

CHAPTER 8

UP FROM THE NURSING HOME

Jeff Gunderson's voice is choked with worry. He is about to reenter the place he calls "the concentration camp." It is a nursing home, one of two where Gunderson, who has cerebral palsy, was sent from the time he was eighteen until he turned twenty-seven.

"I always said if I had to come back here, I'd rather be six feet under," Gunderson says nervously as his attendant tugs him from the car parked outside the nursing home and lifts him into his wheelchair. Nine years have passed since he has lived here. He has returned to this brown-brick building of his nightmares because he wants to introduce me to his former roommate, another man with cerebral palsy who, he says, is anxious to get out.

Gunderson wound up at this Beloit, Wisconsin, nursing home—where he says he was abused and forgotten—after his mother and father divorced. His mother could not lift her large

son out of bed and care for him. To hire an attendant to come into the Gunderson home was not covered by private or public insurance and was prohibitively expensive for the woman who worked on a canning factory assembly line. But Medicaid does pay for all of the costs of a nursing home. So Gunderson's mother, like many other parents of severely disabled sons and daughters, had little choice: she put her teenage son in a nursing home.

Now back at the nursing home, Gunderson sees an ambulance that has pulled to the front door. It is a bad omen, he thinks, reminding him how death was a constant here. The two nursing homes where Gunderson lived were set up to care for the elderly, not for the young. Gunderson was required to follow the same regimen as the generally sickly, elderly people around him. This made it easier for the nursing home staff. He went to bed at 7 P.M., the same time as his first roommate, a man in his eighties. His food was bland, unseasoned, often a form of gruel made for older residents who could not eat solid food. Gunderson admits he rebelled: "I'd have fits."

At both nursing homes, Gunderson says, the staff tried to break him. Sometimes aides tied him to his bed. They would drag him into cold showers as punishment. To make him use the bathroom on a schedule convenient for the nurses, they would put ice cubes down his pants. It was a form of torture for Gunderson, because the cold set off his spastic muscles. On several occasions, Gunderson says he was given a suppository before sleep and, since he could not move by himself, he would spend the night lying in his own feces. (Officials at both homes say they are unaware of the incidents and that such practices would have been against their policies.) Until his last years in this second home, days were spent in bed watching soap operas. "Many times I wanted to kill myself," he says. "I planned it, too."

Inside the nursing home, the antiseptic hospital smell is

strong and the hallway lights are bright. Gunderson is panicky. He greets staffers with a cheery "Remember me?" But he ignores the severely disabled young people, who now live on a separate wing, some of whom are excited to see him. Loud music comes from a radio in one darkened room where a man lies curled up in a hospital bed. Gunderson, wheeled down the hall by his attendant, cannot find George, his former roommate. George is gone, he announces; perhaps he no longer lives here.

Quickly outside again, Gunderson relaxes at a nearby restaurant with a hamburger. An elderly man enters, wearing a white cap, white pants, and an emerald green sweater. It is George's father. He comes to the nursing home every day to feed his son. George, it turns out, had been there and Gunderson had spotted him. He was the man with the radio. But Gunderson had not been able to face him. His reasons are vague. "George probably would have thought I would stay there with him," he explains.

Later, on the telephone, George's father, a friendly retired restaurant owner, explains that his son "got hurt at birth." George's mother takes the receiver. Would they like to see their son out of the nursing home, like Gunderson, in his own apartment with an attendant? It is not possible, says the mother. Her son is "absolutely, completely helpless, he has no communication, he needs to be dressed." The staff at the nursing home is very caring, she says. Only she and a few of the aides know George well enough to understand him when he speaks. One nurse has recently devised a board with pictures. George can point to a picture of "water" when he wants to drink or "radio" when he wants his music. A therapist has begun working with him, softly throwing a ball to George and giving him colored blocks to stack. The mother notes, "They have a program with the children, now." George is forty-nine.

Gunderson, now thirty-six, lives in a subsidized, two-bedroom apartment. He works three days a week at a sheltered workshop where he is paid a piece rate to help pack boxes of chili

that go to grocery stores. He runs up his phone bill, talking long hours to friends. Bowling trophies—he is in two leagues—are scattered around his large living room. His neighbor comes over to watch football. He shares the apartment with his attendant, Shaun Boyd, who helps him dress, bathe, use the toilet, cook, eat, do housework, and get around town. Boyd has become his closest friend. The two eat out together, take rides in Boyd's secondhand car, or stay up late watching rented movies. "I can go out and do things for myself now," Gunderson says. "I used to be a shy person because of all those years living in a nursing home."

Younger people like Gunderson, between eighteen and sixty-four years old, make up 10 percent of the population of U.S. nursing homes; that translated into about 148,000 people in 1987, according to the U.S. Department of Health and Human Services. In nursing homes they lose "the basic rights that the rest of us take for granted, like choosing where they live, who they live with, what they eat, when to eat, who their friends are or if they are going to have sex," argues Tom Hlavacek of the Wisconsin Coalition for Advocacy. "If it happened to us we would scream holy hell and go to the highest court in the land. We do it to people with disabilities all the time and we feel justified by the fact that they have a disability."

Nursing homes have become the new black holes of isolation and despair for young people with disabilities. Today, twice as many working-age men and women live in nursing homes than in traditional state institutions. Millions of others know they could wind up in a nursing home with the loss of a paycheck or social services or because of some other crisis. This threat makes a mockery of all of the disability rights movement's hard-fought gains of civil rights protections and attitude shifts. Following the passage of the Americans with Disabilities Act, disability activists turned to finding alternatives to nursing homes.

Most disabled people in nursing homes have developmental

disabilities, such as mental retardation and cerebral palsy. Others have muscular dystrophy and similar neuromuscular conditions. But a new class of residents includes young people with spinal cord and head injuries, who likely would have died from their accidents before the medical technology of the last two decades made it possible to save them.

In the 1970s, states started closing and downsizing large institutions after lawsuits and newspaper exposés attacked the hellish conditions at many of these facilities. Often residents were removed from one institution only to be dumped into another—a nursing home—that was equally regimented and inappropriate, and sometimes abusive. The number of people with developmental disabilities in state institutions dropped from 195,000 in 1971 to 88,000 in 1990. But the total of developmentally disabled younger people—from eighteen to sixty-four years old—in nursing homes grew by a third in that same period, according to K. Charlie Lakin of the University of Minnesota.

Some of these younger people with disabilities are there because they or their parents prefer it, but most want to live on their own, says Nancy Hansen-Bennett of United Cerebral Palsy of South Central Wisconsin, the group that helped Gunderson move into his own apartment. Even the most severely disabled person can manage outside a nursing home with attendant help and other support, she says. Power wheelchairs, computers with voice synthesizers, and innovative group homes and work programs allow unexpected independence. And living in the community is always less expensive, Hansen-Bennett says, since nursing homes employ costly nurses and doctors, who are not needed by someone who has a disability but is in good health.

Gunderson spent nine lonely and miserable years in nursing homes. He assumed he would die in one, but in March 1981 a county social worker approached him and asked, "Do you want to be the first person to live on your own under a new program?"

Gunderson's first reaction was fear. He had come to take on faith what doctors, social workers, and family had been telling him—that he would never be able to live outside an institution. "I thought it was impossible," Gunderson recalls, "even though I'd always been screaming, 'Get me out.' "

Even then, those close to him only reinforced his doubts. A social worker at the nursing home contested the move, Gunderson says, arguing with county social service officials that he was better off at the home. When Gunderson sought emotional support, the nursing home's psychologist told him skeptically, "You'll never make anything out of yourself." Most disapproving, however, was Gunderson's mother. In her eyes, her son had always been her dependent child, tragically damaged at birth, and she underestimated his ability to fend for himself. One night at dinner at her home, a few years after Gunderson had moved into his apartment, she had carefully cut his meat into small pieces, then speared each one on a fork to feed to him. Finally, Gunderson explained that he could handle a fork by himself.

Gunderson is one of the first users, and biggest success stories, of Wisconsin's Community Options Program, which gets disabled and elderly people out of nursing homes and into their own apartments and group homes. Some 18,000 disabled people are served by Wisconsin's various community programs, but there are another 5,800 on waiting lists, who either live in institutions or with family members. Wisconsin's program is inspired by "progressive thinking," says Hlavacek, but is fettered by "crummy implementation."

Visits to Gunderson and others in Wisconsin—where there are 4,600 people between eighteen and sixty-four in nursing homes, according to the Wisconsin Council on Developmental Disabilities—make it clear that who stays in a nursing home and who gets out is often a quirky business. It may be a matter of not having a friend or family member to be a strong advocate with the bureaucracy, as in the case of James Lee, a gregarious,

intelligent man with severe cerebral palsy that requires him to use a wheelchair. At the skilled nursing home in Milwaukee that had been his residence since 1977, Lee would wake up at dawn but often wait until noon for the nurses at the understaffed facility to get him out of bed.

From the time he was thirteen, Lee lived in state institutions and nursing homes. As one of the few young people at the Milwaukee nursing home, Lee feels out of place. "They play bingo a lot," complains Lee, who watches instead. He cannot remember the last time he slept through the night. Nurses are in and out of the room all night to help his roommate, a sickly man in his eighties. Theft is a problem. Most of Lee's clothes have been stolen, to be replaced by handouts that he knows will disappear, too.

To get out, "I'd move to the moon," says Lee. But he needs an attendant to help him with personal care such as getting in and out of bed, preparing meals, and housecleaning. In 1985, he went on a waiting list for his own apartment, under the program that helped Gunderson. But a large county like Milwaukee, unlike the rural one where Gunderson lives, has hundreds of people seeking to live independently and only a small number of apartments to accommodate them. Once someone gets into one of these apartments, says Maria Ledger, the Milwaukee County official in charge of placements, they rarely leave before they die. State funding has failed to keep up with the demand, and wheelchair-accessible apartments are particularly rare. Lee got lucky when Ledger found him and promised to get him out before his thirty-eighth birthday. But it took persistence—Lee called nearly every day for two years to check on Ledger's progress—and an emergency. When Lee's troubled nursing home was about to shut its doors, Ledger used Lee's impending homelessness to move him to the top of the waiting list. Such emergencies, more than how many years one waits on a list, most determine who gets the scarce placements.

