

CHAPTER 10

CROSSING THE LUCK LINE

The cemetery at Faribault Regional Center, a state hospital for people with mental retardation, offers few clues that this is a place for burying people. I had followed the arrow on the sign, past the residents' neat red-brick households down the side road to the edge of the institution. With ease, I spotted the six-foot-tall white cross that suggested the cemetery was nearby, but it took me several minutes walking back and forth across the small field to realize that coffins were laid under my feet. No headstones jutted out from the ground to dot this graveyard. Instead, each grave was marked by a plain brown stone, a foot long and three inches wide, just big enough for a chiseled number. Each stone was set level with the soil. Once I found one—number 1216, then 1217 and 1218—I knew where to part the overgrown grass to find the others. Some 1,200 men, women, and children had been buried there, with no name, no date of birth or death, not even an epitaph to speak for their

forgotten lives. Another 487 people, those who died at Faribault before 1924, had also been assigned anonymous digits and laid to rest at the bottom of an adjacent hill in an inaccessible plot overgrown with weeds and tall grass.

I had come back to Faribault in southeastern Minnesota to find Jim, a young man whom I had befriended when I was a college student. Jim was thirteen when we first met. He spoke in short staccato sentences, was fascinated by wheels, and usually kept toy cars stuffed in the pockets of his jeans. He lived at what was then called the Faribault State Hospital for the Mentally Retarded. (Until the 1940s, it had been the Faribault State Hospital for the Feeble-Minded and Epileptic Colony.) Faribault was Minnesota's first such institution. It opened to care for "children of weak minds" in 1861. Since then, its red-brick buildings and squat barracks-style residences have sprawled over a sylvan 760-acre campus set among maple and pine trees.

When I first met Jim in the early 1970s, Minnesota, like other states, wanted to empty such large institutions. Jim—he was Jimmy then—was on a list to move out of Faribault permanently to live with a foster family or in a group home. But before he left the institution, he needed the experience of living in a house again, as he had before he was sent to Faribault at age six. He needed to know what it meant to eat family-style around a dinner table, instead of in a noisy cafeteria. He needed to sleep in his own room, instead of in a barracks with three dozen cots in a row. With eleven friends at nearby Carleton College, I started a transition program for Jim and others like him at Faribault. We moved into a rambling, three-story house. We each "adopted" one kid and, shuttling to Faribault and back in a turquoise Cadillac with high tail fins, we brought them for overnight visits.

On my first trip to Faribault, in 1973, staffers had rounded up a number of residents for us to meet, all on a list to leave for group homes and foster families. I chose the shy, blond boy who

watched me intently. A few weeks before his fourteenth birthday, Jim made his first visit to our house. For me, it was a bone-tiring, mind-blurring event. Jim was in perpetual motion, wild with curiosity and drunk on the excitement of a new place and new freedom. He dashed up the three flights of the curved wooden stairs through our Victorian-era house, with me always a few steps behind trying vainly to catch up. He dove through doors, into bedrooms, exploring unfamiliar rooms and examining drawers and desk tops as if they were treasure mines. He sought out anything that was round—the casters on the bottom of a bed frame, a hockey puck left on the floor. He did not communicate. My questions were answered with silence. He eyed me with suspicion; he made noises. If he spoke, his sentences were never longer than one word. I wondered whether I had made a mistake. But over the next few weeks, we connected. Jim's shyness eased and he talked more. I looked forward to our time together as much as he did. When the year ended, I felt guilty leaving him (although another student continued to bring him to campus for the next two years).

At the end of the year, five of our twelve kids had moved into foster homes or group homes. Jim was not one of them, but he remained high on the list to leave.

Sixteen years had passed and I had lost track of Jim. Neatly, the beginning of the disability rights movement could be traced back to about the time I had last seen him. As I wrote about the quickening changes in the lives of disabled people, I thought often about the last time I had seen Jim at our college house. He had brought an Erector Set to build a go-cart big enough to ride in. I, along with my housemates, puzzled over the disjointedly written instructions. Between us—Phi Beta Kappas and magna cum laudes—we could not figure out which bolts screwed into what metal plate to keep the cart sturdy. After waiting patiently for us for well over an hour, Jim tired of our ineptitude. He threw a small tantrum. We had tried our best, I explained to

him softly. Then I left him on the porch to cool down. When I came back a few minutes later, Jim was sitting on the go-cart he had assembled correctly by himself. He could not read the instructions and he had trouble verbalizing his thoughts. But Jim was mechanically gifted, perhaps a mechanical savant.

To find Jim, who would be thirty by now, I had started with a telephone call to Colleen Wieck in St. Paul. As head of the Minnesota Governor's Planning Council on Developmental Disabilities, Wieck is nationally respected as a champion for the rights of people with retardation. There were three possibilities for Jim, she explained. "The worst-case fear is that he is still at Faribault," she had warned. "The next-worse case, but probably the most likely, is that he is in some large group home setting where no one cares about him. The best thing would be if some really good case manager found him, cared about him, and got him into a small group home or on his own and into a good job."

It took just a few phone calls before I tracked down Jim. It was the "worst case": After sixteen years, Jim was still at Faribault.

Now less than one month after I had located him, I was back at Faribault, walking through the unsettling cemetery and collecting my thoughts in the moments before my reunion with Jim. I had come to Faribault to see if he wanted to get out of the institution and if I could help. I was there to spend a few days with Jim, showing him group homes and job programs that could allow him to work and live independently. He had never seen these things before. His social worker at Faribault had told me on the phone that Jim spoke often of wanting to move "into the community," even if he was not precisely sure what that phrase meant. When I had last seen Jim, there were some twelve hundred people at Faribault. Now there were five hundred. There were long waiting lists to get out. Money was tight, and coveted slots in group homes were scarce. Jim, unlike many of those who had managed to leave, did not have any family mem-

bers or friends acting as his advocate. Consequently, he had fallen between the cracks in the system and remained at the institution where death still meant an unmarked grave in the cemetery.

At Faribault, a volunteer coordinator led me to a darkened canteen. When I walked in, Jim fixed on me an intense and curious stare. The look was familiar. So too was his smile, broad and easy, when we recognized each other. We sat at a bench, and I pulled out photos from our last time together, when Jim had deftly assembled the Erector Set go-cart. Jim was tanned, with muscular arms from working on a lawn crew. His hair was blond but thinner. He still carried a toy wheel. If anything, though, Jim now looked older than I did, despite the six-year difference in our ages. There were crow's-feet around his eyes, and he squinted hard when he looked at the photographs. He had been fitted with glasses several years before for his advancing near-sightedness, but he had refused to wear them. He seemed smaller than his five feet, six inches, partly because of his thin frame and stooped shoulders.

Over the next three days, I was reminded over and over why I had enjoyed Jim so much and had found him so intriguing. Our first evening together we went to a county fair in nearby Owatonna to watch noisy sprint cars race around a damped-down dirt track. Jim picked his favorite car on the basis of its white wheel rims. We went on some of the carnival rides. On the bumper cars, Jim showed that, somehow, he had learned how to drive. Must bumper car riders like to crash into each other, but Jim got more kicks from avoiding being hit. He expertly eluded me and other riders in his small red car. He took turns sharply and instinctively seemed to know just when to slow down or speed up. His mind was at work on other rides, too. On the Thunder Bolt, Jim casually studied how our small car was suspended from the ride's center frame and how the gears and levers rocked us and swung us around. We went to see *Days of Thunder*,

the Tom Cruise film about a stock-car driver. Jim reveled in the film, particularly the fast-paced race track scenes.

On our last day together, Jim took me to his storage area, a small room under the cottage that had been set aside for him to keep tires, bicycle frames, and wood. From these, he made sophisticated go-carts patterned after sleek Grand Prix racers with steering mechanisms and real tires bolted to axles. One of the counselors in his household had shown Jim an old *National Geographic* photo of the *Gossamer Condor*, the bicycle-powered glider that had been flown in 1979. From memory, Jim had begun constructing a model of it. He made a ten-foot-long wingspan of light cardboard covered with evenly spaced wire loops to hold the gauzy wing sail and built a light wooden crate to hold the bicycle and rider. The storage room was Jim's magical laboratory. It was a narrow, concrete bunker, dimly lit by sunlight that pushed through a small ground-level window. Here, Jim's mind seemed to whirl at one hundred miles a minute, thinking out designs for new cars. I could not follow his plotting. He started laying out pieces of wood on the floor, asking for my pen to mark where he wanted to cut.

I learned more about how Jim had come to be a ward of the state. Going through his record file, I discovered that Jim was born in October 1959, the fifth of nine children, to a struggling Minneapolis laborer and his wife. Jim's parents had divorced two years before he was born but continued to live together. According to a sketchy social history written in blue mimeograph ink, "Reports from the Hennepin County General Hospital suggests [*sic*] that he was 'abandoned' between age one and two." By the time Jim was two, it was clear he was hyperactive. At age three, his mother found him under the kitchen sink, trying to figure out how to detach the drainpipe. At age four, he began running away from home. At six he had darted into traffic and been badly injured by a car.

A few months later, in February 1966, Jim was placed in Mrs. Ontko's boardinghouse for troubled children in Minneapo-

lis. But Mrs. Ontko and her neighbors were soon complaining that Jim could not be controlled. He ripped the upholstery, the proprietress told social workers, and ran away frequently, only to be returned by police. Testing showed that he had an IQ under 30. A University of Minnesota child psychiatrist examined Jim and concluded: "The final diagnosis was mental deficiency, idiopathic, severe." On September 22, 1966, the board of examiners for the Hennepin County Probate Court held a "hearing on mental deficiency or epilepsy" to decide whether to institutionalize Jim. His mother attended. The examiners determined Jim to be "mentally deficient." By the first week of October—several days short of his seventh birthday—"emergency space" was made available to admit him to Faribault.

