TECHNOLOGY FOR PEOPLE WITH DISABILITIES YESTERDAY, TODAY, AND TOMORROW

STORY BY ERIC TEGLER

People with disabilities have interacted with and relied upon technology and medical science for a very long time. However, our image of what that technology/science looks or acts like depends in large measure on the era in which we've lived.

What image do you picture: a paralyzed individual cueing a plasma screen Internet-linked keyboard via their eye movements? A deaf student watching a 1980s sitcom with closed captioning? A patient with cerebral palsy receiving experimental diazepam (Valium) doses in the 1960s? Could you picture King Phillip II of Spain using the first known dedicated wheelchair in 1595? What about an ancient Greek amputee using a cane?

The changing relationship between those with disabilities and the tools they use to journey through life has largely evolved for the better, if unevenly. The technology available has been influenced both by the pace of scientific progress and Western historical models of disability – the religious, medical/genetic, and contemporary rights-based models that set the tone for society's response to people with disabilities.

Religion ascribed good and evil to disability – virtue and sin. Mixed with the religious aspect were societal conditions that often required people with limitations to execute tasks in line with their capabilities to fulfill the co-operative requirements for survival in the pre-industrial era. Despite the perception of individuals with disabilities as inferior, some efforts were made to aid those who acquired disability after birth, particularly disability stemming from battle.

Thus French army surgeon Ambroise Paré introduced both modern amputation surgery and productive prosthetic design in the mid-1500s. Paré's invention of an above-knee device combining a kneeling peg leg and foot prosthesis with a fixed position, adjustable harness, knee lock control, and other engineering features allowed its users limited walking/crouching mobility in farm fields and workshops.

The medical model of disability that arose following the Enlightenment and industrialization conformed to the emerging commoditization of work, time, and production. Though technology progressed, people with disabilities were ironically further marginalized by advances in mechanization and productivity that they could not access, and by attitudes shaped by a scientific understanding of biology informed by Darwinism.

Viewed as unproductive, they were often segregated and placed in institutions that reinforced their separation. Prevailing attitudes affected the design of assistive devices like the Bath wheelchair, which, though it aided mobility, was designed to be maneuvered by an able-bodied individual. Not until the 1880s were pushrims widely added to wheelchairs for self-propulsion.

Twentieth century medicine and science viewed disability more through the prism of individuality, aiming to provide the person with appropriate skills to integrate into broader society. Though still the focus of charity, and sometimes social purges, those with disabilities began to develop a voice, particularly after World War I. Lobbying for participation in the labor force spurred developments like the application of physical therapy and occupational therapy to disability and the general concept of rehabilitation.

Increasing productivity emerged as a trend in the first half of the century, along with recognition that physical access constraints must be overcome. Such recognition led to development of devices like the stair-lift in the 1930s and a nascent mobility products industry.

With (and out of) the post-World War II civil rights movement came

A Quickie Q7 wheelchair. Advances in wheelchair design have ranged from the addition of pushrims to use of lighter weight materials, powered mobility, and microchips.

a rights-based mentality that gave rise to the term "disability" itself. Emphasis shifted further from dependence to independence as people with disabilities sought a political voice and became politically active, a trend that continues today. Legislation, from the Rehabilitation Act of 1973 to the 1990 Americans with Disabilities Act, shaped what would become known as "assistive technology" for people with disabilities.

In the 1970s, assistive technology paralleled the broader social movement of the disability community, which sought greater self-expression. Augmentative and alternative communication devices like the HandiVoice literally gave those with speech disabilities a voice. Shoebox-sized and operated with a numeric keyboard, the HandiVoice had more than 900 pre-programmed words, selected phrases, and 45 phonemes.

Each word, phrase, or phoneme was stored and accessed via a three-digit code. With the right combination entered (a tedious, cumbersome process), the device would produce voice output. Difficult as it was to use, the HandiVoice exemplified the desire and determination of people with disabilities – speech or otherwise – to communicate.

Though not strictly technological, the notion of eliminating physical barriers to access expanded in the 1960s, gaining momentum and regulatory backing though the 1970s and '80s. It spurred basic infrastructure revisions like wheelchair ramps and designated parking spaces. The concept subsequently yielded everything from "kneeling buses" to elevators with buttons in Braille, flexible drinking straws, and Velcro.

More recent decades have seen the computer/information technology revolution thoroughly permeate assistive technology, affording individuals with disabilities undreamt of potential and increasing productivity. Tablet communication devices with powerful, tailored software, advanced prosthetics with sensory feedback, cochlear implants with 20-plus sound channels, and advanced spasticity medications

with fewer side effects like CTP-354 illustrate the technology revolution.

