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Of Disability Advocacy
1973-2013

U.S. Department of Health and Human Services
Office for Civil Rights
Attention: 1557 RFI (RIN 0945-AA02)
Hubert H. Humphrey Building
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)

The Consortium for Citizens with Disabilities Health Task Force appreciates 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. In addition to this submission of comments, the HTF Co-Chairs request a meeting with OCR staff to discuss in detail our recommendations.

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 non-discrimination protections provided in the Affordable Care Act is crucial to effective implementation of health insurance market reform.

Existing ACA regulations developed by the Department of Health and Human Services (HHS), Department of Labor and the Internal Revenue Service give only the slightest of detail on how the non-discrimination protections in the ACA will be implemented and enforced. It is imperative that OCR develop meaningful nondiscrimination regulations around both Section 1557 and Section 1302 of the ACA to ensure health care reform applies to people with disabilities and chronic health conditions.

Meaningful nondiscrimination regulations would include requirements that health insurance issuers, health exchanges, health systems and health programs (including demonstrations and pilots initiated through HHS or state health and Medicaid programs) provide:

1) Meaningful access to and coverage of essential health benefits (EHB), and the health professionals who provide them, with significant monitoring of benefits critical to people with disabilities, such as rehabilitative and habilitative services and devices and mental health and behavioral health services;
2) Protections against and monitoring for discriminatory health plan design;
3) Programmatic, physical and cognitive accessibility features for individuals with disabilities and chronic health conditions; and

4) Research and data collection efforts to include rare diseases and conditions and a focus on outcome measures meaningful for individuals with disabilities and chronic health conditions, including those measuring function and community integration.

CCD recommends that OCR provide continuing federal input and oversight of ACA nondiscrimination standards, and specifically consider:

- Working with the National Association of Insurance Commissioners to formalize a committee designated to review and make recommendations on national health insurance nondiscrimination standards, including EHB standards, to CCIIO and HHS;
- Creating or designating a department within the Office of Civil Rights to specifically address discrimination in the reformed insurance markets; and
- Formalizing a process for stakeholders to regularly provide feedback on insurance market, EHB and non-discrimination standards and practices.

Please contact Theresa Morgan, CCD HTF Co-Chair, at Theresa.Morgan@ppsv.com or 202-466-6550 with any questions.

Meaningful Access to and Coverage of EHB

All qualified health plans (QHPs) must cover the 10 mandated categories of benefits listed in the ACA. The ACA also requires the definition of EHB in a manner that (1) reflects appropriate balance among the 10 categories; (2) is not designed in such a way as to discriminate based on age, disability, or expected length of life; (3) takes into account the health care needs of diverse segments of the population; and (4) does not allow denials of EHB based on age, life expectancy, or disability. ACA, Sections 1302(b)(4)(A) through (D).

CCD recommends that OCR specify in regulation that appropriate balance standards require QHPs to:

- Cover benefits explicitly listed within the 10 categories of benefits within the statute; and
- Cover EHB benefits across the continuum of care equally; that is, an EHB-benchmark plan cannot impose a financial requirement (such as copayments or coinsurance) or a quantitative treatment limitation (such as a limit on the number of outpatient visits or inpatient days covered) on one benefit category that is more restrictive than the predominant requirements or limitations that apply to other benefit categories.
- Cover all EHB benefits within the settings and by the specialists which provide the current standard of care for the benefit; and
- Prohibit substitution between categories of EHB; and
- Prohibit substitution between benefits explicitly listed by statute within a category of EHB; and
- Protect participant access to appropriate and medically necessary care when allowing substitution within benefits.

CCD recommends that OCR specify in regulation that QHPs take into account the health care needs of diverse segments of the population by:

- Establishing a process for participants to request and receive coverage for benefits not routinely covered by the plan;
- Providing a process that allows an enrollee to request clinically appropriate benefits not covered by the health plan, as proposed for the prescription drug benefit;
- Provide a process for participants to request and receive coverage for benefits beyond the limits set by the plan when medically necessary and appropriate; and
- Provide a process for participants to request and receive coverage of specialist care not routinely covered by the plan when medically necessary and appropriate.

