November 9, 2015

Ms. Jocelyn Samuels
Director
Office for Civil Rights
U.S. Department of Health and Human Services
Hubert H. Humphrey Building
200 Independence Avenue SW
Washington, DC 20201

Re: Affordable Care Act Section 1557 Notice of Proposed Rulemaking (RIN 0945-AA02)

Dear Director Samuels:

We, the undersigned members of the Consortium for Citizens with Disabilities (CCD) Health, Rights, and Technology & Communications Task Forces, appreciate the opportunity to provide comments in response to U.S. Department of Health and Human Services (HHS), Office for Civil Rights, Notice of Proposed Rulemaking (NPRM) regarding Nondiscrimination in Health Programs or Activities.

CCD is a coalition of national disability organizations working together to advocate for policies that ensure the self-determination, independence, empowerment, integration and inclusion of people with disabilities in all aspects of society. We believe that enforcement of the nondiscrimination protections provided in the Affordable Care Act is crucial to effective implementation of health insurance market reform.

Overall, we strongly support the work of the Office for Civil Rights to promote and protect the health care rights of all Americans. We believe that this proposed rule will strengthen those efforts and look forward to the publication of a final rule.

Overall Comments

Intersectional Bases of Discrimination

While disability affects people of all races, ethnicities, genders, languages, sexual orientations, and gender identities, disability does not occur uniformly among racial and ethnic groups. 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.[1] Disability prevalence among American Indians and Alaskan Natives is 16.3 percent.[2] An Institute of Medicine report has already observed that there are "clear racial differences in medical service utilization rates of people with disabilities 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.'"[3] People with disabilities are likely to fall into more than one protected group, and the relationship between race and disability has cumulative impact on creating health disparities. Nondiscrimination protections must take into account these intersectional elements of living with disability. For example:

- Fifteen percent of people with disabilities report not seeing a doctor due to cost, compared to six percent of the general population.[4] 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.[5] People with disabilities 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. Anti-discrimination efforts related to cost-sharing should account for this intersection of poverty, disability, and racial minority status.
- Three out of five people with serious mental illness die 25 years earlier than other individuals, from preventable, co-occurring chronic diseases.[6] 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 likely to be dissatisfied with care.[7] Asian Americans and Hispanics are less than half as likely as whites to receive mental health treatment.[8] People with mental health disabilities are at greater risk of developing chronic conditions, a disparity compounded among people with mental health disabilities from racial and ethnic minorities.

---

[1] Brault, Matthew, "Americans With Disabilities: 2005, Current Population Reports," P70¬117, *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.

[2] "2009 American Community Survey, S1810." *U.S. Census Bureau*, 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.

[3] "The Future of Disability in America," *Institute of Medicine (IOM)*. 2007. Washington, DC: The National Academies Press, p. 92.

[4] Seth Curtis and Dennis Heaphy, "Disabilities and Disparities: Executive Summary," *Disability Policy Consortium* (March 2009), p. 3.

[5] *Id.*

[6] Assoc. of University Centers on Disabilities, "Letter to Kathleen Sebelius" http://www.aucd.org/docs/policy/health_care/CLAS_StandardsDisabilityLetter%201¬2011.pdf. Citing Colton & Manderscheid, 2006; Manderscheid, Druss, & Freeman, 2007.

[7] Whitley, R., & Lawson, W. "The Psychiatric Rehabilitation of African Americans With Severe Mental Illness.," Psychiatric Services, 61(5), 508-11 (2010).

[8] "2008 National Healthcare Disparities Report." Table 15_3_1.1a & 15_3_1.1b. Available at: http://www.ahrq.gov/qual/qrdr08/index.html.

- People with significant vision loss experience a greater prevalence of obesity, hypertension and heart disease, and cigarette use than the general public.[9] However, too often weight loss services are inaccessible to people with visual impairments. 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.[10]
- Diabetes often leads to vision loss, but most modern glucometers have a flat screen interface that is inaccessible to blind people. Adults with disabilities have a 400 percent elevated risk of developing Type II diabetes.[11] 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.[12]
- Among people who are deaf, women of color 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.[13]
- 4.6 percent of Deaf people are infected with HIV/AIDS, four times the rate for the African-American population,[14] the most at-risk racial group in the U.S.[15] 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.

This intersection of disability and other minority and protected classes points to the direct need for Section 1557 and the importance of strong enforcement and implementation to the fullest extent of the law going forward.

Subpart A – General Provisions

92.2 Application

Age Discrimination
We urge the Department to specify in Section 92.2(b)(1) that Section 1557's application to age discrimination prohibits age-related distinctions in benefit coverage, apart from the exclusions in the Age Act for (1) age distinctions contained in a federal, state, or local statute or ordinance that provides benefits based on age, establishes criteria for

[9] Michele Capella-McDonnall, "The Need for Health Promotion for Adults Who Are Visually Impaired," *Journal of Visual Impairment and Blindness* Vol. 101, No. 3 (March 2007).
[10] *Id.* Note that a vision impairment is a visual disability not correctable by glasses or other modifications.
[11] Curtis and Heaphy, p. 3.
[12] Asian American Diabetes Initiative, Joslin Diabetes Center, (2010). Available at: http://aadi.joslin.org/content/asian/why-are-asians-higher-risk-diabetes]
[13] *National Council on Disability*, 2009.
[14] Curtis and Heaphy, p. 8.
[15] Avert, "United States Statistics by Race and Age," (2009). Availabe at: http://www.avert.org/usa-race-age.htm]

participation in age-related terms, or describes intended beneficiaries to target groups in age-related terms, and (2) actions that reasonably take into account age as a factor necessary to the normal operation or the achievement of any statutory objective of such program or activity.[16] Thus, for example, a decision to limit coverage of a service to individuals in a particular age range, even though that service is also effective for individuals of other ages, would violate Section 1557 if the age limitation is not based on a statute or ordinance and is not necessary for the normal operation or achievement of the goals of the service. For example, it should be prohibited to limit services to children below a certain age, even though older individuals could also benefit from those services.

In addition, we urge that the regulations recognize that Medicaid regulations and health plan features may have the effect of discriminating against children, who may need services more intensively and devices more frequently than adults, due to their rapid growth and development. (See "Habilitative and Rehabilitative Services and Devices," below.)

92.4 Definitions

Federal Financial Assistance
We are dismayed that the NPRM continues the exclusion of Medicare Part B providers from the definition of Federal Financial Assistance and has extended this exclusion to compliance with Section 1557. We believe the statutory text of Section 1557 specifically includes Part B providers and that the prior HHS policy excluding Part B providers from compliance with Title VI is based on an antiquated definition of Federal Financial Assistance and thus should not be extended (and indeed should be rescinded for Title VI). In this section, we support the comments of the National Health Law Program on the exclusion of Part B providers.

