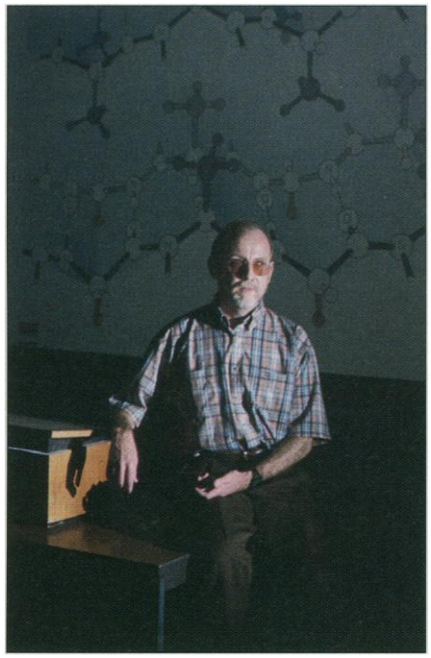
CAREERS IN SCIENCE

Leveling the Playing Field for Scientists With Disabilities

With help from new technologies and old-fashioned willpower, researchers with disabilities are making gains in the workplace

DAVIS, CALIFORNIA—In a lecture to a packed auditorium here, biochemist Larry Hjelmeland is describing the bends and notches that give proteins their shapes. Behind him flash slides depicting fibroin, alpha keratin, and collagen; the cartoons aren't what these substances really look like, of course, but they help the mind develop a picture of how microscopic strings of amino acids link up to form fibrous proteins. Like his students, Hjelmeland, 50, can only imagine the molecular world, invisible to the naked eye. But unlike most people, he is forced to imagine the macroscopic world, too: the tendons, the creases of a smile, all the shapes formed by proteins. That's because Hjelmeland lost his eyesight 15 years ago.



Imaginative. Blind biochemist Larry Hjelmeland makes silk proteins come to life.

A generation ago, people who were blind, deaf, or wheelchair-bound faced long odds in climbing the science career ladder. But thanks to federal laws requiring accessible buildings and forbidding discrimination against people with disabilities, social values emphasizing "inclusion," and—most of all—the computer revolution, it is now possible for someone with almost any kind of impairment to communicate and acquire data. Indeed, a wealth of new technologies, particularly those for blind people (see sidebar), are helping put scientists with disabilities on the same footing as their peers. "Technology has been opening up the world," says Larry Scadden, head of the Program for Persons With Disabilities at the National Science Foundation (NSF). "The greatest boon," says Scadden, who is blind, is "independent access to information."

Only recently has NSF begun to track the number of people with disabilities who have chosen science as a career. In 1996, the agency estimated that 5% of the 3-million-strong science and engineering workforce—about 175,000 people, including 26,000 Ph.D.s—have "moderate to severe" disabilities. By far the most common are dyslexia and other learning disabilities, followed by speech problems—from a stutter to cerebral palsy. Orthopedic disabilities come next, then vision loss and hearing impairments. Still other people suffer from chronic diseases. Crippled by amyotrophic lateral sclerosis, or Lou Gehrig's disease, for example, astrophysicist Stephen Hawking of Cambridge University is confined to a wheelchair and speaks through a computer.

Behind the numbers are compelling stories about how individuals have leveraged high-tech advances—and their own determination—to become productive scientists. Hjelmeland was blinded by diabetic retinopathy, a breakdown of blood vessels supplying the retina, over a 9-month period in the early 1980s while a protein chemist at the National Eye Institute (NEI) in Bethesda, Maryland. "I thought it would be partial loss, but in the end I was left with absolutely nothing," he says. His first reaction, incredibly, was "excitement at facing a new challenge." That was followed by anger and depression. "It was terrible," he says. "I had very high expectations for my career at that point. Basically I felt it was all over."

Fortunately, Hjelmeland's vision loss occurred just as screen readers—software that translates data on a monitor screen into audio—were becoming available. He says NEI offered to create a post for him, as he calls it, as "a minor luminary on how blind people use computers." Instead, he decided to try to make a go of it in academia even though, he says, "I had no sense that I was a salable commodity on the open job market." He won an NEI grant to study the cell biology of scar tissue formation on the retina and obtained a post as adjunct professor at the University of California (UC), Davis, a conveniently flat campus well known for supporting people with disabilities. "My family thought I was nuts" to turn down a comfy bureaucratic job at NEI, he says—especially as he was developing diabetic kidney disease and knew he would be needing a transplant (which he got in 1996). But his gamble paid off: Within 4 years he had won tenure and had secure funding for his eye disease research.

