

April 28, 2014

Submitted online at www.regulations.gov

Office of the National Coordinator for Health Information Technology
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

RE: RIN 0991–AB92 - Voluntary 2015 Edition Electronic Health Record (EHR) Certification Criteria; Interoperability Updates and Regulatory Improvements

Dear Dr. DeSalvo:

The Disability Rights Education and Defense Fund (DREDF) appreciates the opportunity to respond to the ONC’s Notice of Proposed Rulemaking and voluntary 2015 Edition Electronic Health Record (EHR) Certification Criteria (2015 Edition). 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 effective healthcare for people with disabilities.

Our interest in EHR is two-fold. First, we believe that EHR and health information technology (HIT) itself must be fully accessible to consumers, providers, and researchers with disabilities. One of the often stated goals of EHR is to encourage patients to take a proactive role in maintaining their health and well-being through full access to their own health records. This goal will obviously remain unrealized for many people with disabilities and chronic conditions if their EHRs are allowed to be incompatible with the software and electronic technology that they use to gain equal access to information. Second, EHR that appropriately records the functional impairments and accommodation needs of consumers with disabilities can play a critical role in both illuminating the kinds and depth of health disparities affecting people with disabilities, and fostering the widespread availability and use of accommodation and policy modification information that people with disabilities need to gain access to equally effective healthcare.

Accessibility of EHR

We appreciate ONC’s efforts to provide better access and accessibility of health information for individuals with disabilities. We support the inclusion of WCAG 2.0 Level AA within the voluntary 2015 Edition, and its *full* inclusion as a requirement for certification in the next 2017 Edition. Our only caveat is to indicate a preference for Level AAA instead of Level AA. Within and across states, healthcare organizations, government entities and HIT manufacturers are engaging in widespread and large-scale systems as a response to the ACA and HIT initiatives. A “ramp up” approach to HIT accessibility may appear to make sense from a short-term cost perspective, but it

makes little sense from a long-term perspective. Just as in a physical structure, it will always cost more to go to retrofit technology that is not fully accessible to bring it into compliance with higher standards, than to build it to fully accessible standards as the system is developed. Level AAA standards have been worked out already and provide the fullest degree of accessibility to individuals with various disabilities. It makes economic sense for corporate and individual users of HIT systems to move swiftly to require the highest level of accessibility, and also enables healthcare entities to come into compliance as both healthcare providers and as employers with longstanding federal and state disability rights laws to which they are subject.

Demographic Identification of Disability and Accommodation Needs

We support the 2015 Edition's move toward gathering greater demographic information, and especially a more granular standard for recording a consumer's preferred language. However we strongly recommend that the 2015 Edition include a requirement to collect demographic information related to a consumer's disability status and accommodation needs. DREDF has commented in previous letters, such as in our January 2013 comments relating to meaningful use, on the great need for such information to be captured in EHRs. While there is a proposal for the 2017 Edition to require incorporation of the six American Community Survey (ACS) questions relating to functional impairment, we cannot understand why people with disabilities who have current accommodation and policy modification needs must wait until 2017 to have those needs recorded in their EHR.

There is an increasing body of evidence and information indicating how many barriers people with disabilities (PWD) encounter when seeking needed healthcare. Some of the barriers to comprehensive, quality health care are present in the physical environment—for example, cramped waiting and exam rooms, inaccessible bathrooms, and inaccessible equipment (such as exam tables, weight scales, and imaging and other diagnostic equipment).¹ Other forms of discrimination that prevent PWD from attaining appropriate and effective healthcare take the form of the failure to provide needed policy modifications and reasonable accommodations, which in turn affects healthcare treatment decisions and outcomes.

Physical Barriers

With respect to physical barriers, research indicates that more than 3 million adults residing in the United States require a wheelchair for mobility.² The Americans with Disabilities Act requires full and equal access to healthcare services and facilities for PWD, yet patients with mobility impairments are frequently denied services, receive less preventive care and fewer examinations, and report longer waits to see subspecialists despite this mandate. A study recently published in the *Annals of Internal Medicine* reports the results of telephone interviews with specialty practices concerning their

¹ Mudrick, N.R.; Breslin, M.L.; Liang, M.; and Yee, S. (2012) "Physical Accessibility in Primary Health Care Settings: Results from California On-site Reviews," *Disability and Health Journal*, October, Vol. 3, Issue 4, Pages 253-261.

