Enriching life with computers

Imagine life without computers and the Internet. For people with disabilities, access to this technology is even more crucial for living a full and engaged life providing job opportunities, career skills, health information and recreational, social and cultural venues for accessibility and supportive services.

As a result, information and adaptive technologies have been a driving force in enhancing the independence of Inglis residents and consumers. Inglis’ Adapted Technology Lab has helped hundreds of residents find the right adaptive equipment so they can make full use of a computer – currently they log more than 2,000 hours of computer time in the lab each month.

Now, thanks to a three-year grant from The Pew Charitable Trusts, Inglis consumers living in the community will also be able to gain access to adapted computing equipment and build their computer skills. Initially, services will be offered to the nearly 500 consumers in Inglis’ Adult Day Program, tenants in Inglis Housing Corporation properties and consumers of community-based programs. Over time, Inglis hopes to expand the program to serve other people with disabilities in the community.

(See profile of adapted technology therapist Mike Wilkinson on page 13.)

Michael Citro uses a special large-size switch rather than a mouse, to access the computer.
If Annie could only see us now! The Inglis of today is so much more than Annie Inglis and her mother could have envisioned 135 years ago. Who would have imagined self-powered, streamlined wheelchairs replacing heavy wooden chairs pushed by someone else? No one could foresee electronic control units to open your door, turn on your lights and power up your computer completely independently! Can you imagine their excitement at seeing a severely disabled person driving an accessible van or consulting with a doctor over the Internet?

Over the years, Annie’s mission has never changed – enabling people with disabilities – and those who care for them – to achieve their goals and live life to the fullest. Our dedication to people living with disabilities has never wavered. HOW we accomplish that mission, however, has changed dramatically over the years:

**1877-1927** – People with disabilities lived in a home like setting and were cared for as if part of a family. Health care services were minimal and life spans were short.

**1928-1961** – Inglis House opened on its present site near Fairmount Park and was led by a dedicated, hands-on group of extraordinary women who served as the board of managers. Life was dramatically better, but consumers were still “incurables.”

We received a total of $4,500 in government funds in our first 85 years.


**2012+** – Medicare and Medicaid become financially unsustainable. Drastic budget cuts at the Federal, state and local level along with uncertain financial forecasts challenge Inglis to find new, more cost-effective solutions to providing great lives to people with disabilities.

Inglis has weathered many storms in our 135-year history – 29 recessions, the great depression, eight major wars and now the Great Recession. These are challenging times for everyone. Several other organizations that serve people with disabilities have closed or scaled back services. We face daunting financial challenges. Yet we will endure, our mission and our consumers require us to find innovative solutions to our current challenges – just as earlier generations of Inglis people found solutions for their times.

So, innovate we will! Our mission is essential and it is our privilege to serve.
At Inglis House, our Person Centered Care initiatives are engaging residents, staff and families in finding new solutions to creatively live in more cost-effective ways. We are partnering with the Pennsylvania Department of Public Welfare and the Centers for Medicaid and Medicare Services to create an integrated health service system to enable more people to live independently in the community and at a lower cost. Our Adult Day, Employment and Care Management programs are revamping and improving through exciting, cost-effective, consumer-driven ideas.

As Dickens wrote, “These are the best of times and these are the worst of times.” Across generations for 135 years, Inglis turned the worst of times into the best of times by encouraging independence through innovation and with great integrity. We invite you to join us as we celebrate 135 years of service and, more important, work together to create a brighter future for people with disabilities and those who care for them.
Pennsylvania State Senator Christine (Tina) Tartaglione visited Inglis on January 19, 2012. She met with a group of Inglis residents and toured the resident computer lab, physical therapy gym and the community employment program. Here she chats with Inglis resident Paul LoPresti. A wheelchair user since 2003, Senator Tartaglione is a leading champion of disability rights in the Pennsylvania legislature.

Thanksgiving dinner for Inglis House residents is always a popular event for volunteers, family members and friends. Shown here, members of the Gospel Temple Baptist Church Youth Group (Philadelphia, PA) who were among the volunteer groups helping serve food that day.
making electronic medical records easier to access

For many people, personal health records may consist of a disorganized box with handwritten notes and outdated immunization records. Often the information does not reflect a complete picture of previous medical visits and prescribed medicine. Carrying all that information to the next doctor’s visit can be difficult. Electronic medical records can solve the problem – making personal health information accessible anywhere, anytime.

