Viewpoint Paper ■

The Electronic Disability Record: Purpose, Parameters, and Model Use Case

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Abstract The active engagement of consumers is an important factor in achieving widespread success of health information systems. The disability community represents a major segment of the healthcare arena, with more than 50 million Americans experiencing some form of disability. In keeping with the “consumer-driven” approach to e-health systems, this paper considers the distinctive aspects of electronic and personal health record use by this segment of society. Drawing upon the information shared during two national policy forums on this topic, the authors present the concept of Electronic Disability Records (EDR). The authors outline the purpose and parameters of such records, with specific attention to its ability to organize health and financial data in a manner that can be used to expedite the disability determination process. In doing so, the authors discuss its interaction with Electronic Health Records (EHR) and Personal Health Records (PHR). The authors then draw upon these general parameters to outline a model use case for disability determination and discuss related implications for disability health management. The paper further reports on the subsequent considerations of these and related deliberations by the American Health Information Community (AHIC).

■ J Am Med Inform Assoc. 2009;16:7–13. DOI 10.1197/jamia.M2405.

Introduction

The potential of health information technology (HIT) to improve quality and efficiency of healthcare globally has been an important topic of discussion since the beginning of this century.¹ Two key events in the United States helped to turn the focus of this discussion to electronic health record (EHR) and personal health record (PHR) systems. In 2003, the Institute of Medicine published “Key Capabilities of an Electronic Health Care Record,”² which outlined core EHR functional requirements. In April 2004, President George W. Bush set forth an ambitious 10-year goal for EHR adoption throughout the nation, calling it an example of “A New Generation of American Innovation.”³ This paper reflects the substantial interest that has emerged at the national level in advancing HIT solutions across a range of settings.

One of the biggest challenges of HIT is the need to support diverse user groups, from consumers (patients) to providers, payers, and many others. While providers and payers have

been at the center of attention in early HIT implementations,⁴ the introduction of consumer-based PHR products (such as those offered by Microsoft and Google) are examples of opportunities to tailor systems to specific consumer needs. For example, there is increasing interest in HIT systems to support consumers who have chronic illnesses such as multiple sclerosis.^{5,6}

The disability community is a large consumer group that deserves policy and research attention. Among the 100 million Americans with chronic illnesses, more than 30 million are disabled because of their illness.⁷ However, chronic illnesses are not the only reason for disability, as many are born with a disability, develop a disability early in life, or suffer disabling injuries. Disabling impairments may be associated with diseases and active pathology, genetic disorders, accidents, or trauma.⁸ According to 2000 United States Census data, roughly one in five Americans (50 million) is disabled, including those with and without chronic illnesses.⁹

This paper focuses on consumers with disabilities as a specific segment of healthcare consumers and discusses the potential of electronic records to support them throughout their interaction with the healthcare system. Although the immediate emphasis of this paper is on the use of electronic systems to support the disability determination process, a range of opportunities exists to assist those with disabilities in broader areas of health management. We demonstrate that the needs of people with disabilities and their extensive interactions with the healthcare system deserve immediate attention.¹⁰ Our aims include use of health records as medical evidence to make critical decisions regarding disability benefits.⁶

The dimensions of Electronic Disability Records (EDR), a collection of records generated during the disability deter-

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Supported by the Kay Center for E-health Research at Claremont Graduate University. The authors thank Debbie Somers, David Lansky, Mary Jo Deering, Karen Bell, Martin Prah, Kim Nazi, Sue Feldman, Sean Clennon, Deborah Lafky, Elaine Blechman, Susan Daniels, Eileen Elias, David Stapleton, Mark Haas, Nicole Garcia, and Richard Burkhard for their input and advice. The authors also thank Steeve Kay for the leadership and passion that he brings to this issue of disability.

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Received for review: 02/20/07; accepted for publication: 09/30/08

mination process, are outlined in this paper. The EDR's central role in enabling accurate, timely, fair, efficient, and cost-effective solutions and services for people with disabilities is discussed. In making an argument, we draw upon expert discussions that took place at the Kay Center Policy Forums on October 17, 2007 and April 17, 2007 in Washington, DC. We then discuss future directions, drawing upon activities in this area by the American Health Information Community (AHIC).