² Brault M. Americans with Disabilities: 2005. Current Population Reports, P70-117. Washington, DC: U.S. Census Bureau; 2008. Accessed at www.census.gov/prod/2008pubs/p70-117.pdf on 14 December 2012.

willingness to accept and capacity to accommodate patients with disabilities. Medical residents at a hospital in Springfield, Massachusetts telephoned 256 specialty practices in locations across the country and asked if the practice could accommodate a patient who was described as a large individual who used a wheelchair and who was unable to independently transfer. Fifty-six practices (22%) reported that they could not accommodate the patient. Nine practices (4%) reported that the building was inaccessible. Forty-seven (18%) reported that they were unable to transfer a patient from their wheelchair to an examination table. Only twenty-two (9%) reported the use of height adjustable tables or a lift for a transfer director. Finally, the study reported that gynecology is the subspecialty with the highest rate of inaccessible practices (44%).³

Something as fundamental to health management as weight measurement remains elusive for PWD. A California study reported, for example, that among over 2300 primary care practices, only 3.6 percent had accessible weight scales.⁴ Related research reveals that wheelchair users report almost never being weighed even though weight measurement is a crucial metric for many types of health care including determining anesthesia and prescription dosages, and ongoing health and fitness monitoring.

Lack of Programmatic Access

The failure to provide needed policy modifications and reasonable accommodations as required by current disability rights laws, affects healthcare treatment decisions and outcomes. For example, lack of effective communication when Sign Language interpreters are not provided for Deaf patients or print materials are not available in alternative, accessible formats for people with visual impairments can lead to ineffective communication about medical problems and treatment. Accommodations such as alternative formats are not offered or available even when their necessity is clinically obvious and predictable. For example, there is a high correlation between diabetes and vision loss, but printed self-care and treatment instructions in alternative formats such as Braille, large font type, CD, or audio recording, and accessible glucometers, are rarely available although the Americans With Disabilities Act of 1990 and Section 504 of the 1973 Rehabilitation Act requires the provision of auxiliary aids and services when required for effective medication. Other common problems include provider failure to modify routine diagnostic procedures in order to accommodate an individual's disability or to establish policies that allow for extended or flexible exam times. Some patients require additional time to communicate effectively, dress and undress, or transfer from their wheelchair or scooter to a diagnostic device or exam table or be positioned for an exam. When such accommodations are not available, providers may make incorrect diagnosis and treatment decisions and serious health problems sometimes are not properly diagnosed or treated. The result can be unequal healthcare that affects the quality and length of life for many.⁵

³ Tara Lagu et al. Access to Subspecialty Care for Patients With Mobility Impairment, *Annals of Internal Medicine*. 2013; 158:441 – 446.

⁴ Mudrick, Breslin, Liang, 2012.

⁵ Kirschner, K.L., Breslin, M.L., Iezzoni, L.I., & Sandel, E. (2009) "Attending to Inclusion: People with Disabilities and Health-Care Reform," *PM&R*, Oct 1, Vol. 10, Pages 957-63.

Moreover, insufficient knowledge of how to provide accommodations or ignorance about the critical need for accommodations can result in people being injured in the very process of seeking care. For example, patients with disabilities have been injured when they are transferred to exam tables by untrained staff, given improper dosages of medication or anesthesia due to lack of proper weight measurement, and when pressure sores develop because providers waive physical exams for wheelchair users who cannot transfer to exam tables.⁶

Finally, PWD report putting off needed care due to the significant distress associated with seeking and receiving care and therefore frequently must rely on emergency department treatment as a last resort when a treatable condition has become acute.⁷

Documented Health Disparities Experienced By People with Disabilities

Research shows that along with social determinants of health (such as income insecurity and lack of healthcare insurance), the aforementioned barriers contribute to significant health and healthcare disparities for PWD as compared to the general population. For example, PWD are more likely to:

- Experience difficulties or delays in getting the health care they need
- Not have had an annual dental visit
- Not have had a mammogram in the past 2 years
- Not have had a Pap test within the past 3 years
- Not engage in fitness activities
- Have high blood pressure⁸

Moreover:

- Women with disabilities have higher death rates from breast cancer than women without disabilities
- PWD die from lung cancer at higher rates than people who do not have disabilities⁹
- Adults with disabilities have a 400 percent elevated risk of developing Type II diabetes.¹⁰

⁶ J. M. Glionna, "Suit Faults Kaiser's Care for Disabled; Courts, Advocates Say Provider Fails to Give Equal and Adequate Treatment to the Handicapped. Chain Says It Complies with Disabilities Act," Los Angeles Times (record edition), July 27 2000, p. 3.