The institution was a brutal place for residents labeled severely retarded, like Jim. This was chronicled by University of Minnesota psychologist Travis Thompson, who came to work there in 1968. Thompson asked to work with the toughest residents and was taken to Dakota Building, where the institution kept what it called the "high profounds." "I was confronted with sights, sounds and smells which I had never before experienced and hoped that I would never witness again," the young psychologist later wrote. "Seated in the middle of a large ward area, shackled to a chair, was a young man in his twenties, all of his skin abraded from his knees and blood running down his shins. Along the seventy-foot wall of the ward were seated approximately fifteen men, huddled in fetal positions, with their heads between their knees." Thompson described finding sixty-seven residents in the crowded room, sitting in urine and feces, rocking or walking aimlessly, or running around the walls of the room. Some were naked or nearly naked. Others gnawed their hands or twiddled their fingers in front of their faces. That night, when he got home to his shower, Thompson washed his body for a half hour, trying to get the acrid smell of the ward out of his skin.

Thompson worked to train these "high profounds," using

positive behavior modification techniques that would later be imitated at other institutions. For every task completed, no matter how small, a resident was given a reward. When Thompson began his work, 65 percent of the men on the ward did not use toilets. At the end of a year, 81 percent did. Half did not wear clothing in the beginning, but 91 percent did after a year. Forty percent did not feed themselves at first, but 95 percent could eat with a spoon after twelve months. Many, too, were heavily drugged. Seventy-nine percent, he found, were given daily doses of strong tranquilizers. After a year of Thompson's behavior modification, only 56 percent needed drugs, a total that eventually dropped to 20 percent. Any normal person left in Dakota for six months, Thompson told a reporter at the time, would no longer be normal. "They would fit in with the crowd, rocking and rocking, sitting in their own feces."

Faribault's most famous resident was Bill Sackter, whose story was portrayed by actor Mickey Rooney in the Emmy Award-winning television movie *Bill*. Sackter had been labeled "imbecilic" at the age of seven and sent to the institution, where he would spend forty-four harsh years. He was physically abused and put to hard work pushing food trays. Poor medical care resulted in chronic leg ulcerations that would persist throughout his life. "I was there so long I didn't know I was there" was the way Sackter put it to Barry Morrow, who would later chronicle his life for television. An aide—"the mean one," Sackter would explain—had thrown him down a flight of stairs by his hair, yanking out a bloody clump of his scalp. Sackter thought this injury had something to do with his being "crack-brained," and he wore a hat or an ill-fitting wig to cover the scar. Released to a Minneapolis group home in the late 1960s, Sackter eventually got work scrubbing pots in a country club kitchen. There he met and befriended Morrow, an aspiring young filmmaker whose wife, Bev, was a waitress at the club. Sackter moved with the Morrrows to Iowa City and ran Wild Bill's Coffee Shop at the

University of Iowa until his death, at seventy, in 1983. The Minnesota Department of Public Welfare then billed Sackter's estate (which had no money) for \$10,000 to reimburse the care he got at Faribault.

When I first volunteered at Faribault in 1973, Jim slept in a large barracks with three dozen closely spaced beds. He had no place to keep private property. The Christmas presents I sent Jim that year were all stolen within a few days. Meals were served in a clamorous cafeteria, a cavernous room with linoleum floors and tile walls that reverberated the shouts and scraping of dinnerware on hard plastic food trays. Flypaper strips hung from the walls. Before every meal, Jim washed his hands in a common bowl of disinfectant and warm water, a procedure to kill the bacteria that cause dysentery, a problem at Faribault and other institutions. Some residents, children as well as adults, were even less fortunate, passing the daylight hours tied to chairs and beds. Some wailed and screamed incessantly. While Jim attended what passed for a school, where he received the most rudimentary education, adults at Faribault generally passed day after day with nothing to do.

By the time I was reunited with Jim in 1990, he was living in a two-story brick building called Osage, the same cottage where he had been sixteen years before, but there were only twelve men on the wing, now called a "household." Jim slept in a small room with three other men. While one bed was less than five feet from his, he had his own posters of sleek Ferraris and a 1960 Chevy Belair on the wall, as well as his own television, which he had purchased with \$190 he made from his work on the lawn crew. From 8:30 A.M. until 2 P.M., five days a week, Jim and several other Faribault residents cut grass and trimmed lawns in town or, in winter, cleared snow. Jim's salary: \$2.88 an hour, below the minimum wage but higher than what many similarly disabled people earn. Jim was free, during the four hours after work and before dinner, to roam the grounds of the

institution. He would take his new blue bike down to the Nature Center or to the woods, or spend his free time in the woodshop, making cars out of wood and junk.

For the most part, the professional staff at Faribault clearly seemed to care for Jim. Ben Weeks, the soft-spoken shop director, had welcomed Jim, instructed him, given him the freedom to experiment with tools and materials, and then exulted over his inventions. But the month before I arrived, the shop had been placed off-campus, ending Jim's use of it. His job coach, Lori Johnson, would occasionally bring Jim for dinner over the weekend. Corinne Fowler, who supervised the Osage cottage, was another admirer of Jim's. Deb Lenway, a cottage counselor, was Jim's "one-on-one," the staffer who took Jim shopping for clothes and wheels and out for dinner on his birthday. She knew Jim better than anyone. Others, too, tried to make Osage as nice a place as possible to live. One night when we came back, a staffer had made Rice Krispies bars, which Jim ate with milk before going to bed.

Yet at the same institution there were constant reminders that residents could be stripped of the respect and dignity automatically given any other adult. A few weeks after my visit, the Rice County district attorney brought criminal abuse charges against four Faribault counselors. Mark Kern, according to charges laid out in a police criminal complaint and an internal social services department report, had abused one man by pouring a chemical cleaner on his genitals and fed chili powder and hot jalapeño peppers to other residents "for kicks." The twenty-five-year-old Kern was also accused of blowing powdered dish detergent—which he jokingly referred to as "nose candy"—through a straw into the nostrils of two other men, who reacted with "uncontrollable sneezing that would last for about thirty minutes," according to the social services department report.

At trial, prosecutor Karen Lewis said Kern had taken an undiluted industrial cleanser, one so corrosive that he had to don

heavy rubber gloves to pour it into his hands, and spread it over the genitals of a resident identified as K.S.H. The man had seemed to annoy Kern solely because he was severely retarded and black. Twice, a doctor had noted the burns on K.S.H.'s raw scrotum and his painful walking but had let the matter drop.

The prosecution went disastrously. K.S.H. did not have the ability to communicate what had happened to him, and Kern's close-knit colleagues refused to testify against him although, according to the complaint, Kern had freely bragged of his tortures. It was only by accident that the allegations had become public at all. A nurse at the cottage had retired. At a pub to toast her departure, after liquor had flowed freely, she mentioned that she had seen some terrible things and was glad to be leaving. Her supervisor, among the revelers, passed on her allegations to Faribault's superintendent, who, as required by law, called in the local police to investigate. The state had pushed the issue largely because the sister of one of the alleged victims was a state social worker who knew the system. The nurse who had begun the process with her farewell "confession" was Kern's aunt and seemed reluctant to testify against him in court.

When a jury acquitted Kern, prosecutor Lewis dropped the remaining cases and complained that she had been stymied by a "code of silence" on the Faribault campus. A subsequent investigation by the state ombudsman for mental health and mental retardation found that staffers routinely failed to report abuse, because they either did not take it seriously or feared retaliation from their coworkers. Indifferent institution officials, the report concluded, had been guilty of a "failure . . . to provide a clear message that abuse and neglect of clients is not tolerated."

How, then, could the two types of staffers—some nurturing and professional, the others uncaring and sadistic—exist at the same place? Many, I knew, had valued having a job where they could help people in need. At Faribault, which was unionized,

these workers received good salaries, which attracted many skilled staffers and kept turnover at a relatively low level. But Faribault also attracted a large number of others—unskilled workers who received virtually no training when they got hired—for whom this was simply a better-paying job than other options, such as working in one of the town's many fast-food restaurants. Many at Faribault had worked at both.

The ultimate problem, however, was the nature of the institution itself. It had evolved from the model of a prison, not a home, so there was a tacit license to disrespect the "inmates." The bottom line was that Jim was considered a deviant in need of rehabilitation. Everything he did was regulated, from the moment he woke up until he went to sleep at night, a carryover from the behavior-modification techniques Thompson had instituted in the late 1960s. Every morning when Jim woke up a staff person was required to give him the following instruction: "Jim, you are to get dressed, wash your hands and face, brush your teeth, shave, comb your hair, make your bed, and straighten up your room. When you've finished with all of these you are free to do what you want to until 8:30 A.M., when you must be at work." This precise wording was laid out in the "Goal Implementation Form for Problem Behavior" that I found in Jim's file. When he got up he was handed his "token recording sheet" for the day. When he completed a listed task in a "complete" and "compliant" way, such as getting dressed, shaving, or making his bed neatly, he got a smiley face or a check. Those were counted toward tokens that allowed him privileges such as sodas or his beloved free time in the woodshop. When he "misbehaved"—did not do something on time or displayed anger over being required to do the task—he lost his privileges. His goal-implementation form, which was updated yearly, ran for five pages. It regulated everything that he did during the day, from specifying what time he was to wash his hands down to the minute he was expected to check in with his supervisors. If Jim

did not check in at 9 A.M., 12:45 P.M., and again at 6:45 P.M., a staffer was ordered to "search immediately" for him and return him to the building.

As a condition for continued use of his storage space, Jim was to keep the basement room neat. An agreement with his counselors specified that he was to sweep the area each week and keep no more than twelve tires and four bike frames there at any one time. At a weekly inspection, a staffer was to find "no dirt or debris on floor." Similar good housekeeping habits were expected in his small bedroom. All of his clothes were to be hung neatly on hangers. There was to be "no dust on shelves or top of wardrobe" and no loose paper left on top of his television cabinet. He was to do these tasks up to fifteen times without fail in order to prove he could master these chores.

