

ASSISTIVE TECHNOLOGY

Improves Lives Of People With Disabilities

Kathleen Vickery

For many years, “Jennifer,” a young woman with cerebral palsy and quadriplegia, could only speak to her far-flung siblings by pointing to letters on an alphabet board and asking a staff person to say over a phone line the words and sentences she spelled.

Although the old-fashioned “assistive technology” was better than nothing, it was a frustratingly slow and limiting way to communicate, when there was so much more in her head and heart to convey.

But a few years ago, Jennifer was one of the first residents at Mary Campbell Center, an intermediate care facility for people with mental retardation in Wilmington, Del., to benefit from the wave of high-tech assistive technology.

Jennifer was trained by one of the center’s speech pathologists to use a Pathfinder communicator, a device with a keyboard and dynamic display screen that helps her express her thoughts. Jennifer programmed her Pathfinder with phrases and paragraphs of news about herself and with questions she wanted to ask her siblings. For the first time, she could call her brothers and sisters and have a conversation on a speakerphone without an “interpreter.” Jennifer even programmed her Pathfinder to speak in a woman’s voice with a Mid-Atlantic dialect to better represent herself.

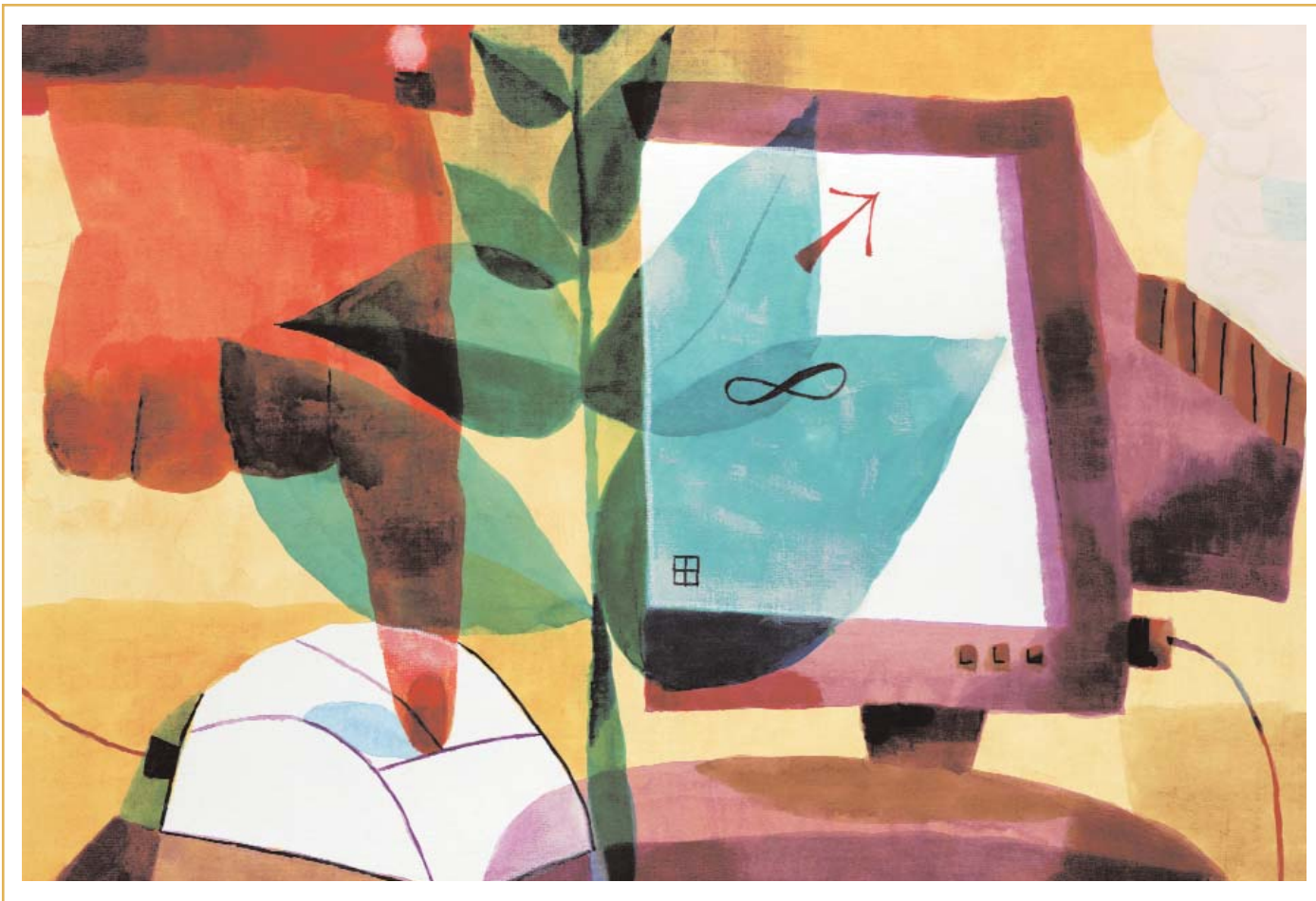
Assistive Technology Changes Lives

Stories of how assistive technologies have improved lives abound at the Mary Campbell Center, which has focused significant energy and funds on making more technology available to its residents.

“Eric,” another Mary Campbell Center resident, is a master’s level chess player, but he can’t speak. “I don’t think there’s any accurate way to measure his intelligence,” says Jerry Spilecki, the center’s executive director. “He may be a genius when he can adapt.”

Eric used to play chess, some 70 games at a time, making move by

A new wave of assistive devices is giving more individuals access to computers, and re-entry into everyday life.



move through mail all over the country. A volunteer filled out his postcards and put them in the mail. “It was a real management problem,” says Spilecki.

At the center, he learned how to use a computer, then e-mail, and now he tracks his games over the Internet and plays online, using a communicator called the Liberator that interfaces with an infrared device on his computer.

Another resident, “Karen,” a former attorney, has multiple sclerosis. Her mind is still sharp as nails, but she can no longer do things like type her thoughts into a computer. Staff at the center and consultants worked with her to configure her communication device and computer with an infrared receiver that picks up light from a reflective dot on Karen’s forehead.

