

December 26, 2012

VIA ELECTRONIC SUBMISSION

Centers for Medicare & Medicaid Services
Department of Health and Human Services
P.O. Box 8010
Baltimore, MD 21244-8010

**Attention: CMS-9980-P
Patient Protection and Affordable Care Act; Standards Related to
Essential Health Benefits, Actuarial Value, and Accreditation**

Dear Sir or Madam:

Disability Rights Education and Defense Fund (DREDF) is a leading national law and policy center that advances the civil and human rights of people with disabilities through legal advocacy, training, education, and public policy and legislative development. As a cross-disability organization, we are acutely aware of the impact that both the lack of health insurance and underinsurance has on the health care, employment, and capacity to live in the community of people with disabilities (PWD). Thank you for the opportunity to comment on the Essential Health Benefits (EHB), actuarial value, and accreditation standards released November 26, 2012 by the Department of Health and Human Services (HHS).

DREDF supports comments submitted by the Consortium of Citizens with Disabilities, the Bazelon Center for Mental Health Law, the National Health Law Program, and Health and Disability Advocates on the proposed EHB regulation. These organizations have clearly indicated where and how the proposed rule sacrifices consumer needs and protections in favor of state flexibility, and have also made excellent recommendations for a more appropriate balance between affordability and the urgent need to provide consumers with adequate, effective health insurance.

We do not intend to repeat the many strong arguments made in the comments mentioned above, and are writing separately primarily to emphasize that long-standing health insurance discrimination experienced by PWD will not be remedied through § 156.125's simple prohibition on discrimination in benefit design and implementation. In essence, the benchmark approach that HHS proposes for the next three years already abdicates an unwarranted degree of control over benefit design and implementation, including limitations imposed on those benefits, to individual states and plans. The absence of specific standards relating to *when* benefit design and implementation discriminates against individuals in terms of age, expected length of life, present or predicted disability, degree of medical dependency, quality of life, or other health conditions," and firm guidance on *how* to make discrimination-free decisions on coverage, reimbursement rate determination, incentive programs, and other aspects of benefit design and implementation, further exacerbates the uncertainty and potential for

underinsurance faced by millions of PWD across the country. HHS cannot ensure that consumers with disabilities have individual and small group insurance choices that are as effective as those afforded to other consumers unless it establishes federal expectations through standards and guidance, *and* sets public transparency and data requirements for states and the insurance industry, as well as concrete monitoring, and implementation roles for HHS itself and the state Exchange infrastructure.

The Affordable Care Act (ACA) frames broad and ground-breaking non-discrimination mandates, but they are newly imposed upon a health insurance infrastructure that has historically relied on actuarial design and benefit implementation practices that limit the coverage of PWD. The “safe harbor” provisions of the Americans with Disabilities Act of 1990 have been interpreted in an arguably overbroad fashion in the legal understanding of private insurance companies and state regulators. Stated at its most benign, the private health insurance industry currently lacks any background of best practices for the full inclusion of PWD. Two areas in particular that need federal guidance, where discriminatory practices against PWD are deeply imbedded in the status quo, are rehabilitative and habilitative services and devices (rehab/hab), and mental health and substance abuse services.

In many states, the EHB category of rehab/hab is not common in health insurance vernacular. “Habilitation” is a virtually unknown concept, and many kinds of devices are more frequently understood as “durable medical equipment” (DME). In California, there is an imbedded discriminatory practice in the small group insurance market whereby the DME benefit is specifically subject to special annual and/or lifetime limitations, imposed on top of substantial cost-sharing measures such as high deductibles or cost-shares that are commonly imposed across benefits. Such extraordinary coverage limitations force employees who have need such high-cost DME needs as power wheelchairs and custom seating to pay thousands of dollars out-of-pocket. The insurance practice also leave employers in the difficult situation of trying to find an affordable small group plan that provides DME parity for employees who have or acquire DME needs, a species of insurance that is increasingly extinct in California, or engage in discriminatory practices such as refusing to hire or retain PWD who have or could acquire DME needs. We have shared these concerns in a prior comment letter, illustrated in considerable detail with examples and data from California’s small group insurance market, that was submitted to the Honorable Secretary Sebelius in February 2012.

Mental health and substance abuse services have been subject to even greater historical discriminatory practices, particularly in the small group market since the plans of employers with 50 or fewer employees are exempt from the Mental Health Parity and Addiction Equity Act (MHPAEA). While we deeply appreciate the proposed rule’s explicit mention of the MHPAEA’s application to EHB plans, there is a dearth of guidance on non-discriminatory plans will look like, and no details on what parity and non-discrimination require in such crucial aspects as medical necessity criteria, treatment limitations, benefit exclusions, or financial and staffing requirements.

These long-standing issues for PWD will not be addressed unless and until HHS provides strong federal guidance and requirements that include:

- Parity among the ten EHB benefit categories in terms of coverage scope, amount, and duration, and equal restrictions on the benefit limitations (both cost-share/deductible and annual/lifetime) that may be imposed on coverage. There must also be parity *within* the components of each category where distinct components are conceived for coverage (such as habilitation and rehabilitation, services and devices), and it must be clear that the lack of parity *is* discriminatory benefit design that leaves some people with certain functional impairments or chronic conditions unable to obtain effective health insurance coverage.
- Explicitly define the EHB category rehab/hab since this is a virtually unknown category to most states and insurance companies. Both rehabilitation and habilitation are critical services for enabling PWD to remain in their communities and lead functional and productive lives.
- Temper the substantial discretion given to states and plans by both removing the “substantial” qualifier that enables a health plan to qualify as an EHB plan when it provides benefits that “are substantially equal to the EHB benchmark plan,” and by establishing clear criteria for how a benefit will be determined “equal” within each EHB category.
- Specify that parity for mental health benefits means benefits that are no more subject to limitations on amount, scope, and duration than benefits intended for physical/medical conditions. HHS should also clarify that mental health services can be a component of other EHB categories, such as the mental health rehabilitation needs that will follow a traumatic medical event.
- Establish ongoing procedures for states and plans to monitor and share data on how they are meeting their benefit design and implementation anti-discrimination obligations over time, and make this information transparently and readily available in at least an aggregate fashion to the public and to health advocates.

Finally, we would like to applaud the agency for many details in the proposed final rule. For example, we strongly support HHS’s decision to disallow benefit substitutions *between* benefit categories, a concept that was contemplated in the earlier EHB bulletin. We also highly favor the provision in the proposed rule that allows all state-required benefits enacted on or before December 31, 2011, even if implemented on a later date, to be considered part of the states’ EHB packages rather than “additional required benefits” for which states must pay.

Once again, we appreciate this unfortunately truncated 30-day opportunity to comment on the proposed EHB standards. We would be more than happy to answer any questions you may have with regard to our comments, above, or provide any other possible assistance.

Yours truly,

A handwritten signature in blue ink that reads "Susan R. Ford" followed by a horizontal line.

EHB: CMS-9980-P
December 26, 2012
Page 4 of 4

Susan Henderson
Executive Director