Background

To achieve the healthcare goals set at the national level,³ the Office of the National Coordinator for Health Information Technology (ONC) developed a strategic framework for the use of EHRs and other HIT. This framework contains four major collaborative goals, one of which emphasized consumer-centric information systems and the use of PHRs.¹¹ The government created AHIC in part to help advance this strategic framework to attain national HIT goals. Moreover, the Consumer Empowerment (CE) Workgroup of AHIC recognized that specific populations warrant special attention, including individuals with disabilities.¹²

As noted in testimony before the CE work group, disabilities comprise a major component of United States healthcare expenditures. Approximately 400 billion dollars are spent by the healthcare industry on disability conditions, primarily by Medicaid and Medicare. Beneficiaries with disabilities account for approximately 40% of all Medicaid expenditures.¹³ Moreover, 42.8% of the disability population has a condition that affects their ability to work.¹³ Considerable medical evidence is required to demonstrate the nature and impact of relevant health conditions in order to obtain financial compensation for the disability. Payments may be delivered in the form of disability benefits and workers compensation. Existing HIT solutions, such as EHRs and PHRs, are at the center of this determination process.

For purposes of discussion, we refer to the instantiation of the electronic and personal health record for disability use as EDR. We define the EDR, describe how it uses EHRs and PHRs, and show how a disability use case can serve as a model for applying such applications to benefit people with disabilities.

Definitions of EHR, PHR, and EDR

To understand the EDR, we must first clarify the meaning of EHRs and PHRs. While a variety of definitions have been offered over the last decade, we adopt those offered by Safran et al., under which the EHR is generally considered the broad, encompassing health information system that includes "personal data created, developed, maintained, and/or provided by clinicians, providers, and allied health providers in direct patient care; an electronic application containing health information about individuals that is used by clinicians, providers, and allied health professionals to provide direct care for the individuals."¹⁴ A PHR, on the other hand, is defined as "an electronic application through which individuals can access, manage, and share their health information, in a private, secure, and confidential environment; personal data created, developed, maintained, and/or provided by individuals about themselves."¹⁴

Drawing upon these definitions, we refer to EHR as any electronic health information about an individual that is

stored and controlled by the healthcare provider. While EHRs may be kept principally for clinical reasons, a major challenge exists in adapting this orientation to the medical evidence and disability management needs in the disability community and industry. For example, a person might have multiple EHRs because of interacting with various healthcare organizations, but integrating these records for disability determination presents many challenges.

A PHR, on the other hand, refers to any electronic health information controlled by the individual. The PHR is consumer-centric, whereas the EHR is provider-centric. Information from the EHR can be populated into an individual's PHR, on the condition that the individual cannot alter the content coming from the EHR. Individual PHRs can also be populated with claims information through the claim records of healthcare payers.

All the information generated and stored in the records discussed above is generated for medical purposes, both for health maintenance and for diagnosis and treatment of illness. It is generally used for clinical purposes, and payers are involved to cover the cost of services provided to individuals during their interaction with the healthcare system. Table 1 presents an overview of different records discussed in this paper.

In the case of disability benefits, a new stakeholder is added to the picture: the disability benefit payer. Disability benefit payers keep their own records, which we refer to as EDR, on each individual who applies for disability benefits. The EDR contains the medical, occupational, financial, health support, and accommodation data necessary for disability payers to make a fair decision about an individual's eligibility to receive health and benefit services, as well as the extent of those services. This process requires assembly of records from different sources to collect evidence about the medical, financial, and legal components of a claim. Disability determination relies heavily on identifying the relevant third parties who own these records and their willingness and ability to share information with the disability benefit provider in a timely manner.

Since the records are derived from different sources, they have various formats and careful processing is required to extract information that is relevant to the specific disability claim. As the disability benefit determination process continues and levels of disability change, beneficiaries may be required to obtain additional medical evidence for inclusion in the EDR.

Table 1 ■ Three Complementary Electronic Health Care Systems

Health Care Record	Primary User	Primary Application
EHR	Health Care provider	Management of patients' medical information
PHR	Consumer (patient)	Management of personal health information
EDR	Disability benefit payers	Determination of disability status and benefits

EDR = electronic disability record; EHR = electronic health record; PHR = personal health record.

