

CHAPTER 4

A HIDDEN ARMY FOR CIVIL RIGHTS

Lisa Carl just wanted to see a movie. But in 1988 when the nineteen-year-old with cerebral palsy wheeled herself to the ticket booth of her neighborhood theater in Tacoma, Washington, the owner refused to take her dollar bill. "I don't want her in here, and I don't have to let her in," the owner later explained, noting the girl had difficulty speaking and getting around. As Carl told U.S. senators the next year, "I was not crying outside, but I was crying inside. I just wanted to be able to watch the movie like everybody else."

Carl told her story in testimony on behalf of the Americans with Disabilities Act, a bill to extend to people with physical and mental disabilities the same protections against discrimination that had been afforded minorities and women under the 1964 Civil Rights Act. The movie theater owner's rejection had been a case of blatant bigotry. But disabled people knew that, sadly, what happened to Carl was no isolated act of exclusion. In

fact, nearly two-thirds of disabled people had not been to a movie theater in the previous year, compared to just 22 percent of the general population. Seventeen percent of disabled people had not eaten a meal in a restaurant, although only 5 percent of nondisabled people had avoided dining out. As compared to only 2 percent of all others, 13 percent of disabled people never shopped in a grocery store. When pollsters from Louis Harris and Associates asked disabled people why they remained so separate, 59 percent explained that they were afraid to go out. They were fearful of being mistreated, as Carl had been at the movies. And 40 percent said their access to public places was restricted by physical barriers, meaning buildings and streets, while 49 percent said transit systems were inaccessible. It was the same poll that found that 66 percent of disabled people were unemployed, although two-thirds of that group said they could work and wanted to work. Either bosses would not hire them, they claimed, or they could not get through the front door of inaccessible workplaces.

No other group of citizens was so insulated or so removed from the American mainstream. Twenty-five years after black Americans had successfully won a legal end to their exclusion from public places and jobs, similar segregation was still a fact of daily life for millions of disabled people. The disability rights victories of the previous decade—a law guaranteeing public education and Section 504—had been not nearly enough to end the isolation. That was why disability activists now turned their attention to winning passage of a broad civil rights bill. For the first time, people with disabilities were asking Americans to recognize that the biggest problem facing them was discrimination. They sought access and opportunity, not charity. Nearly every disabled man and woman has a story like Lisa Carl's, all of which helped fuel the anger and passion that brought about the unexpected and stunning passage of the ADA, the most sweeping civil rights law since 1964. Bob Burgdorf has such a story as well.

Just twenty years old in 1968, Burgdorf was home from college for the summer and about to take part proudly in a new program sponsored by the electricians' union in Evansville, Indiana. The teenage sons of electricians in the Ohio River city would work alongside their fathers and their fathers' friends. When Burgdorf had shown up for his first job, the foreman, noticing how Burgdorf's right shoulder hung lower than the left in his work T-shirt, pulled him aside from the large group of electricians and "summer student assistants" and dismissed him. "We're not hiring any cripples here," he said.

Burgdorf had swelled at the thought of working with his father. His father's oldest son, he had always been proud to be Robert L. Burgdorf, Jr. That morning, he had felt particularly close to his dad as he had tugged on his electrician's belt of tools "slung low over my hip like a holster." The old leather belt filled with pliers, a scratch-awl, and screwdrivers belonged to Burgdorf's father, who had patiently explained how to use each tool.

Even with his paralyzed upper arm, Burgdorf knew he could use any of the tools and do any job. Neither of his parents ever talked about his minor disability. Perhaps it was because his bout with childhood polio, when he was a year old, had been a time washed in fear and ignorance, when the milkman had quit making deliveries rather than come near a "contaminated" house. But Burgdorf's father had taught him not to let his atrophied arm stop him from doing anything any other kid did. He had learned to do everything left-handed, even shoot basketballs.

In his jeans, T-shirt, electrician's belt, and hard hat—his father's uniform—Burgdorf had felt adult and manly. But when the foreman turned him away, Burgdorf would recall later, "My macho bubble was burst." He had wanted to scream, You can't do that. It's against the law. But Burgdorf knew there was no antidiscrimination law to protect a man with a paralyzed upper arm. There would be no chance for Burgdorf to prove himself.

All he could do, then, was retreat to his white 1956 Ford and drive home, where he stripped off the betraying belt and hard hat.

The first version of the Americans with Disabilities Act was proposed by thirteen Reaganites on the little-known National Council on the Handicapped. Seemingly far out of step with the president who had chosen them, these political conservatives had met in a Washington hotel in February 1988 to adopt a sweeping civil rights bill. The legislation had been drafted by the council's thirty-nine-year-old attorney and research specialist, Robert L. Burgdorf, Jr. He was the tall, quiet man sitting at the front of the room, in a suit coat that, unless you knew about it, hid his paralyzed upper right arm.

It had been twenty years since Burgdorf had been refused a job as an electrician's assistant by the small-minded construction manager. In that time, he had gone to law school and become an attorney specializing in disability law. He had plotted the outline of an antidiscrimination law in his head. By the time he arrived at the National Council on the Handicapped in 1984, the bill was virtually in his back pocket. It was Burgdorf's good fortune, therefore, to hook up with Justin Dart, Jr., a member of the council who believed in civil rights for disabled people with a passion that some would say bordered on zealotry. On behalf of the council, Dart, a small, frail-looking man, had embarked on a tour of all fifty states to conduct town meetings with disabled people. He had paid for the trips largely out of his own pocket. At every meeting the consensus was the same: people of various disabilities all said they suffered from discrimination. Sometimes Dart would bring along members of the council, who would be surprised to find people defining protection of rights—not, say, government welfare or health benefits—as their most pressing issue. Shortly after Burgdorf arrived

at the council, he and Dart sat in an office and Burgdorf mentioned his dream of a separate civil rights act. Yet Burgdorf doubted, given the political climate and the conservative council, that such a bill would go anywhere. "How are we going to sleep nights," Dart asked, "if we don't try?"

Both Dart and Burgdorf had contracted polio in 1948, shortly before the vaccine invented by Jonas Salk would effectively wipe out polio in the United States. Dart had been eighteen, Burgdorf an infant. It would be many years before Dart came to see the slights, indignities, and lost opportunities of his life as a paraplegic as a form of discrimination. When University of Houston officials in the early 1950s withheld the credits he needed for his teaching certificate, believing a man in a wheelchair could not teach successfully, Dart accepted it as fact that he would have fewer choices. At the university, Dart had organized the first "integration" club. Members advocated that the all-white Texas university start allowing entry to black students. The club was a miserable failure, unable to get university officials even to pretend to listen. Only five students, on a campus of fifteen thousand, joined. Coincidentally, three of the five integration club members were in wheelchairs. If it was their disabilities that allowed them to identify with another oppressed group, they never let on, or even realized it. During all their many hours of discussions on the correctness of civil rights for black Americans, there were "not even five minutes of discussion on disability rights," says Dart. Reflecting on that time, Dart says, "That shows the sort of subhuman perception that existed of people with disabilities, and how it was internalized even by those with disabilities."

It was not until 1967, on a trip to South Vietnam to put together a report for a world conference on rehabilitation, that all the hurts of being a paraplegic would well up into a traumatic understanding of his own "subhuman status." In war-torn Saigon, Vietnamese officials escorted Dart to an "institution" for

young children with polio brought in from rural hamlets. In his wheelchair, Dart arrived at a large metal shed with a concrete floor "like the kind you find for a public market in the tropics." Dart was unprepared for the vision of hell inside. One hundred young children had been brought to this flimsy shed, left to die and be buried in an unmarked field outside. Children with his own illness had been treated as bereft of worth, dignity, or future. "It was like a branding iron burning that message into my subconscious or onto my soul, to see how human beings were being treated there." The children had been left on the floor, "with bloated bellies and matchstick arms and legs like you see in pictures from Dachau and Auschwitz, with their eyes bugging out, lying in their own feces and urine and their bodies covered with flies." Once in a while, someone would bring a suffering child a bowl of maggoty rice. One dying boy, with big eyes, had slowly held out his hand to Dart, pleading for help. At that moment, Dart was overwhelmed by a mixture of fury, helplessness, grief, and even guilt. "It was one of those things I didn't believe I would ever see," he says. "I had grown up in Chicago with maids and a chauffeur. I had been privileged. In Japan, I was president of a company [a division of the Rexall drugstore chain run by his father]. I lived in a very comfortable place and had a big staff."

Dart quit his business and dedicated himself to figure a way to help other disabled people. He and his wife, Yoshiko, retreated to a snowy mountaintop in Japan, giving up their comfortable life-style to live in an abandoned farmhouse with no running water, no electricity, and no telephone. The house was at the end of a quarter-mile-long dirt road that turned to mud during the rains, making it impassable for Dart's wheelchair. They had no car. When Dart needed to go into town, several miles away, often he would crawl on his hands, dragging his legs, to the end of the road, and catch a ride on a wagon. The children in Vietnam were not given wheelchairs, so Dart would

deny himself use of one, too. Yoshiko describes the period as one where the couple sought to rehabilitate themselves before they could rehabilitate others. Together they read books of philosophy. The Darts, too, started paying closer attention to the accomplishments back home of Martin Luther King, Jr., who soon was to be tragically assassinated by a sniper in Memphis. They began writing to leaders of the student protest movement in Berkeley and elsewhere. Feeling healed, the Darts returned to the United States in 1974, eventually settling in Texas. There, Dart began serving on numerous state disability groups.

Dart's father, Justin Dart, Sr., was a prominent California Republican. The blunt and forceful drugstore magnate was one of Ronald Reagan's few personal friends and the leader of Reagan's "kitchen cabinet," a small circle of California millionaires who had pushed Reagan into gubernatorial politics and, ultimately, toward the presidency. Most people around the younger Dart assumed that his prominence during the Reagan administration had come as a payoff owed his father. This imbued Dart with an aura of power, yet Dart had won the jobs by virtue of his own activism as a Texas Republican. In fact, although he became a prominent spokesman on disability, Dart never talked to Reagan about what he was doing. Nor did father and son, who had a complex and estranged relationship, ever discuss the son's appointment. Only rarely in his life had Dart even told his father—the dashing, athletic industrialist—about his disability advocacy. "As far as I know, my father didn't oppose my being appointed," says Dart. "Otherwise, I assume, I wouldn't have gotten it. But I don't know either that he supported it."

There had been many reminders for Dart and Burgdorf that no matter what they accomplished, in the eyes of many they would always be seen as incapable because of their disability. For Dart it was a severe disability, the loss of his legs. For Burgdorf it was something minor, a withered arm. A parent, too, like Sandra Swift Parrino, the chairperson of the National Council on

the Handicapped, could feel the sting of stigma, just by watching how people discounted her severely physically disabled son's attempts to get an education and go to college. It did not matter if disability came at birth or later, whether the person was rich or poor, or even if it did not interfere with one's accomplishments. To be disabled meant to fight someone else's reality. Other people's attitudes, not one's own disability, were the biggest barrier. This frustration gave rise to the ardor behind the disability rights movement.

Patrisha Wright arrived in Washington in 1980 like a spring storm, clearing the air of Washington's clubby disability lobby. Existing lobbyists came from professional and parents' groups. They had succeeded in establishing and then jealously guarding a multimillion-dollar stream of federal funding for nursing homes, sheltered workshops, vocational rehabilitation, and other disability programs in the traditional medical model. These lobbyists had little sense of the emerging movement of disabled people to take control of the programs that affected their lives. Wright understood this new wind. Wright had set up the lobbying office of DREDF, the Berkeley-based Disability Rights Education and Defense Fund. For the first time disabled people would be represented in Washington by a group they ran themselves.

"I do civil rights," Wright explained during a courtesy call to one of the key disability group lobbyists her first week in Washington. "We do budget. We don't do civil rights," he told her icily. "You will," replied Wright, cutting off the meeting as she swept out of the room. The presumptuous newcomer was proved correct. Wright and the lobbyist would become friends and allies in the 1982 battle with the young Reagan-Bush administration to save Section 504 and the education guarantees for disabled children. Other important civil rights victories would follow, like one for a housing discrimination bill. When

the disability lobby was faced with its most important challenge—passage of the Americans with Disabilities Act—Wright led the charge.

Growing up in Connecticut, Wright had decided early on that she would one day be an orthopedic surgeon. But a degenerative muscle disease in her eyes left her with double vision. She wandered to California, found work in a nursing home, and then latched on to the deinstitutionalization movement of the early 1970s. Hired to run an experimental program for adults coming out of state hospitals, she would take the principles of the independent living movement, which had begun in nearby Berkeley, and apply them to men and women with retardation and cerebral palsy. Wright had set up a large group home in Martinez, a small town north of San Francisco, and taught the residents to be independent. One morning, six months into the job, Wright was called urgently into the director's office. Two of the residents had been caught in bed together the night before, he informed her sternly. "Far out," replied Wright, figuring that was appropriate behavior for two adults recently freed from lifetimes spent in institutions. Wright was fired. The project fell apart and the thirty-two men and women were scattered to geriatric nursing homes.

For Wright, it was a revelation of the lack of respect given disabled people, all in the name of helping. "I realized that it would not be acceptable to say that because someone was born black or a woman that they should live in an institution," notes Wright. "But it was all right if they were born disabled. We had all these euphemisms. We said we were 'providing,' 'caring for,' or 'protecting' them." In 1977, Wright joined the HEW takeover, volunteering as Judy Heumann's personal attendant. She worked with Heumann for two years, getting schooled in the vision of the nascent disability movement, and then joined the newly formed DREDF, which had evolved as the legal arm of Berkeley's Center for Independent Living.

The first version of the Americans with Disabilities Act had

been a bust. Burgdorf's bill was introduced in the closing days of the 100th Congress in 1988 to almost universal disregard. Legislators, on the way home for reelection races, ignored it. Ronald Reagan, in the dwindling days of a presidency thrown into suspended animation by Iran-Contra revelations, apparently did not even know of the bill's existence. The press and the public ignored it.

Now, at the beginning of the Bush administration, the ADA became the property of Wright, of the disability lobby that had been remade in her image, and of Democratic lawmakers. Among Washington officialdom in cookie-cutter dark business suits, Wright stood out in slacks, loose sweaters, and her long, light brown hair flowing straight down her back, as if she had come straight off the 1960s Berkeley campus. Wright was a brilliant tactician, tenacious, detail-oriented, and absolutely driven to win broad civil rights for disabled people. Senators Tom Harkin of Iowa and Edward Kennedy of Massachusetts, working with Wright, rewrote the ADA. This time the liberals were more conservative than the Reaganites on the National Council on the Handicapped. They narrowed the scope of the accommodations to be made, making the bill more palatable to business and therefore more likely to become law.

