Sept. 30, 2013

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

Dear Mr. Rodriguez:

The Consortium of Citizens with Disabilities (CCD) Rights Task Force submits these comments in response to the HHS Office for Civil Rights (OCR) Request for Information regarding Section 1557 of the Affordable Care Act (ACA) and Nondiscrimination in Certain Health Programs or Activities, RIN 0945–ZA01 (Aug. 1, 2013). CCD is a coalition of national disability-related organizations working together to advocate for national public policy that ensures full equality, self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.

Question 1 – Discrimination Under Section 1557

We urge the Department to provide additional guidance concerning the applications of Section 1557 to disability-based discrimination in health insurance. For example, one form of disability-based discrimination is the needless segregation of individuals with disabilities. *Olmstead v. L.C.*, 527 U.S. 581 (1999).[1] See also 28 C.F.R. § 35.130(b)(7) (covered entities shall administer

[1] 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").

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. To give effect to the Section 1557:

OCR should state that discrimination under Section 1557 includes, among other forms of discrimination:

> (1) 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.
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> (2) 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.
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> (3) Designing a particular benefit – such as personal care services – so that it is offered in greater amounts to individuals in segregated settings.
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> (4) 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.[2] 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 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.
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> (5) Excluding, treating differently, or otherwise discriminating against providers based on disability in determining which providers will be covered by insurance plan networks. For example, an insurance company's refusal to allow a qualified doctor into its network based on the doctor's mental health history would violate Section 1557.

Question 2 – Health Programs and Activities

OCR should clarify that health programs and activities include, among other things:

[2] 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).

- 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

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.

Question 6 – Health Information Technology

Other forms of discrimination include the inaccessibility of Health Information Technology (HIT). The ACA recognizes that 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, but if the HIT that supports the U.S. healthcare system must be accessible to individuals with disabilities.

OCR should clarify that Section 1557 requires health care providers, hospitals, clinics, and other healthcare programs and activities to provide fully accessible HIT systems in accordance with the World Wide Web Consortium (W3C)[3] and the Web Content Accessibility Guidelines (WCAG 2.0)[4] establishing accessibility standards for websites and electronic communication.[5] All HIT records or plans must be displayed to individuals and service providers in simple language and have fully accessible and consumer-friendly interfaces.

OCR should clarify that Section 1557 requires HIT records to be compatible with screen reading software and other kinds of software and hardware commonly used by people with various disabilities. Patients and providers with disabilities who use screen reading software, speech recognition software and other technological interfaces must be able to use those devices to read, correct and enter information into health records.

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[3] *See* http://www.w3.org/.

[4] Available online at: http://www.w3.org/TR/WCAG20/.

[5] 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. In addition, OCR should take into account Section 508 of the Rehabilitation Act of 1973[5] and its forthcoming 508 regulations, which will apply to all technology purchased and used in federally conducted programs and activities including those using, managing or directing HIT.

Question 7 – Enforcement

An individual, complaint-driven system of enforcement is particularly limiting in healthcare for a number of reasons. First, many reluctance to submit individual complaints. For example, he 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.

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 MCOs 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.

Sincerely,

Sincerely,

Curt Decker
National Disability Rights Network

Jennifer Mathis
Bazelon Center for Mental Health Law

Sandy Finucane
Epilepsy Foundation

Mark Richert
American Foundation for the Blind

Co-Chairs, CCD Rights Task Force