Jim kept his storage area tidy, with wood stacked up on wood and go-cart frames leaning against the wall. Jim had even figured out how to cover the basement drain with heavy electrical tape so that after heavy rains water would not back up into the small room and soak his projects. Looking at the small, clean room, I realized I would not fare nearly so well if social workers paraded through my home each week to see that I had dusted precisely and not kept piles of mail and paper lying around.

Even Jim's work productivity was carefully measured: how often he worked a machine properly, set up the materials he needed for work, and notified a supervisor when he had a problem. Jim was a hard worker. "Jim has a strong ethic," Ben Weeks in the workshop told me. "You show him how to do it and he'll do it right every time." According to his file, Jim had an 86 percent "productivity rate." That is, he did every last detail correctly almost all the time.

Yet because Jim's actions were so exactly measured, officials at the institution tended to see his life largely in terms of faults and problems that needed fixing. Jim's abilities—as well as the things that made him an interesting individual—were obscured

behind this obsession with the negative. That was clear from reading Jim's file. There, officials at the institution justified why Jim had to live at Faribault and was not ready to live on his own. In short, Jim was deemed a troublemaker. His supervisors wrote that Jim displayed "physically aggressive and destructive behaviors" and that he often "threatened" people verbally. "These behaviors are most prevalent when he does not get something he wants immediately, is not allowed to do something he wants to do, or is required to do something he does not wish to do," said his report. The system of tokens and regulations was designed to break Jim of these behaviors that officials at Faribault considered sociopathic.

Jim's threats, not surprisingly, revolved around cars. His most dire menace was to say, "I'm going to throw rocks at your car" or "I'm going to take the wheels off your car." This was his way of cursing, of venting frustration. In the daily "progress notes" his counselors kept on Jim, I read of one incident a few days before spring when the snow was still piled high in Minnesota. At the evening dinner table, one of Jim's housemates noted that it was going to snow again. Jim "got very upset" and told the housemate to "shut up," the counselor wrote. "He said he didn't like snow, he wanted summer to come. So then I told Jim that he wasn't being very polite, and that I wanted summer to come too." Jim did not like that response and told the counselor that he would "break" his car. That was the kind of seemingly minor irritation that got written up and tracked. Another counselor was more charitable in writing up Jim's maledictions. "Ate breakfast with Jim," says his curt entry. "Threatened to take the wheels off my car. Called it rusty, an accurate statement."

Jim's counselors could proudly tell me how many of these so-called threats he had made. In 1990, there had been nine in March, then fifty-two in April, and only three in May. Nobody could tell me what it was that had bothered

Jim so much in April; nobody had even tried to figure it out.

I had come to Minnesota to show Jim a program called Opportunity Services, which would place him in a job and give him an alternative to living in the institution. Jim's behavior—the aggression, the threats, the destruction of property—sounded pretty serious, but Nancy Gurney, the director of Opportunity Services, just laughed them off. In only a few years, her private nonprofit group had taken hundreds of clients out of Faribault and other state institutions and placed them in jobs. Time and time again, Gurney had picked up a client's file to find the client labeled aggressive, threatening, or worse. Almost always, Gurney assured me, such behaviors disappeared quickly once the person left the institution. "When they walk onto a job site, they see that the other people, who do not have retardation, just do not act that way," said Gurney. "So they stop, too." Jim's threats were a "learned behavior" at Faribault, Gurney said. It was what he had to do to get attention.

Nevertheless, Jim's supervisors at Faribault, starting in the fall of 1989, had begun to chart Jim's incidents of "aggression" and "property destruction." The goal, as laid out in Jim's "monthly maladaptive program progress review," was to cut these incidents down to zero per month for three consecutive months. Before he could be considered a candidate to leave Faribault, officials argued that he had to meet this standard. There had been one particular incident that had led to this intense monitoring of Jim's behavior. In September of 1989, a Faribault social worker backed her black pickup truck out of the parking lot one evening, and the truck's back wheel fell off. Jim was the immediate suspect. After all, of everyone on the Faribault campus, only Jim was considered clever enough to figure out how to loosen the lug nuts of a truck tire. Jim had been angry with the woman, and he had been seen near her car, although no one witnessed him tampering with it. According to Faribault's records when confronted with the evidence, Jim

"confessed" and said he wanted to apologize. The penalty was severe. Jim was to make restitution out of his monthly paycheck for damages to the truck. He was to be placed on twenty-four-hour restriction if he was absent without leave, caught stealing, entered an unauthorized area—like the woodshop, where he sometimes went after hours—or threw rocks at anyone's car.

The incident only added to Jim's reputation around campus for his obsession with wheels and his mechanical brilliance. One result was that whenever someone saw what appeared to be new damage to their car, Jim took the rap. Mike Sheady, Jim's social worker at Faribault, told me that a few months earlier Jim had been blamed for scratches found on another staffer's car. But when, after investigation, it became clear that Jim could not have been involved, the complaint was dropped. Similarly, if a workman misplaced a tool, or something could not be found in a workshop, it was often concluded that Jim had stolen it. I asked Sheady if Jim had been caught with any stolen tools. He could not remember any recent incidents but added that it was assumed that Jim kept purloined goods in secret hideaways that he was said to have fashioned in the woods around the institution. There was no report in Jim's file over the last year of his being caught with stolen goods, although on one occasion he was caught trying to get into a locked classroom. I heard a lot about Jim's alleged thefts. But when I found Weeks, the former high school shop teacher said such reports had been exaggerated and that he knew of no case of Jim ever stealing tools.

I did hear one story of how the campus gardener took off his boots, left them at the entrance to the greenhouse, and later found them missing. They showed up on Jim's feet. It struck me as a creative use of "found" shoes, since Jim's own were always in miserable shape, with holes, mismatched, broken laces, and the leather rubbed so raw that it no longer had color. I also came to wonder about what must have been Jim's different notion of property. Clothing had once been communal, and over the years,

even now, his possessions were routinely stolen. He now had his locked storage room and a key to his closet in the bedroom. When I sent Jim something—photos from a recent visit, a wheel, or a tool—I would call to see if he had received it. "I've still got it" was Jim's inevitable reply. To this man who had grown up without privacy, property was something temporary and passing.

Nothing underscored the system's negative attitude toward its clients more than all the excuses made for keeping Jim at Faribault. Where would he keep all the tires and wood he collected? A group home, Sheady told me, would not have enough room. ("That's easy to solve," said Gurney. "We can buy him a \$100 tool shed from Sears.") Larry Hall, Jim's home-county social worker, explained that state law required that an effort be made to place Jim in the county where his family lived—Hennepin County, which included Minneapolis. But Hennepin County, Hall explained, was not right for Jim. He needed a rural area, someplace where he could ride his bike around freely. In a group house in an urban setting, Hall argued, Jim "could be talked into doing something wrong." There was another reason to keep him away from Minneapolis, Hall explained. Jim's parents feared he was shrewd enough to figure out where they lived. After cutting off contact with Jim, they did not want to find him on their doorstep.

Jim was a ward of the state, and Hall was his legal guardian. Employed by the Hennepin County department of community services, Hall ultimately made decisions for Jim. Hall said he knew of no suitable placements for Jim. I told Hall about Opportunity Services, which could place Jim in rural Minnesota, not too far and not too close to the Twin Cities. I asked Hall to join me when I visited. But when I got to Minneapolis, Hall told me he would not approve of Jim's going into the Opportunity Services program. Now Hall had decided Jim should be in Minneapolis after all. "I'm hoping," he explained,

"there can be some kind of reconciliation with the family."

It had been nearly six years since Jim had last seen his mother or siblings. Jim's father had left instructions several years before not to be contacted about Jim. There had been no family Christmases, birthdays, or visits on "family day" at the institution. His mother, I was told, had asked the staff at Faribault not to let Jim call her on the phone. He had last seen her in a brief visit on Thanksgiving Day six years before. Jim, according to Hall, had "trashed" her home in Minneapolis. His offense: he had pulled down the living room drapes. Looking through Jim's file, I realized that a significant event in his life had occurred a few days before the incident. Jim had been recommitted to Faribault. By law, the state had been required to go to court to determine whether Jim should be let out of the institution or placed in a group home. Jim's mother had told a social worker that Jim was "happy and content at Faribault State Hospital and views it as his home." Jim had told the same worker that he "wants to go [to a group home] in about three years."

Today, the only people going into institutions are adults whose parents die or are too old to keep caring for them. Had Jim been born in the 1990s instead of in 1959, he would have stayed with his family and likely would have gone to the same schools as his brothers and sisters. As an adult, he would have moved into a group home or his own apartment and worked with nondisabled people in a job where he got individual attention from a job coach. In Jim's case, he could have worked in a family business. When I looked in the Minneapolis phone book, I found an auto body shop owned by one of his brothers. Jim's mechanical genius seemed to be a family trait. I drove by the low-level brick garage on a busy city street, watched a tow-truck drive in, and wondered how different Jim's life would have been had he been born in a more generous time.

Given his fascination with cars and wheels, Jim would be a natural candidate for a job in a garage. The women who run

Opportunity Services realized this, too. Their program, based out of Red Wing, a pretty Mississippi River town fifty-five miles southeast of the Twin Cities, had a reputation for creatively tailoring jobs to the skills and desires of its clients. That is how Jim got to an auto garage in Red Wing.

Conveniently, it was owned by the husband of Jill Bengs, who ran Opportunity Services' employment program in Red Wing. When we arrived, Tim Bengs was working under a car hoisted on a hydraulic lift, adjusting the brakes on the back wheel drum. Jim watched intently, fingering one of the small plastic car wheels he usually carried with him. In the back room, where Tim Bengs stored rows of black rubber tires, Jim leaned over to stroke them, as if they were pets. He liked the smell and feel of the rubber and the thumping sound the hollow tube made when he hit it. Jim was enough of a tire connoisseur immediately to spot two round, stocky tires as belonging to a race car. We also visited other Opportunity Services job sites: a restaurant where workers washed dishes and prepared food; a high school where they mopped and dusted; a day-care center where they prepared lunch; and a children's clothing factory where they prepared material for seamstresses. Jim seemed most interested in the job where there were many other nondisabled people around.

