Implanted
Technology and Connection in the Deaf World

by

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ABSTRACT

In 1984, the FDA approved a medical device called a cochlear implant for adult use in the United States. Unlike assistive hearing technologies that came before it, such as hearing aids, cochlear implants could offer wider access to sound even to the profoundly deaf. Given adult success with the device, the FDA lowered in 1990 the required age for implantation to two years old. The following year the National Association of the Deaf published a position statement on cochlear implants comparing them to "cultural genocide."

This thesis explores two parallel stories. Drawing on interviews with implant engineers, surgeons, audiologists, and other specialists, the piece describes how cochlear implants function and how the devices have improved since the 1980s. Equally, the thesis pulls from interviews with bioethicists, deaf and hard of hearing individuals, educators at a signing deaf school, and others in the deaf community to describe the unique attributes and history of deaf culture and the changing and diverse reactions of the deaf community to this medical device.

Thesis advisor: Robert Kanigel
Title: Professor of Science Writing

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Implanted

A bow slides along a violin string: a perfect C sharp. The string vibrates. Pressure waves ripple through the surrounding air.

Some reach your ear. They lap against your eardrum, and an attached three-bone hinge passively flexes in turn. As the hinge moves, it pumps a thin, bone membrane. It's called the oval window, but you can't see through it.

The rap on the window from the tiny hinge creates a violent fluid wave. It courses along two, thirty-millimeter long tubes inside the tight curves of a snail shell shaped bone. That bone is the cochlea. Just as on the violin string, the wave creates forceful vibrations along the tubes' walls. The C sharp trembles not far from the cochlea's entrance; a lower-pitched open G vibrates further in the bone's spiraled depths.

These ringing walls push against a smaller but vital third tube, sandwiched between the other two. Inside, "hair cells" stand at attention in rows, a quiet field. The vibrating walls bear down on them and they bend—just slightly—like deflecting the top of the Eiffel Tower half an inch.

But it is enough. The deflection of the hair cell triggers a current at its base. Here, the mechanical becomes electrical. Neurons at the hair's base call out. The brain's auditory nerve listens. You hear.

At least most people do. About three out of every thousand Americans are "functionally deaf." Hearing is connection—a series of intimately tied causes and effects: an electric current created by fluid waves, set in motion by a tiny hinge, pumped by pressure waves in air. "Functionally deaf" is, medically speaking, disconnected.

Some are born this way. According to the American Speech-Language-Hearing Association, genetics accounts for almost fifty percent of children born deaf. Other causes include ear infections, ototoxic medications, meningitis, measles, otitis media (an inflammation of the inner ear), premature birth, maternal diabetes, and infections such as rubella.

Most deafness is sensorineural—meaning that the disconnect happens somewhere in the sound's delivery from inside the cochlea to the brain. This could mean damaged auditory nerves,

but most often the hair cells are the cause. Instead of standing in an orderly field, the cells knot and tangle. They never respond to the cochlea's rolling waves, and never trigger an electrical signal sent to the auditory nerve.

A cochlear implant bypasses these damaged cells. During a three-hour procedure, a surgeon expertly places the device in the inner ear, coiling a string of electrodes inside the cochlea's spiral tract. The implant can help patients with profound hearing loss, but, since the surgery destroys all residual hearing, implantation is irreversible.

In 1984, the United States Food and Drug Administration first approved cochlear implants for adult use. Eligible patients had to be over eighteen years old, and had to have lost their hearing after acquiring spoken language skills. In 1990, the FDA lowered the approved implantation age to two years old.

The next year, the National Association of the Deaf, America's oldest and largest advocacy group for the deaf and hard of hearing, published a position statement on pediatric cochlear implantation. It described the procedure as an "invasive surgery upon defenseless children" and the devices as "cultural genocide."

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There are two definitions of the word deaf. Deafness seen as a disability requires doctors to find a treatment. Deafness limits opportunities in a larger, hearing world. It can mean isolation and depression.

But, for some, the words "disabled" and "hearing-impaired" are taboo. For them, deafness is a community with its own language, history, and customs. Deafness is connection.

For many in this deaf world, tight embraces mark greetings and goodbyes with both family and acquaintances; they scoff at typical hearing people's loose hugs—their fear of touching one another. Those in the deaf world do not clap at the end of a performance, but raise their arms, waving their hands in the air. They do not toast by clinking Champagne flutes; they give their glasses a twist and bump the backs of their hands. The deaf world also has its own language, American Sign Language, that necessitates connection; grammar includes raised eyebrows and pursed lips, and arguments are always fought face to face.

Some in this deaf world argued that cochlear implant surgery was too dangerous for children. Some argued that the device did not live up to its claims. Some also argued that implantation was an attack on deaf culture.

In his book *The Mask of Benevolence* first published in 1992, Harlan Lane, a staunch and prolific hearing advocate for the deaf community, also makes the last of these claims. He rejects even a perfect cochlear implant.

"Even if we could take the children destined to be members of the African-American, or Hispanic-American, or Native American, or Deaf American communities and convert them with bio-power into white, Caucasian, hearing males—even if we could, we should not," he says. "We should likewise refuse cochlear implants for young deaf children even if the devices were perfect."

Yet few today refuse cochlear implants. In the introduction to her book *Surgical Consent: Bioethics and Cochlear Implantation*, Linda Komesaroff gives statistics. In 1990, one in ten deaf children received an implant. In 2002, this ratio became one in two. In 2007, the year she published her book, Komesaroff reported that almost ninety percent of all deaf children received implants in many countries.

An annual Gallaudet Research Institute survey of over 35,000 deaf and hard-of-hearing grade school children throughout the United States echoes this trend. Though the number of children with the devices has not yet reached ninety percent (since the school system still includes children born in the late 1990s), the percentages have already increased, from 5.3 percent in the 1999-2000 school year to 13.7 in 2007-2008.

