



**COALITION FOR
Disability Health Equity**

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August 26, 2013

United States Department of Health and Human Services
CMS
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

Comments of the Coalition for Disability Health Equity on ACA
Surveys on Health Insurance Marketplace and Qualified Health Plans

The Coalition for Disability Health Equity appreciates this opportunity to provide comments on the proposed Enrollee Satisfaction Surveys on the Health Insurance Marketplace and Qualified Health Plans. These surveys were devised by the Department of Health and Human Services in accordance with Section 1311(c)(4) of the Affordable Care Act.

The Coalition for Disability Health Equity (CDHE) is a coalition of disability self-advocates, researchers, disability public health organizations, and disability advocacy groups, founded to assure the equitable inclusion of people with disabilities in all provisions of health care and health care reform.

Health and Health Care Disparities for People with Disabilities

People with disabilities are far more likely to experience chronic health conditions and risk factors, avoid doctor visits due to cost, and encounter a multitude of access barriers to health care in the areas of medical facilities and equipment, communication, and workforce preconceptions and attitudes.¹ People with disabilities also experience poorer outcomes.

Women with disabilities are more likely to postpone needed medical care, be examined inappropriately in a wheelchair when they do receive medical care, and be diagnosed with breast cancer later with higher fatality rates.^{2,3} A full 50% of Medicaid beneficiaries with disabilities did not visit a physician after discharge from a hospital; 16% were readmitted within 30 days and 53% readmitted within a year.⁴

Gaps in Data Collection

Despite these known disparities, people with disabilities “remain not only underserved but also invisible.”⁵ According to the Centers for Disease Control, disability status remains one of the two disparity areas for which there are critical data gaps.⁶ It is because of these data gaps that the Affordable Care Act mandates collection, for example, of data on disability status for Medicaid recipients that will better document access to care and treatment, accessible facilities, and disability awareness and training in the workforce.⁷ Consistent with these underlying policy considerations in the Affordable Care Act, the data collection at issue in the surveys in issue must address the impact of disability status. Yet neither survey even mentions disability status or contains a single question relevant to disability status. This is precisely the kind of omission that the data collection provisions and the anti-discrimination provisions contained in §1557 of the Affordable Care Act sought to end – to include not exclude – people with disabilities. Frankly, we were rather shocked by the complete omission of people with disabilities from a customer satisfaction survey in light of the needs individuals with disabilities present as customers, and the US’ shared history of ignoring them as customers.

We recognize that CAHPS surveys like the Health Insurance Marketplace and Qualified Health Plans surveys are generally considered reliable and are held in high esteem. However, in compliance with the Affordable Care Act mandate regarding disability data and the prohibition against discrimination in §1557, we recommend that additional questions be included that address availability of accommodations such as communication aids and accessible formats, disability-friendly websites, physical accessibility, and procedures fostering continuity of care. Our recommendations are consistent with – and promote the goals of – the mandates of Title II and Title III of the Americans with Disabilities Act, Section 504 of the Rehabilitation Act of 1973, and Section 1557 of the Affordable Care Act, which require health care providers to provide full and equal access to their facilities and services and reasonable accommodations when necessary to do so. U.S. Department of Justice and U.S. Department of Health and Human Services, “Access To Medical Care For Individuals With Mobility Disabilities,” http://www.ada.gov/medicare_mobility_ta/medicare_ta.htm, and the Barrier Free Health Care Initiative, <http://www.ada.gov/usao-agreements.htm>.

Section 1557 of the Affordable Care Act reads as follows:

SEC. 1557. NONDISCRIMINATION.

(a) IN GENERAL.—Except as otherwise provided for in this title (or an amendment made by this title), an individual shall not, on the ground prohibited under title VI of the Civil Rights Act of 1964 (42 U.S.C. 2000d et seq.), title IX of the Education Amendments of 1972 (20 U.S.C. 1681 et seq.), the Age

Discrimination Act of 1975 (42 U.S.C. 6101 et seq.), or section 504 of the Rehabilitation Act of 1973 (29 U.S.C. 794), be excluded from participation in, be denied the benefits of, or be subjected to discrimination under, any health program or activity, any part of which is receiving Federal financial assistance, including credits, subsidies, or contracts of insurance, or *under any program or activity that is administered by an Executive Agency* or any entity established under this title (or amendments). The enforcement mechanisms provided for and available under such title VI, title IX, section 504, or such Age Discrimination Act shall apply for purposes of violations of this subsection. (Emphasis added)

THE HEALTH INSURANCE MARKETPLACE SURVEY

The Application Process

We recommend inclusion of this question in addition to #2, “Were the instructions for the application easy to understand?”

