DREDF

February 25, 2011

Department of Health and Human Services
Office of the National Coordinator for Health Information Technology
Mary Switzer Building
330 C Street, SW, Suite 1200
Washington, DC 20201
Attention: Joshua Seidman

RE: Meaningful Use Workgroup Request for Comments Regarding Meaningful Use Stage 2 -- HHS-OS-2011-0006

Dear Health Information Technology Policy Committee,

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. Following are our comments relating to the additional specific questions for public comment in Part D of the above request.

2. For patient/family access to personal health information, what standards should exist regarding accessibility for people with disabilities (e.g., interoperability with assistive technologies to support those with hearing, visual, speech, or mobile impairments)?

While we were disappointed that accessibility standards were not included in HHS's July 2010 final rule establishing stage 1 "meaningful use," we are encouraged by the Department's inclusion of disability specific questions in its latest request for comments. We strongly urge the Department to adopt explicit accessible information technology standards within stages 2 and 3 MU to both improve health outcomes for all patients with sensory, cognitive or mobility limitations, and to ensure that a technological system that has been mandated to reduce health disparities does not in itself act to replicate and deepen the disparities experienced by people with disabilities. The inclusion of accessibility standards as early as possible within the MU standards and implementation specifications will help hospitals, clinics, and provider practices to avoid expensive electronic retrofits of their IT systems in future, and prepare them for anticipated Americans with Disabilities Act (ADA) regulations that will likely apply to most if not all of the same entities as the U.S. Department of Justice proceeds with the process initiated through its July 26, 2010 Advance Notice of Preliminary

DISABILITY RIGHTS EDUCATION AND DEFENSE FUND
3075 Adeline Street, Suite 210, Berkeley, CA 94703 • 1616 "L" Street, Suite 700, Washington, DC 20036
tel: 510.644.2555 [V/TTY] • fax: 510.841.8645
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Rulemaking on the Accessibility of Web Information and Services of State and Local Government Entities and Public Accommodations.

Patients with disabilities and family members with disabilities will not be included within the MU objective of engagement in their care unless MU measures at a minimum include the following accessibility standards:

1.   The web portals and sites through which health information and EHR will be offered must be accessible in accordance with Section 508 guidelines and W3C Web Content Accessibility Guidelines (WCAG 2.0 AA). WCAG 2.0 AA is an internationally recognized and sanctioned set of robust technical standards that flexibly encompasses information technology as it evolves to provide programs, services and information. The Department should take advantage of the fact that such guidelines exist and set health information web standards accordingly.

The new regulations should reference the Section 508 technical standards. Industry, people with disabilities, and the public at large need a consistent standard for accessible EIT development, and applying the technical standards of Section 508 to EIT used by ADA Title II and III entities to provide programs, services and information will provide that. (This is different than the new web standards, where Commenters recommend that WCAG 2.0 AA, and not Section 508, serve as the technical standard. Unlike web accessibility, there is no internationally sanctioned direct set of robust and flexible technical standards for EIT that the Department should point to).

HHS should consider adopting a generalized accessibility performance standard for all health information technology which requires technology to be "accessible to and usable by persons with disabilities so that persons with disabilities may access, perform or acquire the same health programs, services and information that is to people without disabilities by means of information technology with a substantially equivalent ease of use." The incorporation of such an overarching accessibility requirement for health information technology will help ensure that, for example, suggested stage 2 measures such as "80% of patients must be offered the ability to view and download via a web-based portal, within 36 hours of discharge, relevant information contained in the record about EH inpatient encounters" will actually include people with disabilities among that 80%. The stricture that data must be available "in human-readable and structured forms" will be meaningless to people with disabilities if "human-readable" only presumes the ability to see and comprehend small font text.

At the same time, the Department must ensure that effective communication for people with disabilities, as required by Section 504 and the ADA, continues to be achieved even when information technology is not being used. For example, the stage 2 measure specifies that electronic discharge instructions for hospitals must be

offered to at least 80% of patients has an accompanying caveat that "patients may elect to receive only a printed copy of the instructions." This is presumably meant to ensure that patients will receive the discharge instructions that are critical to engagement in their own care, even if they do not have ready access to electronic information technology once they leave the hospital. Those instructions must also be available and effectively communicated to individuals with visual impairments or who are pre-lingually Deaf, but presentation with "a printed copy" is highly unlikely to achieve the desired objective of encouraging patient self-engagement in care. The printed copy must be available in alternate formats such as Braille, large font print, audio-recording, and/or an ASL visual recording.