Health Program or Activity
The proposed rule defines "health programs and activities" as "the provision or administration of health-related services or health-related insurance coverage and the provision of assistance to individuals in obtaining health-related services or health-related insurance coverage." The proposed rule further provides that "[f]or an entity principally engaged in providing or administering health services or health insurance coverage, all of its operations are considered part of the health program or activity, except as specifically set forth otherwise in this part."

The proposed rule does not define what it means to be "principally engaged in providing or administering health services or health insurance coverage." The preamble states that this phrase is to be interpreted consistently with civil rights laws, and the proposed rule provides examples of entities principally engaged in providing or administering health services or health insurance coverage: "Such entities include a hospital, health clinic, group health plan, health insurance issuer, physician's practice, community health center, nursing facility, residential or community-based treatment facility, or other similar entity. A health program or activity also includes all of the operations of a State Medicaid program."

[16] See 80 Fed. Reg. 54173 (Sept. 8, 2015); 45 USC §§ 6103(b)(1)(A), (b)(2).

While these examples are helpful, the Department should include in the text of the rule the statement that "principally engaged" is to be interpreted consistently with civil rights laws and should offer an explanation of that interpretation. The Department should also clarify that a health program or activity applies to all of the operations (including, for example, benefit design, coverage decisions, network establishment, and payment structures) of insurance plans available through the Marketplace, and of a State Medicaid program including the Medicaid expansion.

The Department should clarify that health programs and activities include, among other things, the following aspects of both private and public health coverage, including Medicaid programs and Medicaid managed care organizations:

- Setting the terms and conditions of insurance plans including, for example, the scope of services and benefits covered, prior authorization requirements, and other requirements for obtaining reimbursement for services
- Reimbursement for services and benefits under a health insurance plan
- Designing benefits under a health insurance plan
- Determining which providers are covered by health plan networks
- Determining which plans are available through an exchange
- Determining which services and benefits are covered under a state's "Essential Health Benefits" package
- Administering exchanges
- Administering alternative benefit plans under the Medicaid expansion
- Administering a managed care organization (including a Medicaid managed care organization)

These programs and activities are integral to the ACA's implementation. Conducting them in a non-discriminatory manner is critical to ensure that implementation is effective for all participants and that people with disabilities and other protected groups are afforded equal opportunities to benefit from the ACA.

Qualified Interpreter
CCD supports the inclusion of the definition of qualified interpreter as proposed in the definitions section of these proposed regulations. CCD believes the definition would be strengthened, however, if the definition reflected that to be considered qualified, an interpreter be licensed if required by state law in the state where the covered entity is providing services.

92.8 Notice Requirement

CCD supports the comments of the National Health Law Program on notice requirements.

Subpart B – Nondiscrimination Provisions

92.101 Discrimination Prohibited

Section 92.101(b)(2)(i) incorporates regulations enacted under Section 504 that pertain to recipients of federal financial assistance, extending these regulations to include State-based marketplaces. In general we support OCR's aim in paragraphs (b)(1-4) to "incorporate into this proposed regulation the specific discriminatory actions prohibited under each civil rights law on which Section 1557 is grounded."[17]

At the same time, the incorporation of existing Section 504 and ADA regulations must be done carefully and in a manner that will not unnecessarily narrow the ambit of Section 1557. In particular, we object to the application of all of Section 504's program accessibility provisions for existing facilities, 45 CFR §§.84.22 and 85.42, to the many health insurance issuers and managed care organizations that operate health programs and activities in state marketplaces and Medicaid programs, in Medicare, and in the federal marketplaces.

First, the same manner of "confusion and unintended consequences" that OCR foresees in an attempt to harmonize regulatory standards and concepts *between* civil rights statutes is potentially raised by the failure to harmonize regulatory standards and concepts *within* Section 504's cited regulations. 45 CFR §§.84.22 and 85.42 differ slightly in their language, but there is no principled reasons that State-based Marketplaces and Federally-facilitated Marketplaces should apply program accessibility in existing facilities in slightly different ways. Each type of marketplace, for example, should have the same obligation to make existing facilities readily accessible to and useable by persons with disabilities unless it can establish a fundamental alteration or undue burden defense. State and municipal entities are, of course, already familiar with that concept under Title II of the ADA and 28 CFR § 35.150, but 45 CFR §.84.22 does not contain this actual language.

Second, both §§.84.22 and 85.42 incorporate a concept of "program accessibility" that was developed specifically for government programs and agencies. We are concerned that incorporating program accessibility in the context of private insurance carriers and managed care organizations may have the unintended consequence of actually diminishing accessibility requirements for health care providers. A key feature of how these large corporate entities appeal to prospective members is through the quality, size and "choice" offered within each entity's provider networks. At the same time, state insurance and Medicaid agencies and the Centers for Medicare and Medicaid Services work to establish clear guidelines and consumer protections to govern the sufficiency of provider networks. Amidst this backdrop of commercial and regulatory practice, it would be senseless to allow private entities to essentially *decide for themselves* when their provider network is "readily accessible" to people with disabilities. Yet, that is exactly what will happen if such private entities are subject to a program accessibility standard that "does not require a recipient to make each of its existing facilities or every part of a facility" accessible to and useable by persons with disabilities. A large for-profit insurance carrier could arbitrarily decide that,

[17] 80 FR 54181.

among the great majority of its providers who operate in existing facilities, only 10% need to be physically accessible or have accessible equipment. Moreover those accessible providers could be clustered together in some central location, and whenever a member calls member services and mentions the need for accessibility, that member will be actively directed toward "the accessible provider offices."

As written and potentially applied, §§84.22 and 85.42 could gut the concept of provider choice for health consumers with disabilities, and also conflict with state and federal regulations that place provider time and distance or provider-member ratio obligations on insurance carrier and managed care provider networks. While the general prohibition of discrimination in §92.101(5) of the proposed rule is supposed to take primacy over the specific forms of discrimination enumerated in §92.101(2)(b)(i) and (ii), the full incorporation of the program accessibility concept will give covered entities an unintended escape hatch, relegating health consumers with disabilities to second-place status every time they try to gain access to their provider network. The fact is, every healthcare provider is already independently subject to Title III of the ADA, and as a recipient of federal financial assistance under Section 1557, is responsible for ensuring that the "entirety" of its program or activity is readily accessible to and useable by persons with disabilities. It would surely be an unintended consequence if entities that establish extensive provider networks could, by that very fact, escape from their obligations to provide access to people with disabilities.

