



March 1, 2011

Nancy Wilson, M.D., M.P.H.,
Coordinator
Subcommittee to the National Advisory Council on Healthcare
Research and Quality
Agency for Healthcare Research and Quality
540 Gaither Road
Rockville, MD 20850

RE: Health Quality Measures for Medicaid Eligible Adults

Dear Dr. Wilson,

The Disability Rights Education and Defense Fund (DREDF) is a 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. On behalf of DREDF and the undersigned individuals and organizations, we write to urge you to develop and include measures in the Core Set of Health Quality Measures for Medicaid-Eligible Adults that will improve the quality of care for people with disabilities.

According to the Kaiser Commission on Medicaid and the Uninsured, people with disabilities and seniors represent about 25 percent of Medicaid enrollment and about 67 percent of Medicaid spending. Yet, the proposed 51 Core Quality Measures for Medicaid-Eligible Adults do not include mechanisms for identifying quality indicators related specifically to Medicaid beneficiaries with disabilities and seniors who are likely to experience prevalent activity impairments related to mobility, vision, hearing, and cognitive and intellectual functioning.

According to the 2009 report, *The Current State of Health Care for People with Disabilities*, released by the National Council on Disability (NCD), “[p]eople with disabilities experience significant health disparities and barriers to health care, as compared with people who do not have disabilities.” Barriers to both primary and specialty care that can affect people with disabilities disproportionately include limited medical facility accessibility and lack of accessible examination and diagnostic equipment (Drainoni et. al., 2006; Kirschner, Breslin & Iezzoni, 2006); lack of Sign Language Interpreters (Steinberg et. al., 2002; Barnett & Franks, 2002); lack of educational and health care instructional materials in formats that are accessible to people who are blind or have visual impairments (O’Day, Kileen, & Iezzoni, 2004; Capella-McDonnall, 2007); and lack of individualized accommodations that are critical to ensure that people with intellectual, cognitive,

speech and language impairments can communicate effectively with their health care providers (Krahn, Hammond & Turner, 2006). Prevalent disability stereotypes and limited provider training and disability awareness further exacerbate the problem.

Moreover, people with certain types of functional impairments experience specific health disparities. For example, according to NCD and others, women with significant disabilities are likely to have fewer Pap tests and mammograms than women who do not have disabilities (Altman & Bernstein, 2008). Adults who are deaf or who experience significant problems hearing were three times as likely to report fair or poor health compared with those who did not have hearing impairments (Altman; Schoenborn & Heyman, 2007). People with developmental disabilities experience high rates of vision and hearing problems, cardiovascular disease, obesity, poor oral health, and mental health and behavioral problems (Krahn; Fisher, 2004). Three out of five people with serious mental illness die 25 years earlier than other individuals, from preventable, co-occurring chronic diseases, such as asthma, diabetes, cancer, heart disease, and cardiopulmonary conditions. (Colton & Manderscheid, 2006; Manderscheid, Druss, & Freeman, 2007). People with significant vision loss are more likely to experience a greater prevalence of obesity, have hypertension and heart disease, and smoke more than the general public (Capella-McDonnall).

While research has documented health disparities and barriers that affect people with disabilities, a 2010 report issued by the Agency for Health Research and Quality (AHRQ), "Developing Quality of Care Measures for People with Disabilities: Summary of Expert Meeting," found that,

With few exceptions, little scientific evidence is available to inform development of quality indicators for persons with disabilities. Hence, not surprisingly, relatively few quality measures exist specifically addressing disability-related issues. Those examples that do exist focus primarily on biomedical aspects of underlying disabling conditions rather than on functioning, wellness, quality of life, and the broad range of environmental concerns.

In light of these deficiencies, quality measures, at a minimum, can and must recognize that certain key environmental factors logically have an inevitable detrimental impact on the care received by people with a variety of functional impairments, regardless of the dearth of wide-scale scientific or statistical data to support these claims. Specific types of care cannot be received simply because required examination or diagnostic equipment is inaccessible, accommodations that facilitate communication such as Sign Language interpreters for Deaf patients are not provided, or health care providers make incorrect assumptions about care based on disability stereotype. Consequently, measures must be devised that acknowledge that barriers indeed exist and that assess progress toward mitigating or removing them. Measures must also be developed that will indicate progress

over time toward ensuring that more people with disabilities receive generally accepted health promotion and disease prevention tests and procedures, which will help reduce preventable diseases. The failure to establish and adopt such measures perpetuates the invisibility of barriers to care within the nationwide system of health care delivery, which receives substantial public funding to provide care for people with disabilities. Adding a few key measures to the Core Set of Health Quality Measures for Medicaid-Eligible Adults therefore is a critically important first step that will spur action on the part of health policy and care delivery stakeholders, and lead the way for the development of additional measures over time.