Protections Against and Monitoring for Discriminatory Plan Design

CCD recommends that OCR specify in regulation that non-discriminatory plan design standards require QHP issuers to, at a minimum:

- Report data showing they do not discriminate based on age, disability, or expected length of life;
- Prohibit more burdensome participant cost-sharing on some benefits than others; and
- Prohibit unreasonable and arbitrary visit and dollar limits on a specific category of benefits, so as to discourage participation by individuals with certain health conditions or disabilities; and
- Prohibit the targeted use of utilization management techniques for some benefits, and not others; and
- Prohibit defining the benefits in such a way to exclude coverage for those services based upon age, type of disability or expected length of life.

In addition, OCR should require QHPs to meet and adhere to specific network adequacy standards. People with disabilities must have access to and a choice of a wide variety of specialists, therapists and other providers that offer disability specific services in order to receive the medical care needed to maintain and improve function and overall health. Network adequacy must evaluate whether providers of essential health benefits are actually available to enrollees without unreasonable delay or travel. A standard that merely counts the numbers and types of providers should not be considered sufficient.

CCD urges OCR to provide in regulation detailed requirements for QHPS to provide:

- Access to providers of essential health benefits over the continuum of care (i.e. inpatient, outpatient and home and community based providers)
- Access to community-based providers, including non-profit providers, with a documented experience in serving persons with disabilities;
- Access to community-based providers defined in Section 340 (B) (a) (4) of the Public Health Service Act, as required by Section 1311 (c)(1) (C) of the Affordable Care Act (ACA);

- Geographic access, so persons with disabilities are not burdened with great traveling distances;
- Access to disability-specific specialists and services; and
- Choice – each health exchange and qualified health plan (QHP) enrollee should have a choice of primary and specialized provider.

We recommend that OCR provide in regulation examples of discriminatory benefit designs. For example, discriminatory benefit design could result in:

- Exclusions for otherwise-covered services for cases other than those in which the purpose of the treatment is to recover lost functioning or to restore previous levels of functioning. Such exclusions have a disparate impact on individuals with developmental disabilities who rely on services to attain certain functions or to avert their loss or deterioration. While the Affordable Care Act requires coverage of both rehabilitative and habilitative care, this requirement will mean little if issuers are permitted to continue to employ limited ideas of how broad the range of services covered under the category of habilitative care must be.

- Restrictions on "medically necessary" treatment within a benefit category to cases in which the services are required for the treatment of "illness, injury, diseased condition, or impairment." This type of limitation is frequently used to deny coverage for health conditions classified as being present at birth rather than the result of a disease process.

- Exclusions for mental health, substance use disorder, and behavioral health treatments that fail to meet the parity standards required by the Mental Health Parity and Addition Equity Act of 2008 (MHPAEA). Despite these existing parity requirements, state implementation and enforcement of MHPAEA has varied widely. Additionally, patients seeking mental health services are frequently subjected to excessive and inappropriate non-quantitative limitations.

Accessibility Features

CCD recommends that OCR specify in regulation that QHP issuers, providers, programs and systems must, at a minimum:

- Comply with the Americans with Disabilities Act and related civil rights requirements to ensure that persons with disabilities have access to accessible facilities and programs;
- Applications and notices must be provided, as requested, in alternate formats, including Braille, large print, or another effective method of making visually delivered materials available to individuals with disabilities, including individuals who are blind and who have low vision;
- Applications and notices should be in plain language and presented at or below the 6th grade proficiency and comprehension level;
- Call centers operated by QHP issuers must include telecommunications relay services to effectively serve persons who are deaf and hard of hearing;

- QHPs are required to inform consumers of the availability of auxiliary aids and services such as qualified interpreters, note-takers, and materials in alternate formats;
- QHPs must provide auxiliary aids and services at no cost to the consumer;
- Websites and electronic documents must be compatible with screen reader software;
- Websites and electronic documents must meet Section 508 standards or standards that provide greater accessibility to persons with disabilities.

Research and Data Collection

The RFI refers to the 2011 report entitled *Health and Human Services Action Plan to Reduce Racial and Ethnic Health Disparities.* The authors acknowledge that the report "focuses primarily on health disparities associated with race and ethnicity," and does not focus on disability as a disparity. As the ACA requires, it is critical that monitoring of disparities include data collection and review specific to disability.

Thank you for consideration of our comments. Please contact Theresa Morgan, CCD HTF Co-Chair, at Theresa.Morgan@ppsv.com or 202-466-6550 with any questions.

Sincerely,

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