Sometimes it is coldhearted bureaucratic rules that keep people in nursing homes, as in the case of Pamela Erickson, who has no hope of leaving her nursing home until she can get a proper wheelchair. Erickson, with cerebral palsy, is lively and verbal. But her body is so twisted by scoliosis that she needs a customized wheelchair to keep her sitting upright. The special chair would cost about \$4,000. Wisconsin Medicaid, however, will not reimburse for a nursing home resident's wheelchair, unless it can be proven that it helps the person work or live on his or her own. No one else can give Erickson money for the chair since, as a Medicaid recipient, she is not allowed to have more than \$2,000.

So Erickson spent sixteen years in the home lying on a padded, wooden cart with large wheels. It was her prison. The day I met her at her Milwaukee nursing home, Erickson's cabana cart was left in front of a television set. Most of her friends were visiting a botanical garden, but Erickson's cart was too big to fit in a van. Once five years before someone hired an ambulance, her only means of transportation, to take her to a Milwaukee Brewers game. Her only other trips out of the home have been to a hospital; because she spent day after day without sitting up, Erickson developed intestinal blockages. Medicaid, which denied her the chair she needed, paid for four costly hospitalizations to correct her resulting health problems.

In November 1990, a state hearing examiner ordered Medicaid to pay for Erickson's wheelchair. The decision, according to her attorney, Roy Froemming of the Wisconsin Coalition for Advocacy, gave Erickson "the right to leave the place she lives. She wants to go to church, to go to the store. It's an essential right to a meaningful life." Yet it would take another eight months after Froemming's court victory until the woman received her wheelchair. The state Medicaid bureaucracy had thought little of leaving Erickson without a means of sitting up for sixteen years. It thought nothing of letting the forty-three-

year-old woman, even with her rights in hand, waste close to another year of her life while the wheelchair requisition meandered through the bureaucratic process and a state rehabilitation engineer made two widely spaced visits to measure her for the customized chair.

Even disabled people whose families have struggled to keep them at home now face institutionalization as they begin outliving their aging parents. Virginia Helmin, who is fighting cancer, worries about what will happen to her son after she dies. Richard Helmin lives in a simple nine-square-foot room next to his late father's barbershop in Milwaukee. Virginia, who tends to him, lives one floor up. Living at home, Richard can spend time with his girlfriend, who also has cerebral palsy, and can get to a job in a sheltered workshop. There are simple pleasures, too, like his fortieth birthday party, for which his mother hired a belly dancer. "We treated him like a real person and I can't let that go to waste," Virginia Helmin says. "In a nursing home, he'd stagnate."

Her fear is not exaggerated. Consider the case of Jackie, a high school graduate with mild retardation, who reads, writes, can cook, and can take buses around Milwaukee. When her mother died nine years ago she was thrown into a grim and crowded nursing home solely for people with developmental disabilities. At the home, she says, she struggles with theft, violence, and unwanted sexual advances from other residents. She is not allowed to leave the facility because the surrounding neighborhood is considered unsafe. Fearful of retaliation from staff, she asks that her last name not be printed. Her sister, who is fighting for her release, says her sister is losing the skills that once let her live at home. Jackie has been on and off a waiting list for a group home for ten years. "I want my privacy," she whispers in the noisy cafeteria at the home. "I want my freedom. I want to get out of here."

To keep getting people out of nursing homes will require

more money or at least a redistribution of existing funds. Most federal funding is directed to institutions and nursing homes, and that discourages states from setting up community programs, complains Dennis Harkins of Wisconsin's developmental disabilities office. In Wisconsin, two-thirds of such money serves 5,500 residents of nursing homes and institutions, while a third pays for 25,000 people in community programs, he says. Senator John Chafee (R-R.I.) has tried to change this "institutional bias" by proposing legislation that would freeze funding at current levels to institutions with more than fifteen beds, in effect forcing states to spend more on smaller group homes. But Chafee's bill, despite numerous compromises, seems irreversibly stalled, due to forceful opposition from unions fearful of job losses and from vocal parents with children in state facilities who distrust states' ability to provide safe community-based programs.

Recent federal nursing home reform laws are aimed at ending "warehousing" of residents. Facilities are now required to focus on rehabilitation, a tenet of the disability field that is being applied to better the lives of both disabled and elderly residents of nursing homes. Jayn Wittenmyer of the Wisconsin Council on Developmental Disability, a state advisory group, says the changes are double-edged. The reforms assured that Medicaid would subsidize institutional care of younger people, she says, making it "more lucrative" for nursing facilities to set aside beds for young disabled residents. That may make it harder to get them out of nursing homes in the long run. For now, the reforms will bring improvement at some homes for young people, like the Marian Franciscan Home in Milwaukee.

In 1986, the Wheaton Franciscan System, a private Catholic health-care concern, took over the four-hundred-bed nursing home, which had a separate wing for 107 disabled people. The nursing home staff helped Pamela Erickson and thirty others appeal for proper wheelchairs. The previous owner of the home

actively discouraged residents from having electric wheelchairs, since that gave them freedom of movement and made it harder for the staff to control them. But, prodded by federal and state audits, the nursing home has begun an expensive and ambitious program to get younger residents out of the home and into work programs. Forty now leave to work in enclaves with other residents to make garbage bags and sheets of fabric softener that are sold in the home.

"We are trying to correct the mistakes of the past," explains Cynthia Sook, an official at the Marian Franciscan Home. The 1960s promise of getting people out of large institutions was a good one, she explains, but states like Wisconsin shut down institutions without putting enough money into group homes or supervised living programs. Yet even at an institution like Marian Franciscan, which aspires to do the right thing, officials agree that a nursing home is no place for a young person. "How many of us live with one hundred seven other people?" asks Sook. "We try to make it comfortable for young people, but it's still an institution."

When Gunderson left the nursing home in September 1981—Gunderson reels off the precise date as if it were his birthday—he was moved into a subsidized apartment, given an attendant to help him bathe, eat, and perform other tasks he could not do on his own, and sent to work at the sheltered workshop. He would no longer rely on nursing home staff who ran his life on a schedule convenient to them. He would have more control in the one-to-one relationship with the attendant. (Many activists now prefer the less-common term "personal assistant" to get away from the implications of dependency in the word "attendant.") But Gunderson would have to take the assistant assigned to him, someone in a demanding job that paid minimum wage for less than full-time hours.

An attendant can be a resentful bully, like Bette Davis in *Whatever Happened to Baby Jane*, who served up a dead pet parrot

to Joan Crawford, her sister in a wheelchair, or a saintly Mother Teresa, who gives cheerful nurture and comfort. Low wages lead to high turnover and make finding skilled assistants often difficult. Regulation and formal training might improve the quality of attendant care. But many disabled people prefer an untrained assistant, since certified attendants or nurses used in the role are less likely to take direction.

Gunderson went through his share of abusive and bizarre attendants. He says his first believed that his cerebral palsy was a manifestation of the devil. This attendant would slip Gunderson from his wheelchair and lie him on his back on the apartment floor to pray over him. Sometimes the attendant would invite friends over to form a prayer circle around the disabled man to ask for the release of the "devil" who inhabited his body. But when Gunderson did not miraculously start walking, the attendant accused him bitterly of lacking adequate faith. Frightened, Gunderson quit going even to his own church.

His next assistant was more agreeable but had a history of mental health problems, according to Gunderson and the agency that hired him. On several occasions, Gunderson says, the second attendant would decide Gunderson was a tree. He would dress Gunderson in a green sweater and pour chocolate milk over him, talking bizarrely about Gunderson's roots needing "nutrients" to grow. On other days, he decided the disabled man was a boat to be tied to a dock, and would tie Gunderson to his bed. He would give Gunderson uncooked meat to eat for dinner. Nevertheless, Gunderson kept quiet about this terrorization. An even darker terror was to be returned to the nursing home, something he feared would happen if living in his own apartment did not work out. "I would put up with anything, just to stay out on my own," Gunderson says now.

The mistreatment became public knowledge one snowy winter morning when the second attendant disappeared, leaving Gunderson outside in biting cold, wearing a flimsy T-shirt and

a pair of pants, unable to move his wheelchair by himself. The attendant hired as an emergency replacement was Shaun Boyd. He would become a reliable and caring attendant and Gunderson's closest friend.

In their federally subsidized two-bedroom apartment—filled with worn furniture—Gunderson and Boyd depend on each other. Boyd attends to Gunderson's needs—from cooking and cleaning to bathing to toileting—with skill and care. He does all this for little pay. He could make more at a fast-food restaurant, and indeed, from time to time he has worked during his off-hours as a janitor at a local steak house. His attendant's salary is for forty-two hours a week, divided into six hours a day seven days a week. Plus he gets a place to live, rent free.

Gunderson and Boyd are kindred souls. With sadness, Boyd talks of never really knowing his mother. He remembers her only from hospitals and nursing homes. By the time he was born, she was already living in a nursing home, weak from multiple sclerosis. Her doctors had told her that having another child was risky. Boyd invokes wispy memories of his mother—of formal Sunday afternoon visiting hours at her bedside, of a woman growing weaker and sicker, surrounded by nurses and clean hospital walls. When he was nine, she died. As a result of these experiences, the trip with Gunderson back to the nursing home with me was almost as traumatic for Boyd as it was for Gunderson.

Gunderson lives on \$550 a month from Social Security. He considers the money from his job at a sheltered workshop for disabled adults—he made \$1.39 for two weeks of work in one typical paycheck—a joke. He slips cardboard sleeves into plastic bags, the first step to packaging chili cans at the nearby Hormel plant. But there is little work to do and Gunderson spends many hours forced to play alphabet bingo, a child's game that he hates because it is so elementary. This, however, is the only option in his county for someone with a moderate disability, although

larger counties in Wisconsin have begun experimenting with supported employment, the idea of putting a disabled person, sometimes aided by a job coach, in a regular job. Until the system changes, Gunderson must stay at the workshop—a job, no matter how dull and useless, is a requirement to living outside an institution. Without the workshop, Gunderson knows he would be back in a nursing home.