We specifically recommend two areas for which additional measure should be developed and deployed: measures that acknowledge and assess the availability of equipment and policies intended to redress barriers to care frequently encountered by people with certain functional limitations, and measures that report the basic care they receive that promote health and wellness. Two examples of disparities experienced by people with disabilities explain these recommendations. A possible direct link between obesity and a barrier to care was revealed by a recent report that evaluated accessibility data for 2389 Medicaid primary care provider offices in California, the only study of its size currently available (Mudrick, Breslin, Yee, & Liang, 2010). Outcomes revealed that only 3.6 percent had wheelchair accessible weight scales, thus illustrating what the disability community has long known: some people with mobility impairments simply cannot be weighed by their primary care provider.

The first measure within the prevention and health promotion component of the 51-measure draft list that has been compiled by the Subcommittee to the National Advisory Council on Healthcare Research and Quality concerns “Body Mass Index (BMI) Screening and Follow-Up.” It is intended to capture the percentage of patients that have a current BMI calculated and a follow-up plan documented if the BMI is outside of certain parameters. Patients who cannot be accurately weighed because accessible weight scales are not available are highly unlikely to have a current BMI calculated, and therefore equally unlikely to receive any obesity health information and counseling, even if their weight has approached or been at unhealthy levels for years. Unless they are with the extremely rare provider that has policies, practices, and procedures in place for obtaining weight measurement without an accessible scale, or for providing obesity health and wellness information even without a current BMI, any person with mobility or balance issues who cannot use a standard scale will repeatedly fall outside of this quality measure and there will be no means of tracing the problem to a clearly defined and preventable environmental cause such as the lack of an accessible scale. Unless such clear barriers to the operation of a proposed health measure are identified and removed, the measure does not serve to capture the quality of healthcare received by a person with a disability; it only serves to further narrate the inaccessible status quo.

Similarly, according to data collected from the National Health Interview Survey (NHIS), 65 percent of women aged 18 and older with complex activity limitations have received a mammogram as compared with 83 percent of women without disabilities. Complex activity limitations are limitations in the ability to participate fully in social roles, including maintaining a household, working, pursuing hobbies, visiting friends, and going out to activities in the community. While the reasons for these differences are complex, research reports that lack of accessible equipment such as adjustable exam tables and mammography equipment are among them. The same study that reported the lack of accessible weight scales also reported that among the 2389 primary care provider offices surveyed, only 8.4 percent had a height adjustable examination table, thus creating a potential barrier to receiving breast and other exams for women with certain mobility limitations.

However, the “Breast Cancer Screening” measure recommended by NCQA and included in the proposed 51 Core Quality Measures for Medicaid-Eligible Adults, cannot discern if equipment access barriers such as inaccessible exam tables or inaccessible mammography equipment prevent some people with disabilities from receiving an exam or a mammogram. They only indicate how frequently a particular measure was utilized. This disconnect illustrates why additional quality measures are needed that assess the extent to which barriers are acknowledged and removed, thus increasing the likelihood, for example, that people with certain functional impairments can be tested or weighed. These rudimentary measures are particularly important in quality metrics for people who are Medicaid beneficiaries, many of whom are known to have multiple, complex chronic health conditions and diseases for which weighing and regular physical and other examinations are crucial.

Thus we specifically recommend that the following additional quality measures be added to the Core Quality Measures for Medicaid-Eligible Adults.

- Availability of wheelchair-accessible weight scale
- Availability of height-adjustable examination table with a minimum height capacity of 17 to 19 inches from floor to top of cushion
- Availability of mammography equipment for which the imaging receptor lowers to a minimum height of 24 inches from the floor to the top side of the imaging receptor platform; and with sufficient clear knee space from the stand to the front edge of the imaging receptor to enable wheelchair users to go into position for mammography without running into protruding imaging platforms or tube heads connected to the central stand
- Availability of patient print education and instruction materials in alternative formats, e.g., audio recording, large print, digital, Braille
- Availability of Sign Language Interpreters and assistive listening devices

Additional quality measures must also be developed that identify the type of

impairment an individual experiences and link it to measures of basic preventative care such as being weighed, mammography screening, colorectal screening, anti-smoking messages, and so forth. Models already exist for this type of additional measure and include Core Measures 38 – 42 under Management of Chronic Conditions, which target people with mental health conditions. Specifically, quality measure 38 measures “Bipolar I Disorder 2: Annual assessment of weight or BMI, glycemic control, and lipids.” Additional questions could be similarly framed for people with other impairments. For example, “People with (mobility, vision, hearing, cognitive, sensory, developmental, intellectual) impairments: receive a colonoscopy after age 50 (or a mammogram after age 40).”