Our last stop of the day was at a group home. The rambling ranch-style house had a wood-beamed roof and quiet gardens. It felt relaxed and homey. One resident helped the staff cook dinner, another woman sat and watched the woods outside, another man listened to music. Some residents had their own rooms. Jim was impressed by the neatly kept bedrooms, with pictures on the walls and possessions nearby. At one point, Jim put his arm around Joyce Syverson of Opportunity Services and said softly, "I want to live here."

The next day, I told Sheady, Jim's social worker at Fari-bault, about Jim's thrill at visiting the auto shop. The so-

cial worker had one reaction: "Did Jimmy steal anything?"

That type of negative thinking had kept Jim in the institution for many years. But there was a force at play that seemed to guarantee that Jim would one day get out, no matter how unresponsive the bureaucracy. That change, too, was clear to me as I walked through the cemetery of numbered graves.

Seventy yards from the graveyard, I watched workmen sweating to roll out a new silver chain-link fence. The state institution for people with retardation was being turned into a state prison. With crime rising across the country, Minnesota, like other states, had run out of places to incarcerate men and women. A few months earlier, a small group of minimum-security prisoners had been moved into some of the Faribault buildings. The week after my walk through the burial ground, the first group of medium-security inmates would be transferred to the red-brick buildings behind the new fence.

Faribault's population had reached 3,250 in 1958, a time when there was scurrying to build new residences and hire extra staff. Now only five hundred people lived there, so it made sense to fill the emptying buildings with prison inmates. The state had adopted a plan to reduce the number of disabled residents to eighty by the year 2000 and increase the prison population to one thousand. There was a logic, too, in placing criminals and people with retardation side-by-side. Both prisons and state hospitals cut people off from family, friends, and community and constrict their liberties and freedoms. Each seeks to change a person's behavior and personality through isolation, solitude, and regimentation. Both institutions had come out of the same nineteenth-century reformist instinct, notes historian David Rothman, to protect the new American society from deviant people, while at the same time demonstrating the society's generosity in seeking to rehabilitate them. Indeed, under the agreement worked out between the state and Faribault's unions, workers would be offered jobs in the new prison. It was clear that

Jim would leave Faribault sooner or later. It would be easier, I knew, for him to make the transition at thirty-one than at forty-one.

The long-held idea of people with disabilities being deviants is fading only slowly. I wanted to help Jim build on his many strengths to live in the community and work in a job where he would utilize his amazing mechanical skills. But to do so I needed to convince the people in his life to see him in a new and more positive way.

It was this task that brought me back to Minnesota a second time, in October of 1990. At about the time I was reconnecting with Jim, his Aunt Evelyn, inspired by friends with a daughter at Faribault, had sought him out, too. Several weeks before my first trip back to Faribault she had gone there to visit Jim on Family Day. It was the first time since Jim had arrived at the institution in 1966 that anyone from his family had gone to visit him.

I debated calling Evelyn and other members of Jim's family. Jim's family could, after all these years, prefer that he stay out of sight and out of mind in the institution. Even though they had long given up guardianship, their wishes, by state law, could derail any attempt to get Jim into his own apartment. But I knew, most of all, that Jim missed his family. At the end of my first trip I had told Jim that I was leaving to go to Minneapolis, where I would catch my flight back to Washington. "Minneapolis," Jim said in his soft, broken way of speaking. "My mother. Five or six years." I knew what these cryptic fragments meant: his mother lived in Minneapolis and it had been five and a half years since he had visited her.

I decided to contact Evelyn and called her from Washington to invite her to drive to Faribault with me on my return visit. She had thought about her nephew often since seeing him that spring and wished she could do more for him. So early on a clear, brisk Sunday in mid-October, Evelyn was waiting for me on the

stoop outside her apartment building just south of downtown Minneapolis. As I drove up, she came down the stairs, a slight woman with pale skin and wavy gray hair.

On the hour-long drive to Faribault, Evelyn told me more about Jim's family history. It was a different, more sympathetic, portrait than I had heard from Jim's social worker. When Jim was young, his father ran a bar and his mother had helped out. But the parents had found their family had grown too big, too fast. There was little money and no child care.

Jim was hyperactive and hard to handle. But his parents had fought to keep him. When social workers had come to take Jim, his parents, too, had been labeled incompetent. In the confusing, belittling swirl of bureaucracy, they had been unable to save their different son. For years, Evelyn recalled, Jim's mother cried at the mention of Jim's name.

Jim's brothers and sisters, I learned from Evelyn, seemed to share Jim's mechanical skills and sometimes even his fascination with wheels, cars, trucks, and all things round. The oldest brother was the mechanic who had recently given up his garage. The oldest sister was a city bus driver. Another brother had studied engineering. The youngest, a brother, was a gifted artist, who, like Jim, had the ability to imagine something in his head and then create it.

Evelyn told me about seeing Jim, who usually carries a wheel or something round, clutching an orange Frisbee. "Jimmy reminded me so much of his Uncle Fortune. You've heard about his Uncle Fortune, of course," she asked. Taken aback when I said I hadn't, she replied, "Oh, Jim's Uncle Fortune. He won a medal in the Olympics. He was a discus thrower."

When I had invited her to ride with me to Faribault, Evelyn was anxious to get some of Jim's siblings to come as well. It would be the first time ever that someone from Jim's immediate family had gone to Faribault to see him. There had been the rare visits by Jim to Minneapolis to see his family, the most recent

engineered by Evelyn. Jim, with his peers at Faribault, had gone on an outing to a park in Minneapolis, one week after my reunion with him. Evelyn had pleaded with two of Jim's sisters, Peggy and Julie, to go with her to see him there. When they saw him, the sisters made a fuss over Jim, his large hands, and his friendly manner. Peggy and Julie had not seen Jim in several years. They had been fearful of what they would find. One of the sisters had told a Faribault staffer that day in the park, "We expected him to be a vegetable."

Their confusion was understandable. For much of Jim's life, doctors at Faribault had labeled him "profoundly retarded." The family had been told they could not do anything for him. It was an unfortunate simplification that had kept Jim's siblings from knowing him. It was true that, when he was admitted to Faribault, Jim's IQ had tested out at below 30. But IQ tests are often misleading at best and meaningless at worst. A test of intelligence meant little if the person, like Jim, had trouble verbalizing answers. Jim's inability to respond had been taken as not knowing. By his teens, Jim would be reclassified as "moderately mentally retarded." But even that was a stingy label, given his mechanical brilliance. Today, tests might not label Jim as "retarded" but show him to have a "severe learning disability" or an exaggerated form of dyslexia, says Colleen Wieck, the Minnesota advocate who helped me and befriended Jim. Years of living in an unstimulating institution may have exaggerated Jim's disability. Little was expected of Jim intellectually, and he may have imitated the bad behaviors he saw around him. That was why it was so important to get Jim out of Faribault and into a more natural and challenging environment. At one state institution, I had met a resident who had never been labeled retarded, but she had been sent away in 1941 because she was a wild teenager, constantly in minor trouble. Fifty years later she seemed to have the same retardation as her roommates.

During the course of the October visit with Evelyn and Jim's

siblings, Jim's family began to understand that his intelligence was not easily described, and that the loaded label *retarded* sold him short.

Vegetable was the label Jim's family had used. It reminded me of an equally inaccurate and ugly word I had once used: "Zombie." I had never worked with people with retardation before I joined my college friends in the project that led me to Jim. Shortly before moving into the house, however, I had second thoughts. With fears of the demanding academic year ahead, I confessed to a friend uneasily as I headed back to school that September, "I'm worried about coming home after a long day to a house full of Zombies."

My prejudice was the result of ignorance. Like Jim's family, I had no idea what people who had been closeted in institutions would be like. I had only stereotypes and labels to fall back on. I wanted to do a good deed, an act of charity. Soon I would learn that friendship with Jim and the others was rewarding in its own right. The dozen kids who visited us from Faribault were lively, curious, fun, and loving. Each had his or her own talents and distinctive personality. Their delight in their biweekly taste of freedom and family-style living made all of us in Prentice House a little less self-absorbed with our classwork and a lot more relaxed each night.

Evelyn and I drove to Faribault on the day before Jim's thirty-first birthday. When we arrived at Osage at midday, Jim was waiting for us in the bedroom, lying on his bed and watching a football game on his 12" television. The other men in the household watched the same game on the large television in the common room. Jim wore a short-sleeved white shirt, not tucked in, with broad red stripes. He threw on a wrinkled old navy windbreaker, which he buttoned all the way up. Peggy, Julie, and Rob, one of Jim's brothers, were driving separately. Never having been to the institution, they got lost and showed up an hour after Evelyn and I arrived. Jim greeted them eagerly,

although with casualness, as if he saw his brother and sisters every week. If he felt any anger at not seeing them in so long, he did not show it. Jim held hands with his sisters and his aunt and slung his arm around his brother's shoulders.

We went to a restaurant for lunch. After the initial nervousness wore off, Peggy and Julie fussed about Jim's chapped lips, sunburnt and lined face, the effects of working outdoors. Jim resembled his siblings, all blond, attractive, and fair-skinned. Back at the institution, Jim sat on his narrow bed, opening the birthday cards from Peggy, Julie, and Rob. He beamed, happy to be the center of his family's love and attention.

