Personal Health Records - Accessible Electronic & Information Technology (AeIT) for People with Disabilities

HIMSS Personal Health Records Roundtable, January 9, 2009
谨开口, 慢许诺...

Be prudent in speeches and promises...
"The power of the Web is in its universality. Access by everyone regardless of disability is an essential aspect."

Tim Berners-Lee, W3C Director and inventor of the World Wide Web
"The power of the Personal Health Record (PHR) is in its universality. Access by Special Populations regardless of disability is an essential aspect."

Ed. Adaptation - Source: Tim Berners-Lee, W3C Director and inventor of the World Wide Web
Welcome to the **Collision** of Civil Rights and Health Information Technology
AeIT / PHRs – Introduction

From the perspective of people with disabilities, inaccessible personal health record systems are an obstacle that prevents them from participating equally and fully in managing their health care and supporting independence and community living milieus.
Demographics

- The World Population is projected at 6 billion
- The United Nations estimates there are over 1 Billion or 16% of the world population with disabilities
- The U.S. population is projected at 299 Million
- The 2000 U.S. Census indicated that there are 51 million or 19.3% of the population with some type of long lasting condition or disability
The percentage of people with disabilities is larger than any single ethnic, racial, or cultural group in the U.S.

For example, the U.S. State of Florida ranks higher than the national population at 22.2%.

- Miami (for pop. > 100,000) has the 2nd highest percentage of persons with disabilities in the U.S. at 29.4%.

The large and growing market of people with disabilities has $175 billion in discretionary spending, according to the U.S. Department of Labor.

AARP says that 4 million Americans turn 50 each year. People age 50 and older spent nearly $400 billion in 2003. At age 50, adults are likely to experience age-related physical changes that may affect hearing, vision, cognition, and mobility.

Examples of spending power worldwide: UK ~ (L) 50 billion, Australians ~ AUS $26 billion, and Canadians ~ CAN $25 billion.
AeIT / PHRs – Globalization

Electronic Health Record (EHR) Adoption Around the World

Deemed accurate as of January 2006
Unprecedented increase in developed countries’ population is under way

**U.S.**
19% of managerial positions will retire in 5 yrs.

**Japan**
In 7 yrs, > 33M (26% of populations) will be >65 yrs

**Italy**
>22M receiving pensions vs.
21M working

**China**
60M disabled
130M+ over 60 (10% of population),
400M by middle of century

**Australia**
2016, individuals 60-64 expected to double

## AeIT / Disability

**Disability is a normalizing condition**

### Traditional Disabilities

<table>
<thead>
<tr>
<th>Visual</th>
<th>Hearing</th>
<th>Motor</th>
<th>Cognitive</th>
</tr>
</thead>
<tbody>
<tr>
<td>blindness, low</td>
<td>hearing loss,</td>
<td>inability to use a mouse, slow response</td>
<td>learning disabilities, distractibility, inability to remember or focus on</td>
</tr>
<tr>
<td>vision, color-</td>
<td>deafness</td>
<td>response time, limited fine motor control</td>
<td>large amounts of information</td>
</tr>
<tr>
<td>blindness</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

### Other Disabilities

<table>
<thead>
<tr>
<th>Temporary Disabilities</th>
<th>Aging - By 2010, 60% of U.S. population will be over the age of 35</th>
<th>SL – 17.9M people speak a second language at home</th>
<th>Novice Computer Users – 25% of US households do not own a computer and must higher in other parts of the world</th>
</tr>
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</table>
“No matter which motivation works for a particular organization, one principle will always hold true: IT accessibility is most easily achieved when people are at the center of the process. Even those who are simply trying to avoid lawsuits will sooner or later realize that the needs of the target audience people with disabilities must be carefully considered and addressed.”

- Cyndi Rowland, Director WebAim, 2004
Accessibility is now becoming a worldwide imperative

**Global Legislation affects**

**Americas**
- **Canada**
  - Canadian Human Rights Act
  - Ontarians with Disabilities Act – 2005
- **United States**
  - Americans with Disabilities Act (ADA) - 1990
  - Section 508 of Rehabilitation Act - 1998
  - States are enacting similar legislation
  - Massachusetts – Open Document Format decision has fueled heated debate due to lack of accessibility - 2005
- **Brazil**
  - Gov’t Decree affects public sector - 2004

**Europe**
- **Sweden** – Guidelines for computer accessibility, 1998
- **Spain** – Accessibility for computer platforms, 1998
- Mandate for accessible government websites by YE2005
- **UK** – DDA: Web accessibility, public & private sector, 1999
- Public procurement - 2005
- **Germany** – Barrier Free Decree, 2002
- Ireland – IT accessibility guidelines, 2002
- **Italy** – ICT accessibility & government procurement, 2004
- **Switzerland** – Public sector Web accessibility, 2004
- **European Union** – Procurement Directive, 2004
- **Netherlands** – Web accessibility, 2003
- **Portugal** – Web accessibility – 1999
- Investigating software accessibility legislation – 4Q05

