

CHAPTER 2

FROM CHARITY TO INDEPENDENT LIVING

In the fall of 1962, James Meredith, escorted to class by U.S. marshals, integrated the University of Mississippi. That same school season, a postpolio quadriplegic named Ed Roberts entered the University of California at Berkeley. Just as surely as Meredith ushered in an era of access to higher education for blacks and a new chapter in the civil rights movement, Roberts was more quietly opening a civil rights movement that would remake the world for disabled people. The disability rights movement was born the day Roberts arrived on the Berkeley campus.

While Roberts's activism would be shaped by Berkeley, it was first formed in the experiences of being disabled as a teenager—after growing up with all the promises of a full life that are the birthright of the nondisabled. In 1953, polio swept through the modest frame home of Verne Roberts, a second-generation railroad worker, his wife, Zona, and their four sons.

Health authorities quarantined the Robertses' house in Burlingame, a working-class town twenty miles south of San Francisco. Everyone would recover from the virus except for fourteen-year-old Ed, the oldest child. He had been a playground rat. He had played quarterback on the football team. He had shagged flies for Billy Martin, the New York Yankees infielder who returned home to northern California in the off-season. Now Roberts, unable to move more than his head or even breathe on his own, hovered near death in a hospital.

Roberts spent the first year of his illness in a dreary county hospital, confined to bed, never allowed to sit up in a wheelchair. Because the muscles that worked his lungs had been paralyzed, he could not breathe for long on his own. He spent eighteen hours a day in an eight-hundred-pound iron lung. It was yellow, alien looking, and as big as a telephone booth. He lay on his back in the tank, which enclosed his entire body except his head. The lung chamber created positive pressure from a bellows powered by a small electric motor. The uniform pressure over his chest, thorax, and abdomen forced Roberts to inhale air through his mouth. The machine became the boundary of his childhood. During the day, he could go up to six hours outside the lung by "frog breathing," swallowing deep gasps of air to fill his lungs.

Roberts saw himself as a "helpless cripple" overwhelmed by depression, powerlessness, and self-hatred. He asked his parents if he would ever go to college, marry, or hold a job. The answer, based on what doctors, nurses, and counselors had said, was always no. It would have been more humane, a doctor had told his mother, if the high fever of the polio had killed him quickly. Instead, the doctor said, Roberts would live as a sickly "vegetable" for the rest of his life. Roberts had no reason to think that the doctors were wrong. His decision was to attempt suicide by refusing food, in defiance of his private-duty nurse. His weight plummeted from 120 pounds to 50 pounds in seven months. The day the nurse left, he started to eat again. It was his first act

of self-empowerment, albeit a subconscious one. No one would tell this "helpless cripple" when and what to eat. He would decide for himself.

After twenty months of hospitals, he moved back to his room in the house in Burlingame. The iron lung moved with him. Roberts attended school, via telephone. His new classmates (he was now two years behind) sat at attention at their desks at school. Roberts, isolated, listened over the phone, often while lying in the iron lung. When students answered a question, they would pass around the microphone to speak to the classmate they had never seen. Before his illness, Roberts had been, at best, an indifferent student. Homework was boring. He had been slow to learn to read. But from his iron lung, he realized that education would be his power. His mind, he knew, was the one thing that had not been weakened by the illness. As he got healthier, there was no reason—other than his own embarrassment—to keep him from school. He returned, in a wheelchair, for his senior year of high school.

Shy and ashamed of his crippled body, he had rarely ventured outside his home. Over time, he had come to accept his disability, which now was central to his identity. Some regarded him as a freak in a wheelchair, the poor boy in the machine. Yet he had proved wrong all the doomsayers who had thought him better off dead. He had a different life, but it was an okay life. Disproving all those experts had given Roberts a growing sense of his own power. His first day back at school, too, had been a revelation. As he was lifted from the car, he had felt the staring eyes of his schoolmates. Staring was what he had most feared. But the stares that day were not looks of disgust. Those who were discomfited had averted their eyes. Instead, these were stares of fascination and excitement, as if Elvis Presley had suddenly descended upon the school. "It was like being a star," recalls Roberts. "So I decided to be a star, not a helpless cripple."

Despite his good grades, the school principal, a humorless

bureaucrat who did everything by the book, refused to give Roberts his diploma because he had not completed the driver's education and gym requirements. The principal got backing from the assistant superintendent of schools, but Zona Roberts fought back. A former labor organizer, she raised hell, complaining all the way up the line to the school board. Finally, at her insistence, Roberts's physical rehabilitation sessions were counted as physical education, the driver's education requirement was dropped, and Roberts got his diploma. For a disabled person growing up, says Roberts, to have "parents willing to fight for you and include you in that fight" is "the most important skill you can learn to be successful." This was an early example of how only harsh attitudes of others, not his own physical shortcomings, would threaten to hold him back.

After high school, Roberts spent two happy years at San Mateo Community College. Thirsting for more education, he planned on applying to the University of California at Los Angeles, one of four U.S. universities at the time that had special programs and accessible campuses for students in wheelchairs. UCLA had set up a disabled students program for disabled World War II veterans. Roberts, as a disabled man, had been thinking practically—in terms of wheelchair access and a school ready to admit him despite his disability. But Jean Wirth, his academic adviser at San Mateo, insisted that he do what any other student would do and set his sights on the best, not the least restrictive, school. She talked him into applying to the University of California at Berkeley, which had a superior reputation in political science, the area Roberts wanted to study.

But California's Department of Rehabilitation refused to pay for his four-year college education, as it did for other, less disabled students. Roberts's counselor, who had a slight limp, ruled that spending money on Roberts would be wasted since it was "infeasible" that he could ever work. San Mateo's president, the dean of students, and Wirth appealed, arguing that Roberts

had excelled at the community college and deserved the chance to go on. When they were rebuffed, the school officials took Roberts's case to the local newspaper, and eventually the state agency was forced to relent in the onslaught of negative publicity. Roberts had learned another valuable lesson: the press was willing to champion the cause—even if overdramatically—of a worthy "cripple."

Even then, Roberts still had to convince officials at Berkeley to admit him. "We've tried cripples before and it didn't work," one Berkeley dean explained matter-of-factly to Roberts. Practically speaking, he was correct. The classrooms were not accessible, and the library and the cafeterias had steps. But Roberts had sidestepped this problem at San Mateo by relying on attendants or friends to lift him out of his wheelchair and carry him into classrooms. The bigger problem at Berkeley was where to live. No dormitory had floors strong enough to take the weight of the eight-hundred-pound iron lung.

But another thing Roberts had learned was not to stop at the first roadblock. He knew he had to keep searching until he found a sympathetic person who was open to bending the rules. Roberts found one in Dr. Henry Bruyn, the director of student health services. Bruyn offered a solution: Roberts, with his iron lung, could move onto the third floor of the university's Cowell Hospital. Living in the student infirmary, making it a one-man dormitory, was not exactly the college experience Roberts had in mind. But it was a way onto what had been a closed campus. As Berkeley tried its experiment, a local newspaper wrote about Roberts in a story with the headline **HELPLESS CRIPPLE GOES TO SCHOOL**.

At Berkeley, Roberts needed someone to push his wheelchair and help him get dressed and eat. Sometimes a friend helped willingly. But for the most part, he hired attendants, including sometimes his brother Ron, also a student at Berkeley. State funding paid for the attendants. California had the nation's first

such program. "It wasn't inexpensive, a couple hundred dollars a month," says Roberts. "But as it turns out, it was a real breakthrough." Money, Roberts suspected, had been the real reason it had been deemed "infeasible" for him to attend Berkeley. Education at San Mateo had been inexpensive: he had lived at home in Burlingame and tuition at the junior college was cheap. For a quadriplegic like Roberts, joining the nondisabled world would sometimes require extra spending.

Roberts could stay away from the iron lung for up to several hours at a time. "That was enough time to go to classes and even go out and drink a little," he recalls. Most buildings were accessible, but he had to find back doors and circuitous paths without steps to the elevators. There were innovations to keep up with classwork. He could move the pages of a book, for example, with a stick that he clenched between his teeth. He read while lying on his back in the iron lung. The book slipped into a reading stand on the mirror one foot above his head.

Getting onto a vibrant college campus was a liberation. He had the typical college experiences of the 1960s: he found intellectual discussion exciting, and he experimented with drugs and sex. Each typical college experience pushed him farther. By 1967, Roberts's mother, Zona, had moved to Berkeley to take classes and be near her son. Judy was her neighbor and a student, too. Judy, recently abandoned by the husband she had helped through medical school, and Ed would engage in long discussions of their vulnerability and their feelings of having to fight stereotypes to win opportunities. Soon, their neighborly relationship turned into a romantic one. Roberts was dependent on someone, often his mother or brother, to push him in his wheelchair. A new innovation, a wheelchair powered by a twelve-volt battery, was on the market. But rehabilitation counselors had told Roberts that his weak hands could never manipulate the joystick control. Motivated by love and a need for privacy, however, Roberts learned to navigate one with only an hour and

a half of practice. The power wheelchair represented independence. For the first time since the polio, Roberts was free to move when he wished to move, to go where he wished to go, anytime he wanted.

Roberts was alone on the empty wing of Cowell, but word of his experiment traveled quickly. Soon the university began admitting other physically disabled applicants. The first, the following year, was John Hessler, who had heard about Roberts from his physical therapist. A lanky six-foot-seven-inch quadriplegic, Hessler had broken his neck in a diving accident. Roberts, Hessler, and the other disabled students who were soon to join them got caught up in the political upheaval of the times, which burned intensely on the Berkeley campus in the Free Speech Movement, the anti-Vietnam War protests, and other causes. Roberts watched and learned from the civil rights movement and the nascent women's movement. Women rejected that "anatomy was destiny" and were struggling to control their bodies. Disabled people, too, were questioning the medicalization of their lives. Particularly, Roberts noted how feminists used stereotypes about them—as the weaker, milder sex—to their advantage. The women would let their opponents fall into such tired assumptions, then catch them off guard with the force of their anger and the unassailable correctness of their demand for equality. Roberts saw that he, too, could use the charitable and protective instincts of his enemies. When someone saw a severely disabled man and felt compelled to help, Roberts would use that compassion as an opening to blast away at the low expectations, including the assumption that he would never work or could not get around a campus.

Roberts finished his undergraduate degree, got his master's degree in political science, and began work on his doctorate. By 1967 there were twelve severely disabled students living in Cowell. They called themselves the "Rolling Quads." In late-night bull sessions on the hospital floor, Roberts and his friends,

in their wheelchairs and iron lungs, would strategize constantly about breaking down the common barriers they faced—from classrooms they could not get into to their lack of transportation around town—and dissect the protests for self-determination of minority students.

In 1968, the dormitory became a formal program run by the state department of rehabilitation. When one counselor tried to evict two men from Cowell, complaining about their low grades, the rest of the Rolling Quads rebelled. "She wanted us all to get A's and to carry a certain number of credits," recalls Roberts. Some of the men were moving through Berkeley slowly, either because their disabilities made it hard to study or because they wanted to delay the inevitable departure from this rarest commune of like-minded brothers. But the counselor was threatening to cut off state funding for those who did not follow her instructions. And to justify the eviction of the two men, she brandished the bureaucratic label of "infeasible" for work. "Nobody was going to threaten our independence, or the program itself," says Roberts. So he led a rebellion, petitioning university administrators and appealing to Berkeley's liberal student body. It was unfair, he argued, for the freewheeling campus to apply stricter rules of behavior to a pocket of disabled students. Thinking back to his own fight to get into Berkeley—and then the protest movements he had seen on campus—Roberts put in telephone calls to the local newspapers, radio, and television stations. "We haven't had a villain like this in a long time," one reporter confided to Roberts. Other students at Berkeley offered words of encouragement on the street. Within a few weeks, the counselor was reassigned.

Back in Cowell, the late-night discussion sessions focused on total self-sufficiency. The Rolling Quads wanted to be their own counselors, or case service managers, so they would never again have to kowtow to a bureaucrat who controlled their funding. They needed to know how to get a job on their own, so they

would not become dependent on any state program. They talked about whether the know-it-all assumptions of their rehabilitation counselors were motivated by a need to control their clients if for no other reason than to make sure their own jobs did not become obsolete. The Rolling Quads realized that they would have to think of themselves as consumers of state services, not as clients.