The moment that forever changed the family's understanding of Jim came when I suggested that he take us to his basement storage room where he kept his completed projects and works in progress. A high-backed wheelchair of wood, with two bicycle wheels on the back and two small wooden casters on the front, looked clumsy. But Jim maneuvered it smoothly across the concrete floor. Evelyn pulled out her Instamatic camera and flash bulbs to take a picture of it, so that she could show a few friends of hers who used wheelchairs. Julie picked up what looked like a bicycle pedal enclosed in a small wood frame. Jim explained that it was a part to his pedal-powered flying machine. He showed her the cardboard-and-wire wingspan he had assembled and then pointed out the wooden frame for the pilot and his bicycle. He told her he realized the frame was too heavy and that he needed to find a way to make it lighter for it to fly. Jim discussed these things with an almost studied casualness. He kept his right hand tucked in his pocket and pointed with his left, as if he were a college professor speaking from a lectern in the science hall auditorium.

I watched the stunned looks on the faces of Evelyn, Peggy, Julie, and Rob. "Jimmy, can you fix that bicycle?" asked Rob, pointing to a broken one in a corner. Only several weeks before, Jim's siblings had thought him a "vegetable." Now they were

trying to figure out if he could work in a bicycle repair shop. It was an entirely correct way to be thinking about him.

It was David Hancox, who ran a Minnesota program to teach parents of children with disabilities how to pressure school boards, health agencies, and other parts of the bureaucracy, who told me about Personal Futures Planning. Families in Minnesota were successfully using futures planning to help people with retardation set long-term goals for themselves. The idea was to bring together a small group of people who cared about Jim—who would advocate for him and could see him positively—to brainstorm with him about how he could fulfill his dreams. The point was to build a group of friends who would make the system work for him.

The team would plan for his future by putting Jim—his wants, his needs, his desires—first. It was for those meetings that I returned in October. There would be a Personal Futures meeting on Monday and Wednesday. In between would be a contrasting third meeting: Jim's annual review, led by personnel at the institution, which focused on his problems to be fixed, not his strengths. "I hate meetings," Jim had told me, referring to these accusatory annual reviews. Personal Futures planning was supposed to be different—friendly and positive. I had even picked a neutral site, off the grounds of the institution, in the oak-paneled conference room of the pretty nineteenth-century Faribault City Hall.

We took our seats around four long conference tables set in a square. Jim sat at the center of one. Our facilitator, Marijo McBride, from the University of Minnesota, explained that our purpose was to help Jim define what was important to him and then strategize ways to help him achieve it. With McBride's help we reconstructed Jim's history, which she wrote on poster paper set on an easel. A stick figure, representing Jim, was drawn in the center. I had invited state and county workers who could help Jim get out of the institution. Among the dozen

invitees were the few people from Faribault I felt would be strong advocates for Jim. Instead, Jim's entire social services team showed up. They were defensive and suspicious.

Soon the faultfinding began. Neil Farnsworth, the cottage psychologist, started talking about how Jim had a mean temper. McBride noted that Jim seemed extremely sociable. "When you wear one of his tires around your neck, you don't think of him as very sociable," the psychologist responded. He was speaking figuratively and of no specific incident. Another Faribault staffer said Jim would steal tools or other things needed for his inventions. And the psychologist added that Jim was a "pack rat" unsuited for living in a place of his own. "A gymnasium might last a week," the psychologist pronounced. "He'd fill it."

Throughout this wild faultfinding, Jim appeared not to be listening. He played with a small metal toy car. But after a while he looked up and glowered at Deb Lenway, his Faribault counselor. It had fallen on her to get Jim, always suspicious of a meeting, into her car and bring him to the session. "You're dead, Deb," he muttered angrily under his breath, shooting her a withering glance. "I'm going to break your car."

I was forced to hustle Jim out of the room and back to the institution. "I don't go to meetings anymore," he said petulantly in the car. "I hate meetings. Meetings are boring." I cursed myself, fearful that my efforts to help were about to collapse in hurt, anger, and recrimination. I worried that I had betrayed Jim. But I was particularly fearful that Jim had made a bad first impression on his new case worker.

I had been disappointed that Hall, Jim's social worker of several years, had taken no steps to get Jim out of Faribault. He had denied me access to Jim's records. When I got them I understood why. Jim's individual assessment plan, although required annually by law, had not been done in a number of years. Nor had there been a screening as required before Jim could be considered to go to his own apartment. I realized that

Hall had an expanding caseload and, perhaps because no one was pushing for Jim, it was easy to let Jim's needs drop to the bottom of the pile. I requested a new social worker to be assigned to Jim, and within weeks, Steven Schmit came on the job. I liked him immediately. He was young, energetic, and creative. He was intrigued by my stories of Jim and by what he had read in Jim's file. Unlike Hall, he did not believe that Jim would fail outside the institution. Jim, he told me over the phone, should be out of Faribault. I worried that Jim's outburst, at this first meeting with his new social worker, would alter Schmit's generous thinking about Jim. There was no need for concern. Schmit was experienced enough to understand, just as I had, that Jim was only responding to the unfair criticism that he was hearing.

Things seemed to work out better once I rejoined the group for the last hour of the meeting. McBride had done a good job of keeping things positive. Together the group seemed to take a good first step toward identifying Jim's preferences. Things went even better at our second meeting, which was held two days later in St. Paul so that family members could attend. The distant location reduced the number of negative Faribault staffers, too. Jim smiled broadly when he entered the conference room and saw his aunt and sister Peggy and, at the end of the meeting, his brother Dennis.

I had also asked Irving Martin to be there. He is a self-advocate, active in People First of Minnesota. A large man, with a loud, hearty laugh and genteel manners, Martin had recently been in Washington, where I first met him, to witness President Bush sign the Americans with Disabilities Act. Martin worked at the dietary center of a nursing home, helping to prepare and distribute food. Every day after work he went to Mickey's Diner, which he affectionately called a "high-class greasy spoon," for an afternoon cup of coffee. But what he called the "highlight of my life" was being able to address the congregation at his church, telling them what it meant to have mental retardation.

It was Martin whose common sense and wisdom again changed Jim's family's definition of retardation. At the first meeting, the cottage psychologist had claimed that if Jim were to live outside the institution there was a good chance of his getting into trouble stealing and possibly "ending up in jail." (Jim has heard this so often that he believes it. When he has done something wrong, he will say abjectly, "I'm no good. I'm going to go to jail." Consequently, this kind of talk in front of Jim struck me as emotionally abusive.) At the second meeting, Martin rose to say it was important to let Jim learn from his own mistakes and that he was sure to grow once he left the institution. "I myself am retarded," Martin would say to preface his remarks. "My way of thinking is that you take one step at a time. If he takes one step at a time, with lots of room for mistakes, he'll be okay. There is not one person in this room who has not made mistakes in their life, and why can't he? People learn from their mistakes."

The team now began to talk about Jim leaving Faribault as a given and no longer as a big risk. (There had been no such assumption that Jim was ready to leave Faribault at his annual institutional review the day before. Staffers there had catalogued Jim's shortcomings and stressed how much he needed to change before moving to a group home.) We agreed to accelerate Jim's family contacts, to help him continue to develop his mechanical skills, probably by helping him find work—a bike shop, an auto body shop, and a junkyard all came up as good fits—and to get Jim into a group house or apartment. The group process, despite my initial doubts, had truly worked. Jim seemed to catch the shift in mood, too. He was no longer bored or angry. At one point, McBride asked Jim what he would like in his house. "How about a cat in the house?" Jim said in his slow, soft voice. He, too, had begun to feel empowered.

That night between the two Personal Futures meetings, Jim and I had gone to Owatonna to shop. That meant cruising the

aisles of auto parts shops, tire stores, and farm implement dealers. We looked at car tires, tractor tires, motorcycle tires, and all-terrain-vehicle tires.

At dinner, Jim mentioned that Robin, a woman who had lived at Faribault, now resided in Owatonna. The first time I had heard of Robin was at the initial Personal Futures meeting. She had been listed as one of Jim's friends—the closest thing he had to a girlfriend. "Jim, if we can find Robin, would you like to visit her after dinner?" I asked. "Yes," he said, smiling. A half hour later we were at the front door of Robin's group house.

It was clearly a "girls' " apartment, a nice four-bedroom apartment for Robin and her roommates, decorated in pinks and sky blues, with straw bonnets and dried flowers on the walls. There were yellow stencils of a woman in a bonnet with a goose on the wallpaper. The sofa was white with a pink-and-green floral design. A big television sat against the wall in a small living room that also doubled as a kitchen and dining area. When we walked in, I could not figure out if Robin was present. Four women said hello, but none made any special greeting. Jim kept close to my side. "Is Robin here?" I asked out loud. One of the women, with a pleasant, round face, short hair, and pretty eyes, raised her head and smiled.

Jim and Robin sat on a loveseat while the rest of us watched a TV movie. Robin placed an orange plastic bowl of popcorn between her and Jim. At first they made only halting, awkwardly shy conversation. But soon Jim was talking away—talking more and faster, it occurred to me, than I had ever heard him talk to anyone. From time to time, Robin would excuse herself to take a trip to her bedroom. She would come back with something to show Jim: a coffeepot she had bought; a new pair of shoes from her sister. She showed Jim that she had a key to her room and explained that nothing was ever stolen from her. Soon Robin had moved the popcorn bowl from between them. I sat in front of them, and occasionally I would turn around. Jim kept an eye trained on me, but from my stolen glances I could

see that, when he thought I was not looking, Jim would timidly run a finger along Robin's knee.

I wondered if the staffers at Faribault would be annoyed with me, but I figured Jim, at thirty-one, was old enough to be "dating," or whatever this was.

After seeing Jim at Faribault and at the Personal Futures meeting, Jim's sisters and brothers had talked excitedly to their mother about their talented brother. She sent word that she wanted Jim to visit for Thanksgiving. Evelyn sent a letter to the institution asking that arrangements be made, as was routinely done, to drive Jim to the Twin Cities.