All of the information in the EDR will be used to make a final decision about the claim for disability benefits. If the decision is in favor of the claimant, the payer will continue populating the EDR with benefit and health status information as long as the claimant remains eligible. If the decision is not favorable, an outcome that is fairly common at the preliminary stage, the claimant may elect to continue to populate the EDR for use in subsequent appeals and adjudication processes.

How an EDR Extends EHR and PHR

The idea of developing modernized systems to assist in disability benefit determination and provisioning dates back to the 1990s. The Veterans Administration's (VA) disability compensation claims processing has been shifting from a paper-intensive to an automated, modernized electronic system since 1992.¹⁵ The Social Security Administration (SSA) initiated its Modernized Disability Systems process in 1992, with the intent of redesigning the disability claims process to emphasize the use of automation to achieve a paperless processing capability.¹⁶ In 2008, new HIT developments in EHRs and PHRs are creating timely opportunities for payers to provide more efficient and timely services to claimants, and to meet claimants' demands for fast and fair decisions.

The EHR systems can play an important role in the disability process, from the initial disability determination through the entire span of the disability. However, the primary purpose of these systems is to support treatment-oriented processes in the healthcare environment.¹⁷ The EHR systems follow standard codes such as ICD-10 or SNOMED to classify illnesses or treatments. On the other hand, disability determination process has its own codes and classifications defined by the disability benefit payers and these listings do not necessarily match with existing treatment oriented codes. It is not always possible to use a claimant's EHR as medical evidence without first extracting and translating the relevant information that can help classify the health condition into a listed disability category used by the disability payers. There is a clear need for EDR systems that are designed to assist extracting and translating the EHR medical record information that can provide evidence for the disability claim.

Many consumers also wish to be involved in this process. This presents the need to extend PHR systems to provide an access point for patients (claimants) to interact with the EDR to retrieve and populate claim-related information. This could enable claimants to view the progress of their claims and allow them to take timely action when delays occur.

The EDR stores information generated during the entire disability benefit process. Unfortunately, this rich and meaningful disability-related history is typically not available to claimants for use in monitoring their claim and/or in using for health management. Under the EDR concept, this history would be displayed using standards that relate to disability determination standards, such as the authorized release of information for nonclinical purposes under development at SSA and others at the federal level. Others in the private sector have shown interest in contributing to these standards. The information contained in an EDR can potentially assist all stakeholders in the disability process through

Figure 1. Interaction between systems.

coordination of services and supporting the disability community in obtaining customized services. Detailed analysis of aggregate information contained in EDR systems can also allow analysis of trends and conditions in the disability community, thereby providing empiric support for policy reforms and improvements.

Active participation by large disability payers such as SSA and VA is necessary to ensure successful integration of PHR and EHR solutions into disability determination and service coordination systems. The EDR systems developed by payers now have the opportunity to adjust their system requirements and collect medical information directly from EHRs and PHRs through real-time connections. (Figure 1 illustrates the interaction between systems as we envision them.)

One way to envision the EDR is as a hybrid record that pulls, as needed, from the EHR, the PHR, and various claims systems. In this sense, the EDR depends upon the technical specifications, standards, and business processes of these systems, but it also has unique characteristics in terms of how personal, medical, and disability claims data are brought together for disability determination and health management. These real-time system connections are needed for information sharing, but will require architectural adjustments to support existing and future systems.

The SSA is already working on ways to transfer data directly from existing, well-established EHR systems. For example, John Halamka, CIO of Harvard Medical School, recently outlined the process underway at Beth Israel Deaconess Medical Center, Boston, to test the real-time exchange of disability-related data based on SSA disability guidance. Dr. Halamka notes that while HITSP has yet to develop standards for this specific use case (an issue that will be raised later in this paper), there are a variety of relevant standards that can be used, such as the Continuity of Care Document (CCD).¹⁸

The potential benefits of such an EDR-EHR connection are considerable. In 2008, SSA will spend approximately 500 million dollars per year attempting to obtain medical records for disability determination.¹⁹ As will be described below, the average initial response time is approximately 97 days, with final resolution often taking up to three years for more complex cases. Conversely, a properly organized dis-

ability record can substantially reduce the time and increase the quality of electronic processing. Furthermore, this time reduction and better quality collection of medical evidence could lead to demonstrable public savings by decreasing the amount of money spent by SSA chasing medical evidence. Additionally, claimants benefit from expedited decisions, including reducing the personal and financial hardship that can often accompany a prolonged claim adjudication process. Achieving these benefits requires a detailed understanding of the medical evidence information flow in disability determination; it is this process that we take up next.