2. EHRs and health care information must be accessible in accordance with the guidelines established by Section 508 and WCAG 2.0 AA. This will include the requirement that all on-screen information, whatever the media format, must include audio description tags, and all text must be capable of onscreen magnification. Any audio components must include captions or visual descriptions. Forms that require input should be fillable and submittable online, as well as printable to maximize the independence and privacy of individual patients (and healthcare employees) with various disabilities.

3. Health plan, hospital, clinic, and individual practice locations that provide patients or members with computer terminals, kiosks, or any other stationary or portable means of gaining access to, and/or inputting information to, their health records must ensure that access points are accessible to individuals with sensory, physical or learning disabilities.

- People with mobility disabilities, including people who use wheelchairs, may require:
    - Controls and writing surfaces that at a minimum meet the counter and workspace height requirements of the 1991 Americans with Disabilities Act Accessibility Guidelines (ADAAG);
    - Viewing angles of controls, displays or information to be within 43-51 inches of the floor (as contemplated by the Guidance accompanying the 1991 ADAAG);
    - Size, placement, slope and surface of path of travel and clear floor spaces that comport with ADAAG standards.

- People with vision disabilities may require:
    - Touch screen interfaces with audio and tactile input options;

    - Visual (on-screen or printed) information with audio, tactile, large print, or high contrast output options;
    - Video information with audible description;

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- Biometric authorization, authentication, or identification mechanisms that depend on the presence of a retina or iris.

- People with manual dexterity disabilities may require:
  - Media objects used for interaction with electronic systems (styli, credit card swipes, keypads, mobile devices) that can be easily retrieved, held, positioned, manipulated, and stowed;
  - Keypads and buttons or switches (physical or on-screen) that are large enough to obviate the need for precise motor control, and that can be operated with prosthetic devices.

- People with hearing disabilities may require:
  - Audio or video information that is captioned or otherwise available in visual format;
  - Volume control for audio information;
  - Systems that have been tested for non-interference with hearing aids.

- People with cognitive and learning disabilities may require:
  - Content, authorization/authentication systems, and navigational controls that are straightforward, offer simple cues, and avoid using multiple media at the same time.

- Many people with disabilities, and seniors who may have or may be acquiring functional limitations, require:
  - Input mechanisms that do not time out quickly or at all;
  - Interactive or security mechanisms (such as facial recognition or body scanning) that assume a particular "standard" appearance, size, or posture (sitting versus standing).

3. What strategies should be used to ensure that barriers to patient access – whether secondary to limited Internet access, low health literacy and/or disability – are appropriately addressed?

We again stress that the primary strategy is to imbed accessibility standards – physical, communication, policy – within MU as early as possible. EHR is not a goal in itself, but rather support for better patient care. The fact that Medicare and Medicaid providers are incentivized for the "meaningful use" of EHR makes this clear. Electronic health technology must be accessible for EHRs to "improve quality, safety, efficiency, and reduce health disparities" for people with disabilities, and to engage people with disabilities and family members with disabilities in their care. While stage 1 has unfortunately passed without specific measures for disability access, stages 2 and 3 can begin to redress the situation by including standards as recommended in the response to question 2 above.

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Another critical component of a long-term strategy to address barriers to patient access is data collection. Section 4302 of the ACA mandates the collection of data on "disability status for applicants, recipients, or participants" by "any federally conducted or supported health care or public health program, activity or survey." In addition, Section 4302 also requires the collection of additional information related to specific, known barriers to healthcare that affect individuals with disabilities and that contribute to the health and health care disparities they experience. By doing so, the ACA acknowledges that disability is a population characteristic that is linked to health and healthcare disparities.