The next battle would come the following year, when the city of Berkeley was renovating the main shopping street south of campus. Curb cuts, at that time, were not a standard part of street design. Because their wheelchairs could not ride over five-inch curbs, Roberts and his friends rarely left campus. But eight members of the Rolling Quads showed up at a city council meeting—eight wheelchairs in one room, Rolling Quad Donald Lorence would explain later, is a dramatic statement in itself—and won a commitment of \$50,000 a year to ramp city streets. From these seemingly small victories emerged a sense of political power.

From Campus Life to Independent Living

It was about this time that the idea of living in Cowell began to get stale. Residing in a hospital still stigmatized the Rolling Quads; they were students by day and patients by night. And that was exactly the image they wanted to erase. Despite their polio or spinal cord injuries, they were as healthy as other students on campus. The original idea was to find an expansive communal house off campus, but some members balked. Independence meant having choices about where to live and not needing to live always with other wheelchair users. They could not, after all, spend their entire lives together as part of some sort of disability frat house. Yet, finding apartments that could be made accessible would be a herculean task. Two students had already tried to move out of Cowell, but only one had succeeded

in finding a wheelchair-accessible apartment. The other had returned to Cowell, discouraged. Nevertheless, with their new sense of collective power, the Rolling Quads began planning to set up a support group to help each other live independently. An important break would come from an old Roberts connection: Jean Wirth, his counselor at San Mateo. Wirth had started a program there to cut down on the high rate of black and Hispanic dropouts. Traditionally, dropping out was seen as an academic problem. But Wirth understood that often, particularly with her minority students, it was the problems of everyday living that led to school failure. So Wirth asked other students to be peer mentors. If a minority student was about to quit because he or she had no transportation to school, the mentor arranged a carpool. If the student could not afford school, the mentor helped find a job. Wirth's College Readiness Program worked so well that a federal education official asked her to come to Washington to try to replicate the program on a national level. In 1966, at Wirth's request, Roberts flew to Washington to help her write provisions to include disabled students among the listed minorities.

Wirth and Roberts specified that the disabled students' antidropout programs were to be run by disabled people whenever possible. Since this provision was little known and there were only a handful of other schools with special programs for disabled students, the Rolling Quads were virtually assured that their grant proposal to Washington would be received favorably. The Department of Health, Education and Welfare speedily approved \$81,000, and the university kicked in \$2,000. By the fall of 1970, the Physically Disabled Students' Program, or PDSP, as it was known, was open for business in a newly ramped office on campus.

Roberts and his colleagues drew on their own experiences to figure out what was needed to live independently. In essence, PDSP was Wirth's antidropout program for minorities, but it

was applied to disabled students. The PDSP hired disabled counselors who would scope out available and accessible apartments for people in wheelchairs. They put together a pool of potential attendants, who would help prepare meals, push wheelchairs, and do whatever else was needed to help the students. In Berkeley, where people came for the countercultural life-style, it was easy to find attendants who would work odd hours, even if the job was often difficult.

Wheelchairs were a major obstacle to independence. They had been invented for people living at home or in institutions. They had not been constructed sturdily enough for the vanguard of radicals who were redefining what it meant to be paraplegics and quadriplegics by zipping around the spread-out Berkeley campus. Consequently, Roberts and his friends found that their wheelchairs broke down frequently, an event that could keep a student out of classes for weeks. So PDSP set up its own wheelchair workshop, staffed twenty-four hours a day by the self-taught band of wheelchair wizards, who were soon tinkering with their own designs for a better, stronger wheelchair. Others would learn the latest designs to modify cars and vans so that those unable to use their legs could work the brake and gas pedals with their hands. The Rolling Quads also ran PDSP's advocacy department, walking students through the maze of red tape and bureaucracy that accompanied attendant-care funding and other benefits and services.

The student program was radical. The medical model of disability measured independence by how far one could walk after an illness or how far one could bend his legs after an accident. But Roberts redefined independence as the control a disabled person had over his life. Independence was measured not by the tasks one could perform without assistance but by the quality of one's life with help. The health care system offered only custodial help. Roberts rejected this in favor of innovative self-help and group organizing. Disabled people themselves, the

newly christened "independent living movement" assumed, knew better than doctors and professionals what they needed for daily living. And what disabled people wanted most of all was to be fully integrated in their communities, from school to work.

Independence. Self-sufficiency. Mainstreaming. Disability as a social problem. These were the principles that guided the PDSP and the disability rights movement of which PDSP was the leading edge. As the program grew, it soon became clear that the fight for rights had to embrace a wide range of disabilities. Traditionally, various disability groups worked separately for their own members, with little sense of common purpose. Even the Berkeley program was for "physically" disabled students and was run by people in wheelchairs. But shortly after it opened, PDSP started getting requests from blind students who saw the similarities in their own struggles for independence. The attendant referral service, for example, was expanded easily to include a pool of readers for the blind. It was not lost on Roberts, who was studying community organizing, that political power expanded with coalition building.

When the PDSP started, John Hessler, Berkeley's second quadriplegic, had gone off to France to study. But Roberts wrote an airmail letter asking him to head the new students' program. Hessler understood that something big was starting and wanted to be part of it. He returned to Berkeley, even buying a modified van. It was common for paraplegics to drive cars and vans with brakes and gearshifts they could move with their hands and arms. But even for a grand thinker like Roberts, the sight of a quadriplegic like Hessler, with his limited arm strength, moving such levers, was mind-boggling. Hessler's driving was so impressive that he would show off his van to new disabled students the program was trying to recruit.

There had been a few other college programs for disabled students. The University of Illinois had been the first, setting up a similar but less ambitious program in 1950 to help disabled

veterans returning from World War II. By 1961, there were 163 disabled students, 101 in wheelchairs. Students got the campus ramped, had their own fraternity, and published an annual magazine. A fleet of buses equipped with hydraulic lifts made an hourly route around campus and to shopping spots. There were separate wheelchair sports teams, including softball, as well as a cheerleader squad of women in wheelchairs. There were even wheelchair square dances. Although people disabled by polio would eventually go to school there, most at Illinois were less disabled than those at Berkeley, and few of the Rolling Quads would have qualified for the Illinois program, which required students to be able to fend for themselves, without attendants. Nor did the Illinois program—which was run by university officials—incorporate the self-help approach of the Berkeley students.

The Center for Independent Living

The PDSP in Berkeley was an instant success. A staff of nine full- and part-time workers quickly had a list of one hundred student clients. Disabled students moved out of Cowell quickly and succeeded in school. But from the beginning there was one problem: the nonstop requests for the same help from disabled people who were not students. Staffers at PDSP rarely turned anyone away. But by spring, they found they could not keep up with the needs of the students and others as well. That May, Roberts, Hessler, and the other PDSP leaders got together to discuss how to set up a parallel program for nonstudents. The idea for the Center for Independent Living was born.

Incorporated in the spring of 1972, the Center for Independent Living—or CIL, as it was known—would work on the same principles as the disabled students' program. It would be run by disabled people; approach their problems as social issues; work with a broad range of disabilities; and make integration into the

community its chief goal. Independence was measured by an individual's ability to make his own decisions and the availability of the assistance necessary—from attendants to accessible housing—to have such control. Unlike the student program, which had modest resources, CIL operated on a shoestring. The student program donated office space—a large closet—supplies, and some secretarial help. A door balanced on a small table became the center's desk. Roberts, cofounder Phil Draper, and others put aside 10 percent of the pot of their occasional Friday night poker games to keep the center running. A donated Volkswagen van became the center's transportation program. People in wheelchairs could not get onto city buses or into taxis. The van took them to jobs or around town to shop or play. Crucial grants came from Washington and the university. But the money would stop and start the first few years, at times forcing the center to shut down until the next grant came in.

Roberts took over as head of CIL in February 1974, a job he held for eighteen months. He had left Berkeley briefly to teach community organizing to black residents of East Palo Alto. Like Hessler in France, he, too, had felt a gnawing sense of missing something important back on the Berkeley campus. It seemed time to use his expertise as an organizer to help his own people. He started talking more explicitly of disability being a civil rights issue, although there was resistance to drawing such a bold parallel with the problems of black Americans. "We were talking about self-empowerment, self-hatred, and discrimination," Roberts says, "all the same issues." The center's extraordinary new grant writer, Joan Leon, raised a phenomenal \$1 million, and the program's financial picture brightened.

Then, in 1975, California's new governor, Jerry Brown—at Roberts's suggestion after he took Brown on a tour of CIL—appointed Roberts the director of the state Department of Rehabilitation. Roberts delighted in the irony of being the chief of the agency that a decade and a half earlier had deemed it "infea-

sible" that he would ever hold a job. Now he was about to be married to Catherine, who had once been his physical therapist. Starting a family—the couple was soon to have a son, Lee—only underscored for Roberts the silliness of a system that tried to write off people based on the severity of their disability.

Roberts set about altering the California rehabilitation system. Like CIL, the Department of Rehabilitation drew on a variety of services. Funding to these agencies was based on how many people were placed into jobs, something that was easy to measure. This, Roberts complained, forced a practice called "creaming." Rehabilitation counselors tended to help those with the most minor disabilities. Severely disabled people—like Roberts—were written off as too hard to help into jobs. Roberts had responded to this by setting up CIL, which had "independent living," a more vague and hard-to-measure outcome, as its goal. When Roberts assumed his post, he merged the seemingly contradictory principles of independent living and rehabilitation services. He expanded funding for attendants to help disabled people with the things they needed for daily living, from eating to dressing. In California, every disabled person was to be helped, no matter how severe the disability. Although the department under Roberts would reach out to more disabled people, federal funding formulas were still based on the number of people placed in jobs, and the debate over creaming continues to this day. Roberts's reforms turned the department upside down, and many employees quit, bitter about the change. But many, to Roberts's surprise, also realized that deemphasizing numbers and concentrating on quality was the proper direction. Their director's own unexpected success served as testament to the error of lowering expectations for the most severely disabled.

Berkeley was not the only place where the lessons of civil rights and student protest were shaping a new generation of disability activists. In the spring of 1970, one year after she graduated from college, Judy Heumann was denied a license to

teach in New York City's public schools. She fought her exclusion and emerged as another powerful disability rights leader. Heumann, like Roberts, was a quadriplegic, the result of polio. Hers had struck when she was eighteen months old, so, unlike Roberts, she never had a sense of self-identity without being disabled. Heumann was the eldest of three children born in Brooklyn to German-Jewish immigrants. A doctor urged Werner Heumann, a butcher, and his wife, Ilse, to put the child in an institution. Relatives told the couple that their misfortune must have been the result of some horrible sin on their part. Later, the local elementary school principal deemed the young girl in a wheelchair a "fire hazard" and for three years sent a teacher to give her home instruction twice a week for a little over an hour each visit.

But Heumann's mother, with a Jewish immigrant's respect for learning, knew this was not a real education. Besides, her daughter was isolated and not making friends. Ilse Heumann became a battler, emboldened by small victories, who fought to get Judy into a regular school. At first Judy went to a special elementary school for disabled children—where she realized that the parents of many of her classmates had low expectations for their children and that the teachers, when not prodded by pushy parents, responded accordingly. It was a city policy that when children in wheelchairs reached high school age they would return to their families for home instruction. Ilse Heumann asked the March of Dimes, where she had done volunteer work for years, to help. But the charity's officials declined, saying they wanted to stay out of politics. Banding together with other parents, Ilse Heumann brought enough pressure on the school board that it reversed the policy. Judy Heumann entered high school in 1961, a time she remembers for the parallel efforts of black Americans to force their way into closed institutions.

Heumann would pick up her mother's zest for battle. She was accepted at Long Island University, an urban school in the

middle of Brooklyn. There she led her own battles, forced to insist on everything from the right to live in a dormitory to getting someone to lift her wheelchair over the steps to the classroom buildings. She organized other disabled students to fight for ramped buildings. She took part in protests against the Vietnam War as well.

Heumann studied speech therapy with the goal of helping elementary school children. But she was denied her teaching certificate, despite passing the oral and written parts of the exam, when she flunked the medical exam. The testing physician questioned whether she could get to the bathroom by herself or help children out of the building in an emergency.