Burgdorf, Dart, and their conservative colleagues the year before had written a radical "flat earth" bill. Within two years, everything would have to be made accessible—every bus, subway station, restaurant, and theater. A second-floor barbershop would have to install an elevator, unless doing so would likely put it into bankruptcy. The modified bill stipulated that only new buildings, or old ones undergoing major renovation, would have to be made accessible. Such changes could be made for less than 1 percent of a new building's total cost. Also dropped from the original bill was a provision that would have allowed disabled people to sue for punitive damages if they faced discrimination from a business. Beyond Washington's Beltway, activists

like *Disability Rag* editor Mary Johnson worried whether Wright was giving up too much.

Even modified from Burgdorf's original bill, the ADA was a striking departure from existing civil rights law. What made disability rights controversial—and trickier than granting rights to blacks, women, and other minorities—was that it could cost businesses money. The 1964 Civil Rights Act had simply required businesses to change their practices. But the ADA would require businesses to spend money, if necessary, to avoid being discriminatory. A restaurant might have to pay several hundred dollars to build a ramp over the steps outside. A developer building an office or a shopping mall more than two stories high would have to include an elevator. A clothing store might have to widen its aisles so someone in a wheelchair could pass through. A company would be expected to make inexpensive modifications to the workplace to accommodate disabled employees. The 1973 Rehabilitation Act amendments had required similar changes of employers, but as a quid pro quo for getting government funding. This time such change was the law without expectation of reimbursement from Washington.

Aware of the potential burden on business, the ADA specified that modifications were to be made only if they were easily achieved and at reasonable expense. A small business might be required to spend a few hundred dollars, a larger one several thousand dollars, depending on the resources of each. The law, however, did not set a dollar figure. It would rely on logic and eventually, if necessary, the courts to determine a company's obligations. To make stores accessible, the rule of thumb was that an owner would usually be able to recoup his investment in new business. And in accommodating workers, companies that had complied with the 1973 Rehabilitation Act had discovered that most changes were simple and cheap. A 1982 study for the Department of Labor found that half the accommodations made in the workplace cost little or nothing. For example, it was easy

to put a desk on blocks to raise it for a wheelchair user. Another 30 percent of the accommodations were achieved for between \$100 and \$500.

Many businesses, particularly small ones, complained that the law was vague and potentially costly. Yet despite these concerns, business groups' opposition to a bill that would open companies up to a potential spate of lawsuits was surprisingly muted, especially when compared to the business community's vociferous fight against the 1964 Civil Rights Act. This time, however, no business lobbyist wanted to look like a bigot fighting a civil rights bill, particularly one that was rushing to passage with strong bipartisan support from lawmakers and the new, sympathetic Bush White House. More important, however, was that businesses had come to see disabled people as a new source of both labor and customers.

There were other costs of the ADA to spread around. New buses and major transfer stations would have to be accessible to wheelchair users. Telephone companies would be required to hire operators who could take a message typed by a deaf person on a telecommunications device for the deaf and then relay it orally to a hearing person on another phone. Government programs could not treat disabled people differently from others.

What the ADA mainly required was common sense and a creative way of thinking about the way disabled people fit into the workplace and society. Burgdorf liked to engage a blind attorney, Chris Bell, in challenging discussions of how guaranteeing rights to disabled people would work. It was Bell who first talked of changing what he called the "social context." He would ask people, "Could a deaf woman be a secretary?" Of course not, they would tell him. How would she answer the office telephones? But why, Bell would counter, should we think that every secretary needs to answer the telephone? In an office with more than one secretary, one secretary could answer the phones and another could do more of the filing and typing.

A Hidden Power

Given the sweep of the ADA, it seemed a formidable task to win passage. For one thing, disability rights constituted a stealth civil rights movement. Although its activists pointed to the black, women's, and gay rights movements as models, unlike those causes, the disability rights movement had never filled the streets with tens of thousands of protesters. It had no Martin Luther King, Jr., to bring it together, no Betty Friedan to write its manifesto. It had no unifying touchstone moment of courage or anger like the Montgomery Bus Boycott, the Freedom Rides, or the Stonewall riots. There was virtually no attention from the public or press. The fight for disability civil rights was a largely invisible, almost underground, movement.

Yet the disability movement had a power unlike any other. Representative Tony Coelho of California argued that its strength came from a "hidden army" of people who had an instinctive understanding of the stigma of being disabled. Either they had a disability themselves, or someone in their family had one. The ranks of this army were vast, given that more than one in seven Americans had a disability that would be covered under the ADA. It was no surprise to Coelho, then, that many on Capitol Hill were part of this army. Coelho was part of it himself. After a truck accident on his family's dairy farm, Coelho, then sixteen, started having mysterious blackouts and body spasms. When a doctor finally diagnosed the condition as epilepsy, Coelho was dismissed from a Jesuit seminary where he was preparing for the priesthood. At the time, Catholic canon law barred ordination of those "who are or have been epileptics, insane or possessed by the devil." Coelho's parents, too, had reacted with terror. In Portugal, where the family was from, epilepsy was a sign of the devil, the cost of some ancestor's past sin. On every job application he was forced to check off epilepsy and then was turned down from one job after another. California

made him give up his driver's license. Even when Coelho was in position to run for Congress in 1978, his opponent meanly called him "a very sick man" and asked voters, "What would you think if Coelho went to the White House to argue a critical issue for you and had a seizure?" Coelho won anyway, but he did not forget the rejection he felt because of his disability. He realized, however, that it was the prejudice of others—not the seizures, which were controlled by medicine—that was his biggest barrier.

Coelho had been the bill's original House sponsor. In the Senate, the first version of the ADA had been championed by Republican Lowell Weicker, the father of a son with Down's syndrome. There had been seemingly momentous setbacks for the ADA when Weicker lost reelection in 1988 and then Coelho, in 1990, was forced to quit Congress abruptly after acknowledging errors in public disclosure of a controversial junk bond investment. Nevertheless, there were other members of the "hidden army" to step in and capably guide the bill. In the House, Coelho asked his closest friend, Maryland Representative Steny Hoyer, to take over. What Coelho and Hoyer knew—but which Hoyer had not discussed even privately with other lawmakers—was that Hoyer's wife, too, has epilepsy. In the Senate, leadership of the bill would fall to Harkin, who would deliver part of his floor speech in sign language so that his deaf brother watching television could understand. Edward Kennedy spoke of his son, Teddy, Jr., who lost a leg to cancer. In addition, the senator's sister is retarded, and the Kennedy family in the 1960s had helped lead the parents' movement that brought retardation out of the family closet. Senate Republican leader Bob Dole had a paralyzed right arm, the result of a World War II injury from enemy gunfire as he tried to rescue one of his men on an Italian battlefield. Senator Orrin Hatch of Utah cried openly on the Senate floor as he talked about his brother-in-law, who had polio and slept in an iron lung at night, and how Hatch had once

carried the man up the long steps of a Mormon temple in California.

Crucial help, too, came from Ralph Neas of the Leadership Conference on Civil Rights, who convinced often reluctant civil rights leaders to put disability rights at the top of their agenda. Neas saw that disabled people faced discrimination and realized the benefits, too, of expanding the civil rights coalition. But Neas also understood disability. A 1979 attack of Guillain-Barré syndrome, a paralyzing neurological disorder, left him close to death and unable to speak or breathe without a respirator. After over one hundred days in a hospital intensive care unit, he slowly recovered.

But of all the members of the "hidden army," the most surprising, and perhaps the most important, too, turned out to be President George Bush. He, too, had dealt with the pain of disease and disability in his family. In 1953, the Bush's three-year-old daughter, Robin, was diagnosed with leukemia and died an agonizing death from it. One Bush friend would call the girl's struggle the most searing moment of the future president's life. Bush's son Neil has a severe learning disability, which in part prompted Barbara Bush to make literacy her White House campaign of choice. The youngest Bush son, Marvin, had a section of his colon removed in 1985 and wears a plastic ostomy bag. He became a spokesman for the Crohn's and Colitis Foundation of America, wanting to calm others' fears about the operation and explain that it did not hurt his professional life, his ability to play sports, or his relationship with his wife. Bush talked of the "courage" of his favorite uncle, surgeon John Walker, who contracted polio at the height of his career and could no longer pick up a scalpel. The polio made Walker, who had been the family's best all-around athlete, a quadriplegic. Bush spoke with admiration of his uncle's total absence of bitterness.

Still, George Bush seemed strangely cast to become the

shining knight for the disability rights movement. Indeed, in 1982, as vice president, he had seemed to be its most formidable enemy. He was poised to wipe out the movement's two biggest accomplishments: the 1975 law that had guaranteed a public school education to all disabled children and the amendments to the 1973 Rehabilitation Act. In 1982, state and local governments were complaining of the expense of educating disabled children. Similarly, businesses and state governments worried about the cost of the largely untested antidiscrimination law. Although the law had passed in 1973, the regulations that put it into place were not promulgated until 1977. The Reagan-Bush administration had been sworn into office in 1981 with a mandate for deregulation. Bush was given his first significant vice presidential chore in being chosen to lead Reagan's Task Force for Regulatory Relief. Its purpose was to pare away at the thicket of government regulations. Among the first regulations under attack was Section 504 and the guarantees of an education for handicapped children.

Disabled people and parents responded quickly and in large numbers. Mail sacks, with some 40,000 cards and letters, were dumped at the White House. Bush understood that he was dealing with a hidden grass roots constituency. "The protest was spontaneous and it was swift," recalls Bush's legal counsel, C. Boyden Gray. "Obviously it was not a cynical, political thing coordinated in a cynical, political way. It was a genuine response. And that demonstrated to me and to [Bush] that this movement had enormous impact." Clearly, disabled people could be mobilized to cause controversy for the new administration. Bush agreed to meet with disability groups to negotiate the administration's plan.

So it was that Vice President Bush found himself face-to-face with disability rights activist Evan Kemp, Jr., across a table in the Old Executive Office Building. Kemp, an attorney who had long identified himself as a Republican, then worked for con-

sumer activist Ralph Nader, as director of the Nader-funded Disability Rights Center. With his six-foot, three-inch frame seated in a bulky power wheelchair, Kemp was a commanding figure. Yet he was a gentle man, given to speaking slowly in a soft voice.

Trying to convince the new vice president not to heed the alarmist complaints of business groups hostile to the antidiscrimination law, Kemp used a conservative argument. Disabled people wanted independence, Kemp told Bush. They wanted to get out of the welfare system and into jobs. They did not need a paternalistic government to help them. The "eye-opener" for Bush, according to Gray, was that disabled people were seeking self-empowerment rather than looking for "some captured bureaucracy in Washington, D.C., which usually was the thing that Washington, D.C. interest groups wanted." When the administration held hearings around the country, disabled people and their parents were visible at every stop to protest any changes in the disability protections. By March of 1983, Bush announced that the administration had dropped its objections to Section 504 and the education rules. Kemp and the disability groups had prevailed, and the disability movement came away with a new confidence in its own power as well as with a new political sophistication.

In 1964, Kemp had graduated near the top of his University of Virginia law school class. Yet thirty-nine applications to law firms netted thirty-nine rejections. Some employers told him up front they doubted a disabled man could handle the demands of being a young associate, particularly the airplane travel. Luckily, Kemp had a well-connected uncle, powerful Washington political columnist Drew Pearson, who helped him get hired at the Internal Revenue Service. Later, Kemp would move to the Securities and Exchange Commission. Kemp, who had a neuromuscular disease, did not use a wheelchair until he broke his leg in 1971. During his first seven years in government, Kemp had

enjoyed steady raises. Once he began using the wheelchair, he would not get another raise for six years. Finally, he sued the SEC for discrimination and won.

Kemp and Bush came away from the confrontation over rules as mutual admirers. Later, they became potent allies. Bush began paying attention to disability issues. When he spoke to disability groups, the vice president would seek Kemp's touch in drafting a speech. In 1987, Reagan, on Bush's recommendation, named Kemp a commissioner to the Equal Employment Opportunity Commission, the federal agency responsible for fighting employment discrimination. In 1989, Bush, as president, named Kemp the EEOC chairman.

For Kemp and the disability movement, another and perhaps even more significant friendship came out of those 1982 meetings. It was with Gray, Bush's legal counsel. Kemp and his partner in the White House negotiations, Patrisha Wright, the lobbyist for the Disability Rights Education and Defense Fund, spent hundreds of hours with Gray in his office, explaining their vision of disability as a rights issue. Gray, a lanky six-foot, six-inch man whom *The Washington Post* once described as a "stoop-shouldered Ichabod Crane with a somewhat distracted, professorial air," started visiting Kemp's apartment on Q Street in Georgetown for late-night bridge games. Their friendship grew.

Kemp and Gray came from similar, privileged backgrounds. Both saw the law as a means to change society. And, in a city that usually rewarded play-it-safe politics on issues everyone could agree upon, both had taken on what seemed like quixotic or unpopular causes. Around the White House, Gray was sometimes looked at askance for what was considered his eccentric support of alcohol-based fuel for automobiles. He parked his old, battered methanol-powered Chevy in the lot next to the West Wing of the White House. Both Kemp and Gray became vanguard champions of disability rights.

Having lived with a death sentence over his head, Kemp had been imbued with an understated self-confidence. He could rock the boat, even attack a well-loved figure like Jerry Lewis, and know he could handle the fallout. The disability that made him different freed him of any pretense to honor convention.

Gray was not disabled, but he had an instinctive understanding of the fight for self-worth of Kemp and other excluded people. When Gray was ten, his mother died. Gray, an heir to the R. J. Reynolds tobacco fortune, was sent from his North Carolina home to boarding school at St. Mark's in Massachusetts. There in the mid-1950s, and even later at Harvard, he found his Northern classmates automatically assumed he and all Southerners were bigots, rednecks, and stupid. Even the fact that he eventually would graduate second in his class at St. Mark's did not dispel the prejudice. "The stereotype was that you spoke with a Southern accent, so you've got to be dumb," Gray would recall. It was that painful experience of prejudice that allowed Gray to empathize with the desires of disabled people to overcome low expectations and their distaste for being stereotyped.

Gray's growing friendship with Kemp made Kemp's talk of discrimination concrete. For the first time, Gray had a friend whom he could not take to his favorite restaurants, because they had steps that blocked access to a quadriplegic in a heavy electric wheelchair. Even Gray's home was off-limits, made inaccessible by a flight of stairs. During the negotiations over Section 504, David Stockman's Office of Management and Budget drafted a new White House position that applied a cost-benefit analysis to proposed disability benefits. To the bean counters at OMB, it seemed sensible. The less disabled a person—and presumably the more likely that person was to work and live independently—the more help and rights he or she got. The more disabled someone was, the less he or she was guaranteed. When Kemp confronted Gray with a leaked copy of the OMB memo, Gray agonized. Kemp, after all, was severely disabled. And Gray

knew he could not justify a position that would put a price tag or a cost-effectiveness formula on his friend's worth. The proposal was killed.

"It was a wonderful period in my life," says Gray of the fight over the regulations. "It was one of the most exciting times." Kemp, says Gray, "was a great teacher, patient beyond belief." He reached out to explain the experience of disability, "not to scream at me," Gray said, or accuse him of being "some Neanderthal reg-basher." Gray, years later from his wood-paneled office atop the West Wing of the White House—at a time when he was being portrayed in the press as the heavy holding up an agreement on a civil rights bill to reinstate employment protections overturned by Supreme Court decisions—spoke nostalgically of the "remarkable collection of individuals" who had come together on the disability rights issue. "Maybe that's what it takes," he said. "Leadership that is not monolithic and closed."

