

February 6, 2015

***Via Electronic Submission***

Dr. Karen DeSalvo, M.D.  
National Coordinator for Health Information Technology  
U.S. Department of Health and Human Services  
200 Independence Avenue SW, Suite 729D  
Washington, D.C. 20201

**Re: Federal Health IT Strategic Plan 2015-2020**

Dear Dr. DeSalvo:

Thank you for the opportunity to comment on the draft Federal Health IT Strategic Plan 2015-2020. 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. We strongly support the potential of Health IT to promote healthcare policy goals that are important to the disability community. These goals include increasing consumer participation, promoting the range of care coordination that is often needed by those with complex disabilities and multiple chronic conditions, and the gathering of accurate information about the breadth and degree of healthcare disparities experienced by people with various disabilities. For DREDF, the achievement of these goals requires Health IT to prioritize two fundamental things: first, data capture regarding an individual's disability status, and information concerning the individual's corresponding reasonable accommodations and policy modification needs, and second, electronic health records that are truly accessible to consumers with communication and print disabilities, and their families and personal assistants as appropriate.

DREDF has signed onto and supports the Consumer Partnership for eHealth's overarching comments on the Federal Health IT Strategic Plan 2015-2020. Our comments below are directed at some specific aspects of the Health IT Strategic plan that are of particular concern to the disability community.

**Data Capture**

We reiterate the need to track disability status, specific functional impairment, and reasonable accommodation or policy modifications needed as a critical first step to measuring and understanding the health disparities experienced by people with disabilities. We also emphasize that information about an individual's disability status is **not** the same as information about an individual's medical diagnosis. A patient's medical record can indicate that she has cerebral palsy and needs additional testing for some lumps that she has felt in self breast examinations. This diagnostic information does not necessarily inform her providers that the patient is also a wheelchair user, has

a level of speech impediment, and requires assistance with undressing and dressing, height-adjustable examination tables for transfers, accessible weight scales and MRI scanners, and longer appointment times for effective communication. All of this latter information, however, is necessary for ensuring that the patient receive timely and effective healthcare examinations and treatments.

Ensuring that all federal health electronic information is fully accessible to people with disabilities is important because patient engagement with their health records and the capacity to input disability status and reasonable accommodation and policy modification needs voluntarily and privately in one's own medical records as one's functional needs change over time is an ideal way to ensure updated and relevant information in the patient's electronic health record. At the same time, it will also be important to provide consumers with some guidance on what accommodations or policy modifications are as individuals, and especially older persons, who have a newly-acquired disability or chronic condition may be unaware of both their own disability-related civil rights and the range of reasonable accommodation and policy modifications that are required and available under federal and state laws.

With regard to data collection, we do also want to point out that the Section 4302 of the Affordable Care Act of 2010 requires the Secretary of the federal department of Health and Human Services to establish data collection standards for race, ethnicity, sex, primary language, and disability status, and calls for these categories to be consistently collected and reported in all national population health surveys that rely on self-report. Section 4302(b)(1) also requires the collection of data on these five demographic characteristics in Medicaid and CHIP adhere to the data-collection standards developed in 4302(a). While the data collection standards of Section 4302 is an ongoing process, there must clearly be some kind of cross consideration between data collection standards and the actual, increasingly technologically oriented means by which data is collected. It strikes us that the Federal HIT strategic plan provides an ideal forum for the federal government to play a leadership role in promoting fully accessible electronic health records, and transparent coordination of HIT with the data collection elements required under Section 4302. Perhaps this is already a priority between HHS and the Office of the National Coordinator for Health Information Technology (ONC), but we are not aware of actual outreach or engagement with the broader cross-disability community or specific components of the community on disability concerns and experiences with HIT accessibility, privacy or elements of needed data capture.

### **Emphasizing Health IT Capacity**

We wanted to briefly provide additional support for the Consumer Partnership for eHealth's comments concerning a need to explicitly address *capacity* within a strategic plan goal. From the possibly unique vantage point of an organization that has engaged in both litigation and structured negotiations with very large federal and state entities concerning the need to ensure accessibility of information technology, it is absolutely necessary to explicitly require increased capacity of electronic health records and health IT to integrate additional relevant information such as disability status, physical and

programmatic inaccessibility, and social and environmental determinants of health. Something as simple as apparently not having a field in existing online forms and data storage of the information in those forms has motivated federal and state entities to strenuously resist adopting information technology that will take account of a consumer's disability and corresponding need for a reasonable accommodation.