Characteristics of Disability Evaluations and Benefit Determination

When we focus on the business process, there are two critical decision points during the formation of an EDR. The first is the point when the patient chooses to file for disability benefits, which initiates the formation of the EDR. Without a disability claim, health and medical information generated through various provider contacts are stored in multiple, disconnected EHR and PHR systems and paper folders. After the disability claim is initiated, the EDR system should be able to collect information from these sources to support the process and any other disability related services that follow.

To make a decision on a disability claim that has been filed, benefit payers first request existing medical evidence from the claimant's known healthcare providers. Disability evaluators require access to an individual's supporting medical records and financial information, which is often scattered across multiple providers. For example, in the case of SSA disability claims, regardless of the condition, SSA requests information from the primary care physician.²⁰ In case of psychiatric disability, this information is coupled with medical evidence from specialists and other resources where the "primary care physician is but one source contacted by the SSA for clinical information."²⁰ For each claim, SSA must identify these clinical sources and request medical records to prepare the file for disability determination. In the absence of a PHR, identification of providers depends solely on claimants' ability to remember their own provider history.

Once providers are identified, the payer will generate a written or electronic (including fax) request to retrieve the claimant's medical records. Providers often delay their response or choose not to respond because they are not adequately compensated, if compensated at all, for the time spent compiling the requested information. This results in delayed or incomplete medical evidence and, subsequently, further efforts at evidence collection.

After a disability claim is evaluated by the SSA field office for financial eligibility, it is forwarded to the state-run Disability Determination Service (DDS) office for medical eligibility review.²¹ The decision-making team at the DDS office attempts to develop a complete medical and functional history of the claimant for at least the 12 months preceding the application for disability benefits.²² The length of the time allocated for medical and functional history collection indicates that the process is not a trivial one. The average claim processing time is 3 months for an initial response to an SSA claim and up to three years for a final decision.²¹ Even though the factors affecting processing

time are not limited to medical and functional history collection, it is widely accepted among disability experts that improving this portion of the process will help federal agencies shorten claim processing times and help claimants receive benefits in a more timely manner.¹⁹

Indeed, there are various benefits to be realized from a more integrated system where disability is a significant component. Payers benefit with the ability to collect more complete and relevant information by using previously generated medical records regarding an individual's disabling condition. This can reduce the need for further evidence collection, which usually leads to new medical examinations or duplicate laboratory tests to determine the condition and source of the disability claimed. Consumers with disabilities will be able to actively and transparently manage their disability from a financial, health, employment, and services perspective with the help of an EDR. We postulate that end-to-end involvement of users in the claims and benefits process will raise awareness of how beneficial services can be more efficiently used. Empowering these individuals by providing access to records concerning their health is expected to have a positive effect on the overall wellness of this population, which is the primary goal of all health systems.

The second important point in the lifespan of the EDR is when a compensation decision is made. The type of information collected about an individual is different before and after this decision point. Prior to a decision, the EDR is heavily populated with historical medical, financial, occupational, demographic, and accommodation data that is directly related to the claimed disability. After a decision is made, data collected in the EDR changes to support the individual and their daily activities, including medical and concierge-type support services. The EDR will also contain information about past and present financial compensation received in relation to the disability, rehabilitation information, and information on other services received.

The EDR system should be designed to cover the complete lifespan of a disability with one goal in mind: to support people with disabilities in a complex environment where interaction with various parties is mandatory to receive the benefits to which they are entitled.

The medical records related to the disability claim become medical evidence in the disability determination process and must be managed as such by the claimant and payer. The same medical record can be used by different benefit payers based on the claims initiated by the disabled claimant. A linkage between EDR and PHR systems can solve the information-sharing problem by allowing the claimant to be the central point for their health information. In this fashion the EDR benefits from standards developments, such as for the CCD, endorsed in 2008 by HSTP and HL7.²³ The CCD contains elements for several disability-related conditions ("problems") as well as other typical PHR data. It is not surprising therefore that Google Health uses a portion of the CCD, and the charted roadmap for implementing CCD suggests it will be a useful standards platform to represent disability applications.²⁴

This potential value of a PHR in disability benefit management was raised during the AHIC Consumer Empowerment

workgroup hearing on PHRs.^a This workgroup, which continues to explore possible steps to ensuring PHR usage among people with disabilities, has raised a set of issues for consideration in the health informatics community, including design requirements for ensuring access to such records regardless of disability, innovative means for allowing multiple caregivers to use electronic and personal health records throughout the course of care, and creating efficiencies and transparencies in the disability determination process.^b These activities confirm the value of moving forward with a new way of thinking about how electronic personal and related health systems can be devised and refined to meet the needs of this important health consumer.