"What holds Jim McMahon together is a medical mystery," begins a profile of the quarterback in *Sports Illustrated*. McMahon's chronic tendonitis in his elbow is so painful that not only is throwing a football difficult but combing his long hair, too. "In fact the left hand must help the right move the brush through the postgame tangle. And putting his ponytail up, just reaching behind his head, causes him to grit his teeth," according to the magazine. After one game, the quarterback's elbow was so sore that he had to ask his Philadelphia Eagles roommate, 280-pound tackle Ron Heller, to tie his ponytail into a knot for him. He had to ask backup quarterback Brad Goebel to reach into his "left armpit to administer a dose of roll-on deodorant. McMahon's personal hygiene is a team project, although the Eagles say nothing clears a clubhouse quicker than the sound of McMahon calling out, 'Ron? . . . Brad?'"

In the vocabulary of the disability rights movement, McMahon's teammates were performing personal assistance services. They aided him in the tasks that he could do for himself if his elbow did not hurt. McMahon needed help with a few small activities of daily living but could otherwise do his work, in this case lead his team to victory on a football field.

Most disabled people know that there is often a thin line of luck between independence and institutionalization. Often it hinges on something as simple as having someone around to roll on your deodorant, get you out of bed, or help you eat. Evan Kemp, who left the Equal Employment Opportunity Commis-

sion in 1993, depends on personal assistance three hours a day, every day, to help him get out of bed, use the bathroom, wash, dress, cook breakfast, and get into his wheelchair so he can go off to work. Kemp has the money to afford assistance whenever he needs it. But he has "met disabled people in nursing homes who are more capable, brighter, better advocates than I will ever be. There is a fine line between me as chairman of the BEOC and a patient in a nursing home."

Personal assistance services are the new, top-of-the-agenda issue for the disability rights movement. The Americans with Disabilities Act guaranteed that stores and restaurants could not discriminate against people with disabilities and that employers could not refuse to hire someone on the basis of a disability. But what good are such protections for someone who cannot get the help needed to get out of bed in the morning? Activist Judy Heumann says personal assistance is now the movement's "major civil rights issue." After the ADA was passed, ADAPT, the grass-roots protest group, quickly became American Disabled for Attendant Programs Today, junking its original name of American Disabled for Accessible Public Transit. It reaimed its confrontational tactics at the nursing home industry and the federal Department of Health and Human Services, instead of at public transit and the Department of Transportation.

Personal assistants help disabled people with the tasks they cannot do on their own. That includes dressing and undressing, grooming, feeding and bathing, getting in and out of bed, a wheelchair, or a bathtub. For a severely disabled person who cannot breathe on his own, an attendant will clear a respirator's air hose or help someone with bowel and bladder movements and catheterization. Depending on the severity of a person's disability, an assistant might do light cleaning, shop, prepare meals, or, when helping someone with a head injury, mental illness, or mental retardation, balance a checkbook, pay bills, or deal with landlords.

Some 7.7 million Americans need some form of personal

assistance. But although this service is widely regarded as the right thing to do for these people, only 860,000 of them, about 11 percent, received aid through publicly funded programs in 1985, according to one 1990 study. At least 77 percent of those who receive publicly funded personal assistance services are over the age of sixty. Wider access to assistance can keep young and old people out of nursing homes and save states money. For example, it costs Utah \$15 a day for the three-hours-a-day attendants who visit Julian Sanchez. But before the young paraplegic moved into his own apartment and began attending college it cost the state \$80 a day to keep him in a nursing home.

Despite these savings, states are reluctant to provide such humane assistance. States worry that the savings they currently enjoy from these programs would evaporate if such help is made widely available. Of the 7 million Americans in need of long-term care, only 1.5 million are in nursing homes. The rest live at home. Since three-quarters of caregiving is provided by unpaid relatives, 70 percent of whom are women, states fear that families would come "out of the woodwork" to demand funding for what they already do for free. One study suggests that making attendant services widely available would quickly eat up the savings states now enjoy when they get people out of nursing homes. Yet the experience of a few states with larger programs, like Arizona, suggests that expanded programs can pay for themselves.

Even disability activists clash on how much an extensive system of personal assistance should cost, since it depends on who would be eligible for the service. Estimates range from \$500 million a year to serve 50,000 working-age people nationally, to up to \$10 billion a year to assist 9 million disabled men and women regardless of age, income, work status, or the severity and type of their disability.

Most states now provide limited attendant services for disabled and elderly people, using money from Medicaid, Social

Security, or federal social service block grant funds. But these programs are purposely kept small, even inadequate, out of fears of the "woodwork" theory. In almost every case, says Simi Litvak of the World Institute on Disability, existing services are too fragmented to foster independence.

In America's often perverse health care universe, however, it is not the most efficient or the most humane system that thrives but the one that makes the most money. In the early 1970s there were a dozen postacute rehabilitation centers for people with brain injuries. But as private insurance began paying for expensive stays, many nursing homes began converting. By 1992, there were 800 of these facilities to treat the survivors of head trauma, usually the result of automobile accidents, assaults, bicycle accidents, and falls. The average stay in one of these centers is fifty-one days, William Graves of the National Institute on Disability and Rehabilitation Research told Congress, at an average cost of \$1,069 a day. Yet, doctors and survivors claimed, these centers did little rehab and often excelled only at a "wallet biopsy," the practice of keeping someone as long as their insurance was paying, even if they wanted to go home, and then kicking them out the minute the insurance ran out, even if they wanted to stay. "Steal from the rich and keep it" was the way Dr. Kenneth Hoelscher described the practice of his former employer, the New Medico chain. Another former staffer said her job was to scour local newspapers for stories of car accident and plane crash survivors and then pressure the grieving families to admit their injured relatives. New Medico and other owners denied such charges, but the whole industry is coming under investigation by state and federal law enforcement agencies.

Head injury survivor Sherry Watson says the solution is inexpensive attendant service. Watson, after her accident, lived in an institution where, in addition to her daily stay, physical therapy was charged to her insurance company at \$125 an hour, and "cognitive therapy" at \$150 an hour. But her biggest im-

provement came when she joined a health club at \$25 a month to redevelop her muscles and paid a tutor \$5 an hour to help her learn to read again. The cost of a typical stay in a rehab facility, Watson says, could pay for "years of support" with personal assistance in one's own home.

It is helpful to look at assistance services as falling on a continuum, says Gerben DeJong of Washington's National Rehabilitation Hospital. At one end is the ideal, what DeJong calls the "Independent Living Model." The consumer has control. He can hire, fire, and train attendants. Sometimes a local agency gives an attendant's wages directly to the disabled consumer, who is then in the position of being a true employer in charge of paying the attendant. Assistance is an extension of the social service system. Almost no existing programs fit this ideal model for independent living.

Most fall closer to the other extreme on the continuum, what DeJong calls the "medical model." These most resemble nursing home care. An extension of the health care system, they are designed for a patient with an acute or chronic condition and include supervision by a doctor and a registered nurse. This is often called home health care. The disability rights movement consciously steers clear of the word "care," which suggests that a disabled person is a sick and passive recipient of an attendant's help. Personal assistance, in the eyes of the disability rights movement, is an item of social liberation—just like a lightweight wheelchair or a bus lift—not a form of medical care.

Yet most existing personal service programs send a message that the recipient is a patient, not an independent consumer. Often an assistant's decision or a program's rules substitutes for a disabled person's judgment. One attendant in Montana refused a request to put a bag of Oreo cookies in a disabled woman's shopping cart and then scolded her client for being too fat. This stripped the recipient of her right to self-determination, says Sara Watson, who studied Montana's services for the Washing-

ton Business Group on Health, and followed traditional patterns of paternalism by caregivers toward disabled people. More tricky, says Watson, is Montana's rule that prohibits an attendant from acting to help a disabled recipient drink alcohol—from putting a six-pack of beer in a shopping cart to popping the tab on the can. States, Watson says, have a "legitimate concern about legal liability" if a person drinks to the point of danger, but advocates such as Heumann contend that disabled people should have the same right as anyone else to make decisions, even foolish ones about drinking.

An attendant is not a caretaker, advocates argue, but should be a neutral extension of the disabled person. In this way, an attendant is best compared to a piece of assistive technology, like an environmental control system, that simply translates a person's request to turn on the lights; a speech synthesizer that speaks what is typed into a computer; or a robotic arm that can pick up a beer can. Sign-language interpreters are a better model yet. They are guided by a strict code of ethics that demands anonymity and distance. An interpreter must never insert his or her thoughts into a conversation. It is considered bad form for a hearing person to speak to the interpreter or address questions in the third person, instead of speaking and looking directly at the deaf person.

While states try to hold the line on costs, some disabled people are pushing assistance service to a new frontier—their right to be parents. Leigh Campbell and Bill Earl met in a Michigan nursing home in 1978 when they were both fifteen. Both have severe cerebral palsy and use wheelchairs, and Leigh sometimes operates a voice synthesizer to talk. They took advantage of changing attitudes, new laws, and breakthrough technology to go to college, marry, and, in 1988, move into their own apartment, where a state-funded attendant helps them seventeen hours a day. In 1992, Leigh gave birth to a daughter, Natalie. With assistance, Leigh could breast-feed the infant, but she

could not pick her up to bathe her or change a diaper. The state, however, prohibited the assistants from handling the child. If Michigan helped the Earls with parenting, state officials reasoned, it would be required to provide similar service to other parents as well. (One irony was that the attendants would have been authorized to handle the child if she had been born disabled.) The couple, both of whom were unemployed, could not afford child care on their own. So county social workers talked of putting their daughter in foster care.

To Bill Earl, this was another example of society devaluing and underestimating people with disabilities, just as it had been to consign him to a nursing home as a teenager. Earl looked forward to seeing Natalie "say her first word, take her first step," he said in a statement submitted to a hearing before state legislators. "Don't take away this family because it is not like your family." To Barbara Faye Waxman, a disabled woman who writes about reproductive rights and disability, the county's eagerness to take away the child was a case of outright prejudice. "The feeling is that there are more deserving able-bodied white middle-class infertile couples in the world," she says. The Earls managed to hold off losing Natalie when friends volunteered to provide round-the-clock child care, while the couple fought the state.