**Asia Pacific**
- **Japan**
  - JIS standards, Government & industry cooperation, 2004
  - Law of integrated welfare, 2006
  - Law of developmental disorder, 2005
- **China**
  - Extending law to cover IT accessibility by YE2006
- **Australia**
  - DDA: Web accessibility, public & private sector – 1996
- **India**
  - Begun process to add IT accessibility to existing law - 2005

Source: With Permission of IBM Human Ability and Accessibility Center, 2007
AeIT / PHRs – *Laws & Standards*

**Use Case ~ U.S. Accessibility Trickle Down**

- The Federal Government implemented the Section 508 Technical Standards June 2001
- By the end of 2004 most U.S. states implemented a Web accessibility policy, standard, or law
- By the end of 2004 14 states implemented an Application Development accessibility policy, standard, or law
- By the end of 2004 23 states implemented an IT Procurement accessibility policy, standard, or law
- Florida was one of the last states to implement an enterprise accessibility law in 2006
The Americans with Disabilities Act – 1990

- 28 C.F.R. Part 35
- Department of Justice ruling (09/09/1996):
  - ADA accessibility requirements apply to the Internet
    (10 NDLR 240)
- Central issues focus on:
  - Effective Communication and
  - Public Accommodation

“Covered entities under the ADA are required to provide effective
communication, regardless of whether they generally communicate through
telecommunication devices, print media, audio media, or computerized media
such as the Internet. Covered entities that use the Internet for communications
regarding their programs, goods, or services must be prepared to offer those
communications through accessible means as well.”
- Department of Justice
Section 504 of the Rehabilitation Act

- It was the first civil rights legislation in the United States designed to protect individuals with disabilities from discrimination based on their disability status.
- The nondiscrimination requirements of the law apply to employers and organizations that receive federal financial assistance. This statute was intended to prevent intentional or unintentional discrimination based on a person's disability.
- The message of this section is concise; Section 504, 29 U.S.C.§794, states:
  - No otherwise qualified individual with a disability in the United States... shall, solely by reason of her or his disability, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.
Section 508 of the Rehabilitation Act

- This section requires the Federal government to procure electronic and information technology (E&IT) goods and services that are not fully accessible to those with disabilities.
- Provides the legislative language and standards for the design of Accessible Electronic Information Technology. (effective: June 21, 2001)

Section 508 is important because:

- It provides the first federal accessibility standard for the Internet
- It provides compliance language that can be automated and monitored at a distance
- State governments can be held accountable under the Assistive Technology Act of 1998
- Businesses must comply with Section 508 when supplying Electronic and Information Technology goods and services to the federal government and now many state governments
AeIT / PHRs – *Laws & Standards*

**Assistive Technology Act**

– Section 101(e)(3) of the Assistive Technology Act of 1998 (AT Act) requires that States receiving AT Act funds must also comply with Section 508 and the standards. To gain access to this funding, each state **MUST ASSURE** the federal government they will implement all conditions of Section 508 within their state entities (including higher education).

WebAim, 2004; ITTATC, 2005
AeIT / PHRs – Laws & Standards

Telecommunications Act of 1996

– Section 251 as amended 2000

• 47 CFR 6.1 – 6.23, & 47 CFR 7.1 – 7.23

 Manufacturers and providers of voicemail and interactive menu services and products are reminded of their obligations to take the appropriate measures to ensure that their products and services are accessible to and usable by people with disabilities.

[Note: Many Voice Over IP systems are not accessible]
AeIT / PHRs – *Laws & Standards*

**Telecommunications Act of 1996**

– Section 255 as amended 2002

  • This was the first product design law to attempt to drive the market to create accessible products.

    – 36 CFR 1193.37 "Information Pass-Through" requires telecommunications equipment and customer premises equipment to pass through codes, translation protocols, formats or other information necessary to provide telecommunications in an accessible format.