Small, controlled movements of her head can move the cursor on the screen. Karen wrote her autobiography in that way, a book that was published independently and distributed locally.

“Melissa” was interested in photography, but she couldn’t press the shutter button of a camera. So the assistive tech group came up with a way to mount an adaptive digital camera on the wheelchair. The shutter is wired to a “jelly button” switch—a six-inch button that she can hit with her forearm on the armrest of her wheelchair. “We’re teaching her to upload and download the photos she takes onto a computer to store them in an album. It’s a way for her to get some recognition for her talent in this area,” says Spilecki. “Technology is a way to make that happen.”

“Billy” is a young Johnny Cash fan who uses the Internet to collect songs and keep tabs on nearly every Johnny Cash Web site in the world. “The Internet is a tremendous tool for learning about anything for anybody, as well as staying in touch,” Spilecki says.

The Mary Campbell Center

“Technology” conjures images of computers; “assistive technology” is what makes using the computer possible for people with disabilities.

Assistive technology, as defined by the Assistive Technology Act of 1998, is “any item, piece of equipment, or product system that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities.” Such devices include screen readers and magnifiers, closed captioning, ►

Telehealth And Assistive Technology

At a Carlton Palms residence in Florida, staff teach a young man how to make spaghetti; watch while he takes his medication; and pop in to check on him before he goes to bed, so that he knows he's safe and someone's thinking about him.

This is not so unusual for a residence caring for people with developmental disabilities. The difference is that this young man, living alone in his supportive living apartment, can get in touch with staff, and they with him, any time of the day or night simply by turning on an interactive video system.

It's a bit of technology, called Cnow, that Carlton Palms developed five or six years ago, when it was expanding and found it difficult to get enough qualified staff to keep pace, says Tom Shea, Carlton Palms' program director. The system, which complies with the privacy mandates of the Health Insurance Portability and Accountability Act, provides two-way, real-time video interaction over a broadband Internet connection, allowing managers to check in on staff, and clients to get face-to-face help 24 hours a day.