Hjelmeland says it took about 5 years to make the transition—psychologically and logistically—to being sightless. The secret, he says, is "to redefine yourself" in light of your limitations "and be born as a new person with a new identity." On the whole, he considers himself lucky. "My story is a story of privilege. At every turn of the corner, I have received pretty massive support."

Geerat Vermeij, on the other hand, never had to redefine himself. Blinded by glaucoma in early childhood, he has earned an international reputation at UC Davis for his work in a discipline that most people would assume requires a sharp eye: evolutionary biology. For Vermeij, however, a sharp eye depends on the eye of the beholder. He has done extensive fieldwork, using his fingers to trace the subtle evolutionary adaptations that show up in snail fossils over millions of years.

Unlike Hjelmeland, Vermeij relies heavily on Braille, typing up detailed notes from papers read to him by his assistant or by his wife, Edith. Hundreds of tiny drawers in his office contain specimens, with a strip of stiff paper marked in Braille coiled around each. Vermeij also considers himself fortunate: He's doing exactly what he's always wanted to do and admits, he says, to being "surprised at how little problem I have had with [other] scientists" on account of his disability.

Others have faced greater obstacles. Jim Caldwell, an IBM engineer currently on loan to the St. David's Foundation in Austin, Texas, was badly burned, blinded, and paralyzed from the waist down in 1962 when a can of boat stove fuel being used in a backyard barbecue fire exploded. After the accident, Caldwell says, his doctors at the hospital "said I had no rehab potential." Prospective employers wrote him off, too. "I couldn't even get into an employer's office to talk about a job," he says. He finally landed in the Baltimore phone company as a computer programmer in 1966.

Budding scientists get much more help

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these days with launching a career. Besides NSF's disabilities program, which promotes education for children and career development for adults, the American Association for the Advancement of Science (publisher of *Science*) has been serving as an information clearinghouse, as a resource for teachers, and as an advocate through its Project on Science, Technology, and Disability, started more than 20 years ago. Such programs have helped change attitudes in the scientific community. Rebecca Jackson, who lost the use of her legs after falling from a balcony in 1979, says that when she went to scientific meetings a decade ago, there were no services to accommodate disabilities. Now, says Jackson, an endocrinologist at Ohio State University in Columbus, "people call and ask if you have any special needs."

Whereas ramps into a building are essential to wheelchair-bound scientists, on-ramps to the information highway have been key to keeping people with disabilities in science careers. Take NSF's Scadden, who went through school with the aid of a slate and stylus after losing his sight from a household accident at age 9. Now he has a panoply of technologies at his fingertips, including a computer with talking screen reader and a machine called "Reading Edge" that scans documents into his computer or reads them with a voice synthesizer. He takes notes with a "Braille Lite"—a portable device with a refreshable display into which he can type information in Braille and retrieve it in Braille or in a digital voice.

Gadgets are also making life easier for Ken Barner, an assistant professor of engineering at the University of Delaware in Newark. A freak injury from diving into a pile of hay at a fraternity party in his freshman year left him paralyzed from the neck down in 1983. Now studying ways to form tactile representations of scientific concepts, Barner has mostly forsaken arduously pecking things out on a keyboard in favor of "Dragon Naturally Speaking," a computer program that recognizes his speech and turns it into writing.

Hjelmeland says there's no way he could do his current job without such tools. "To me it was a no-brainer when I lost my eyesight" to go digital, he says. Without computers, he says, "I'd be dead in the water." Hjelmeland spends about half his day on the computer and the other half talking to people. Fortunately he has a "killer memory," as he has never learned Braille and relies only on prompts from a tape recorder when he lectures. He doesn't do hands-on work in the lab, but as colleague Claire Gelfman notes, "most professors are more involved in grant writing and mentoring students than doing the actual bench work." Working with a blind lab chief, she says, "requires you to be more descriptive when presenting data." However, Gelfman adds, "those of us who work with him do not see him as a disabled person at all."