"Home health care can hardly be termed a revolution," notes sociologist Irving Kenneth Zola. "For most of recorded history, the home was the preferred site for the delivery of health services." Disabled people have led the return to home care. It was not until the 1950s, with new technology, that medicine revolved around hospitals and doctors' home visits became a rarity. At the same time, however, people with chronic illness and disability were living longer and had come to understand that the hospital was a cold place and that status as a patient frustrated their efforts to live as normal a life as they knew they could. California started the nation's first In-Home Supportive

Services program in the 1950s to help hundreds of postpolio quadriplegics who realized they could live better, and at less cost, outside a hospital. It was no accident that the beneficiaries of this program, people like Ed Roberts, would later start the disability rights movement with their focus on independent living.

Today, the nursing home reform movement is catching up with the disability rights movement. Nursing facilities mushroomed in size in the 1960s and 1970s, the exact time that institutions for people with mental illness and mental retardation started shutting down. Nursing home construction fed on the billions of dollars provided by Medicare and Medicaid, which were created in 1965. Today, nursing home critics expose the same horrid conditions that led to the deinstitutionalization of people with mental illness and mental retardation: restraints and tying of residents; overuse of drugs; neglect and abuse by aides; institutionalization of people who, with social service support, could live better lives on their own. The trend is toward making nursing homes the institution of last resort, and those who live in them now tend to be the most frail. Leaving an institution, older Americans are saying, is a choice. They are questioning medical models and demanding maximum self-determination. It is one more example of how the disability movement has quietly transformed America's social landscape.

CHAPTER 9

NO LESS WORTHY A LIFE

The intensive care unit was the wrong place to put a young man like Larry James McAfee. It was a stopping-off point for patients near death. But McAfee was not dying; he wasn't even sick. Trapped in his hospital bed, he felt as if the weeks were ticking off in slow motion while around him the intensive care unit seemed to whirl at hyper-speed. Patients were wheeled in from surgery or wheeled out to the morgue, nurses and doctors hurried through, machines hummed, and lights glared. After three months, in the spring of 1989, McAfee, fed up, called a lawyer with a request. Help me, he said, "I want to die."

Larry McAfee, then thirty-four years old, was a quadriplegic, the result of a motorcycle accident in the mountains of northern Georgia. The muscles that worked McAfee's lungs and air sacs were paralyzed from his injury. So a respirator, which was attached by a tube inserted down his throat, pushed air into his

lungs to make him breathe. McAfee's request for the right to die brought Fulton County Superior Court Judge Edward Johnson quickly to Atlanta's Grady Memorial Hospital for an unusual bedside court hearing. Life as a quadriplegic, sustained by a machine and dependent on attendants for everything from eating to coughing, had been "intolerable," McAfee told the judge in the ICU. He spoke in a strained voice—unanimated, almost robotic—trying to be heard over the soft whooshing sound of the air passing through his respirator. He recounted how he had been moved from one far-flung nursing home to another and that he no longer foresaw a life out of a hospital bed. "It is very heartbreaking," McAfee said to the judge. "Everyday when I wake up there is nothing to look forward to."

McAfee, an engineering student, even told the judge how he planned to end his life. The method had come to him while he had been lying in the ICU. He described the device he invented to kill himself in the same matter-of-fact tone he would use to explain any other engineering project. It consisted of a time switch, one relay, and two valves. The simple invention would force the air from the respirator to spill ineffectually into the room instead of into his lungs, without setting off the alarm. A friend would assemble it according to McAfee's instructions. Someone else, with permission from the court, would help McAfee swallow a sedative. Then, before he drifted into a deep sleep, McAfee would clench a mouthstick between his teeth and use it to turn on the timer. It would tick off the last seconds of air pumped into his lungs. Death would come—gently, comfortably—in his drug-induced sleep.

Three weeks later, the judge summoned McAfee's parents and three younger sisters to his chambers. Johnson would allow the young quadriplegic to end his life. They all cried, and tears came to the judge's eyes. McAfee's mother hugged the judge and thanked him for his compassion. "That was the hardest decision of my life," he told Amelia McAfee. "But that young man made

the biggest impression on me of any young man in my life."

To disabled people, however, Larry McAfee's story was not a simple right-to-die case. Instead, it was another chilling reminder of how a disabled life was dismissed—by doctors, judges, and the public—as a devalued life. As they viewed it, a judge saw a man with a translucent plastic coil connecting a hole in his throat to a machine and eagerly ruled this a life not worth living. It did not matter that about fifteen thousand Americans living outside of hospitals use respirators. A nondisabled man who asked the state to help him take his life would get suicide-prevention counseling, but McAfee had not been considered rash or even depressed. Instead, a judge had praised him as sensible and brave. It was a bitter insult to the millions of other people with disabilities who were living successfully on their own—including those so severely disabled that they used respirators daily.

From a disability rights point of view, the McAfee decision was better understood as the story of how this country fails miserably to care for severely disabled people. Instead of getting help to live on his own, McAfee was sentenced to indifferent nursing homes and hospitals and stripped of basic decision making about his life. It is not an ignorant system. Rehabilitation therapists have perfected programs for returning injured people to their homes to live and their jobs for work. There is astounding technology—like the wheelchair McAfee could control with his mouth and the portable respirator that fits on its back—to allow for new levels of independence. Nor is the system a stingy one. Over \$1.5 million in private insurance, state Medicaid, federal Medicare, and Social Security payments was spent on McAfee in the four and a half years between his accident and the final court decision.

But the generosity was often misspent and misplaced. For example, state Medicaid would pay every penny of McAfee's expenses in a nursing home. Yet it would not pay one cent for

what he needed to live at home so that he could go back to work and be a taxpayer instead of simply taking welfare. Social Security and Medicaid are based on out-of-date assumptions that severely disabled people simply need support payments to be attended by family or in a nursing home because they are close to death and can expect little more. This may have been true as recently as Medicaid and Medicare's inception in 1965. Indeed, it has been only in recent decades that someone with an injury like McAfee's had even reasonable odds of survival. Kidney infection and bedsores quickly took the lives of those who lived past their initial injury. Today, doctors save eight thousand people a year who become paralyzed by accidents, from nightmarish highway smashups to mundane slips in the bathtub. There are some 250,000 survivors of spinal cord injuries nationwide.

McAfee was victimized not by a mean-spirited system, just a life-deadening one. Many severely disabled people hold jobs, live in their own homes, marry, and bring up families. Many others, like McAfee, get exhausted trying to cope. Clinical psychologist Carol Gill, a quadriplegic who uses a wheelchair and specializes in counseling disabled clients dealing with depression, calls what McAfee went through "disability burnout." She describes it as the frustration of trying to work through an unresponsive and bureaucratic system of health care that too often promises more than it delivers.

When I met McAfee I found a man angry about his loss of control over his body but more angry still about his loss of control over his life. He was living in a gloomy Alabama nursing home room, his bed separated by a pink curtain from the next bed, which had been home to a succession of elderly men on respirators. McAfee was a large man—he stood six feet, six inches before the accident—propped on his side in a hospital bed. He had no shirt on, and his body was covered by a white blanket. Nurses had not bothered to shave him, and there was

a three-day-old stubble on his face. Out the window next to his bed, he could see only sky and desolate trees. A stack of unopened mail sat on the windowsill, along with a bouquet of balloons from his mother and a framed picture of an attractive woman in a nurse's uniform. McAfee spoke in a distant, distracted voice, except when describing the pain of his lowly status as a disabled man. "You're looked upon as a second-rate citizen," he said, the bitterness rising in his voice. "People say, 'You're using my taxes. You don't deserve to be here. You should hurry up and leave.' " Nurses and doctors talked about his prognosis and problems while standing at the bottom of his bed, as if he were invisible. Attendants pulled his body roughly, at times dropping him to the floor, and some, he felt, made it clear they considered caring for him a loathsome chore. "I didn't ask to be like this at all," McAfee said. "You reach a point where you just can't take it anymore."

At the time of his accident, the man his family called "Bubba" was close to completing his engineering degree at Georgia Tech in Atlanta, while he worked full-time at an engineering firm. He was bright and had an aptitude for math, but he never applied himself in school, either at the private academy in rural Sandersville where he finished high school or in college. He planned to become a mechanical engineer. He had a girlfriend in Atlanta but was not ready for marriage. After the accident, in his self-pity, he ended their relationship, even though she had remained supportive.

It is a myth that being disabled means being in bad health. A person may need a wheelchair for help in moving or a respirator for help in breathing yet live a long and healthy life. McAfee's health was in danger for the two weeks after the accident. At Georgia Baptist Hospital, McAfee was stabilized. Holes were drilled into his skull to attach a brace for traction. Another hole was opened in his throat to insert the plastic tube from the respirator. Once his health improved, he was sent to

Atlanta's Shepherd Spinal Center. Quadriplegia means full or partial paralysis of the arms and legs. In rare cases, quadriplegics, like James Shepherd, who founded the Atlanta center after being injured in 1973 while body surfing on a beach in Rio de Janeiro, can even walk with the aid of crutches. "High quads" like McAfee, who have had injuries to the top vertebrae in their spinal column, are completely paralyzed below the neck. Their internal organs—kidneys and liver, for example—still work.

Contrary to common expectation that disabled people become sexless, most men and women with spinal cord injuries report satisfying, and often more adventuresome, sex lives. Many report the physiological sensation of orgasm. They develop secondary erogenous zones—the back, the neck, the breasts. Most men still get erections and many can still father children. Drugs and electrical stimulation methods can help. Many quadriplegic women can get pregnant and bear children.

Another myth is that disabled people are forever depressed. Steve Shindell, the director of psychological services at Shepherd, notes that some studies have found the suicide and divorce rates for quadriplegics are roughly the same as for the population at large, although other studies show higher divorce rates. People whose lives have purpose and inspiration—a spouse, children, or an enjoyable job—are the most motivated to adjust to injury. The "best predictor" of how someone fares, says Shindell, is how well they coped with stress before their injury. Others at Shepherd and the various nursing homes and hospitals where McAfee lived, questioned whether he ever had those coping skills.

