model uses a HIT record system that is 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 was not free to linger over certain notes and look up related questions when reviewing patient notes before an appointment).[89] These unnecessary constraints are senseless in an era of technology. From the provider's perspective, HIT has replaced an old system of difficult-to-communicate, hand-scribbled pages with an electronic data system that remains equally inaccessible. HHS OCR's development and enforcement of accessibility standards under Section 1557 for HIT benefits consumers and employees with disabilities. Clear standards will also provide HIT manufacturers and innovators with systemic motivation to develop HIT systems that will enable health care providers, hospitals, clinics, and

[88] U.S. Department of Health and Social Services, (2010) Healthy People 2020, available at: http://www.healthypeople.gov/2020/about/disparitiesAbout.aspx.
[89] Personal communication with Silvia Yee, senior staff attorney at DREDF (March 4, 2013).

MCOs to come into compliance and offer accessible HIT to consumers and providers with disabilities.

Compliance and Enforcement Approaches

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

   (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?

Compliance Procedures

In practice and theory, the compliance procedures under federal civil rights laws are primarily complaint driven. Individuals can file an administrative complaint with HHS-OCR as the federal agency designated under the Americans with Disabilities Act (ADA) to investigate complaints of discrimination on the basis of disability by state and local government health and social service agencies. HHS-OCR is also the agency that is responsible for enforcing disability non-discrimination with regard to programs, services and activities that receive federal financial assistance, and programs and activities conducted by HHS itself. Like all public interest civil rights laws, Section 504 includes certain structural incentives to encourage members of the public to act as "private attorneys-general": the private right of action to seek compensatory/punitive damages and injunctive relief is not subject to prior administrative exhaustion,[90] and fee-shifting

[90] *See* H.R. Rep. No. 101-485, at 98 (1990), *reprinted in* 1990 U.S.C.C.A.N. 267, 381 ("As with section 504, there is also a private right of action . . . which includes the full panoply of remedies. Again, consistent with section 504, it is not the Committee's intent that people with disabilities need to exhaust Federal administrative remedies before exercising their private right of action."

enables individuals who win their lawsuit to also recover their attorney fees for bringing the action.[91]

Nonetheless, these attempts to help individuals participate in the enforcement of disability non-discrimination laws in a healthcare context are not enough to overcome myriad factors that dissuade PWD from initiating a complaint or lawsuit. These disincentives include:[92]

- As current patients PWD are in an extremely vulnerable position of needing to maintain an ongoing relationship with a healthcare provider or providers, some of whom may be rare specialists.
- At the conclusion of a course of treatment or health event, a potential plaintiff may lack the standing to request injunctive relief against discriminatory providers or entities because the plaintiff is unlikely to ever require or seek further medical treatment from the specific defendants.
- PWD are frequently in the midst of a health crisis when discrimination occurs and, as our first-hand accounts from Questions 1 and 4 illustrate, are unable to assert their right to, or even request, a reasonable accommodation or policy modification.
- Many people with functional limitations and disabilities do not identify with the disability community and know virtually nothing about disability rights. After years of sub-standard examination facilities, equipment and practices, those who have chronic conditions may come to accept that inferior care is inevitable, unavoidable and their own fault for not being "normal." Those with newly-acquired disabilities, particularly those who are aging, can similarly assume responsibility for inaccessibility, blaming themselves for no longer being able to independently get on an examination table, hear or follow the provider's questions and instructions, or read the small print on a pill bottle.
- Anyone undergoing medical treatment will already be taxing their internal and financial resources, as well as their personal support networks. Private litigation is time consuming and demands personal attention and possible financial outlays, even if those are potentially recoverable at the conclusion of litigation years down the road.
- The sheer complexity of the American healthcare system makes it difficult for individual cases, and even class action lawsuits, to initiate sustainable systemic impact. Numerous and dissimilar providers discriminate at the level of direct consumer interaction. Providers in turn contract with physician groups, clinics and hospitals, managed care organizations, and state and federal governments through Medicaid and Medicare. HHS-OCR or a federal court may find a provider, large hospital, or even an entire managed care organization in violation of Section 504, but similar entities are not made aware of the findings or may not