“If you are a person with a disability who requires accommodations in written materials, such as Braille or large print, did you find the instructions for the application easy to access?”

Premium Tax Credit Eligibility and Appeals Process

We recommend the addition of this question after #10, “Was it easy to understand how to appeal if you disagreed with a decision about the Advanced Premium Tax Credit or Medicaid?”

“If you are a person who requires accommodations due to a disability, were you informed about and assisted with obtaining those accommodations (e.g., Braille or large print, video relay service) in order to apply and find out about your eligibility for insurance affordability programs?”

Information Seeking on the Website

Section 508 of the Rehabilitation Act of 1973 requires federal entities’ websites, as well as private websites receiving federal funds, to make electronic and information technology accessible to people with disabilities. In the context of Internet information, Section 508 mandates a web browser that includes accessible software and access to needed assistive technology for users with disabilities. Accordingly, we recommend the addition of this subquestion within #13, “Were any of the following a reason you did not get the information you needed from [Marketplace] website?”

“(g) You could not access the software or were unable to obtain the assistive technology you require due to a disability.”

We also recommend the addition of this subquestion within #15, “What kind of information on the [Marketplace] website was **not** easy to use?”

“(m) You could not determine whether a health plan’s provider network would provide health care accommodations needed because of your disability.”

Information Seeking over the Phone

We recommend the addition of this subquestion within #21, “Were any of the following a reason why you did not get the information or help you needed when you called the [Marketplace] customer service Help Line?”

“(h) There was no video relay service available for persons like myself who are Deaf.”

Information Seeking In-Person

We recommend the addition of the following question after #28, “In the last 6 months, did you get help filling out the application for health insurance or otherwise seek help using the [Marketplace] customer service staff in-person?”

“Did you want in-person help but were unable to get it because the space/facility was not accessible?”

We recommend the addition of the following subquestion within #30, “Were any of the following a reason why you did not get the information or help you needed when you met with the [Marketplace]’s customer service staff?”

“(e) There was no ASL interpreter or video relay service available for persons like myself who are Deaf.”

Comparing Health Plans

We recommend the addition of the following question after #38, “In the last 6 months, did you compare the benefits and cost of each plan?”

“If you are a person with complex health conditions, did the [Marketplace] assister help to explain plans that provide the specialists you need?”

Continuity of care in terms of both physicians and sites has been shown to be a significant factor in receipt of health care services by people with disabilities.⁸ Accordingly, we recommend the addition of the following question after #43, “In the last 6 months, how often was it easy to compare the doctors that participated in each health plan?”

“Were you provided sufficient information to find a health plan or health plans that would help you continue to receive services from your current providers?”

Interpreter Services

We recommend that Question #50, which defines an interpreter as “someone who helps you talk with others who do not speak your language” be modified to define an interpreter as

“someone who helps you talk with others who do not speak your language, **including American Sign Language.**”

About You

As discussed above, disability status remains a disparity area in health care for which there are critical data gaps – a factor recognized in the requirement of the Affordable Care Act that data collection be increased in this area. It is striking, therefore, that not one of the demographic questions in the “About You” section collects any data on disability status. Accordingly, we recommend inclusion of an additional question, as follows:

“Do you identify as a person with a disability? If so, please identify the type or types of disability:

- 1. Physical**
- 2. Mental**
- 3. Cognitive**
- 4. Sensory**

THE QUALIFIED HEALTH PLAN SURVEY

Your Health Care in the Last 6 Months

The U.S. Department of Health and Human Services and U.S. Department of Justice have correctly noted that individuals with mobility disabilities are often not weighed, despite the fact that a patient’s weight is essential to proper diagnostic care, treatment, and medication determinations and that accessible scales are available. Similarly, these Departments have made it clear that exam tables should be made accessible and that a medical examination not on a table is generally not acceptable. “Access To Medical Care For Individuals With Mobility Disabilities,” http://www.ada.gov/medcare_mobility_ta/medcare_ta.htm Accordingly, we recommend the addition of the following two questions after #21, “When you visited your personal doctor for a scheduled appointment in the last 6 months, how often did he or she have your medical records or other information about your care?”