We would like to point out that evidence and data-based systems that do not collect data on the health characteristics and accessibility needs of patients with disabilities is effectively treating people with disabilities as if they are invisible. The failure to explicitly address the inaccessibility of information technology, or to mandate the importance of tracking accommodation needs within patient records as a whole, is not a simple error of omission. It perpetuates the falsehood that inaccessibility is a problem that the individual patient must deal with while the system as a whole need only concern itself with improving clinical practices for the "average" person without accessibility needs. "Meaningful use" cannot only be meaningful use of records, data, and information provided to and collected from the "average" person, but this will remain the hidden false assumption until meaningful use includes measures specific to accessibility and accommodation.

7. In stage 1, as an optional menu objective, the presence of an advance directive should be recorded for over 50% of patients 65 years of age or older. We propose making this objective required and to include the results of the advance-directive discussion, if available. We invite public comment on this proposal, or to offer suggestions for alternative criteria in this area.

We appreciate the importance of gathering information about patient-centered health care and the recording of patient preferences as a measure of meaningful use. However, we have some concerns over how making the recording of the advance directive mandatory could lead to individuals being pressured to fill out advance directives, and the possibility of negative consequences being attached to the refusal to fill out an advance directive. Some patients over 65 years may freely elect to designate a substitute decision-maker in the event that they cannot make their own medical decisions for any reason, without addressing an entire advance directive form or menu, and should be free to do so without bringing any kind of negative consequence upon the provider for not having a fully recorded advance directive

We know that some professionals have raised concerns over the effectiveness of advance directives. That is, there are doubts that advance directives are widely used, the best way to discover and record an individual's anticipation or desires for receiving

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care at the end of their lives, or achieve meaningful outcomes. Given this lack of unanimity over advance directives as a tool, and even on the language of "advance directives," we recommend that advance directives continue to be presented as an optional menu objective, and that the specific choices recorded in advance directives be collectively tracked to enable research into the types of advance directives that are being made by individuals of different ages, with varying medical conditions, and after different types of advance directive discussions. This will enable researches to consider the effectiveness of advance directives and the factors that may or may not influence the outcomes of advance directives, and also begin to evaluate the effectiveness of advance directives as a measure of meaningful use.

8. What are the reasonable elements that should make up a care plan, clinical summary, and discharge summary?

In addition to the need for care plans, clinical summaries and discharge summaries themselves to be accessible to patients with disabilities, in electronic or any other form, many people with disabilities need their health care accommodation needs to be part of the care plan. This information is not simply ancillary to treatment. If, for example, a patient's need and preference for mechanical lift/transfer assistance and adjustable examination/treatment equipment is not both recorded and readily available as an integral part of a patient's care record and clinical summary, that patient's encounters both with new providers/specialists, and even with the *same* providers, will be rife with risk for additional injury and wasted time and effort on the part of the patient as she or he repeatedly shows up for appointments where provider staff are unprepared to provide needed accommodations. As a result, critical exams and appointments can be delayed by a few hours to days or months. The same can be true of a patient who requires American Sign Language interpretation, or assistance with forms. An informed and prepared hospital or provider who knows the accommodations that a patient requires for an effective exam or treatment will obviously be providing clinical services of higher quality, safety, and efficiency to that patient.

A patient's accommodation needs, as well as their long-term home health care needs (e.g., need for accessible home modifications when a patient is discharged with a newly-acquired mobility impairment, whether temporary or permanent), can also be an extremely important element of a care plan, clinical summary, and discharge summary. The capacity of a patient's care team members to actually meet these needs is a separate and additional issue, but care coordination will not even begin to acknowledge and address these needs if they are not even recorded, even though these are the ongoing care needs that are likely to spell the difference between a patient being able to return to the community and live as independently as possible. This is particularly true for those individuals with multiple conditions and physical impairments. While it may be understandable that the stage 1 care coordination objective and its measures are focused on issues such as medication reconciliation,

we advocate that to be effective, care coordination's ultimate goal is to return an individual as fully as possible to a life of independence in the community, and this cannot be achieved without meeting an individual's accessibility needs. Again raising the principle that it is best to plan ahead and universally design for the needs of people with disabilities instead of "retrofitting" after the fact, electronic care plans, clinical summaries, and discharge summaries should be designed from the beginning to record and highlight a patient's accessibility needs as they develop.

Thank you for your consideration.

Sincerely,

Susan R. Henderson
Executive Director