On Thanksgiving morning, Jim's mother baked two apple pies for her son. Dinner started, but Jim never arrived. Later, staff at the institution apologized to Jim's disappointed family. Evelyn's letter had gotten lost, they said, and they were unaware of the family's desire to see Jim. But I knew that this excuse was untrue. I had made two telephone calls the week before Thanksgiving to make sure the car arrangements were made. I got a bureaucratic shrug. It was in the pipeline, I was told. I did not have the time to march Evelyn's request from person to person to make sure the car pool worked. Evelyn was too polite to do more than write her kindly letter of request.

There was a reunion on Christmas Day. The family video shows Jim sitting quietly in a chair in his sister's living room, beaming with joy, as he watched his boisterous family kidding and exchanging presents. Jim happily soaked it all in, as if his being there for Christmas were a regular occurrence. But the kind of miscommunication and bureaucratic slow pace that had sabotaged a Thanksgiving reunion was delaying efforts to get Jim out of Faribault.

Another year went by, and Jim happily joined his family for a second Christmas, but still he was waiting for a placement out of the institution. It took nineteen months between the October meetings and the time when he finally moved.

My promises of "a few more months" kept spreading out to

still "a few more." Midway in this process I had been at a conference where I heard Gerald Provencal, a Michigan advocate for people with retardation, talk about the double standard of time we apply to people with disabilities. "We're far more tolerant of the passage of their time than we are of our own," he said. Nineteen months might not seem unreasonable for getting a man out of an institution. Yet, as Provencal noted, "the passage of time is something as precious to someone with a disability as it is to us." Just because he had spent a lifetime in an institution did not mean Jim had another year and a half to waste. "If you're in a Club Med, time flies," said Provencal. "If you're in a day room, it is agony."

Even to the end, Jim's status as a disabled man made him a little less worthy, a little less of a priority. People who were pitied were also a little more disposable. Things were going well for Jim. He had advocates; he had friends; he had family. Yet we could not get him out of the disrespectful double standard of time that applied to people caught in the disability system.

But once it was a fact that he was leaving Faribault, Jim suddenly did gain respect. Staff at the institution began to speak of him in a new, positive way. He was retested three months before he moved. Now the man who supposedly needed to stay at Faribault because he was "moderately mentally retarded"—and who had been labeled "profoundly mentally retarded" most of his life—was found to be "mildly mentally retarded." Even that newly generous label seemed to underestimate him. At the discharge planning meeting two weeks before his move, staffers at the institution told newly glowing stories about Jim's capabilities. Residents of the town surrounding the institution would call and ask for Jim by name to mow their lawns. He was so responsible, the lawn crew job coach explained, that Jim would be left at a house with his lawn mower while the rest of the crew went to some other job. When they returned an hour or so later, Jim invariably would be sitting on the stoop, wait-

ing, lawn mower at his side, having done the job to perfection.

Jim left Faribault in May of 1992 and moved to an old farmhouse on ten acres of land in the exurbs of Minneapolis. He shared the small house with two other men but had the entire second floor to himself. He adjusted with ease and happiness, as if he were always meant to live there. Freedom for Jim meant falling asleep at night while listening to his new clock radio—his clothes still on and the overhead light still brightening the room. That had been impossible in a life of three or more roommates. Freedom meant eating lunch with the nondisabled men on the work crew at the state park. Nobody seemed to mind that Jim did his job, riding a small tractor and grading the softball fields, faster than the nondisabled man who had the chore before him. Freedom also meant borrowing a tool from a neighbor, then getting on his bicycle and riding a few blocks to return it. Freedom meant having a barn where he could retreat, at any time of day, to hammer and saw. The cars he built got bigger and more elaborate. But Jim left his flying machine at Faribault, perhaps to aid someone else plotting an escape.

Epilogue

How the Disability Rights Movement Is Changing America

NEW YORK—Women's groups protested the city's plans to install public outdoor toilets, but not include any for women. City officials feared the women's larger toilets would attract junkies needing a place to shoot up and homeless people looking for somewhere to sleep. . . .

No city, of course, would be foolish enough to build public toilets, but just for men. Yet substitute "wheelchair users" for "women" in the paragraph above to understand what New York City did to infuriate disabled activists at the moment that the Americans with Disabilities Act was being implemented nationwide.

When disabled people protested that they were being unlawfully excluded from a public service, they got little sympathy. Typical was a *Wall Street Journal* editorial that scolded the complainers for putting the narrow self interests of a small number of wheelchair users over the common good of the far greater number of able-bodied people who could use the inacces-

sible toilets. The *Journal* saw it as an issue of "weighing civil rights against common sense," and came down against the expectation of rights by people in wheelchairs. But to disabled activists, like Frieda Zames of New York's Disabled in Action, the exclusion was as blatant an example of discrimination as if the city had put up toilets and then hung a WHITES ONLY sign on each one. Most galling for Zames was that disabled people were being expected to forfeit, without complaint, their newly won rights to accessibility.

By the time New York unveiled a four-month test of its new toilets in July 1992, the same month that the last title of the ADA went into effect, the city had placed three large wheelchair-accessible toilets next to three regular ones. But side-by-side toilets took up a lot of space, were twice as expensive to build, and disabled users still complained about the unequal compromise that seemed designed to fail: to use their toilets meant going to a nearby city office during business hours to get a special key card (so that officials could keep out the junkies and homeless). In addition, disabled people got second-class toilets, which, unlike the ones for everyone else, were neither heated nor self-cleaning. As a result of complaints by disabled activists, a worker with a mop was posted outside all day long, a quickly ridiculed use of manpower and money that left the future of accessible toilets in doubt after the test run. To Zames the solution was simple: build one toilet that could be used by all. Anything else, she argued, was separate and unequal.

What happens when Congress grants a new group minority rights, but society has little understanding that those rights have been awarded or why they are needed? As the newly recognized minority—disabled people—starts asserting those rights, there are many new breakthroughs for equality. But there are also clashes, misunderstandings, even a backlash. The ADA, which promised integration, will have more impact than any civil rights law since the 1964 act that banned discrimination against

blacks, women, and ethnic and religious minorities. But disabled people got their rights without dramatic Freedom Rides, church bombings or "I Have a Dream" speeches to stir the conscience of a guilty nation. African-Americans had changed a nation's attitudes and then won civil rights law. But for disabled Americans the reverse was true. Now disabled people fear that a society that did the right thing—but without the benefit of significant consciousness-raising—has begun to question those rights.

Such doubt is raised not just on seemingly small matters, like the right to use a public toilet. Discord is present, too, on the most pressing social issues like reforming health care. Just a few weeks after the full ADA went into effect and the New York toilets went up, the Bush Administration—citing the disability civil rights law—struck down what was being hailed as the nation's boldest effort to redesign health care. Oregon's Medicaid rationing plan sought to resolve the great hypocrisy of American medicine: those with insurance get the world's best medicine, while the uninsured fourteen percent may get nothing. As part of a plan to provide health coverage to its uninsured residents, Oregon wanted to extend Medicaid to an additional one hundred and twenty thousand uncovered poor people. But to do so would necessitate savings elsewhere in the Medicaid system. Oregon's solution was to ration services. It ranked seven hundred and nine conditions and their treatments on the basis of effectiveness and cost, figured out how much state Medicaid could spend, and then drew a cutoff line at item five hundred eighty seven. Nothing below that would get funded. To put the rationing scheme into effect, Oregon needed formal permission, called a waiver, from federal officials.

There were compelling reasons to support rationing. It was a daring experiment at a time when the federal government seemed too timid to solve the problem of providing health care for some 37 million uninsured Americans. But Oregon's plan

came with a cruel twist dictated by an era of fiscal limits: it was offering health coverage to more poor people by cutting back the treatment that other even poorer people already received. Oregon health officials justified this by noting that another kind of rationing already existed. When government said it would pay for the health care of the poorest, but not for that of the slightly less poor, that was, in effect, an implicit method of rationing health care among haves and have nots. Oregon would try to bring some logic to the system by rationing on the basis of what treatment was most certain to improve someone's life, not on the basis of where one fell on the poverty scale. It was in trying to make decisions about what was worthwhile treatment that Oregon's plan ran into problems with treating disabled people fairly.

In early 1992, officials at the Department of Health and Human Services recommended giving the plan a go-ahead and President Bush himself, in his budget plan, had praised the rationing scheme as a "noteworthy" example of state experimentation. But in March, at a brief Oval Office photo opportunity with officers of the National Right to Life Committee, Bush was urged to stop the Oregon program. Bush, who at first seemed unmoved by the antiabortion group's objections, perked up when the group's vice president, Robert Powell, claimed, "If that plan had been in effect when I was born, I'd be dead." The President listened intently as Powell, who uses crutches and a wheelchair, explained how, when he was just five months old, a malignant tumor had attacked his lungs and spinal cord. Doctors said the cancer was incurable, and the infant lived only because his parents found another doctor (one who used a wheelchair, it turned out) who was willing to aggressively treat the "hopeless" case. Oregon, Powell said, would stop paying to treat such incurable cancers. Bush, who had once struggled to find doctors willing to treat his young daughter dying from leukemia, ordered White House legal counsel Boyden Gray to check

Powell's contention that the Oregon plan violated the ADA. The legal opinion that came back supported Powell.

Oregon's rankings, Gray's office concluded, reflected commonly-held prejudices that a disabled life was a lesser one. The classifications had come on the advice of doctors and medical experts. So it was not surprising, for example, that medical treatment for traumatic brain injury fell far below the cutoff. Surviving traumatic head injury was something new, and medicine still has little understanding of how to improve the lives of survivors. But people are now living long after such injury.