In light of the above, we recommend that 45 CFR §§.84.22 and 85.42 be harmonized primarily though the amended language of §85.42 as follows:

> § 85.42 Program accessibility: Existing facilities.
> (a) *General.* The agency shall operate each program or activity so that the program or activity~~, when viewed in its entirety,~~ is readily accessible to and usable by individuals with handicaps. This paragraph does not—
>
> > ~~(1) Necessarily require the agency to make each of its existing facilities accessible to and usable by individuals with handicaps; or~~
> > ~~(2)~~ Require the agency to take any action that it can demonstrate would result in a fundamental alteration in the nature of a program or activity or in undue financial and administrative burdens. In those circumstances where agency personnel believe that the proposed action would fundamentally alter the program or activity or would result in undue financial and administrative burdens, the agency has the burden of proving that compliance with§ 85.42(a) would result in such alteration or burdens. The decision that compliance would result in such alteration or burdens must be made by the agency head or his or her designee after considering all agency resources available for use in the funding and operation of the conducted program or activity in question, and must be accompanied by a written statement of reasons for reaching that conclusion. If an action would result in such an alteration or such burdens, the agency shall take any other action that would not result in such an alteration or such burdens but would nevertheless

ensure that individuals with handicaps receive the benefits and services of the program or activity.

(b) *Methods.*

(1) The agency may comply with the requirements of this section through such means as redesign of equipment, ~~reassignment of services to accessible buildings,~~ assignment of aides to beneficiaries, home visits, delivery of services at alternate accessible sites, alteration of existing facilities and construction of new facilities, use of accessible rolling stock, or any other methods that result in making its programs or activities readily accessible to and usable by individuals with handicaps. The agency is not required to make structural changes in existing facilities where other methods are effective in achieving compliance with this section. ~~The agency, in making alterations to existing buildings, shall meet accessibility requirements to the extent compelled by the Architectural Barriers Act of 1968, as amended (42 U.S.C. 4151-4157), and any regulations implementing it.~~

(2) In choosing among available methods for meeting the requirements of this section, the agency shall give priority to those methods that offer programs and activities to qualified individuals with handicaps in the most integrated setting appropriate.

(c) *Time period for compliance.* The agency shall comply with the obligations established under this section within 60 days of the effective date of this part except where structural changes in facilities are undertaken; such changes shall be made within three years of the effective date of this part, but, in any event, as expeditiously as possible.

(d) *Transition plan.* In the event that structural changes to facilities must be undertaken to achieve program accessibility, and it is not expected that such changes can be completed within six months, the agency shall develop, within six months of the effective date of this part, a transition plan setting forth the steps necessary to complete such changes. The agency shall provide an opportunity to interested persons, including individuals with handicaps or organizations representing individuals with handicaps, to participate in the development of the transition plan by submitting comments (both oral and written). A copy of the transition plan shall be made available for public inspection. The plan shall, at a minimum—

(1) Identify physical obstacles in the agency's facilities that limit the accessibility of its programs or activities to individuals with handicaps;

(2) Describe in detail the methods that will be used to make the facilities accessible;

(3) Specify the schedule for taking the steps necessary to achieve compliance with this section and, if the time period of the transition plan is longer than one year, identify steps that will be taken during each year of the transition period; and

(4) Indicate the official responsible for the implementation of the plan.

Please note: We have incorporated comments regarding 92.101(b)(2)(i)'s discussion of 45 CFR 84.23(c) and the Uniform Federal Accessibility Standards (UFAS) in our section on 92.203 on Accessibility Standards for Buildings and Facilities.

Examples of Discrimination
92.101 (a) of the proposed ACA regulations provides: "An individual shall not, on the basis of race, color, national origin, sex, age, or disability be excluded from participation in, be denied the benefits of, or otherwise be subject to discrimination under any health program or activity to which this part applies." CCD strongly supports this provision and asks that OCR provide further guidance to covered entities on specific forms of discrimination prohibited. This request is further discussed in Section 92.207 below.

Subpart C – Specific Applications to Health Programs and Activities

92.201 Meaningful Access for Individuals with Limited English Proficiency

We support the comments of the National Health Law Program in this section.

92.202 Effective Communication for Individuals with Disabilities

CCD strongly supports the incorporation of the Title II ADA standards into the proposed regulation under §92.202 regarding effective communication for individuals with disabilities. CCD agrees that Title II is the higher standard and is pleased to see the higher standard used, especially because Title II requires a covered entity to give primary consideration to the choice of an aid or service requested by the individual with a disability. In addition, CCD agrees that it makes sense to have one uniform standard for both state and private entities receiving Federal funding and engaged in health programs or activities and supports the use of the Title II standard.

CCD believes that the proposed effective communication regulations could be strengthened by including the proposed rules regarding the restricted use of certain persons to interpret or facilitate communication contained in §92.201(e) for individuals with limited English proficiency in §92.202 for individuals with disabilities. All of the same rationales for including this section in §92.201 for individuals with limited English proficiency apply for including it for individuals with disabilities. Making this explicit for individuals with disabilities will remove any confusion regarding the obligations of covered entities in regard to individuals with disabilities.

In addition, CCD supports the comments submitted by the National Association of the Deaf suggesting the addition of several requirements under this section: 1) regarding honoring the request for an interpreter of a particular gender if made by an individual; and 2) for a policy ensuring that there is not an over reliance on video relay interpreting in meeting the requirements of these regulations.

92.203 Accessibility Standards for Buildings and Facilities

We support OCR's position in the draft rule to adopt the 2010 ADA Standards for Accessible Design (2010 Standards) as the relevant standard required in any facility or part of a facility in which health programs or activities are conducted that is constructed or altered by or on behalf of, or for the use of, a recipient or State-based marketplace. We agree with OCR's observation at 80 FR 541(i)(6) that "nearly all of the facilities covered under the proposed rule are already subject to the 2010 Standards." As a result, we are uncertain why the proposed rule gives new construction and alteration an additional time period to come into compliance with the 2010 Standards. That is, the proposed rule applies the 2010 standards to new construction and alteration that is commenced 18 months after publication of the final 1557 rule. However, the 2010 Standards themselves applied to newly constructed State and local government facilities if they were constructed on or after March 15, 2012. The vast majority of facilities covered by this proposed rule were already subject to the 2010 standards as of March 15, 2012. We do not think there needs to be another "safe harbor" period for facilities in which health programs or activities are conducted that are newly constructed or altered between March 15, 2012 and a date that is 18 months after publication of the final 1557 rule.

We recognize that there may be some ADA Title III entities participating in the federal or state marketplaces that arguably did not yet know that specific new construction or alteration standards would apply to them under Section 1557 absent OCR's proposed rule language. Such new construction or alteration would in any event have fallen under Appendix A of the 1991 Title III regulation, which is republished as Appendix D to 28 CFR part 36, containing the ADA Standards for Accessible Design (1991 Standards). We would therefore support, if this were found to be necessary, the tailored recognition that such facilities, where construction or alterations were commenced before 18 months from the final date of the rule, are deemed to comply with the requirements of this proposed rule and with 45 CFR 84.23 (a) and (b), cross referenced in §92.101(b)(2)(i) with respect to those facilities, if they are in conformance with the 1991 Standards or the 2010 Standards.

