Ms. Vanessa Jones  
Centers for Medicare & Medicaid Services  
Department of Health and Human Services  
P.O. Box 8016  
Baltimore, MD 21244-8016  

Re: Request for Information under the Patient Protection and Affordable Care Act: Reducing Regulatory Burdens and Improving Health Care Choices to Empower Patients (CMS-9928-NC)  

Dear Ms. Jones:  

Disability Rights Education and Defense Fund (DREDF) appreciates the opportunity to respond to the Health and Human Services Department’s Request for Information (RFI) concerning existing regulations and guidance enacted under the authority of the Patient Protection and Affordable Care Act. DREDF is a leading national law and policy center that works to advance the civil and human rights of people with disabilities through legal advocacy, training, education, and public policy and legislative development. We are committed to increasing accessible and equally effective healthcare for people with disabilities, and eliminating persistent health disparities that affect the length and quality of their lives.  

We consider disability to be a natural part of the human condition and something that touches virtually every life, experienced among one’s family and friends over one’s lifetime and individually as one ages. Therefore, we understand the need for quality and effective healthcare for people with disabilities as a universal necessity and not a “minority” or specialty interest concern. A healthcare delivery system that is prepared to deliver medically necessary care, services and supports to people with disabilities has been recognized as a policy priority by such major U.S. health institutions as the Institute of Medicine and Healthy People.

In this RFI, HHS has reiterated key principles of affordability, accessibility, quality, innovation, and empowerment for the agency’s work. Specifically, HHS has requested public comments in four specific goal areas for individual and small group health insurance markets. We will be addressing three of the four goal areas.


1. **Empowering patients and promoting consumer choice.** What activities would best inform consumers and help them choose a plan that best meets their needs? Which regulations currently reduce consumer choices of how to finance their health care and health insurance needs? Choice includes the freedom to choose how to finance one's healthcare, which insurer to use, and which provider to use.

Historically people with disabilities (PWD) have had extremely little or no choice in the field of individual and small group markets. Insurers were free to discriminate against people with pre-existing conditions by outright denying coverage, and charging prohibitive premiums on those rare occasions when private insurance could be had. In addition, the insurance that PWD could obtain invariably had high deductibles, annual and lifetime caps, high co-pays, and numerous coverage exclusions, often directed at the very conditions and disabilities which necessitated medical care.

The passage of the Patient Protection and Affordable Care Act (ACA) was nothing short of historic in providing genuine private insurance choices to individuals with disabilities, their families, and the many small businesses owned by or employing PWD. Some key regulations enacted under the ACA that have enhanced consumer choice and finally provided PWD with the ability to finance their healthcare needs include guaranteed issue and renewal for PWD, establishing categories of Essential Health Benefits (EHB) that are important to people with and without disabilities, prohibiting annual and lifetime caps on EHBs, mandating purchase which has greatly enhanced the pool of the insured, and providing subsidies and tax credits that allow lower income individuals to purchase needed healthcare insurance. Eliminating or reducing the effectiveness of any one of these important regulations will result in directly taking freedom away from PWD, who are likely to be restricted by states to high-risk pools that have historically failed to provide PWD with adequate health insurance. We must emphasize that for many PWD, adequate health insurance is **literally** the key to freedom: the freedom to live in their communities with friends and family, to go to school or work, and to lead productive and fulfilling lives.

The support of Navigators and other key information, consumer education, and outreach channels developed under the ACA is also an important component of empowering patients and promoting consumer choice among PWD. DREDF was part of an early coalition effort financed by the Robert Wood Johnson Foundation to provide disability-specific information and support to Navigators in the Federal Exchanges. The purchase of insurance, even with the coverage and Summary of Benefits and Coverage standards initiated under the ACA, remains a complex personal decision for PWD and their families; details matter. We urge HHS to continue to fund and support Navigators in the frontline work that they have been doing since 2013, especially in light of several changes recently instituted in HHS’s Market Stabilization Rule.

We wish to stress the importance of preserving Section 1557's prohibition against discrimination on the basis of factors such as health status, disability, age, race, gender, gender identity, and sexual orientation. Section 1557 helps empower patients and promote consumer choice by ensuring that consumers, including consumers with disabilities and pre-existing conditions, do not encounter discriminatory administrative or
coverage barriers that prevent them from finding and purchasing insurance products that offer effective healthcare services. Moreover, many insurers and state regulatory agencies have already incorporated Section 1557 within their notices and disclosures, as well as more substantively within their benefit design requirements; these industry and state leaders should not be disadvantaged by disruptive changes to such a critical consumer protection.

Finally, we stress that Medicaid expansion under the ACA has also been critical to freedom of choice among PWD. Medicaid expansion closed the gap in many states between Medicaid coverage and private insurance coverage. For PWD whose disabilities may make it extremely difficult to work full-time, or who work for themselves to gain flexibilities of scheduling that are necessitated by their own disability or the disabilities of family members, varying income levels over the course of a year make it very difficult to maintain private insurance or traditional Medicaid. PWD want to and are able to work, but they cannot do so if they do not have avenues to maintain needed health insurance and stable healthcare. A December 2016 report by lead author Jean Hall, a health and disability policy researcher at the University of Kansas Medical Center in Kansas City and the University of Kansas, Lawrence, highlighted the increased employment of PWD in states that had Medicaid expansion. Medicaid expansion is therefore a key component, along with affordable private insurance and a robust Medicaid program, of the range of health coverage options that gives PWD true freedom of choice as patients and consumers.

3. **Enhancing affordability.** What steps can HHS take to enhance the affordability of coverage for individual consumers and small businesses?

On the point of affordability, we stress that HHS must not only consider the costs of premiums, but also the elements of deductibles, co-pays, out-of-pocket costs, and all the other elements of affordability fostered under the ACA. For PWD, and any individual who faces significant healthcare costs, whether known because of a chronic condition or unexpected because of an accident, new diagnosis, or simple aging, the EHB regulations and requirements are critically linked to the affordability of medically necessary healthcare.

4. **Affirming the traditional regulatory authority of the States in regulating the business of health insurance.** Which HHS regulations or policies have impeded or unnecessarily interfered with States’ primary role in regulating the health insurance markets they know best?

DREDF does not believe that HHS regulations or policies have unnecessarily interfered with the role of States’ in regulating health insurance markets. We certainly acknowledge that states do have primary jurisdiction over their local insurance markets, and in fact, strongly support each state’s right to impose regulations and standards among all insurers that sell insurance products to state residents, including any insurers that try to sell across state lines. We note here that the National Association of Insurance Commissioners as well as most state insurance officials do not support the practices of selling insurance across state lines as it is a practice that will impede a state’s authority to establish consumer protections and standards for their own
residents. Federal authorization of health insurance sales across state lines by insurers would constitute unnecessary interference with state insurance authority.

At the same time, even as we recognize state primacy over insurance regulation, we strongly believe that the federal government and HHS has a vital role to play in ensuring that states recognize the civil and constitutional rights of all its citizens, including Americans with disabilities. PWD have the right, affirmed by the Supreme Court in the 1997 *Olmstead* decision, to live in the community with appropriate services and supports rather than be institutionalized. PWD have a right of mobility, and that right is deeply undercut if they cannot leave to pursue career opportunities or be with family in another state that severely curtails healthcare options for PWD. These are not “local” concerns or variations, but true national concerns.

Thank you again for the opportunity to provide comments. We would be happy to answer any questions you may have about the above.

Yours Truly,

Silvia Yee
Senior Staff Attorney