Is There an App for That?

Assistive Technology and Community Health

ELIZABETH ANN SCARBOROUGH

My mother was an RN, a well-read, hard-working, environmentally conscious woman who sometimes worked in doctors' offices, as head nurse in nursing homes and (in her early career) as a private duty nurse. She put in a vegetable garden and flower beds every year, fed the birds, answered questions about health for our neighbors and friends and, without charge, gave them injections prescribed for allergies or other conditions and took blood pressures.

When she lost her hearing, she had some difficulty caring for my father (her husband of 53 years) when he was stricken with cancer, because she couldn't hear him when he called, or respond to his stories when he desperately needed to talk. After he died, she rapidly began losing her vision. She was the victim of uncontrolled hypertension and osteoarthritis that warped her hands and fingers and pushed her knees together while splaying out her feet.

Then she developed breathing difficulties, and the doctors didn't know why. I talked to her on the phone every day, and heard the fear in her voice, and the loneliness. She could no longer do the other thing she loved most besides my dad — read — nor could she see or even hear the birds singing in her yard.

With each loss, she grew more and more isolated from the people around her, even after my brother and his family moved in with her. She was still isolated inside herself, with no distractions except worry, and little sensory stimulus except discomfort. Because she was on oxygen, she couldn't have her gas stovetop on to cook meals. She could neither work nor enjoy herself. By the time she passed away, little remained to keep her

among us. This is bad enough at 86. Mom bore it stoically, but I was aware of the pain and frustration it caused her, and the sense of unfairness.

WORSENING VISION

When I first met Jay, I was reminded of my mom's situation. Jay seems much younger than his 70 years and has experienced all sorts of fascinating adventures and lived all over the world, but his vision had deteriorated. Because of macular degeneration and a hereditary eye condition, he knew he soon would be blind.

In the two or three years I've known him, Jay's vision has become much worse. He sometimes asks friends to help him count change or tell him which harmonica to select for the key he needs to play in. Sometimes he says, "I'll just follow you," when we are entering or leaving a building. He can no longer drive.

His computers have helped to some extent. He has a desktop, a laptop and tablet, plus a big telephone that talks to him like an electronic personal assistant. He is frustrated, though, by icons and fonts on his various screens that are too small for him to see and can't be enlarged.

A mutual friend, Chris, worked in information
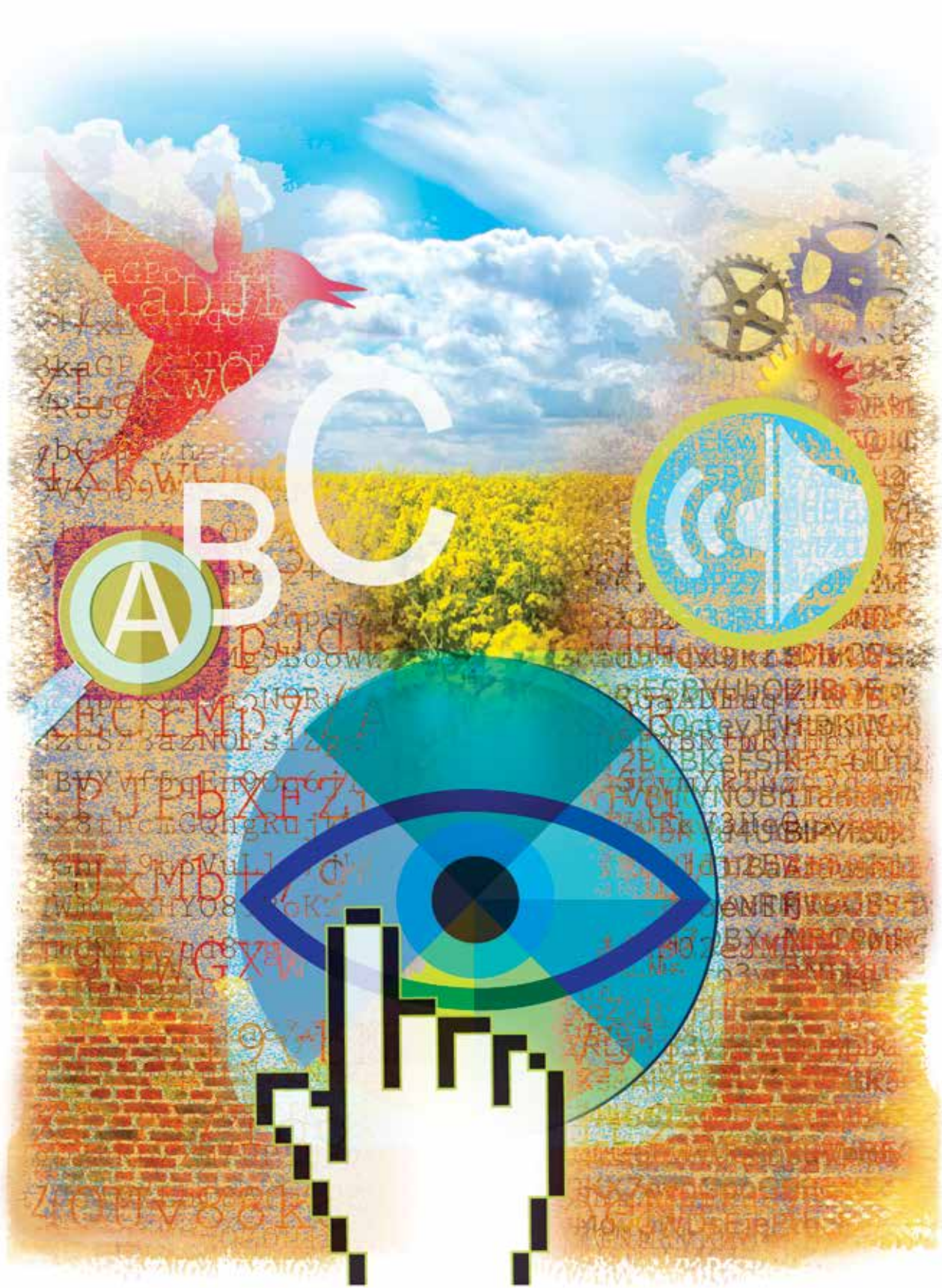
technology before he retired. He said he would simply design a program if Jay couldn't find a suitable one to enlarge email fonts and icons.