But there's no way Hjelmeland could keep up without help. He prefers to have papers read to him rather than scanned and spoken by machine. "My independence is not as important to me as getting the job done," he says. Assistant Rosemary Motz guides him to appointments, sets up computer-based video projectors in class, and reads papers to him.

Others with disabilities, however, are forced to give up long-cherished goals. After losing his eyesight to diabetes while in graduate school at the University of Chicago in 1981, Mark Dubnick had to abandon plans to do bench research as a mammalian cell culture geneticist. He retooled as a computer scientist at the National Institute of Neurological Disorders and Stroke in Bethesda, Maryland. But his heart is still in the lab.

Karen Sadler also reluctantly let go of her dream. Sadler, who is deaf, went back to college at the age of 34 in 1990 to study neuroscience at the University of Pittsburgh. She says she abandoned the idea of having her own lab when she realized how long it was going to take to attain her goal. She was also swamped trying to keep up with course work. In class, she says, she would struggle to take notes while watching a sign-language interpreter, the professor, the blackboard, and maybe an overhead projector. "It is just too much input," Sadler says. She eventually switched to a Ph.D. program in education, where she is developing materials to educate the deaf community about AIDS as well as for teaching science to deaf people.

People with disabilities have to know exactly what their needs and limitations are if they want the world to have confidence in their abilities, says Sheryl Burgstahler, who directs a 6-year-old program called DO-IT at the University of Washington, Seattle, which helps high school students with disabilities get into science. Dubnick, for example, says that although he had "excellent support" from his department, it was he who had to figure out how to fulfill his Ph.D. requirements—by obtaining a grant to hire an assistant to perform lab work. "You have to be extremely independent and extremely brass-ballsy to make it," he says.

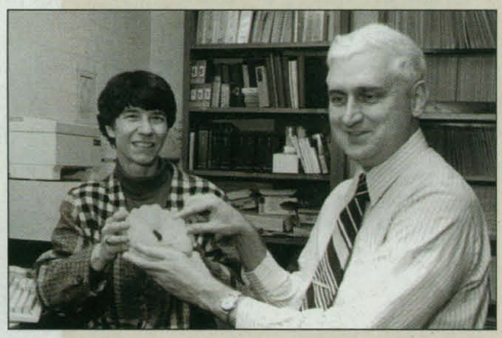
And you have to have faith. Even during the darkest times, says Hjelmeland, "I always thought things would be all right."

–CONSTANCE HOLDEN

Opening New Vistas for Blind Scientists

Technology offers a wealth of opportunities for scientists with disabilities. Blind researchers, in particular, are benefiting from innovations and gadgetry. Here's a sampling of what's in the works:

• **Sightless math.** Math is ordinarily represented in Braille by the Nemeth code, a variation on literary Braille that is tough to follow. So researchers are devising other ways to help blind people absorb mathematics. One project is the Audio System for Technical Readings developed by T. V. Raman, a blind computer scientist who works at Adobe in San Jose, California. Notation is converted to LATEX, a system that puts symbols in the order in which they are spoken. Then an Audio Formatting Language turns symbols into varied speech and nonspeech sounds. Superscripts, for example, come across in a raised voice.



Shape of things to come. Blind chemist William Skawinski and colleague Carol Venanzi show off prototype of 3D molecule.

• **Virtual reality by feel.** Ken Barner of the University of Delaware in Newark is developing what he calls a sense-of-touch, or haptic, environment. He is refining a computer-controlled, thimblelike device that, as you move your finger, presses against your fingertip in patterns that convey location on scientific plots or weather maps, for instance. A speech synthesizer supplies each data point.

• **Molecules in 3D.** Blind chemist William Skawinski of the New Jersey Institute of Technology in Mount Laurel has devised a technique using laser stereolithography for building three-dimensional (3D) replicas of molecules from computer graphics. A computer directs the construction of an enzyme model, for example, from photosensitive liquid resin that is modeled by an ultraviolet laser and cured in an ultraviolet oven. Scadden calls the feat "really incredible." Building on this work, Anshuman Razdan of Arizona State University in Tempe is creating a library of 3D models for teaching

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