

FOR IMMEDIATE RELEASE

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A Joint News Release from:

The Children's Hospital of Philadelphia and the Inglis Foundation

John Ascenzi

The Children's Hospital of Philadelphia

(267) 426-6055

ascenzi@email.chop.edu

Jorja Mathers

Inglis Foundation

(215) 581-0707

jorja.mathers@inglis.org

Grant Will Help Bridge Digital Divide for People with Disabilities

--The Children's Hospital of Philadelphia, Inglis Foundation and WGBH Partner to Make Personal Health Records Accessible--

Philadelphia, Pa., Nov. 7, 2011—Personal health records have been going electronic, and patients, caregivers, and healthcare providers are learning to navigate the new digital world of health information. Now three institutions are teaming up to discover how a large population—people with disabilities—can best access this information.

The Children's Hospital of Philadelphia and the Inglis Foundation, also based in Philadelphia, are partnering with Boston public broadcaster WGBH's Carl and Ruth Shapiro Family National Center for Accessible Media (NCAM) on a joint project to explore how adaptive technology can make personal health records accessible to people with disabilities. NCAM is the project leader and principal recipient of the three-year, \$600,000 grant, awarded by the U.S. Department of Education.

The grant, titled "Accessible Designs for Personal Health Records," is funded by the Department of Education's National Institute on Disability and Rehabilitation Research. The project began operations last month.

"Approximately 20 percent of the U.S. population has some type of disability, and three percent has a severe disability, but there has been little research on how people with disabilities access their own electronic health records," said Dean Karavite, lead human-computer interaction specialist at the Center for Biomedical Informatics (CBMi) at The Children's Hospital of Philadelphia. "As with any patient, accessing such information gives someone more control over their own health care."

Project staff members will systematically observe consumers served by Inglis Foundation as they perform tasks and seek information in their own electronic health records (EHRs). Inglis serves over 900 adults with physical disabilities in the Philadelphia area through its skilled nursing facility, Inglis House, and for those living independently in the community, through its accessible apartments, care management, and employment and adult day services.

“As electronic medical records become commonplace, it is essential that persons with disabilities have full access to their medical records,” said Gavin Kerr, President and CEO of the Inglis Foundation. “Today’s systems have not been designed with accessibility in mind. As a result people living with disabilities cannot be fully engaged in their care, and employees with disabilities who work with electronic medical records can no longer be fully effective in their jobs.”

For all patients, using computers and other electronic devices to manage their health care includes scheduling appointments, exchanging messages with their physicians or therapists, refilling prescriptions, and viewing lab results. For people with disabilities, more specific needs come into play—for people with visual impairments, getting non-visual information; for people with limited hand mobility, having adaptive technology to access computer keyboard, screens and mice; for those with cognitive impairments, having minimal distractions and perhaps simplified terminology.

In addition, other issues will be identified as project staff members evaluate how people with disabilities use the current systems and define what needs to improve.

After the project’s initial assessment of the current EHR situation, the staff will develop guidelines and recommendations for better accessibility. Karavite said that making information systems more useable and accessible for people with disabilities will also benefit broader populations of users. “We can make analogies to curb cuts in sidewalks or ramps in buildings,” he said. “These were originally designed for people in wheelchairs, but parents pushing strollers also benefit.”

Karavite gave other examples of how improving accessibility has had broader impacts: “Captioning, which WGBH developed in the 1970s for people who are deaf, is used by everyone in noisy airports or waiting rooms. Word prediction, designed in the late 1980s to help people with physical disabilities type with fewer keystrokes, now is a standard feature for anyone using a smart phone. Universal design can benefit everyone.”

For more details, see the project website at http://ncam.wgbh.org/invent_build/web_multimedia/healthitaccess

Note to reporters: Please contact either of the press contacts listed above to arrange for interviews with CHOP or Inglis Foundation staff members, or with Inglis consumers who can describe their own experiences in accessing personal health information.

About CBMi and The Children’s Hospital of Philadelphia:

The Children’s Hospital of Philadelphia was founded in 1855 as the nation’s first pediatric hospital. The Center for Biomedical Informatics (CBMi) at The Children’s Hospital of Philadelphia is the home for the development of innovative solutions to healthcare’s immediate and long-term informatics needs. CBMi provides informatics-focused services, applications, and educational programs to Children’s Hospital clinicians and researchers, and seeks to transform their craft with high-impact, low-cost solutions. For details, see <http://cbmi.chop.edu>

About the Inglis Foundation:

Inglis Foundation is a community-based foundation that is committed to using technology and healthcare information to empower people with severe physical disabilities to live life to the fullest. Inglis maintains a skilled-nursing care facility and independent-living facilities as well as care management, adult day and employment services for people with disabilities living in their own homes. <http://www.inglis.org>

About NCAM and WGBH:

WGBH Boston is America's public broadcasting powerhouse—PBS' largest producer of TV and Web content. The Carl and Ruth Shapiro Family National Center for Accessible Media at WGBH is a research and development organization that works to make existing and emerging technologies accessible to all audiences. NCAM is part of the Media Access Group at WGBH, which has been providing captioning and video description services for people with disabilities since 1972. For more information, visit NCAM at <http://ncam.wgbh.org>.