Chris explained that if he *were* to design an app to do what Jay wants, "I would sit down with Jay and have him explain in minute detail what he needs. The method I would use to write the requirements is called the use-case method, but it basically calls for the identification and description [in words and in pictures] of every separate function that Jay needs the software to do for him. I would then ship that off to the consulting company [that Chris used to work for and whose assistance he would enlist] and then act as the ongoing liaison between them and Jay as the end user."

I asked Jay to talk about the challenges his vision loss has created in his life. He said knowing that the hereditary condition would dim his sight some day, he'd had more time to prepare than most — and regretted not spending it more wisely. In an email message, he said:

"I did not expect or plan for:

■ How much I had come to depend on my computer and smartphone for things such as banking, bill paying, email, music, research, managing messages, voice mail, etc. As I've told you, I can live without TV but struggle daily with the computer and phone.

"Sometimes, it's the little things like...

■ Family photos, documents, will, etc. Like most people, I have boxes of "stuff" that I now wish I had gone through before becoming legally blind. Now, it's nearly impossible to sort through, or find the things I need to or want to see. My plan for this is to use my magnifying screen, but it's a very slow process.

■ Home repairs. I used to love to tinker around the house and really miss being able to use my tools.

■ Shopping. This is so difficult now that I just don't do it unless my girlfriend Harmony is with me. One thing that is very difficult is the use of an ATM card at the store or at an ATM machine. I don't know if you've noticed, but those machines are not standardized. Just about the time I memorize the keypad on one, they update and it changes. Using cash is not ideal either, for obvious reasons.

■ Cooking and cleaning. I love to cook and still do, but it's the little things like reading labels, finding a spice, using the wrong ingredients, etc. I now clean the house by feel, but miss a lot, I'm sure.

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■ Car trips. I used to love to drive and explore new places but now dread those trips. It's very frustrating to hear people talk about that great sunset, vintage boat or beautiful bird. I don't blame them at all, but find that I'd now rather just sit home with a book [on tape].

■ The biggest surprise of all to me is how small my world has become over the past year. As you know, I was once outgoing, active, curious, adventurous and a people person. Now, I find that I'm avoiding people unless I know them well. I've lost the confidence and the will to put myself out there. I decline most invitations and avoid initiating new friendships. It's become easier to just stay home, for the most part. I recognize that this is not healthy, but it's real.