Enumerating all of the medical and technological advances would require a book, but we can better understand their respective significance with perspective from John D. Kemp, president and CEO of The Viscardi Center, a respected New York-based nonprofit dedicated to educating, employing, and empowering children and adults with disabilities, and, as a person who uses four prostheses, someone who understands disability firsthand.

Looking back over the last 50 years, Kemp singles out, in his opinion, advances in communication as the most meaningful to the disability community.

"Since 1964, the greatest advance has to be around the issue of communications and the power of computing. It has changed everything – from hearing and sight aids to software which assists those with diminished power of speech, to communication for paralyzed individuals."

Modern speech-to-text hardware and software represent one of the highest profile advances in augmentative communication, but it was preceded by several innovations that proved equally important, including closed captioning (CC).

People without disabilities take it for granted today, usually only noticing closed captioning when in loud public places like bars or airports, but prior to its advent, deaf people were only able to partially participate in the revolution that TV and movies precipitated.

One of the earliest demonstrations of CC was done in February 1972 at Gallaudet College, where ABC and the National Bureau of Standards demonstrated closed captions embedded within a normal broadcast of *The Mod Squad*. Closed captions were successfully encoded and broadcast in 1973 with the cooperation of PBS station WETA,

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Top: Closed captioning has enabled people who are deaf or hard of hearing to access televised entertainment and information. Above: A man uses a custom augmentative and alternative communication device. People with disabilities that affect speech can use such devices to express themselves.

which thereafter began selected CC broadcasts of pre-recorded programs like *The French Chef*.

Real-time captioning, the process for captioning live broadcasts, was developed in 1982, but regular live CC broadcasts weren't a feature of television until the late 1980s. Federal Communications Commission (FCC) rules requiring all analog television receivers manufactured with screens of 13 inches or greater to have the ability to display CC didn't come into force until 1993. The ADA itself (Title III) required public facilities, from hospitals to museums, to provide access to verbal information on televisions, films, or slide shows.

As recently as February 2014, the FCC set new rules for TV closed captioning, resolving concerns on captioning quality and providing guidance to programmers and distributors. Though developed with the deaf foremost in mind, CC benefits the broader population, constituting an effective emergency communications tool and helping improve literacy skills. For non-native English speakers, English language captions improve comprehension and fluency as well.

There are less obvious ways in which assistive technology advances have improved quality of life and productivity, sometimes the more basic, the more effective.

"I use four prostheses and the weight and technology have really advanced," Kemp said. "The materials that are used, like titanium, are so much lighter that the energy used to move, to ambulate, is so much less."

Fundamentals like materials technology create secondary effects, frequently finding new application and giving rise to design possibilities, including prosthetic advances coming from research centers like the Rehabilitation Institute of Chicago and Walter Reed National Military Medical Center. Recently, these have included coordinated articulating fingers – all five digits – that allow a double-arm amputee to pick up an egg without breaking it.

Kemp calls it nothing less than incredible, but he also recognizes that the unfortunate causes of disability often drive meaningful developments in the field. "The perversity of this is that the major funding for almost all this research is the Defense Department, driven by the need to solve the problems of wounded warriors."

Innovation born from conflict is an age-old phenomenon. Less

recognized, however, are assistive technologies inspired by disability that have found application across society.

Closed captioning is one example. The typewriter is another. The first working typewriter is credited to Pellegrino Turri, an Italian who built it for his blind friend, Countess Carolina Fantoni da Fivizzano in 1808. Letters she wrote using Turri's typewriter still exist, though the device itself was lost long ago. Nevertheless, Turri's desire to develop an aid for disability produced an invention that, with refinement later in the 19th century, became central to written communication worldwide.

Major swaths of today's communication landscape rely on the Qwerty keyboard developed for the typewriter; it remains the primary interface for computers and connected devices. The Internet is a crucial tool for people with disablities for education, information, entertainment, and particularly socialization. Yet access remains an issue, with just 54 percent of individuals with disabilities using the Internet versus 81 percent of those without disabilities. The chief factors are the lack of alternative user interfaces and economic obstacles, monthly broadband costs in particular. The importance of being connected, Kemp says, is illustrated by usage.

"Once a person with a disability is connected to the Internet, they stay on twice as long on average as a non-disabled user," he said.

No discussion of disability technology can overlook the wheelchair and mobility in general. It was not until relatively recently, Kemp reminds us, that truly significant progress in design and development of this fundamental disability aid was made.

"There was essentially one international wheelchair producer [50 years ago] called Everest and Jennings. In the 1960s, they had 99 percent of the market. They built very stiff, heavy, metal collapsible wheelchairs. They were rigid. You had to sit vertically. They were just the boxiest, worst design. Finally, along came a couple of hip wheelchair manufacturers, people like Marilyn Hamilton.