An approach which emphasizes the uniform application of the 2010 Standards upon publication of Section 1557 rule will enable greater consistency among implementing agencies, given the overlapping jurisdiction that OCR has with the Department of Justice, which will apply the 2010 Standards to Title II facilities constructed or altered after March 15, 2012. Complainants with disabilities should not be implicitly influenced toward one administrative forum or another by the date on which a healthcare facility's construction or alteration began. More substantively, the 2010 Standards have specific provisions that apply to "Medical care facilities" which recognize the importance of having accessible patient bedrooms in all areas of a facility in order to facilitate access to needed medical specialty providers and equipment by people with disabilities. Such specificity makes the 2010 Standards especially appropriate for the widest possible adoption in the Section 1557 regulations.

Under a similar rationale, we strongly agree with OCR's decision in §92.101(b)(2)(i), with respect to existing facilities, to not adopt "the program accessibility provision at [45 CFR] §

84.23(c), addressing conformance with the Uniform Federal Accessibility Standards for the construction and alteration of facilities, because these standards are outdated." We do not, however, understand or agree with the ongoing incorporation of the Uniform Federal Accessibility Standards (UFAS) in § 92.203(b), which states that compliance with UFAS shall be deemed to be in compliance with Section 1557 for newly constructed or altered facilities "if the construction or alteration was commenced before [18 MONTHS FROM DATE OF PUBLICATION OF FINAL RULE]."

We object to the ongoing incorporation of UFAS because UFAS is functionally deficient for people with disabilities. Accessibility barriers are permitted under the old standard that particularly affect people with mobility and strength disabilities. In November 2007, the Department of Veteran Affairs (VA) issued *A Barrier Free Design Guide: A Supplement to the Uniform Federal Accessibility Standards.*[18] The purpose of the guide was to tailor UFAS requirements so that health care facilities, in particular, would meet the barrier free needs of the Department of Veterans Affairs (VA). A quick glance at the footnotes of the guide reveal the extent to which UFAS standards fall short of ensuring accessibility for people with disabilities:

> 4. The disabled population used by UFAS to determine an acceptable slope for using public accommodations is stronger and younger than are veterans at VA facilities.
> 5. UFAS used a younger, more fit population to determine the minimum slope and distance for a disabled person's travel capability.
> 7. UFAS is based on an active, independent population. Little consideration was given to accessibility in medical care facilities, except in Section 6.[19]
> 12. Tests show only those with good upper body strength can manage a ramp slope of 1:12. Slopes greater than 1:16 create safety hazards for any wheeled vehicle.
> 20. Window sills must be low enough that seated (wheelchair) and bedridden patients can see outside.
> 24. The UFAS 900 mm x 900 mm (3'-0" x 3'-0") shower has a folding seat which requires the patient to transfer from the wheelchair. The UFAS 750 mm x 1500 mm (2'-6" x 5'-0") shower admits a wheelchair, but just barely. There is no room for the patient to maneuver or for attendants to help.[20]

The VA website currently states that it:

> follows GSA [the General Services Administration] and other standard-setting agencies in replacing UFAS with the Architectural Barriers Act Accessibility Standard (ABAAS) for Federal Facilities. In addition, VA uses

[18] Available at: http://citeseerx.ist.psu.edu/viewdoc/download?rep=rep1&type=pdf&doi=10.1.1.204.2449 [last visited October 14, 2015].
[19] Section 6 of the UFAS is a relatively short section on "Health Care" that requires an entrance canopy or overhang over health care facility or building entrances to protect from weather, and otherwise deals exclusively with patient bedroom measurements in such facilities.
[20] See *Guide,* available at: http://citeseerx.ist.psu.edu/viewdoc/download?rep=rep1&type=pdf&doi=10.1.1.204.2449 [last visited October 14, 2015].

> the Barrier Free Design Guide to meet the needs of the Department of Veterans Affairs in its health care facilities.it has officially adopted the 2010 Standards in place of UFAS.[21]

The VA and other federal agencies were able to replace the UFAS as the relevant standard for recipients of federal financial assistance because of actions taken by the Department of Justice. In a March 29, 2011 memo written by then Assistant Attorney General, Thomas Perez, to Federal Agency Civil Rights Directors, he noted that:

> Several federal agencies have asked the Department, pursuant to its coordination authority for Section 504 under Executive Order 12250, if they have the authority to allow their recipients of federal financial assistance to use the 2010 Standards in lieu of UFAS. These agencies recognize that most of their recipients of federal financial assistance are also subject to the ADA and wish to minimize covered entities' need to comply with multiple accessibility standards. In addition, many covered entities would prefer to use the 2010 Standards because they are written using language that is more consistent with the language used in many state building codes.[22]

In light of the above, the OCR's retention of the UFAS standards for recipients and State-based Marketplaces appears to reward those few construction or alteration projects that did not have the foresight to take account of the needs of healthcare consumers with disabilities. The proposed rule, after all, only addresses facilities in which health programs or activities are conducted, not for example, a General Services or US Post Office building primarily intended for housing machinery.

Ultimately, this rule reflects the Department of Health and Human Services' commitment to ensuring the accessibility of federally-funded health care programs and activities for people with disabilities. OCR and HHS overall should provide technical assistance to assist those few covered entities conducting health programs and activities in UFAS-only compliant facilities to come into compliance with the 2010 or 1991 Standards.

Medical Diagnostic Equipment

Overall, we support OCR's plan to enforce the standards for accessible medical diagnostic equipment. We, too, eagerly await the release of final standards from the U.S. Access Board. In the meantime, we encourage OCR to enforce existing anti-discrimination laws and access standards whenever an individual with a disability is denied medical services because of the physical inaccessibility of the equipment. We also encourage OCR to use the Access Board's Advisory Committee Report and Proposed Standards as guidelines for this enforcement.

[21] Available at: http://www.cfm.va.gov/til/accessibility.asp. [last visited October 14, 2015].
[22] Available at: http://www.ada.gov/504_memo_standards.htm [last visited October 28, 2015]

92.204 Accessibility of Electronic Information Technology

We are appreciative of OCR's unequivocal recognition that health-related information and technology must be accessible to and usable by people with disabilities in order to ensure effective and nondiscriminatory provision of health care services, and we strongly support HHS's inclusion of explicit requirements in the proposed rule for accessible websites and electronic and information technology (E&IT). While it is true that Titles II and III of the Americans with Disabilities Act (ADA) and Sections 504 and 508 of the Rehabilitation Act already provide both strong legal protections for consumers and a wealth of clear guidance for covered entities, we agree with OCR's assessment that an express recapitulation of the general requirement to ensure accessible E&IT and websites is a critical regulatory reaffirmation which should raise the profile of the need for dramatically greater compliance with current law.