"I was very excited about the new digital smart glasses. I tried the four that are now on the market. I kept my favorite, Irish Vision 3D glasses by Samsung, for a week before returning them. Basically, they are very good for TV, but impractical for computing, walking, shopping and riding in a car. I could not justify twenty-five hundred bucks to watch TV. I'm sure they will improve, so I plan to try them again in a year or so.

"I downloaded Voice Dream Reader and Voice Dream Mail, two of the highly rated apps that you found for me. I believe the Mail app will help me, but the Reader app is complicated. The app developer did not design this app to 'enlarge' with a keystroke, like some apps do. Therefore, I can't read the instructions on how to use the app. This is ironic and maddening to me that a developer would create an app for low vision that is not accessible."

INDUSTRY INITIATIVES

Having a person with a disability in one's community or family has spurred some eminent people in the computer business to look to their work for solutions.

Satya Nadella, chief executive officer of Microsoft, has written about the importance of assistive technology, inclusive design and empathy in serving people with disabilities. Nadella is the father of a child with special needs whom he describes as "the joy of our family, whose strength and warmth both inspire and motivate me to keep pushing the boundaries of what technology can do."[1]

In May 2018, Brad Smith, Microsoft's president and chief legal officer, announced a $25 million, five-year program "to put AI tools in the hands of developers to accelerate the development of accessible and intelligent AI solutions to benefit the 1-billion-plus people with disabilities around the world."[2]

Computer scientist Richard Ladner, PhD, who retired as a professor emeritus at the University of Washington, is the hearing son of deaf parents. He has a deep understanding of the problems deaf people encounter in gaining access to various aspects of life that hearing people take for granted. In 2008, he received a Purpose Prize from the San Francisco-based Civic Ventures (now Encore. org), an organization founded to redefine the concept of "later life" and transform retirement years into a time of renewal and contribution.

Ladner's prize was awarded for work on solving the problem deaf people have using cell phones. Other programs he has been associated with include mapping sidewalks to help people with impairments walk around town more safely. On the very high-tech end of the spectrum, Ladner has helped develop tactile graphics, which use a raised image on paper or aluminum with hand-embossed, raised lines and textures. This touchable technology is not only useful for simple mapping, but it goes beyond Braille to help visually challenged people "read" charts, layouts of buildings, schematic designs and images of geographic figures.

Tactile graphics used in conjunction with optical character recognition help low-vision people "read" the charts, graphs and symbols used for engineering, science and technical subjects. Graphs, bar charts, diagrams and maps may be turned into tactile graphics (with images transferred to raised lines and shapes and colors replaced with textures), and the information on the graphs is translated into Braille.[3] These kinds of renderings mean people with natural abilities and aptitude for math and science don't have to be thwarted by low vision.

In a 2016 CCTV America interview about trends in innovation to assist the disabled, Ladner said that other people's attitudes often are the main obstacles to people with disabilities being employed in technical and scientific fields. Doubts about their capabilities keep them from being allowed to take on work they are very capable of doing, Ladner said.

In the same interview, Ladner further stated that there is a big thrust in the technology industry toward "mainstreaming" assistive technologies.[4] The startup cost often is low, he said, and investment in assistive technology can be low risk: Trying to fill the needs of people with disabilities can lead to products that are popular with everyone — such as the electric toothbrush, which originally was designed for people who couldn't perform the brushing motion themselves.

3D PRINTERS, VOLUNTEERS WHO ASSIST

Another technology is widely used around the world to replace bones and other body parts — 3D printing. Because of the global nature of friendships these days, I know some details about 3D printing because an Australian friend's son, Paul D'Urso, a neurosurgeon, is the executive director of Anatomics, a company that uses the technol-

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ogy to custom-reproduce bones of people who need them, as well as implants and prostheses. Anatomics uses CT scans of specific patients to model bones created for implants. D'Urso said the 3D parts also are useful to educate patients about their condition beforehand. He described printing a 3D skull model for a child with a birth deformity.