In a 2001 Academy Award-nominated documentary *Sound and Fury*, filmmaker Josh Aronson introduced audiences to the Artinian family of Long Island, New York. In the film, the Artinians debate whether or not two cousins, Heather, age six, and Peter, age one and a half, should receive cochlear implants. "If somebody gave me a pill that would make me hear ... would I take it? No way," Heather's deaf father signs in one scene. In a much different scene, Heather's deaf mother visits an audiologist and questions if she herself might benefit from an implant. At the end of the film, Peter's hearing parents decide to give him the implant, and—it seems—Heather's deaf parents decide to forgo the procedure for both mother and daughter.

Seven years later, a teenage Heather spoke on National Public Radio's *Talk of the Nation*. She had received the device four years after Aronson filmed his documentary, and had left her deaf school behind to enter a mainstream school for hearing children. She described a "love" for her new school, but also a desire to stay in touch with both hearing and deaf friends. She also expressed her wish that she, like her cousin, had received the implant at a younger age, and thus

the possible benefits of earlier implantation. "They have an easier way to communicate," she said of hearing peers. "I wish I had that ability."

Heather's father said that his daughter was now happy with her implant, but he did not regret his decision to wait.

"We were concerned about deaf culture," he said, ". . . our legacy."

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In 2000, the National Association of the Deaf's published statement on cochlear implants changed. It no longer calls cochlear implants genocide; it simply asks parents to consider all options, doctors not to portray the device as a "cure," and the media to be more balanced in their reportage.

"Parents of deaf and hard of hearing children need to be aware that a decision to forego implantation for their children does not condemn their children to a world of meaningless silence," the statement says. "Regardless of whether or not a deaf or hard of hearing child receives an implant, the child will function within both the hearing and the deaf communities."

Jeff Bravin is a big name in the deaf cultural community, and not just because of his childhood acting career. In 1979 he starred in the television movie *And Your Name is Jonah* along with Sally Struthers and James Woods, playing a deaf boy with hearing parents for whom a misdiagnosis meant three years in a mental hospital.

Fourth-generation deaf, Bravin describes himself as an "unusual breed." "My first language was American Sign Language," he said using an interpreter, "so communication was there from day one—just as any hearing child born to a hearing family." He described his relationship with his deaf parents, learning naturally the traditions and norms of the deaf world, and following in his parents' footsteps when he attended Gallaudet University.

Bravin is now Director of Special Projects at the American School for the Deaf, the United States' first deaf school, founded in 1817. He does not believe that the devices, despite their controversial past, change the way his students interact.

He describes two girls. The first has an implant for each ear, but struggled in a mainstream school. The second moved to the United States from China in 2005, with no language skills and no implants. Though one girl has implants and the other none, the two girls helped each other to learn American Sign Language, Bravin explained, and together at the American School for the Deaf they discovered deaf traditions and history. Together, they also found deaf role models, successful teachers who showed them their deafness as a cultural difference, and not as a

handicap. The girls bonded. "They are now best friends," Bravin said. "They are from completely different worlds, but they share the same thing—they are both deaf."

Bravin's example shows that the device itself does not exclude a child from attending a deaf school, learning American Sign Language, and becoming part of a minority community.

But some wonder if the implant allows a more subtle cultural threat. The device, when performing best, effectively allows the culture of a deaf child to be a parent's choice, just as getting the implant in the first place. If a device can help a child communicate without a once necessary community, will most hearing parents choose to teach their young children a language and cultural identity different from their own? What if, in Bravin's example, the little girl with implants had performed well with the device? Would she have come to his school in the first place? Would he still consider her deaf?

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"Anyone who has traveled the highways of America and has become used to the height of normal overpasses, may well find something a little odd about some of the bridges over the parkways on Long Island," Langdon Winner wrote in his 1980 article *Do Artifacts Have Politics?* They are low, he explains, sometimes no taller than nine feet over the curbs. Like many of New York City's bridges, public parks, and roads built from the 1920s through 1970s, Robert Moses designed them. They also cover the only route from Manhattan to another of Moses's creations, the regal Jones Beach. Winner uses Moses's bridge as an example of what he calls technological politics.

"In our accustomed way of looking at things such as roads and bridges," Winner says, "we see the details of form as innocuous and seldom give them a second thought." The second thought he then makes clear is that Moses built the bridges to exclude. Upper and "comfortable" middle classes who drove cars, easily fit under the bridge; poorer urbanites, mostly black, who had to use tall public buses, were cut off.

Winner gives a wide range of examples to show that an object itself can force certain social relationships, from nuclear power (requiring government) to the design of certain buildings (unsuited for the disabled). Though Moses deliberately designed his bridges, Winner explains that social consequences of technology don't have to be conspired; they can be, and most often are, unintended.

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Today, three companies manufacturer cochlear implants in the United States: Cochlear, Med-El, and Advanced Bionics. Each of their devices consists of three major parts: a microphone, a sound processor, and an implanted receiver with electrode array. Users wear the sound processor and the microphone externally. The microphone picks up sound and the processor breaks it down into its component frequencies. Using radio waves at around 80 kHz, the processor then transfers this data through the user's scalp to an implanted receiver.

Using the latest Advanced Bionics device, the HiRes 90K, as an example, the receiver sits in a well, carved three millimeters into the mastoid bone near the base of the skull, placed far enough behind the ear to allow the recipient to wear eyeglasses or an over-the-ear sound processor comfortably. This receiver includes a magnet (which holds the external microphone in place) and a telecoil (to receive the processor's signals) in an oval, silicon housing unit. This housing unit's clear silicon tail ends in a set of 16 tiny platinum iridium alloy plates, an electrode array inserted 18 to 22 millimeters into the cochlea. The array has changed drastically from the first device, which only had one electrode. Today, Cochlear's Nucleus 5 system has 22.