Heumann quickly slapped the Board of Education with a lawsuit, charging discrimination. Then she went to the local newspapers, which were happy to tell the story of a qualified teacher up against a coldhearted bureaucracy. "You Can Be President, Not Teacher, with Polio," said the New York *Daily News* in a headline. "We're not going to let a hypocritical society give us a token education and then bury us," Heumann angrily told the newspaper. When it became clear that the board would likely lose its case, it settled out of court, and Heumann was given her certification. Yet no one would hire her, until the principal of the elementary school she had attended in Brooklyn offered her a job.

The experience taught Heumann that she would always have to fight for her rights. Even then, attitudes would still be barriers. But as a result of the press coverage, Heumann received hundreds of letters, largely from others with disabilities with similar complaints. From the base of those contacts—and ones with disabled friends from special summer camp and from college—Heumann in 1970 started her own disability rights group, Disabled in Action. She was twenty-two.

Unlike Roberts's organizing in California, Heumann's DIA would be explicitly political and it did not provide direct ser-

vices to help disabled people live independently. Instead, it engaged in political protest. In 1972, DIA traveled to Washington to demonstrate at the Lincoln Memorial after President Richard Nixon vetoed a spending bill to fund disability programs. Then, in the closing days of the presidential election, Heumann joined with a group of disabled Vietnam veterans to take over Nixon's New York reelection headquarters to demand, militantly if unrealistically, an on-camera debate with the president himself.

The following year, summoned by Roberts, Heumann moved to Berkeley to work at CIL. California was a revelation. She was picked up at the airport in a friend's van with a hydraulic lift. She could get the state to pay for her personal attendant. In the growing West, she could find newer buildings that had been made accessible. Most of all, she found disabled people who had come together in a common group identity. From 1975 through 1982, Heumann would serve as the deputy director of CIL, blending her East Coast political activism with the Berkeley disability community's focus on providing independent living services. In California, Heumann, along with Roberts, would continue to rewrite the history of the disabled.

The History of Disabled People in America

Throughout most of its history America has been inhospitable to people with disabilities. In colonial America, the settlement of a vast new rural society meant that early colonists put a premium on physical stamina. The early colonies tried to prevent the immigration of those who could not support themselves and would have to rely on state help. People with physical or mental disabilities who were potentially dependent could be deported, forced to return to England.

The nation's attitude softened somewhat during the Revolutionary War. When the Continental Congress paid for up to 50

percent of the pensions of disabled soldiers, it was the first time the federal government helped the states care for their disabled. A system of marine hospitals was established in 1798 to provide for sick and disabled sailors. The Marine Hospital Service would later evolve into the Public Health Service, and in 1922 some of these hospitals became the first Veterans Administration hospitals. The nation's sense of indebtedness to men who became disabled while fighting its wars was to inspire many major disability programs throughout U.S. history.

There are few historical records of disabled people in the early years of the new nation. What does exist suggests that many disabled people were able to fit easily into society. Gouverneur Morris, who helped draft the Constitution and was later a U.S. senator from New York, wore a "rough stick" to replace the left leg he lost in a 1780 carriage accident. Stephen Hopkins referred to his cerebral palsy when he signed the Declaration of Independence, saying, "My hand trembles but my heart does not."

Larger colonial towns, reflecting Elizabethan poor laws, had built almshouses for the poor and the physically and mentally disabled. These had continued to grow during the first half of the nineteenth century as the nation's population grew and a simple rural society became industrialized and urbanized. Dorothea Dix, a Boston schoolmistress, led reformers in the 1840s who demanded that the states take control of miserable local almshouses, where adults and children, the disabled and nondisabled, criminals, and those with retardation, epilepsy, and mental illness were all thrown together. Dix had found people with mental illness and retardation "in cages, closets, cellars, stalls, pens! Chained, naked, beaten with rods, and lashed into obedience." The result was that states took over such institutions, built more, and set up specialized facilities for the criminals, disabled, and others who had populated the almshouses. In 1854, Congress, at Dix's urging, agreed to break with past

practice and to provide federal funding for separate facilities for what were then called the deaf, dumb, and blind and mentally ill. But President Franklin Pierce vetoed the measure, saying that the care of the physically and mentally disabled was not a federal responsibility. Historian John Lenihan noted, "Pierce's veto became a landmark precedent limiting federal intervention in welfare matters for the next half century."

Doctors and educators working with the blind and deaf, following experiments in France, were among the first to understand that disabled people could be integrated into society rather than sent away to institutions. A school for the blind was opened in Baltimore in 1812, and Thomas Hopkins Gallaudet founded his school for the deaf in Hartford in 1817. Samuel Gridley Howe would open the Massachusetts Asylum for the Blind, later the Perkins Institute, in 1832 with a curriculum that paralleled that in other schools. His theory was an early form of "mainstreaming," in which he prepared blind youths to find work and live self-sufficiently in their communities. Howe's success in teaching Laura Bridgman, who had been left blind, deaf, and unable to speak by an attack of scarlet fever when she was two, brought visitors such as Charles Dickens and American educators, and with them a recognition that reformers were right that people who were both blind and deaf could be educated. This success also encouraged Howe to open the first state school to try to train "idiots and feeble-minded youth" in 1848. The work of Howe, Dr. Hervey Wilbur, and others showed that mental retardation could not be cured, as they had hoped. Nor could people with retardation be easily educated. As a result, these schools became more custodial in their care than were the schools for the blind and the deaf. As historian Lenihan noted, however, "If the gap with the mainstream of society was not closed, at least retardation was no longer considered an incurable disease tantamount to insanity."

The Civil War forced the nation, for the first time, to deal

with large numbers of physically disabled citizens. The South, because of heavy casualties and poor medical care in the Confederate Army, was particularly hard hit. Mississippi, in 1886, spent 20 percent of its state revenue on artificial arms and legs. In the North, a National Home for disabled Union soldiers was established in 1866. The rise of orthopedic medicine began to develop partly in response to the returning Civil War wounded. But, as historian David J. Rothman writes in *The Discovery of the Asylum*, the American reformers' experiments with institutionalization were falling apart by the 1850s, a trend that was exacerbated by the added demands of the Civil War.

These institutions continued to grow, but, losing their grounding in charity, they became places of abuse, isolation, and segregation. The rise of social Darwinism and the eugenics movement at the end of the nineteenth century—two related schools of social thought that challenged whether it was even desirable to have a society with disabled people—brought new hostility.

As the new century opened, Washington, for the first time, was to play an extensive role in welfare. Once again, returning disabled war veterans stirred the nation's sense of obligation. Medical advances, including the development of new medicines, allowed far higher rates of survival for people who became disabled. Nowhere was that more evident than in the returning World War I veterans. So many, who would have died before, returned with disabilities that Washington was forced to establish the Veterans Bureau in 1921 to deal with their needs. Adding to a new national awareness of disability—fed by muckraking journalists and labor unions—was the rise of industrial accidents. Congress passed major rehabilitation programs in 1918 and 1920, guaranteeing federal funds for vocational training and job counseling. Charitable groups also set up employment bureaus for the disabled, including the American Red Cross. A 1921 law established child and maternal health centers

to reduce the nation's infant and maternal mortality rate. This would lead to a broader federal role following the Depression. In 1935, Franklin D. Roosevelt signed the Social Security Act, which, for the first time, created a program of permanent assistant to disabled adults.

Roosevelt became the country's most famous disabled person. Americans admired his battle with polio. They sent money to the March of Dimes, which he helped found, and schoolchildren even sent their dimes to build him a White House pool for exercise. Historian Hugh Gregory Gallagher notes, however, in *FDR's Splendid Deception*, that Roosevelt went to great lengths to hide the extent of his handicap. Roosevelt could not walk, although Americans held a contrary impression. "The generally accepted line was that FDR had had polio and was now a bit lame; he had been paralyzed, but now he was recovered. He was a 'cured cripple,' " writes Gallagher. He was never seen in public, nor photographed in private, in his wheelchair. This was still possible in an era before television. He, his son, and Secret Service agents had devised elaborate ways to get him in and out of buildings. If he had to enter in public view, his son and agents would walk closely by his side, and FDR would lift himself on their arms, as if he were a gymnast on parallel bars. He would seem to be walking although he was, in effect, being carried. Washington was a wheelchair-accessible city—or at least the parts frequented by FDR—with ramps at the White House, Capitol, the War, State and Navy Building, and St. John's Church across Lafayette Square. It would be another thirty years before such access was required by law.

Once again, disabled soldiers returning from war, this time World War II, spurred another expansion of federal rehabilitation programs. There was renewed national dedication to helping this most highly visible population of disabled Americans. The Paralyzed Veterans of America formed in 1946 to promote their medical care, and the President's Committee on Employ-

ment of the Handicapped was founded the following year to convince business of its obligation to hire them once they left rehabilitation. Most important, however, was the creation of rehabilitation medicine during World War II by Drs. Howard Rusk and Henry Kessler. Working independently, these men set up rehabilitation centers that worked on a revolutionary idea. They would go well beyond acute care to put together all the medical services—from physical therapy to occupational therapy—that a newly disabled person required to return to a normal life. The independent living movement that Roberts created twenty years later was both an improvement on this and a rebellion from it. The independent living movement endorsed physiatry's ground-breaking emphasis on looking at the whole person, but it rejected the medical model that could view that person only as a patient, in the context of a medical setting.

For the most part, it was government or charitable groups that helped people with disabilities, but there were a few scattered cases of disabled people rising up on their own. Deaf and blind people had been the first to set up national advocacy organizations, beginning in the last two decades of the nineteenth century. Such groups proved effective. Blind relief laws, providing special financial assistance, were enacted in twenty-seven states in the 1920s and early 1930s. But when economic times were good, others argued that to take special assistance only furthered perceptions that blind and deaf people were incapable of living without charity. Robert Irwin, the blind Harvard-educated man who led the American Foundation of the Blind through its early years in the 1920s and 1930s, promoted self-reliance and opposed automatic pensions or special schools for the blind.

Disabled people turned to civil disobedience for the first time during the Depression. Historian Paul Longmore tracked down the lost story of the short-lived League for the Physically Handicapped, a group of three hundred disabled New York

pensioners—most with polio and a few with cerebral palsy—who occupied the Works Progress Administration offices in Washington to protest that they were being routinely rejected for WPA jobs. Another important self-help group started in 1958 when Gini Laurie, who volunteered with patients on a Cleveland polio ward, started the *Toomey j Gazette* as an “alumni” newsletter for people leaving the hospital. Soon people were writing in with tips about how they took care of a baby from a wheelchair, managed on a trip to France, or started their own mail-order business working at home over the telephone. The newsletter turned into a journal of self-reliance—today it is the *Rehabilitation Gazette*—and soon won a worldwide readership, including a young Ed Roberts in California.

But it was the rise of a parents’ movement that would most change the course of disability policy in the years following World War II. A proliferation of new disability groups like the United Cerebral Palsy Associations, founded in 1948, and the Muscular Dystrophy Association in 1950 were started by parents. As more children survived disability, more parents sought to keep them from being institutionalized. They realized they shared their struggle with other parents who were also frustrated by the paltry support offered by doctors or social service agencies. Their biggest common concern was to get their children educated. These new parents’ groups took their case to Congress, which, in 1966, created a federal bureau for the handicapped. The groups sent permanent lobbyists to Washington, and in 1970 the bureau began providing funds for training special-education teachers and developing separate materials for teaching the children in these classes.

Section 504

The first civil rights law for disabled people, however, would not be the end result of a hard-fought battle. Disabled people did

not even ask for it. Nor had they lobbied for it. Section 504 of the Rehabilitation Act of 1973 was no more than a legislative afterthought. The overall act authorized \$1.55 billion in federal aid to the disabled to be spent over two years. For President Richard Nixon, as well as for Congress and even disability groups, including Heumann's DIA, this was simply a spending bill. Nixon had vetoed two earlier versions he claimed were too costly. But at the very end of the bill were tacked on four unnoticed provisions—the most important of which was Section 504—that made it illegal for any federal agency, public university, defense or other federal contractor, or any other institution or activity that received federal funding to discriminate against anyone “solely by reason of . . . handicap.”