The system enters the realm of assistive technology when individual clients use the same technology to contact a staff member or clinician at a remote location if they need help.

For example, the client mentioned above has Cnow in his kitchen and living room, says Luke Baker, chief executive officer of Cnow, the telehealth services company, once part of Carlton Palms, that created the technology. "And it's so crisp and clear, we can actually read his medicine bottle" to make sure he's taking the correct med-

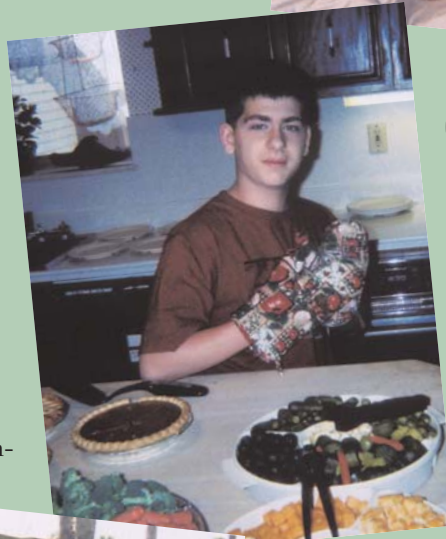
ication at the right time, Shea says.

An Integrated Step-Down Approach

Carlton Palms, in Mount Dora, Fla., is a CTEP, a comprehensive transitional educational program for people with developmental disabilities and severe emotional disturbances, such as con-



duct disorders, aggression, sexual acting out, or self-injury. Being a CTEP means the company provides the whole shebang, from a medically intensive residence to group homes and supported living apartments. The CTEP specializes in "people who aren't improving despite all attempts at treatment and training," says Shea.



Carlton Palms residents can interact with caregivers 24 hours a day.

The organization's goal is to move as many people as possible to the lowest possible care levels or back out into the community. "People come in receiv-

ing very intensive treatment and move through a series of treatment and residential options with the goal of returning them back to the community," says Shea. Having control of all programs—Carlton Palms also provides education at a fully approved school for all grade levels and job training—means that it can keep rules consistent between, for example, school and home. It allows the facility to give people a trial period in a new program or level of care to see how well prepared they are, keeping open the option of moving them back if they're not quite ready after all.

"The whole focus of the program came out of frustration," says Shea. He, Baker, and clinical Director Jim McGimsey worked for the state of North Carolina running an intensive intervention program for people with maladaptive behaviors, especially those with autism. They noticed a high rate of people not transitioning well into the community and decided that ➤

being able to control the programs at all levels of care would help ensure that people adapted well to being more immersed in the community.

Futuristic Staffing

“Five or six years ago, we didn’t have enough staff to keep up as we expanded, so Kenneth Macy, the founder, decided to do a live television feed,” says Shea.

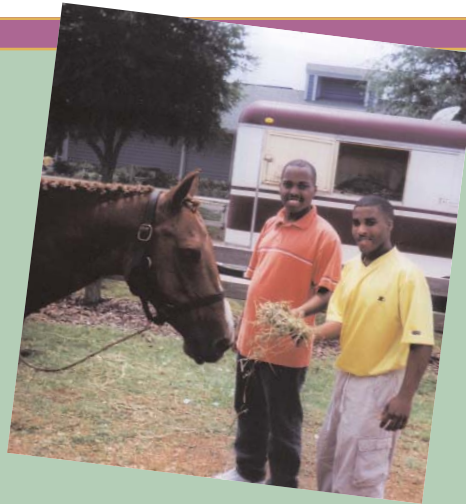
“I can dial in any group home and take a look, pan or zoom.” The staff, equipped with wireless headphones, can contact Shea at any time if they have a question, making it possible for Shea to consult with and advise staff without having to leave his office. It also allows management to observe, train, and modify the behavior of staff, and to do so in a consistent way from one setting to another. Staff trainers broadcast from one location to many.

Privacy concerns did alarm some people. “We did have some raised eyebrows at first,” says Baker. But, adds McGimsey, “when it’s used in positive ways, staff react very positively. They see it as a tool that helps them do their job.” A session must be initiated by a call from one location to another, “and that call signals to people on one side or the other that someone is now interacting with them,” McGimsey says. “It’s never been intended to be Big Brother; it is entirely an interactive tool for doing the same thing that you’d do in your typical job.”