[91] Robert V. Percival & Geoffrey P. Miller, *The Role of Attorney Fee Shifting in Public Interest Litigation*, 47 Law & Contemp. Probs. 233, 241 ("Congress generally authorizes fee shifting where private actions serve to effectuate important public policy objectives and where private plaintiffs cannot ordinarily be expected to bring such actions on their own. Fee shifting is designed to remove some of the disincentives facing public interest litigants . . .").
[92] Some of these disincentives are in Reis, Breslin, Iezzoni, & Kirschner, 2004.

recognize that there are broader implications beyond the particular disability or set of circumstances in question.

HHS-OCR and private lawsuits have a critical role to play in Section 504 enforcement as provider networks expand to include LTSS, newly created entities like the state and federal Marketplaces begin to operate, and qualified health plans that offer products through the marketplaces come into compliance with new state and federal regulations. Enforcement cannot, however, rely so heavily on "after the fact" individually-driven complaints or lawsuits. The problems illustrated in our prior answers show that there are too many players, a great lack of general knowledge, and too much of the public interest at stake.

Our recommendations for resolving these systemic problems and imbedding disability non-discrimination within healthcare programs and activities include:

- Involving the Health Resources and Services Administration (HRSA) in developing and mandating requirements on disability culture, meeting accessibility needs, and disability non-discrimination for professional provider education and ongoing training.
- Incorporating HHS-OCR at the front end of when the Centers for Medicare & Medicaid Services contracts with state healthcare agencies and MCOs, to ensure that contracts and applicable standards include disability non-discrimination policies, practices and procedures, as well as monitoring measures and appropriate consequences for the failure to comply with non-discrimination obligations,
- Incorporating surprise consumer visits to providers and other healthcare entities that receive federal financial assistance as a proactive integral component of ensuring accessibility, instead of an exclusive reliance on self-evaluation and complaint mechanisms.
- Ensuring that disability-specific accessibility quality measures for clinical care and member services also include measures designed to check how healthcare entities inform consumers about their right to non-discrimination and meet those rights.
- The separation of funding and technical assistance from state and federal disability rights enforcement is necessary, but at the same time there must be *some* parity of authority and resources between these separate elements.
- CMS as an agency must formally and structurally recognize the importance of accessibility requirements for the delivery of equally effective healthcare to the populations served by Medicare and Medicaid, and strengthen its relationship with HHS-OCR and the federal Department of Justice (DOJ). DOJ has a recognized *Olmstead* expertise that is very relevant to healthcare programs and activities, for example, when CMS authorizes structural changes in how LTSS is delivered or develops standards for what will constitute an integrated setting for HCBS funding.
- Working to integrate, elevate and prioritize accessibility requirements *within* existing regulatory standards such as hospital accreditation and managed care regulations, thereby leveraging additional monitoring and implementation bodies in the effort to achieve accessible and equally effective healthcare.

- Ensuring that Exchange Marketplaces and their consumers know of the existence of Section 504, ADA and ACA rights, as well as HHS-OCR's jurisdiction over disability discrimination in all aspects of the Exchange marketplaces, such as eligibility, enrollment, web accessibility, and discrimination by QHPs.

The following recommendations are specifically linked to *Olmstead* enforcement, and to the *Olmstead* information provided in our response to Question 3. While that section emphasized service delivery in Medicare and Medicaid, Section 1557's expansive reach to QHPs means that HHS-OCR's non-discrimination regulatory reach extends to many private insurers that choose to participate in the Exchange marketplaces.