The implant's array manipulates the cochlea's natural organization for determining different pitches. The microphone picks up a violin playing a C sharp, and the sound processor recognizes the frequency and activates electrodes near the cochlea's entrance. The microphone picks up an open G, and electrodes further along the array turn on. Just as in normal hearing, high frequency sounds mean electrical stimulation near the cochlea's oval window entrance, and low frequency sounds, deeper inside. Unlike normal hearing, the hair cells never move. Instead, the electrodes directly stimulate the auditory nerve.

Designing the structure of this array was one of the earliest difficulties in engineering the device. Graeme Clark is the researcher whose work in the late 1960s and 1970s led to the first cochlear implantation in 1978, which he helped to perform at the Royal Victorian Eye and Ear Hospital in Australia, and also the formation of the Nucleus company that is now Cochlear, the world's leading cochlear implant manufacturer.

Many of Clark's initial tests with electrode arrays failed. Those too flimsy would never bend around the cochlea's curved course, while those too stiff would damage the organ's fragile inner structures. As Michael Chorost describes in his 2005 book, *Rebuilt: How becoming Part Computer Made Me More Human,* Clark discovered the answer one day on an Australian beach. He attempted the procedure with various twigs and blades of grass, and a spiraled seashell. A very flexible blade curled too easily and a stiff twig never made it at all, but if the grass had a

flexible tip and stiffer base, it slid in effortlessly. Today's arrays each use a silicon version of the grass's structure, what is called differential stiffness. The flexible tip pulls increasingly rigid silicon behind it.

Though upgrading the implanted portion of the device would of course require surgery, manufacturers can improve the external microphone and sound processor, and significantly upgrade the device's programming throughout the patient's life.

Leo Litvak, an engineer at Advanced Bionics, explained these improvements. Some are for convenience, such as increasingly small processing units (from waist pouch to behind the ear), longer battery life (from hours to over a day), and a change to more durable casing material (from ceramic to titanium with a plastic cover). But Litvak's forte is creating new processing patterns—the computer representations of sound's complexities.

When sound enters the microphone, the sound processor uses a fast Fourier transform, a mathematical procedure, to sift a complex mixture of sounds into independent frequencies. The device's programming determines how to represent this mixture by selecting when and for how long to activate electrodes at various points along the array.

Litvak's 2002 MIT doctoral thesis outlines one of these strategies. At the time of his research, cochlear implant users complained that the device distorted high frequency sounds. The problem, Litvak and others suspected, was the auditory nerve. Auditory nerves send electrical signals to the brain, but they cannot send these signals continuously. Instead, they communicate in short bursts, and, after delivering each message, they need a moment to recover.

Most implants stimulated all of the nerves in a region, but this was no good. If every cell fired together, that meant every cell recovered together. For high frequencies, when the implant stimulated the nerve again, few cells were ready. Using a "dsynchronized pulse train," Litvak came up with a plan to stimulate different cells at different times, so that there were always cells ready to receive the implant's message. He successfully tested the procedure in deafened cats, and concluded in his thesis that the strategies, "may substantially improve performance enjoyed by cochlear implant users."

Now a star at Advanced Bionics, Litvak won a 2006 award from Boston Scientific for his work.

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In a bottom desk drawer in her research lab office, Dr. Konstantina Stankovic, a cochlear implant surgeon at the Massachusetts Eye and Ear Infirmary, keeps an Advanced Bionics resident

training kit. Inside is a transparent plastic cochlea in a transparent plastic block. An opening near this simulated cochlea's round window is easily accessible. Stankovic loads into "the insertion tool" a bright blue practice electrode array. "The real one isn't blue," she says, slowly advancing the tool's handle as the array slowly glides into the clear path ahead. From above, she sees a perfect blue spiral.

Stankovic specializes in otology and neurotology, which includes structures and diseases of the ear, nose, and throat. She has earned two undergraduate degrees from MIT (in physics and biology), an MD *Magna Cum Laude* from Harvard Medical School, PhD in Auditory Neuroscience from MIT, and post-doctoral training in Molecular Neuroscience at Harvard Medical School and Children's Hospital, Boston. This training allows her to treat many cases that general surgeons would never touch, and to complement her practice with research into the fundamental causes of deafness.

She describes the isolation that many of her deaf patients feel. Family and friends ignore some elderly deaf, mistaking their deafness for dementia, and even younger patients' difficulty communicating perpetually keeps them on the outside of loved ones' conversations. "This is a common problem," she says of hearing loss. "I think there is a huge potential to make a difference."

Still, at the Massachusetts Eye and Ear Infirmary, the decision to undergo this surgery is not taken lightly. A patient must see an internist, a social worker, a psychologist, the head of the cochlear implant center, and a surgeon before he (or, in the case of a child, his parents) receives approval. The process from the time the patient decides that he wants an implant to the surgery can take up to six months. "The goal of all of this is to make sure that they are good candidates and they have realistic expectations," Stankovic explains. She goes on to describe the variability in the sound quality patients perceive while using the device. "There are some outstanding performers, but we have no way of predicting who those will be."

Stankovic also understands that some considerations are not medical. She discusses deaf parents of deaf children. "Parents usually feel very strongly that they want the child to be a part of the deaf culture," she says. "They don't consider it a handicap." She rarely sees these parents.

At 7:30 on a March morning, Saint Patrick's Day, Dr. Stankovic prepares for surgery. The patient, an eighty-year-old Irish woman, wanted to wear green for the holiday and for good luck, but surgical gowns only come in blue. "We'll wear green for her," Stankovic says, pointing to her green-rimmed visor. A retired nurse, the patient lived a very active life. Though almost

completely deaf in both ears, she still wears a hearing aid in her right, a remnant of her hard of hearing days. The aid gives her no access to sound, but she keeps it anyway. As the scrub nurses prepare the surgical field, the patient waits, anesthetized and unconscious, unaware of the dialogue over her exposed left ear.

In surgery, Stankovic starts one centimeter behind the ear, making about a five-centimeter incision. After pulling back and cauterizing the protective layers covering the skull, there is very little blood. Now, she must drill. Looking through a microscope, she tours, for her, a familiar landscape. Drilling through the mastoid bone at the base of the skull, she exposes the facial recess, a triangular landscape with borders defined by chorda tympani (a nerve involved in taste), facial nerve, and ear canal. She points these out to her resident.