In addition, the person on either end of the video can mute or turn the video off entirely. The protocols for the technology’s

alternative keyboards, and other special software and equipment that makes information devices more accessible.

A mere device may seem like a small thing, but, like Jennifer’s Pathfinder and Eric’s Liberator, they



Carlton Palms’ program emphasizes more than just technology.

use prohibit recording, and caregivers can’t pan and look into a bedroom, even if the door is left open.

Appropriate software wasn’t available at the time, so Carlton Palms created it themselves. “With other programs, the video was jumpy,” says Shea. The company’s software allows caregivers to split a screen to pull up and refer to an individual’s electronic health records while discussing a situation with staff or the individual himself or herself.

The system also includes a database that measures, for example, how many difficult behaviors occur and such things as what staff members were with the individual at the time.

Behavior Analytic Technology

Carlton Palms plans to take this video technology even further. The CTEP is supporting an effort to develop a center where parents of children with disabilities and difficult behaviors can come for assessment and diagnosis “and then go back home with the Cnow

can dramatically improve a resident’s life, says Spilecki, who has been at the center since 1984.

Mary Campbell Center started as an organization of parents who had children with special needs. Today, the 66-bed center specializes

system for their child so that they can call us up and talk to one of our bank of experts,” says Shea.

The experts’ work, especially in the case of autism, a prevalent condition at Carlton Palms, centers around something called “behavior analytic technology.” “It’s very intensive,” says McGimsey. “You’re looking at many hours a day across a week in the early life of a young child with autism.”

The center is proposing a new program for early intervention for people with autism. “What this project will be about is using our video technology to enhance how that early intervention works,” says McGimsey. Carlton Palms is working with Celeste Foundation on the project.

Carlton Palms and Cnow hope to provide the technical expertise associated with doing telehealth services, says Baker. Celeste will recruit families from around the country to come for a week, stay at the center under development, and undergo a week of behavior tracking and analysis.

Ultimately, Cnow hopes to be the authority for a telehealth protocol that emphasizes the ability of technology to be personal, to protect privacy, and to promote dignity. “We’re excited about it because we think national leaders would like more telehealth,” McGimsey says.

Shea does most of the tours of Carlton Palms, and he finds that parents “are all amazed and delighted to see such a system in place. Parents walk away knowing that we have the ability to keep an eye on their children far better than other programs do.”

in providing services to residents with multiple disabilities in a homelike atmosphere, while promoting dignity and growth of the individual.

“The thing that concerns me is this notion that if you have more than four beds you’re bad, you’re an institution,” says Spilecki.

“We really are not that. But it takes





Charlie Sileo (top left) sends an e-mail to a friend using an infra-red interface, Missy Grimaldi (top right) uses a camera mount attached to her wheelchair, and Kirtie Simpkins (left) travels throughout the center using his remote elevator control.

there are new products developed every day, and old products after a while are just old,” he says. “You buy it, and a year later it’s slow and can’t do what you want.” Spilecki says it’s important to have an ongoing process for researching and evaluating new technologies.

“You need a group of people who are keeping their ear to the rail and being able to try things. A lot of this stuff doesn’t cost a lot of money, but you have to find it.”

When the family of a resident who had passed away donated \$10,000 to the center, Spilecki set up an assistive technology fund. A \$20,000 award from MBNA, a financial services company, fattened the fund. Spilecki put together a team of staff members to research and evaluate technologies that the center didn’t have but that would benefit its residents.

In the past year and a half, the center has spent \$35,000—mostly from donations—on assistive technology, ranging from \$300 for a portable word processor that interfaces with the printer, to \$6,000 for a wireless infrared remote control system for residents to use to operate elevators.

One of the earliest new assistive technologies the committee identified was a small computer keyboard that also functions as a mouse. Because of its small size, residents who can control the muscles in their fingers bet- ➤

people getting in here to see that that’s not the case.”

The center has a full-time education program, along with a large hydrotherapy program in a heated tub with a moveable floor, and is immersing itself in the new assistive technologies available for its residents.