- Make *Olmstead* training a detailed, mandatory requirement of new integrated service delivery programs, especially as LTSS contracting and delivery networks are widely extended and the network of federal financial assistance grows.
- Require MCOs to specifically determine the impact of a range of medically needed durable medical equipment (DME) options or other complex rehabilitation equipment purchases and repairs on a member's capacity to live as independently as possible in the community, and prohibit MCOs from authorizing less expensive options that have a substantial negative impact on a member's capacity to live in, work in, remain in, or return to the community.
- Require any MCO that proposes raising member copayments and cost-shares, making substantial alterations in how HCBS are delivered, and cutting the availability or hours of categories of HCBS for members to study the impact of the proposal on the capacity of members with disabilities to remain independently in their communities, and make the study and stakeholder feedback publicly available.
- Prohibit insurers from making coverage decisions that result in PWD being served needlessly in segregated settings. For example, failure to cover services essential for people with psychiatric disabilities to live in their own homes or in supportive housing would violate the non-discrimination provision if it results in individuals being served in segregated settings such as hospitals, nursing homes, or board and care homes and covering the services to support them in integrated settings would not be unduly expensive.[93]
- Prohibit insurers from setting reimbursement rates for coverage in a way that results in individuals with disabilities being served needlessly in segregated settings. For example, states cannot set reimbursement rates for services (including medications) in segregated settings (such as hospitals) higher than rates for similar services in integrated settings.
- Likewise, OCR should prohibit insurers from designing a particular benefit – such as personal care services – so that it is offered in greater amounts to individuals in segregated settings.

Experience with Self-evaluation

[93] This and the following recommendations are drawn from Section 1557 comments submitted by the Bazelon Center for Mental Health Law, which we support.

As disability rights organizations, our experience with ADA self-evaluation by the counties and monitoring by the states is not encouraging. The requirement for self-evaluation is either ignored, or if it is carried out it is implemented in a mechanistic fashion which fails to understand that the failure to provide accessibility and reasonable accommodations and policy modifications deprives PWD of critical services and their civil rights. The situation is exacerbated by states placing a low priority on completed self-evaluations, and lacking the resources and/or the will to sufficiently monitor self-evaluations, or enforce the remedial action plans that should be produced as a consequence of poor self-evaluations.

On July 13, 2012 DREDF submitted an extensively documented HHS-OCR complaint (available at: http://dredf.org/access-to-public-benefits/HHS-OCR-COMPLAINT-7-13-12-REDACTED.pdf) concerning county adherence to non-discrimination requirements in the administration of welfare and healthcare eligibility and enrollment functions. While the complaint was accepted for investigation, it has been very difficult to know how the investigation is progressing or whether and when it might bring improvements in California's state mandated county self-evaluation procedures. Since the state is undergoing current, 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, and adherence to Section 504. 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.

Ultimately, self-evaluation is only as good as the willingness and capacity of the supervising entity to closely monitor the self-evaluation process, implement significant corrective actions, and enforce follow-through. CMS's capacity to engage with entities that must undergo self-evaluation and the entities responsible for monitoring self-evaluation should be strengthened under Section 1557, but problems with self-evaluation will remain. Disability non-discrimination standards involve technical and precise physical requirements, as well as the flexibility to engage with PWD in the determination of reasonable accommodation preferences and needs. Even when dealing solely with clearer physical accessibility requirements, provider entities overestimate their own accessibility and fail to recognize or remember barriers in their own environment.[94] Unless employees are strictly and consistently trained over time to keep track of their responses to reasonable accommodation needs and requests, there will be an even greater tendency to overlook programmatic accommodation failures. Self-evaluation, whether conducted by providers, counties, or MCOs, will always tend to exaggerate compliance and remedial efforts and minimize problems. There is clearly an unresolved level of conflict if the person(s) in charge of the evaluation are employed by the same entity that is being evaluated, and potentially will suffer consequences if the evaluation is not positive.

[94] Sanchez J, Byfield B, Brown TT, LaFavor K, Murphy D, Laud P. Perceived accessibility versus actual physical accessibility of healthcare facilities, Rehabilitation Nursing, 2000;25(1):6-9.

Experiences and Lessons

In general, grievance and complaint procedures put in place within healthcare entities do not distinguish between substantive healthcare delivery failures such as denials of treatment or malpractice-related complaints, and civil rights complaints involving discrimination. While this is not necessarily an inherent problem, it can become problematic in a number of ways.