The facial nerve is a key landmark, but also a dangerous obstacle. It points her way to the cochlea, but, if damaged during surgery, means certain facial paralysis. Fifty thousand rotations per minute, a one-millimeter diamond burr spins as she expertly navigates this tiny world. Certain of her bearings, she exposes the bony lip covering the cochlea. Further still, the cochlea's round window appears, barely distinguishable for lay eyes even through a microscope: a slightly darker circle in a pure white wall. With a different drill she makes a tiny hole, and using a "claw tool" inserts the electrode array. It slides in with no resistance, a perfected synthetic blade of grass in a miniature shell of bone.

On an infant, Stankovic would take other special precautions, as the layers of bone protecting the brain are thinner. Otherwise the procedure is the same. An implant fitted into a child's cochlea may never need adjusting because of growth. The inner ear's tiny bone is the body's only one that is immutable. The fact fascinates her.

After surgery, Stankovic, still in her blue scrubs, reviews an X-ray just taken of the patient's head. As she zooms into the black-and-white image, it shows clearly the ear's replacement and Stankovic's skill. The receiver sits in a drilled valley, and is tied securely to the skull. Lower in the image, in the distant inner ear, she sees the electrode array—a tiny spiral.

For now, these electronics can give the patient no more access to sound than her quiet hearing aid. The device will remain off for six weeks while her body heals. When she recovers, the patient will meet with her audiologist. She will begin therapy and will work to hear again.

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The reality provided by a cochlear implant initially confuses many patients. One recipient said everyone's voices sounded like Alvin and the Chipmunks', another as if she was

scuba diving, and a third as if "a hand was grabbing" inside his head. Donald Eddington at the Massachusetts Eye and Ear Infirmary describes many patients belief that they are going to hear "Donald the Duck" or "R2D2" speech.

"After they've had the device for a few months they are pleasantly surprised that isn't the case," he said. It takes a few months, because post-surgery an audiologist must "fit" the patient's device. Usually, during a first visit, the audiologist uses a computer to systematically turn each electrode on and off, waiting each time for the patient to respond and then setting the appropriate stimulation level. Follow-up appointments over the next year adjust the implant's programming. Audiologists call this process "mapping" and use it to determine the best representations of different types of sound (conversations, music, telephone) for the individual user.

Eddington is the director of the Infirmary's Cochlear Implant Research Laboratory. In the 1970s, he led a medical computing and biophysics group at the University of Utah, one of several groups around the world that helped to pioneer the first multiple electrode cochlear implant. Today, he is one of the key specialists whom Infirmary patients must see before they get approval for the procedure. He also continues to investigate the limitations of the device and design new signal processing strategies to produce clearer hearing. Eddington describes implant users as some of the hospital's most satisfied patients—a typically "very happy group."

He says the device can provide a rich variety of information to its best performers. He tells stories of volunteers with the device who have come to his clinic for testing and could tell the difference between different graduate students' accents, and a wife that could distinguish, without looking, the difference between her husband's voice and the doctor's. But, for others, the quality is not nearly this good. "Some people have said it's like tuning the radio station a little bit off," he said. "It's just not clear enough to recognize what the person is saying."

Eddington described the clinic's usual test, where a patient must identify a spoken, one-syllable word. Cochlear implant users often rely on other cues, such as lip-reading, to help them. Without lip-reading, Eddington said, the median score for the one syllable test is usually around fifty percent, and the performance can range from 98 percent recognition to zero.

Performance variability arises in part from patient variability. Since the 1980s, tests of implanted adults have linked those best able to recognize speech with those who lost their hearing after acquiring spoken language, and those whose period between losing their hearing and receiving the implant was the shortest.

Other factors are unpredictable. For example, in the rare case that the cause of sensorineural hearing loss is a damaged auditory nerve and not damaged hair cells, no amount of electrical stimulation will lead to better hearing. Since there is currently no way to biopsy the inner ear without destroying it, physicians cannot predict beforehand whether this is the reason the patient is deaf.

Still, Eddington's clinic sees even some users performing at zero on the one syllable word test as "successful" patients. "Here, success is defined as the person communicates more effectively after the implant than before the implant," he said. He described a recent study where he followed five patients all below twelve percent in their one-word recognition scores. He looked at their ability to recognize spoken sentences—since, given the context provided by neighboring words, sentences are relatively easier to understand than a single syllable. With lip-reading alone, they successfully recognized about forty percent of the sentences. With the implant on and still lip-reading, they scored around seventy percent. "In terms of their ability to move more fluently in the hearing world," Eddington said, "They benefited tremendously."

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If quantifying and predicting the cochlear implant's performance in adults is difficult, determining the performance in children is harder still.

From 2006 to 2008, Tina Grieco-Calub, now a professor in the School of Allied Health and Communicative Disorders at Northern Illinois University, studied infants' ability to recognize words both in quiet and with background noise. She used what's known as the looking-while-listening test.

In a soundproof room, a female voice with a high, "infant-directed register" asked a child to look at one of two familiar objects (a ball, baby, shoe, or dog) projected on a screen. Using a video-tracking system to record eye-movements, Grieco-Calub could determine how long, when, and where the child looked. She compared 26 children with cochlear implants to 20 typical hearing children of about the same age, around thirty months old.

In quiet, the hearing children accurately identified the object about 85 percent of the time, and children with implants about 70 percent of the time. The reaction times differed in a similar way, with typical hearing children taking, on average, 598 milliseconds to look at the correct object and children using the device taking 858 milliseconds.

Some of the children with implants performed at the same level as normal hearing children and some much worse. Using subjects at this very young age, the study found no link

between the usual traits (such as higher residual hearing and earlier implantation) and the best performers. Given that the children could recognize the words at better than chance odds, the implants were certainly helping most children to recognize spoken language, but the study was unable to predict which factors predicted that outcome. Grieco-Calub pointed to the variability in adult implant studies adding that, when studying children, researchers must add the variability of normal child language development.