Inglis, The Children’s Hospital of Philadelphia and Boston public broadcaster WGBH’s Carl and Ruth Shapiro Family National Center for Accessible Media (NCAM) are teaming up to discover 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’s National Institute on Disability and Rehabilitation Research.

In the first phase of research, Inglis consumers who participate in the study will be observed as they perform tasks and seek information in their own electronic health records. Inglis President and CEO Gavin Kerr observed, “As electronic medical records become commonplace, it is essential that persons with disabilities have full access to their medical records. 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.”

After the project’s initial assessment of electronic health records, the staff will develop guidelines and recommendations for better accessibility. For people with disabilities, this may include ways to get non-visual information; adaptive technology to access computer keyboards, screens and mice; and possibly simplified terminology.

Dean Karavite, lead human-computer interaction specialist at the Center for Biomedical Informatics (CBMi) at The Children’s Hospital of Philadelphia, notes 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 says. “These were originally designed for people in wheelchairs, but parents pushing strollers also benefit.”
INGLIS HONORED ITS MANY SUPPORTERS AT THE ANNUAL PATRONS’ RECEPTION, HELD SEPTEMBER 21, 2011. ATTENDEES WERE TREATED TO A SPECIAL GIFT – SILK SCARVES AND POCKET SQUARES HAND-PAINTED BY INGLIS RESIDENTS.

In addition, at the event, VSA Pennsylvania presented Inglis with the VSA Arts Outstanding Community Partner Award. Inglis and VSA PA have partnered on a variety of arts programs for many years.

Inglis is grateful to all its donors for supporting us in so many ways.
leadership fund supports Inglis staff development

FEW NONPROFIT ORGANIZATIONS ARE ABLE TO MAKE THE COMMITMENT TO UPGRADING STAFF SKILLS AND CAPABILITIES THAT INGLIS HAS THROUGH THE LUISA RABE FUND FOR LEADERSHIP DEVELOPMENT. A THREE-YEAR ANNUAL CHALLENGE GRANT PROVIDED BY THE HESS FOUNDATION AS WELL AS THE GENEROSITY OF MANY INGLIS BOARD MEMBERS AND OTHERS SUPPORTS THE FUND.

This year, Inglis was able to hold five Leadership Development Institutes for 70 management supervisors focusing on practical applications such as time management, computer training, conflict resolution, accountability, performance management and establishing an Inglis communication protocol. All of these elements are critical to Inglis’ mission of helping people with disabilities – and those who care for them – live life to the fullest.

Inglis President and CEO Gavin Kerr said, “Leadership at Inglis is based on the concept that we are all potential leaders in life and that leadership is a characteristic, not a position.”

In seeking to promote a culture of excellence, Inglis has adopted new Standards of Excellence based on LIST ONE values. These values – Learn, Integrity, Service, Teamwork, On Time/On Budget, No Excuses/No Blame and Excellence – have been presented to staff in a variety of forums and formats. They serve as a touchstone for employees at all levels to connect personal behaviors with the larger mission. And they provide the commitment to excellence needed for Inglis to become a recognized innovator in serving people with physical disabilities, a national catalyst for best practice diffusion and a high performing, financially self-sustaining organization.
portrait day at inglis

JALEEL KING WAS AN INGLIS HOUSE RESIDENT IN 1995. BY THE NEXT YEAR HE MOVED TO HIS OWN ACCESSIBLE APARTMENT IN PHILADELPHIA, AND LATER BEGAN A CAREER AS A PROFESSIONAL PHOTOGRAPHER (WWW.JALEELKING.COM). WANTING TO GIVE BACK TO THE COMMUNITY, HE JOINED THE HELP-PORTRAIT PROJECT A FEW YEARS AGO.

Initially organized by celebrity photographer Jeremy Cowart in Nashville, TN, today Help-Portrait mobilizes photographers around the world on the first Saturday of December to volunteer their time taking portraits of people who may never before have had a picture of themselves. More important, each person receives a copy of the portrait – free of charge.