We commend OCR for proposing to apply the nondiscrimination requirements to all of a covered entity's E&IT and not to restrict the obligations only to websites or to specific classes or categories of E&IT. All too often, covered entities apply a piecemeal approach to ensuring that consumers of health information with disabilities do in fact have full and equal benefit from their services, programs, and activities. Far too frequently, if access is provided at all, it is limited to a given context, such as accessible informed consent forms, and there is an utter lack of appreciation for the need to provide access at every stage of service delivery where all consumers are expected or invited to interact with online information or specific pieces of equipment. It is essential that covered entities understand that failing to afford access to consumers with disabilities at every stage of service delivery – from appointment setting, to in-person check-in, to interaction with any and all devices with which a covered entity expects consumers to use both in the in-patient and out-patient contexts, to review of medical records, billing and insurance data – not only discriminates against people with disabilities, but such failure puts patients at tremendous risk as the patient (or family member of a patient) with disabilities cannot fully understand diagnosis and treatment, to make informed choices about health care providers, or appropriately respond to specific interventions. The risk extends to the consumer's ability to maintain health coverage and needed benefits, or even choose an appropriate health plan in the first place, since billing and procedural coding errors cannot be timely reviewed when billing statements, summary notices, and summary of benefits documents are all too often partially or fully inaccessible, even when provided in an electronic format.

In addition to addressing the range of needs of consumers with disabilities, we anticipate that the proposal to cover *all* of a covered entity's E&IT will assist healthcare professionals with disabilities to achieve greater independence and functional capacity as they exercise their profession. We know of numerous examples where people with disabilities in professions ranging from medical stenographer to licensed psychologists face additional E&IT barriers after they have already undergone rigorous training, educational and testing regimens because a hospital or managed care organization's provider note and record systems are inaccessible to screen reading software, for example. There is no principled reason for any aspect of a covered entity's E&IT systems to be designed or maintained in a manner that cannot interface with the range of functional human capacities affecting

vision, hearing, and speed and range of motion; this holds true for E&IT regardless of whether it is intended primarily or incidentally for public use. We strongly support the proposed rule's requirement that all aspects of a covered entity's E&IT be fully accessible. We also note that training, employing and retaining healthcare professionals with disabilities is a key means of reducing the widely recognized healthcare disparities experienced by people with disabilities.[23]

We believe that it would be useful for HHS to publish guidance or FAQs that include examples of the various stages of health care delivery wherein online and E&IT means employed by covered entities need to be accessible. While we support the proposed text of §92.204(a), we believe that a non-exhaustive set of examples would reinforce HHS's intent to ensure applicability of these nondiscrimination requirements to all points at which covered entities use technology both now and in the future.

We recommend that §92.204 include some explicit reference to the effective communication regulations that remain the legal origin point for the obligation to make websites and E&IT technology accessible. While not all of the regulations concerning auxiliary aids and services applies to the E&IT and website context, some are appropriate to incorporate. For example, where a covered entity may give sighted members the option to receive notices through email, a website portal, or electronic CDs, the covered entity may not impose only one of those options upon a member who is blind or visually impaired simply because that option is more convenient for the entity. The explicit incorporation of relevant aspects of 35 CFR §35.160(b)(2) informs covered entities that they must consult and work with members with disabilities as part of the entity's effective communication obligation.

The following suggested language for §92.204(b) encapsulates the above recommendations:

> (a) Covered entities shall ensure that their health programs or activities provided through electronic and information technology are accessible to individuals with disabilities, unless doing so would result in undue financial and administrative burdens or a fundamental alteration in the nature of the health programs or activities. When undue financial and administrative burdens or a fundamental alteration exist, the covered entity shall provide information in a format other than an electronic format that would not result in such undue financial and administrative burdens or a fundamental alteration but would ensure, to the maximum extent possible, that individuals with disabilities receive the benefits or services of the health program or activity that are provided through electronic and information

[23] *See* "CMS Equity Plan for Improving Quality in Medicare." *Centers for Medicare and Medicaid Services, Office of Minority Health*. September 2015. Accessed October 16, 2015. http://www.cms.gov/About-CMS/Agency-Information/OMH/OMH_Dwnld-CMS_EquityPlanforMedicare_090615.pdf; Krahn, Gloria L, Deborah Klein Walker, and Rosaly Correa-De-Araujo. "Persons With Disabilities as an Unrecognized Health Disparity Population." *American Journal of Public Health*. Vol 105, No. S2 (2015): S198-206.

technology. *In determining what types of electronic and information technology are necessary, a public entity shall give primary consideration to the requests of individuals with disabilities. In order to be effective, electronic and information technology must be provided in a timely manner, and in such a way as to protect the privacy and independence of the individual with a disability.*

(b) State-based Marketplaces and recipients shall ensure that their health programs and activities provided through Web sites comply with the requirements of Title II of the *ADA in accordance with the standards found at 28 CFR 35.160(a)(1) and (2), 35.160(d), 35.163, and 35.164. Where the regulatory provisions referenced in this section use the term "public entity," the term "covered entity" shall apply in its place.*

With respect to the application of ADA Title II or Title III standards to §92 covered entities' website obligations, we recommend that the proposed rule require that E&IT comply with a specific set of standards such as Section 508 by the Access Board at 36 CFR part 1194 (Section 508 Standards), or the Worldwide Web Consortium's Web Accessibility Initiative's WCAG 2.0 AA (WCAG Standards). While we appreciate that Section 508 regulations are hopefully being finalized, we think it is important in this proposed rule to reaffirm the rights of people with disabilities, and redress current violations that occur when people with disabilities are given E&IT that fails to meet existing, readily available, and widely accepted standards.

This approach would have the benefit of clarity and consistency, and greater specificity will assist OCR in actual enforcement of the section. It will clearly inform OCR investigators that E&IT that falls short of the 504 or WCAG Standards falls within OCR's jurisdiction and their authority to require correction from covered entities. We appreciate that covered entities will and should continue to engage in an interactive process on how to make E&IT fully accessible to individual consumers and employees, but it will be much more efficient to have compliance with the Section 508 or WCAG standards as the starting point in that discussion. The fact that DOJ is applying WCAG standards in its own Title II and III settlements supports our position that OCR should also adopt the 508 and WCAG Standards as interim standards before final Section 508 regulations are issued. To the extent that there is overlap between the Section 508/WCAG Standards and the Section 508 regulations, and such overlap is likely to be substantial, covered entities will be encouraged to take a head start towards what will eventually be required compliance with the Section 508 regulations.

This approach still leaves room for the expected evolution of E&IT requirements. Even the way in which we talk about categories of technology today, both domestically and internationally, is evolving; the term E&IT has itself fallen out of favor in the policy and other contexts in favor of the term information and communications technology (ICT). We therefore support HHS allowing this evolution to occur while providing, through the interim adoption of Section 508 and WCAG Standards, a specific and currently enforceable

statement of law that can only help to improve the full and equal participation of people with disabilities in America's health care marketplace.