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"It was a crude model, but I was able to show the patient's mom what was happening," he said. "She couldn't really speak English, was scared and obviously this was a major event for her child."[5]

In addition to such highly technological innovations, there are many more computer-assisted devices already meeting special needs. Electric wheelchairs or motorized scooters make mobility possible for those who would otherwise be totally dependent on others to get from one place to another. Marketa Zvelebil, PhD, formerly the team leader of cancer informatics at the Institute of Cancer Research in London, has been unable to walk without crutches since childhood. Now retired and living in a small French village, she had a personal elevator installed — partially paid for by the French government — in order to have access to the outdoors. Now she uses her all-terrain scooter to walk her dog and the neighbor dogs all over the French countryside, taking photographs.

In my town, which is full of retirees beginning to have cataracts, hearing loss and arthritic knees, hips and backs, a volunteer organization — the Ecumenical Charitable Helping Hands Organization, or ECHHO — loans walkers, wheelchairs, commodes, bath stools, all of those enabling devices that help people with mobility difficulties continue to function.

DASH (Disabled Access Starts Here), another volunteer organization, provides lists of accessible local restaurants and presented a program in which city council members were asked to try out walkers in order to understand the difficulties of getting in and out of places while using them.

The Jefferson County Council for the Blind in Port Townsend has helped Jay and other low-vision people in the area get free audiobooks and a player, among other things.

Carl Jarvis, director of Peninsula Rehabilitation Services, has been blind since birth but has made it his mission to provide information, encouragement and emotional support to other people adjusting to blindness.

The Hearing, Speech and Deaf Center in Seattle coordinates with local people with hearing difficulties and communication challenges.

We also have a good-sized population of people who are mentally ill. The National Alliance on Mental Illness works to get help for these people, lobbying a hospital to include facilities for the mentally ill to be included in a new hospital wing, for example. It also supports laws that don't unduly target or punish the mentally ill, and advocates for measures to provide assistance and support for families and caregivers of people with mental illness or dementia.

Computer technology and the internet are critical to the organizers of all these local groups, making it possible to research and distribute information and resources, keep up with recent innovations, communicate with members and maintain records. Valerie Phimister, president of NAMI's chapter in Jefferson County, Washington, said apps have been developed for people suffering from various mental illnesses and disorders to use with or between therapy sessions to help them stay on track.

CONCLUSION

My mother died in 2009 at the age of 86. During her lifetime, people in her neighborhood bor-

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rowed medical equipment from friends who no longer needed whatever it was, either because they got well or died. Until it was too late and her bones were already warped out of shape, no one thought to replace my mother's hips and knees. When she was no longer able to see her computer screen, even with big letters, she could no longer read. Her hearing loss remained a source of constant frustration, and no one could offer any

kind of help. Perhaps some of the programs now in development will, in time, come up with a solution for people who can neither see nor hear well.

Jay already has more options to try than Mom did before she died. He and other articulate potential users of assistive tech, if they continue communicating their needs to the designers, have the opportunity to reclaim even more parts of themselves that their disabilities robbed them of. New devices and ways to use them are breaking down the walls isolating them from other people.

Equally, if not more important, communities need not be deprived of the talents and skills of members with disabilities. Thanks to assistive technology, conditions that once seemed like the end of the line may become no more than a bump in the road.

ELIZABETH ANN SCARBOROUGH is a former Army nurse who served in Da Nang, South Vietnam, during the Vietnam War. A prolific science fiction and fantasy novelist, her book *The Healer's War*, which won a Nebula Award in 1989, is loosely based on her war experiences. She lives in Port Townsend, Washington.

NOTES
1. Satya Nadella, "Satya Nadella, Microsoft CEO: 'The Moment That Forever Changed Our Lives.'" *Microsoft Accessibility*, blog, Oct. 21, 2017. https://blogs.msdn. microsoft.com/accessibility/2017/10/21/satya-nadella-the-moment-that-forever-changed-our-lives/.
2. Brad Smith, "Using AI to Empower People with Disabilities," *Microsoft on the Issues*, blog, May 7, 2018. https:// blogs.microsoft.com/on-the-issues/2018/05/07/using-ai-to-empower-people-with-disabilities/.
3. To see what tactile graphics look like, watch this YouTube video, "Quick Tip: Guidelines for Design of Tactile Graphics," posted Sept. 3, 2014, by American Printing House for the Blind. www.youtube.com/watch?v=IyA_MSMCrTE.
4. CCTV America, "Current and Future Trends in Innovation to Assist the Disabled," *Starting Block*, April 15, 2016. www.youtube.com/watch?v=1j7tA7EiJUw.
5. Personal conversation with Paul D'Urso, 2018.

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