Disability Rights Education & Defense Fund



June 28, 2016

Submitted online at www.regulations.gov

United States Department of Health and Human Services
Centers for Medicare and Medicaid Services
Office of Strategic Operations and Regulatory Affairs
Division of Regulations Development
Attn: Document Identifier/OMB Control Number ____
Room C4-26-05
7500 Security Boulevard
Baltimore, Maryland 21244-1850

Re: Agency Information Collection Activities; Proposals, Submissions, and Approvals (CMS-10488)

Disability Rights Education and Defense Fund (DREDF) appreciates the opportunity to provide comments to the Centers for Medicare and Medicaid (CMS) on its proposed revisions to the Consumer Experience Survey Data Collection on Health Insurance Marketplace and Qualified Health Plans (QHPs). 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 eliminating barriers and increasing access to insurance coverage and effective healthcare for people with disabilities, and eliminating persistent health disparities that affect the length and quality of their lives.

DREDF is writing to strongly support CMS's proposal to add six disability status items to the QHP Enrollee Survey. This addition will place the QHP Enrollee Survey into compliance with section 4302 of the Affordable Care Act, and the questions were already tested during the 2014 psychometric testing of the survey. Substantively, the addition will potentially allow enrollees and potential marketplace enrollees with disabilities to participate in the anticipated benefits of information that will be derived from the survey. These benefits include providing consumers with the information they need to make informed choices among competing health plans, providing QHPs with actionable feedback on their performance, and providing information and giving insight to regulators and accreditation agencies on how plans are or are not meeting the needs of consumers.

People with disabilities often encounter particular barriers when seeking healthcare coverage that arise when carriers do not provide effective communication through auxiliary aids and services, when they fail to provide sufficient detail concerning benefit coverage on such items as drugs, mental health treatment, or durable medical equipment, or when they cannot provide information about the physical or programmatic

CMS Office of Strategic Operations and Regulatory Affairs (CMS-10488) June 28, 2016 Page 2 of 2

accessibility of the providers within the carrier's provider network. There is a growing body of literature documenting the various barriers that people with disabilities encounter when seeking healthcare service and coverage. One recent publication was issued in September 2015 by the CMS Office of Minority Health, which included the two priorities of improving communication and language access for people with disabilities and individuals with limited English proficiency, and increasing physical accessibility of health care facilities, among its six stated priority areas.¹

Clearly, the experience of people with disabilities in the marketplace cannot be seen, analyzed or understood if people with disabilities remain completely unidentifiable among QHP enrollees and potential enrollees. DREDF appreciates that the smaller numbers of people with specific disabilities may present a challenge to researchers who wish to use the survey information as a longitudinal database for consumer research, and also potentially presents a challenge for deriving statistically valid conclusions from the information specifically attributable to self-identified people with disabilities. Nonetheless, it is critical to begin somewhere, and the general public and survey population must be consistently exposed to granular disability information just as they were exposed to granular race and ethnicity information over a substantial period of years before understanding the need and purpose for providing such information. We believe that interesting and valuable data can be obtained through inclusion of the six disability questions in the QHP Enrollee Survey even if the response numbers are relatively low when the survey is first administered.

Thank you for the opportunity to comment on this critical matter of disability data collection in the Marketplace and QHP consumer surveys. We continue to look forward to CMS, and the QHP Enrollee Survey instrument, providing a leading example for states and QHPs to identify and address the health experiences and barriers experienced by people with disabilities. Please do not hesitate to contact me at 510-644-2555 if you have any further questions or wish to discuss the above. I also wish to disclose that I am a member of the Technical Expert Panel (TEP) Meeting for the Health Insurance Marketplace (HIM) Consumer Experience Survey (CES) Project. I sit on the TEP panel as a consumer representative from a disability rights organization and my positions on the panel are in accord with the comments made in this letter on DREDF's behalf.

Yours Truly.

Silvia Yee

Senior Staff Attorney

¹ Centers for Medicare & Medicaid Services, Office of Minority Health. "The CMS Equity Plan for Improving Quality in Medicare" September 2015.