Jaleel organized 14 Philadelphia area photographers and assistants to come to Inglis on December 10, 2011, to take portraits of residents, consumers, tenants and staff. The photographers set up stations around Founders’ Hall with back-drops and props as people lined up for their pictures. The printers never stopped running as portraits came out, were framed and distributed. Gift wrapping was even provided for those who wanted to present the portrait to a loved one.

Other photographers went to individual residents’ rooms to take portraits of those who weren’t able to come to Founders’ Hall. A Philadelphia Inquirer reporter, Jeff Gammage, came to observe and stayed almost three hours, marveling at the energy and excitement in Founders’ Hall. (Click on the Inquirer story link in the Media Coverage section of the News & Events tab on the Inglis website, www.inglis.org.)

PORTRAIT DAY PHOTOGRAPHERS AND ASSISTANTS (from left to right): Back row: Philip Barile, Kevin High, Jennifer Januzelli, David M. Matthews, Ian Siriani, Fred Esguerra. Front row: Jamie Raddatz, Lauren Pupillo, Jaleel King, Jewell Newton, Natasha Esguerra. INSET: Jaleel King sets up resident Kevin Patterson’s portrait. (Photos courtesy of Jaleel King.)
celebrating future legacies – inglis’ 135th anniversary

ON APRIL 19, JUSTIN HINES, A SINGER/SONGWRITER FROM TORONTO, ONTARIO, WILL KICK OFF INGLIS’ 135TH ANNIVERSARY CELEBRATION WITH A CONCERT AT WORLD CAFE LIVE IN PHILADELPHIA. (VISIT WWW.INGLIS.ORG FOR COMPLETE CONCERT DETAILS.)

Justin, a wheelchair user, has the inherited condition Larsen’s syndrome, which is characterized by congenital dislocation of multiple body joints. In his music, Justin integrates motivational and inspirational stories based on his life experiences.

He recently released his fourth album, Days to Recall, and with it has been breaking into the U.S. market. His single “Tell Me I’m Wrong” hit the Top 30 charts in the U.S. in 2011. Justin and this album are also the focus of a PBS special, that will air on WHYY-TV in Philadelphia on March 23 (check local television listings for air times).

Through his own private foundation, Justin also collaborates with organizations that support people with disabilities. In addition to the public concert on April 19, Justin will perform an acoustic concert in Founders’ Hall for Inglis residents and consumers.

“I’ve come to realize that true fulfillment begins with believing that each one of our lives can serve a purpose for the greater good. At this point in my journey, I feel honored to be in a position where I can combine my passion for music with my desire to spread a message of love on a large scale. I feel it is my duty as a human being to at least attempt giving back as much as I have taken from this Earth. This is a lofty goal but I’ve witnessed firsthand the power of unselfishly assisting those who desire and deserve help. I, like many others, simply want to help.” – Justin Hines
Her disease altered her abilities and now, at age 43, she says, “I can’t play basketball or softball like I used to. So I looked to different things. When you start something new, you don’t have expectations of how you should be able to perform. It’s all new.”

**A NEW BEGINNING**
For three years Kubiak was in and out of the hospital, and then lived in her parents’ basement. Since 2008, she has lived independently at Inglis Gardens at Elmwood, a 20-unit complex in southwest Philadelphia. “This is such a blessing in so many ways – a dream come true!” she exclaims. “It’s totally accessible, so I can be completely independent. It gives me the confidence needed to live life and to go out and try new things.”

One of those new things was adaptive rowing – she heard about the sport rowing from fellow Inglis Gardens tenant and long-time rowing enthusiast, Ishmael Vasquez. She rows once a week on the Schuylkill River during the summer months with Philadelphia Adaptive Rowing. Last year, she competed in the Thomas Eakins Head of the Schuykill Regatta® and the Bayada® Regatta – the nation’s oldest and largest adaptive rowing competition. “That one’s really competitive,” Kubiak notes. “There are lots of people trying to get on national or Olympic teams.

“I’m not there yet, but maybe one day …” she adds.

“Rowing is freeing. It makes me feel strong and confident,” she says. “It’s a lot of fun, and you meet people with all kinds of disabilities. Everyone’s very positive, and they’re a good source of information about other options available for people with disabilities.”

Kubiak’s favorite activity, though, is scuba diving. She took a trip to Honduras last year and went on a shark dive. “It was the best thing ever!” she enthuses. “When you’re underwater, you’re just like everyone else. We’re all in an environment that we’re not used to.”