    – 36 CFR 1193.39 "Prohibited Reduction of Accessibility, Usability and Compatibility" and provides that no change shall be undertaken which decreases or has the effect of decreasing the net accessibility, usability, and compatibility of telecommunications equipment or customer premises equipment.
Section 508 Accessible Electronic & Information Technology Standards

– Subpart B -- Technical Standards

• 1194.21 Software applications and operating systems.
• 1194.22 Web-based intranet and internet information and applications. 16 rules.
• 1194.23 Telecommunications products.
• 1194.24 Video and multimedia products.
• 1194.25 Self contained, closed products.
• 1194.26 Desktop and portable computers.
AeIT / PHRs – *EIT Standards*

**Section 508 Accessible Electronic & Information Technology Standards**

– Subpart C -- Functional Performance Criteria
  
  • 1194.31 Functional performance criteria.
    – People with visual impairments
    – People who are deaf or hard-of-hearing
    – People with speech impairments
    – People with motor impairments
AeIT / PHRs – *EIT Standards*

**Information Technology Industry Council**

Volunteer Product Accessibility Template (VPAT)

<table>
<thead>
<tr>
<th>Product Category</th>
<th>1194.21</th>
<th>1194.22</th>
<th>1194.23</th>
<th>1194.24</th>
<th>1194.25</th>
<th>1194.26</th>
</tr>
</thead>
<tbody>
<tr>
<td>A/V Equipment as identified in the Standards</td>
<td>O</td>
<td></td>
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<tr>
<td>Copiers (not multi-function document imaging - see Note 1)</td>
<td></td>
<td></td>
<td>O</td>
<td></td>
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<tr>
<td>Digital Copiers</td>
<td>O=PC Soft</td>
<td>O=Web Interface</td>
<td>O=PC Soft</td>
<td>O</td>
<td></td>
<td></td>
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<tr>
<td>Scanners</td>
<td>O=PC Soft</td>
<td></td>
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<tr>
<td>Smart Card Readers</td>
<td>O=PC Soft</td>
<td></td>
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<tr>
<td>Operating Systems, Application Software</td>
<td>O</td>
<td></td>
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<tr>
<td>Websites</td>
<td>O</td>
<td></td>
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<tr>
<td>Printers</td>
<td>O=PC Soft</td>
<td></td>
<td></td>
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<tr>
<td>Handhelds</td>
<td>O=PC Soft</td>
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<tr>
<td>Personal Computers (Desktop, Notebook, Portable, including displays)</td>
<td>O</td>
<td></td>
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<tr>
<td>Servers and Workstations</td>
<td>O</td>
<td></td>
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<tr>
<td>Fax machines (public line or via the Internet)</td>
<td>O=PC Soft</td>
<td></td>
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</tr>
<tr>
<td>PBX (in-house electronic exchanger)</td>
<td>O=TAPI</td>
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<tr>
<td>Telephone answering machines</td>
<td>O</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Telecommunications devices (wired, analog and digital wireless, Internet)</td>
<td>O=PC Soft</td>
<td>O=Web Interface</td>
<td>O=PC Soft</td>
<td>O</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

"O" = Applies - "PC Soft" is the application software bundle - "TAPI" is the Telephony Application Programming Interface - "Web Interface" refers to browser applications - "Tuner" refers to a television tuner/receiver. Note 1: If a product provides the equivalent functionality of a combination of the products listed above, all relevant standards apply. Source: ITIC
## Detailed Table

**Section 1194.21 Software Applications and Operating Systems**

### IDEAL Conference® Voluntary Product Accessibility Template

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Supporting Features</th>
<th>Remarks and Explanations</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) When software is designed to run on a system that has a keyboard, product functions shall be executable from a keyboard where the function itself or the result of performing a function can be discerned textually.</td>
<td>All of the functions of IDEAL Conference® are executable from a keyboard. In addition, IDEAL Conference® provides a hot key setup utility that enables users to change hot key settings in support of fine-tuning the interoperability of IDEAL Conference® with a wide range of third-party assistive technologies;</td>
<td>In addition, IDEAL Conference® provides its users with the ability to easily remap all of the key combination commands of the system. This feature permits users to eliminate any incompatible keystroke between IDEAL Conference® and third-party assistive technology applications.</td>
</tr>
<tr>
<td>(b) Applications shall not disrupt or disable activated features of other products that are identified as accessibility features, where those features are developed and documented according to industry standards.</td>
<td>IDEAL Conference® should not disrupt or disable activated features of other products that are identified as accessibility features, where those features are developed and documented according to industry standards. Should an occasion arise when this does happen, IDEAL Conference® provides a hot key setup utility that enables users to change hot key settings in support of fine-tuning the interoperability of IDEAL Conference® with a wide range of third-party assistive technologies;</td>
<td></td>
</tr>
<tr>
<td>Applications also shall not disrupt or disable activated features of any operating system that are identified as accessibility features where the application programming interface for those accessibility features has been documented by the manufacturer of the operating system and is available to the product developer.</td>
<td>IDEAL Conference® is interoperable with many, popular, commercially available, assistive technologies including. In addition, IDEAL Conference® is interoperable with a third-party: <em>Speech modification application in support of people with speech impairments (interoperable and compatible 3rd-party, application)</em>; <em>Graphics equalizer for adjusting frequency to better accommodate people with hearing impairments</em>; <em>Magnifying glass; Speech recognition application for command and control</em>; <em>Shared documents with version control</em>;</td>
<td></td>
</tr>
</tbody>
</table>
AeIT / PHRs – EIT Standards

Website – Section 508.Gov

Section 508

Search Section508.gov

Search
Clear

Additional Links
- Communications/Media
- 508 Tools & Resources
- AT Showcase

508 News Release

The Interagency Disability Educational Awareness Showcase (IDEAS) is GSA’s yearly premier event focusing on topics of interest to the 508 and 504 community. On November 19, 2008, IDEAS will introduce educational sessions on acquisition practices, electronic and information technology accessibility, 508 law and standards, tools to research and locate 508 products and services, and assistive technology products exhibits. Register for this exciting event at www.ideas508events.com!

