August 27, 2013

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
c/o Kathleen.Jack@cms.hhs.gov
cc: jamaa.hill@cms.hhs.gov

Re: Affordable Care Act, Enrollee Satisfaction Surveys
Health Insurance Marketplace Survey and Qualified Health Plan Survey
CMS-10488/OCN Number 0938-NEW
Federal Register Notice 6-28-2013

Disability Rights Education and Defense Fund (DREDF) appreciates the opportunity to provide comments to the Centers for Medicare and Medicaid (CMS) on its proposed Enrollee Satisfaction Surveys on the 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.

Failure to Identify People with Disabilities and Barriers to Effective Care

Section 4302 of the Affordable Care Act (ACA) amends s. 3101 of the Public Health Act as follows:

2 ‘‘TITLE XXXI—DATA COLLECTION, ANALYSIS, AND QUALITY
SEC. 3101. DATA COLLECTION, ANALYSIS, AND QUALITY.
(a) DATA COLLECTION.
(1) IN GENERAL.—The Secretary shall ensure that, by not later than 2 years after the date of enactment of this title, any federally conducted or supported health care or public health program, activity or survey (including Current Population Surveys and American Community Surveys conducted by the Bureau of Labor Statistics and the Bureau of the Census) collects and reports, to the extent practicable—
(A) data on race, ethnicity, sex, primary language, and disability status for applicants, recipients, or participants;
(B) data at the smallest geographic level such as State, local, or institutional levels if such data can be aggregated;

(C) sufficient data to generate statistically reliable estimates by racial, ethnic, sex, primary language, and disability status subgroups for applicants, recipients or participants using, if needed, statistical oversamples of these subpopulations; and (D) any other demographic data as deemed appropriate by the Secretary regarding health disparities."

CMS references Section 4302 in its entirety as footnote 2 to Part A of its *Supporting Statement for Information Collection Requirements Contained in the Enrollee Satisfaction Survey Data Collection*. While the text of the supporting statement acknowledges that "[d]irect information from consumers' about their experiences over time is essential to detecting and correcting disparities through the quality improvement process," CMS has required **only** "survey-based performance scores for racial, ethnic, and income subgroups within each state."[1] To be very clear, we fully support CMS's efforts to identify race, ethnicity, and income sub-groups and unearth their specific experiences with the marketplaces and QHPs. However, we have deep concerns with CMS's failure to even attempt to identify people with disabilities as a group that experiences disparities, and both unique and common barriers to effective healthcare services. The Supporting Statement recognizes that s. 4302 comprises a "legal basis" for undertaking the proposed surveys and making the information available to consumers, issuers, and regulators, but by failing to include any questions relating to disability status and inaccessibility, CMS appears to be unilaterally amending s. 4302 and expunging disability status from the letter of the law. Moreover, the failure to address disability status is a disservice to Marketplace and QHP consumers, including individuals of a minority race or ethnicity, or with lower income levels. Disability, unlike other immutable personal characteristics, can be experienced by any person at any time as a natural and inevitable part of life, *but* disability health and healthcare disparities are *not* inevitable. Any lost opportunity to identify and redress those disparities will have a negative impact on every Exchange consumer.

We recognize the strengths that CMS has identified behind its proposal to use the Consumer Assessment of Health Providers and Systems (CAHPS), including design principles that prioritize the production of psychometrically sound, credible and useful data, but a preference for CAHPS does not preclude the inclusion of survey questions that identify and address disability status and healthcare barriers. The Supporting Statement mentions CMS undertaking a "comprehensive review of the literature and related surveys, focus groups, stakeholder discussions, and [receiving] input from the technical expert panel (TEP)," [2] but this review apparently disregarded at least one available CAHPS tool that directly addresses the plan and provider experience of people with disabilities (PWD). The *Assessment of Health Plans and Providers by People with Activity Limitations* or "AHPPPAL" is a modified version of the Medicaid Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey that was revised to address the needs of adults with physical, sensory, and/or cognitive disabilities. AHPPPAL is available in English and Spanish and can be administered to people with and without disabilities, allowing also for proxy respondents. A team led by

[1] June 11, 2013 *Health Insurance Marketplace Enrollee Satisfaction Surveys, Supporting Statement—Part A* at 4.
[2] June 11, 2013 *Health Insurance Marketplace Enrollee Satisfaction Surveys, Supporting Statement—Part A* at 2.