It was such success winning over people in power that gave advocates faith that Washington was ready for a disability rights bill. A key but little-noticed moment came in May of 1988. Kemp and other activists, in town for the annual meeting of the National Council on Independent Living, met in a downtown Washington hotel. Most of the advocates were Democrats, others were Republicans. They divided the campaigns of the 1988 presidential contenders. Each would go to work for one of them. And each, they vowed among themselves, would try to push their candidate toward the same goal: they wanted a statement of rights for disabled people, like the ADA, which had been introduced in Congress that same month.

Kemp took the Bush campaign. Three months later, Bush pledged, "I'm going to do whatever it takes to make sure the disabled are included in the mainstream." Those simple seventeen words, spoken during Bush's image-turning acceptance speech at the Republican National Convention, marked the first time that an American presidential nominee had acknowledged

disabled people as a political force. The Republican nominee had scored with his promise of a "kinder and gentler" presidency, and inclusion of disabled people in the mainstream would be a prime example he would mention on several other occasions. For several years Bush pollster Robert Teeter presciently had advised his political clients that disabled people and their families were growing into an untapped constituency.

At the polling firm of Louis Harris and Associates, company vice president Louis Genevie was proving Bush's instinct correct. Genevie was tracking the voting preferences of disabled voters. Immediately following Bush's words at the New Orleans convention and on a few other occasions when he spoke of disability rights, disabled voters in Genevie's survey swung markedly to Bush. After Bush crushed Democrat Michael Dukakis in the November election, Genevie wrote to Bush that disabled voters who had switched to Bush had constituted up to one-half of the four million difference of popular votes between Bush and Dukakis. This made up one to three percentage points of Bush's seven-point margin of victory, Genevie figured. In part, this reflected the tremendous overall shift by all voters to Bush, who started the campaign seventeen percentage points behind, according to one poll. By the time of Genevie's last poll—before Bush's election-eve commercial in which he again embraced disability rights, presumably sending his support up again—the Republican candidate had 44 percent of the disability vote compared to 49 percent for Dukakis. Genevie considered the narrow margin highly significant, given that disabled people, by virtue of their poverty and dependence on government social services and welfare, were considered near monolithic in their support for any Democratic candidate. His polling did not even count family members, who could be equally strong activists. "A candidate ignores the issues of disabled people at his own peril," Genevie would later say.

* * *

The disability movement's strength—the ubiquitousness of 35 to 43 million people with disabilities—was also a weakness. The disability rights movement spanned a splintered universe. There are hundreds of different disabilities, and each group tended to see its issues in relation to its specific disability. There were groups for people with head injuries, different groups for blind people, and still others for cancer survivors or those with diabetes, arthritis, learning disabilities, and mental illness, all fighting for specific programs, funding, and laws to address the needs of members of their own group. Sometimes the groups clashed. Wheelchair users fought for curb cuts. In some cities in the 1970s, activists had even secretly taken to destroying curbs with sledgehammers. But blind people with canes, who tapped curbs for a sense of location, often wanted them kept in place. Sometimes there were bitter disagreements among the same class of disabled people. Members of the National Federation of the Blind made a lonesome break with other disability groups and withheld support of the ADA. Federationists reject any special help that might let sighted people conclude that blind people are inferior. They object to crossing beepers at traffic signals or elevators that announce a floor number. They insist on being allowed to sit next to an airplane's emergency exit, and several federationists have let themselves be arrested rather than move. However, other large groups representing blind people, like the American Council of the Blind, dismissed the rival federation's objections to traffic signals and airline seating restrictions—which they lauded as conveniences and understandable rules—and fully supported the ADA.

The ADA brought this fragmented population together in a fight against discrimination. "People with epilepsy now will be advocates for the same piece of legislation as people who are deaf," said ADA lobbyist Liz Savage. "That has never happened

before. And that's really historic." There were 180 national organizations that endorsed the bill, from large charities like the National Multiple Sclerosis Society and the American Diabetes Association to smaller ones like the National Ostomy Association, the Association for Persons with Severe Handicaps, and the International Ventilator Users Network. There were groups representing all the major disabilities, including spinal cord injuries, deafness and visual handicaps, mental retardation and mental illness, as well as those for newer or less-well-known conditions, such as AIDS, Tourette's syndrome, and chronic fatigue syndrome. To win passage of the ADA, disabled people had to forge historic alliances not only among different disability groups and politicians but with the professionals who had cared for them for so long. Some disabled people complained that these health-care workers, particularly nondisabled ones, were controlling and paternalistic. Too often, therapists and social workers assumed they knew best instead of trusting the wishes of their clients. Many professionals felt threatened by the new group consciousness of disabled people. They were afraid or reluctant to share decision making or give up power that, in some cases, might even threaten their own jobs. Others embraced the quest for self-control and saw themselves as partners working with, not for, their newly militant clients. More and more of the younger professionals were disabled themselves.

Back home in Austin, Texas, Bob Kafka and Randy Jennings usually fought each other. Yet both came to Washington the same week in 1990 leading delegations of Texans to lobby for passage of the landmark civil rights bill for disabled people. They shared the same goal, although their style and tactics could hardly have been more different.

Kafka, a savvy protest veteran and paraplegic who used a wheelchair, brought thirty militant activists, all disabled and all members of American Disabled for Accessible Public Transit, or ADAPT. They came to disrupt Congress with protests, sit-ins,

and other acts of civil disobedience. Jennings and his seventeen colleagues—only one of whom had a disability—were rehabilitation professionals who belonged to the Texas chapter of the National Rehabilitation Association, or NRA. They had come for polite meetings with members of Congress to explain why their clients needed their rights protected. Together these two groups formed a powerful coalition that would successfully raise the consciousness of Congress to the countless acts of discrimination that disabled people faced daily.

ADAPT had been founded in 1983 to empower disabled people to engage in direct action protest. The group made a priority of getting all city buses equipped with lifts. Riding a bus was the most basic symbol of equality, resonant of the black civil rights movement. It meant being able to go to work, to see friends—in short, to be independent. As Atlanta activist Mark Johnson put it, “Black people fought for the right to ride in the front of the bus. We’re fighting for the right to get on the bus.”

In eight years, there had been several hundred arrests of ADAPT members in civil disobedience protests around the country. The group disrupted every national convention of the American Public Transit Association (APTA), the association of public bus systems. By offering themselves up to mass arrests, they forced each city, from St. Louis to San Antonio, to consider the injustice of excluding disabled people from using buses. But it had been a lonely battle. Even Rosa Parks had shunned them. ADAPT had asked the symbol of the Montgomery Bus Boycott to march with them when they went to Detroit, where Parks lived. She agreed but then, after pressure from Detroit Mayor Coleman Young, who was seeking to please the visiting APTA convention, sent a letter of withdrawal that blasted ADAPT for its civil disobedience tactics, which would “embarrass” the city’s “guest.”

Despite its outsider image—even most disability groups dismissed it as a marginal maverick—ADAPT’s founder, Wade

Blank, had begun to make the organization a player behind the scenes. Once again, the key link was Evan Kemp. The radical and the Republican were diehard fans of the Cleveland Browns. They also had in common their devotion to disability rights and spoke often on the telephone of their latest strategies. The timing of ADAPT's Washington march had been set to Kemp's judgment of when it would be best to pressure Congress and send a message to the White House.

Blank's discreet line to the White House had given ADAPT new power. Several months before the Washington march, ADAPT had taken over the federal building in Atlanta to demand that the Department of Transportation agree not to fund any city purchases of buses unless they had lifts. Some city bus lines were trying to buy the cheaper buses before the ADA went into effect. A curious thing happened in Atlanta: police dragged ADAPT protesters out of the federal building only to be ordered to escort them back in to stay overnight. The police even provided blankets to keep the demonstrators warm as they slept in the lobby and hallways. A call had come from the White House on behalf of the president. Transportation department officials were then flown to Atlanta to negotiate the temporary ban on inaccessible bus buys that ADAPT had sought. In Washington, ADAPT had returned the favor by refusing to chain themselves to the White House gate. Patrisha Wright had urged them to do so, arguing that Bush could do more to pressure House Republicans to support the ADA.

To Bob Kafka, rehabilitation professionals, or "suits," like Randy Jennings, were part of the problem. Rehabilitation services, such as job counseling, training, and placement, were required by an act of the U.S. Congress in 1920. The National Rehabilitation Association formed five years later. Today, rehabilitation is a \$2-billion-a-year industry, funded by federal and

state governments. One million people were served in 1989, of whom nearly a quarter found jobs. Yet despite those numbers, the system reaches only one of every twenty people who need help, according to NRA officials. Kafka complains that rehabilitation counselors "cream," or take on the easiest clients and do little or nothing for those who need help the most. Few of the thirty protesters Kafka brought to Washington had full-time work. Most were angry over having slipped through the cracks of the rehabilitation and welfare systems.

Jennings, too, wanted to see more of his disabled clients working. Rehabilitation professionals were restricted by funding limits and by the law, which said only someone deemed employable can get help. The ADA bill, he said, would significantly boost the numbers he could serve by, among other things, requiring employers to make inexpensive accommodations in the workplace. The need for a bill like ADA first became apparent to Jennings years before when he found a nineteen-year-old paraplegic a job in a muffler shop but could not get him to work the next day. No city buses had lifts. "This bill is the most significant piece of legislation to come along for disabled people in a long time," said Jennings. "It's civil rights; it's what's needed." Best of all, he said, the ADA would make interaction commonplace. "We'll see people in chairs going to the opera. They'll be sitting with us in the same ballpark," said Jennings. "And for the first time we'll all be able to go together. We won't have to segregate them in a special bus."

Professionals like Jennings, and other disabled people, too, tended to keep their distance from Kafka's ADAPT, which, with its philosophy of civil disobedience and mass arrests, was regarded as a militant fringe group. But ADAPT's Wheels of Justice March was to be a show of grass roots force. An invitation had been extended to all other groups. By coincidence the National Rehabilitation Association's legislative convention was taking place that same week. So the rehabilitation professionals

canceled their morning sessions in order to join the protest. That was how members of the two Texas delegations led by Kafka and Jennings came together in front of the White House on a Monday in Washington during an unseasonably warm week in early March 1990.

Some 475 people, many in wheelchairs, spread across the sidewalk in front of the White House for the start of the protest march. Another 250 people joined them at the Capitol. In the scheme of Washington demonstrations—where a march on either side of the abortion issue will turn out up to 250,000 protesters—the ADAPT march had attracted a minuscule number, too puny to rate even a line in the next day's *Washington Post*. Disability marches never attracted large numbers. People who found it physically difficult to get to jobs—and therefore were often poor—or even out to restaurants or movie theaters, found it still harder to get across country to protests. At the hotel where two hundred ADAPT demonstrators were based, only three rooms had bathrooms accessible to wheelchairs. There had been a few demonstrations of similar size on behalf of the Section 504 regulations. But never had so many people, including professionals, representing so many disabilities come together in one protest.

The small numbers belied the protest's power. Boyden Gray appeared at the White House gate to address the crowd briefly. President Bush, he assured the crowd, was committed to signing civil rights legislation for disabled people. "If it seems slow, remember how slow things were twenty years ago," he said, referring to the struggle of the black civil rights movement. The marchers, with Kafka near the front, took off for the Capitol at the other end of Pennsylvania Avenue. At the base of the Capitol, by the elegantly curving marble steps to the West Front, Kafka introduced the speakers. The first was Dart, newly sworn in as the chairman of the President's Committee on Employment of People with Disabilities. One of Dart's first acts, upon getting

his new job, had been to change the committee's name from the President's Committee on Employment of the Handicapped, to show the new sensibilities of the emerging civil rights movement. From his wheelchair, Dart lauded the protesters as "the pioneer patriots of the twentieth century." To growing applause, Dart urged, "We are Americans and we will struggle for however long it takes for the same civil rights other Americans have."

Brief remarks followed from a few members of Congress: Kemp, I. King Jordan, the first deaf president of Gallaudet University, and James Brady, the former White House press secretary who had been shot in the head during the 1981 assassination attempt on President Ronald Reagan. But the power of the crowd seemed to surge forth when ADAPT's national leader, Mike Auberger, came to the microphones to tell his story from his motorized wheelchair. He wore jeans and an ADAPT T-shirt. The braids of his long hair came down to his lap, in which he held his speech, written out on a yellow legal pad. In a steady voice, without emotion, Auberger recalled a visit to the Capitol he took as a younger man, a student on a ninth grade class trip to Washington. "Twenty years ago, I walked up these steps a wholly equal American citizen," said Auberger, referring to the steep flights of stairs to the top of the Capitol that loomed above him. Then, with more feeling in his voice, he added, "Today I sit here with you as less than second-class citizens who are still legally discriminated against daily."

As Auberger's voice built with anger describing his devalued citizenship, the crowd responded in shouts and increasing applause. "The steps we sit before represent a long history of discrimination and indignities heaped upon disabled Americans. We have faced what these steps have represented. Among us are those who have been forced to live in institutions against our will. There are those among us who have had our children taken away solely because we are disabled. We have been denied hous-

ing and jobs. These indignities and injustice must not go on." The crowd rocked with cheers as Auberger concluded, his voice rising with emotion. "We will not permit these steps to continue to be a barrier to prevent us from the equality that is rightfully ours. The preamble to the Constitution does not say 'We the able-bodied people.' It says, 'We the People.' "

The cries from the protesters drowned out Auberger's words. "Access is our civil right," they chanted. At that point about three dozen ADAPT demonstrators, according to a prearranged plan, threw themselves out of their wheelchairs. They began a "crawl-up" of the eighty-three marble steps to the Capitol. Each struggled up the steps carrying a scrolled paper with the opening words of the Declaration of Independence to present to lawmakers once they had pulled themselves on their hands and knees inside the Capitol building.

The sight of paraplegics dragging themselves across each step was both fascinating and repelling. At the end of the day, some activists, including editor Mary Johnson, worried that the grueling "crawl-up" had conveyed precisely the image disabled people wanted to avoid—of being pitiable, inspirational, and childlike. Indeed, the cameras had zoomed in on an exhausted eight-year-old, Jennifer Keelan, struggling forward on her hands and knees. It would be the one photographic image from the ADA fight to register in the public memory. Yet the network news reports that night stressed exactly the message ADAPT wanted to get across: that disabled people were demanding civil rights.

For the next day, Tuesday, ADAPT had scheduled its members for a "tour" of the Capitol. It was to begin where tourists traditionally gathered, in the Capitol rotunda, under the structure's cast-iron dome. But the tour, as ADAPT members knew and Capitol police suspected, was a sham. The real agenda was to take over the Capitol rotunda, a place decorated with huge murals of the signing of the Declaration of Independence and

other key moments in the building of the republic. ADAPT members would demand that the ADA bill go to the floor of the House for a vote the very next day.