DARPA image

The DEKA Arm System, an advanced robotic prosthetic capable of manipulating power tools and handling objects as delicate as grapes and eggs, was invented by Dean Kamen and funded by the Defense Advanced Research Projects Agency, an agency of the U.S. Department of Defense.

"She developed a wheelchair, called the 'Quickie,' and people began to realize you could have cambered wheels and dispense with push handles, allowing people to control their own destiny – a big message. Wheelchair design became consumer responsive, then adopted lightweight materials, powered mobility, and microchips. It kept on going to a chair that Dean Kamen invented, a predecessor to the Segway, that used gyroscopic technology to stand up on its back two wheels, balance itself, and put people at eye level. It could overcome some of the environmental barriers that exist today. There have been tremendous changes in 50 years just in wheeled mobility."

The impact of Hamilton's Quickie and Kamen's later iBot (ironically no longer in production) isn't limited to the physical mobility they helped advance, Kemp says.

"If you just focused on what wheeled mobility advances did to get an individual from point A to point B, you'd miss the real benefit of how [a wheelchair] goes to the very core of their identity, how they view themselves, and how they want the world to view them. It's a nuance that underlies all of these technologies: Can I be a productive employee? Can I be a good family member? Can I be a sportscar driver? Can I accomplish my dreams?"

The prospect of more people with disabilities reaching their dreams abetted by technology is certainly enticing. But technology usually also has unintended consequences, and they affect the disability community as well. A recent rise in Braille illiteracy has been linked to the audio-interface tools in greater use by blind individuals than ever. Even simple changes like the trend toward self-serve consumer technology have implications.

"The idea of self services – pumping your own gas, banking, and travel kiosks – is very efficient for the companies [that provide the services]," Kemp said.

"But when I go to an ATM, I cannot put my card in the card-reader and pull it back out with my [prosthetic] clamps. The consequence

Photo by Steve Jurvetson

A Toyota Prius modified to operate as a Google driverless car drives through a test course.

for anyone with quadriplegia or hand-dexterity issues is that, like me, they have to turn their card over to someone standing in line behind and say, 'Will you swipe my card for me and turn around while I enter my code?' We [people with disabilities] accept the trade-off of being able to get money any time of day or night and other conveniences, but sometimes it does diminish the independence we'd prefer."

Technology also creates conundrums centering on quality of life for people with disablities, Kemp points out.

"Many premature babies are ending up in our [Viscardi Center] school. They have various complications and medical complexities, but pharmaceutical and medical technologies have allowed them to be here. Now that we can identify Down syndrome and intellectual disabilities before a baby is born, parents are faced with horrible decisions. They don't know, if the child will live, what kind of life it will have. I think the disability community is out to prove you can live a good life if you are properly supported by government, family, friends."

There is a flip side to better medications, of course. Drugs now aid in the management of mental health/depression and promote productivity by managing conditions like bowel/bladder infection. They even offer hope of one day regenerating nerve cells to reconnect the spinal column.

"These have enabled a lot of people who otherwise would not be able to function well in society or within their families. Mental health is one of the bigger areas where advancements have aided those with disabilities. It's been a late bloomer in the disability movement," Kemp said.

Despite the variety of challenges they face, children educated at The Viscardi Center are just like their counterparts without disabilities in so many ways. Kemp cites the fact that they address the same issues as other schools, such as bullying – an ironically refreshing reminder that kids are kids. One of the chief lessons students there learn, Kemp explains, is recognition that advances in technology that offer people with disabilities historic opportunities merit responsibility in turn.

"You don't get a free pass in this world just because you have a disability. You have a responsibility to be as productive and independent as anybody else. One of the tenets of our school is empowerment. As long as we have access to technology, we can send our thoughts anywhere in the world. We can publish anything we want in blogs, we can create. We do have a responsibility to say what we want to say and not just be passive recipients of charity and empathy."

What future technological innovations will further enable individuals with disabilities? They'll be broad-based technologies like Google's emerging driverless car, whose implications for mobility are far-reaching. Similarly, wearable tech from Google Glass to the Apple Watch may offer greater utility to the disability community than anyone else. Dedicated technologies like software that can provide object recognition, real-time two-way speech-to-text recognition, emotional interpretation, and communication will be part of the landscape, as will increasingly effective surgical intervention that can implant the brain with sensory and control functionality it lacks.

In turn, technology has the power to refashion the way in which society views disability, shifting focus from dependence to independence, from method to outcome.

"Do you really care how something is done rather than what the outcome is?" Kemp asked. "Does it really matter that someone is typing with their feet or speaking to Dragon dictation software?" ■