Dr. Susan Palsbo at the Center for Health and Disability Research developed the AHPPPAL Survey and Dashboard, which was field-tested with three Medicaid plans in California and became available in 2011. Additional information as well as further technical assistance briefs and tools can be downloaded at: http://www.chcs.org/publications3960/publications_show.htm?doc_id=1261224.

AHPPPAL is a modification of the Medicaid CAHPS, but it is difficult to see why this fact would disqualify AHPPPAL items and tools from review and consideration by the TEP and CMS. In many cases, as in California, the same commercial and non-profit managed care plans that are functioning as Medicaid plans will also be offering products in the Exchange as Qualified Health Plans. However, the Medicaid reference does perhaps capture one possible reason that disability has been so comprehensively ignored in the conceptualization and development of these proposed surveys. There is an enduring stereotype that people with disabilities rely solely on public health programs such as Medicaid and/or Medicare, and therefore will not participate in the Exchange marketplaces or interact with QHPs as consumers.

It is true that disability status is associated with lower rates of both higher education and employment, and PWD are therefore disproportionately likely to be living at lower income levels, but this does not automatically equate with Medicaid eligibility. We have estimated that in 2010, there were as many as 3.5 million adults with disabilities living in the community with household incomes between 100 and 133% of poverty. Many of these individuals with disabilities will be state Exchange consumers at one point or another, whether their state elects to expand Medicaid eligibility in line with the Affordable Care Act or not, since they are living at the edges of Medicaid eligibility with often variable incomes.

Moreover, people with various functional impairments and chronic conditions are in the workforce, struggling to maintain and get by on exorbitant private individual and small group health insurance policies. Families of children with disabilities obtain multiple policies in an attempt to cover the coverage gaps of each policy, and seniors with disabilities face similar gaps and out-of-pocket expenses when they seek supplemental coverage. One 2008 study of over 28,000 households conducted by the University of North Carolina at Chapel Hill found that “solidly middle-class” families with children with disabilities “are struggling to keep food on the table, a roof over their heads, and pay for needed health and dental care.” These reports and others show that Marketplaces and QHPs consumers will include PWD and their families. The healthcare barriers and disparities faced by PWD merit attention in the proposed surveys.

People with Disabilities Are Exchange Consumers

People with various disabilities, including those with significant functional impairments that affect hearing, vision, mobility, speech, concentration, memory, and the capacity to independently perform tasks such as dressing, bathing, cooking, shopping, and performing common errands, are **not** all on public health programs such as Medicaid or Medicare. As individual working adults and family members, people with disabilities seek and rely on private insurance, and many have historically been unable

to obtain that insurance, or have paid for insurance with inadequate coverage while paying very significant healthcare related expenses out-of-pocket.

A closer look at California-specific information will further illustrate these points. Rather ironically, the federal CMS Office of Communication, in a presentation entitled "An Overview of CMS Consumer Research Related to Audience Segmentation for the Emerging Health Insurance Marketplace," found that 8.2% of the uninsured nationally are disabled.[3] The same report divided the uninsured population into 6 market segments, characterizing the largest, 23.2%, as "sick, active & worried." These are mostly Gen X and Baby Boomers, likely to be in poor health, and many are also caregivers. They actively seek information for health issues, but may need help interpreting it. 79% of this group indicates that cost is a major reason they are uninsured, and 72% say they would be interested in shopping for insurance in the new marketplace. If we cross these numbers from the national CMS research with the finding from the California HealthCare Foundation's December 2012 Report, *California's Uninsured: Treading Water,*[4] indicating that there are 7.1 million uninsured under 65 in the state, we get a figure of 582,000 uninsured individuals with disabilities. If I use CMS's 23.2% figure, I get 1,647,200 "sick, active and worried" folks in the state of California alone. Beyond these numbers it is very hard to get more information about people with disabilities who are uninsured or who are on private insurance. We honestly do not know of any tool/survey that collects that information directly.

Rather than perpetuate this lack of information, the proposed surveys are a critical opportunity for CMS to actively seek and gather information about the needs of consumers with disabilities, where those consumers seek care, and the effectiveness, accessibility, and quality of the care that they receive through the Marketplaces and QHPs.