While the Capitol tour guides, in their red jackets, waited patiently nearby, 150 ADAPT members gathered in the center of the rotunda. The takeover began with ADAPT's demand to speak to leaders in the House of Representatives. Although few of the shouting ADAPT demonstrators realized it, this, too, was a carefully staged event. ADAPT leaders planned to take over the Capitol for several hours and end their protest only when House leaders were forced to come to see them. That would demonstrate the group's power. Patrisha Wright, too, wanted the protest to have impact, so that wavering House members would feel the impatience of disabled people. But she could not put House leaders in the awkward position of being seen weakly caving in to end a protest. Wright called in chits to summon House Speaker Tom Foley, House Minority Leader Robert Michel, and Representative Steny Hoyer to hear ADAPT's demands. They would talk to the demonstrators at the beginning of the protest, not the end.

"I can understand that you're frustrated," said Michel, who stood in the center of a wide circle of wheelchairs. Activist Mark Johnson shouted down the Illinois representative: "We're not 'frustrated,' we're pissed off." That set off a chorus of chants, yells, and horn blasts that reverberated off the rotunda's marble walls, eventually sending a bemused Michel and a scowling Foley scurrying from the rotunda. Kafka and other ADAPT members pulled out chains and bicycle locks to link their wheelchairs together in a phalanx of metal. As Capitol Hill police moved in to make arrests, one confused tour guide leaned over the wall of wheelchairs to ask Auberger if this meant the group did not want to take the scheduled tour.

One Washington disability activist was distressed when Senator Robert Dole, a stalwart supporter of disability causes,

walked by the rotunda sit-in and said, "This doesn't help us any." Jennings, of the Texas rehab delegation, agreed. Jennings felt Kafka and ADAPT were good at grabbing attention with their shouting but lacked credibility because they then refused to sit down and negotiate. That was not ADAPT's role, countered Kafka. ADAPT demonstrators, he said, knew they were seeking the impossible when they demanded an immediate vote on the ADA bill in the Capitol rotunda. The point was to force a confrontation to show that disabled people—104 of them on this day—cared deeply enough to go to jail for their rights.

As Kafka sees it, forcing confrontation and getting arrested gave disabled people a sense of empowerment after lives of dependency. "Most people see disabled people as childlike and helpless," said Kafka. "We're not Jerry's Kids. We're not going to be passive recipients of charity anymore. We're changing our image. We're demanding our rights." These rude protests grab attention because they challenge widely held expectations of disabled people to be unfailingly polite, explained activist Eleanor Smith. Exhausted after driving over twelve hours to Washington from Atlanta, she had moved her wheelchair into the elevator at her hotel on arrival in Washington. "What floor would you like?" asked a woman in her early thirties who was standing near the control panel. "Three," said Smith, who is forty-seven. "Aren't you forgetting your manners?" asked the woman's husband, who added in a treacly tone, "It's 'Three, please.' "

While U.S. Capitol police carried the ADAPT protesters down an elevator only big enough for one wheelchair at a time, members of Jennings's Texas NRA delegation were making the rounds of congressional offices. Seven of the women met with Representative Pete Geren, who had been in Washington only six months, after winning a special election. He had been lobbied on the ADA within twenty-four hours of his arrival in the capital but said he was listening seriously to complaints

from small business about the cost of compliance. The women got straight to the point. Rehabilitation professionals, they explained, could show business how to use the bill to their advantage, to get good employees.

Accommodations did not have to be expensive, noted Elizabeth Gaspard, who used a silver lightweight wheelchair. The chronic pain in her feet, she said, made it hard to walk long distances or to stand. For her, accommodation meant simply that her employer left a chair in the photocopying room so she could rest on it when she did her copying. As a high school student, when the pains began, she feared an end to her future dreams of career and family. Fortunately, rehabilitation and vocational counselors were around to tell her how to get along at school. Now she was proud that she had graduated from college and become "a taxpayer, not a tax user." ADA, she explained, would protect her. "Equal employment won't do a thing for me if transit passes me by on the street or I can't get in the front door. How could I be a competitive employee?"

Meanwhile, across the street from the Capitol in the Rayburn House Office Building, the Energy and Commerce Committee was marking up the ADA bill. Tom Sheridan, a lobbyist for the AIDS Action Council, stood outside the committee room, urging lawmakers to vote against several amendments that would exclude people with AIDS from the protection offered by the disabilities act. Many disability activists were envious of the public fascination with the gay rights movement. The week before ADAPT arrived, a national newsweekly devoted a cover story to ACT-UP, the AIDS activist group that takes angry, confrontational politics beyond ADAPT's version. But Sheridan watched in awe the score of disability lobbyists, representing hundreds of disabilities from epilepsy to mental illness, working outside the committee room. Because of the influence of these established groups, including the National Rehabilitation Association, federal and state governments would spend

\$60 billion on disabled people in 1990. People with AIDS do not have the same network of federal programs to give them such clout on Capitol Hill, Sheridan noted. Although the gay rights movement was far more visible, more cohesive, and much more in the public's consciousness, gays and lesbians in 1990 could only dream of the type of national antidiscrimination legislation that was moving quickly through Congress for disabled people.

Because AIDS is a chronic disease, people with AIDS or who are HIV-positive were protected from discrimination under the ADA bill. The alliance between the disability and gay communities helped spur the bill. But that alliance worried some lawmakers. "I don't want to hand out anything more to those damn homosexuals," Ralph Hall, a Texas Democrat from the rural district descended from former House Speaker Sam Rayburn, told the NRA women at their next visit. Hall, like all other members of the Texas congressional delegation, was getting stacks of letters from fundamentalist churches urging him to oppose the ADA because it included rights protections for people with AIDS. Gay people, Hall argued, get AIDS because, by their own choice, they engage in risky sexual behavior. "We don't make judgments when we help people with head injuries," shot back Valerie Jean Schwille, who had followed in her father's footsteps to become a rehabilitation counselor. "We don't ask first, 'Were you speeding in that car crash?' Or, 'Did you have too much to drink?' We still help them." Hall conceded, "You've got a point there."

On Wednesday, the ADAPT demonstrators, off the high of their sit-in the day before, planned an even bolder action: to close down the subway system that links the Capitol to the House office buildings. The plan went awry when four groups of demonstrators got lost in the subterranean maze of walkways under the Capitol. As he flew out on to Independence Avenue in his motorized wheelchair, Mike Auberger cursed himself for his botched strategy and made a mental note "never again" to

diminish the group's power by dividing into small units. The demonstrators regrouped to take over the office of Representative Bud Shuster (R-Pa.), author of an amendment to exclude sparsely populated areas from making new buses accessible. There were fifty-nine more arrests.

After two days of steady arrests, Thursday was spent in courtrooms. "When I was born, I had a problem with my left arm, which was paralyzed. There were a lot of things I couldn't do. But I didn't break the law," explained D.C. Superior Court Judge Robert Scott. He told the ADAPT demonstrators how, despite his disability, he went on to law school and was eventually appointed to the bench. Then the sixty-eight-year-old judge meted out punishment, some of the toughest, ADAPT leaders said, they had ever received. Auberger was fined \$500 and put on supervised probation for one year—in essence, putting ADAPT's captain out of action by forcing him to avoid arrest or else be brought back to Washington to serve jail time.

Scott's tough sentencing infuriated the ADAPT activists. Even worse, they felt Scott had slighted those who had trouble speaking by addressing questions to people next to them instead of letting them struggle with their words. Another ADAPT leader who got a heavy fine, Stephanie Thomas, who is married to Bob Kafka, said Scott is a familiar disabled type—one who hides his disability to "pass" in the nondisabled world. Scott, in an interview later, noted his long-standing reputation for being a no-nonsense judge and said he treated the protesters the same as he would anyone else. "If they expect because they are in wheelchairs to flaunt what is clearly the law and not expect anything to happen," he said, "they're crazy."

Tied up in court all day, the ADAPT activists reluctantly ruled out taking further action. They returned to their hotel dispirited, unsure what Friday and another day of courtroom appearances would bring.

Friday started with one more reminder of exclusion. Auberger, Thomas, and the three others sentenced by Scott showed

up, as ordered, at the parole office—only to find that there was no wheelchair ramp to the building. A court officer eventually met them outside, but Timothy Cook, the group's attorney, quickly filed a half-million-dollar lawsuit against the court. The 1973 amendments to the Rehabilitation Act, the prototype for the ADA, required that any federal building be accessible. One of the strongest selling points for the ADA was that this 1973 law, which had been pushed by rehabilitation professionals, proved such antidiscrimination measures could be effective without being burdensomely expensive.

If the day before the court proceedings had gone poorly, the remaining ADAPT members to be sentenced could hardly have been more surprised by the reception they got from Judge Bruce Beaudin. It started when Arthur Campbell, whose severe cerebral palsy makes speaking difficult, asked if someone could read remarks he had written out. The judge agreed. "Take this courtroom," Campbell wrote. "We cannot use the jury box. . . . We cannot get on the witness stand. . . . And we cannot get on to the judge's bench."

Beaudin was moved by Campbell's words, and soon everyone in the courtroom was speaking, telling their most personal stories of discrimination and struggle. For many it was the first time anyone in authority had listened to their tales of pain. People who could not speak, like Claude Holcomb of Connecticut, slowly spelled out their statements, letter by letter, on boards they carried marked with the alphabet. People who rarely talked at all, out of shyness and fear, spoke with eloquence. The courtroom took on the air of a revival meeting and a political rally. People clapped, shouted, and cried.

George Roberts of Denver asked that ADAPT founder Wade Blank be allowed to tell his story of being abandoned by his parents "on the doorstep of an orphanage" to spend twenty-five lonely years in institutions and nursing homes until he got help to sue to get out.

Even Judge Beaudin was choking back tears by the time the

last speaker, Wayne Spahn of Austin, told his story. "When I was a baby, they wanted to put me away. But my mother and father fought and I stayed home with them," he said. "All we want is education and jobs, good jobs, to try to get out in the community and be like everybody else."

It ended with Beaudin praising the demonstrators. "The rightness of your cause is a big one," he said. He imposed minimal \$10 fines. "I'm going to take a break, I can tell you that," Beaudin said, teary now himself. And with that, the judge stepped down from the bench and went around the courtroom, shaking the hand of each of the activists.

With the support of a powerful coalition of disabled people and their families, politicians, and disability professionals, the ADA moved swiftly through Congress. On July 26, 1990, Bush signed the ADA into law with three thousand joyous members of the "hidden army" on the South Lawn of the White House. The President greeted one of the guests, Lisa Carl of Tacoma, Washington, who "now will always be admitted to her hometown theater," the president noted. To applause, Bush declared, "Let the shameful wall of exclusion finally come tumbling down." He put his pen to the bill. Then Bush turned to Evan Kemp, who was sitting next to him on the podium overlooking the Washington Monument, and gave him an affectionate kiss on the head.

Bush's administration would promptly issue regulations for the ADA. There would be no four-year fight like that over Section 504. The law took effect in 1992. Many companies, particularly large ones, complied eagerly and reaped the rewards—new customers, new workers, and good publicity. Passage of the ADA was an earthshaking event for disabled people. It signaled a radical transformation in the way they saw themselves—as a minority that now had rights to challenge its exclu-

sion. But it was an odd victory; as radical as the ADA's passage would be for disabled people, nondisabled Americans still had little understanding that this group now demanded rights, not pity.

CHAPTER 5

INTEGRATION: OUT OF SHADOWLAND

The postmaster in a small town was told that he would have to make his post office building accessible to people in wheelchairs. There were twenty formidable steps leading to the only public entrance, and the revolving door there was too narrow for even the smallest wheelchair. The postmaster objected to any renovation for disabled patrons. He sputtered in protest, "I've been here for thirty-five years and in all that time I've yet to see a single customer come in here in a wheelchair."

For disabled people, there is more at stake in such exclusion than just the right to buy postage stamps. Segregation—whether the result of stairs or attitudes—creates harmful myths and stereotypes. Worse, it sets up a self-fulfilling prophecy for failure. That disabled people are invisible or separated, Americans like the postmaster have long assumed, is proof that they do not need inclusion or are not even capable or worthy of it.

"Most people assume that disabled children are excluded from school or segregated from nondisabled peers because they cannot learn or because they need special protection. So, too, the absence of the disabled coworkers is considered confirmation of the obvious fact that disabled people can't work," writes disability rights attorney and theorist Robert Funk. "These assumptions are deeply rooted in history. Historically, the inferior economic and social status of disabled people has been viewed as the inevitable consequence of the physical and mental differences imposed by disability."

The result of this history, argues Funk, has been treatment of disabled people as a "dependent caste." An American apartheid has existed for them. School districts fund separate schools of special education in which the instruction is often inferior to what is offered to nondisabled students. Cities, rather than put wheelchair lifts on all buses, establish parallel "paratransit" systems of vans: separate and unequal transportation, since these first-come, first-serve systems usually require passengers to reserve a ride at least twenty-four hours in advance. In most cases, a nondisabled person is not allowed to ride the van with a disabled friend. Charities set up "sheltered workshops" for people who because of their blindness, cerebral palsy, or other disability—people who may be exceptionally intelligent—are paid at a piece rate, often for pennies a day, toiling at some dull task like sorting nuts and bolts. Although some sheltered workshops have begun teaching real work skills in hopes of graduating their employees to regular jobs, most workshops remain little more than segregated adult day-care centers. States still run separate and isolated institutions and state hospitals—often resembling prisons more than homes—to house people with retardation and other disabilities.

The story of the small-town post office is a favorite of Harold Russell, who ran the President's Committee on Employment of the Handicapped in the 1980s. But he is best known as the star of

the 1946 movie *The Best Years of Our Lives* about a World War II veteran who returns home paralyzed. Russell himself had come back from war without use of his arms.

As more and more disabled people like Russell survived after a trauma, they and their families began insisting on having the same opportunities to live and work as anyone else, rather than be forced into an institution or remain behind closed doors in a family's home. This was particularly true of people who became disabled after birth. They saw no reason suddenly to forfeit the first-class citizenship they had grown up to expect as a birth-right. Yet the postmaster's reaction was the norm; in a society where disabled people are remote, we have not understood the need to adjust attitudes, programs, and laws to fit the changing reality of disabled people who now seek independence.

As a result, integration—into the work force, the classroom, the community—has become a primary goal of today's disability movement. It was first demanded by parents, beginning in the 1950s and 1960s, and now it is disabled people themselves who are most forcefully demanding to come out from the shadows.

For me, it was a group of autistic adults who made it clear that integration is not just a goal for a few with the mildest disabilities but a feasible and common good and a right for all. These were the autistic men and women clients of Community Services for Autistic Adults and Children. CSAAC (pronounced SEE-sack) helped them find work and live in their own homes in Montgomery County, Maryland, a suburb of Washington, D.C. I visited Susan Goodman, then CSAAC's director, in her spartan office of dully colored linoleum and cinderblock in a converted Rockville, Maryland, schoolroom.