“Most of the people who live here use wheelchairs, and so there are a lot of supports, like help getting out of bed or eating a meal,” says Spilecki. “But once people are in their power chairs and have their communication devices” and other kinds of assistive technology, “the technologies we’ve found make them even more independent.”

Obtaining a general equivalency diploma and, eventually, employment,

is a very important goal for many residents, says Spilecki. “Technologies have been very important for residents to practice skills, learn new skills and knowledge, and for being able to access the computer for drill and practice activities, or just through independent study,” he says.

Setting Up For Better Assistive Technology

It’s important to be strategic about acquiring assistive technology: It’s something that can quickly become outdated, and while it doesn’t have to be expensive, it’s still money that must be carefully spent, Spilecki says.

“One of the things we’ve made a commitment to is that technologies are here with us, but they’re changing;

Technology Boosts Quality Of Life At The Boston Home

At The Boston Home (TBH), a not-for-profit nursing care facility that houses some 50 adults with physical disabilities, advanced assistive technology is adding a strong measure of comfort, convenience, and control for residents whose conditions often limit their ability to move freely, communicate effectively, or otherwise navigate their environment.

Thanks in part to the excellent planning and oversight of TBH's clinical services and facilities management departments, a variety of innovative systems that encourage residents to act more autonomously are now in place.

Wireless Aids

Wireless elevator and door access, overhead lifts, and ergonomic shower chairs are among the latest examples of TBH's progressive approach to technology.

"We're constantly investigating creative ways to give residents more control of their world and promote their independence," says adaptive equipment technician Don Fredette.

Recent high-tech additions include:

- **Overhead lifts.** Descending from a ceiling track in every resident room is a lift mechanism and sling designed to lift, lower, and move residents to and from their beds, wheelchairs, physical therapy mats, and shower chairs.

According to TBH seating specialist Faith Saftler Savage, the advantages over the former floor lifts are numerous. For one, she says, residents no longer need wait for an available floor lift. In addition, residents are lifted from more of a sitting position, which means that less physical maneuvering is required. This saves lots of time and reduces the risk of injury to both residents and staff. Another big advantage is that no storage space is required.

The lifts will next be added to the facility's physical therapy area, shower rooms, and new resident rooms.

- **Wireless door and elevator access.** Residents no longer need ask staff to push elevator buttons, and they're more apt to move about on their own, says Fredette. When residents are within range (usually 11 feet) of the elevator or door, a wheelchair-mount-



Overhead lifts in each person's room keep residents from waiting for floor lifts and offer body-friendly transfers.

ed pass automatically sends a radio-frequency signal to a "reader" next to the elevator or door. The reader calls the elevator to the floor or opens the door.

"This system is the biggest boost to my independence ever," says TBH resident Lillian Carr.

Adds resident Don Dalpe, "It has saved me from wasting a lot of my time waiting for or stuck on elevators."

Currently, 28 wheelchairs, two elevators, and the facility's new front door are fitted with the wireless technology. And soon, Fredette says, 12 more wheelchairs, two new elevators under construction, and the facility's back door, which leads to a garden area, will also be equipped with the wireless devices.

- **Ergonomic shower chairs.** The power tilt on TBH's four new shower chairs allows staff to ease residents comfortably and securely from the sling to the shower chair. Previously, residents had to lie flat in a shower bed or sit upright in a shower chair. Now, says Savage, "We can put our residents into any position and adjust for any weaknesses. This is the best shower chair I've seen, and residents are very pleased."

Hands-free Equipment

TBH is also home to a host of hands-free equipment, including wheelchairs; computers; and environmental controls for beds, nurse calls, phones, and TVs. What's next? Ten new resident rooms will be fitted with X10 remote-control technology. With X10, thermostats, lights, TVs, radios, and VCRs plug into sensors that will plug into electrical outlets, and the resident's wireless remote will emit radio-frequency signals to "talk" to the sensors. The remote can be hand-, voice-, or chin-activated, depending on need.