First, staff involved in receiving and evaluating complaints may simply have no idea how civil rights apply, and this is particularly true of disability civil rights. There is a far greater ambient societal awareness of, for example, racial and ethnic discrimination, than disability discrimination. Staff may not understand that a complaint can be fully justified and merit investigation *regardless* of whether a healthcare employee had bad intentions or malice. If a needed reasonable accommodation such as lift assistance or assistance with filling out forms was refused because an employee was ignorant, busy, or preoccupied, it remains a denial of a legal rights and a potential civil rights violation. Meritorious complaints can therefore be prematurely dismissed by a healthcare entity, or treated purely and lightly as a "customer service" issue.

Second, the association with medical negligence can lead healthcare entities to an automatic mechanistic and damage control response. It is true that the failure to accommodate can lead to consequences that include delayed diagnoses and other results raising malpractice implications, but that does not alter the need for the entity to resolve its failure to recognize the non-discrimination rights of people with various disabilities. An individual with a disability who cannot get a hospital room with an accessible bathroom, or whose managed care plan denies them needed HCBS and cannot therefore leave their home or work productively needs immediate assistance without receiving form letters in the mail or being required to sign malpractice waivers

Thirdly, a number of healthcare entities choose to impose arbitration requirements in their insurance or healthcare contracts with individual members. These arbitration clauses generally require that complaints against the entity be resolved through third party arbitration, and typically severely limit the complainant's recourse to a private lawsuit. We strongly submit that such arbitration clauses have no place in a civil rights context. PWD who suffer discrimination *must* have their recourse to administrative complaints forums such as HHS-OCR *and* their right to bring an individual lawsuit fully preserved, regardless of a healthcare entity's desire to impose limiting contractual language. As shown above, civil rights litigants act not only on their own behalf, but on the behalf of the public interest in fighting discrimination in such important institutions as healthcare. It is also highly unlikely that the arbitrators who act in this arena, usually chosen by the healthcare entity, will have the familiarity with disability civil rights laws and accessibility obligations that would be needed to come to a fair resolution of a disability access matter.

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

One key issue that is implicitly raised throughout these questions is how Section 1557 interacts with HHS's authority to regulate and establish standards for various programs and activities, whether that authority is newly granted or modified by the ACA. For example, HHS has already enacted important regulations on Essential Health Benefits (EHB) and established requirements for Qualified Health Plans (QHPs) that offer products through the Exchange Marketplaces. Similarly, the Centers for Medicare & Medicaid Services (CMS) within HHS has established numerous guidelines relating to development and implementation of the dual Medicare and Medicaid eligible integration projects, and have finalized or are finalizing "three-way contracts" with states and managed care organizations (MCOs) concerning the operationalization of the "duals integration projects." Many of these existing regulations and standards include references to non-discrimination and some establish accessibility standards.

While we welcome the agency's clear incorporation of non-discrimination principles within specific ACA regulations, such references cannot establish parameters for Section 1557's broad mandate to enforce non-discrimination in any program or activity receiving federal financial assistance, as expansively defined under the ACA. In the same way, HHS OCR's preexisting authority to enforce ADA and Section 504 in federally funded and federally conducted healthcare programs and activities is in no way limited to specific or general references to non-discrimination in, for example, the Medicaid or Medicare acts.[95] We first recommend that HHS-OCR explicitly clarify this point for all entities that receive federal financial assistance, and especially those newly created under the ACA, such as the exchange marketplaces, as well as the QHPs participating in the marketplace. Such newly created entities are most likely to be unfamiliar with HHS-OCR's authority and responsibility for monitoring and enforcing non-discrimination.

The failure to recognize overarching non-discrimination laws, and especially disability civil rights and accessibility obligations, is a longstanding problem even among well-established healthcare entities that are familiar only with their obligations under directly controlling healthcare regulations. For example, hospitals tend to be wholly preoccupied with meeting an admittedly complex network of state regulations and accreditation standards, with an additional strong interest in managing medical malpractice liability. In contrast, most hospitals have little awareness of how federal disability non-discrimination laws apply to them, and spend few resources on developing, implementing and improving policies, practices and procedures for providing physical and programmatic access, despite the reality of innumerable daily interactions with PWD.