When sociologist Richard Scotch later studied the act's legislative history, he found that congressional aides could not even remember who had suggested adding the civil rights protection. But the wording clearly was copied straight out of the Civil Rights Act of 1964, which ruled out discrimination in federal programs on the basis of race, color, or national origin. There had been no hearings and no debate about Section 504. Members of Congress were either unaware of it or considered it “little more than a platitude” for a sympathetic group, says Scotch. Professional and charitable groups representing disabled people were sophisticated in winning multibillion-dollar federal funding, but had not focused on civil rights legislation.

Roberts and Heumann, however, would soon recognize the significance of what had fallen into their laps, even if the anonymous Capitol Hill staffers who had crafted Section 504 had not. The Ford administration would understand the significance of Section 504, too. The Department of Health, Education and Welfare estimated that compliance would cost billions of dollars and stalled the issuance of the final regulations. When Ford's presidency ended, HEW left behind a 185-page draft of the regulations.

The new president, Jimmy Carter, had made a campaign promise to complete them. But his new HEW Secretary, Joseph Califano, was quickly alarmed by the scope of Section 504, too, and assigned a group of lawyers to write new regulations. Carter and Califano were afraid of the public outcry if alcoholics, drug addicts, and homosexuals were to claim protection under the law, although an HEW team already had concluded they would not be eligible to do so. Califano pleaded for time. While Frank Bowe, the head of the American Coalition of Citizens with Disabilities, negotiated, impatient colleagues led a group of demonstrators in wheelchairs, holding candles and praying, to Califano's home shortly before midnight on April 3, 1977, to demand that he sign the regulations immediately and without weakening them. Two days later, activists loosely organized by Bowe's group staged demonstrations in Washington and eight regional offices of HEW. Three hundred people took over Califano's offices, and most remained overnight. The HEW secretary, infuriated, retaliated by refusing to let in food and by cutting off telephone communication. After twenty-eight hours, the demonstrators left.

In San Francisco, however, the sit-in endured and turned into a national attention-grabbing moment of conviction. Led by Heumann, the demonstrators occupied the sixth floor of the regional HEW office in UN Plaza for twenty-five days. When they arrived the first day, recalls protester Mary Jane Owen, they were furious at the condescending treatment they got from HEW officials, who served them cookies and punch, as if they were schoolchildren on a field trip. Heumann was angry about her colleagues in Washington being "starved out" of their occupation. As in Washington, HEW officials in San Francisco, too, tried to shut down the protest at first by refusing to let in food, cutting off telephone lines, and even barring entry to attendants. Some of the most severely disabled protesters were literally putting their lives on the line, since they risked their health to be without

catheters, back-up ventilators, and the attendants who would move them every few hours to prevent bedsores, or who, with their hands, would cleanse impacted bowels every few days. None of these deprivations, however, deterred the demonstrators. Instead, they backfired. The protesters' success, in the face of forceful opposition, only bolstered their euphoria and determination.

Particularly helpful was the fact that protest movements held a place of honor in the activist atmosphere of the Bay Area. On the fourth day, Roberts, now the state director of rehabilitation, showed up to give his official blessing to the sit-in, which by then had grown to over 120 demonstrators. "We've got to keep up the pressure," he said from his electric wheelchair on this first of several visits. And then he noted, correctly, that federal officials "have underestimated the commitment of this group." On the sixth day, Representative Phillip Burton, who represented San Francisco, demanded that food get past the guards in the lobby and won the installation of three pay phones. Two other pay phones on a distant floor had quickly broken down, clogged by uncollected coins. Heumann had found other more creative ways to get messages out of the building. The demonstrators unfurled banners with their messages from windows; deaf protesters used sign language to convey information to those watching outside; and at one point members of the Butterfly Brigade, a group of gay men who patrolled city streets on the lookout for antigay violence, smuggled in a set of walkie-talkies. On the thirteenth day, Mayor George Moscone brought in twenty air mattresses and hoses with shower heads, over the objections of HEW regional director Jose Maldonado, who complained, "We're not running a hotel here."

Nevertheless, food donated by a local Safeway store, Goodwill Industries, McDonald's, unions, and civil rights groups was prepared by the Black Panthers, including an Easter dinner of meatloaf, green beans, and mashed potatoes that arrived steaming and covered in tinfoil. Several priests lived with the demon-

strators to help out with everything from preparing food to doing pastoral counseling and celebrating Easter Mass. A rabbi came in to lead a Passover seder. There was even clandestine help, including food smuggling, from some of the federal employees who kept working in the building through the twenty-five days of occupation. One HEW deputy wore a ceramic pin with a snake twisting through it and promised that, if his bosses ordered police in to storm the floor and arrest the demonstrators, he would surreptitiously warn them beforehand by turning the pin upside down.

The continued miscalculations of HEW officials were clear again on the twelfth day, when Burton and another Bay Area lawmaker, George Miller, held a congressional hearing in the occupied building. Gene Eiderberg, the low-ranking HEW assistant dispatched to California to testify, disclosed that Califano was considering twenty-two changes in the regulations that would set up what Eiderberg impolitically described as "separate but equal" facilities for the disabled. Among the changes, he said, were exceptions to rules requiring ramps and free access to hospitals and schools and a proposal to have some disabled children educated in special schools rather than at regular schools adapted for them. "We will not accept more segregation," Heumann told Eiderberg heatedly. "When you erect buildings that are not accessible to the handicapped, you enforce segregation. There will be more sit-ins until the government understands this." Roberts, too, blasted Eiderberg's suggestion of a "separate but equal world" for the disabled. "Integration is the key word," said Roberts. "People with disabilities have to come back into our society."

The San Francisco sit-in marked the political coming of age of the disability rights movement. Disabled people had risked arrest and their health by turning to civil disobedience tactics and had surprised a nation—and themselves—with their own power. The protest built on the early efforts at cross-disability

activism by the CIL. "People went into that building with some kind of idealism, but they didn't have much knowledge of other disabilities," says Mary Jane Owen, who stayed for the twenty-five days. "Up to that point you had blind organizations, organizations for deaf people, for wheelchair users, for people with spina bifida or people with mental retardation."

Such parochialism changed at San Francisco. On the sixth floor of the federal building, demonstrators created their own disability city, a mini-Woodstock in close quarters where there was no privacy. They not only came together in the joint recognition of their second-class citizenship, but became close friends and administered to each other. One young woman, who walked on crutches, fell in love with the attendant of another demonstrator. One night the young woman and a dozen others sat in a circle during a typical late-night talkfest. They went around the circle, each saying what they would ask for if given one wish. "For Califano to sign the regs," said one. "For a hamburger," said someone else. Then it was the young woman's turn. "I used to know what I would wish for," she said. "I wanted to be beautiful. I wanted to stop being a cripple. But now I know I am beautiful." Says Owen, "We all felt beautiful. We all felt powerful. It didn't matter if you were mentally retarded, blind, or deaf. Everybody who came out felt, We are beautiful, we are powerful, we are strong, we are important."

On April 28, 1977—four years after the law had been passed—Califano caved in to the protest that showed no signs of diminishing and signed the regulations, without changes. And on April 30, the protesters marched out together in victory—thrilled to have won, but bittersweet at seeing their idealized disability city end. They left singing "We Have Overcome."

At the same time, Califano signed the regulation for the Education of All Handicapped Children Act. Congress had passed it in 1975, but Califano had blocked it, too, along with Section 504. When he signed the two together, schools were

required to guarantee the best possible public education—in-
stead of the inferior home teaching Roberts and Heumann had
been forced to accept—to every disabled child. This gave angry
parents a new tool to demand quality schooling, alongside non-
disabled children, for their disabled sons and daughters. The
new law would give rise to a new generation of well-educated
disabled children, who then went on to college in record num-
bers.

Backlash

Yet the movement that seemed so promising as the demonstra-
tors left would soon falter. What existed in the San Francisco
area simply did not exist elsewhere. Although nearby Berkeley
had already been labeled a “mecca for the handicapped” by the
press, other communities did not have the center of activism that
Roberts and Heumann had helped build in California.

Shortly after Califano signed the regulations, costs would
come up time and time again as a reason for denying full rights,
no matter how hard won, for disabled people. News stories
attacked the Section 504 regulations, for example, as an instance
of costly and nit-picking federal rule making. Newspapers
widely reported the outrage of people in Rudd, Iowa, a farming
community of fewer than five hundred people. An HEW re-
gional official had informed the town that its public library had
to be made accessible. Town officials said it would cost \$6,500
to build a ramp, even though no one in the town used a wheel-
chair. As historian Edward Berkowitz would later note, there
was a sudden realization that antidiscrimination measures for
people with disabilities carried a price tag. This was quite differ-
ent from the black civil rights movement, where the end of
separate accommodations had meant financial savings. “Admit-
ting James Meredith to the University of Mississippi cost noth-
ing in an economic sense,” Berkowitz wrote. “All of the costs

were political. Meredith required courage to attend classes, not ramps and wide toilet stalls with grab bars." But "to admit James Meredith's handicapped counterpart to a university would cost money rather than save it. It would mean that the physical plant would need to be expanded or modified, and it would require the university to pay the administrative cost of complying with the federal regulations."

Architect Ron Mace of Barrier Free Environments says university officials and others wildly overestimated the cost of accommodating disabled people. North Carolina education officials, says Mace, estimated it would cost \$15 billion to make state university buildings accessible. In fact, many changes were simple and inexpensive. To accommodate students in wheelchairs, universities moved classes to ground floors rather than install elevators to carry students to higher floors. The total cost to the state, Mace says, turned out to be only \$15 million. A 1982 study for the Labor Department, too, found it was "no big deal" to accommodate disabled workers, since 50 percent of changes in the workplace cost little or nothing. A company, for example, could change a wheelchair user's work hours to conform with the schedule of lift-equipped buses. Another 30 percent of the accommodations were achieved for between \$100 and \$500 per employee—these included such ideas as giving a telephone headset to a quadriplegic telephone operator. At the high end were the 4 percent of changes that exceeded "the low figure of \$2,000 [per employee]." These low costs would later win over a generation of businessmen as well as disabled people. But in the years immediately after Califano signed the Section 504 regulations, there were still fear and concerns about limits on federal funding. The courts, so crucial for advances in the black civil rights movement, proved less hospitable to disabled people. The Supreme Court, in *Southeastern Community College v. Davis*, ruled that a deaf woman, Frances Davis, could be denied admission to a nurses' training program at a North Carolina commu-

nity college on the ground simply that her deafness would prevent her from participating in clinical training. Disabled people were not insisting that they be hired for jobs they could not do. Davis argued her deafness did not prevent her from going to school or being a nurse, unless she was refused accommodations along the way.

In 1980, with the election of Ronald Reagan, there was an administration in place that would review the regulations considered ominous to business and government agencies, particularly Section 504 and the Education Act. By 1984, sociologist Scotch would write that "the effectiveness of the disability rights movement appears to have peaked in 1978" and that since Reagan's election "the decline in influence has continued and quickened."

It would be several years after the San Francisco sit-in before the independent living movement, as it started in Berkeley, would grow across the country. But once it began to spread, it spread rapidly. In 1977, according to disability policy expert Margaret Nosek, there were just fifty-two independent living centers in the United States. Within a decade, there would be close to three hundred, all bringing a similar fervor of advocacy and group activism. Most modeled themselves after Berkeley's center, which not only had the distinction of being the first independent living center but was considered to be the most activist and most thriving. By 1976, one reporter noted, the center was already serving "some one thousand disabled persons with a variety of programs, including housing and transportation assistance, crisis counseling, attendant and reader referrals, wheelchair repair, mobility training for the blind, a computer training project, and an education program for rehabilitation professionals." By 1988, the center reported it helped 1,807 clients who received an average of eighty-one hours of assistance throughout the year. Three of every four clients lived in poverty.

A key moment came in 1978 when Congress, listening to testimony from Roberts, gave the federal commissioner of Reha-

bilitation Services the discretionary power to award money to the states to operate independent living centers. This assured a stream of money so that disabled people would have a significant role in running their own programs. However, because the centers depended on federal dollars, many over time were forced to tone down their overt political activism.