According to TBH's Chief Executive Officer Marva Serotkin, "With our building renovation upgrades and our exciting new technology applications, we are making great strides in maximizing residents' comfort and control in their wheelchairs or beds. Our plan calls for the systematic integration of assistive technology throughout The Boston Home, as well as the optimal fit between resident and technology."

The systems may be very sophisticated, she adds, but the goal is simple: A resident's wish should be technology's command.

Contributing writer MARVA SEROTKIN is chief executive officer of The Boston Home, Boston.

Assistive Technology Meets Neuroscience

Cyberkinetics Neurotechnology Systems, Foxborough, Mass., has an astonishing bit of assistive technology, currently in clinical trials: a neural implant that allows an individual to control other assistive technologies merely by thinking about it.

The device, called the BrainGate Neural Interface System, has been successfully used by the first patient in the clinical trial, a man who suffers from quadriplegia, to operate a computer, environmental controls, and a robotic limb simply by thought.

Because it is driven by thought, the implant's use isn't impeded by any disabilities of movement or speech a person may have, and it doesn't require a lot of training time for the person to learn to operate.

The brain-computer system consists of an internal sensor to detect brain cell activity and external processors that convert these brain signals into signals recognized by a computer.

The sensor is a silicone chip the size of a baby aspirin with 100 electrodes that detect the electrical activity of neurons. The sensor is implanted on the part of the brain responsible for movement, the primary motor cortex. A small wire connects the sensor to a pedestal, which is mounted on the skull, extending through the scalp. A cable connects the pedestal to a cart containing computers, signal processors, and monitors that enable the researchers to determine how well the individual can control his neural output.

The goal of the BrainGate program is to create a universal operating system that will allow people with physical disabilities to quickly and reliably control a wide range of devices using their thoughts, including computers, assistive technologies, and medical devices.

The development is patterned on that of successful long-term implant-

able devices for the treatment of Parkinson's disease and epilepsy and for the restoration of hearing in people with profound deafness. More than 100,000 people in the United States now use these devices.

Clinical Results

The two primary goals of the clinical study are to characterize the safety profile of the device and to evaluate the quality, type, and usefulness of neural output control that patients can achieve using thoughts.

According to results presented at the annual meeting of the American Academy of Physical Medicine and Rehabilitation in Phoenix, Ariz., the first patient in the BrainGate pilot trial has passed six months from initial implantation, with no adverse events being reported.

Immediately after the device was implanted, the patient was able to send signals from his brain in response to directional commands even though he had not moved his arm in more than three years due to a spinal cord injury. Cyberkinetics has developed a system to generate cursor control from these neural signals, enabling the patient to perform tasks and operate basic computer functions in numerous trials.

The patient's control of the cursor was reported to be immediate and intuitive, and the patient was able to perform tasks while speaking and moving his head.

Cyberkinetics plans to enroll another four individuals with quadriplegia into the pilot study and will focus on a second generation of the program in which patients would be able to move a cursor on a screen toward a specific target with their thoughts.

ter than their hands or arms are much better able to use a computer.

The center spent \$15,000 for two "MotoMeds," computerized exercise chairs that can sense spasms and automatically adjust to relieve them.

Committed To Technology

The entire Mary Campbell facility, not just its computer lab with its readers and voice-recognition software, has high-speed Internet access, and at the past year's annual Founder's Day, residents demonstrated some of the many high-tech assistive technology devices they're using—the camera mouse, for

Tips For Selecting Assistive Technology

- Have a research and evaluation committee.
- Include the individual in the planning process.
- Focus on the individual's goals.

example, which is a computer mouse that senses an individual's movements in a wheelchair and moves the cursor in the desired direction, and the "easy phone," which allows residents to use their own, familiar communication device to dial or answer the phone, talk, and hang up.

Assistive technology also has a way of multiplying. "The successful use of one technology makes us think, 'What if we tried something else, what if we added this component? Then she could do this thing that she's been wanting to do,'" Spilecki says.

To keep everyone up to date with the latest assistive technologies available, the technology committee has begun publishing a newsletter called the *A.T. News*.

"At some point, hopefully, this leads to employment," says Spilecki, "but there are meaningful things people can do to have a sense of purpose, and that can really lead to other good things." ■

