Labor Of Love Helps Severely Disabled Communicate

Boston College

How can we tell if people with severe disabilities have an active mental life? That's a question Jim Gips has grappled with for more than 20 years. It's a significant problem for those who lack voluntary muscular control for speech, typing, sign language or other forms of communication.

"I think these folks have a double whammy. They have a serious physical disability, but also people don't always take them seriously as human beings," says Gips, a computer science professor at Boston College in Chestnut Hill, Mass. "They look at this person in a wheelchair — who might be drooling, unable to control spittle — and they say 'This person doesn't have an active mental life, there's nothing going on inside.'"

Those assumptions are often incorrect. A device called EagleEyes — developed by Gips and his colleagues — proves it. By controlling a computer screen with eye movements, EagleEyes allows severely disabled people to express themselves. And it shows just how wrong first impressions can be.

"Cool" Technology Finds a Greater Purpose

The springboard for EagleEyes dates back to a 1992 lunchtime discussion between Gips and a colleague, regarding projects they'd like to tackle. "We decided it would be great to control the computer with our minds," says Gips. Initially, he wondered if that might be possible with EEG (electroencephalography), which uses electrodes to detect the brain's electrical activity. After visiting Boston College's electrophysiology lab, they realized EEG wasn't a viable option — at least, not at that time (over the years, technological advances eventually led to EEG-controlled computers).

Instead, Gips and his colleagues turned to EOG, or electrooculography. By detecting electrical signals, EOG can track eye movements. That's possible because eyes have different charges — the cornea is positive, and the retina (located at back of the eye) is negative. For each degree of eye movement, the EOG signal changes approximately 20 microvolts. Electrodes placed temporarily on the skin around the eyes detect those signals.

Using this technology, Gips and his colleagues developed EagleEyes, which received initial funding from Boston College. EagleEyes uses the signals from eye movements to control the position of a cursor on a computer screen. They also developed software that allows users to spell out messages or play simplistic video games — all by shifting their gaze. Initially, they didn't plan to help people with disabilities. Says Gips: "We really developed EagleEyes because we thought it was cool to control a computer through the electrodes."

Can You Help Me?

That changed with a fortuitous turn of events. After Gips presented the device at a scientific conference, it caught the attention of national media. One day, a film crew called — it wanted to shoot a segment for national TV and wondered what Gips could do with EagleEyes beside play video games. Gips told the crew, "Well, maybe it can help children with severe disabilities." He and his colleagues had considered that possibility, but hadn't yet tried it.

Fortunately, Gips didn't have to look far for someone to test it out, because Boston College has a campus school for children with profound disabilities. Gips called the school director and explained his situation, and they were able to have a disabled young woman try EagleEyes, while being recorded for national TV. "It worked — she was happy, we were happy," says Gips. Soon after, Gips and his colleagues placed EagleEyes within a classroom at the university's campus school for children with severe disabilities, and word spread quickly among parents. They called Gips, wanting to know if their child could try EagleEyes. And the calls weren't just local — Gips heard from parents in England, Italy, all over the world. They had the same basic question: Can you help me?

Gips saw the overwhelming demand but lacked the resources to make EagleEyes more widely available. He talked with about a dozen entrepreneurs and venture capitalists, but kept hitting the same fundamental roadblock with potential investors. Although EagleEyes could have a huge impact on the lives of people with severe disabilities, it would never have much potential for profitability.

"This was in the early 2000s, and things reached a bit of a standstill," says Gips. "It was difficult. How do I get the invention out of my laboratory, and into the hands of people who can use it? I couldn't really see a path through."

A Nonprofit Makes Wider Distribution Possible

In 2004, the answer came from a chance encounter. After Gips demonstrated EagleEyes at a technology conference in Boston, an attendee told him, "There's someone you really need to talk with."

That turned out to be Debbie Inkley, executive director and founder of the nonprofit Opportunity Foundation of America (OFOA), based in Salt Lake City, Utah.

OFOA had been facilitating a job-skills training program for Discover Card to support individuals with physical, emotional and financial challenges to gain employment in the company's U.S. call centers. But after 10 years, that program was coming to an end, and OFOA needed a new focus.

Soon after speaking at the technology conference, Gips traveled to Salt Lake City and met with Inkley and OFOA's board. From there, things moved quickly. "Our board made the decision within a month, that we wanted this to be our new project and our only project," says Inkley. Within just a few months of meeting Gips, OFOA signed an exclusive license agreement with Boston College in 2004 to provide manufacturing, distribution and training for EagleEyes.