Most people with such disabling injuries go through periods of severe depression, but McAfee's was unrelenting. He was difficult, demanding, and sullen. He seemed to want to sabotage any plan to help him and turn against anyone who reached out. There had been bitter rejection for him, for sure. His best friend, who had been riding with him the day of the motorcycle acci-

dent, could not handle seeing his friend so disabled and cut off contact, as did McAfee's grandmother and, most devastatingly, the adored grandfather who used to take him hunting. His mother moved to Atlanta for the first six weeks of McAfee's rehabilitation at Shepherd, sleeping either on a rollaway cot in a counselor's room or upright in a chair, with her head on her son's arm and a hand on his mouth in case he needed anything. After that, however, it was hard for the family, several hours away in Sandersville, to make more than infrequent visits. Yet there would be others devoted to him, including a nurse from one of the nursing homes—the one in the picture at McAfee's bedside, a nurse who Amelia McAfee says was in love with her son—who took her two weeks of vacation to be with McAfee when he moved from one nursing home to the next.

At Shepherd, therapists worked to show McAfee that he could live independently. He could do just about anything he had done before, they told him, even though he could no longer move his legs or hands. They taught him to control an electric wheelchair equipped with a "puff-and-sip" switch. If he gave a hard puff on a plastic straw, the chair moved forward. With a sip, it moved backward. One of the first things the Shepherd therapists do is to determine what a person likes to do most, then show him a new way to do it. A painter is taught to hold a paintbrush between his or her teeth. A photographer is shown how to trigger the shutter of a camera by using a puff-and-sip device. There are puff-and-sip kayaks and sailboats. For a hunter, like McAfee, there are rifles, mounted on a lap board, that can be aimed and fired with a puff-and-sip switch. McAfee, however, never showed any interest in taking up hunting again. He went through the rehabilitation program at Shepherd twice, spending fifty-three weeks there. The average stay for a quadriplegic was twenty weeks.

Yet McAfee's future looked bright enough that the spinal injury center even used him in one of its advertising campaigns.

The print ad shows a smiling McAfee working at a computer terminal that was programmed to recognize the sound of his voice so he could control it with verbal commands. At his side was a machine that turned the pages of a book for him. CASE STUDY: LARRY MCAFEE . . . said the ad headline; PROGNOSIS: PROMISING. By the spring of 1986, McAfee was home in his own apartment. He talked of looking for a new job as a computer consultant. His insurance payment from his job at the engineering firm where he had worked before the accident paid for the round-the-clock attendants he needed. He needed medication and had to be turned every three hours to prevent the bedsores that are common with quadriplegics and can lead to life-threatening infections. McAfee, scared and accustomed to the top-quality care he had received at Shepherd, insisted on hiring nurses, although less-skilled and less-expensive attendants would have sufficed. His insurance company paid less than the going rate for private nurses. The result, McAfee claimed, was that the agencies sent him their worst nurses, ones who did not care for him properly. He went through nurses and money quickly.

The year at Shepherd and the expensive care quickly ate up his million-dollar insurance payment. After seventeen months, before McAfee had taken serious steps to return to work, his money ran out and his real nightmare began. Without money, McAfee was dependent—like many quadriplegics—on state Medicaid funding. His parents could not take him into their modest home. “An individual family can’t do it for twenty-four hours,” explained his mother. “We would have ended up hating him and he would have ended up hating us. We looked at it from every way.” Had he been disabled in California, he would have received up to \$1,200 a month for attendants so that he could stay at home. Georgia would not pay for such help, although it would pay a skilled nursing home \$100 a day to care for him.

Yet here was the McAfee Catch. No nursing home in Georgia would accept such a severely disabled client for so little reimbursement. Because he was on a respirator, he required more attention than the typical nursing home client, an elderly person who can bathe and eat with little or no assistance. Georgia paid nursing homes the same daily rate, whether a patient used a respirator or not. Consequently, Georgia nursing homes refused the costly clients who depended on respirators.

Other states are more generous. Ohio paid nursing homes close to \$300 a day to care for someone like McAfee, so he was moved to a nursing home in a small town near Cleveland. It would be for just a few months, he was assured, until another facility could be found closer to home and his friends and family, but McAfee spent fourteen months in Ohio. The promises from Medicaid officials in Georgia stopped. There was no longer any talk from optimistic therapists about the possibility of a job. The twenty-bed ventilator unit was made up almost entirely of geriatric residents. Most, says McAfee, had not been taught how to speak over the ventilator tube. McAfee tried to show them. He spent lonely days staring out the window. His roommate was an elderly man in a coma. Growing more and more frustrated, and upset about what he thought was poor care, McAfee filed complaints about his treatment with Ohio health officials. Michael Coury, director of the Aristocrat Berea Skilled Nursing Facility, says his staff tired of McAfee's grievances and, after talking to McAfee, felt it was best if he left. McAfee says he was given no say in what happened next.

The morning after the Super Bowl, in January of 1989, administrators at Grady Memorial Hospital, Atlanta's large public hospital, got a 6:30 phone call from Ohio. An ambulance plane, carrying Larry McAfee, a resident of Georgia, was on its way to Atlanta. He had been paralyzed in a motorcycle accident, hospital officials were told, but they were surprised to discover when he arrived that the accident had occurred not that day but

four years earlier. Georgia Medicaid had given permission to the Ohio nursing home to transfer McAfee but did not warn Grady Hospital. Otherwise, the hospital would not have accepted someone in McAfee's good condition. Once McAfee had been admitted, the hospital by law could not discharge him unless it found another place for him. But the McAfee Catch applied to them as well: no nursing home in Georgia would take a young man on a respirator.

So McAfee sat in the intensive care unit at Grady, growing more and more furious at the way he had lost all control of his life. Because he was in stable health he did not belong in a hospital at all—much less in an intensive care unit. But the ICU was where the hospital put people on respirators. He spent nearly three months on the noisy intensive care ward—when he called the lawyer—and then five more in a step-down section of the intensive care unit. There was no privacy, and only rarely did nurses have time to get him out of bed. When McAfee's parents brought his electric wheelchair to the ward, McAfee says, the staff locked it in a closet. Grady was old, run-down, understaffed, and the last resort for the poor, the uninsured, and the patients that no one else wanted. "He actually smelled when he was there. They didn't bathe him," complained Amelia McAfee. "They clipped his hair off down to his scalp. They would cut his hair on Thursday and when I came to see him on Saturday the hair was still on the pillow and lying on the floor."

Every day McAfee stayed in the hospital, Grady lost money. Medicare ruled that because he was healthy, it was inappropriate for him to be in a hospital. Therefore, Medicare would not pay the hospital costs. Medicaid would pay, but only if he was in a nursing home. Hank Selinger, a discharge planner at Grady, repeatedly called one hundred nursing homes in search of one that would take a quadriplegic on a respirator. McAfee's hospital bill for seven months came to \$175,369, says Grady spokeswoman Beverly Thomas, of which Medicaid would reimburse no

more than \$3,000 to \$8,000. The hospital and state taxpayers picked up the rest.

McAfee's call for legal help went to an agency that assigns volunteer lawyers. The case went to Randall Davis, a young associate in an Atlanta firm. Davis specialized in aviation law, but he knew how to fashion the strongest legal argument for any position. Davis went to Grady to meet McAfee and was appalled to find someone who "shouldn't have been in the depressing atmosphere of the ICU, especially when he was alert." In his brief, Davis played up the tragedy to McAfee's life: he had lost control over his body and found no enjoyment to his life. In short, his life was not worth living.

But Davis had a legal problem. He had to convince the court that to let McAfee turn off his respirator would not be suicide but an act of passive euthanasia, like that practiced daily in hospitals across America. Passive euthanasia occurs when a doctor either withholds or withdraws life-sustaining technology—such as a respirator or feeding tube—from someone in an irreversible coma or a persistent vegetative state who would otherwise die. Medical ethicists, courts, and the American Medical Association sanction passive euthanasia in carefully controlled circumstances, and doctors say the practice is common. More taboo is active euthanasia, in which a doctor deliberately acts to bring about death. In the Netherlands, doctors are allowed to give patients legal injections of drugs, and supporters there say the practice accounts for 2 to 3 percent of all deaths in that country. Some American doctors say it is not uncommon in this country for doctors to help dying patients overdose on drugs, although at the time of McAfee's request the practice was rarely discussed openly and opposed by many medical ethicists and the AMA.

Davis argued that McAfee's respirator was an artificial system of life support. To turn it off, he said, was simply to refuse treatment to prolong his life. McAfee's parents and his three

sisters supported his decision to die. The Georgia State Attorney General and even the Catholic archdiocese of Atlanta wrote briefs in support. Nationally, the Catholic Church has been one of the most stalwart opponents of assisted dying, but David Brown, the archdiocese's attorney, compared McAfee's situation to trying to end life support for someone who was "brain-dead."

Davis's argument blurred the line between active and passive euthanasia, since McAfee was otherwise healthy and was in no danger of dying as long as he had his respirator. True, he depended on a machine to breathe. But it was not the respirator itself that required McAfee to be in hospitals and nursing homes. It weighed thirty pounds and was portable. He could go to work with it or travel in an airplane around the world with it. He needed the respirator in much the way he needed an electric wheelchair. Each compensated for a part of his body that no longer functioned. And each represented freedom and independence.

Nevertheless, legal doctrine firmly supports a person's right to refuse medical treatment. Judge Johnson agreed with Davis. To let McAfee turn off his respirator, the judge concluded, would merely be allowing the "injury process to take its natural course." In other words, McAfee would not be committing suicide. He would be dying from the injury of the motorcycle accident of more than four years before. Johnson never considered how the health care system had failed McAfee and even contributed to his wanting to end his life. Instead, Johnson spoke of the tragedy of the "boy who loved sports" and "teased his sisters" before the accident but who, as a disabled man, could no longer find "quality in his existence."

Disability activists in Atlanta reacted with a visceral anger. It was as if McAfee's decision to die—and the sympathetic nods of approval from both church and state—were a direct judgment that their lives were not worth living either. Mark Johnson and Eleanor Smith, two Atlanta-based activists, led demonstrations

outside the courtroom. If McAfee could end his life, they asked, didn't that mean the state put a lower value on the life of a disabled person than on the life of a nondisabled one? Why should there be an exception to the ban on state-assisted suicide only because a man was disabled? The activists feared that the court ruling sent a message that disabled people had a duty to die rather than be a burden to their families and society. Because of McAfee's paralysis, the judge's ruling was considered a humane gesture. Yet had McAfee gone to court but not been disabled, a team of psychiatrists would have been dispatched to lift him from his depression and give him suicide-prevention counseling, argued Smith.