**MORE THAN A HOME**
Kubiak is thrilled to have found Inglis Gardens at Elmwood. “I really appreciate the opportunity to live independently, and the management is great,” she says. “They’re always willing to listen to concerns and try to help.”
Paul Finegan was honored upon his retirement on October 27, 2011, at a tree planting ceremony. In addition to the tree, a portion of the Inglis House Courtyard walkway was named Finegan’s Way to commemorate his unprecedented success in growing the Inglis endowment during his 25-year tenure as Investment Committee Chair. Shown here at the tree dedication ceremony, left to right: Paul Finegan; Investment Committee Chair JoAnne Fredericks; Board Chair Sankey Williams, MD; and Inglis President and CEO Gavin Kerr.

FORMER MEMBERS OF THE INGLIS BOARD OF DIRECTORS attended a luncheon in their honor at the Merion Cricket Club in November to hear an update on Inglis programs and plans for the future. Shown here (left to right): Front row: Elizabeth McGee-Wood, MD; Pamela Merriman; Dixie Wigton; Janet White; Harriet Soffa; Jackie Jerrehian and Pat Morley. Back row: Board Chair Sankey Williams, MD; Linda Fisher; Barbara Rogers; Barbara Carper; Kimberly White; Inglis President and CEO Gavin Kerr; and Emily Riley.
shelley van scoyoc

“I CAME INTO INGLIS HOUSE AND WAS GIVEN THE BREATHE OF LIFE!”

As a Medical Social Worker in Central Pennsylvania, Shelley had an aptitude for relating to people, especially when they were facing difficult challenges. She never counted on being the one to need care until she was diagnosed with multiple sclerosis. For 10 years her health deteriorated. Her fine motor skills began to fail, and then her sight. Work became impossible.

When Shelley and her husband, David, moved to suburban Philadelphia she felt like a prisoner in her own home. Her condition, combined with their apartment’s floor plan meant that except for the occasional doctor’s appointment, she couldn’t get out the door.

Shelley, at 50 years old, has a strong urge to continue being active and living independently. She and David persevered, but it wasn’t the kind of life that either of them wanted for each other. “My ever-loving and devoted husband could no longer find adequate care for my extensive needs. Community services could not help me so that I could stay at home,” Shelley remembers.

“Inglis House has been a godsend. Best of all is that I was once again married to my husband instead of my caregiver.

“Inglis House is nothing like the nursing home of my nightmares. The people are nice. There are activities, both indoors and out. We all have private rooms and can continue to have our private lives.” That includes David’s regular visits and their going out together.

She quickly got involved in Inglis activities. “I go to three or four groups each day, plus socials and dances. I especially like groups where I’m thinking, like the Women’s Issues group.” Shelley, who was always a writer, began in earnest when her condition kept her inside all of the time, “to keep my brain active,” she says. Now she writes throughout the day. David picks up the notebooks and transcribes them – from humor to short stories, there’s always something on her mind, waiting to spill out.

“I’ve already learned so much and taken back control of my life. I’ve met so many wonderful people. I’m involved. Yes, I do have crying times, and that’s OK. My goal here? To get people to laugh with me!”
For Inglis Community Adapted Technology Therapist Mike Wilkinson, finding the correct adaptive devices and software that will make a computer accessible to someone with a disability is key to the success of the consumer and ultimately the Community Computing Program. And each person’s needs are different. As he explains, “I had to sit down and learn to use the tools myself because I can’t teach it if I don’t know it. And it blew my mind – it’s truly amazing equipment and it overwhelms my heart because I can see how important it is for someone with a disability to be able to communicate with family and friends.”

In a typical training session, Mike helps consumers get comfortable with the equipment and onto the Internet within an hour and a half. The exact set-up depends on the individual. “Some people may use a voice module to access screen icons. Another may use a clicker button instead of a mouse to do everything they want on the computer. A chin or an elbow or whatever they can use to hit the button, gives them the access they need,” he explains.

The results are very gratifying, too. “It means a lot to consumers to be able to connect with the world outside,” Mike says. “One person explained that when he’s in a chat room he’s able to forget his disability. The people he’s chatting with don’t see his physical body, they see his mind!”