In making its list, Oregon also had relied upon a telephone survey to gauge people's attitudes about illness and disability. This, the White House argued, had further polluted the rankings with the public's uninformed stereotypes of a disabled life as a sad and pitiable one. The phone survey, the administration concluded, was tied to a significant reranking of at least one hundred and twenty conditions and their treatments. Medical treatment was not covered for amyotrophic lateral sclerosis, or Lou Gehrig's disease, a particularly frightening illness to most people since the degenerative neuromuscular condition was considered fatal. Yet ALS was not a death sentence for everybody. Scientist Stephen Hawking, after all, has lived long and productively, even though ALS has made his life a far more difficult one. At the very least, each person's case had to be considered separately. To write off everyone with ALS was, in effect, discrimination based on diagnosis. It was to buy into the myth that a disabled life was a tragic one and not worthy of prolonging with medical treatment.

There were other examples where Oregon's list conflicted with the ADA. Although Oregon would pay for a liver transplant in the case of liver failure, it would not pay for the transplant if the patient had a history of alcoholism, no matter if that addiction was five, ten, or twenty years in the past. But the congressional Office of Technology Assessment criticized

this rationing of liver transplants, noting that the operation had a similar rate of success whether a person had a past history of alcoholism or not. (No doctor will give a liver transplant to someone currently abusing alcohol, since that would be a waste of a rare liver donation.) The ADA prohibits discrimination against someone on the basis of past alcoholism or drug abuse.

Many of Oregon's decisions had been moved by logic, even if they were flawed with society's automatic devaluing of people on the basis of disability. Saving an extremely premature baby can cost a quarter of a million dollars or more. Prenatal care, which can significantly reduce the chance that a baby will be born prematurely, costs only a few hundred dollars. So Oregon, seeking to emphasize prevention, put crucial prenatal care high on its priority list. But ranked seven hundred eight, next to last, was saving a baby weighing less than eighteen ounces and born before twenty-three weeks gestation. One Oregon official explained to me that the low ranking "is not a problem for our doctors, since they don't try to save babies like that anyway." Indeed, the chances of such a baby surviving are slim, at, by one estimate, about one in ten and even then there is a significant likelihood that the child will grow up disabled. Yet just a few weeks before the Bush Administration's decision, a healthy baby, Zascha Villamar, left a Miami hospital after five months of treatment. She was born after only twenty-two weeks in the womb and she weighed fifteen ounces—a testimony to medicine's ever-growing ability to save younger and smaller babies. Technology and new drugs sometimes could save such premature infants, as long as doctors and governments did not write them off first.

Once Washington told Oregon to redesign its rationing experiment, disabled people and their new civil rights law came under swift and pointed attack. "So now we have the architects of the Americans with Disabilities Act deciding that Oregon's plan, the product of an arduous political consensus within that

state, simply doesn't fit the grand design of their legislated benevolence," the *Wall Street Journal* grumbled in an editorial. "The Americans with Disabilities Act is beginning to have the look of Big Brother." The *New York Times*, in an editorial titled "A Bold Medical Plan, Derailed," called the administration's claims of disability bias "unconvincing."

The Oregon decision was a coming-of-age for the ADA. It was an early test that showed the law's vast power to change society and sweep away vestiges of bias. Even most disabled people had not fully realized the enormity of the law's potential. The ADA had been underestimated as just another be-nice-to-the-handicapped law, in part because the two most visible titles of the act required businesses to be accessible to workers and customers. It looked like a law simply to put wheelchair ramps on buildings. Overlooked was the even more significant promise of a third section, which required that all government services, from public toilets to health care, be provided equally. Rights, unlike charity, carried some costs to all. If America was truly committed to providing equality to disabled people, there would be complications and trade-offs, as there had been in the Oregon decision. Oregon's modified health plan took effect in 1994. But rationing would become an issue again with the push for national health care reform and caps on spending.

The potential for backlash was clear in the gap between the newly militant self-perception of disabled people, and the confused, still stereotypical thinking of the rest of the country. On the eve of the enactment of the ADA, the pitiable poster child and the inspirational "supercrip" remained the defining images of disability. A Louis Harris and Associates survey, released in the fall of 1991, found that 92 percent of Americans said they usually felt admiration when they met people with severe disabilities and 74 percent said they felt pity. Another 47 percent said they reacted with fear "because what happened to the disabled person might happen to them," 16 percent said they

felt anger "because disabled people are an inconvenience," and 9 percent said they felt resentment at "the special privileges disabled people receive." But few people, only 18 percent, said they were even aware of the ADA. Americans had missed the new self-definition of disabled people as a group whose primary issues were ones of discrimination and respect, not health, inspiration, and charity. Even to most disabled people, however, the ADA was a revelation. Even while their world was changing, most had internalized the messages of pity and powerlessness that had permeated their lives. The deliverance of rights with the ADA was a license to get angry, instead of politely asking for help and becoming indebted to the kindhearted.

Dr. Richard Edlich had never heard of the ADA until November of 1991 when an official at the University of Virginia, where Edlich teaches medicine, mentioned in passing that the school planned to make its campus accessible in order to comply with the new civil rights law. When asked, Edlich noted that the annual Christmas party was held in an inaccessible location. The university moved it. Then he pointed out that he had been unable to participate in graduation ceremonies since 1987, when he began using a motorized scooter-wheelchair after his multiple sclerosis worsened. The university purchased temporary ramps so that Edlich and other wheelchair riders could join the graduation procession down the Lawn, the majestic quadrangle designed by Thomas Jefferson.

University officials simply followed the law. But the experience radicalized Edlich. In the past, like most disabled people, the plastic surgeon had not wanted to "bother" anyone and thought of his full inclusion as an imposition, not as a right. But after the university welcomed him back to its graduation ceremonies, he decided to attend his nephew's graduation at an elite New York City high school. When the headmaster dismissively said Edlich would have to find someone to carry him up the stairs, Edlich filed a complaint under the newly enacted public

accommodations section of the ADA. A Justice Department lawyer flew to New York and the school quickly built a ramp. Back in Charlottesville, Edlich, energized by the way the world was opening up to him, began a survey of his favorite stores and restaurants, and filed more complaints whenever he found a business out of compliance and unwilling to change. It was not that Edlich was bitter or angry, or stood to make any money off his complaints. He simply began asserting his right to full inclusion. The ADA, the doctor says, "has made life a celebration instead of being filled with apologies and continually saying 'thank you' and 'please help me.' " He had made what he called the "lonely journey" to becoming an activist.

While the cautious were getting militant, the militant were gaining respectability. In Denver, on the day in July that the final title of the ADA went into effect, city officials honored ADAPT. The city erected a plaque to commemorate ADAPT's first protest, in 1978, when nineteen people in wheelchairs sat at an intersection and blocked two city buses for twenty-four hours to demand that wheelchair lifts be added to buses. Only several weeks before ADAPT was hailed in Denver, its members had disrupted a commencement speech by U.S. Health and Human Services Secretary Louis Sullivan, in the type of hostile demonstration that the Bush Administration official had come to expect from contentious ACT-UP protesters demanding more AIDS research. ADAPT insisted on more government spending for personal assistance services and less for nursing homes.

A few months later, in October, ADAPT got the promise of support it wanted after its members took over Bill Clinton's presidential campaign headquarters in San Francisco and refused to leave. Clinton dispatched his top rehabilitation official from Arkansas to negotiate with the demonstrators, and a strong statement was issued in Clinton's name backing the new spending emphasis sought by ADAPT. "I believe that every individual has a right to personal care," Clinton said, and proposed

using a national service corps as one way to increase the number of personal assistants. Clinton endorsed the disability movement's insistence on the consumer's "maximum control" over the personal assistance they receive and pledged to reconsider federal regulations and funding that create "a presumption in favor of institutionalized care over home and community-based services." Clinton's promise was a sign of the growing respect that politicians paid to disabled voters and that even the most militant of them were treated with seriousness.

Still, even a strong rights law could not make old barriers fall overnight. The Hockenberry Rule—the idea that the ability of disabled people is always underestimated—did not disappear, as journalist John Hockenberry, himself, would find out when he got evicted from a Broadway theater. He had paid \$60 for his ticket and had checked in advance that the theater was accessible. But when he showed up, the theater manager refused to help seat him. "You are a fire hazard, sir," the manager complained. Prior to the ADA, theater owners in most parts of the country were free to make such judgments. This time, Hockenberry filed a bias suit against the theater, citing the public accommodations section of the ADA, which had taken effect just two months before his run-in on Broadway.

For Hockenberry, the experience was a "coming out" of sorts. Like most disabled people, he had put up with such insults and discrimination daily. Even at National Public Radio's offices, there was never an accessible rest room he could use. But like many disabled people, he had tried to ignore such slights and limits by concentrating on personal achievement. "I thought that what defined me was not disability but background and talent," he explained to journalist Mary Johnson. "The biggest joke played on me—and it's my own damn fault—is that I thought that, by accepting no limits, as my geographic reality enlarged, my sense of limits would go down. And just the opposite has happened."

Hockenberry, who that summer was lured to ABC News, could cover some of the biggest stories around the world. But as a disabled man he was still hostage to the underestimation of others. At the theater, said Hockenberry, "that guy just decided I wasn't going in, and everyone then behaved as though it was impossible to get me in. If you spend a lot of time in the Third World and you come back to the United States you realize the obstacles are just guys standing there, telling you it's impossible. And you know it's not." After a lifetime of being told to make it on his own, Hockenberry admitted, he felt a little uncomfortable about making a claim to rights.

Millions of other disabled people were getting angry, too, and like Hockenberry and Edlich were coming to see themselves as a class, united in discrimination and empowered by law. Their expanding ranks would give the disability rights movement soaring power, educate others to their issues, and in the end, create a society more hospitable to all. They are full players now in a civil rights struggle, complete with progress and backlash. But the change in their mind-set is powerful enough to win rights and perhaps eventually convince a nation and the world that people with disabilities want neither pity-ridden paternalism nor overblown admiration. They insist simply on common respect and the opportunity to build bonds to their communities as fully accepted participants in everyday life.

Postscript

A Single Garment of Destiny

Kevin Holmes and Reynaldo Rodriguez never called themselves disability activists. They were just cops. They didn't even think of themselves as disabled. Nor did anyone who knew them. But these two Illinois patrolmen were among the first beneficiaries of the Americans with Disabilities Act.