### **Incorporation of Long-Term Services and Supports Information**

We endorse Objective 1A, to "Increase the adoption and effective use of health IT products, systems, and services to include long-term service and supports (LTSS) providers," as well as various references to incorporate LTSS information as a component of the federal strategies' stated goals. We do think, however, that it is vitally important to both cast a wide net when it comes to considering who is a LTSS provider, and to build in technical assistance and specific incentives for participation by these providers. It will perhaps help to provide an illustration of a typical situation for LTSS consumers.

An elderly woman, Ms. X, who lives in a rural county of California has a long-standing mobility disability, as well as a medical need to address cataracts developing in her eyes and ongoing physical therapy needs relating to relatively recent pain and joint issues. She is a member of a managed care organization that has approved physical therapy services and cataract surgery, but many of the various medically necessary appointments that she needs are at locations that require considerable travel to use approved network providers. While Ms. X is eligible for paratransit in the area, the service typically requires a lengthy 90 minute or longer window for pick-up and drop-off. She can take accessible public transportation consisting of passenger trains, but they run on fixed schedules that, for example, only make it feasible for her to have hour long physical therapy appointments at noon; if these are not available then her weekly therapy session has to be delayed. Her managed care company indicates that it provides non-emergency medical transportation, but insists on contracting with low bidding national wheelchair transportation companies who are unfamiliar with the county and have been unreliable in the past, rather than the accessible local transportation company that has given her safe, accessible and courteous transportation in the past. The upcoming cataract surgery requires her to visit a new facility that is located in another county, requiring that Ms. X to facilitate the sending of proof of her paratransit eligibility from her home county to a neighboring county. When she undertakes the surgery, and for some of her other appointments, Ms. X schedules the assistance of a personal long-term assistant to help her dress and undress and find her way through an unfamiliar medical complex.

This is not something that comes out of our imaginations, nor is it a particularly complex situation. It is a common occurrence for many seniors and people with disabilities living in rural areas across the country. Health IT has immense potential to make a critical difference in how LTSS services and medical services can be coordinated and simplified for those individuals who rely on the availability of both to rely safely in their own homes and communities. But to play an effective coordination role, health IT must:

- Take adequate account of the variety and availability of LTSS service providers, including important “ancillary” providers such as accessible transportation specialists and Durable Medical Equipment/wheelchair seating specialists.
- Provide tailored technical assistance, incentives and opportunities to participate in health IT to the experienced community-based providers who are commonly relied upon for the provision of various aspects of LTSS, and especially consumer-directed home and community-based services (HCBS) such as community-based adult services centers; many of these entities are already enmeshed in trying to adopt business and billing practices that make it possible to work with the large managed care entities that are taking over the administration of Medicaid delivery in many states.
- Ensure that consumers themselves, and family members where appropriate, can read, enter, and correct LTSS information in health IT, as in some instances the consumer is the only one who actually knows the full gamut of medical and LTSS providers present in their lives. HCBS providers can, for instance, change quickly if an employer with a disability finds it necessary to dismiss one and hire another, and the individual with a disability is the best one to be able to update the information and maintain their individual privacy. Consumer access for many individuals who have functional impairments related to vision, print, or mobility (e.g., the capacity to manipulate a conventional keyboard or mouse quickly) means that health IT has to incorporate features that will accommodate the software needs and response time issues that ensure a record is accessible to consumers with disabilities from the very beginning.

### **Consumer and Conflict of Interest Safeguards for Health IT Access**

Once consumers have fully accessible access, they are also an invaluable source of information regarding the quality and person-centered care that they do or do not receive in particular long-term care contexts. At the same time, there must also be safeguards in place to ensure that consumer information is provided in a conflict-free and confidential manner in those situations where the consumer’s contact with health IT is almost sure mediated. For example, residents in nursing facilities and institutional settings, and even potentially in some group homes, may have no or little private access to computers or even telephones).

The broad accessibility goals and explicit mention of people with disability in the Federal Health IT Strategic Plan 2015-20 are welcome. Even more welcome would be the opportunity to work with the National Coordinator to devise particular strategies, incentives and standards that would make the broad goals come to practical life for millions of consumers with disabilities.

Thank you again for this opportunity to comment.

Yours truly,

A handwritten signature in black ink, appearing to read "Silvia Yee". The signature is written in a cursive style with a horizontal line underlining the name.

Silvia Yee  
Senior Staff Attorney