Boston College did not patent the technology, says Jason Wen, Ph.D., director of the university's Office of Technology Transfer and Licensing, who came to Boston College at the end of 2012. Instead, it initially granted a know-how license to OFOA. That meant OFOA wasn't paying fees, but it needed to renew the license every 10 years and couldn't make changes to the device without approval from Boston College. When the license came up for renewal in 2014, Wen decided to grant OFOA a permanent license for EagleEyes and its software system, with all the rights to further develop the technology. The process began in late September and was completed in November, and only included a minimal one-time payment from OFOA, says Wen. "Normally I could charge much more," he says. "But we value the public good much more than any financial return."

Gips says the technology transfer office has been very helpful. "I'm guessing they're usually more interested in projects with more commercial application, but with EagleEyes, no one is going to be making money. So it is always a labor of love," says Gips. "It's a labor of love at the technology transfer office as well, because they wanted to see the system helping as many children as possible. They enabled that to happen."

Cause-and-Effect Games Create a Path to Communication

Since receiving the initial license, OFOA has placed about 285 EagleEyes systems, primarily in the United States, but also in Canada and Ireland. About 60 percent of those systems are in schools and organizations, and the rest are in individuals' homes. OFOA charges $800 for EagleEyes, which is the cost to manufacture it. That makes EagleEyes an affordable option for families and schools, says Inkley. "Technologies that are similar to what we do can cost between $10,000 and $15,000," she says.

OFOA has certified trainers who help people with severe disabilities — and their families — understand how to use EagleEyes. The first step in that process involves teaching the disabled person to play cause-and-effect games, like drawing a picture on the screen by moving their eyes. It's vital for EagleEyes users to start with those games, so they understand that they have control over movements on the screen.

"With our users, everything has been done for them," says Inkley, whether it's having diapers changed or being fed through a tube." Professor Gips developed a game where you start blinking, and all of a sudden you see flashes of red and yellow, and you can modify it to be circles, stars or squares." That may sound like a very basic game — but it's a profound one for people who've had no control over their environment. "It's incredible, because the user is doing something for the very first time in their life on their own," says Inkley. Some EagleEyes users immediately understand they are controlling the screen, and others need to try four or five time before they internalize that cause-and-effect dynamic.

From there, EagleEyes users move on to educational games, which can teach things like colors, letters, numbers and shapes. After that, they can use a communication board on the computer screen, says Inkley. "Mom and dad can ask them a very simple yes-or-no question, and they can also go to a choice board where it might say 'I want…' and they

can choose from small icons on the screen, like a favorite book, toy, or movie."

The journey from cause-and-effect games to communication board does not take place overnight. It depends on the child, Inkley says, but the process can last nine months to a year.

"It takes parents who are really committed to using the technology with them on a daily basis, because we're talking about getting the brain stimulated," she says. "You just don't put the electrodes on and say, 'OK, I'll be back in an hour.' It takes time."

During the past decade, EagleEyes has undergone a few design improvements. The first EagleEyes system was rack-mounted — now it's much more portable, about the size of a paperback book. EagleEyes' basic functionality hasn't changed much over the years, but it has created seismic shifts for the people who use it.

Gips has witnessed this first-hand. It is a life-changer, he says, not only for the children and young adults who haven't been able to express themselves, but also for their families. He remembers an uncle, who saw his 12-year-old nephew use EagleEyes for the first time. "The uncle breaks down into tears and says, 'Wow. That's my nephew, that's my nephew.' His entire life, he hadn't attributed there was anything going on inside."

Inkley says her organization aims to distribute 100 EagleEyes systems this year. She's already seen dozens of life-changing moments from the systems currently in use. "Usually the statement we hear is, 'I always knew my little girl or my little boy was bright. I always knew she had an intellect," says Inkley. "The moms and dads jump up and down and have a smile on their face."

As exciting as those revelatory moments can be, EagleEyes' lasting effect — forging stronger bonds through communication — is just as thrilling. "Often times, when kids have severe disabilities, they are loved but they are put in the back of the room," says Inkley. "With EagleEyes, you can plug it into a screen, and mom and dad can be there. Brothers and sisters can be there." This is one of the biggest benefits, she says: "It brings the family together."

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