Of the universe of people with disabilities, Goodman explained, those with autism are usually the most segregated of all. "Because people with autism are the most difficult to serve, they are the first to be written off," she said. For decades, she added, people with autism were society's disposables, "relegated to the

back wards of institutions and for the most part termed hopeless."

They were discarded because autism is a rare and lifelong brain disorder with no known cure. They were ignored because some can barely speak and are seemingly unable to communicate with others. Many seem trapped in their own world of fears and visions. Some scream, yell, bang their heads, or engage in other self-injurious behavior when they are frustrated. Autism affects approximately 200,000 Americans, and symptoms usually appear in the first three years of life. Little is understood about what causes it, nor is it known why four out of five people with the condition are male. In addition, at least 70 percent of people with autism are considered to have some degree of mental retardation. Another 10 percent are savants, clinically retarded but spectacularly gifted in some areas such as music, numbers, art, or memory. One CSAAC client, Richard Montgomery, has calendar memory. Ask him any date and with invariable accuracy he instantly tells the day of the week it falls on. But despite this extraordinary talent, Montgomery could not do the basic mathematics that would help in his job of affixing price tags to merchandise in the back of a Kmart department store.

The CSAAC program, Goodman explained, aimed at no less than turning upside down the perceptions that autistic people make up a "hopeless" population. Its purpose, she said, was to show that "with the proper support these people can live and work in the community." CSAAC was started in 1979 by several parents of autistic children, who were distressed at the lack of programs to help their adult sons and daughters live at home or on their own, instead of going into institutions. It grew to sponsor fifty-two autistic teenagers (including Goodman's son) and adults working in twenty-eight businesses and to gain national recognition for pioneering work in taking autistic adults out of institutions and placing them in what is called community-supported employment and living. CSAAC even

made a point of finding its clients jobs outside the traditional ones usually offered people with developmental disabilities like autism and mental retardation, the so-called "food, filth, and flower" positions as pot scrubbers, janitors, and lawn crew workers.

I visited Goodman in 1989, the year *Rain Man* won an Academy Award as the year's best movie. *Rain Man* is the fictional story of Charlie Babbitt's discovery that he has an older brother who is autistic. The family had hidden Raymond in a private, tree-lined mental institution. But Charlie, a young hustler, learns of his lost brother's existence when he questions the mysterious distribution of his late father's three-million-dollar estate. The self-centered Charlie (Tom Cruise) discovers and then kidnaps Raymond (Dustin Hoffman) in a vengeful plot to gain what he believes is his rightful share of the inheritance, taking his brother on a colorful road trip across America. It is Raymond's liberation, but even more important, it brings Charlie's revelation that this brother is not the simple disabled man he had first seen. Rather, Raymond is a complex, fascinating, and endearing man. He is an autistic savant who memorizes the phone book and can count 246 falling toothpicks as they hit the ground. During a stop in Las Vegas, Raymond's memorization skills help Charlie win nearly \$90,000 at the blackjack table. (Kim, the retarded savant who was the model for *Rain Man* story writer Barry Morrow, works as a payroll clerk and keeps the salary, hours, taxes, and deductions of eighty-four employees in his head.) Naturally, the bonds of brotherhood blossom by the time Charlie and Raymond reach Los Angeles.

The film fades with Raymond on an Amtrak train, escorted by his doctor back to his private institution in Ohio. Charlie has lost his plea to keep Raymond with him. An autistic man like Raymond, argues the doctor, cannot cope outside the institution. The evidence comes in a climactic scene where Raymond panics in screaming, head-bashing terror at the incessant whine

of a smoke detector he has triggered in his brother's apartment.

But this is one movie where a typical Hollywood, happily-ever-after ending would have been more appropriate than the sad departure scene of *Rain Man*. Tom Cruise was right. The Rain Man didn't have to go back to the institution. Raymond could have coped quite well on his own. He could have gotten a job. He could even have lived in his own apartment. Approximately 300,000 similarly disabled adults, some with far fewer skills than Raymond, have done so. The autistic men and women I met in Maryland proved it.

Among those was Mary Sauerbier, who, like Raymond Babbitt, is autistic. But Sauerbier takes two buses by herself to work Monday through Friday at FIC Corporation, where she dependably assembles fuses for nuclear submarines and military aircraft. Before getting the job, she had lived over twenty years as a castaway in a locked unit at a regimented institution, doing nothing all day. Now the quiet woman shares a house with three other autistic women and two counselors. Instead of eating bland institutional food, she enjoys cooking steak dinners. Instead of wearing communal clothes, she shops at Bloomingdale's. Sauerbier had traveled to Disney World in Florida and was saving up for a boat cruise to the Caribbean. I met, too, her work partner, Bill Novotny, also autistic, who, like Raymond Babbitt, could precisely rattle off baseball batting averages and, after seeing *Rain Man*, had memorized lists of previous Academy Award winners.

It was not out of do-gooder, hire-the-handicapped instincts that businesses employed the autistic workers. The reason was more selfish: they got dependable workers. Some traits of autistic people, particularly their frequent need for ritual and an ability to do repetitive tasks, made them especially prized workers. At FIC, Sauerbier wraps fuse lamps, a tedious, exacting job that

requires twisting slender metal threads around a small resistor. Floor supervisor Nancy Mitchell admitted she was "skeptical" when Sauerbier first came to work. What she said she found, however, was that "Mary is quite meticulous. She's a perfectionist. If she wrapped five thousand lamps, they would all be wrapped exactly the same way." In some tasks, particularly ones that were repetitive and dull, Sauerbier and Novotny could perform at a level up to 200 percent higher than their coworkers, according to their job coach, Carla Lubore. Sauerbier has taken a sick day only twice in eight years at FIC. "We have breaks," said Mitchell. "Fifteen minutes in the morning and fifteen minutes in the afternoon. They'll go back quicker than we do." Indeed, Sauerbier broke off an interview with me at precisely 10:15 to pick up a small knife and get back to scraping excess plastic and metal from fuse screws. At the other end of the work floor, her colleagues continued to chat over coffee for several more minutes.

In addition to two good workers, the bosses at FIC got an extra supervisor in Lubore, the job coach, whose salary was paid by CSAAC. Whatever Sauerbier and Novotny were expected to do, Lubore learned it first. She broke down any new job task step by step and then taught it to Sauerbier and Novotny. A few CSAAC workers get to the point that they no longer need the help, but in most cases a job coach works beside an autistic employee every minute of the workday.

Novotny and Sauerbier are success stories, but they were relatively easy cases for CSAAC. Both, after all, have rather mild autism, are good workers, and display none of the behavior problems such as head banging and screaming that make many people with autism troublesome clients. But CSAAC does not shy away from getting jobs for even the hardest cases, people with minimal skills and the worst behavioral problems. With the right support from CSAAC's staff of job coaches and a psychologist, argued Goodman, any autistic individual could become a successful worker. Sam Dashner was one such case.

When I approached Dashner at the back of the hardware store where he works, he ran up, arms flailing, and put his face right in front of mine. He started rattling questions nonstop. "What's your name? Where do you live? How did you get here? What kind of car do you have? What's your name?" Before I could answer, he was repeating the same rapid-fire litany of questions. There is an engaging friendliness in Dashner—but he is hyperactive and easily distracted. A job coach had to be assigned to work with Dashner at all times. Dashner tags prices—all of which he has memorized—on store merchandise.

One problem that makes this Rain Man a most unlikely candidate for a job is his fear of rain, but CSAAC psychologist Marcia Smith taught Dashner to control his anxiety, which before had often erupted in outbursts of anger. Smith showed Dashner how to check the weather report each morning before leaving home. At the slightest chance of precipitation, he learned to carry a raincoat and umbrella. When it does rain, Smith has instructed him to repeat over and over again, "That's too bad, it's raining." These devices make Dashner feel more in control and remind him that there are simply some things that no one could change. After learning these tricks, said Smith, Dashner's outbursts became rare. A man who before coming to CSAAC had been ruled unable to work by other programs was now employed part-time, making more than minimum wage. Dashner enjoys working, lives in a group home, and supports himself with the money he earns.

Smith's job is half Sigmund Freud, half Sherlock Holmes. She has to figure out the unarticulated cause of a client's frustration—which may be something as seemingly irrational as a springtime drizzle—and then devise a strategy to help the autistic adult cope. "We all have incentives to make us work," she explained. "For most of us, our incentive is our salary. For some of our clients, you may have to pay them every fifteen minutes with a smile or a pat on the back, instead of with a paycheck every week." For a worker whose outbursts came when he was

hungry, Smith found a simple solution: making sure the job coach kept plenty of snacks nearby at all times.

Roger Beach, who employs two autistic men at his printing company, found this system worked well. "Any person who works for a company has their quirks. In a program like this, not only are the quirks identified, but the job coach is there, trained to handle them," Beach notes. "A pressman may have a bad day and starts being rude to people around him. That happens every day in business and you just try to live with it."

Even in the worst-case scenario, when one of the autistic workers does act out, the job coach is trained to defuse any problem quickly. When a worker in the back of one store, frustrated for reasons he could not express, sat down on the floor and had an eruption, the job coach pulled the man out of sight. Then he hit his beeper to signal a "Triple Zero," an emergency call that brought another CSAAC staffer within ten minutes to help out. During the brief commotion, three women coworkers nearby ignored the problem and kept on working.

Such tolerance by coworkers is the rule rather than the exception, said Pat Juhrs, a CSAAC founder. When nondisabled people work next to disabled people, they begin to understand disabled people more, she explained. "Coworkers begin to see them as employees, instead of as handicapped," according to Juhrs. "They look to them as an asset to their company and as taxpayers, rather than as a burden to society." Occasionally there is prejudice. At Beach Brothers, a printing company, one worker threatened to quit if she had to keep working alongside autistic employees. Roger Beach told her she could leave. The woman stayed and eventually, said Beach, began treating the autistic employees the way she did any other fellow worker.

Even more noticeable than the growth in workers' perceptions of disabled people, adds Beach, is the social growth of his autistic employees. Frank Morgan, loquacious and lively, would tell other employees at the printing plant about the *Sound of*

Music sound track his father played for him, or what he bought on his last grocery shopping trip. But when Morgan first came to the printing company ten years earlier, from an institution where he had lived for twenty-three years, he used only two words, "hi" and "fine."

CSAAC succeeded because it made a simple, humane assumption: that people with autism deserve a place in the community like anyone else. Yes, autism is a perplexing and difficult disability. But people with autism are not, as tradition has it, to be regarded as sick. Nor is it realistic to insist that they have to be cured of "bad" or different behaviors as a prerequisite to living among others. Agitated behaviors are not regarded as pathological, but rather a frustrated effort to communicate. CSAAC insists that it is the responsibility of society to make a place for the person with autism. People with autism should be placed in real jobs and taught meaningful work skills. It is up to coworkers and neighbors to accept them, or at least tolerate them.

Although community-supported work programs like CSAAC save money by employing people with severe disabilities, instead of simply institutionalizing them in expensive facilities, such operations are still hard to find. Only 74,657 people were enrolled in such programs in 1990. Still, that was up sharply from the fewer than 10,000 served as recently as 1986. By 1990, workers in supported employment earned a mean hourly wage of \$3.87 and 81 percent worked at least 20 hours per week. Sixty-five percent of them had mild to moderate mental retardation and another 24 percent had long-term mental illness. The rest included people with autism, cerebral palsy, sensory disabilities, and traumatic brain injury. These workers decreased their dependence on entitlements like Supplemental Security Income the longer they worked. Despite these savings, of the \$11.7 billion dollars states and the federal government spent on programs for people with developmental disabilities in

1988, only \$62.5 million was spent on community-supported employment.

Despite the success of programs such as CSAAC, the assumption too often still prevails that it is impossible to integrate people with autism into society. At the Behavior Research Institute in Providence, Rhode Island, for example, the priority is the management of autistic behaviors. BRI uses controversial "aversive therapy" to treat teenagers and young adults with autism. BRI seeks to alter the most troubling behaviors of clients with an escalating series of punishments that include pinching, slapping, being sprayed with water vapor or a vapor mixed with ammonia, cold showers, or being strapped into a sensory deprivation helmet that plunges the offender into blackness and the constant sound of radio static. Students are also rewarded for "proper" behavior or for successful completion of tasks and exercises. Rewards included hugs or the piling up of privileges to spend time in a playroom, an in-house midway of games, toys, and even a small merry-go-round.

Dr. Matthew Israel, BRI's founder and director, maintains that his system of rewards and punishments is a caring therapy that allows him to help clients who have been failed by other programs. He was supported in his use of aversives by the American Psychological Association and other professional groups, which argue that a therapist needs the freedom to draw on a variety of treatments in order to correct a person's aggression or self-injurious actions. Critics of aversives, however, charge that Israel uses scientific jargon to legitimize a treatment so harsh that it would not be allowed for any other population, including prison inmates. "You can't say a little bit of cruelty is all right," said Gunnar Dybwad, a Brandeis University professor emeritus of sociology who was an early advocate for the rights of people with developmental disabilities. At best, aversive therapy is ineffective and only further agitates the autistic students, Dybwad argues, escalating the hair pulling and other self-

injurious behavior that the program seeks to eradicate. At worst, he says, such treatment of young students is inhumane.

In 1985, twenty-two-year-old Vincent Milletich died after BRI workers "pushed his head between his legs, cuffed his hands behind his back, put a helmet on his head with radio static hissing into his ears and masked his face. He went limp and was declared dead on arrival minutes later at Rhode Island Hospital in Providence." A court later found no evidence of a link between the school's treatment and Milletich's death. But the Massachusetts Office for Children quickly moved to suspend the licenses of seven BRI group homes, located just over the Massachusetts-Rhode Island state boundary. Mary Kay Leonard, director of the Office for Children, called BRI's punishments "excessive," and state inspectors later testified how BRI records noted that one female student had received more than one thousand physical punishments—including finger pinches, muscle squeezes, vapor sprays, and spankings—in a three-day period to correct aggression such as banging her head. Some parents withdrew their children from the school, complaining that their children had been injured by the aggressive punishments.

But other parents of BRI students came to the school's defense most fervently. They argued for their right to have this school of "last resort" as an option, claiming that BRI often took students rejected by other schools. A group of parents sued the Massachusetts office for \$15.4 million in damages when Leonard's attempt to bar the use of aversives threatened to close down BRI. The right of parents to choose won out. In a settlement, Leonard sent a letter of apology to the parents, and her office paid \$580,000 to the school and parents in attorneys' fees.

Israel studied psychology under behaviorist B. F. Skinner at Harvard, where he received a doctorate in psychology in 1960. Fascinated by Skinner's 1948 novel, *Walden Two*, Israel had set up two Boston communes in an attempt to create the utopian community based on behaviorist principles. Later, suspecting

that the communal houses failed because they were self-centered and provided no service, he applied behavior modification techniques to treating autistic children. Skinner himself gave contradictory statements about the use of aversives. At times he denied that punishment could effectively change human behavior, but at the time of Israel's legal problems he said that some people might be "out of reach" of positive reinforcement. When Israel showed his former professor film of his work, Skinner, according to Israel, expressed shock at the level of disturbance of BRI clients. "I didn't know," Skinner was quoted by Israel as saying. "These aren't people; they are animals."