The proliferating independent living centers spread the new philosophy of the disability rights movement to disabled people, their families, and disability professionals in cities, towns, and even isolated rural communities across the country. They proclaimed a new ideal of independence. The centers argued that no one—not even doctors or therapists—knew more about the needs of disabled people than disabled people themselves. Above all, the centers provided a model of disabled people running their own self-help programs, making decisions for themselves.

The post-San Francisco generation of disabled Americans would be the beneficiaries of the Education of All Handicapped Children Act and the new sensibility of the independent living movement. Disabled children who began school in 1977—the first group to be assured rights—would start graduating high school in the late 1980s. It was no accident that the time of their leaving school—for a world where the rights of disabled people were not protected as they had been in school—became a period of new disability activism. As a group, this protected generation was more self-assured about standing up for themselves than had been the more downtrodden generation that preceded them. The Gallaudet student protests and the passage of the Americans with Disabilities Act, an expansion of Section 504, would pick up where the brief flurry of mid-1970s disability rights activism of the San Francisco sit-in generation had left off. These events in the late 1980s and early 1990s would bring about a renewed public sense of the minority identity of disabled people and carry on the self-help and activist vision that had taken root in Berkeley.

CHAPTER 3

THE DEAF CELEBRATION OF SEPARATE CULTURE

The 1988 protest by deaf students at Gallaudet University was a defining moment for the disability rights movement. It was the closest the movement has come to having a touchstone event, a Selma or a Stonewall. True, protesters with a wider array of disabilities had taken over the San Francisco HEW headquarters in 1977. But that was just a blip on the screen of national consciousness. It had come a decade too early for Americans—even for many disabled—to view disability as a civil rights issue. The Gallaudet campus takeover, by contrast, was a made-for-television solidarity phenomenon, thick with drama. Cameras feasted on the sea of hundreds of outstretched arms signing “Deaf President Now,” over and over, in a rhythmic choreography. A school that prided itself on preparing deaf students for the hearing world had decreed a deaf person not ready to lead a deaf university.

The uprising that followed resonated for people of all

disabilities, who empathized with the students' revolt against the paternalistic care of well-meaning but insensitive people who were not disabled. Gallaudet gave Americans a new rights consciousness about disability. It was reflected in post-Gallaudet journalism, which focused less on "supercrips" and sad cases, according to a study by Beth Haller of Temple University. Newspaper stories began using the words "disability" and "rights" in the same paragraph. Lawmakers, too, made the connection. The Americans with Disabilities Act was introduced two months after the Gallaudet protest and, for a law with such sweep and so many potential enemies, took a rocket course toward passage. Argues Lex Frieden, then of the National Council on the Handicapped, "It would not have happened without Gallaudet raising people's consciousness."

The Revolution of Seen Voices

The Gallaudet *student* protest. That is how the March 1988 Gallaudet revolt is remembered. But the students were the last of the Gallaudet family to get involved. It was the anger of young alumni, battling the sting of prejudice and discrimination in the hearing world, who set it all in motion.

It began in August 1987, when Jerry Lee, the school's hearing president, announced he would leave the university in December. In early February of 1988, six young graduates met, and their discussion turned to the Gallaudet search committee that was winnowing a list of candidates to succeed Lee. To be deaf, the friends agreed, was to struggle constantly against the low expectations of the hearing world. What an insult, then, that the world's premier school for the deaf should buy into this underestimation. There had been brief talk in 1984, when Lee was chosen, of whether the job should have gone to a deaf man. Gallaudet's six presidents over 124 years had served for an average of twenty years, although there had already been three

presidents in the 1980s. This might be the last shot for several years, the friends realized, at making a stand for a deaf president. Jeff Rosen, a young Washington attorney at the meeting, says the group decided to sponsor a campus rally to unite students, faculty, and alumni into a massive coalition that could not be ignored.

Support for the rally came from two local alumni entrepreneurs, John Yeh and David Birnbaum, who were bitter that the university had shown little interest in giving contracts to local deaf businessmen. Once out of the protective cocoon of Gallaudet's Washington campus of Victorian red-brick buildings, these alumni had confronted the mindless exclusion and condescension of the hearing world. It was an outrage, Yeh and Birnbaum felt, that their school played into these attitudes by dismissing deaf businessmen. It gave the lie to the school's mission of preparing students for the hearing world.

On campus, as Gallaudet alumni director Jack Gannon notes in his history of the strike week, students paid scant attention to the discrimination that faced them beyond the school's gates. Replacing a president seemed little more than a campus administration issue. "Many deaf persons had been conditioned to accept limits—to believe that hearing is better," explained Roslyn Rosen, dean of Gallaudet's College for Continuing Education. Confusing, too, was that Gallaudet's student body was made up not just of those with total hearing loss—who make up 10 percent of the 22 million Americans with hearing disabilities—but those with profound and severe hearing loss who could be helped with a hearing aid. The different groups often formed cliques, and those who used hearing aids felt more sanguine about integrating into the hearing world. The task for the rally's sponsors was to crystallize the presidential selection as a civil rights battle.

"It's time!," said the fliers Yeh printed up to promote the rally. "In 1842, a Roman Catholic became president of the

University of Notre Dame. In 1875, a woman became president of Wellesley College. In 1886, a Jew became president of Yeshiva University. In 1926, a Black person became president of Howard University. AND in 1988, the Gallaudet University presidency belongs to a DEAF person." Yeh underwrote most of the costs of the rally, including the printing of thousands of blue-and-yellow buttons that said DEAF PRESIDENT NOW, which became the protest week slogan.

The civil rights theme was hammered home at the rally on March 1, an exuberant revival that moved from point to point on campus, followed by 1,500 excited students, alumni, and faculty, chanting and waving "high fives"—the deaf sign-language applause of hands stretched straight up and fingers fluttering that would soon be familiar on television screens across the country. It was a sunny day with brilliant blue skies, and the sense of deaf pride that coursed through the crowd was electrifying. Jeff Rosen, wearing a red sweatshirt with the words DEAF PREXY NOW, stood on the flatbed of a pickup truck and signed to the crowd, "People have died in the civil rights movement. People were jailed in protesting the Vietnam War. I stand here in 1988 asking, What do you believe in? What is your cause?" Another of the two dozen speakers, Professor Allen Sussman, drove home the point: "This is an historical event. You could call this the first deaf civil rights activity." This was a powerful cry. Even many of the students who listened to him had never thought of the way deaf people were treated as a civil rights issue.

By coincidence, moments before the rally, the names of the three finalists were announced. I. King Jordan, deaf since young adulthood, was Gallaudet's popular dean of the college of arts and sciences. Harvey Corson, deaf since birth, was the president of a Louisiana residential school. Elisabeth Zinser, the one hearing candidate, was an administrator at the University of North Carolina at Greensboro. Also by accident, it was the same day

that the new student body president took office. Greg Hlibok would become the national spokesman for the students, a reassuring symbol with his blond and preppy good looks. Tim Rarus, the outgoing student body president, along with Jerry Covell and Bridgetta Bourne, who before the rally had been campaigning for a woman president, would also emerge as leaders of the protest. All four had deaf parents and had grown up with self-confidence, not feeling left out because of their disability.

On Sunday, March 6, some five hundred students and alumni gathered at the main gate to the campus at 8:30 P.M. That was when they had been told to expect an announcement by the board of trustees. But the choice had already been made public, in a press release, two hours earlier. Hearing reporters had been told before the students: Elisabeth Zinser, the lone hearing finalist, was the new president of Gallaudet University. The eruption of anger was immediate. There were speeches, tears, burning of press releases.

Shouting "Deaf President Now," the group spontaneously marched the few miles downtown to the Mayflower Hotel, where the trustees were said to be at a party to celebrate their choice. Policemen lined the hotel entrance as the students shouted and signed speeches. Hlibok, Rarus, and Jeff Rosen were invited upstairs to meet the board. There, they said, Jane Bassett Spilman, chairwoman of Gallaudet's board of trustees, gave her insulting explanation that "Deaf people are not ready to function in a hearing world." Later, Spilman vigorously denied making the remark, saying she had been misquoted by an interpreter. But even this excuse was an example of what the students saw as the school's paternalism. Spilman had served on the board of trustees for seven years and she still couldn't speak to the students in their language. Why hadn't she learned to sign?

The next morning, Monday, students closed down the school. At 5:30 A.M., they began parking university cars and

buses, hot-wired by a street-smart student from New York City, in front of all the campus entrances. Gallaudet's provost got past the angry protesters only after security guards cut a hole in a chain-link fence. Classes were canceled, and a hastily assembled group of students, faculty, and staff took a list of demands to Spilman. Rescind the choice of Zinser, they ordered, and appoint a deaf president. Spilman must resign and a majority of deaf members be named to the board of trustees. There could be no retribution against student and faculty demonstrators. Spilman rejected the demands but agreed to address an assembly, confident she could explain the logic behind choosing Zinser.

But the meeting in the field house was a debacle. There were one thousand noisy students. They screamed and rhythmically swayed their arms to sign "Deaf Power," which was formed by holding the left hand over the left ear to signify "Deaf" and raising the other fist in the air for "Power." They signed "Zinser Out," using, as they did all week, the sign for the word "sinner" as a close and mocking approximation of her surname. Spilman and the other trustees waited onstage, protected from shouting students by a line of security police. Before Spilman could speak, mathematics professor Harvey Goodstein, a member of the delegation that had met with her, walked onstage to sign that she had rejected all of their demands. He encouraged the crowd to leave, and most took off, marching again to the Capitol and the White House, snarling rush-hour traffic. A policeman tried to control the crowd by shouting directions through a megaphone. Then, realizing he could not be heard, he disgustingly flung the megaphone into the back of his patrol car and slammed the trunk. Police were reduced to giving the students an escort downtown. A small group of students stayed behind to hear Spilman in what would be an emotionally charged meeting and one more stumble for Spilman.

As the remaining students yelled in protest, some of the departing ones pulled the fire alarm. "We aren't going to hear

you if you scream so loudly that we can't have a dialogue. It's very difficult to be heard over the noise of the fire alarm," the hapless Spilman told the students. "What noise?" students shouted or signed back. "If you could sign," one deaf student responded, "we could hear you." Spilman took a hard line, declaring the choice of Zinser was "lawful, proper and final." It was that scolding attitude that led Bridgetta Bourne to tell a newspaper reporter, "We want to be free from hearing oppression. We don't want to live off the hearing world, we want to live as independent people." That day, visiting professor Harlan Lane had scheduled a lecture on paternalism. It was canceled, along with all other classes. "Real life overtook it," he explained.

The students' ardor did not cool. Classes resumed on Tuesday, although all but about 10 percent of students boycotted them. Protesters burned effigies of Zinser and Spilman. Some 1,500 people gathered for another protest rally at the statue of the school's namesake, Thomas Hopkins Gallaudet, teaching the alphabet to a kneeling girl. "We will not give up," Hlibok signed to the crowd to cheers. "Now is the time to . . . show that we can help ourselves and control our own lives and our futures."

Most important, the protest had grabbed national attention. Students at other deaf schools from Georgia to California demonstrated and sent letters of support. Some students and alumni even came from around the country to the Gallaudet campus to help out. Local businesses sent fruit baskets, pizza, soda, and other provisions. A linen company donated forty bed-sheets for banners. A local law firm offered pro bono representation. The students, improvising as the protest grew, put together a sophisticated operation. The protest leaders camped out at the alumni house, where, fortunately for them, the school had set up a bank of telephones and TDDs, telecommunications devices for the deaf, for the semiannual Alumni TDDathon. The students used these to make hundreds of calls to reporters and to people around the country to raise funds. Some seventy inter-

preters arrived on campus to volunteer their services for the students when reporters and others arrived.

Zinser showed up in Washington on Wednesday, declaring, "I am in charge." Full of bravado, and thinking the protest was the work of only a handful of disgruntled students, she believed she could end the unrest. "I like to rise to the occasion of a challenge," she told reporters during a press conference at the National Press Club and hinted that she was ready to get tough with the demonstrators.