She also paralleled the difficulties in predicting the children who will best recognize spoken speech to the difficulties predicting those who might best produce speech. She described older children that visited her lab, then at the University of Wisconsin-Madison. "With some you could sit down and have a whole conversation with them. Their production was amazing," she said.

But for others this was not the case. "The implants may have been the same. They may have even had the same source of their hearing loss and their production wasn't there. They could comprehend speech and language, but they weren't speaking as well."

Ruth Litovsky the head of the Binaural Speech and Hearing Lab at the University of Wisconsin-Madison was a co-author of Grieco-Calub's project. She describes variability as the "hallmark" of cochlear implant studies. Determining the reasons for this variability, Litovsky explained, is not only important for understanding child hearing and language production, but also for clinical reasons as doctors try to accurately determine which patients will most benefit from the devices.

"You're dealing with a different brain, a brain that has never experienced acoustic hearing and you are stimulating it with electric hearing," Litovsky said of deaf children. "Not all implants are created equal and not all kids are the same . . . It's not like a factory where you have a child who is deaf, you have an implant, you put it in and the two pieces sit together beautifully."

Grieco-Calub reiterated that conveying this uncertainty is essential for the child's wellbeing. "There is this misconception sometimes that a person with a cochlear implant has normal hearing," she said. Though she believes the devices benefit children, she sees this misconception as an "injustice." "They are still not hearing 'normally.' . . . we still need to recognize that they are listening through an electronic device, a computer with limitations compared to our ears."

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"You have to look at the whole child," said Andrea D. Warner-Czyz at the Dallas Cochlear Implant Program. "It's not just what they say and it's not just what they hear, it's what they do with it and how it impacts them as a person." Warner-Czyz co-authored a study, published in the February 1, 2010 edition of *American Academy of Otolaryngology – Head and Neck Surgery*, in which she and her colleagues tried to determine the overall wellbeing of children using cochlear implants.

Warner-Czyz looked at children from 88 families from sixteen different states. She then divided this group by age of implantation into eight to eleven years old and twelve to sixteen year olds. The survey asked Likert Scale questions—that ranged from "never" to "all the time"—about physical wellbeing, emotional wellbeing, self-esteem, family, friends, and school. A question on friends, for example, asked, "During the past week did you feel different from other children?"

Overall, the quality of life ratings did not statistically differ between children with implants and normal hearing children. Yet there were statistically significant differences when researchers looked at subcategories, such as school and family life.

For example, the eight to eleven year old cochlear implant users rated quality of family life lower than the normal hearing group. This surprised Warner-Czyz and her colleagues. Her group assumed that parents' increased attention on the children, given their difference, would lead to higher quality of life ratings. "Then we wondered, is that why?" she asked. "Do they feel there is too much focus on them? Do they feel like they are a burden to their family?" Given that the questionnaires for this test were not open-ended, she cannot yet tell.

Another statistically significant result was that twelve to sixteen year olds with implants rated school life and relationships with friends lower than normal hearing children did. Though the surveys included both mainstreamed and deaf school educated children, the analysis did not break down the difference in survey results

Warner-Czyz stressed that all of these tests are difficult, again in part given the variability of users and devices. Still, in general, she believes the quality of life for most deaf children has improved over the past thirty years. Before the 1970s, she explained, doctors had to rely on parents to identify deafness, and often parents didn't realize that their child was deaf until two to three and a half years of age, the end of the critical language learning period, after which, research shows, learning a first language is difficult. Today, specialists screen 98 percent of infants before they leave the hospital in 47 states. "Now we are identifying these kids early and they are getting treatment," she said.

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In his memoir *Rebuilt*, Michael Chorost considers if he had been born a little more deaf. "I might have had a happier life," he says.

Born hard of hearing in 1964, Chorost lost all of his hearing in his thirties. In 2001, he opted for an Advanced Bionics cochlear implant. His book is equally about the device and trying to find companionship. In one chapter, he discusses visiting the "oralist" school of his childhood that did not teach or use sign language. Chorost speculates on a different life. Had his deafness been more profound or if his parents (one an audiologist) had not provided hearing aids and therapy earlier, he supposes that he would have spent his childhood in a residential school for the signing deaf.

He goes on to describe American Sign Language; since it requires face-to-face contact, he explains, it "binds its speakers together in a community of extraordinary tightness and intimacy." He looks at the rich signing deaf communities that gather in regions "seeded" by deaf schools. He wonders what he left behind.

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In a narrow hallway, hand-drawn pictures of American states hang on a wall. One shows Connecticut, a box with a tail shaded in with red crayon. A black Magic Marker dot indicates Hartford and above appears the young cartographer's caption: "American School for the Deaf, Founded 1817."

This hallway is in a portable, prefabricated building—one of several at the school. Usually, schools use such portables for overcrowding, but the American School for the Deaf's main building, Gallaudet Hall, is in fact empty. Red brick and crowned with a steeple, this was the school's first building when the campus moved to West Hartford in 1920. It now waits for a renovation that has run out of funding. The building bears the name of Thomas Hopkins Gallaudet, the man who founded this school and whose son would found the world's only deaf liberal arts university.

Gallaudet visited his parents' home in Hartford, Connecticut, on break from his divinity studies at Yale College. As he watched his siblings play among their Prospect Street neighbors, he noticed a nine year-old girl named Alice, the deaf daughter of physician Mason Fitch Cogswell. Gallaudet stooped into the sand where the girl sat, handed her his hat, and traced its three letters in the sand. Alice matched the squiggles in the ground with the hat Gallaudet had handed her. Later she pointed to herself. She wanted to see her own name.

"While this sounds like it has all the makings of myth," said Gary Wait, archivist at the American School for the Deaf, "We have every reason to suppose that this is the correct history." He describes a record of the account from Alice's brother-in-law and second headmaster of the School.