On my visit to Providence, BRI struck me as a human-sized Skinner box or a scene from some fictionalized Orwellian future. In the basement of BRI's nondescript building, "students" were lined up at workbenches, doing mundane tasks in several classrooms, as young, fresh-faced staffers, many newly armed with college psychology degrees, carefully patrolled the rooms and watched over shoulders. Upstairs, in a locked room with banks of television screens, staff monitors watched each classroom through closed-circuit hookups. Not only were the clients constantly watched and graded but the classroom workers were, too, who could also win rewards such as extra pay or vacation based on their performance. In the first classroom I visited, one young man tired of his exercise of picking out matching shapes on a computer screen. He indicated he wanted to stop by removing his hands from the computer screen. But his teacher demanded that he continue and pinched him on the palm for disobeying. The young man, wearing a protective white helmet, made a guttural noise of protest and tried to get up. In a second, two staffers had thrown him facedown on the floor. This only made him more agitated. Then came a squirt in the face with the water spray. The man spent a minute on the floor, trying to move and protest, but was restrained by one staffer's knee in his back and another's grip on his arms. When he gave up his struggle, the man was returned to his workbench.

I met one mother, her face wan and lined by years of stress, who had moved her family to New England so that Israel could work with her son. He had been rejected or expelled from numerous other schools for his violent behavior. Within weeks at BRI, she had seen tremendous improvement and was grateful for the simple progress of being able to take her son out to lunch at a restaurant and have him sit through the meal.

Later, over tea in Dybwad's office at Brandeis, I asked him how he would respond to the strong argument of such a desperate parent, who had devoted her life to finding an effective program that would help her son. "I defend parents very strongly," he said. "If I tell a parent to cease and desist, they have a right to say, 'Tell me what else to do.'" Dybwad saves his strongest blame for public school officials, who leave such parents with few options. Research has shown that the most effective treatment of autism—and other developmental disabilities—is to stimulate the child with an intensive program of learning and playing, starting by the time the child is three. Dybwad is not alone in this belief. Perhaps the most compelling support comes from Temple Grandin, a lecturer on autism who calls herself a "recovered autistic." Today she can describe how the constant attention of a nanny and her mother helped pull her out of her childhood autism. "I argue with our school system, which has failed to deal with these children and deal with them early," states Dybwad. "Because obviously a child doesn't start early gouging its eyes out." As with most disabilities, claims Dybwad, this country has proven programs to help people with autism. But they are not in place because of a lack of will and a continuing prejudice that the lives of disabled children are of less worth than those of nondisabled ones.

Critics like Dybwad claim that Israel's aversive therapy at best has only short-lived results. At BRI I also met Janine, a young girl who had been one of Israel's star pupils. Visitors to BRI first see a tape of the institute's work. One of the most disturbing images is of Janine on the day in 1981 when she was

admitted to BRI. She jumps up and down, slapping her face with both palms. She cries. Her teeth chatter. She bashes her head on the floor, hits her head with her hands to the point that blood trickles from her mouth. When her helmet comes off, her scalp is marked by scabs and blood where the young girl has yanked out divots of her own hair. The next image of Janine, shot eight and a half months later, shows her playing happily on a swing. Her parents became leaders of the group that sought to keep BRI open. When a reporting crew from the ABC television newsmagazine "20/20" came to BRI in 1985, it filmed Janine, by then a teenager, sitting on a couch with her parents, calmly and happily singing the theme from "Sesame Street." Her helmet was off, her hair had grown back in, and she had even started wearing makeup, a sign of new self-esteem.

Four years later, on my tour of BRI, staffers took me to every classroom but one. When I asked to go back to see what was behind the locked door of that classroom, I met Janine. She had regressed. The helmet was strapped on again. There were fresh, oozing scabs on her scalp. Flanked by two staffers, she sat at her bench sorting colored rings. One staffer gave Janine frequent pinches on the palm—each one counted out and recorded—to try to correct her nearly constant moaning. A second staffer sat by in case Janine acted out. A small television camera, only a few feet away, broadcast Janine's behavior to the monitor in the locked video room upstairs. During fifteen-minute breaks between tasks, Janine would dive into a beanbag chair in the middle of the classroom, wrap herself tightly in a blanket, curl up into a fetal position, and moan softly to herself. She seemed to have become inured to the frequent hand pinches and other punishments. Israel said he was considering employing his harshest punishment, an electrical shock device known as the Self-Injurious Behavior Inhibiting System, or SIBIS, that would require a court's permission to use.

SIBIS was invented to stop such behavior as hair pulling and

head banging exhibited by an estimated 160,000 people with retardation or autism. A band of electronic sensors is wrapped around a user's head. When the device detects sudden motion, like that of the head being hit, it sends a mild electric shock through the wearer's body. The sensation is described as feeling like a hard snap of a rubber band. This negative reinforcement is supposed to teach people not to hit themselves.

Some professionals, like Israel, argue that SIBIS is a useful and humane tool of last resort to stop people like Janine from hurting themselves. Others, like Tom Nerney, the former director of the American Autism Society, have fought for state bans on SIBIS, which he calls a crude and ineffective "torture." Instead, he points to nonaversive programs such as CSAAC to prove that there are humane, effective options.

A scientific panel brought together by the National Institutes of Health backed the use of such aversive devices in 1989. Nerney called the NIH process flawed, noting that some conference members were scientists who had helped develop SIBIS or whose universities had a financial interest in it. Dr. Duane Alexander of NIH, for example, was an unpaid member of the scientific advisory board to the American Foundation for Autistic Children, whose founders, Leslie and Mooza Grant, invented SIBIS. Despite the objections of Nerney and others, SIBIS has been slowly winning acceptance by psychologists and educators around the country, even being sold directly to school districts to use on children with autism or retardation.

BRI would come to rely heavily on SIBIS. Only a few students were considered candidates for being shocked when I met Janine. Three years later, in the summer of 1992, SIBIS was used on at least forty-two of BRI's approximately sixty-three students. Dependence on the shock device drew the institution into a soaring spiral of punishments. The initial benefits soon faded as students adapted to the shocks and Israel debated how to make the punishment effective again. He considered a new

generation of the shock device that delivered three times the electrical jolt. But Dr. Ogden Lindsley, the chairman of BRI's senior peer review board, scoffed at that as too soft and "a blueprint for adaption" once again by the students. Lindsley's advice to Israel was to up the pain threshold so dramatically that once shocked the student would truly be deterred from acting out again. "You should punish maximumly to get rid of the ongoing behavior," Lindsley explained. "These kids are case-hardened. We need something different."

The Rise of Institutionalization

For the first half of the century, Americans with mental retardation (called "idiots" or "feeble-minded"), mental illness, cerebral palsy, and, until as late as the 1940s, those with epilepsy, were viewed as a menace that threatened to lower the health and intelligence of future generations. As a result, these people—with disabilities that were not fatal—were segregated in isolated institutions. There they lost control of their lives and their liberties, solely by virtue of their disability. Often they faced involuntary sterilization. Oliver Wendell Holmes may have been one of America's most distinguished jurists, but even he voiced the standard prejudices of the day. "It is better for all the world, if instead of waiting to execute degenerative offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind," Holmes wrote in the 1927 Supreme Court majority ruling in the case of *Carrie Buck*. Doctors at the State Colony for Epileptics and Feeble-minded of Virginia, where the eighteen-year-old woman was a resident, had sought to sterilize her after she had given birth to a child. Buck's own mother lived in the same institution. (Both Buck and her daughter, and probably her mother as well, were of normal intelligence. But poor women thought to be incorrigible—like Buck and her mother,

who both gave birth to illegitimate children—were often institutionalized and written off as “feeble-minded.”) Wrote Holmes: “Three generations of imbeciles are enough!”

The Nazi eugenics experiments, however, largely discredited such thinking, and following World War II a new approach, thought to be more humane, emerged. Such disabled people were no longer treated as threats but as patients. They were considered sick people in need of help, education, and correction, not elimination.

For those so sick they could not be cured, institutions were considered compassionate places that provided food and shelter. Neither treatment nor activity was prescribed since it was assumed that no benefit would come of it. People with mental retardation were mixed indiscriminately with those who had serious problems of mental illness. The most difficult patients were segregated among other troublesome ones, where they copied the screaming, moaning, head banging, and other behaviors they saw every day. This modeling, rather than being viewed as the understandable outcome of mistreatment and neglect, was blamed on the person's disability, not the environment in which the person lived. People with severe retardation did such things, it was assumed, and could not be made to stop.

It would be misguided to equate slavery and institutionalization on a scale of moral horrors, but it is instructional to note the parallels. Slavery was a malignant system that treated human beings as property, while institutionalization arose out of a reformist impulse to protect and help people believed unable to care for themselves. Yet, as with slaves, people in institutions were regarded as “inferior.” They, too, were cut off from their families, and their own possibilities for marriage—a right now common for people with mild retardation—were ended. Slavery existed, above all, because economically it was a profitable labor system for the South. Disabled people were never sent to institutions for economic reasons. But at institutions they were put to

work, often backbreaking work, for long hours and without pay. Many state facilities had their own farms, where inmates grew crops and raised animals to feed the institution. Others worked as maids, janitors, and cooks or made blankets and other items for sale to raise money for the running of the facility. As with slavery, institutional life exposed people to deficient diets; cheap, often ill-fitting, and inadequate clothing; and cramped, lightly furnished barracks where they slept with large groups of people. As late as the 1960s, it remained common for inmates at state hospitals to be bathed by stripping off their clothes, forming them into a line, and spraying them with water from a garden hose.

There was inordinate cruelty, too, from "masters." Just as enslaved women were routinely considered the sexual property of their white owners and foremen, people in institutions have also often been subjected to sexual assault. Slavery, notes one history textbook, "robbed the Negro of his manhood, encouraged infantile and irresponsible behavior, and put a premium on docility. In short, slavery deprived a whole race of the opportunity to develop its potentialities and of the freedom that white men treasured so highly." So, too, has institutionalization regarded adults with disabilities as children, placing them in wards where they model the screaming, rocking, and worst behaviors of their peers, expecting them to be docile patients, and removing their basic rights to choice, opportunity, and claim to community.

Such institutions became places of shame and scandal. State hospitals became prisons of bedlam. In the late 1960s and 1970s, parents, professionals, journalists, and even some residents, like Bernard Carabello at Willowbrook in New York, would expose the horrid conditions of these institutions. In 1965, Robert Kennedy, then a U.S. Senator from New York, visited two state institutions where he revealed overcrowded wards of patients, many naked and wandering about aimlessly or lying in their own feces and urine, and what he described as

"young children slipping into blankness and lifelong dependence." In December of that year, inspired by Kennedy, Burton Blatt of Boston University, along with photographer Fred Kaplan, who toted a hidden camera attached to his belt, made a similar tour to record the "depths of despair" in the locked back wards of five state institutions. Their shocking photographs and text of Dark Ages conditions were published in an inflammatory book, *Christmas in Purgatory*. Kaplan's grainy photographs taken secretly of residents, many naked and sitting on bare floors, eerily echoed the disturbing photos of emaciated and benumbed survivors of Nazi concentration camps. They recorded children with legs and hands bound and, at one institution, one thousand crying babies abandoned and lined up in separate cribs without interaction with any adult. The stench of feces was so strong that Blatt and Kaplan had to send their clothes to be dry-cleaned after each visit.

This sort of exposé created policies to transfer some of the 195,000 residents of state institutions to community group homes and foster families in the 1970s and 1980s. Federal court judges took an interest, declaring that states like Alabama had violated the rights of residents with retardation by letting them live under such conditions. Advocates of institutional reform won help in 1971 by getting such institutions regulated and funded under the joint state and federal Medicaid program. As a result, existing institutions are now structured to somewhat resemble homes. There are dayrooms with televisions and only small groups share bedrooms. There are limits, too, on how many live in a unit and requirements to design some sort of work or activity program for each resident. It is a sizable improvement although, as Dybwad notes, "It's not hard to predict that when bureaucrats are building a house, it is not a home."

The closing of institutions was spurred by the rise of the concept of "normalization." This represented a sociological approach, rather than a medical one, to disability. People with

disabilities thrive, the theory argues, when they leave institutions and are placed in "normal" settings—in homes, schools, and jobs alongside other, nondisabled people. An import from Scandinavia, normalization was spread in this country in the 1970s by Dybwad and his wife, Rosemary, and Wolf Wolfensberger of Syracuse University. Labeling people creates a cycle of failure, they argue. When doctors label someone as mentally retarded or mentally ill, that label is a direction to the public to consider that person a deviant who, according to societal norms, should be segregated. Nondisabled people have been conditioned to consider labeled people as hopelessly ill and of no potential. A child placed in an institution, the Dybwads and Wolfensberger argue, would make little progress because instructors would expect little of him and he in turn would expect little of himself.

It is better, they say, to see the person as "normal," deserving, like everyone else, of the same right to full participation in society. That means an opportunity for the same education, work, and even for love, sex, and possibly marriage. Normalization means the right to have choices and to claim the "dignity of risk."

Yet today deinstitutionalization has stalled. Some 100,000 people remain in state hospitals. It was not until 1991 that the first state, New Hampshire, would close the doors to its last institution, Laconia. "It's a classic chicken and egg problem," says Paul Wehman, a professor at the Medical College of Virginia at Virginia Commonwealth University. "If you shut down all the institutions, you don't have all the community programs in place yet. But if you don't put a ceiling on institutions, there are no incentives for community programs." Most federal money continues to be directed to large state institutions, although group homes and community programs are less expensive in the long run. State institutions are more costly because of their extensive size and staffs. States spend, on average, \$56,000

yearly for each person in a state institution, according to a 1988 study by David Braddock of the University of Illinois at Chicago. Community programs like CSAAC cost slightly more than half that amount, according to Goodman.

Neighborhood resistance has remained strong to group homes, despite numerous studies disproving myths that such facilities mean high crime rates and lowered property values. There has been opposition to closing institutions from unions that stand to lose some ninety thousand jobs nationwide. Particularly influential has been a small but vocal group of parents. All mothers and fathers worry about who will look after their disabled children after they die. Those who put their trust in large institutions tend to be older parents, in most cases the ones who on the advice of doctors decades ago made the difficult decision to put a child in an institution.

Dr. Bernard Rimland is a hero to parents of autistic children for his research that discredited once-dominant psychological theories that branded the mothers and fathers of autistic children as "refrigerator parents." His studies in the 1960s shattered Dr. Bruno Bettelheim's emotional causation theories that autism was triggered by the parent's lack of love for their infant and firmly established the biological origin of autism. Rimland is also the father of an adult son with autism. He praises community-supported programs like CSAAC but says they should be just one more choice for parents, along with state and private institutions. "What will guarantee thirty years down the road that CSAAC will not fall on hard times?" he asks.