But Zinser never set foot on campus. To keep her out, students at the barricades thoroughly searched incoming campus security cars, even checking the trunks. Students even planned to stop Zinser from arriving by helicopter by lying on the ground, if necessary, to prevent it from landing. Zinser summoned a group of student leaders to her hotel but was refused a request to address the entire student body. The students did not recognize her as president, Hlibok explained, and would not give her such legitimacy by letting her address them. There was a setback for the protesters, however, when Zinser got backing from the two deaf candidates she had defeated. Spilman released a supportive letter from Corson. A stricken-looking I. King Jordan showed up at Zinser's side at the press conference. Earlier in the week, he had given a moderate endorsement of the student protest, encouraging students to "continue this in a positive way." Now, he explained, he felt an obligation as a dean to support the school first. Other faculty and staff members, however, voted to support the student demands by near-unanimous margins.

Wisely, the students had focused on taking their cause to Congress. Gallaudet is a federally chartered university, and in 1988 75 percent of the school's budget, some \$61 million, came from Congress. Many politicians, who already understood the political power of disabled people, were eager allies. Senator Bob Dole and Vice President George Bush, now locked in battle for

the Republican presidential nomination, had already urged the school to name a deaf president. So had House Majority Whip Tony Coelho. And Michigan Representative David Bonior was quoted on the front page of Wednesday's *Washington Post* warning that Zinser's appointment imperiled continued congressional largesse toward the school. On Wednesday morning, Democrat Bonior and Republican Representative Steve Gunderson of Wisconsin, both on Gallaudet's board, met with Hlibok and faculty and alumni protesters. Later that day, Zinser and Spilman called on the lawmakers, too, in an attempt to reassure members of Congress that they were in control despite the brief spark of revolt. Instead, Bonior urged Zinser to resign. That evening, Hlibok and Zinser faced off on the ABC news program "Nightline," which ran open captions for the first time. Zinser said that she believed "very strongly" that a deaf person would one day be the president of Gallaudet. "This statement, 'one day a deaf president,' is very old rhetoric," Hlibok shot back. "We've been hearing this for one hundred twenty-four years."

By the following day, it became clear to Zinser that she could not win. The board had reaffirmed its decision to appoint her, but the protest showed no signs of dying out as students pledged to stay on campus the following week, even though it meant giving up their spring vacation. A symbol of the changing tide had come when Jordan, smiling, showed up at the day's rally to recant his support of Zinser of the day before and express his "anger at the continuing lack of confidence that [members of the board of trustees] have shown in deaf people." It was a risky move for a university dean. Later Jordan would explain, "I realized I might just be dean for a week. But I would be a deaf person for the rest of my life." That evening at about 7:30, Zinser turned to Spilman and said simply, "I resign." Shortly before midnight, the university put out a press release to announce Zinser's resignation.

The next morning, Zinser read her resignation statement at

a press conference. She had concluded, she said, "that the best way to restore order and return this university to its business of education" was to resign and allow the appointment of a deaf president. She ended her statement by giving the sign-language hand signal for, "I love you." Even after this victory, the protest was not over. There was still a new president to name, and the students' other demands remained on the table. Shortly after Zinser's press conference, about three thousand cheering students and supporters left campus and marched once more to the U.S. Capitol, signing and chanting "Deaf president now" and "We will not back down."

On Sunday, one week after the protests had begun, seventeen members of Gallaudet's board of trustees met in a downtown hotel to choose a president. In the seven-hour meeting, they decided to give the students everything they were seeking, and more. Jordan, the popular dean, would become the school's first deaf president. The new chairman of the board would be Philip Bravin, an IBM program manager and the deaf head of the presidential search committee who had angered students earlier in the week. Half of the board of trustees would be deaf. There would be no sanctions against the demonstrators.

Outside the hotel, before ecstatic students and in front of television cameras that recorded the moment for the world, an exhilarated Jordan accepted his new appointment. "This is a historic moment for deaf people around the world," he signed, and spoke in his clear voice. "In this week we can truly say that we, together and united, have overcome our own reluctance to stand for our rights and our full representation. The world has watched the deaf community come of age. We can no longer accept limits on what we can achieve."

Spilman announced her own resignation, saying, "In the minds of some, I have become an obstacle to the future of the university. And because I care very, very deeply about Gallaudet's future, I am removing the obstacle." Even to the end,

however, she insisted that the "best choice [for president] was a hearing candidate."

A few days later, Hlibok wrote a letter to Zinser, who had returned to her school in North Carolina. "You were, of course, an innocent victim and unfortunate target for our collective anger," he wrote. Zinser would take to wearing a necklace with a silver charm shaped in the hand sign for "I love you."

That it had taken until 1988 for such a stunning expression of deaf pride was no accident. Like other disability group protests, the one by deaf students reflected a growing sense of oppression. It gave voice to anger bottled up over years of being seen as pitiful and sick. Social, demographic, and technological trends, too, had created the sense of an emerging deaf minority group in the 1980s. It was not until 1971 that a television show—an episode of Julia Child's "The French Chef"—was captioned for deaf viewers. Television news first became accessible in 1973 with the titled and rebroadcast ABC's "World News Tonight." By the year of the Gallaudet protest, some 180 hours a week of network, cable, and public television shows were captioned. Deaf people, as a result, were more informed and felt more a part of the world. Even more important, the telephone was becoming accessible. In the 1970s and 1980s came the development of portable, affordable TDDs. Interpreting grew as a profession, as deaf people became more numerous and more independent. Before, interpreting had been left largely to the hearing children of deaf parents.

The disability rights movement, too, had led to new opportunity. More deaf children went to mainstream schools and colleges. Many at Gallaudet would see mainstreaming as a threat to the separate schools that fostered a sense of deaf identity, but by 1985, 44 percent of deaf students were in mainstream public schools and only 29 percent in deaf residential schools. Still, civil rights protections for the disabled often had limited applications for the deaf. Few schools and businesses interpreted these laws

to mean they needed to hire costly interpreters for deaf students or employees.

Once again, medicine helped spur a movement by saving people, who then would live with a disability: the number of school-age deaf children doubled as a result of the rubella epidemic of 1964–65. This new generation of deaf, born in the middle of the civil rights and Vietnam eras and molded by the new technology and laws for disabled people, had higher expectations for themselves. They were more militant, too, and talked of their deaf identity and culture. Some were studying at Gallaudet in 1988; others were among the young alumni who had bankrolled the protests.

Yet there was great irony in the fact that it should be Gallaudet students who would succeed in equating disability with civil rights: to them, deafness is not a disability but a culture—like being Jewish, Irish, or Navajo. Some deaf people make this distinction by spelling deaf with a capital *D* when referring to cultural deafness, and with a small *d* when talking about an auditory condition. Deaf people argue that they share their own complex language, American Sign Language, as well as a culture and a group history. Disability is a medical condition, argued the Gallaudet student leaders. Deaf people felt they had long been oppressed by those who saw their hearing loss as a disability or pathology in need of correction. In concert with the broader disability rights thinking, they argued that they had been held back by those who pitied their deafness and felt them, therefore, less capable. As John Limnidis, a hulking Gallaudet football player from Canada who played a small part in the movie *Children of a Lesser God*, would explain: "Deafness is not a handicap. It's a culture, a language, and I'm proud to be deaf. If there was a medication that could be given to deaf people to make them hear, I wouldn't take it. Never. Never till I die!"

Lost Language, Lost Culture

Indeed, there are strong historical arguments for the profound power of a separate deaf culture and for the viability of deafness as a way of life different from, but equal to, traditional hearing culture.

For 250 years, deafness was commonplace on Martha's Vineyard. The first deaf resident, a fisherman named Jonathan Lambert, settled there in 1694. He carried a recessive gene for deafness and, as a result of frequent intermarriage among the isolated islanders, this trait spread through generations of Lambert's descendants. A few villages, like Chilmark and Tisbury, had unusually high numbers of deaf citizens. By the middle of the nineteenth century, one in twenty-five residents of Chilmark was deaf, and in one neighborhood the ratio was one in four. As anthropologist Nora Ellen Groce notes in her book, *Everyone Here Spoke Sign Language*, the result was an easy, almost natural fusion of deaf and hearing cultures.

With such a large population of deaf citizens, the entire community learned to use sign language—even when there was no deaf member of the family—and sign was not for the exclusive use of communicating with deaf residents. Hearing fishermen would use it to communicate from one distant boat to another. People even signed to talk in church. If hearing people were talking among themselves and a deaf person joined them, they would all switch to sign.

The last deaf islander died in 1952, but when neurologist and author Oliver Sacks visited Martha's Vineyard some thirty-five years later, he found that older hearing people still communicated in sign language to tell stories or converse with their neighbors. One of the oldest Sacks met, a woman in her nineties, "would sometimes fall into a peaceful reverie" all the time moving her hands as if she were knitting. "But her daughter, also a signer, told me she was not knitting but thinking to herself, thinking in Sign," Sacks writes. "And even in sleep, I

was further informed, the old lady might sketch fragmentary signs on the counterpane—she was dreaming in Sign.”

There were no language barriers on Martha's Vineyard and, as a result, no social ones either. Deaf people participated widely in community affairs, from town politics to church events. Deaf and hearing islanders led similar lives. Eighty percent of deaf people on Martha's Vineyard married, about the same rate as that for hearing islanders. In the nineteenth century, only 45 percent of American deaf people married. Both deaf and hearing islanders had an average of six children, while nationally in the 1880s, the average deaf-hearing couple had only 2.6 children. On this island separated by a short span of Atlantic Ocean from the Massachusetts mainland, deaf and hearing islanders held the same jobs and therefore enjoyed similar income levels; they played cards and drank together. Deaf people held town positions from school committee member to highway surveyor and served in the militia.

One difference was that deaf islanders tended to be better educated. The state of Massachusetts paid for ten years of their education, and most went to the American Asylum for the Deaf and Dumb in Hartford while their hearing brothers and sisters who stayed on the island often dropped out of school early to help farm or fish. Some of the “less educated hearing people would occasionally bring a newspaper or legal document to their deaf neighbors to have it explained,” writes Groce. By the mid-1800s, greater mobility slowed the pace of intermarriage, and the genetic anomaly that created the deaf community disappeared.

Martha's Vineyard was a nineteenth-century deaf utopia, where deafness was ordinary, not a sickness. Nor was it disabling, largely because the island's hearing residents were bilingual.

The tolerant atmosphere of Martha's Vineyard may not have been universal in America, but for most of the nineteenth cen-

ture the predilection of the deaf for signed communication was acknowledged and endorsed. The most influential educator of deaf people, and an early advocate of ASL, was Thomas Hopkins Gallaudet. One day in 1813, Gallaudet, a Congregationalist minister, watched a neighbor girl playing with other children in his garden. The child, Alice Cogswell, had become deaf in 1807 when she contracted spotted fever. Unable to communicate with her friends, Alice was aloof and shy. Gallaudet talked to the girl's father, a prominent physician named Mason Cogswell, and found out that no American schools taught deaf children, although a few wealthy families had sent their deaf children to Europe, where exciting new pedagogy had been developed. The next year, Gallaudet, with financial backing from Cogswell and others, set off for Europe to find a deaf teacher to bring to America.

His first stop was England, where he met the Thomas Braidwood family. They ran several schools of oralism, a method to teach deaf people to speak like hearing people. But after several trying months, Gallaudet's negotiations with the Braidwoods fell through. They insisted on maintaining their profitable franchise over their oralist method for which another Braidwood, John, was already attempting to establish an American school. Frustrated, Gallaudet left for France. In Paris, he went to the Institute of Deaf-Mutes that had been opened in 1755 by the Abbé de l'Epée, a man often wrongly credited with inventing sign language. (Sign language is innate, not invented.) L'Epée had noticed that deaf children had their own communication system, which he combined with French signed grammar in order to teach them. It was at this school that Gallaudet met a young teacher named Laurent Clerc, himself deaf and without speech. Clerc had traveled little beyond the confines of the school, but he accepted Gallaudet's offer of adventure. On the fifty-two-day journey back in 1816, Clerc taught Gallaudet to sign, and Gallaudet taught Clerc to use English.