In fact, McAfee had sent away social workers and therapists who came to his bedside at the ICU, in part because it was open and public and hardly a comfortable place to be spilling the tale of one's most private misery. But a psychologist did visit him when he sought to die—not to determine if he was depressed but simply to report back to Judge Johnson that McAfee was mentally competent to make a decision to die. Attorney Davis objected that activist Smith was “paternalistic” to suggest McAfee was not clear-thinking enough to make his own decision. “McAfee has a unique personality,” said Davis. “He is very independent and he abhors being reliant on others.” But what about Smith and other disabled people, even those on respirators, who insisted that life was still rewarding? Replied Davis, “To those, he says, ‘I salute you, but it's not for me.’”

One thing that made the McAfee case particularly ominous was that he was seeking an easy suicide, approved and assisted by the state. McAfee argued that as a disabled man he needed someone to help him end his life. But others, including disabled historian Paul Longmore, noted that there were many ways a respirator-dependent quadriplegic could kill himself. McAfee could run his electric wheelchair into a lake and drown or crash it down a flight of stairs. Certainly a man mechanically clever

enough to figure out how to clench a mouthstick in his teeth to turn off his respirator could also figure out how to trigger a gun. To die during a drug-induced sleep was a sure out, free of blood and pain. It made suicide inviting. What frightened Longmore was the way the courts were encouraging and applauding McAfee, opening the doors wide to his idea, simply because he was disabled. As a historian, Longmore was disturbed by this echo of past efforts to help disabled people die, often against their will.

In Nazi Germany, doctors marked children and adults with mental retardation, mental illness, epilepsy, chronic illness, and severe disabilities for mass murder. Disabled children, and later disabled adults, were put to death by lethal injection of Luminal, a sedative, or, if that did not work, morphine-scopolamine. Others died in the regime's first experiments with lethal carbon monoxide gas. Some 200,000 disabled men, women, and children would die, according to historian Hugh Gregory Gallagher. "Lebensunwertes Leben"—life unworthy of life—was the concept the Nazi doctors used to justify their practice of direct medical euthanasia. Later the Nazi regime would extend its grim biomedical vision to other undesirables—6 million Jews and other victims of the Holocaust.

The Nazi biomedical campaign came out of the worldwide eugenics movement of the 1920s. As historian and psychiatrist Robert Jay Lifton notes in *The Nazi Doctors*, the early German practitioners of eugenics looked with envy at their American colleagues, who with ease could enforce coercive sterilization, using a simple form of vasectomy first developed at a U.S. penal institution around the turn of the century. By 1920, twenty-five states had laws requiring compulsory sterilization of the "criminally insane" and others considered genetically inferior. German physician Fritz Lenz, a leading advocate of sterilization, complained in 1923 that his country was far behind the United States in experiments with sterilization. Lenz praised America

for having laws that prohibited marriage by people with epilepsy and mental retardation and banned interracial marriage. And he bemoaned Germany's lack of eugenics research institutions to compare with those in the United States, where, Lifton notes, work carried on by Charles B. Davenport at Cold Spring Harbor, New York, was funded by the Carnegie Institution.

Unlike in Germany, flirting with the eugenics movement in the United States never resulted in mass extermination, but a few American doctors and scientists did argue for the extermination of people with mental retardation, epilepsy, mental illness, blindness, and "deformations," so that they would not have a chance to perpetuate future generations with their "deficiencies." One of these was Dr. Foster Kennedy, a man with impeccable credentials as professor of neurology at Cornell Medical College and director of the Department of Neurology of Bellevue Hospital. He was also the president of the Euthanasia Society of America, which was created in 1938. Writing in the *American Journal of Psychiatry* in 1942, Kennedy outlined a proposal for killing "defective" children—he referred to them as "defective products" and "Nature's mistakes"—which he proposed was a humane alternative to letting them live. When a "defective" child turned five, Kennedy suggested, the parents or guardians should be allowed to ask a panel of doctors that the child "be relieved of the burden of living." Kennedy compared this to the "solace" given a "stricken horse." If the panel found the child to have "no future nor hope of one," Kennedy wrote, "then I believe it is a merciful and kindly thing to relieve that defective—often tortured and convulsed, grotesque and absurd, useless and foolish, and entirely undesirable—of the agony of living." Kennedy's support of involuntary euthanasia was scorned, particularly as World War II ended and understanding of the roots of the Holocaust spread.

But the idea that it was somehow right or humane to end the lives of disabled people never went away. In 1972, when a

Florida state representative, who was also a doctor, introduced a "death with dignity" bill, he suggested that some 1,500 people in state institutions, 90 percent of the total, "might qualify for elimination." The House passed the bill in principle, but it did not become law. In their 1985 book *Should the Baby Live? The Problem of Handicapped Infants*, ethicists Helga Kuhse and Peter Singer wrote, "We think that some infants with severe disabilities should be killed" and proposed that it be made legal to kill such a child within approximately the first twenty-eight days of life. And in 1991, David Larson, the codirector of the Center for Christian Ethics at Loma Linda University, suggested taking the hearts of disabled children to keep monkeys alive. Asked about the ethics of the Baby Fae case, the first human to receive a heart transplant from a baboon, Larson replied, "If a primate's capability was higher than that of a human—say a severely mentally handicapped child—I think it would be appropriate to support the opposite approach of Baby Fae, a transplant from a child to save the life of a healthy baboon or chimpanzee."

Throughout U.S. history, doctors have routinely starved or ended the lives of infants born with Down syndrome or various birth defects, although those children were in no danger of dying. The practice was given national exposure in 1983, when the Reagan Administration opposed the parents of "Baby Jane Doe," a Long Island infant born with spina bifida. The baby's mother and father chose to withhold medical treatment, agreeing with their doctors that it was more humane for the severely disabled child to die. Surgeon General C. Everett Koop argued that this amounted to involuntary euthanasia. He knew it occurred often. In 1973, two doctors, writing in the *New England Journal of Medicine*, revealed that forty-three infants with various disabilities had been allowed to die in the special care nursery of the Yale-New Haven Hospital "rather than face lives devoid of meaningful humanhood." A California state court in 1979 ruled in favor of the parents of Philip Becker, a thirteen-year-old with

Down syndrome, who wanted to withhold life-saving heart surgery, arguing that his life was not worth living. He was spared death only because another couple adopted him.

To the disability activists, McAfee's case was an example of a disabled life devalued. It was a reminder of the many other cases where an easy right to die was extended to a disabled person as an act of compassion. In 1983, Elizabeth Bouvia, a twenty-six-year-old social worker with severe cerebral palsy, checked into a Los Angeles hospital and asked for painkillers while she starved herself to death. With the help of an American Civil Liberties Union attorney, she argued that her severe disability made her want to die and that she had a right to refuse life-saving treatment. Three mental health professionals who examined her agreed but ignored the recent emotional crises in her life. She had lost a child to miscarriage and her marriage had broken up; her brother had died; she was financially troubled and had been forced to withdraw from graduate school. A California judge also ignored her depression and concluded that the hospital should help Bouvia die, given "her helpless and, to her, intolerable condition." But Bouvia was far from being the helpless woman described by the judge. Instead, as historian Longmore noted, she "is a woman who operated a power wheelchair, was halfway toward a master's degree, married, made love with her husband and planned to become a mother. This is a woman who still could and might do all of those things if she were given appropriate psychiatric and medical treatment."

Bouvia set the case law that a patient could refuse treatment, regardless of his or her motives, age, or health. Her struggle got nationwide press attention. Less well remembered is that Bouvia never followed through on her death wish. Nor did she get the support she needed to live independently. A reporter in 1988 found Bouvia in a Los Angeles hospital, living in a tiny, \$800-a-day isolation room and registered as "Jane Doe," still talking of wanting to die.

David Rivlin was a quadriplegic on a respirator. While surfing at the beach with his girlfriend in 1971, a crashing, foamy wave drove Rivlin headfirst into the sand. The force of the wave broke his neck, leaving Rivlin paralyzed except for some movement in his arms and upper body. He tried to carry on with his life, moving back to Michigan, where he grew up, and enrolling in college. He studied philosophy and lived with an attendant. When he began to lose the limited function of his arms, he moved into a nursing home in Dearborn and fell in love with a woman who worked on the office staff. They were engaged and Rivlin moved into her home in 1980. But the relationship was troubled and short-lived, with Rivlin bitterly blaming the breakup on "the burden of my being a quadriplegic." Both of his parents had died. When his strength continued to deteriorate and he was returned to a nursing home in 1986 he thought about dying.

"The case law is quite clear," concluded Oakland County Circuit Court Judge Hilda Gage, responding to Rivlin's petition in July of 1989. "We are dealing with a competent adult. He has the right to refuse treatment." The thirty-eight-year-old quadriplegic made an appeal through the local newspapers for a doctor who would help him die. "The vent [his respirator] takes away all choice in your life," he told a reporter several days later. "I don't want to live an empty life lying helplessly in a nursing home for another thirty years. Death means to me that I can just rest in peace." Fifteen days after Gage's ruling, Dr. John Finn of the Hospice of Southeastern Michigan gave Rivlin a mixture of Valium and morphine. As Rivlin drifted into unconsciousness, the respirator was shut off. Three close friends, including the woman he had been engaged to, watched. In a half hour, Rivlin was dead.

It was the Rivlin case that had inspired McAfee to seek death, and it was Rivlin's plea for a doctor's help that would inspire Dr. Jack Kevorkian, the Michigan "suicide doctor" who

the following summer helped Janet Adkins take her life with the "mercy machine" he had invented. Kevorkian had met Rivlin when the quadriplegic had sought out a doctor to help him die. With \$30 of spare parts collected from junkyards and flea markets, Kevorkian built a suicide machine so that someone like Rivlin could pull the plug on himself. It was a more sophisticated version of the suicide machine that McAfee had invented a year before. Kevorkian's had three vials strung to a small metal frame, connected to an electric motor.