Quality measure 38 assumes either an established diagnosis or self-disclosure, and in either case, there is a need for clearly identifying those who have a disability in order to measure the quality of care that they receive. There are a number of national population surveys conducted or supported by the federal government that collect data on disability status using categories of functional impairment that could inform the development of such measures. For example, the American Community Survey employs the following questions:

- Is this person deaf or does he/she have serious difficulty hearing? (17a: Hearing Disability, asked of all ages)
- Is this person or does he/she have serious difficulty seeing even when wearing glasses? (17b: Visual Disability, asked of all ages):
- Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions? (18a: Cognitive Disability, asked of persons ages 5 or older)
- Does this person have serious difficulty walking or climbing stairs? (18b: Ambulatory Disability, asked of persons ages 5 or older)
- Does this person have difficulty dressing or bathing? (18c: Self-Care Disability, asked of persons ages 5 or older)
- Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor's office or shopping? (19: Independent Living Disability, asked of persons ages 15 or older)

We also urge you to consider adopting “Assessment of Health Plans and Providers by People with Activity Limitations (AHPHAL),” an enabled survey of primary care, which sets forth adjustments to the current Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey to measure and reflect the experiences of people with disabilities (Palsbo, et. al., 2011). This new instrument has been cognitively and field tested, and provides for multiple administration modes. In light of the growing body of research identifying gaps in access to care and processes for people with disabilities, this enabled CAHPS Clinician and Group Survey provides an important, new tool for measuring quality.

While the identification of the initial core set of health quality measures recommended for Medicaid-eligible adults was prepared as required by Section 2701 of the Affordable Care Act, we think that this mandate must be implemented in concert with Section 4302 (a) of the Act, which requires data collection and reporting on health care access and quality by race, ethnicity, and language and other factors such as health status or disability. In collecting data, the Secretary or designee also is expected to require that reporting imposed for purposes of **measuring quality** under any ongoing or federally conducted or supported health care or public health program includes requirements to collect data on individuals receiving health care items or services under such programs and activities by race, ethnicity, sex, primary language, and **disability status**. (Emphasis added.) Section 4302 also requires that health care providers be surveyed and that other procedures be established in order to assess access to care and treatment for individuals with disabilities and to identify, **“the number of providers with accessible facilities and equipment to meet the needs of the individuals with disabilities, including medical diagnostic equipment that meets the minimum technical criteria.”** (Emphasis added).

Our recommendations for additions to the Core Quality Measures interact with and respond to these provisions of the ACA.

We also recommend that quality measures include elements related to patient empowerment and self-management as the Health Information Technology (HIT) Policy Committee’s Measure Concepts provide. Moreover, we recommend that quality measures also include mechanisms to evaluate health equity to meet the goals of quality care and decreased disparities for people with disabilities articulated in the ACA and Healthy People 2020, which lists elimination of health disparities for people with disabilities and others and improving the health of all people among its four foundational health measures. The Core Quality Measures should also include measures of the social determinants of health as outlined in Healthy People 2020, since these determinants significantly affect access to and the quality of health care provided to people with disabilities. Moreover, quality measures should include measures of access to home and community based services for improving and sustaining community participation. To assist in identifying examples of some of these proposed measures, we refer you to

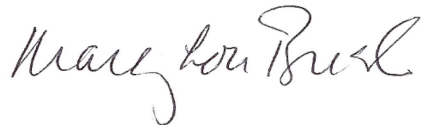
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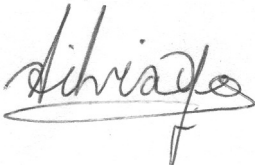
additional, specific Medicaid quality indicators for individuals with disabilities identified with support from the National Institute on Disability and Rehabilitation Research (NIDRR). (See references.)

Thank you for the opportunity to present our recommendations.

Sincerely,



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