Together they raised money and in 1817 opened the American Asylum for the Deaf and Dumb in Hartford. Alice Cogswell was the first student. The teachers were fluent signers, and most were deaf themselves. With the advent of ASL instruction, there was an impressive rise of literacy among the deaf, and the school was hailed as a great humanitarian experiment. Other schools, modeled after the one in Hartford, opened around the country. In 1864, Congress created the Columbia Institution for the Deaf and Blind in Washington, the first school of higher learning for the deaf. Edward Miner Gallaudet, the eighth and youngest son of the famous educator, had persuaded Abraham Lincoln to charter it, with the aim of training deaf teachers for the deaf. Edward Gallaudet then became the first principal of the school, which would later be renamed for his father. Originally, sign language was used for all instruction at the Columbia Institution.

It would not be long, however, before the founding of a school opposed to sign-language instruction. In 1867, the Clarke School for the Deaf was established by a millionaire Bostonian named Gardiner Greene Hubbard. His young daughter, Mabel, had become deaf after contracting scarlet fever at the age of five. He had hired tutors to help her keep up her speech, which declined over time. Hubbard's belief in oralism had come from two prominent educators. One was Samuel Gridley Howe, who had established the Perkins Institute, the first school for the blind, where he had won national attention for his success in educating Laura Bridgman, who was blind and deaf. Howe and educator Horace Mann had visited European schools that claimed important success teaching oralism, and the two had returned to America, hoping to replace sign-language instruction with oral methods.

One of the first teachers at the Clarke School was a young inventor and speech expert named Alexander Graham Bell. He was born in Edinburgh and came from a long line of elocution-

ists and teachers of speech to the deaf. George Bernard Shaw praised his father, Alexander Melville Bell, in the preface to *Pygmalion*, and the father has been credited with being the model for Professor Henry Higgins. In 1873, Alexander Graham Bell, then twenty-six, began tutoring Mabel Hubbard. It was to be a fortuitous union. For one thing, Gardiner Greene Hubbard was a patent attorney, interested in the telegraph and Bell's experiments with the telephone. In 1876, Hubbard helped Bell get the first patent on the telephone, although other inventors were registering similar designs and there would be years of litigation to protect the patent. Bell and Mabel Hubbard married soon thereafter. Some Bell biographies say he invented the telephone in search of a device to help Mabel Hubbard communicate with other people in the same house. Instead, it would only cut deaf people off more from the world, depriving them not only of communication but of jobs and a full place in the hearing community.

Oralism fit well with the conformist spirit of the times. The Victorian era was unsparing toward minority culture. The Welsh language was banned from schools in Wales; English was made the administrative language of the Indian subcontinent. Even the usage of gestures when speaking English was considered improper since, notes Arden Neisser in her history of sign language, "gesturing was something that Italians did, and Jews, and Frenchmen: it reflected the poverty of their cultures and the immaturity of their personalities. Sign language became a code word with strong racial overtones." Speech was God given. It was what separated man from beasts. If one did not have speech, then one did not have language and, went thinking that dated back to Aristotle, was presumably unable to reason. To remain silent, then, was to be prey to the devil.

All this suggested that deafness was a sickness, something that needed to be cured. Oralism held out the hope of correction. It was a laborious method that required intensive one-on-one

instruction. By comparison, sign could be taught to many students at once. When someone succeeded in the oral method, however, his ability could be awe-inspiring and his deafness would seem almost irrelevant.

Oralism spread in the nineteenth century, although Bell's own family showed the method's shortcomings. His wife was never considered a good speaker or lip-reader, despite the years of special tutoring from Bell and others. Even Edward Miner Gallaudet, cognizant of the shifting theories of the times, visited oralist schools in this country and abroad and came back advocating that both manual and oral communication be used. After all, it had been accident more than philosophy that resulted in his father's returning from France with Clerc, instead of from England with a Braidwood, in tow.

In 1880, the year of the International Congress of Educators of the Deaf at Milan, oralism was adopted as the universal teaching method. From the end of the nineteenth century through the early 1970s, American educators embraced the method. They taught the deaf to speak and lip-read, and therefore to use the language of the dominant culture. Deaf students were molded in the image of the hearing world, and their inability to speak was seen as a shortcoming in need of correction. ASL was dismissed as a crude slang. Linguists taught it to apes and chimpanzees, but it was considered useless for real thought and communication.

Few deaf people, however, ever mastered oralism. Those who did tended to be people who had lost their hearing after they already had language—the adventitiously or postlingually deaf—or who had significant residual hearing and could use hearing aids. Those who learned oralism could move easily between the hearing and deaf worlds. But lip-reading was a skill of superachievers. "It can be compared with breaking an eighty in golf or painting a masterpiece in oils," writes deaf educator Leo Jacobs. "Speech-reading talent has absolutely no correlation

with intelligence." Even in the best circumstances, only 30 percent of speech can be read from lip movements. Oralists can speech-read only those who move their lips distinctly, and even then can only do so in good light or at a near distance. "I can consistently understand somewhat fewer than 50 percent of the people I meet for the first time, but familiarity will raise the level of understanding to 75 to 80 percent," writes Henry Kisor, a talented lip-reader who is book editor of the *Chicago Sun-Times*. "Perhaps 10 percent of the people I come across will always be impossible to lipread." Kisor called his autobiography *What's That Pig Outdoors?*, a reference to his misreading of his son's question, "What's that big loud noise?"

Deaf students in the 1850s who had been taught ASL at the American Asylum for the Deaf in Hartford were equally literate as their hearing peers. As educators insisted on teaching oralism, however, deaf students' academic achievement deteriorated. Many deaf people became functionally illiterate, a trend that continued for the next century. A 1972 study by Gallaudet researchers found that the average eighteen-year-old deaf high school graduate read at only a fourth-grade level. By the 1960s, alarm about this low academic achievement forced educators to find new methods of instruction.

Cued Speech, invented in 1966, used fourteen handshapes formed near the mouth to signal to a speech-reader the sound being made, in order to distinguish similarly formed words such as mitt or bit. But this system was useful only if both people knew it. In the 1970s, most teachers switched to Total Communication, usually a combination of speech and signed English. This was a minor breakthrough since it acknowledged that oralism was not always the best method. There are many different forms of Total Communication, but all, like oralism, depend predominantly on the use of English. One method, called Sim Com, requires teachers to speak and sign simultaneously. Linguistically, this is nearly impossible, since it is the equivalent of

speaking in one language and simultaneously writing in another. Speaking tends to slow down, and signing gets sloppy.

ASL is not English. It has its own syntax and grammar. ASL is a separate innate language that belongs to people who become deaf at birth or before they learn to speak. The deaf in every country have their own form of this native language. American Sign Language is different from French Sign Language, even from British Sign Language. In the Southern United States, black deaf people, kept segregated from white ones, developed separate sign dialects. Only in the 1970s would ASL be studied by academic linguists, who then realized it has a highly complex and nuanced structure.

It is only now that researchers are beginning to argue that a deaf child's brain is structured to pick up ASL and that learning ASL first can make it easier to pick up English later. Most proponents of ASL agree that it is important to be bilingual and to learn signed English along with ASL. The deaf children of deaf parents, called "native signers," pick up ASL naturally from seeing their parents use it. Scientists recently discovered that deaf babies of deaf parents use this language, and develop it, first babbling at ten months, at times parallel to the learning of spoken language by hearing babies. Before, linguists had assumed that language was the same as speech and that the maturation of an infant's vocal cords determined language development. Five-year-old native signers possess vocabularies of about five thousand words, the same amount as the average five-year-old hearing child. But deaf children of hearing parents—the case 90 percent of the time—often enter school with a vocabulary of less than fifty words. As a result, some researchers have begun calling for teaching ASL to all school-age children.

Even today, ASL is rarely taught to deaf students. Most teachers use a signed version of English. The argument for this is that deaf students, to get along in the world, need to know the language of the dominant, hearing culture. Another reason is

simply practical. Most teachers of the deaf are hearing and English is their native language. It is hard enough to learn to sign in English (and many deaf students complain about the poor signing of their teachers). To learn and use ASL would be like teaching in a foreign language. That would be a considerable burden on teachers. Yet using any other method is an imposition, too, on deaf students, since research is showing that ASL is their natural language.

For ninety years after the 1880 Milan conference the use of sign language would be banned from American schools. Students who disobeyed got their hands slapped or tied down. Deaf teachers—who by 1869 totalled 41 percent of instructors of the deaf—were driven from the classroom. By the turn of the century, that percentage had dropped to 25 percent and to only 12 percent by 1960. Gallaudet became the only institution to use manual instruction, but, more and more in the minority, teachers there quit using ASL and instead signed in a version of English. (In the 1890s, the football huddle was invented at Gallaudet, to keep other teams from reading their signs.) ASL came to be viewed as no more than a slang gesture language.

Alexander Graham Bell's profound influence on educators for the deaf was a major force in the denigration of signing. Bell's motives were mixed. This prominent educator of the deaf also was a proponent of another popular movement of the day—eugenics. To avoid the emergence of a "defective" race, Bell suggested a typically eugenicist solution: Laws to forbid "the intermarriage of deaf-mutes." But there were shortcomings to such an approach, as Bell conceded in a major address on the subject to the National Academy of Science meeting in 1883. Deafness could skip generations. Although Bell's contemporaries were ignorant of Mendelian genetics, Bell realized that congenital deafness ran in families in some way. Many of his students and the deaf residents of Martha's Vineyard whom Bell had visited were not born to deaf parents but had deaf relatives.

For that reason, Bell thought there was genetic logic to drafting marriage bars very broadly to forbid "the intermarriage of persons belonging to families containing more than one deaf-mute." Even such legal proscriptions, the practical Bell knew, would not keep deaf men and women apart. Indeed, it "might only promote immorality," as deaf lovers sought out each other in secret trysts.

Far more effective, then, would be to keep deaf people from associating with one another. Bell looked at the state of deaf education and declared that it was perverse. If keeping deaf people away from one another was a necessary goal, then everything deaf schools did was wrong. "We take deaf children away from their homes and place them in institutions by the hundred, keeping them there from early childhood to the commencement of adult life," he told the scientists at New Haven. And then, when these students became adults ready for marriage, the schools held reunions and published newspapers with "personals" to keep readers informed of deaf social events around the country. The schools created lifelong networks of friends, and in every large city they formed social clubs. "After the business of the day is done, the deaf-mutes of the city meet together for social intercourse and on Sundays for public worship," Bell noted. There were state associations of the deaf, too. "Periodical conventions are held in different parts of the State, attended by deaf-mutes of both sexes. At these meetings they amuse themselves in various ways. Sometimes they hold fairs; have theatrical representations in dumb show, spectacular tableaux, dancing, &c," he said, in words dripping with disdain. More ominous, he added, was that deaf people were beginning to form national associations, and recently the Second National Convention of Deaf-Mutes brought hundreds of deaf people to New York from across the United States.

Bell's address came at the beginning of the international movement to bar sign language from the classroom. The one

thing that most united deaf people was their "gesture language." Bell acknowledged that sign was a language that deaf people thought in, a separate language "as different from English as French or German or Russian." But the use of sign, he said, was the biggest deterrent to integrating deaf people with hearing ones. Deaf adults often lacked fluency in English, Bell complained, and communicated with hearing persons by writing "in broken English, as a foreigner would speak." They were unable to appreciate great English literature or comprehend "the political speeches of the day, the leading editorials," Bell told the scientists. Yet there were misguided attempts, he said, to legitimize sign language, including a Canadian school principal's plan to write a dictionary of sign symbols. Bell's remedy was simple: use the oral method of teaching—only 14 percent of deaf students then used speech—and stop letting deaf teachers—who used gesture language in the classroom—instruct deaf students.

To his fellow scientists in New Haven, Bell made an early call for what today we would call mainstreaming. At a time when people with disabilities were being removed to closeted institutions, Bell's "grand central principle" was to educate the deaf and the hearing side by side. Deaf students would be located in the same schools as hearing ones, with limited, separate instruction in some subjects, but in the same classroom as hearing pupils for any subject "in which information is gained through the eye," such as writing, drawing, geography, arithmetic, and sewing. "For other subjects special methods of instruction would be necessary, and these demand the employment of special teachers," Bell said. In another argument that parallels those for integrated education today, Bell called for teaching deaf students in their neighborhood schools. This would save money, he noted, by ending the practice of building costly, distinct facilities.