The reality that people with disabilities will comprise a significant portion of the Marketplaces' consumer base leads to the need for detailed and concrete plans and standards for ensuring that outreach and education encompasses people with disabilities, including those with communication impairments that impact hearing, vision, and comprehension. The hope is that the inclusion of PWD in the survey, and CMS' active engagement with developing a survey process that is fully accessible to consumers with disabilities in compliance with Sections 504 and 508 of the Rehabilitation Act and the Americans with Disabilities Act, will lead to proactive, front end, fully accessible survey materials and administration procedures. Furthermore, CMS's inclusion of survey questions that specifically address disability-related barriers in the Marketplace and in QHPs will prompt states and health plan entities to develop the policies, plans and procedures needed to maintain accessibility throughout the selection, purchase, and maintenance of insurance through the Exchange by PWD.

Assuming that a PWD can get and afford a plan that actually provides the

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[3] Presentation is available online at: http://marketplace.cms.gov/ExploreResearch/socialmarketing-research-for-the-health-insurance-marketplace.pdf

[4] Available online at: http://www.chcf.org/~/media/MEDIA%20LIBRARY%20Files/PDF/C/PDF%20CaliforniaUninsured2012.pdf

coverage that she or he needs in the exchange, there is still the matter of being able to visit providers that can provide effective health care services. This squarely raises the issue of disability healthcare disparities.

Disability Healthcare Disparities

The past decade has seen a growing body of research documenting the type and prevalence of health disparities among PWD. Such mainstream and disability-specific entities as the U.S. Surgeon General, the Institute of Medicine (IOM), the National Council on Disability (NCD), the Centers for Disease Control and Prevention (CDC), the Agency for Healthcare Research and Quality (AHRQ), the National Institute for Disability Rehabilitation Research (NIDRR), and agencies of the National Institutes of Health have published seminal reports documenting unequal access to health care and health disparities experienced by PWD. The U.S. Department of Health and Human Services (HHS), in its Healthy People 2010 initiative, specifically called out the need to promote the health of PWD, prevent secondary conditions, and eliminate disparities between people with and without disabilities in the American population, also recognizing that these goals would be increasingly important to an aging American population that will have an increased propensity to acquire functional impairments and disabilities.[5]

My colleagues at Access Living in Chicago and Coalition for Disability Health Equity in Virginia have provided you in their comments with excellent additional information concerning disability health disparities. DREDF would like to provide just one additional specific illustration of a healthcare disparity experienced by people with mobility disabilities, for whom effective healthcare necessarily involves being appropriately examined and weighed during a medical appointment. Data derived from reviews of over 2300 primary care provider facilities in 18 of California's 58 Counties, serving about 2.5 million Medicaid enrollees and an unknown number of non-Medicaid enrollees, reveals the extent to which height-adjustable exam tables and accessible weight scales are absent from provider offices.[6]

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[5] DREDF has prepared a brief that with numerous references to the health and healthcare disabilities experienced by people with particular disabilities, focusing especially on the generally unexplored impact of the double barriers experienced by people with disabilities of color, *available online at*: http://dredf.org/healthcare/Health-and-Health-Care-Disparities-Among-People-with-Disabilities.pdf.

[6] These results have been published in *Physical Accessibility in Primary Health Care Settings: Results from California On-site Reviews*, N.R. Mudrick, M.L Breslin, M. Liang, S. Yee, Disability & Health J. July 2012; 5(3):159-167. Additional related publications include: *Access to Subspecialty Care for Patients With Mobility Impairment: A Survey*, T. Lagu et al., Ann Intern Med. 19 March 2013;158(6):441-446 (Of 256 practices, 56 (22%) reported that they could not accommodate the patient, 9 (4%) reported that the building was inaccessible, 47 (18%) reported inability to transfer a patient from a wheelchair to an examination table, and 22 (9%) reported use of height-adjustable tables or a lift for transfer. Gynecology is the subspecialty with the highest rate of inaccessible practices (44%)); *Accessible Medical Equipment for Patients with Disabilities in Primary Care Clinics: Why Is It Lacking?*, J. Pharr, Disability & Health J. April 2013, 6(2): 124-132; *Predicting Barriers to Primary Care for Patients with Disabilities: A Mixed Methods Study of Practice Administrators*, J. Pharr and M. Chino, Disability & Health J. April 2013, 6(2):116–123.