Only in the rarest cases do young children go to institutions anymore. Today families get support like respite care and other social services, as well as the right to put their children in public schools, so that disabled children can grow up at home. Younger parents, like Goodman, have come to see their disabled child's protection in his or her ability to become self-reliant. It is an

independence, they see, that comes only when their sons and daughters are fully included in their communities. And if all severely disabled people had such opportunities, none would need to live in institutions, argues Goodman. These parents have little patience for gradual integration. Backed by law, they sue school districts to give their children a chance to go to integrated, neighborhood schools. By the time the children get out of high school, they have inherited the same assumptions that they have a right to integration and opportunity.

Proponents of institutions use as their most powerful arguments the disastrous deinstitutionalization of another population—people with mental illness. After World War II, mental health reformers had argued for closing state mental hospitals and caring for people with mental illness in the community. State hospitals provided no effective therapy. Drugs were used almost indiscriminately. State legislatures rewrote laws to make it difficult to commit people to such hospitals against their will. In the 1960s, Congress began funding community mental health centers, which, along with halfway houses, were supposed to provide outpatient care for people with chronic mental illness. That care, it was argued, could be provided at less expense than at large institutions.

But that vision was never realized. The doors of hospitals swung open, but people with mental illness had nowhere to go. Governments never provided the money for community programs. Some hospitals simply took construction grants and built unrelated facilities—in some cases, swimming pools and tennis courts for other patients. Few halfway houses were ever built. Community mental health centers eschewed treating people with difficult chronic illnesses and instead turned to easier and more profitable patients. The result was a tragedy that can be seen in the large numbers of homeless people—some 30 percent—with serious mental illness, mostly schizophrenia and manic depression.

Advocates for those with mental retardation have learned from the grim mishandling of those with mental illness. By law, no one with a developmental disability is allowed to move into the community unless the move is carefully planned. Those leaving institutions go to a group home or apartment, where they are supervised. Usually a staffer lives or stays at the house. Those with mild retardation who can live on their own—some are even buying their own homes—still have someone come by periodically and check on them. Every year, case workers evaluate their progress. A work program during the day is mandatory. Only on the rarest of occasions does someone with mental retardation leave an institution and wind up homeless, but these tend to be people with mental illness as well as retardation. Little by little, the dream of integration is being fulfilled.

Knocking on the Classroom Door

In 1973, children's advocate Marian Wright Edelman launched the Children's Defense Fund with a survey. One U.S. Census figure haunted her. Some 750,000 American children between the ages of seven and thirteen did not attend school. Who were they and why were they being denied an education? Edelman, whose civil rights advocacy had been born in forcing Mississippi to fund Head Start programs of early childhood development for poor black children, felt certain that she knew the answer. They were black children, she assumed, shut out of segregated school districts. But the survey returns showed the highest number of nonenrolled children lived in predominantly white areas, such as Portland, Maine, Appalachian Kentucky, and western Massachusetts.

"Handicapped kids were those seven hundred fifty thousand kids," Edelman recalls finding to her surprise. "We'd never thought of handicapped kids. But they're out there everywhere." Schools had simply turned them away, saying they were unable

to educate them. Children were rejected if they had developmental disabilities like mental retardation or autism, which raised doubts about whether they could learn. But even intellectually superior students were left uneducated, because conditions like cerebral palsy made it difficult for them to speak or because muscular dystrophy, spina bifida, polio, or paralysis forced them to use wheelchairs and the school building was filled with stairs.

Edelman's detective work helped lead to a parents' campaign to pass a 1975 federal law, the Education for All Handicapped Children Act, which guaranteed an education for the nation's 8 million children with disabilities. Public Law 94-142 was the disability movement's equivalent of *Brown v. Board of Education*. Like black Americans, disabled ones were looking to the schools for equity and social justice. Millions of disabled children have since gone through school under the act (now renamed the Individuals with Disabilities Education Act, although sometimes still known by the old title), often in "mainstreamed" schools with children not disabled. The law requires teaching disabled students in the "least restrictive environment," that is, with nondisabled children whenever possible. The law covers children with disabilities such as mental retardation, who traditionally were segregated in their own schools, and those with chronic illnesses like AIDS, who often find themselves turned away at the schoolhouse door.

The U.S. Supreme Court has acknowledged the right of all children to an education—no matter how severe their disability or how much the cost. Timothy W. is about as severely disabled as a child can be. He has profound mental retardation as well as cerebral palsy and a seizure disorder. In addition, he is blind and a quadriplegic. His New Hampshire school district argued that he could not learn "even the most rudimentary skill" and that it made no sense to spend the estimated \$15,000 a year required to keep him in school. But Timothy, according to his mother and child-care workers, "responds to talking, touching, motion, familiar voices, taste, smell, pain, temperature, bright lights and

music." Although he does not talk, he smiles when he is happy and cries when he is sad. But the 1975 law, a federal court noted, is clear that "all handicapped children between the ages of three and twenty-one have the right to a free appropriate education." The Supreme Court let this lower court's ruling stand. The law, much like the CSAAC program for autistic adults, works from the assumption that we cannot presuppose that a person with disabilities is limited. (Indeed, the popular Head Start preschool program to raise the school performance of poor children came out of Sargent Shriver's knowledge of early intervention programs that had raised the IQ levels of children with retardation.) Timothy may have seemed unlikely to be educated, but he could learn something. And both he and his peers would learn about interacting with a diversity of people just by virtue of his being in the classroom.

Parents of disabled students speak the language of a civil rights movement. They demand an end to "segregated" schools filled only with disabled students. Instead, they want their children—from those with almost imperceptible learning disabilities to those with severe disabilities such as children who now live long enough to leave hospitals and come to class on respirators—to attend neighborhood schools with nondisabled children. "Mainstreaming" is the practice of putting disabled students in the same school *building* as nondisabled students but generally separating them into smaller, special education classrooms. Sometimes a child takes a few classes—music, art, shop, or academic ones depending on the student's skill level—with nondisabled schoolmates. Often, however, "mainstreaming" has been no more than an empty promise of equality, as disabled kids are kept isolated in their own classrooms. Sometimes they even have separate lunch hours. As a result, parents today have begun insisting on an "integrated" education or "full inclusion," which means that the disabled student sits in the same *classroom* with nondisabled peers.

In September 1990, Sacramento school officials said Rachel

Holland's moderate retardation and short attention span meant that she could not keep up with nondisabled students in her kindergarten class. The girl's parents sued, making a cutting-edge argument before state courts to expand the interpretation of the 1975 act to guarantee their daughter's right to a totally integrated education. Special education, the girl's parents argued, set her up for failure—because less was expected of students segregated in separate classes. It was another case, they claimed, of separate but unequal programs justified on the basis of a person's disability. "When Rachel is placed with retarded children she tends to act retarded," said her father, Robert Holland. But she learned more when a private school placed her "with her regular friends and in a creative environment," in which a teacher modified assignments for her and other students helped her learn. A special hearing officer agreed with the family, forcing the school district to include the girl in a regular first-grade class.

Parents such as Rachel Holland's cite studies showing that even children with the most severe disabilities learn better in integrated settings. Disabled students set higher goals for themselves when they have nondisabled peers to model. And the teachers in integrated classrooms are more likely to push them as well.

Getting into mainstreamed schools and even integrated classes, however, is no guarantee of acceptance. Former Representative Steve Bartlett tells the story of a girl with Down syndrome from Harlingen, Texas, whose parents fought to get her into a regular school, only to find that insensitive school officials excluded her from pep rallies and refused to let her pose with her schoolmates for her class picture. The principal at one Chicago high school barred Jim Stan, an eighteen-year-old with cancer, from graduation ceremonies on the ground that his presence would be disruptive, since he could not walk. Bad publicity forced the coldhearted principal to relent. Sascha Bittner, a

seventeen-year-old with cerebral palsy, had to bring a lawsuit to force her San Francisco high school to reverse a decision to prevent her from attending a class picnic because her motorized wheelchair was too heavy to transport. Similarly, another California high school allowed Christine Sullivan, who has cerebral palsy and uses a wheelchair, to attend regular classes but refused to let her bring her service dog, Ford. A judge ruled that the school had denied the girl her "choice" of ways to "overcome the limitation created by her physical disability," in effect dooming her to fail.

Particularly important for parents is that their sons and daughters get a chance to make friends and not feel like outsiders. Studies of disabled children show that they master social skills far more easily when they go to school with nondisabled children. In addition, the other classmates learn empathy and many take on a sense of responsibility for helping a disabled classmate.

That was clear when I visited a noisy homeroom at the Levy Middle School in Syracuse, New York. There was rap music flying off the walls of this homeroom of five students with autism and eleven other "typical" students. Eddie, one of the autistic kids, made himself a cup of calming herbal tea on the stove in the adjoining kitchen. Michael, another autistic student, and his friend Dante had pushed the desks aside in one corner of the room to play a game of Nerf basketball. Tasha, an autistic girl, leafed through copies of *Glamour* and *Mademoiselle* with Maria and Rachel. Jamal, also autistic, rode one of the two exercise bicycles. Two other boys read the newspaper sports page, and another played a game on the computer. The homeroom was rowdy by design, with plenty of things that stimulated the autistic kids but also attracted "typical" kids from throughout the school to want to voluntarily interact with these different students.

The tactic payed off. When Ben, a six-foot-tall boy with

autism, started slapping himself, another student took his hands reassuringly, then put them in his lap. Jamal, modeling the behavior of these other students, also learned to help Ben, telling him soothingly, "Don't cry." Ben and Dante became good friends, with Ben taking Dante, who lives in the city, to his home in the country. "These [autistic] kids are ready for the world with all its complexities and the community is learning how to deal with them," explained Luanna Meyer of Syracuse University, who helped design the program. "We're not postponing this inevitable need to prepare these two groups of people for how to deal with each other."

Most of the autistic students take gym, music, art, and shop classes with their nondisabled classmates. Some, accompanied by a teacher's aide, take regular classes, like reading, and two of them are in the top ten of their science class. All of them work two days a week in the community, at sites including a hardware store and a library. Pattie Johnson, the special education teacher who runs the homeroom, was initially skeptical of the fully integrated approach. "I've worked with kids who have been segregated and there's a big difference with these kids," she remarked. "Their behavior is so much better and their intellectual level is much higher, too. People who are segregated before high school are still working on separating nuts and bolts." Three of the students at the Syracuse school had been at BRI in Rhode Island. There would be even bigger surprises to come. Three years after I met Ben, he had become a columnist for his high school newspaper. He was taking academic classes and was proud of the B he earned in biology class. He even passed the mathematics section of New York's statewide Regents' examination. Not bad for the autistic kid whose teachers believed he could not even spell.

Ben, the adopted son of Sue and Bob Lehr, is the prototype of the student written off as incapable of learning because of his disabilities but who, in reality, is held back largely because of

others' low expectations. In Ben's case, the key to letting others see his potential came with a new and controversial teaching technique called facilitated communication. It required little more than a keyboard and human touch. A "facilitator"—usually someone with a day or two of simple training—holds the person's hand lightly and follows it over the keyboard. Often, over time, a facilitator can reduce the support, moving the touch to the arm, shoulder, or back. Although the power of touch is not fully understood, this gentle assistance seems to allow people like Ben to type out thoughts and feelings that they otherwise could not articulate. However, critics, including many researchers in autism, say it works on the same principle as a Ouija board: the facilitator, consciously or even subconsciously, moves the person's fingers to the correct letters.

Douglas Biklen, a Syracuse University special-education professor, first saw facilitated communication in action in 1989 in Australia, where teacher Rosemary Crossley used it with students with cerebral palsy. That made sense, since cerebral palsy does not affect intelligence, although people with it often have difficulty speaking and moving their hands. So Biklen was skeptical when Crossley started using the method with an autistic student. But the extraordinary results he witnessed made him a convert. He returned to the United States to teach the method, attracting parents, teachers, and speech pathologists to his training sessions. He began using it not just with students with autism but with those labeled retarded as well.

While autism researchers criticized Biklen for failing to do the testing that would provide qualitative scientific proof, parents eagerly embraced the method based on observation of their own children. In South Dakota, Marilyn and Steven Schiller were convinced when their eight-year-old son, Kurtis, began rattling off the surface temperature of Venus and other arcana about the planets. At school he was being taught his colors, but it turned out he had been reading his father's astrophysics books,

not just staring at the pretty pictures. In Syracuse, Richard Meives told his father "I love you," a first for the twelve-year-old with Down syndrome and autistic-like behaviors who was thought incapable of expressing spontaneous emotion.

Yet some autism researchers, like Eric Schopler of the University of North Carolina, call facilitated communication a cruel hoax being "recklessly" promoted to play on parents' unfounded dreams for their children. After all, he asks, what parents wouldn't prefer to believe their child really has a 130 IQ and can say "I love you"? Biklen counters that skeptics cannot deal with facilitation because it shatters their own theories. Biklen's surprising conclusion is that autism is not a thinking deficit as much as a physical one, with uncontrollable and sometimes violent body gestures, odd words, and grunts blocking real speech. Ben Lehr has said as much. "Listen to what I type, not what I say," he has typed.

Many parents side with Biklen. If the facilitator is doing the cueing, they ask, then how could Schiller pass his father's quiz on the planets when his mother—who did not know the answers—was holding his hand? If someone was making up his words, why were tears streaming down Mieves's face when he typed, "I want a real friend"? And how could it have been that a Chicago boy, thought at first to be typing gibberish, was really spelling all his words backward? Parents often find themselves fighting for the use of facilitation in schools, where officials are often skeptical about buying the computers in the absence of scientific proof. Schopler thinks facilitation may help 2 percent of people with autism; Biklen, who was once quoted at putting the figure at 90 percent, now says simply that the number is high.

It is not that facilitation is pure joy for families. Even for the most devoted parent advocate, there is sheer terror and profound guilt for having underestimated their children. "It's wonderful, but it's not fun," said Rebecca Susag of Minnesota. She regretted

not pushing her autistic daughter, Marta, further in school. Suddenly, she faced protecting a ten-year-old who, after all, still had a severe disability but was harder to protect now that she could express her own wants and choices. Susag's friend Jennifer Otto felt guilt over having never told her multiply disabled twenty-eight-year-old son about God. And Ben Lehr began talking about going to college, although success at that level certainly would not come easily for the young man who still sometimes throws tantrums at school.

School districts have balked not only at facilitated communication but at the costs of integrating disabled students. Schools spend an estimated \$6,335 per year on each student receiving special education services, compared with \$2,686 per year for students in regular classes. "It's not just a matter of having ramps and special rest-room facilities," explained Carol Arnesen, special education director for Orange County, California, schools. "Sometimes, it's special medical equipment, changing tables for older children who are incontinent, specialized cafeteria services because many are tube fed. . . . It's like running a mini-hospital."

Temple University Professor Margaret Wang figures that the cost gap could be closed. Schools spend at least \$1,000 per child with a disability on useless testing, she claims, and existing segregated special-education schools add cost for separate transportation and buildings. Meyer argues that integrated programs can save school districts money. Most, rather than set up programs like the one at Levy Middle School, will pay the tuition at private schools, even residential schools, which can cost \$50,000 to \$100,000 a year, says Meyer. But the Syracuse program spends about \$10,000 per autistic student, which includes the cost of extra aides who sometimes accompany the autistic students to regular classes.