Wait's eyeglasses are similar to the round frames once worn by Gallaudet, one pair now resting in a glass case near the museum's entrance. The two men might even have shared the same sign name; one hand pulled quickly across the eyes, it now signifies not only the man, but also the world's only deaf liberal arts university. Instead, the school's students chose to highlight Wait's formal vests, pulling fingerspelled Gs (for Gary) down their chests as if to make suspenders.

"The Cogswells decided, if Alice can learn, why not other deaf children?" In one afternoon, Dr. Cogswell's wealthy friends raised enough funds to send one person to Europe to learn the techniques of the Braidwood's English school for the deaf. "Happily for us," Wait said, "Gallaudet agreed to go."

Wait described Gallaudet's first attempts to learn deaf teaching techniques from the Braidwood's school, a for-profit institution that demanded not only a five-year apprenticeship, but also a cut of the tuition charged every student taught using their system. Gallaudet only had the funding for one year in England, and the Braidwood's charge would make deaf education prohibitive for many families. Wait made the sign for frustration, placing his flattened hands quickly in front of his face, as he described Gallaudet's dilemma.

It was fortunate that the director of the French Institute for the Deaf in Paris, Abbé Sicard fled France for London in 1815. Sicard, a royalist, had come close to losing his life in 1792 during the Reign of Terror (apparently spared only after appeals from the French deaf community); he now traveled through England with his two deaf assistants, Jean Massieu and Laurent Clerc, lecturing on the French technique for deaf instruction. Sicard invited Gallaudet to return to France with him after Napoleon's final defeat—to learn at no cost at the French Institute and return to America when he wished.

One of the most famous stories of deaf history describes the birth of American Sign Language as Gallaudet's 1816 return voyage across the Atlantic. Gallaudet convinced Clerc to travel with him to Hartford to start a school. During the voyage, Gallaudet taught Clerc English, and Clerc continued teaching Gallaudet the methods of the French Institute's manual language.

This is why American Sign Language, although completely distinct from any spoken language, is more closely related in syntax to French than English.

Today, in the school they founded is a small 1815 painting, the oldest known portrait of a deaf person signing. "If you look above the distinct C, you'll see a shadow C," Wait said, pointing to a faint oil-painted arm and hand, hardly visible on the painting's dark background. "After we had the painting cleaned, I had the startling discovery that the painter was trying to show movement . . . We think that this was the original sign name for Laurent Clerc."

On April 15, 1817 Clerc and Gallaudet started the American School for the Deaf in Bennett's City Hotel on Main Street in Hartford. A fireproof cabinet now contains the School's "admission's register number one" which has Alice Cogswell's name entered in neat script on the first line of the first page. The 1817 class of seven students included deaf artist John Brewster, Jr. and Abigail Dillingham, the first American deaf person trained as a teacher.

The museum itself was once the Principal's Residence, built in 1926 after the school's 1921 relocation to West Hartford. Wait spends most of his day on the second floor, sitting at an 1863 writing desk constructed by student Samuel Thomas Greene, who later founded the Ontario School for the Deaf. The desk is one of many antique projects created by American School for Deaf alumni—the products of the school's vocational training program that started in the 1820s, the first such program in Connecticut. For girls, training included homemaking skills and tailoring; boys learned carpentry, shoemaking, and later printing, skills to give them employment and opportunities in a larger world.

This tradition continues. Jeff Bravin's office is in the school's vocational building. As its director of special projects, his job includes managing PrintWorks, a company run by students that teaches printing, graphic design, and color digital publishing—a modern opportunity for connection and a useful skill in the larger world.

"Many children born into hearing families, have no communication, no language at an early age," Bravin said. He believes these "deaf-of-hearing" children especially benefit from deaf schools. Though public schools might have a resource room where students can interact with a few other deaf children, a deaf school, he believes, can provide more. "It's different here," he said. "They are interacting with 200 deaf students. They have role models that can foster growth."

Bravin also believes deaf schools can provide resources harder to find at a public school. "If parents choose to enroll their student in a public school, they have to fight to make sure that their child receives all of the support services needed." These services include interpreters, note-

takers, speech and audiological training. "But parents often don't know where to start and don't know their rights . . . . A school for the deaf, the support is already there."

The Gallaudet Research Institute also releases statistics on students' educational settings. In the 1999-2000 academic year, 28.7 percent of students attended a special school or center such as the American School for the Deaf. In 2007-2008, this number was 24.3 percent. Over the same period, those in programs where teachers use American Sign Language dropped—from 54.8 to 46.3 percent.

"In general, all over the United States, student populations in schools for the deaf are declining," Bravin said. He described the inconvenience of such schools in larger states such as Texas, where parents might drive for eight hours to go to their "local" deaf school, forcing them to keep their children in dorms. "More and more parents want to have their child close to home. I don't blame them."

There is another, medical reason for the decline. With a 2009-2010 population of 193 students, the American School for the Deaf's enrollment is less than half of what it was in the 1960s. This drastic change is likely the result of a vaccine. A rubella epidemic in pregnant women between 1963 and 1965 increased the American deaf population by between 6,000 and 8,000 people. Many called it the "rubella bulge," the deaf equivalent of the baby boom. "We now have a much smaller population," Bravin said. "The schools have declined, but the numbers have been more stable than they were."

Alyssa Pecorino, student support services coordinator at the school, still worries about the future. She is candid with her American Sign Language class. "Deaf schools are struggling and that is an understatement," she said, describing annual layoffs and closures. Unlike some of its sister schools, the American School for the Deaf benefits from the additional income provided by outreach services and special programs. Still, Gallaudet Hall's empty corridors show the school's need for more support.

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Though Pecorino works at this deaf school, she never attended one. As a child, she wasn't deaf—her father scolded her if she even used the word. Yet she knew that she wasn't hearing. She coped with hearing aids throughout her mainstream schooling. But after she graduated from college, her hearing continued to deteriorate, and communicating with her family grew increasingly difficult. She also grew deaf in another way. She started dating a culturally deaf man, a recent graduate of Gallaudet University, and made friends in the deaf community.