Previous published literature had found that height-adjustable exam tables were present in 17-44% of provider offices, but those were studies with small numbers of participants (40 in 1 study, 68 offices in another), using sites that had essentially self-selected. From the California surveys, we found that 8.4% of provider sites have a height-adjustable exam table, and 3.6% have an accessible weight scale.[7]

What happens when a member with a plan purchased through the Exchange needs accessible equipment, or needs longer appointment times because she or he assists a non-verbal adult child with developmental disabilities, or needs American Sign Language interpretation for their own or a minor child's appointment? Are they entirely on their own when it comes to finding primary care doctors or specialists or clinics who can provide them with effective care? Whose problem is it? And most critical for this comment, how will the extent of the problem even be raised if the proposed surveys ignore people with disabilities as marketplace and QHP consumers? Supporting Statement Part A strikingly references "CMS' obligation to minimize disparities in the use of the Marketplace and QHPs."[8] This obligation explicitly encompasses disparities experienced by PWD, as well as those who experience disparities as a result of race, ethnicity, or other personal characteristics.

Recommendations and Conclusion

Our primary recommendation is that the proposed surveys are re-worked to include questions that enable the granular identification of people with various disabilities, and enable respondents to identify particular barriers that are routinely experienced by PWD in the administration of health insurance and delivery of healthcare services. These questions should be developed in consultation with PWD and disability advocates and organizations. The questions must be broad enough to enable respondents to identify Marketplace or QHP failures to provide a range of reasonable accommodations and policy modifications, whether in person, over the phone, or online. My colleagues at Access Living have providing excellent examples of the types of questions that should be added with respect to survey instructions, American Sign Language translation, premium tax credits eligibility and the appeals process, online accessibility, and website tools (especially for preserving provider and treatment continuity of care). We do differ somewhat with respect to our specific suggestion for including questions that will enable the identification of PWD in the demographic "About You" section. It must also be noted that the inclusion of these questions will not, in themselves, substitute for appropriate recruitment and notice measures for PWD, and the assurance of accessible formats and methods for taking the surveys.

The American Community Survey (ACS) has already provided a set of six questions on disability status that have been psychometrically tested, are highly readable, and reliably capture people with various impairments and chronic conditions who do not necessarily identify as a "person with a disability." If the full set of six questions cannot

[8] June 11, 2013 *Health Insurance Marketplace Enrollee Satisfaction Surveys, Supporting Statement—Part A*, p. 4.

be included, then we recommend the following shortened version, which is based on the ACS-6 questions. We unreservedly recommend this set of four questions above the single disability-status question that is used in federal draft single streamlined application; we were personally informed by federal staff when questioned by us that the draft streamlined application was developed without any input from PWD or disability focus groups. The following questions will enable the identification of Marketplace and QHP consumers with disabilities without insisting that these individuals "identify" as a person with a disability or understand a particular set of terminology for specific impairments or conditions, and without suggesting that an individual must require a nursing facility level of care to "count" as a person with a disability.

"Do you have serious difficulty hearing OR seeing even when wearing glasses?

Do you have difficulty walking or climbing stairs?

Do you have serious difficulty concentrating, remembering, or making decisions?

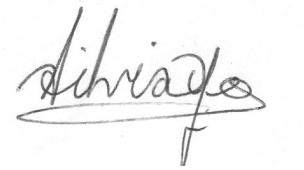
Do you have a difficulty doing daily activities such as dressing and bathing, or running errands alone?"

There are individuals and family members with disabilities who, for various reasons, do not qualify for Medicaid/Medicare, or who require additional insurance. These are all potential exchange consumers, and the current proposed surveys ignore every single one of them. The proposed surveys fail to identify them demographically. The marketplace survey ignores their rights under Section 508 to an accessible website and online tools. The QHP survey ignores the multiple barriers that PWD face when seeking healthcare services. And finally, the administration of the survey and its multi-year development proposal ignores CMS's own obligation as a federally conducted program to comply with the effective communication regulations that govern its actions,[9] as well as sections 4302 and 1557 of the ACA. If an exchange consumer with a communication disability somehow learned of the survey and wished to take it, it is unclear how CMS would accommodate this simple request from a member of the public. There do not appear to be any concrete policies or procedures to ensure that marketplace and QHP consumers with disabilities will be provided with reasonable accommodations and policy modifications to ensure their equal participation in the survey process. Clearly if no participants with disabilities are surveyed or even identified in the first place, they will be unable to provide feedback that will make later iterations of the survey more accessible or relevant to PWD.

Thank you for the opportunity to comment on this critical matter of data collection and Marketplace and QHP quality review. We look forward to CMS, and the proposed survey process, providing a leading example for states and QHPs to identify and address the health and healthcare disparities experienced by PWD. Please do not hesitate to contact us if you have any further questions or wish to discuss the above.

[9] 45 C.F.R. §85.51.

Yours Truly,



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