92.205 Requirements to Make Reasonable Modifications

We are pleased to see the requirements to make reasonable modifications for individuals with disabilities as proposed and agree that the language is consistent with the ADA. However, we believe this section could be strengthened if additional, clarifying language was added which specifies that modifications to add medically necessary care for individuals with disabilities, or eliminating exclusions of medically necessary services, are not considered fundamental alterations to the nature of the health program.
In addition, we would also recommend that HHS provides examples of programmatic modifications that may be needed by individuals with disabilities. Such examples should include:

- Coverage of anesthesia for dental services when necessary for an individual with a disability to access dental or other medical care; and
- Modification of wait times, office hours, and other business practices that may not be accessible for individuals with disabilities.

Further examples of programmatic access are available from the Disability Rights Education and Defense Fund: http://dredf.org/healthcare/Healthcarepgmaccess.pdf.

92.207 Nondiscrimination in Health-Related Insurance and other Health-Related Coverage

§92.207(b) states in very general terms that plans shall not "deny or limit coverage of a claim, or impose additional cost sharing or other limitations or restrictions, on the basis of an enrollee's or prospective enrollee's race, color, national origin, sex, age, or disability; [or] (2) Employ marketing practices or benefit designs that discriminate on the basis of race, color, national origin, sex, age, or disability in a health-related insurance plan or policy, or other health-related coverage." While CCD applauds the overarching goal of this requirement, we are concerned that absent more specificity, its scope will not be clear.

We urge the Department to provide additional guidance in the final rule concerning what constitutes disability-based discrimination in health insurance, including discriminatory benefit design, discriminatory payment structures, discriminatory network design, and discriminatory coverage decisions. The bare statement in the proposed rule that Section 1557 prohibits discriminatory benefit design offers no information to beneficiaries about their rights under Section 1557 and no information to plan administrators, Medicaid officials, and others about their obligations under Section 1557. In order for Section 1557 to be implemented effectively, covered entities and protected individuals must have more guidance concerning the meaning of disability-based discrimination in health insurance.

This additional guidance is crucial because insurance companies discriminate against people with disabilities in a variety of ways, including through drug formularies, narrow networks, increased cost-sharing, wellness programs, utilization management programs,

and limits or caps on certain services. These discriminatory practices are often driven by a desire to reduce costs. However, limiting access to health care for people with disabilities or chronic conditions is pennywise and pound foolish, often resulting in further complications and avoidable hospital admissions and readmissions.

We urge HHS to adopt the following principles in the final rule:

(1) Coverage that Promotes Needless Segregation

One form of disability-based discrimination is the needless segregation of individuals with disabilities. *Olmstead v. L.C.*, 527 U.S. 581 (1999). See also 28 C.F.R. §35.130(b)(7) (covered entities shall administer services to individuals with disabilities in the most integrated setting appropriate to their needs). The Americans with Disabilities Act and Section 504 of the Rehabilitation Act require covered entities to serve individuals with disabilities in integrated settings unless doing so would "fundamentally alter" their service systems. HHS has recognized in the context of Medicaid managed care that insurance plans must comply with the ADA's integration mandate, including having payment structures that encourage community-based care and benefits coverage that does not promote segregation.[24] Section 1557 explicitly incorporates Section 504's prohibitions against disability-based discrimination. Hence disability-based discrimination under Section 1557 necessarily includes needless segregation just as it does under Title II of the ADA and Section 504.

To give effect to Section 1557, OCR should state clearly in the text of the final rule that discrimination under Section 1557 includes, among other forms of discrimination:

> (a) Making coverage decisions that result in people with disabilities 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.

---

[24] Department of Health and Human Services, Centers for Medicare & Medicaid Services, *Guidance to States using 1115 Demonstrations or 1915(b) Waivers for Managed Long Term Services and Supports Programs* 3 (May 20, 2013) ("All MLTSS programs must be implemented consistent with the Americans with Disabilities Act (ADA) and the Supreme Court's Olmstead v. L.C. decision. Under the law, MLTSS must be delivered in the most integrated fashion, in the most integrated setting, and in a way that offers the greatest opportunities for active community and workforce participation."). *See also Id*. at 10 ("In keeping with the intent of the ADA and Olmstead decision, payment structures must encourage the delivery of community-based care and not provide disincentives, intended or not, for the provision of services in home and community-based settings"), and 13 ("States that exclude specific services from their MLTSS programs will be expected to routinely assess whether there is any negative impact as a result of the exclusion and whether there are any violations of federal requirements, including the ADA or Olmstead").

(b) 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.
(c) Designing a particular benefit – such as personal care services – so that it is offered in greater amounts to individuals in segregated settings.

(2) Unequal Coverage

OCR should state clearly in the text of the final rule that discrimination under Section 1557 includes, among other forms of discrimination:

(a) Failing to offer coverage that is as effective for individuals with disabilities as for individuals without disabilities – and similarly, failing to offer coverage that is as effective for individuals with a particular type of disability as for individuals with other types of disabilities.[25] Cf. 28 CFR §35.130(iii) (covered entities under Title II of the ADA shall not provide a qualified individual with a disability with an aid, benefit, or service that is not as effective in affording equal opportunity to obtain the same result, to gain the same benefit, or to reach the same level of achievement as that provided to others). For example, a plan that fails to cover core services commonly needed by people with HIV, or by people with intellectual or psychiatric disabilities, would violate Section 1557. Similarly, failure to cover durable medical equipment and assistive technology commonly used by individuals with physical disabilities would violate Section 1557. In addition, an insurance plan that covers organ transplants for most people but refuses to cover organ transplants for people with certain disabilities, based on stereotypes about people with disabilities and not on the likelihood that the transplant would provide a medical benefit, would violate Section 1557.

(3) Disability-based coverage distinctions that are not justified by actuarial data.

OCR should clearly state in the text of the final rule that, in addition to other forms of discrimination, Section 1557 prohibits:

(a) Making disability-based distinctions in coverage that are not justified by legitimate actuarial data. Section 504 extends to the terms and conditions of insurance policies, and not simply to whether or not an individual is afforded insurance coverage. See, e.g., 28 C.F.R. Part 36, App. B, § 36.212 (Department of Justice regulations implementing Title III of the ADA, stating that "[l]anguage in the [ADA] committee reports indicates that Congress intended to reach insurance practices by prohibiting differential treatment of individuals with disabilities in insurance offered by public accommodations unless the differences are justified;" 29

[25] Non-discrimination laws such as the ADA reach discrimination among different disability groups. See *Olmstead v. L.C.*, 527 U.S. 581, 602 n. 10 (1999).

