

---

## Findings from the Kay-Cornell Policy Forum on Electronic Disability Records

---

Bengisu Tulu  
Assistant Professor, Worcester Polytechnic Institute  
Research Associate, Kay Center for E-health Research

bengisu@wpi.edu

## Theme

“Electronic Disability Records (EDR):  
How to link the needs of people with disabilities to  
the national health initiatives?”

- Disability policy considerations
  - EDR for disability determination
  - EDR for service coordination and personal health management
- Integration with
  - Electronic Health Records (EHR)
  - Personal Health Records (PHR)

## Participants

Moderator: Susan M. Daniels

Host: David Stapleton

- American Academy of Physical Medicine and Rehabilitation
- Association of People with Disabilities (AAPD)
- National Alliance for the Mentally Ill
- National Association of People with AIDS
- National Disability Rights Network
- National Organization of Social Security Claimants' Representatives (NOSSCR)
- The Arc
- United Spinal Association
- Centers for Medicare/Medicaid Services
- Social Security Administration
- Axis Healthcare
- Partners Healthcare
- Claremont Graduate University
- Cornell University
- University of Colorado-Boulder
- Worcester Polytechnic University

Third Annual Kay-CGU Symposium - December 1-2, 2006

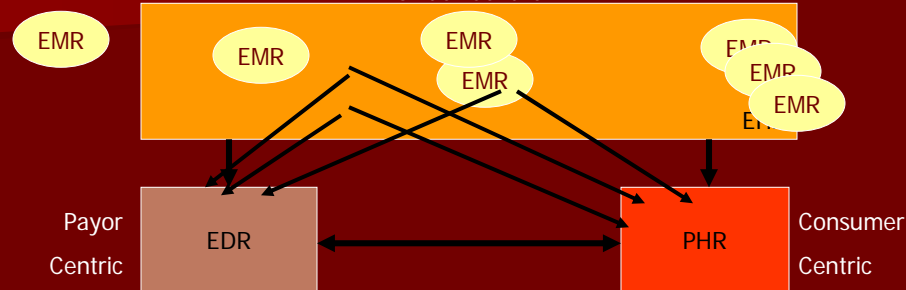
## Electronic Disability Record (EDR) Overview

- EDR contains the medical, occupational, financial, and health support data necessary for the individual to receive efficient, fair, and effective services for their disabling condition.
- It assists an individual throughout the entire disability process, from the initial determination throughout the lifespan of the disability.
- Developments in EMR, EHR, and PHR represents a major opportunity to apply emerging technological innovations to health management and benefit needs of the disabled community.

Third Annual Kay-CGU Symposium - December 1-2, 2006

## Electronic Records for Consumers with Disabilities

Provider Centric



### ■ Disability Determination

- Have read-only access to EMRs
- Store demographic information about the claimant
- Store financial information about the claimant
- Store benefit information about the claimant

### ■ Health management

- Have read-only access to EMRs
- Store personal demographic information
- Store personal health information daily
- Share health information with other parties
- Manage health related activities

Third Annual Kay-CGU Symposium - December 1-2, 2006

## Findings from the Forum

- Identify tangible benefits of using electronic records such as:
  - improving medical outcomes
  - saving time for providers
  - increasing efficiency of medical information exchange
- Understand the implications of the differences between medical procedures for disability ratings and for regular treatment visits on developing electronic records
- Identify the impact of delays encountered on the determination process as a result of missing medical records on people with disabilities

Third Annual Kay-CGU Symposium - December 1-2, 2006

## Use Case 1: EDR for Benefit Determination of Disabled Persons

- Disability assessment and rehabilitation involves a diverse group of assessors, providers and insurers, who have varying levels of electronic health records integrated in their practices.
- EDR promises
  - efficiencies in assembling relevant records,
  - improved disability determination process,
  - better coordinated care throughout the duration of the disability.
- Medical evidence collection is a critical part of the process and affects the outcome significantly.