“When you visited your personal doctor for a scheduled appointment in the last 6 months, how often were you weighed on a scale?”

“When you visited your personal doctor for a scheduled appointment in the last 6 months, how often were you examined on an exam table?”

Your Health Plan

We recommend the addition of the following question after #35, “In the last 6 months, how often did the written materials or the Internet provide the information you needed about how your health plan works?”

“If you are a person with a disability who requires accommodations in written materials, such as Braille or large print, how often in the last 6 months were you provided these materials to find out how your health plan works?”

The safe and timely provision of durable medical equipment such as wheelchairs is essential to the maintenance of health and wellness for people with physical disabilities. We therefore recommend modification of question #36 as follows, “Sometimes people need services or equipment beyond what is provided in a regular or routine office visit, such as care from a specialist, physical therapy, a hearing aid, ~~or~~ oxygen, **or a wheelchair.**”

We recommend the addition of the following question after #40, “In the last 6 months, did you get information or help from your health plan’s customer service?”

“If you are a person with a disability who requires accommodations in written materials or an ASL interpreter, how often in the last 6 months were you provided those accommodations by your health plan’s customer service?”

We recommend the addition of the following question after #46, “In the last 6 months, how often were the forms that you had to fill out available in the language you prefer?”

“If you are a person who is blind or has low vision, how often in the last 6 months were you provided forms in Braille or large print to fill out?”

About You

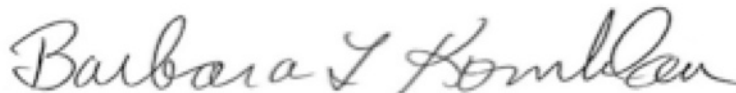
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- 1. Physical**
- 2. Mental**
- 3. Cognitive**
- 4. Sensory**

We thank you for this opportunity to comment on this important matter.

Very truly yours,



Barbara L. Kornblau, JD, OTR
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Coalition for Disability Health Equity

¹ Illinois Department of Public Health, *Illinois Disability and Health Data Report*, pp. 7, 14-26, 41 (2007-08), <http://www.idph.state.il.us/idhp/2010DataReport.pdf>; Disability Rights Education and Defense Fund (DREDF), letter to Health

Resources and Services Administration (HRSA), July 10, 2010, <http://www.dredf.org/healthcare/FINAL-DREDF-HRSA-letter-6-09-10.pdf>

² Susan L. Parish and M. Jennifer Ellison-Martin, "Health-Care Access of Women Medicaid Recipients: Evidence of Disability-based Disparities," *Journal of Disability Policy Studies* 18, no. 2 (2007), pp. 109–116.

³ J. Shapiro, Medical Care Often Inaccessible to Disabled Patients, NPR September 13, 2007, <http://www.npr.org/templates/story/story.php?storyId=14362338>

⁴ T. Gilmer, A. Hamblin, Center for Health Care Strategies, Inc., "Hospital Readmissions Among Medicaid Beneficiaries With Disabilities: Identifying Targets of Opportunity," Center for Health Care Strategies, Inc. (2010), http://www.chcs.org/usr_doc/CHCS_readmission_101215b.pdf

⁵ Disability Rights Education and Defense Fund (DREDF), letter to Health Resources and Services Administration (HRSA), July 10, 2010, <http://www.dredf.org/healthcare/FINAL-DREDF-HRSA-letter-6-09-10.pdf>

⁶ CDC Health Disparities and Inequalities Report, United States 2011, p. 7 <http://www.cdc.gov/mmwr/pdf/other/su6001.pdf>

⁷ Patient Protection and Affordable Care Act, Section 4302.

⁸ Allen SM, Wieland S, Griffin J, Gozalo P, "Continuity in provider and site of care and preventive services receipt in an adult Medicaid population with physical disabilities," *Disabil Health J.* 2009 Oct; 2(4): 180-7; Mark P. Doescher, Barry G. Saver, Kevin Fiscella, and Peter Franks. "Preventive Care: Does Continuity Count?" *Journal of general internal medicine* 19.6 (2004).