NOW AVAILABLE!! SAW TRAINING.

View the hearing webcast from May 1, 2008 on Draft Legislation Enhancing Access to Broadband Technology and Services for Persons with Disabilities. Also, view the Draft Act.

VENDORS! The new BuyAccessible Product and Services Directory is available! You can:
- Create your account

If you have already registered for the 508 Universe please click this link.
- Secure Login

If you have never registered for the 508 Universe before please click this link.
- Register For 508 Universe

Having problems with the 508 Universe? Review the User Guide.
AelT / PHRs – EIT Standards

The “Buy Accessible Wizard” is an excellent tool to assist you in determining which accessibility standards you need to use for procurement and development of PHR systems [http://app.buyaccessible.gov/baw/](http://app.buyaccessible.gov/baw/)
AeIT / PHRs – Preparing

Rules of Thumb…. :-)

– Don’t ignore AeIT…or it will come back and bite you when you least expect it (go ahead and prepare your Peril-Sensitive sun glasses, Source: Hitchhikers Guide to the Galaxy)
– You better allocate some real resources to support it
– You better have a good handle on the issues and document your PHR program thoroughly
– When you outsource NEVER take the word of a vendor (or the accuracy of their VPAT – if they have one) that they can deliver an accessible PHR system without seeing working examples and talking with reliable references. Have solid protections in your contract.
– AeIT can be a show stopper. Retrofitting an inaccessible PHR system to implement AeIT will be very expensive and lead to significant delays in taking it to production.
Build Your PHR Accessibility Business Case

• Developing a successful business plan includes these factors:

  – **Social Factors** addresses the role of Web accessibility in equal opportunity for people with disabilities; the overlap with digital divide issues; and benefits to people *without* disabilities, including older people, people with low literacy and people not fluent in the language, people with low bandwidth connections to the Internet and older technologies, and new and infrequent Web users.

  – **Technical Factors** addresses interoperability, quality, reducing site development and maintenance time, reducing server load, enabling content on different configurations, and being prepared for advanced Web technologies.
The PHR Accessibility Business Case (continued)

- **Financial Factors** addresses financial benefits from increased PHR portal use and direct cost savings, and cost considerations including initial costs and on-going costs.

- **Legal and Policy Factors** addresses requirements for Web accessibility from governments and other organizations in the form of laws, policies, regulations, standards, guidelines, directives, communications, orders, or other types of documents.

AeIT / PHRs – *Preparing*

**PAL ~ Partnership – Advocacy – Leadership™**

- AeIT must be person-centered
- There must be a partnership between the Disability Community – Government – Private Health Care Sector – IT Industry
- The National Protection and Advocacy System State Programs provides civil rights and legal remediation
- The Independent Living movement supports community living
- The Tech Act State Programs support AeIT across the nation and territories
- The respective Disability Associations have a strong track record of accessibility litigation in the public and private sectors
AeIT / PHRs – Where will they go?

Certification Commission for Healthcare Information Technology (CCHIT)

AeIT public comments and written recommendations were made on draft Personal Health Record (PHR) 09 Criteria (Draft 01) certification standards.

The PHR Advisory Task Force Recommended:

The Task Force recommends that certification should apply to any products/services that perform either or both of these:
• Collecting, receiving, storing, or using personal health information as part of a consumer data stream or PHR
• Transmitting or disclosing to a 3rd party any personal health information (PHI)
• Privacy should be the #1 goal of certification
• Consumer Policy Practice Areas in the CFH (Connecting for Health) Framework for privacy criteria
• Privacy involves organizational policies and behavior, not just versions of software
• The Task Force recommends Consumer Technology Practice Areas in the CFH Framework as starting point for security criteria
AelT / PHRs – Conclusion

What role will HIMSS play?

Will we take a leadership role nationally and internationally?

Are we willing to collaborate and embrace the disability community as stakeholders?

Will we advocate politically?

Will we leverage our influence in the HIT field to support the development of AelT PHRs and other applications?

Remember disability is a normalizing condition. We will all experience it...
AeIT / PHRs – Contacts

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one laptop per child
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