Disability Use Case

The National Health Information Network (NHIN) has promoted the concept of use cases as a generic way to identify the functional requirements of the HIT systems that will be implemented. This paper follows the same approach and outlines a use case for disability. Our discussion is based on the presentations provided during the Kay Center Policy Forums, which included researchers and policymakers in medical information systems, as well as related American Health Information Community efforts.^c The objectives of the forums were to review health and disability policy trends and technological developments, to identify use cases for EDRs, and to determine research opportunities. After these forums, the American Health Information Community (AHIC) established a subgroup on Disability (co-chaired by one of the authors), where disability issues were examined in considerable detail.

A consistent theme throughout these events was the acknowledgment that more could and should be done to facilitate the use of PHRs among the millions of Americans with disabilities. This included a range of efforts that could be undertaken by healthcare providers, technology providers, disability benefit payers, and policy makers such as ensuring access to PHRs regardless of disability and developing applications that could ease the coordination of information among caregivers. For reasons that have already been outlined above, it also became clear that there was value in outlining a use case specific to the disability determination process.

Use Case: Disability Determination for Benefit Purposes

The focus of this use case is on the claim process for obtaining disability benefits (i.e., Social Security Disability Insurance). The target group for this use case is the approximately six million Americans who file for disability benefits each year.^{25,26} For the purposes of this use case, we consider the establishment of an EDR as occurring at the time an individual sends the initial claim application to a payer for benefits because of a disabling condition.

This use case assumes that (1) the individual's PHR is populated with information from various resources, including the individual, provider-based EHRs, pharmacies and pharmacy benefit management companies; (2) all information is in electronic form at the time of filing; (3) all treating sources keep medical records in their EHRs; and (4) EHRs have the functionality to release medical information for nonclinical purposes. While the use case focused on SSA, it would also have application to private sector disability insurers, though some of the steps would need to be amended to comply with company-specific workflows.

Filing Process

The individual assembles a claim by compiling the required information within their PHR, including demographic information, problem list, treating sources, medication history and summary of clinical reports, in the format specified by a payer such as SSA. Using the PHR, the claimant submits the claim file to the disability benefit payer. When doing so, the claimant specifies which episodes of care from providers' EHRs are relevant to the case and can be released to the payer. This serves to streamline the amount and relevancy of information funneled to determination examiners and eliminates the information overload that so often occurs.

Claim Handling

The payer's EDR receives the new claim and alerts the local field office. Using the EDR, the claim is reviewed for financial eligibility and, if approved, a notice is sent to the state DDS that the new claim in the EDR is ready for medical examination. The SSA extracts medical evidence from providers' EHRs and a medical review is conducted. If EHR extracts are not received in a timely manner, and/or further support is needed, a new medical examination request is generated.

Further Medical Evidence Collection

If there is missing or no medical evidence to process the claim, then the state DDS submits requests for medical records to the various providers, listed in the claim, through their EHRs. The EDR sends status updates to the claimant's PHR, allowing them to track progress and follow-up with providers who are not responding to requests in a timely manner. If further medical examination is requested due to a lack of medical evidence, the claimant will receive this as a progress update in the PHR. The claimant can then see the appropriate provider and add the required administrative information to the PHR, which subsequently updates the EDR. A request will then be sent to the new source of medical evidence and the medical records will be extracted from the provider's EHR and forwarded to the EDR. Another medical review is conducted, a decision is made, and the EDR notifies SSA DDS.

Benefit Decision

The SSA DDS reviews the claim and makes a benefit determination based on the medical decision and other information submitted in the claim file. The status of the claim is also updated on the EDR. From this point on, the EDR will be populated with information on the benefits received by the claimant. The claimant's PHR is also populated with relevant information.