Another example of regulatory "tunnel vision" is the very recent enactment of eligibility and enrollment regulations at the September Covered California Exchange Board meeting. The regulations include some references to Exchange and QHP obligations around effective accommodation and the provision of auxiliary aids. Some QHP representatives at prior board meetings when the draft regulations were first introduced

[95] For example, 42 U.S.C. § 1396b(m)(2)(A)(V) (prohibiting discrimination on the basis of health status in Medicaid managed care contracts), and 42 CFR 422.110, 422.2268(c), 423.2268(c) (prohibiting discrimination by Medicare managed care plans).

commented on how the few accessibility provisions in the regulations were vague, overreaching and unlimited. These comments are made in the vacuum of having no awareness that there are decades of federal and state laws, regulations, jurisprudence, and guidance on what effective communication means and the obligations of covered entities. The fact that these QHPs were doubtless already responsible, to some degree, for ensuring effective communication and disability non-discrimination under at least Title III of the ADA, only emphasizes the general depth and breadth of ignorance among covered entities when it comes to accessibility for PWD.

HHS and OCR must assist QHPs, MCOs, Exchanges, and numerous additional subcontracting layers of providers to understand that they have obligations under Section 1557 *independent* of the healthcare regulations and standards that appear to more immediately control their daily operations. HHS must lead the way in proactive monitoring and enforcement of disability standards, and CMS in its own administration of Medicare operations must model for the states things like training on Olmstead compliance for participating managed care organizations and making accessibility information on providers available to the public in programs.

HHS must ensure that OCR has the resources and the mandate to enforce non-discrimination among *all* of the agency's operations regardless of existing regulatory standards. So, for example, federal EHB regulations have been issued and endorse the tenets of non-discrimination. Nonetheless, the regulations allow individual state exchanges to choose the existing health insurance plan that will act as the plan benchmark for EHB coverage. In California, the exchange has chosen a managed care small business plan, which carries with it certain historical coverage limitations on specific categories. So, for example, Durable Medical Equipment (DME) has a non-cumulative annual coverage limit of two or three thousand dollars, which forces PWD who have complex rehabilitation needs to easily spend well over ten thousand dollars more out-of-pocket on an electric wheelchair and/or special seating needs.[96] This is a clear and particular example of coverage discrimination against PWD which has spread among small business insurers without any kind of actuarial justification or actual legal analysis. The non-discrimination provisions of the ACA that prohibit annual and lifetime limits and categorical deductibles are eviscerated if imbedded "special" coverage limitations on EHB categories or sub-categories are allowed to remain as a pre-existing component of benchmark QHP coverage. Even if federal and state regulation of EHB fails to recognize and prohibit such forms of imbedded discrimination, HHS-OCR has the authority and obligation under Section 1557 to address these and other ongoing discrimination issues affecting PWD.

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[96] DREDF February 14, 2012 letter to the Honorable Kathleen Sebelius regarding HHS's Essential Health Benefits Bulletin more fully explains the EHB benchmark coverage issue in California at pp. 4-8, and is available at: https://www.google.com/url?q=http://dredf.org/programs/DREDF-comment-EHB-Bullet-2-14-12.pdf&sa=U&ei=LhBKUv7kD8b62AWQyIGgCg&ved=0CAoQFjAB&client=internal-uds-cse&usg=AFQjCNFbRaB0rMk3LEmfOpnss05w6qJNoQ. ("There is little point to enacting a law that would prevent one form of insurance discrimination, such as a refusal to insure individuals with pre-existing conditions, while simultaneously allowing another form of discrimination, such as a refusal to cover the treatments, devices, and prescriptions that individuals with pre-existing conditions require to maintain health and function.")

As the primary body with monitoring and enforcement authority under Section 1557, HHS-OCR must have expanded resources and capacity, both within the many components of HHS, and among federal agencies that may have overlapping jurisdiction for enforcing disability non-discrimination. For example, in our recommendation under Question 5, that QHPs cannot be considered qualified unless they can demonstrate that their provider networks include providers with accessible examination and medical equipment, HHS-OCR, and not the state's own exchange board, would be required to monitor the requirement and ensure that QHPs either have the equipment, or commit to acquiring accessible examination equipment through a plan with clearly enforceable goals and timelines. At the same time, there are opportunities for HHS-OCR to establish cooperative agreements with another agency, such as the federal Department of Justice (DOJ), in such areas as accessible equipment, where there is a clear overlap with DOJ's authority.