Adkins, living in Oregon, heard about Kevorkian and his machine through a newspaper article. The fifty-four-year-old former English teacher had been diagnosed as being in the early stages of Alzheimer's disease, although doctors told her that diagnosis could turn out to be wrong. She remained physically active, beating her son at tennis one week before her death. But she no longer remembered how to keep score. When she first contacted Kevorkian, he encouraged her to continue with medical treatment. But when an experimental drug failed to help, he invited her to Michigan. She and her husband, Ron, were members of the Hemlock Society and talked about "dying with dignity." One friend said Janet Adkins saw ending her life as "a gift to her family, sparing them the burden of taking care of her."

In June of 1990, Kevorkian drove Adkins to a Michigan park with an electrical outlet for campers (no hotel would accept Kevorkian and his "self-execution machine"). In the back of his rusty Volkswagen van, Kevorkian tried three times before he could hook the machine's needle into the small veins in Adkins's arm. When she was ready to die, she thanked Kevorkian. "Have a nice trip," he replied. Then she pressed the button which emptied the harmless saline solution from the first vial into her veins; then the second vial of thiopental sodium, which made her lose consciousness; and then the final vial of potassium chloride, which caused her heart to stop.

Since the 1970s, with advances in life-sustaining technol-

ogy, Americans have demanded more control over the end of life. There have been notable court challenges over how long to keep comatose patients like Karen Ann Quinlan and Nancy Cruzan on life-support machines. Kevorkian's supporters saw him as a compassionate man, helping people avoid ignominious death. Others saw him as a frightening figure who spouted bizarre ideas about farming organs of dying prison inmates and suggested, with echoes of Nazi Germany, that people with severe disabilities should seek out suicide. Because Michigan was one of the few places that has no law against assisted suicide, a judge later threw out murder charges against Kevorkian. Eight disabled or ill women would die in Michigan with Kevorkian's help before the state's governor signed a law banning assisted suicide in December 1992. Kevorkian vowed not to be deterred and, after some disability activists noted that only women were choosing euthanasia, the pathologist known as "Dr. Death" helped a man die in January 1993. Kevorkian would help twenty people die before, in May 1994, a jury would acquit him for assisting in the death of a thirty-year-old man with Lou Gehrig's disease. Shortly after, a Michigan appeals court ruled the state suicide ban unconstitutional. The mixed outrage over Kevorkian, and debate in states like California and Washington over legalizing euthanasia, demonstrate that the controversy over how life should end is becoming as passionate and divisive as the debate over abortion and the beginning of life.

Five Atlanta lawyers, as well as the American Civil Liberties Union, refused the request of disability activist Eleanor Smith to write an *amicus curiae* brief in opposition to letting McAfee end his life. They demurred, saying they supported an individual's right to choose. McAfee's choice to die was based on the same constitutional right to privacy that was the basis of the right for a woman to choose abortion. Ultimately, the National Legal Center for the Medically Dependent and Disabled, an Indianapolis-based right-to-life law center, wrote the friend-of-the-court appeal to the Georgia Supreme Court. It made a force-

ful argument "not to join in a misguided campaign to champion Mr. McAfee's right to die" and asked that McAfee get help from a therapist expert in the field of suicide.

The joining of the Indianapolis right-to-life group and the disability activists was an uneasy marriage of convenience. Legalized abortion is one of the most divisive issues for the disability rights movement, one that the movement has dealt with largely by keeping its distance. Opponents of legalized abortion had seen a natural alliance with disability rights groups, starting with their battles to win medical treatment for infants born with severe disabilities. When the United States intervened in the "Baby Jane Doe" case, it relied on the existing civil rights protection for disabled people. It sued under rules drawn from Section 504 of the Rehabilitation Act, arguing that the hospital, which received federal funds, was illegally discriminating against Baby Jane Doe on the basis of her handicap. Doctors claimed that the girl was so severely disabled that she would never know joy, would live her life bedridden and in constant pain. It was an argument similar to McAfee's. At issue was whether it was right to allow an infant to die if that child had a severe but manageable disability that was not life-threatening. Right-to-life groups called the practice infanticide and took up the fight with vigor. Disability rights groups were divided and fought for "Baby Jane Doe" with less certainty.

To their secret horror, almost every disabled person knows that had his or her condition been congenital, he or she likely would not have survived past the nursery or would not have been born at all. Some, like Evan Kemp, have been told as much by their mothers. California ADAPT activist Lillibeth Navarro calls abortion "this holocaust that is also wiping out our tiny brothers and sisters with disabilities." Of the 1.6 million legal abortions each year in America, about 1 percent of the women have been told the fetus has a defect and 12 percent believe the fetus has been harmed by environmental factors. When told that a fetus

has a serious genetic defect, just under 50 percent of women choose abortion.

Proponents of legalized abortion at times have played shamelessly upon parents' fear of giving birth to a child with birth defects—using exaggerated pity talk of “defective children,” “a gruesome demand,” and “a maimed and distorted human-without-a-future” to defend a woman's option to choose abortion. This is anathema to the disability rights philosophy that disability is not a tragedy and that the quality of a disabled person's life is usually vastly underestimated. “Baby Jane Doe,” the girl whose real name was Keri-Lynn, grew up to disprove the dire predictions about her life. After a delay of weeks, her parents, caught in a crossfire of advice by doctors and litigation by the government, changed their minds and allowed medical intervention. *Newsday* reporter Kathleen Kerr visited the family seven years after the girl's birth and found a happy child in a wheelchair, who laughed and played with her parents and friends. “Baby Jane Doe is learning at a level far beyond what doctors testified she would,” Kerr wrote, noting that the girl was considered “educable retarded” and took special education classes. Former Surgeon General C. Everett Koop told Kerr that had the girl gotten more active treatment right at birth, “she probably would have been normal today.”

Yet leaders prominent in the disability rights movement—and it is a movement with a large percentage of female leaders—often find themselves balancing their anger over selective abortion and their belief in the right to unrestricted childbearing rights. There are basic issues that link the disability rights and abortion rights movements: the control over one's own body and a distrust of leaving such decisions to doctors. Opposition to forced sterilization, for example, was both a feminist and a disability rights issue.

Medical ethicist Adrienne Asch, who is blind, argues the importance of a woman's right to choice. But selective abortion

on the basis of disability, she says, is wrong. Most women who abort a fetus diagnosed with a disability like Down syndrome, spina bifida, cystic fibrosis, or muscular dystrophy, she claims, lack knowledge of how the disability rights movement is improving the quality of life for children with these conditions. This reflects society's exaggerations of the tragedy of such disability. Asch draws a distinction between ending a pregnancy and selective abortion. "Aborting because of our own lives says something very different than aborting because we don't like what we find out about the potential life we carry," she argues. To abort on the basis of disability, she says, suggests that a disabled person's life is not worth living. A woman's right to choice is also violated, she argues, when a society expects her to abort a fetus that may be disabled.

The National Right to Life Committee, the nation's most prominent antiabortion group, has tried to play to this schism in the disability rights movement. In 1991 it chose Robert Powell, a paraplegic, as its president. "I am concerned with the theory gaining in popularity that it is better to be dead than to be disabled," Powell said, echoing the concerns of the disability rights movement. "Many of us find it alarming that it is considered acceptable to abort an unborn child just because of disability."

Disability groups, torn among themselves and wary of compromising their effectiveness on other issues by taking sides on abortion, have sidestepped the volatile abortion debate. They will not be able to keep doing so. New research is allowing more and more conditions to be identified through genetic counseling, making more parents face the choice of selective abortion. Recombinant DNA technology now allows scientists to spot genes responsible for inherited conditions such as Duchenne and myotonic muscular dystrophy, cystic fibrosis, Huntington's disease, retinitis pigmentosa, and fragile-X syndrome. These breakthroughs carry uncharted ethical dilemmas. Could an insurance

company, for instance, refuse to pay for the health costs of a child born with cystic fibrosis if the parents knew they carried the gene but had a child anyway, or knew their child carried the illness but chose not to abort? Dr. Paul Billings of California Pacific Medical Center says there have already been such cases, including that of a Houston woman who was told that her health maintenance organization would not pay for the birth of her second child with cystic fibrosis. After she objected, the health provider relented. New experiments with gene therapy and the Human Genome Project, a biological moonshot to map all the genes in the human body, may bring breakthroughs to cures but also usher in the day that parents can choose to endow children with genes for good looks, height, or superior intelligence—or choose to avoid even mildly disabling conditions.

By the time Johnson made his ruling, McAfee was in a new nursing home in Alabama. That complicated McAfee's ability to end his life, since the court order applied only to Georgia. That summer, while McAfee was pursuing his court case, a brochure had come across Hank Selinger's desk at Grady advertising a nursing home in Alabaster, Alabama, that was opening a new ventilator wing for clients who used respirators. On August 16, two days after Johnson's bedside hearing, McAfee was transferred to the Briarcliff Nursing Home, half an hour's ride south of Birmingham.

There was pressure for McAfee to end his life quickly. The state attorney general had asked the Georgia Supreme Court to set guidelines for future McAfee cases. It was possible that the higher court would overturn Judge Johnson's decision. Despite saying he still wanted to die, McAfee took no steps to be returned to Georgia. A few days before Thanksgiving, the state supreme court upheld McAfee's right to end his life. But McAfee's slowness to act seemed to prove right his opponents.

They had argued that his legal suit did not reflect a sincere death wish but an angry lashing out at the way the health care system had mistreated him. This ambivalence gave a group of people an opportunity to befriend McAfee in an eleventh-hour attempt to save his life.

Pivotal in this effort was Russ Fine, who latched on to McAfee as his defender and, no matter how sullen McAfee's moods, never let go. Fine was not a disability rights activist, although he was the director of the injury prevention research center at the University of Alabama, studying ways to prevent the kind of accidents that had made McAfee a quadriplegic. Preventable injuries, including vehicular accidents, falls, drownings, and fires, are the biggest cause of death and disablement, notes Fine. However, the most militant disability activists are wary of injury prevention specialists like Fine, since, they argue, to prevent disability is to suggest there is something pejorative about it. "We want more disabled people, not fewer," was the sardonic explanation of the late Timothy Cook, director of the National Disability Law Center, whose point was that prevention is a health issue, not a disability issue. Fine got through to McAfee in part because he did not bring a strong ideology with him. He simply wanted to show McAfee that there could be a better life. Fine made it clear from the beginning that he supported McAfee's right to end his life. But he wanted the disabled man to pursue all his options first. McAfee was openly skeptical and gave Fine little sign of encouragement. He had heard all the promises of independence before—starting at Shepherd—but found they were hollow if the only option was to live in a nursing home or a hospital ICU.