Pecorino's increasing silence pulled her in two directions. She debated getting a cochlear implant to reconnect to the hearing world, but also worried that it might separate her from a minority culture that welcomed her.

She has now had an implant for eleven years. She recalled some initial reactions to her decision. "There are people who would comment, 'Oh, you're denying who you are. Why did you get it, cyborg?'" Yet as the device is now relatively common, even in culturally deaf adults, such comments have become something of a joke. Pecorino sees them as manifestations of an old fear from older deaf generations. "They are kidding," she said, "but at the same time they are trying to hurt you."

As student support services coordinator at the American School for the Deaf, a job that requires disciplining teenagers with behavioral problems, Pecorino isn't easily offended. She thinks the implant—or the choice it presented—helped her to more fully recognize her deaf cultural identity. She continues to work at a deaf school. She promotes deaf community events, like productions from the National Theatre of the Deaf. She teaches six community sign language classes each year. Though, before, she never went without her hearing aids, she spends large parts of her day without her speech processor connected. She says it helps her to think.

Pecorino believes she benefits from the device, which allows her to communicate with her hearing family. Still, she calls her decision a "very personal choice," and never advocates for others to get implanted. "I would get labeled as a cyborg pusher," she jokes.

Parri Tantillo has been called worse. She described sitting at a booth at a deaf conference in 2008, where a woman came up to her and called her evil. Tantillo works for Cochlear Americas, which controls over 65 percent of the worldwide market share for the device. She holds question and answer sessions, meets with implant candidates to discuss concerns, and informs new users about support services. She also travels to deaf community events run by deaf cultural institutions such as Deaf Nation and the National Association of the Deaf. For many of these, she is placed at an exhibit hall table with information about the devices—normally at the back, and normally near deaf religious organizations. "I think they figure they'll be nice to us," she said.

"I understand the concern about deaf culture going away and I believe that it is a culture," Tantillo said. "I don't think cochlear implants started that shift." But she recognizes that others do. She responds politely to comments from concerned deaf community members and from protestors, whom, she notes, are often American Sign Language students who can hear. As

an implanted deaf woman she finds insults from these hearing students most frustrating. "I'm still deaf," she said. "Take off my sound processor and I can't hear anything." At the same time, Tantillo says, some culturally deaf are starting to approach her for a different reason—to ask about implants for their deaf children.

Pecorino described these pediatric cochlear implants as the current controversy in her community. Children don't have the information or ability, she noted, to make the choice for themselves. Asked if she would opt for the surgery, if she gave birth to deaf children, she was certain of her preference. "I would want them to be a little bit older so that they could understand," she said. Despite the research that earlier implantation might lead to better speech understanding, Pecorino called infant implantation unnecessary. "This, to me, is almost like cosmetic surgery," she said. "There is nothing wrong with my kid."

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In *The Mask of Benevolence: Disabling the Deaf Community*, republished in 1999, Harlan Lane focuses on a different part of deaf history. Besides authoring the 1991 National Association of the Deaf's statement on cochlear implants, Lane, a MacArthur Fellow and professor of psychology and linguistics at Northeastern University, has written several books on deaf culture, deaf historical figures, and American Sign Language. Lane places cochlear implants in a tradition of other "cures" presented to this community.

In a chapter on heroic treatments, readers meet Jean Marc Itard, resident physician at the Paris school for the deaf. After forcing students to learn without sign language failed, Itard attempted to cure pupils' deafness by piercing their eardrums, exposing them to leeches, and fracturing their skulls with hammers. "Whatever they believe," Itard wrote in 1853, "deafness is an infirmity and we should repair it whether the person who has it is disturbed by it or not."

Lane also introduces a lesser-known side of Alexander Graham Bell. In his 1883 *Memoir Upon the Formation of a Deaf Variety of the Human Race*, Bell presents data from deaf schools throughout the country, including the "American Asylum in Hartford," then 66 years old. Intricate trees growing black and white circles, charts warning of these "undesirables" tendencies to intermarry, cover several pages. Bell championed preventative measures. Residential schools must close, he said: they taught deaf children their own separate language; they kept them in communities segregated from hearing people; they led to alumni associations and adult social intercourse.

Though certainly with a different perspective, Bell foresaw today's debates about deaf schooling; he championed mainstreaming students, having hearing and deaf students learning alongside one another. He also engendered another schooling debate that preceded mainstreaming—the choice between manual instruction in American Sign Language or oral in English. A leader of the oralist movement, Bell pushed for deaf children to abandon manual communication in favor of speech and lip-reading.

Some oralist deaf schools bound children's hands, forcing them to communicate with speech or not at all, and punished them if they snuck away to sign in secret. Other schools made children learn language by feeling hearing teachers' throats.

Lane believes that this disconnect between expectations and speech production still exists today, and that the implant still sacrifices many children's wellbeing. "The main benefit sought, ability to communicate orally, is rarely achieved with children who have never heard spoken language," he said in an email. "The research literature is quite small, it is published in second-rate journals and leaves unclear whether any children have acquired spoken language thanks to the implant." He also points at what might seem a current manifestation of the oralist movement, "Finally, the routine practice," he said of the speech training children receive, "urges the parents not to allow their child to sign . . . . Since those children cannot learn ASL and do not yet know English they are left language less for some time if not indefinitely until as adults they make their own choices."

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A Massachusetts Eye and Ear Infirmary website describes the Infirmary's pioneering advances in cochlear implant technologies, and adds what seems a testament to their achievements. "Cochlear implants have revolutionized treatment of nerve hearing loss . . ." the site says. "Today, schools for the deaf are closing as the direct result of success with cochlear implantation in children."