Most crucial to integration, Bell understood, was to excise irrational "fallacies" and "fear" of the deaf. It was segregation

that created unkind myths. Such "incorrect ideas" were created because deaf students were collected "into institutions away from public observation," he noted. Contact between deaf and hearing people would erase these myths. "Whatever the cause, it is certainly the case that adult deaf-mutes are sometimes hampered by the instinctive prejudices of hearing persons with whom they desire to have business or social relations," Bell said. "Many persons have the idea they are dangerous, morose, ill-tempered, etc." A deaf person, he added, "is sometimes looked upon as a sort of monstrosity, to be stared at and *avoided*." One deaf man in Alabama, he noted, had been shot dead by a man who became alarmed by his unfamiliar hand gestures. Such words won Bell acclaim as a great champion of deaf people. But his progressive-sounding call for full acceptance and integration of deaf people only masked his dark eugenicist vision.

Bell's words carried great weight. Thomas Gallaudet had died twenty-two years before, and the oral method Bell advocated was winning international primacy. By the time of his 1883 speech, Bell was emerging as the nation's foremost authority on educating the deaf. That deaf people needed a hearing savior was dubious, given that they were well-educated, quickly entering professional jobs like teaching, and setting up extensive social networks. Yet Bell's words were considered a compassionate defense of deaf people. Underlying this presumed sympathy, however, was the oppressive belief that deafness was a cause for commiseration. The most merciful thing to do was to end deaf culture and language—even to prevent deaf people from being born. Coming from a renowned expert on the deaf—indeed, from a man hailed as their greatest champion—the oppressiveness of this pity was hard to refute. As disabled people would instinctively understand, prejudice cut deepest when it came from the charitable, not from the most bigoted.

The denunciation of sign language would not change until the 1960s, with the publication of the work of William

Stokoe. The young linguist had come to Gallaudet in the late 1950s to teach Chaucer and English literature. On the Gallaudet campus, Stokoe became fascinated with the graceful sign language students still used outside class. He began to study the signing of students who were the children of deaf parents. Gallaudet administrators frowned on his work. But in 1960, Stokoe, who was hearing, published a seminal paper arguing that ASL was a complex, three-dimensional language, and in 1965 he published *A Dictionary of American Sign Language*. Such manuals of sign language had been out of print since around 1918.

Today, deaf people are beginning to reclaim ASL as their birthright, a natural language that has been denied to them for over one hundred years. The National Association of the Deaf, in a position paper, says that deaf people should have "the right to become fluent" in both ASL and English and the right to choose to use whichever language they prefer in the classroom or elsewhere. Gallaudet and some other schools now teach ASL again. But other classes, according to Gallaudet's official policy, are conducted in signed English. I. King Jordan, who lost his hearing—and almost his life—in a motorcycle accident when he was twenty-one, uses signed English and speaks clearly. On the Gallaudet campus, this is a source of lingering criticism of Jordan, who otherwise has become a folk hero at Gallaudet and among deaf people around the world.

Since the 1988 Gallaudet rebellion, there have been brief flare-ups of student demands to make ASL mandatory for classroom teaching. In 1990, there was tragedy when one of these protesters, a student named Carl Dupree, died of asphyxiation when, following a dispute over a grade with an instructor, he struggled with four campus police officers. Students complained that the security police had only further agitated Dupree by handcuffing the hands he used for speech. Dupree was protesting his grade in a basic English class, required to stay in school, but which proponents of ASL said should be dropped. Controversy

over the use of ASL arose again at the 1992 trial of the four security police, who were acquitted of charges of using excessive force: there were several disputes over the exact translation into English of the courtroom testimony given in ASL by deaf witnesses.

The Common and Tribal

The world of deaf people, say deaf authors Carol Padden and Tom Humphries, revolves around a "different center." To be unable to hear is the norm, whereas society sees deafness as a pathology. This is the same complaint of the disability rights movement that rejects the medical definition of disability as an illness. This "different center" is clear in language. In ASL, to say someone is "very hard of hearing" means the opposite of its definition in English. To deaf people, to have no hearing is the standard. To be "very hard of hearing" is to deviate greatly from the standard, or to hear quite well.

The central tenet of the disability rights movement is complete integration into the community. At the end of the rainbow is a day when a person's disability will no longer matter. Integration will come through mainstreamed schools and civil rights laws that guarantee full access to public accommodations and the workplace. Just give us a chance, disability activists say, and we will be like everyone else.

The 1988 Gallaudet uprising was a primal roar of rebellion against decades of an expectation to adopt the dominant hearing culture and its demands for oralism, at the forfeiture of a rich deaf identity. It was a declaration that deaf people should celebrate their differentness. A person's disability will always matter, the students argued, and it will always set disabled people apart. Deaf people, they said, should make their own world. This debate echoes the integrationist argument of the last three decades among black Americans. It was the appeal-

ing Gallaudet students, with their clean-cut and All-American good looks, who made the radical argument for disability separatism.

For deaf students, a separate world meant education in their own schools, to be run more and more by deaf presidents. To them, one of the first great victories of the disability rights movement—the mainstream education law—was a threat. It led to cuts in public funding for segregated deaf schools, in part because regular schools began welcoming deaf and other disabled students. Mainstreaming, complained David Wolfe of the National Information Center on Deafness, was “like trying to solve the race problem by making everybody white.” Trying to force deaf students to fit into an alien world would only reinforce their sense of inferiority. After the Gallaudet protest, there would be renewed clamor for separate deaf education where students would learn their own language and the values of deaf culture. California’s legislature even passed a law to require deaf students to be educated with groups of deaf peers and taught by teachers “proficient” in sign. Governor Pete Wilson vetoed the legislation, which would have largely resegregated deaf students in separate schools or isolated classes.

There are reasons to believe in the idealistic and hopeful integrationist scenario that is most common to the disability rights movement. Disabled people often have more in common with the general population than do members of other minority groups. Disabled people are almost always brought up by non-disabled mothers and fathers, with nondisabled sisters and brothers. They may marry nondisabled spouses and then have children who are not disabled. Most disabilities, however, are not as isolating as deafness, which cuts off communication from others. Many deaf leaders, too, like Frank Bowe, who headed a federal commission on deaf education shortly after the Gallaudet protest, have argued that too much faith in “deaf pride, deaf culture” can cut off deaf people from the benefits of the dis-

ability rights movement. "For too long, deaf people have stood by themselves, fought for themselves alone," said Bowe. "But it is time for them to recognize that they share so much with people who are blind, who have cerebral palsy, and we all need to work together." Indeed, many deaf leaders embraced the expansion of rights spelled out in the Americans with Disabilities Act, and Jordan became a visible proponent of it on Capitol Hill.

After Gallaudet, the hearing world became more welcoming. Hlibok, for example, entered law school, saying he no longer questioned his place at a hearing school. Bridgetta Bourne's father, a Department of Defense computer expert, got a promotion. He had been passed over for many years by hearing bosses who, until they watched the daughter's protest, had underestimated his ability.

Separatist deaf pride flourished, too. One writer proposed renaming Gallaudet as Gallaudet and Clerc University, to give proper credit to the deaf member of the founding team. Many objected when the woman chosen Miss Deaf California played a Bach piano concerto for the pageant's talent competition. Should the title have gone to someone with enough hearing to play music, or picked for her ability to do something that other hard-of-hearing people could not appreciate? And deaf people protested more stridently when hearing actors played deaf movie roles—the "moral" equivalent of "putting a white actor in blackface," complained deaf activist Bobbie Beth Scoggins.

Some thoughtful disability rights activists think there is much to learn from the deaf separatist model. Judy Heumann argues that it is important for disabled people, as they overcome segregation, to hold on to their sense of identity and history of struggle. Growing up, she knew she was always "different." Even when she had reached mainstream schools she still never felt "completely accepted by my peers." She yearned for the dignity and opportunities that were second nature to nondis-

abled people, but she rejoiced in the bonds made with disabled people. Best of all was camp for disabled kids, which she attended every summer from the time she turned nine until she was eighteen. With kids who were blind, deaf, or had physical disabilities and mental retardation, she confessed secrets and found others shared her doubts and worries. "We had the same joy together, the same anger over the way we were treated and the same frustrations at opportunities we didn't have," she says. For the first time, Heumann confided that she suspected people stared at her in her wheelchair and that it made her uncomfortable. To her delight, every other kid with polio had the same feeling. At home she watched "American Bandstand," but disabled kids, she was told, "were not supposed to dance." At camp, "we danced and we danced so well that we felt good about ourselves." A kid in a wheelchair could be just as cool as "American Bandstand" dancers—at camp, anyway—and not be just another sick kid excluded from dances, dates, and even sex. Crippled girls were never expected to get married. Motherhood was thought out of the question. No boy would ever give them a second look, they were told. But at camp, Heumann recalls, they dated and "talked about getting married, where you couldn't talk about it at home." At camp she could feel comfortable and self-confident about being disabled, much as students at Gallaudet could feel secure in their deafness.

There are few places today for this kind of bonding among disabled people. Heumann is heartened by the rise, however slow, of disability culture. There are poets and writers like Vassar Miller and Anne Finger. There are novels like *The Body's Memory*, Jean Stewart's beautiful story of a disabled woman's politicization, to counter literature's more familiar embittered cripples, like Flannery O'Connor's unappealing victim who gets her wooden leg stolen by a traveling Bible salesman. Most common remain the autobiographical memoirs, which are becoming ever more political, like Lorenzo Wilson Milam's *The*

Cripple Liberation Front Marching Band Blues or John Callahan's *Don't Worry, He Won't Get Far on Foot*. Disability studies classes are being taught on college campuses. Lively magazines, including *The Disability Rag*, *This Mouth Has a Brain*, and *Mainstream* vent the new anger. There are even disability comedians and theater groups. Not surprisingly, the center of disability performance is Berkeley, home of performance artist Cheryl Wade and performance groups like the Wry Crips and remnants of Frank's Church, an avant-garde troupe that used nudity and sexual themes to discuss nondisabled people's fear of disability.

Yet disability expression lags behind the thriving deaf arts. The rediscovery of ASL sparked a deaf cultural renaissance, starting with the decision of the National Theater of the Deaf in 1972 to perform in the expressive native language of deaf people. "Once the resistance had been broken, and the new consciousness established, there was no stopping deaf artists of all sorts," writes Sacks. "There arose Sign poetry, Sign wit, Sign song, Sign dance—unique Sign arts that could not be translated into speech. A bardic tradition arose, or re-arose among the deaf, with Sign bards, Sign orators, Sign storytellers, Sign narrators, who served to transmit and disseminate the history and culture of the deaf, and, in so doing, raise the new cultural consciousness yet higher."

Not all disability activists, however, share Heumann's celebration of a separate disability culture. Robert Funk, one of the founding philosophers of disability integration, argues that deaf culture grew out of the unique experience of having a distinct language. For most disabled people, he argues, "disability will disappear as an issue," once they ease into mainstream society. This is dreaming, says Heumann, noting that the integrationist dream circa 1960s of the black civil rights movement proved unattainable. (Heumann notes that as a wheelchair rider she is more restricted and therefore more pessimistic about full integration than Funk, who uses crutches.) Funk says it will be

possible for disabled people, who come from nondisabled families and "all strata of society" to blend into an integrated world. He thinks businesses will come to accommodate disabled workers, and architects will embrace universal design, the idea of making buildings accessible to all, and homes that can be rearranged as owners age.

Today Funk's view is dominant. Civil rights legislation for disabled people was based on making physical and mental limitations irrelevant; but, like all minority groups, disabled people have had to draw on their history of oppression to become politicized and demand those rights. Disability pride is emerging and being embraced just like deaf pride before it. Funk warns that disabled people must not get caught in the trap of identifying themselves as victims, something that he argues has snared blacks and other minorities. Disabled people may succeed in balancing pride and a separatist identity borne of past discrimination, without playing the role of victim. The disability rights movement, after all, is a rebellion against being cast by society as pitiable victims. This is one minority group that understands that claiming the role of victim is self-defeating.

The disability movement would seek civil rights protection in the Americans with Disabilities Act, but the act would not demand affirmative action programs or guaranteed equality of results. Disabled people would optimistically argue that all they needed was integration and an equal opportunity to achieve. Still, there are questions. Will nondisabled Americans understand how disabled ones are reexamining what it means to have a disability? Will disabled people get a true shot at being fully included citizens?