C.F.R. Part 1630, App., § 1630.16(f) (EEOC interpretive guidance for regulations implementing Title I of the ADA, stating that a covered entity cannot deny a qualified individual with a disability equal access to insurance or subject a qualified individual with a disability to different terms or conditions of insurance based on disability alone if the disability does not pose increased risks). Section 504 prohibits all disability-based distinctions in insurance coverage that are not justified by legitimate actuarial data or actual or reasonably anticipated experience. 29 C.F.R. Part 1630, App., § 1630.16(f). Such data or experience cannot be based on generalized information about the cost of covering individuals with a particular condition or covering particular services, and must be consistent with the Affordable Care Act's community rating provisions.

Examples of Disability Discrimination

The disability community included many examples of disability discrimination in health programs and activities in response to the RFI and we would refer OCR back to those comments.[26] In addition, CCD also wishes to provide OCR with additional specific examples of disability-based discrimination, which we urge OCR to include in the final rule:

(1) Organ Transplants

An example of a "health care program or activity" in which people are regularly discriminated against today on the basis of disability alone, rather than on the efficacy of the treatment, is organ transplantation. People disabilities – particularly people with intellectual disabilities and developmental disabilities – are regularly denied access to organ transplants on the basis of their disability. According to multiple studies conducted on organ transplant centers in the United States, many centers consider the mere presence of intellectual or developmental disability to be a contraindication to transplantation.[27]This was more likely to be true of heart transplants than other transplants.[28] Ironically, heart transplants are of critical utility to people who also have co-occurring congenital heart conditions, such as those that often occur in Down Syndrome.[29]

While this form of discrimination is prohibited under federal anti-discrimination provisions (such as the ADA and Section 504 of the Rehabilitation Act), there is very little guidance that has come out from the federal government for providers on the difference

[26] Disability Rights Education & Defense Fund, Comments, Re: Docket No. HHS-OCR-2013-0007 (Request for Information Regarding Nondiscrimination in Certain Health Programs or Activities) (2014), available at http://dredf.org/wp-content/uploads/2013/10/1557-Disability-Comment-Final.pdf.

[27] Levenson JL, Olbrisch ME. "Psychosocial evaluation of organ transplant candidates: A comparative survey of process, criteria, and outcomes in heart, liver, and kidney transplantation." *Psychosomatics* 1993 Jul-Aug;34(4):314-23.

[28] Richards CT, Crawley La Vera M, Magnus D. "Use of neurodevelopmental delay in pediatric solid organ transplant listing decisions: Inconsistencies in standards across major pediatric transplant centers." *Pediatric Transplantation* 2009:13:843–850.

[29] ASAN Organ Transplantation Policy Brief, http://autisticadvocacy.org/wp-content/uploads/2013/03/ASAN-Organ-Transplantation-Policy-Brief_3.18.13.pdf.

between a medical decision and a decision that is based purely on discrimination.[30]Many clinicians incorrectly presume that they have discretion to turn away patients with disabilities for reasons having nothing to do with the likely efficacy of the treatment itself.

We feel that clarifying that Section 1557 of the Affordable Care Act prohibit discrimination on the basis of disability in health care treatment options as well as "health care programs" would support the anti-discriminatory purpose of the revisions.

(2) Prescription Drugs

Health plan enrollees living with chronic health conditions and other disabilities have witnessed discriminatory benefit design by some insurers, particularly in the coverage of prescription medications, which many beneficiaries living with chronic and serious health conditions rely on to remain healthy and alive. Some marketplace plans are placing all or almost all medications to treat a certain condition on the highest cost tier.

In the preamble of the Notice of Benefit and Payment Parameters for 2016 and in the 2016 Letter to Issuers, HHS has gone on record and stated that these practices could be discriminatory. In the Letter to Issuers, CMS cautions issuers from discouraging enrollment of individuals with chronic health needs and provided examples of discriminatory plan designs. One example identified was "if an issuer places most or all drugs that treat a specific condition on the highest cost tiers, that plan design might effectively discriminate against, or discourages enrollment by, individuals who have those chronic conditions."

In order to protect beneficiaries and to provide clarity to state and federal regulators, CCD urges HHS to include in regulatory language the practice of placing all or nearly all medications to treat a certain condition on the highest tier to be discriminatory.

In addition, plan enrollees with disabilities have experienced other design benefits that amount to discrimination, including not covering certain medications or not following treatment guidelines, imposing excessive medication management tools such as unreasonable prior authorizations and/or step therapy, charging patients high cost sharing, requiring patients to "try" lower tier drugs before accessing a higher tier, and having narrow provider networks.

Therefore, in the final rule or through further guidance or FAQs, CCD recommends that HHS stipulate that employing these types of practices is clearly defined as discrimination. Standards and parameters for benefit and plan design should be detailed in the final rule, along with acceptable practices. Unfortunately, the proposed rule is completely silent in this area and regulators, beneficiaries, and insurers are not provided with any clarity on what constitutes discrimination.

(3) Habilitative and Rehabilitative Services and Devices

[30] ASAN Organ Transplantation Policy Brief.

EHB benchmark plans and qualified health plans (QHPs) often demonstrate discriminatory benefit design in providing coverage for habilitative and rehabilitative services and devices. Within this category, people with disabilities experience discrimination on the basis of age, disability, and the type or severity of their disability. Below are several examples of discrimination that OCR should include as examples of discrimination in its final rule on non-discrimination.

(a) Habilitation and Developmental Disability:

Habilitation refers to services or devices that help people *gain* or maintain skills or functioning that they have never had. Rehabilitation refers to services or devices that help people *re-gain* or maintain skills or functioning that they have lost due to illness or injury. People with developmental disabilities are routinely denied coverage for habilitative services, such as physical therapy, needed to gain skills or improve functioning while an identical service is provided to individuals who would require rehabilitative care to restore functioning. We contend that these types of blanket service exclusions should be considered "unlawful on its face" in the same manner that is proposed to apply to gender transition-related care, as excluding habilitation coverage systematically denies services for people with developmental disabilities and is prohibited discrimination on the basis of disability.

Essential Health Benefits are required to cover habilitation. However, a few insurers have limited the availability of habilitative services and devices to people with specific diagnoses or developmental disabilities, at the exclusion of people with similar disabilities or health care needs. The essential health benefit category of rehabilitative and habilitative services and devices is a broad grouping of services and supports that benefit a wide variety of people with disabilities, and remediate a wide variety of developmental conditions. The Congressional intent of this provision was expressed by The Honorable George Miller, Chairman of the House Committee on Education and Labor, a committee with primary jurisdiction over the House health reform bill, when he explained that the term rehabilitative and habilitative services:

> "…includes items and services used to restore functional capacity, minimize limitations on physical and cognitive functions, and maintain or prevent deterioration of functioning. Such services also include training of individuals with mental and physical disabilities to enhance functional development." [Congressional Record, H1882 (March 21, 2010)].

Limiting the coverage of habilitative services and devices to people with certain disabilities is discriminatory towards people with other disabilities and fails to ensure that coverage decisions focus on the individualized health care needs of each person.