Pecorino watches as these schools close. "I don't consider it the sole reason," she said of the device. Instead, she places cochlear implants in the context of a changing view of disability education. For many children, cochlear implants provide enough hearing to make public school feasible, but Pecorino points also at the legislation and the mainstream perspective, that defines it as preferable.

The 2004 U.S. Department of Education's Individuals with Disabilities Education Act (IDEA) was written to protect deaf and hard of hearing children. But Pecorino points to the Act's

definition of ideal, the "least restrictive" educational environment. "To the maximum extent appropriate," the Act says, "children with disabilities . . . are educated with children who are not disabled."

"They are pushing for deaf students to go to a mainstream school . . . .You have to fight to get a kid into a deaf school," Pecorino said. "Most hearing parents are never going to do that." She noted what she sees as a great difference between the deaf community, and other groups that label themselves as disabled, for example, the blind community: "We want the choice to be separate. We want the option to go to a public school, but also a school for the deaf."

Again, though Pecorino does not blame the device alone for deaf schools' troubles, she explains that pediatric cochlear implants do change deaf education. One particular difficulty is a change in a school's teaching methods. Traditionally, deaf schools used either entirely manual language or entirely oral instruction. Yet the presence of children with cochlear implants makes this exclusivity difficult. In a classroom that has both deaf children and assisted hearing children trying to develop aural skills, instructors must provide speech and signing. This is complicated since the structure of spoken English and American Sign Language differs greatly—it's almost like speaking English while simultaneously writing the French translation—and some teachers argue detrimental to the learning of either language.

"There is a big controversy over that," Pecorino says. "Do you teach using ASL and then you go over to voice? Do you use both at the same time?" At the same time, it creates a difficulty in schools that traditionally hire their own graduates. "Then what do you do if the teacher is deaf?" she asks.

Asked if this problem already existed when children first started using hearing aids in deaf schools, Pecorino describes what she sees as the major difference between the two technologies: "with the implant, the expectations are that much higher." She described parents' drive, given the surgery and therapy required to use the device, to see their children understand and produce speech.

But like Bravin, Pecorino doesn't see the devices really influencing the way her students interact with one another. Though cochlear implants may allow the choice to remove a child from the deaf world, the implant itself does not bar a child from learning deaf history, language, and customs. Just as it is easy to conflate deafness with disability, it's easy to conflate implantation with removal from the deaf world.

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What if one day the devices are working perfectly in almost every patient? What if researchers develop a way to do more—to give deaf children natural hearing? Since many hearing parents currently do not feel the responsibility to teach their children the customs and language of this minority culture, as the devices continue to improve, one wonders if this has any chance of changing.

Jeffrey Borenstein a program leader in the Biomaterials and Tissue Engineering laboratory at Draper Laboratories is working on this next step. If cochlear implants can approximate hearing, gene therapy may one day restore it altogether.

"Molecular biology is rapidly advancing in terms of the ability to regenerate hearing," he said. "It's something that even a few years ago people thought was going to be extremely challenging." He devotes his research to that ongoing challenge. Though molecular biologists and geneticists have not yet developed the drug, Borenstein and colleagues have already created the tool that might administer it—a micromechanical pump that has successfully delivered test drugs to guinea pig cochlea without damaging the organ's fragile inner structures.

In a microliter balancing game, the pump must remove exactly enough fluid from the organ to equal the volume of the drug entering it. "Everything has to be done very delicately and very carefully," Borenstein said. Depending on the drug, such a device could help stop hearing loss in those with deteriorating hearing, or perhaps restore damaged hair cells entirely. "If a drug comes out that can completely regenerate lost or damaged hearing then the sky is the limit," he said.

Still, Borenstein sees existing treatments as a high bar to reach. "The cochlear implant is an incredible advance, a towering achievement of technology to help people," he said. "We want to build on that."

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When asked about the acceptance of new technologies, Erik Parens, a senior research scholar at the Hastings Center in Garrison, New York used an example from genetics. When geneticists first contemplated the theoretical possibility of modifying the germline—the genetic material passed from parent to child for generations—many argued that they never should. Yet once it became possible to do that and healthy babies were born, he explained, the controversy subsided. "It's easy to reject a terrible technology; it's harder to reject a good one."

As cochlear implant manufacturers work to improve their already popular device, the deaf world is certainly divided about its implications. "Deaf people aren't any more monolithic

than Jewish people, black people, or bicycle riders," Parens said. He believes disability rights movements are changing in ways similar to the feminist movement in the late 80s—a move from a unified, but simplified, identity to a more nuanced understanding of the group's diversity.

He also believes that this first stage was necessary for the second—without realizing that there is a deaf culture, no one can acknowledge the multiple perspectives within that culture. "Yes, it's possible to have a great life with a trait like deafness," he said, "and, yes, deafness does limit opportunities . . . for oneself or for one's child."

Parens discussed other cultures that have disappeared, for example, the oral culture the West enjoyed before the time of writing; he laments that this culture has died. He also laments the warnings of deaf culture's own decline. "We can hope only that in its place, children born deaf will be able to have other opportunities," he said.

Choices about technology shape social relationships. Cochlear implants are bridges to connect children to a larger hearing world. Yet, when children receive these devices but no knowledge of the deaf world, its language, and its culture, cochlear implants can cut them off from it.

"You need these two lenses, the social and the medical, but we're not very good at this," Parens said. "We're not good at holding two ideas in mind at once, but we really need to."

Some in the deaf and hearing worlds trust that cochlear implants will provide ever-greater opportunities to profoundly deaf children. Some stress that one of these opportunities must always remain sharing in a unique culture. There is concern, but also hope.

Before moving to Massachusetts for her current job in Cochlear's New England office, Parri Tantillo worked at a summer program in Colorado specifically for children with the devices.

She described her favorite time as 'lights out' right before sleep. Though campers spent the whole day singing and shouting to develop their oral and aural skills, just before bed their speech processors came off. In the shadows of the darkened cabin, she witnessed the children's bilingualism. "Everywhere," she said, "you see hands."

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