The ACA established Section 510 of the Rehabilitation Act of 1973,[97] which charges the U.S. Access Board with developing accessibility standards for medical and diagnostic equipment. DOJ's adoption of these standards in ADA regulations, and adding the scoping element that will further clarify the obligation of covered entities to acquire accessible equipment, will make the standards legally enforceable. As illustrated in our response to question 3, accessible equipment is a critical component of achieving non-discriminatory healthcare programs and activities. HHS-OCR and DOJ share responsibility for ensuring consumer and provider education, and provider compliance with accessible equipment standards, and we strongly recommend that the two agencies develop a relationship to determine how best to monitor and enforce forthcoming regulations concerning accessible equipment.

A cooperative agreement and relationship with DOJ would also enable HHS-OCR to call upon DOJ's recognized expertise around notifying, monitoring and enforcing *Olmstead* obligations. While DOJ has historically focused on the states and LTSS entities such as nursing facilities that are most directly implicated in the unwarranted and unwanted institutionalization of PWD, the increasing involvement of MCOs and other intermediate providers in the delivery of LTSS warrants DOJ's involvement and technical assistance. The equally effective delivery of healthcare and LTSS in the community is integral to PWD living as independently as possible in the community. DOJ could provide mandatory *Olmstead* training to covered healthcare entities and assist with monitoring *Olmstead* requirements, such as consumer notice and peer choice counseling that HHS-OCR develops and regulates under Section 1557.

Thank you again for this opportunity to respond to the Section 1557 RFI.

Yours Truly,[98]

Access Living

[97] 29 U.S.C. §794f.

[98] We would be happy to provide the full contact information for any or all of the undersigned organizations upon request. For this or any other questions, please contact Silvia Yee, senior staff attorney at DREDF, at syee@dredf.org or 510-644-2555 (510-841-8645 fax/tty).

ADAPT Montana
AIDS Alliance for Women, Infants, Children, Youth & Families
AIDS Foundation of Chicago
AIDS Legal Council of Chicago
American Association on Health and Disability (AAHD)
American Association of People with Disabilities (AAPD)
American Federation of State, County and Municipal Employees (AFSCME)
American Public Health Association, Disability Section
American Network of Community Options and Resources
The Arc of the United States
Asian & Pacific Islander American Health Forum
Association of University Centers on Disabilities
Autistic Self Advocacy Network
Bazelon Center for Mental Health Law
California Center for Rural Policy, Humboldt State University
California Institute for Mental Health
California Pan-Ethnic Health Network
Center for Accessible Technology
Center for Independence of the Disabled of New York
Claire Heureuse Community Center, Inc
Coalition for Disability Health Equity
Colorado Cross Disability Coalition
Commission on the Public's Health System
Community Service Center of Greater Williamsburg
Disability Advocates Advancing Our Healthcare Rights Coalition (DAAHR)
Disability Law Center
Disability Policy Consortium
Disability Rights Education and Defense Fund (DREDF)
Disability Rights California
Disability Rights Legal Center
Disability Rights Wisconsin
Easter Seals
The Global Justice Institute
Greater Boston Legal Services (GBLS),
Health & Disability Advocates
HealthHIV
Harlem Independent Living Center, Inc.
Harris Family Center for Disability and Health Policy
Institute of Social Medicine & Community Health
Latino Commission on AIDS
Metropolitan Community Churches
National Association of State Head Injury Administrators
National Center for Lesbian Rights
National Center for Transgender Equality
National Council on Independent Living
National Disability Rights Network (NDRN)
National Federation of the Blind
National Hispanic Medical Association

National Respite Coalition
National Senior Citizens Law Center (NSCLC)
New York Lawyers for the Public Interest
Not Dead Yet
Social Medicine & Community Health
Southwest Women's Law Center
Spina Bifida Association
United Domestic Workers/AFSCME Local 3930
United Spinal Association