⁷ A recent study by National Institutes of Health researchers found that working-age adults with disabilities account for a disproportionately high amount of annual emergency department visitors. Rasch, E. K., Gulley, S. P., & Chan, L. (2012). Use of emergency departments among working age adults with disabilities: A problem of access and service needs. *Health Services Research*, 48(4), 1334-1358. Retrieved from <http://onlinelibrary.wiley.com/doi/10.1111/1475-6773.12025/references>

⁸ Altman, B., & Bernstein, A. U.S. Department of Health and Human Services, CDC National Center for Health Statistics. (2008). *Disability and Health in the United States, 2001–2005*. Retrieved from website: <http://www.cdc.gov/nchs/data/misc/disability2001-2005.pdf>

⁹ Iezzoni, L. I. (2011). Eliminating health and health care disparities among the growing population of people with disabilities. *Health Affairs*, 30(10), 1947-54.

¹⁰ U.S. Department of Health and Human Services, Healthy People 2020. (2013). *Disability and health*. Retrieved from website: <http://www.healthypeople.gov/2020/topicsobjectives2020/nationalsnapshot.aspx?topicid=9>

- Three out of five people with serious mental illness die 25 years earlier than other individuals, from preventable, co-occurring chronic diseases¹¹
- Adults with disabilities are three times more likely to commit suicide than peers without disabilities¹²

Adding to this picture of healthcare inequality, scientific evidence is lacking about effective treatments for PWD, especially those who develop common conditions of aging (e.g., cancer, heart disease, diabetes) because they are routinely excluded from clinical trials and creating comparative effectiveness research aimed at PWD presents complex challenges.¹³ Healthcare professionals therefore have access to limited comparative treatment information and evidence about therapeutic options. It also becomes very difficult to discuss or refute the often unexpressed bias that poorer health, shorter lifespans, and a lesser quality of life are inherent features of living with a disability, regardless of the functional impairment or clinical condition in question, and without respect to whether or not healthcare facilities are accessible and legally required accommodations have been provided.

DREDF is not asserting that the mere inclusion of full demographic information and requirements will fix all of the problems outlined above. But it is absolutely a necessary first step. Thus the urgency behind our recommendations to include questions concerning functional capacity and accommodation needs.

Other Proposals

We would like to reiterate the need for communication accessibility to be considered across the full gamut of the ONC's proposals. For example, the Blue Button Plus program is intended to be a simple way for consumers to enable other chosen locations or providers to gain access to their EHR, but unless ONC ensures that the technology is fully accessible to blind visual impairments. We also want to highlight that certification of HIT for pediatric data elements must take into account the accessibility needs of parents of minor children, as well as the accessibility needs of children themselves.

Thank you again for this opportunity to comment on the 2015 Edition. Our urgency comes from the understanding that EHR certification criteria can have a profound impact on the quality and accessibility of care for people with disabilities. Every moment that accessibility criteria are delayed impacts on the health, lives, and capacity of people with disabilities to live full and productive lives within their communities.

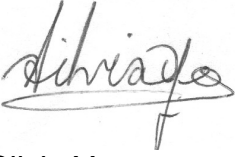
¹¹ Assoc. of University Centers on Disabilities, "Letter to Kathleen Sebelius" http://www.aucd.org/docs/policy/health_care/CLAS_StandardsDisabilityLetter%2012011.pdf. Citing (Colton & Manderscheid, 2006; Manderscheid, Druss, & Freeman, 2007).

¹² Seth Curtis and Dennis Heaphy, Disability Policy Consortium: Disabilities and Disparities: Executive Summary (March 2009), p. 3.

¹³ *Identifying effective health care services for adults with disabilities: Why study designs and outcome measures matter*. (2011). Presentation at the Mathematica Policy Research Center on Health Care Effectiveness (CHCE) Issue Forum. Retrieved from http://www.mathematica-mpr.com/CHCE/forum_archives/July_2011/powerpoint.pdf

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Yours truly,

A handwritten signature in black ink, appearing to read "Silvia Yee", with a horizontal line underneath the name.

Silvia Yee
Senior Staff Attorney