(b) Hearing Aids:

In the most recent release of benchmark plans for determining Essential Health Benefits for the 2017 plan year, the Habilitation Benefits Coalition found the following limits in on coverage for hearing aids in all 50 states and the District of Columbia.

- The benchmark plan offers no coverage for hearing aids in Alabama, Alaska, Arkansas, California, Florida, Georgia, Idaho, Indiana, Iowa, Kansas, Michigan, Mississippi, Montana, Nebraska, North Dakota, Ohio, Pennsylvania, South Carolina, South Dakota, Utah, Vermont, Virginia, Washington State, Washington, DC, West Virginia, Wyoming.
- The benchmark plan covers hearing aids only for children, while denying coverage for adults in Colorado, Connecticut, Delaware, Illinois, Kentucky, Louisiana, Massachusetts, Maryland, Maine, Minnesota, Missouri, New Jersey, New Mexico, North Carolina, Oklahoma, Oregon, Rhode Island, Tennessee, Texas, Wisconsin.

Hearing aids and similar technologies are "rehabilitative or habilitative devices" and, as such, must be covered under every state's EHB benefit package for 2017. Failure to cover hearing aids and similar technologies violates both the ACA's statute and regulations. Failing to cover hearing aids discriminates against people with hearing impairment, and coverage of hearing aids for children only and not for adults also violates the ACA prohibition against discrimination in plan design based on age.

(c) Prosthetics and Orthotics:

The 2017 Essential Health Benefits benchmark plan for New York State initially included a policy limiting coverage to only one external prosthetic device, per limb, per lifetime. This would have served as the baseline for QHPs in the New York State Health Insurance Marketplace and had disastrous implications for people with disabilities who need prosthetics. The policy would have effectively meant zero coverage for the individual based on their disability once the useable life of their first prosthetic had ended. Limiting the number or frequency of replacements for prosthetics or orthotics also has a discriminatory impact on children with disabilities, who need frequent replacements as they grow. Such policies not only violate the ACA requirements for coverage of habilitative and rehabilitative services and devices, but also provides an example of the kind of limits and utilization management that specifically target people with disabilities, and are discriminatory.

(d) Visit Limits:

The ACA, in describing requirements of Essential Health Benefit packages, requires that the Secretary "not make coverage decisions…or design benefits in ways that discriminate against individuals because of their age, disability, or expected length of life." (ACA Section 1302(b)(4)(B)). Section 1557 further prohibits discrimination on the basis of disability. Finally, the ACA disallows monetary caps on coverage. However, EHB benchmark packages approved by the Secretary continue to include hard limits on the coverage of habilitative and rehabilitative services and devices, especially in a total number of visits allowed. These limits are a de-facto annual monetary cap on coverage, which violates the ACA. Further, these limits discriminate against people with more significant disabilities who need higher levels of therapy, thus violating Sections 1302 and 1557. Limitations on the number of covered visits without regard for medical necessity, best medical practices, or the extent of therapy prescribed to the individual discriminates against people with more significant disabilities who need this extensive habilitation or rehabilitation in order to gain, regain, or maintain functioning.

In the proposed regulatory language, Section 92.207(b)(1) prohibits a covered entity from limiting a health insurance plan, policy or other health coverage, or limiting coverage of a claim, or imposing limitations on the basis of an enrollee's disability. Section 92.207(b)(2) prohibits a covered entity from employing marketing practices or benefit designs that discriminate on the basis of disability. Any caps on coverage of habilitative or rehabilitative services or devices would violate these proposed regulations. OCR should finalize these regulations and then issue guidance describing this discrimination.

Subpart D – Enforcement

Individual Enforcement:

We urge the Department to clarify that disability discrimination claims brought under Section 1557 claims may be privately enforced and that damages are available. The preamble correctly notes that "based on the statutory language [that enforcement mechanisms under Title VI, Title IX, the Age Act, or Section 504 apply for violations of Section 1557], a private right of action and damages for violations of Section 1557 are available to the same extent that such enforcement mechanisms are provided for and available under Title VI, Title IX, Section 504, or the Age Act with respect to recipients of Federal financial assistance."[31] It is well established that claims under Section 504 may be privately enforced and that damages are among the remedies available for violations of Section 504. To provide clarity, however, it is critical that this language be included in the text of the final rule and not simply in the preamble.

Government Enforcement:

An individual, complaint-driven system of enforcement is particularly limiting in healthcare for a number of reasons. First, many individuals are understandably reluctant to submit individual complaints. For example, the need for ongoing relationships with healthcare providers (and particularly specialists in practice areas where there is a shortage of practitioners, and in rural areas where practitioners are in short supply) makes it difficult for individuals to file complaints concerning discrimination by providers. Second, individual complaints cannot typically produce resolutions in time to address pressing health care needs. Third, the complexity of Affordable Care Act implementation may make it difficult for many forms of discrimination to be addressed through the individual complaint process. Fourth, individual complaints are often a poor vehicle for creating needed systemic change. OCR should prioritize enforcement of Section 1557 with respect to systemic problems and should involve the Justice Department (DOJ) whenever DOJ has concurrent authority, including referring matters to DOJ for litigation whenever appropriate.

[31] 80 Fed. Reg. 54192 (Sept. 5, 2015).

In addition, we urge that OCR, as part of its efforts to enforce Section 1557, work with CMS to ensure that CMS contracts with state health care agencies and managed care organizations include non-discrimination provisions and consequences for failing to comply with these provisions. OCR should also ensure that compliance reviews concerning accessibility do not rely on self-evaluations and also include unannounced visits to providers and health care entities to review accessibility.

We, the undersigned members of the CCD Health, Rights, and Technology & Communications task force thank you again for the opportunity to comment on such an important regulation, and strongly support the antidiscrimination and enforcement efforts of OCR. If you have any questions please contact Rachel Patterson (rpatterson@christopherreeve.org).

Sincerely,

ACCSES
American Association of People with Disabilities
American Association on Health and Disability
American Association on Intellectual and Developmental Disabilities
American Foundation for the Blind
American Network of Community Options and Resources
American Occupational Therapy Association
American Therapeutic Recreation Association
Association of University Centers on Disabilities
Autism Speaks
Autistic Self Advocacy Network
Bazelon Center for Mental Health Law
Brain Injury Association of America
Christopher & Dana Reeve Foundation
Dialysis Patient Citizens
Disability Rights Education and Defense Fund
Easter Seals
Epilepsy Foundation
Family Voices
Lupus Foundation of America
Lutheran Services in America Disability Network
National Alliance on Mental Illness
National Association of Councils on Developmental Disabilities
National Association of State Head Injury Administrators
National Council on Independent Living
National Disability Rights Network
National Down Syndrome Congress
National Health Law Program
National Multiple Sclerosis Society
Paralyzed Veterans of America

Rehabilitation Engineering and Assistive Technology Society of North America
SourceAmerica
The Arc of the United States
United Cerebral Palsy
United Spinal Association