Yet long after the 1975 law that opened schools to disabled students, they continue to get a second-class education. Some 67

percent are still taught in separate schools, classes, and resource rooms, while only 31 percent spend most of their day in a regular classroom, according to the U.S. Department of Education. Forty percent of students with disabilities drop out of school, compared to only 15 percent of their nondisabled peers. The problem is not a lack of know-how. Successful models, like the Syracuse program, provide a quality education for even severely disabled students. The problem is largely one of a lack of will on the part of school districts, which continue to see disabled students as a burden, to be separated and given low priority, and teachers who often expect too little, coddling disabled kids and teaching them less. The state-funded Massachusetts Developmental Disabilities Council concluded that segregation in that state had *increased* in the 1970s and 1980s, contrary to the intent of the 1975 schooling law. The council blamed schools for failing to set up integrated programs, as well as disincentives in federal and state school funding regulations, which reimburse towns at a higher rate if they send disabled students to private residential schools like BRI.

Particularly worrisome is that special education often becomes a catchall category for any student having trouble in class. A child may be there because of a disability, because a teacher cannot motivate him, or because his grades are falling due to some problem at home. Getting into these classes often stigmatizes children and relegates them to an inferior status. Nearly 10 percent of all students are enrolled in special education, according to a 1991 report to Congress. Fifty percent of these are categorized as having learning disabilities; 24 percent with speech or language impairments; 11 percent with mental retardation; 9 percent with serious emotional disturbance; and 6 percent have hearing, visual, orthopedic, or other health impairments. Yet state-by-state fluctuations show that determining who goes into special education is an inexact science. In Massachusetts, 17 percent of students take special education classes; in Hawaii, less than 7 percent. In Connecticut, nearly 19 percent

of students in these classes are labeled seriously emotionally disturbed, yet in Idaho less than 3 percent are classified that way. Minority students are especially likely to be placed in special classes, further raising suspicions that these classes are simply dumping grounds for unwanted students. In Massachusetts, 27 percent of minority students are labeled as special-education students, compared to only 16 percent of white students.

The number of students requiring special education will continue to grow, warns Wang. She cites the rising number of teen pregnancies. "Teenage mothers tend to have premature or low-birthweight babies, and these children often develop health and learning problems," she writes. "Many of them become permanently disabled, needing a lifetime of medical care and supportive services." In addition, a new generation of "crack babies" are entering school, challenging teachers with their short attention spans. A 1991 report by the Department of Education notes that the number of students identified with disabilities has increased every year since 1976 and is expected to continue that trend through at least the end of the century.

Despite the often begrudging commitment by schools, a better-educated class of young disabled people is providing the shock troops for the disability rights movement. The first generation of disabled students fully protected by the Education for All Handicapped Children Act began graduating from colleges in the early 1990s, the first disabled Americans to grow up assuming that they have safeguarded rights to equal opportunity. Their success under this law has encouraged parents of younger disabled children to settle for no less than full inclusion.

Integration on the Playing Fields

These new militants consistently demand full integration. This creates some often surprising controversies, like the one over the Special Olympics.

By drawing six thousand athletes from ninety-four coun-

tries, the International Special Olympics Games in Minneapolis became the biggest sporting event in the world in 1991. Forty-five thousand spectators at the gala opening ceremonies took in the pageantry of athletes in brightly colored warm-up suits basking in the thrill and glory of competition; seventy-five corporate sponsors poured millions of dollars into the event.

It was a far grander event than the first Special Olympics in 1968. Then, doctors had warned the event's creator, Eunice Kennedy Shriver, that the participants' fragile hearts could not withstand a run of more than 400 yards. But in Minneapolis, Savvas Vikelis ran a victory lap with the white-and-blue flag of his native Greece wrapped around his sweat-soaked body after he won a gold medal in the 13.1-mile half-marathon. In 1968, the experts had warned, too, that people with retardation could not swim. "One old shibboleth was that they had misshapen bodies and would sink to the bottom of the pool," recalled Sargent Shriver. "There must have been a dozen lifeguards around the pool at those first games. We didn't want a child to sink." He pronounced the last word in a voice dripping with sarcasm. The lifeguards, he explained, were deployed to assuage the lawyers worrying about liability. His wife knew otherwise. An accomplished athlete herself, she taught children and adults with retardation to swim in the pool behind the Shriver house at the summer day camp she had started in 1963.

The disability movement is filled with disabled people and their family members who have devoted themselves to disproving the accepted wisdom of various experts. Eunice Shriver, the younger sister of John F. Kennedy, was one of those debunkers. It started with a promise to her father to take up the issue and to look after her older, retarded sister, Rosemary, who lived at a Wisconsin institution run by a Catholic order of nuns. The Joseph P. Kennedy, Jr., Foundation, which she had helped set up in the 1950s, would research new ways to educate and serve people with retardation. But it was the Special Olympics for

which she would be best known. The games presented people who until then remained a closeted and dreaded population in a positive way to the world. For dispelling fears and myths about retardation, Shriver rightly became a hero, and the Special Olympics gained status as a revered American institution.

Yet in Minneapolis there were signs that the Special Olympics was having trouble keeping up with the new militancy of younger parents demanding full integration. There, many parents, like Barbara Gill and her son Amar, boycotted the event. Barbara Gill objects to Special Olympics because it is a segregated and special recreation that would place her son in a program with only other similarly disabled children. "We have separated people with disabilities into a shadow world," complained Barbara Gill. "It's an imitation world and it can never be as rich or meaningful as the real world." The Special Olympics, she argued, was just one more separate but unequal place in the shadows.

The week before Vikelis won his gold medal, Amar Gill, who is retarded, and five other twelve-year-olds won medals in the Milk Carton Boat Race at the Minneapolis Aquatennial Festival, a yearly celebration of the city's lakes. Amar helped his friends, none of whom were disabled, build the fifteen-foot long boat of plastic milk cartons and wood, painted green and shaped like a dragon. He paddled, too, along with the others. To Barbara Gill it was an important moment because "he felt accepted. He felt he was part of a team."

When the Shriviers started the Special Olympics, recreational activity for disabled people was a rarity. Then, 75 percent of children with retardation got less than an hour a week of physical education, says University of Minnesota professor and recreational therapist Stuart Schleien. Today, however, parents like Gill complain that the existence of segregated events like the Special Olympics only removes the pressure for creating truly integrated programs. When Gill's friend Sue Swenson asked her

playground to help her multiply disabled eight-year-old son, Charlie, play with his friends, she was told to send him instead to a segregated program like the Special Olympics. "It just furthers the pity impulse and the impulse to separate because it's special," complained Swenson.

Schleien argues that separation in recreation is especially illogical, since physical ability is the one place where people with retardation often match up best against all others. Schleien, for example, has successfully integrated adults with retardation into a long-standing Minneapolis bocce league. Although for most people the Special Olympics evokes images of cute children with Down syndrome struggling to cross a finish line, the competitors also include adults, the clumsy, and the athletically gifted. Mental retardation does not necessarily affect physical development, particularly among those with mild retardation.

Indeed, Special Olympians have gone on to fame by setting international track records, winning boxing titles, and playing in the National Basketball Association and National Football League. One former Special Olympian is one of the most widely recognized names in sports today. He declines, through a spokesman, to talk about his participation. Past and present Special Olympics officials will confirm the accomplishments of this athlete and others, but they refuse to make the names public, citing reasons of privacy. That there is such a stigma to going public, argued Gill, is just one more reason not to have separate games.

Jack Hourcade of Boise State University complains that the Special Olympics only masks the wide-ranging abilities of people with retardation because it is a segregated event, with a "childlike atmosphere" that includes "huggers" at the finish line, an appeal to charity, the use of yellow school buses to transport athletes, and the presence of clowns at events.

At the Minneapolis games in 1991, Special Olympics organizers worked hard to dispel stereotypes. Press officers pushed

the stories of accomplished adult athletes, like twenty-three-year-old Andrew Leonard, a five-foot-tall power lifter who could dead lift four times his weight; and Loretta Claiborne, a thirty-six-year-old who had run twenty marathons, including the Boston Marathon. Special Olympics officials even handed reporters a guide to proper usage of disability language. Despite their efforts, the media tend to cover the games as a feature story, not a sporting event. So it was not the accomplished athletes who drew the cameras but the cute kids, like the irresistible Chinese girl who thought the race was over halfway through and then, waving her little American flag, joyfully jumped into the arms of a hugger.

The future of the Special Olympics may lie in its tentative acceptance of integration. In Minneapolis, a concept called "unified sports" was on display internationally for the first time. About 4 percent of members of bowling, volleyball, basketball, and other teams were not retarded. Unified sports matches up teammates of roughly equal athletic ability. The idea first emerged in the early 1980s when a Massachusetts softball team decided to integrate itself. Gus Piazza of the Massachusetts softball team that pioneered the concept says the unified teams meet the ideals of integration: disabled athletes get opportunities, and friendships develop. The result was a fairly skilled level of play, as high or higher as on any coed softball league anywhere in America. Piazza says he has watched his teammates with retardation "lose their shyness" and blossom both socially and athletically. Before that year, the Soviet Union, denying even the existence of retardation in that country, declined to participate in the Special Olympics. But in Minneapolis, the first Soviet team to compete was particularly curious about the unified events and announced it would try this American innovation of mainstreaming back home.

Some Special Olympics critics, like Schleien, think unified sports is a step in the right direction. Others, like Barbara Gill,

remain skeptical. She argues it would be better to guarantee her son "space in the real world" and the chance to join any league along with his friends who are not disabled. It is not enough, she says, for Amar to grow up having to rely on the willingness of "some good people to be in the shadow world for a while."

Not by Law Alone

Laws alone cannot guarantee integration. Even after *Brown v. Board of Education*, blacks faced George Wallace blocking the schoolhouse door. Even after the 1964 Civil Rights Act, there would be decades of racism, hostility, and neglect. Compared to black Americans, disabled ones have found an advantage in the fact that public reaction to them is often motivated by compassion and charity, even if it is mixed with fear and revulsion. And because at least one in seven people have some disability or chronic illness, many Americans are likely to have someone in their own family who is disabled, giving them some understanding of what it means to live with a disability. Yet integration for blacks, compared with integration of disabled people, has been a more consciously adopted societal goal. There are affirmative action programs, minority set-asides, college scholarships, and other efforts to open up opportunities.

Integration has been more quirky and halting for disabled Americans. Even after passage of the 1975 Education for All Handicapped Children Act, school systems continue to run separate schools. Often they respond only when sued by parents, even though the courts, almost routinely, have ruled in favor of the children, even for ones as severely disabled as Timothy W. The history of segregation has been every bit as devastating for disabled Americans as it has been for black ones. Today, the unemployment rate among disabled people is 66 percent. Only 15 percent take part in postsecondary programs. Many depend on some form of welfare. For those with developmental disabili-

ties, for example, 65 percent of their total income comes from public sources, compared to 17 percent for all Americans. Twenty-five percent of people with developmental disabilities live in families with incomes below the poverty line.

In the long run, integration will cost society less. A good education allows a disabled student one day to become a worker and a taxpayer rather than a costly tax burden. But school districts, hard-pressed for resources, tend to resist steps that will ease the drain on someone else's budget in the future. They avoid training a regular classroom teacher to include a child with severe dyslexia or ramping the schoolhouse door.

Recognizing the political reality of fiscal limits, the disability rights movement has been forced to accept a long, slow road to achieving full integration. Even the Americans with Disabilities Act, for political expediency, rejected an instant "flat earth" philosophy in order to phase in integration over time. Cities, for example, are required to equip buses with lifts, but only the newly purchased buses. It will be decades before the older buses—in essence, segregated facilities to wheelchair users—go out of use. Laws that guarantee nondiscrimination in employment and public accommodation mean little for a young disabled person who, due to antiquated Medicaid and Medicare laws, has no option but to live in a nursing home. And laws that govern construction of new homes require only a small percentage to be wheelchair accessible, ensuring that people who use wheelchairs almost always will be unable to visit friends and even family in their own homes for years to come.

The result is that disabled people and their families often have legal protection but few true options. As the ex-chair of the education committee of the Association for Retarded Citizens of Maryland, Nancy Rhead is a fervent advocate for integrated schooling. She understands that schools are the first public institution to shape people's attitudes and are therefore crucial to moving people into the mainstream. All this became painfully

clear for Rhead one day when she walked through a store several paces behind her son. David has mild retardation and mild cerebral palsy that gives him an odd gait. "It was chilling," Rhead recalls of seeing the cruel stares directed toward her son. But she knew that people who got to know her son at school found him gentle and friendly. "If you grow up with these kids in your gym class and cafeteria, you get used to people being different. You get comfortable with it." That was Rhead's ideal world, but in Rhead's real world, she did not always have the choice of sending David to integrated schools. He went to a regular public high school when he was eighteen. But because he could not pass the state's newly instituted basic-skills test in math, reading, and language, he was moved to a segregated special-education school. He mourned the lost familiarity of his old school and friends, and his performance slipped. Ideally, there would have been space in a community-supported work program—similar to CSAAC—in his community. But instead, David became one of four thousand adults with retardation on a waiting list for the few such publicly funded positions that do exist in Maryland. So Rhead had to send David to a private residential school—the very sort of option she opposed as an advocate.

David attended the Benedictine School for Exceptional Children on the Eastern Shore of Maryland, run by Sister Jeanette Murray, a dynamic administrator who had adopted community work and living programs in her separate school. Students went through high school in segregated classes, but then were moved into community-supported work programs and group homes every bit as state-of-the-art as those funded by CSAAC, upon which they were modeled. David's three years at the Benedictine school gave him the good job habits and social skills that later allowed him to live in his own apartment several miles from his mother and to work with a lawn maintenance service. He became active in his community, doing volunteer work at the local

library and even testifying, with other neighbors, at a county hearing in opposition of a plan to end a bus line that served his area and which he depended upon to get around.

Today, blacks and women often choose to go to separate colleges for the comfort and experience of being with peers of a like identity. But disabled people have few of the options offered other minorities. Nancy Rhead chose a segregated school because it was the only real possibility open to her. "Families ought to have the opportunity to make a choice," says Rhead. "But that's not true right now."

Go-slow integration only creates a cycle of failure and frustration. When a family chooses a segregated school, there is less pressure to integrate other school programs. When a parent enrolls a child in a private residential school that uses aversive therapy, it becomes harder to argue that such punishment is outmoded and should be abandoned. When disabled people are herded into sheltered workshops to earn below-minimum-wage salaries for piecework, employers lose the impetus to hire good workers, and taxpayers foot the bill. When separate recreation programs like Special Olympics exist, parents get turned away when they seek inclusion for their sons and daughters at neighborhood playgrounds. Disabled people remain segregated, and non-disabled people do not get to know them. The only force for overturning the status quo is a growingly militant generation of disabled people and their parents, whose anger and targets will surprise those who remain unaware of the growing frustration.