Third Annual Kay-CGU Symposium - December 1-2, 2006

## Findings from the Forum

- There is a need to identify the **data elements** that are necessary in a PHR to mark baseline information of our health state if we ever become disabled.
- There needs to be a clear means for **linking** the data elements to the disability determination criteria.
- Processing the medical information and **getting the relevant pieces** from the medical record is the key to success in disability determination.



Third Annual Kay-CGU Symposium - December 1-2, 2006

## Use Case 2: EDR (PHR) for Health Management of Disabled Users

- Use of EDR and PHR by disabled consumers can
  - promote continuous personal care management
  - enable integration of medical assessment and treatment records
  - allow active user involvement
  - support a range of programs, including SSA, workers compensation, private insurers, etc.

Third Annual Kay-CGU Symposium - December 1-2, 2006

## Findings from the Forum

- There is a lack of representation from disability related advocacy groups and watchdog agencies in the discussions that define functional requirements for PHR.
- There are significant usability challenges raised by the diverse attributes of disabled consumers that needs to be addressed while developing PHR systems.
- In the case of disability, there is a lot of medical records available; however, there is a need for integration.

Third Annual Kay-CGU Symposium - December 1-2, 2006



## Issues Identified

- Privacy
  - Use of health information by employers and other parties against the owners of information is a great concern in disabled communities.
  - The subjective nature of medical judgment is a concern for disability claimants.
  - In the case of mental health patients the information exchange becomes harder as a result of conflicting forces.
- Concierge Service Model
  - Different solutions are needed to support consumers who are not competent to manage their own health.
- Security
  - Utilize solutions that exist in other domains
  - Find the balance where there is enough security and privacy that the benefits override the risks.

Third Annual Kay-CGU Symposium - December 1-2, 2006

## Future Directions

- Semantic interoperability
  - to present health and medical information to all consumers using plain language.
- Integration into SSA and related federal procedures:
  - Develop broad value propositions
  - Look for Global applicability for buy-in
  - Become a part of the national activities
  - Target standards
  - Find the right size steps
- Well people lack motivation to use such systems whereas disabled people are motivated. This presents an opportunity to jumpstart PHR implementation and use.

Third Annual Kay-CGU Symposium - December 1-2, 2006



## Research Needs

- Studies that clarifies definitions and issues.
  - By identifying important issues, better systems can be developed and implemented.
- Case studies which present the value of new systems in a qualitative manner.
- Research that examines the usability requirements and subsequent perceived value within the disabled community.
- Studies that reflect the current state of PHR and EHR use and implementation.

Third Annual Kay-CGU Symposium - December 1-2, 2006

## Related Publications

- Tulu, B., Burkhard, R.J., Horan, T.A. (2006) "Continuing Use of Medical Information Systems by Medical Professionals: Empirical Evaluation of a Work System Model", *Communications of the Association for Information Systems*, forthcoming
- Lafky, D. B., Tulu, B., Horan, T.A. (2006) "A User-Driven Approach to Personal Health Records", *Communications of the Association for Information Systems*, Vol. 17, Article 46, 2006.
- Tulu, B., Hilton, B. N., Horan, T.A. (2006) "Improving Disability Evaluation Process Productivity: Linking Innovative Business Models with Information Technology", *International Journal of Healthcare Technology and Management*, Vol. 7, Nos. 1/2, pp.168–182, 2006.
- Tulu, B., Li, H., Chatterjee, S., Hilton, B. N., and Horan, T. A. (2005) "Implementing Digital Signatures for Healthcare Enterprises: The Case of Online Disability Evaluation Reports", *International Journal of Healthcare Technology and Management*, Vol. 6, No.4/5/6, pp. 470 – 488, 2005.

Third Annual Kay-CGU Symposium - December 1-2, 2006

Thank you!

---

- Bengisu Tulu
- Assistant Professor, Worcester Polytechnic Institute
- Research Associate, Kay Center for E-health Research

■ [bengisu@wpi.edu](mailto:bengisu@wpi.edu)