Another program participant – a 93-year-old woman – began doing her grocery shopping on line at a local supermarket’s website after just one session. Besides being more empowered, she is also more safe and secure. Another innovative project started when a daughter began preserving a 30-year-old short story written by her father.

Mike sums up the entire project, “It’s a win-win situation, all the way around!”

**MS SOCIETY TECHNOLOGY GRANT**

As technology becomes increasingly a part of the daily lives of people with disabilities, there is a growing need to support the computers and other personal electronic devices Inglis House residents use in their rooms. Inglis deeply appreciates a recent generous grant of $20,000 from the Greater Delaware Valley Chapter of the National Multiple Sclerosis Society to purchase adaptive equipment and hire a part-time on-site technician dedicated to supporting residents’ personal computers and electronic devices.
WILLIAM GRIM, NHA, HAS BEEN NAMED CO-EXECUTIVE DIRECTOR AND ADMINISTRATOR; WHILE MARJORIE HARDING, RN, BSN, MBA, HAS BEEN PROMOTED TO CO-EXECUTIVE DIRECTOR AND DIRECTOR OF NURSING AT INGLIS HOUSE.

According to Gavin Kerr, Inglis President and CEO, “Both Marjorie and Bill share a deep commitment to helping people with disabilities – and those who serve them – live great lives. They both have strength of character and give much more of themselves than we could ever ask.”

Establishing the Co-Executive Director structure recognizes the strong, peer-level partnership needed between operations and clinical services and allows shared accountability for the day-to-day leadership of Inglis House.

Grim, who has served as Inglis’ Interim Executive Director and Administrator since July 2011, spent 18 years as the Executive Director and then as CEO for Saunders House and Bryn Mawr Terrace. These facilities provide long-term care and rehabilitative services in suburban Philadelphia.

Harding came to Inglis in 2000 as a unit nurse manager before becoming a community administrator. Prior to her recent appointment she served as director of nursing since 2008.

Nicole Pruitt (left) has been appointed Director of the Inglis Adult Day Program. A Certified Occupational Therapy Assistant (COTA/L), she worked in the Inglis Rehab Services program since 2004. She holds a bachelor’s degree from Holy Family University. She is also certified by the National Multiple Sclerosis Society as an MS Care Specialist. Vicki Cuscino is Director of Inglis Community Employment Services. She was Director of Organizational Development for Liberty Resources in Philadelphia from 2008 until she joined Inglis in 2011. Vicki holds a bachelor’s degree from Pennsylvania State University and a Master’s from Temple University.
The screen’s the limit!
AN UPDATE ON THE TELEVISION PROJECT

Thanks to the support of the parents and family of former Inglis House resident Arthur Stapler, proceeds from a past Golf Outing and the gifts of other wonderful friends of Inglis, we are now 56% of the way to our goal of outfitting each resident room with a wall-mounted flat-screen TV! To date, Inglis has purchased 165 new wall-mounted flat-screen televisions. They free up space in resident rooms and provide high-quality TV and computer connections to the outside world.

While we are purchasing more TVs with funds recently donated, we still need your help to reach our goal of providing new TVs for all 297 Inglis residents! To contribute to the TV Fund, call Meredith Quirin at (215) 581-0703 or write “The TV Fund” on the enclosed envelope with your contribution.

A GIFT OF $350 WILL HELP US PLACE ANOTHER TV IN A RESIDENT’S ROOM!

Long-time Inglis supporter Gordon Keen was presented with an Annie Inglis Gold Coin award at a dinner in his honor with Board Members and friends. Gordon, whose mother was a Board Member and whose father served on the Men’s Advisory Committee, was one of the founders of the A-May-Zing Committee, which raised funds for more than 25 years through its annual Inglis 5K Run in Fairmount Park. He is also an original supporter of the Inglis Golf Outing, which has raised more than $1 million for Inglis over the past 10 years. Gordon is shown here (third from left) with Inglis President and CEO Gavin Kerr, Board Member Jim Logue and Board Chair Sankey Williams, MD.
UPCOMING EVENTS

THURSDAY, APRIL 19, 2012
Justin Hines Concert
World Cafe Live
Philadelphia, PA

MONDAY, JUNE 4, 2012
11th Annual Inglis Golf Outing
Waynesborough Country Club
Paoli, PA