Holmes injects himself daily with insulin to control his diabetes. Rodriguez was treated briefly for a back problem after he slipped off a forklift in a previous job. As a result, both were denied entry to the police pension program in Aurora, Illinois. That meant there would be no retirement pension; no disability benefits, even if they were shot in the line of duty; and no survivor benefits, were they to be killed, for their wives and children. To Holmes, that was clearly "unfair" since he was "required to perform the same duties as other police officers" and took the same high risks when investigating homicides or chasing burglars. The U.S. Department of Justice agreed, and in December 1993 it sued Illinois and Aurora.

Both Holmes and Rodriguez had traveled a long and sometimes difficult road before realizing their dreams of becoming police officers. Holmes had grown up in inner-city Detroit, the son of an automobile assembly-line worker. He had taught school before becoming a cop. Now Holmes was a familiar figure in Aurora, whether cruising the suburban Chicago city in his patrol car on the busy night shift or coaching son Kevin Jr.'s playground baseball team.

Rodriguez was a native son of Aurora, by his own account once a bit of a "punk" who dropped out of school at sixteen and "started hanging out with the wrong crowd." He and his friends would stand on street corners in their neighborhood "and when a cop would go by on the street we'd flip him the finger, just to make him chase us." A stint in the Marine Corps as an infantryman straightened him out, and he returned home with a wife and family. He wanted to reach out to other poor kids of single parents who, as he once had been, were on the brink of wasting their lives. As a police officer, Rodriguez had such an empathetic presence that he was hand-picked for a new crisis intervention unit to handle domestic disputes and child abuse cases. He had been decorated numerous times, including once for talking a man with a butcher knife to his own throat out of suicide.

Holmes, as a black man, and Rodriguez, as an Hispanic one, had confronted racism, but it would not prevent them from becoming police officers. The discrimination they faced after they became cops was based on their minor disabilities. No matter that Holmes's diabetes did not diminish his ability to handle any assignment or that Rodriguez had never missed a day of work due to his long-ago back injury. Holmes heard about the ADA on a radio show, but did not think it applied to his fight with the pension board until his lawyer decided to use it. Holmes then told Rodriguez about the antidiscrimination law. The two Aurora police officers won their battle, in 1995, when Illinois agreed to rewrite the pension code.

Dennis Bell learned about the ADA from a friend. The ex-Chicago firefighter did not think of himself as disabled either, yet there was no denying the amputation of his left leg from just below the knee. Fighting a fire in 1975, Bell had climbed through smoke and flames to search for children said to be inside the abandoned building. He fell fifteen feet through a collapsing stairwell and shattered his ankle. Bell, a Vietnam veteran, would choose to undergo nearly thirty surgeries in a defiant attempt to heal his injuries so that he could rejoin the fire department. Finally, in 1991, the leg was amputated.

The prosthesis turned out to be a revelation for Bell. His leg pains were gone, he walked without a limp, he could dance again with his wife and play golf with his buddies. The artificial leg, along with his discovery of the ADA, made Bell reject his own reflexive shame of being disabled. For seventeen years he had sought cures; now he sought accommodations. "I have a prosthesis. Okay, big deal," Bell would come to explain. "I walk and I'm doing fine."

He still, as he put it, had "smoke in my veins" and longed to return to the firehouse. Bell missed the close-knit bonds among firemen from Chicago's South Side. He still went to the Gaelic Fire Brigade meeting hall for a drink or to watch a ball game on television. Other firefighters helped him build the recreation room and bar in his basement where, on the wood paneling, Bell had hung framed photographs of Notre Dame football heroes Paul Hornung and Ara Parseghian, Chicago Bears stars Dick Butkus and Gale Sayers and White Sox infielder Nellie Fox, along with a photo of the city's late political boss, Mayor Richard Daley. Bell knew he could no longer be expected to climb 100-foot ladders or drag hoses into burning buildings anymore, but that part of firefighting was a young man's game, anyway. He could, however, investigate arson, train young recruits at the firefighter's academy, or work as a driver or dispatcher. He decided to bring suit against Chicago and the

Pension Board to be reinstated. He wanted to terminate his disability benefits and get back to work. Chicago settled the lawsuit and Bell began a new job: teaching safety to school kids. As Bell saw it, his lawsuit was not only for himself but for future firefighters facing injury. "It means so much to be back at work and be part of society," he said, "because people then forget about your disability."

Disability rights activists made the commitment to winning an antidiscrimination law. But disabled America is a diverse commonwealth. So the ADA gets invoked often to help people who do not even call themselves disabled. As Holmes, Rodriguez, and Bell saw it, they were insisting on simple fairness and common sense, rather than waging civil rights battles. Yet the discrimination they faced was as wrong and brutal as any other prejudice. Such use of the ADA shows the power of the disability rights movement to change the way Americans think of civil rights. Today, civil rights have come to be seen as belonging to specific constituencies. Fairly or not, civil rights are equated with group rights. The disability movement, however, is a reminder that all Americans have a mutual investment in protecting civil rights. And the ADA is a reminder of the original promise of such rights movements: that people must be seen as individuals—judged by the content of their character, not stereotyped on the basis of factors such as race, gender, or ethnicity. That was why the ADA forces an employer to look first at an applicant's talents and qualifications, and only then consider whether or how his or her disability could be accommodated. Holmes and Rodriguez proved that a disability need not prevent someone from becoming a talented police officer. Bell knew that a man who had lost a leg could have skills and experience to offer the fire department.

The early enforcement of the ADA would fall largely to a

new president, and Bill Clinton's administration quickly made it more than a paper law. This commitment would stem, in no small measure, from the day that Attorney General Janet Reno visited a small town outside of Washington and discovered a reassuring vision of America in the era of ADA. Patrisha Wright, the lobbyist who had led the battle for the ADA, invited Reno to her home community of Takoma Park, Maryland. Wright, looking for a model of ADA compliance to hold up to other communities, had convinced small businesses on Takoma Park's quaint main street to make the easy modifications required under the ADA.

So on July 26, 1993, the third anniversary of the ADA, Reno strolled the shopping quarter of brick sidewalks and family-owned stores. There she met the pharmacist who showed how for \$70 he had smoothed out the step in front of his store, removed a turnstile post, and widened an aisle to make his store wheelchair-accessible. A gift-shop owner explained how he had installed a doorbell at the front door for anyone needing the newly purchased portable ramp kept behind the door, all for \$370. Only a women's health center had had to make a major expenditure for its modifications, paying \$4,800 to ramp several stairs at the entrance and buying a \$3,000 examining table that could be raised and lowered. That may seem a high price for the clinic's rare client who uses a wheelchair. But the greatest appreciation came from the everyday patients: pregnant women. Again, the ADA had universal benefits, showing that it was not simply a law giving rights to some remote and little-seen minority, but one that offered independence and convenience to many.

In a speech later that day from the gazebo in the town's city park, Reno applauded businesses that had already complied with the ADA and reassured others, particularly small companies worried about cost, that the ADA was a "reasonable and flexible" law. "To all America I say," declared Reno, "Don't be fearful. Don't be afraid of what it takes to comply with the

ADA." It was time, she said, to end the phase-in period of educating Americans about the ADA and to "finish the job of turning the ADA's promise into reality" by vigorously enforcing the new law.

The ADA's sweep was displayed in the array of Justice Department suits and threats of litigation that followed. Owners of the Empire State Building agreed to make its observation decks accessible to wheelchair users; a state board of examiners gave a woman with a learning disability extra time to complete the licensed clinical social worker test; an Illinois city agreed to reinstate a custodian who had been fired after having a seizure; a drugstore chain changed its no-pets policy to allow people who used guide dogs in the store; a Phoenix trade school agreed to pay for the student with a vision impairment it had turned down; the nation's largest review courses for the bar and certified public accountants' exams agreed to provide interpreters for deaf students; and the city of Philadelphia instituted HIV-treatment training to all of its emergency medical workers and firefighters after paramedics had refused to lift a man with AIDS onto a stretcher.

The Equal Employment Opportunity Commission litigated cases with a similar breadth. An Illinois security company was forced to pay the executive it fired because he had terminal cancer; pension funds and health programs were challenged that denied or limited payment of expenses for AIDS-related illnesses; a chemical manufacturer was sued for insisting on giving a rotating shift to a senior lab technician with bipolar disorder, or manic depression, who needed steady sleep hours to keep his medication effective; and a Rhode Island state mental retardation facility was told to rehire a woman who was fired because she had a severe weight problem. Even more telling was the fact that of the first 25,000 ADA complaints filed with the EEOC, the largest single category, at 20 percent of total cases, was for back problems. And 88 percent of those complaints came from

people already on the job. These were not the traditional disability populations widely expected to be served by the ADA's job protections. The disability rights movement had made the workplace more fair and accommodating for all workers.

President Clinton acknowledged the power of the disability community to change America in a May 1994 meeting with 150 disability activists at the White House. (Among the invitees were two dozen ADAPT protesters who, it turned out, had outstanding warrants for their arrest stemming from a civil disobedience takeover of the U.S. Capitol the previous year. The threat of a canceled meeting was avoided by an eleventh-hour solution that once more showed the inside power of the disability movement's most radical soldiers: The Secret Service "lost" the list of those who should have been arrested at the White House gates.) Clinton, noting the tremendous power of the disability community's hidden armies, asked them to help end discrimination in health care. Disabled people had long been at the forefront in seeking universal coverage, in-home services, and other guarantees of independence. "Never forget that you are carrying on your shoulders now not only your cause, but ours as well," Clinton told the noisy, cheering crowd in the East Room. Despite that moment, the disability movement, unlike other civil rights causes, remains rarely recognized and little celebrated. Yet it is a trailblazing crusade. It quietly offers a renewal of civil rights. And it gives America a model for a more fair society that values the talents of all.