"Larry McAfee is the embodiment of everything that is wrong with the health care delivery and reimbursement system today. It is high tech and low touch," said Fine. "By that I mean we have the technology literally to resurrect the near-dead but not the additional components to address quality of life. The

question becomes, Whose needs are we addressing? Are we doing it for our colleagues and professional peers just so we can go to meetings and deliver papers? Do we just want to demonstrate our prowess and expertise in maintaining life in catastrophic illness injuries, where a generation ago our predecessors couldn't do it?"

It was Fine's unconventional manner that eventually led McAfee to trust him. Despite being a health care professional himself, Fine shared McAfee's sneering impatience for the officious nursing home staffers who were constantly citing their rules and demanding that McAfee, like some naughty schoolboy, obey them or be sent back to Grady Hospital. Over the objections of the nursing home staff, Fine brought McAfee the beers and copies of *Playboy* he had been denied. He set up a VCR in McAfee's room and brought an occasional soft-porn movie, and then raised hell when the offended nurses unplugged McAfee's television. "The guy is still a young male," said Fine. "That gets to the quality-of-life issue. They're deciding what he sees. What kind of crap is that?"

Others worked to show McAfee that he could live independently. Engineer Rick Rice hooked up an environmental control system, a remote-control device that McAfee could activate with his voice in order to work the telephone and television in his nursing home room. Kirk Tcherneshoff, a paraplegic who ran the local independent living center, took him in his van on a shopping outing. Gary Edwards, the director of United Cerebral Palsy of Birmingham—who saw McAfee, like his own clients, fighting an indifferent bureaucracy to live independently—added his own vast understanding of how to wade through the social welfare funding system. His assistant, Brenda Carson, figured out ways a quadriplegic could work as an engineer.

McAfee's parents were convinced before their son was that there was a better way. Several months earlier, while sitting in a waiting room to see her son, Amelia McAfee had flipped

casually through a medical magazine. A story caught her eye. It was about a Canadian quadriplegic named Walt Lawrence. He and five others—five of them respirator dependent—had left a nursing home and set up Creekview 202, a custom-built apartment suite in Vancouver. Her heart jumped. Maybe it would change her son's mind about dying. At Creekview, each of the men had his own room with access to a balcony and a view of mountains. The kitchen was fitted with appliances at wheelchair level. In the bathroom there was a wheel-in shower and a bath equipped with a hydraulic lift. A "homemaker"—an attendant—hired by the residents came into the apartment to help cook and clean. A registered nurse was on duty for two hours each day. All of the men worked. Two were financial investment counselors, two were artists, another was a computer analyst. Lawrence was about to marry and leave.

Amelia McAfee decided to try to build the Larry James McAfee Apartments, a version of Creekview, in Atlanta. She hoped it would make Larry want to live. Finding money would prove frustrating. At a meeting with Governor Joe Frank Harris, Amelia McAfee explained how Creekview had cost less than half of the men's nursing home expenses. But the governor said the state could do little and the McAfees were shown the door. Later an attempt to raise the money through private donations turned up only a few hundred dollars. More discouraging still was McAfee's initial attitude. His mother's idea "will help some people, but I doubt if it will help me. I've already made up my mind," he said three months after moving to Alabama. "I'm tired. I want to get it over with."

But with his parents and the group of activists fighting hard to change his mind, McAfee began to waver. Particularly crucial was another machine—a voice-activated computer that cost five thousand dollars. With it, McAfee could put to work his training as an engineer. Bob Stockwell, a California computer specialist, saw a television news report on McAfee and flew to Alabama

to set up the computer for him. The computer was programmed to recognize the sound of his voice. McAfee could turn it on and off and command it to do many tasks just by speaking. With special software, he could make sharp architectural renderings of buildings and apartment layouts by drawing on the computer screen with a sonar beam directed from a band strapped to his head. He drew by moving his head, and the beam went with it. But when the computer first arrived at the nursing home, nurses would not let McAfee set it up, saying that the institution could not be "liable" for the expensive equipment in case it was stolen. Fine got McAfee's doctor to overrule the nurses and soon McAfee was practicing a few hours a day to the point that he was good enough to show off his skills to a prospective employer.

The computer excited McAfee. For the first time he talked of preferring to live, instead of dying. By February 21, 1990, when he was invited to speak before the Georgia State Senate, McAfee sounded like a full-blown disability rights activist. "Medicaid and Medicare policies that do not work in the best interest of the disabled have caused me and those like me to become prisoners of bureaucracy," said McAfee, from his wheelchair on the floor of the senate, as Fine held a microphone to his mouth. He had been turned into a "prisoner of fate and bad luck," he said, by "a bureaucracy that will pay for the warehousing of the disabled but one that does not address or even consider the quality of our shattered lives."

No matter how good McAfee got on the computer, he still was destined to bounce from one nursing home to another or, worse, to go back to the ICU at Grady. After consulting with Fine and Edwards, McAfee asked for something simple: have Georgia Medicaid take the money it would pay for him to stay in a nursing home and spend it instead on the live-in attendant and other support he needed to move into his own apartment. This was similar to the idea behind the Creekview apartments his mother had read about. In Washington, Allan Bergman of

the United Cerebral Palsy Associations drew up a plan for McAfee that would cost \$265 a day, compared with the \$475 to \$650 a day that the Alabama nursing home was billing Medicare to care for McAfee. Once again, McAfee ran into the McAfee Catch. At \$265 a day, it was cheaper to let McAfee live at home than in Briarcliff. But Medicare had a limit on how many days it would pay for nursing home care. After April 10, 1990, the Medicare payments to Briarcliff would end. McAfee would be the responsibility of Georgia Medicaid again, and that program still paid a skilled nursing home only \$100 a day. Officials at Briarcliff made it clear that they would evict McAfee the minute the higher Medicare rate ended, rather than accept the lower \$100-a-day Medicaid rate. Georgia nursing homes also continued to refuse to care for a high-quadruplegic for only \$100 a day. Medicaid officials said McAfee might wind up again at Grady, although officials there did not want him. "If I go back to Grady," McAfee vowed, "I will kill myself." His parents, Fine, and Edwards felt he was sincere and saw that there was a new deadline to meet.

It was McAfee's bad luck to be disabled in Georgia. Aaron Johnson, the state commissioner of medical assistance, said it would be "prohibitively expensive" for Georgia to offer home care to people like McAfee. It cost less, he argued, to put someone in a nursing home. But McAfee could not live in a nursing home, because none would take him at Georgia's low reimbursement rate. Complained Amelia McAfee, "Prisoners get better treatment."

When the April 10 deadline arrived, McAfee was caught in a bureaucratic twilight zone. Briarcliff evicted him. Grady Hospital refused to readmit him. No Georgia nursing home would take him. Worse, Georgia Medicaid insisted that McAfee was the responsibility of Grady Hospital, since that was the last place he had lived in Georgia. Either that or the responsibility of Medicaid in Alabama, where McAfee had lived the last eight

months. Grady argued he had always been the responsibility of Medicaid in Georgia. Alabama Medicaid agreed. Nor did McAfee want to fall under Alabama's program, since it was one of the few whose reimbursement to nursing homes was even less than Georgia's. McAfee was being handed off like a piece of radioactive waste; the bottom line was that he had no place to live. McAfee's newfound optimism was shattered. Edwards stepped in at the eleventh hour by putting McAfee in a United Cerebral Palsy group home. It was to be a temporary placement, for a week or two while negotiations continued with Georgia Medicaid.

Back in Atlanta, McAfee had new allies. They were the same disability rights activists who had stood outside the courthouse the previous September and angrily denounced his decision to die. On April 10, the day McAfee's Medicaid ran out, Mark Johnson led two dozen protesters to occupy the office of Georgia Medicaid director Aaron Johnson to demand home-care programs for McAfee and others with severe disabilities in the state. (By now there were three other young paraplegics at Grady, two from gunshot wounds, looking for a place to live.) "We're going to disrupt your business until you quit disrupting our lives," Mark Johnson said during a ninety-minute meeting with Aaron Johnson. From the commissioner's office, the protesters made a telephone call to McAfee in Alabama to offer words of support. Ten days later, Mark Johnson would lead a dozen demonstrators in another takeover, this time for six hours in the governor's office.

With negotiations on McAfee's fate dragging out over months, not days, Edwards's organization far outspent its budget on McAfee's housing and round-the-clock attendant care in the group home. His board members grumbled about the fiscal drain. McAfee lost more hope. At one point, visibly and understandably depressed, he was transferred to a psychiatric hospital for several weeks. McAfee's plight got national press attention,

and even President Bush asked the Department of Health and Human Services, which administers Medicaid, to put pressure on Georgia.

Not until July did Aaron Johnson relent, and McAfee was able to return home to Georgia. On July 11, McAfee, in his puff-and-sip wheelchair, boarded an ambulance van and was driven to Augusta. Medicaid officials had insisted that he stay at the Medical College of Georgia Hospital for evaluation. But after a month he was moved to a new group home in Augusta, much like the apartment that had been envisioned by Amelia McAfee. There was a round-the-clock attendant, accessible bathrooms and kitchen. There was space for McAfee's computer. Within a year, a few other severely disabled Georgians moved in. Johnson said he hoped the facility would be a model for the nation. Later, Georgia started a new program to give severely disabled people money for attendant care, one that would give recipients broad control that is rare in choosing and hiring attendants. It took over a year, however, for Georgia Medicaid to buy the additional computer equipment that it promised to purchase McAfee and that delayed their helping him find work. But McAfee was freer to get in and out of the house. He took a van to go shopping. He saw his family. His mood bounced up and down, often paralleling occasional respiratory problems. But on the whole, he pronounced himself happy to be alive, living a "good" life that had given him "hope."