In this scenario, we assumed that the claimant provides information on medical evidence sources using the PHR and

^a<http://www.hhs.gov/healthit/ahic/materials/meeting09/ce/b/williamcrawford.doc>.

^bConsumer Empowerment Work Group Recommendations on Disabilities were approved by AHIC on Apr 22, 2008.

^cThe podcasts of these events can be found at <http://www.kaycenterpodcasts.org/>.

payer retrieves the actual medical evidence through providers' EHRs. An alternative is using the medical record summaries stored in the claimant's PHR as medical evidence. However, this raises an important concern: the reliability and accuracy of the information provided by the claimant to the EDR. It can be argued that the indirect link to medical records generated by providers introduces the opportunity for forged documents to be submitted to the EDR. This is a valid concern that must be addressed at the implementation level, before PHRs can reliably interact directly with EDRs. One viable solution is using digital signature techniques, which make it possible to determine a document's authenticity with a single click.

There are important benefits to be realized from relying on the PHR-EDR interaction versus the EHR-EDR interaction for information retrieval. First, individuals filing for disability benefits are highly motivated to complete the required documents as quickly as possible, which can speed up the evidence collection process. Providers, on the other hand, have no motivation to provide information stored in their EHRs, nor will they be motivated to implement EHR systems compatible with disability benefit payers' EDRs unless there are significant cost savings involved with such implementations. Once consumers and providers widely adopt PHR systems, they can provide a valuable, efficient, and continuous connection between claimants, providers, and payers.

Second, SSA alone issues 20 million medical record requests each year to compile medical evidence for approximately 6 million claims.²⁷ As noted by SSA experts during the Kay Center Policy Forums, these requests represent a massive, yet inefficient, means to arrive at a complete record. Use of PHRs has the potential to reduce the number of medical record requests made each year and to streamline and expedite the evidence collection process. A similar savings could potentially occur in the private sector, as disability and workers compensation insurers also make requests for millions of medical records a year. Use of HIT has the potential to reduce this vastly inefficient paper shuffle and the time is ripe to do so.

Future Directions

The focus of this paper has been on a distinctive need within the disability community: use of electronic systems to streamline the onerous process of disability benefit determination and management. We have used the concept of "Electronic Disability Records" to outline the means by which electronic personal and health information can be brought together to achieve this result. During the course of AHIC and Kay Center events in 2007–2008, the general sentiment of the participants has been one of validation of the general necessity of addressing the needs of the disability community and the specific necessity of using electronic personal health records and related systems to improve the disability determination process. However, using the NHIN framework to address the diverse needs of people with disabilities requires action in various areas. One of the most critical areas is the development of standards and technical architectures, such as release of information for nonclinical use, to support the use of electronic records throughout the disability benefit determination process.

While the EDR and EDR-PHR interaction may make conceptual sense, the path to implementation and adoption remains another matter. There are four major groups of disability compensation payers in the United States: SSA and VA, which operate at the federal level; Workers Compensation, which is regulated by individual states; and private disability insurance companies. Each uses a different claim procedure and provides different services once a disability is found compensable. Payer support of and commitment to the development and use of the EDR is critical to increase adoption of these technologies and streamline the disability claim process. Beyond the organizational issues are the personal/privacy issues. It will be important to attend to issues concerning privacy, fair use of electronic health information, and the exchange of data between disparate systems at the early stages of architectural design to avoid future integration problems. Indeed, disabilities such as mental health and HIV/AIDS represent some of the most sensitive health conditions. Therefore, ensuring the privacy and security of the information are critical aspects of EDR design.

Finally, while we have focused on how an EDR can be used to improve the disability determination process, it is important to note that this is but one possible, albeit important, application of electronic systems within the disability community. The AHIC Consumer Empowerment workgroup Subcommittee on Disability has outlined a range of issues and opportunities, including the value of a use case encompassing disability determination and care coordination applications. On April 22, 2008, AHIC formally approved the disability recommendations of this Workgroup, setting the stage to a broad consideration of policy and use case applications.

As the successor to AHIC assembles its priorities, we hope that disability considerations will be given proper attention. In many ways, disability applications challenge the main promise of HIT solutions, that is, to deliver demonstrable health and financial value to those consumers who really need it. Activities suggest the disability community is ready to take the Health IT community up on its promise. We believe it is a promise worth delivering on.

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