

CHAPTER 6

PEOPLE FIRST

“**O**ne thing we’re going to vote on is a revolution!” Deepfelt cheers erupt from the crowd at the first-ever convention of People First of Connecticut. “Resolution” is the word that T. J. Monroe wanted, but revolution, really, is more like it. Monroe and the three hundred people in the hotel ballroom are trailblazers of the self-advocacy movement, a new and spreading crusade of people with mental retardation to make their own decisions about everything, from where they live to what they are called.

“You have to do two things today,” Monroe exhorts his rapt followers. “You have to make thunder. You have to speak for your rights.” For his listeners, just gathering at this meeting in 1990 is a daring and heady act of subversion. Others have always laid out their lives for them, telling them what to do and what to think. “You’re not gonna get in no trouble speaking for yourself, because there aren’t going to be laws in this

room," Monroe reassures the audience. "I want to hear thunder!"

By the end of the day, a revolutionary declaration of independence will be passed with raucous joy, unanimity, and plenty of thunder. The resolutions concern issues of the greatest importance to people with retardation. Close down all state institutions for people with retardation. Give us paid sick leave, vacation time, and holidays at our job sites and at sheltered workshops. Recognize our right to have relationships, even to have sex with those we choose in our institutions and group homes. And, because "retarded" is an ugly word that makes us seem childlike and dependent, change the name of the state Department of Mental Retardation, and avoid the word whenever you can. Refer to us as people with retardation, if you must. See us as people first.

Self-advocacy is the new rights movement of people with retardation. It is the parallel cry of self-determination by another group of disabled people rebelling against being long underestimated, deprived of choices, treated as eternal children, and thought to lead lesser lives. Self-advocacy is both part of the overall disability rights movement and a separate version that focuses on issues affecting people with mental retardation. (Many self-advocacy chapters include members with other developmental disabilities, including cerebral palsy and sometimes autism and head injuries. Often these other self-advocates have been institutionalized in facilities primarily for those with retardation.) In California, self-advocates picketed the state capitol to protest cuts in social service programs; others in Denver went on strike at a sheltered workshop, where they were paid at piece rates, to demand the same pay as nondisabled employees there; self-advocates affiliated with the Kennedy Institute in Washington, D.C., started a voter registration and education project; and in Connecticut Monroe helped self-advocates still living at a state institution call a well-attended press conference to demand their release from the institution into group homes.

There are 10,000 self-advocates at 374 chapters of People First and similar groups, according to an informal nationwide survey in 1990 by Rick Berkobien of The ARC. That compared to 200 known chapters in 1987 and just 55 in 1985.

The movement's impact belies its numbers or newness. Most significantly, professionals and parents' groups have begun to include people with retardation in decision making about the programs that affect them. Often this is just tokenism, not real power sharing. But in 1991 the Association of Retarded Citizens voted to change its name to The ARC, to reflect the demands of self-advocates to stop using the word "retarded." It was not an easy name change for the nation's largest group of parents and professionals advocating for people with retardation. It became difficult, for example, when fund-raising, to explain what The ARC was all about once it no longer had a defining word in its title. But the name switch was the first demand of the self-advocacy movement, and The ARC's action showed the new regard for joint decision making.

Self-advocacy is a second wave of revolt against the professionals who have run programs for people with retardation. The first came in the parents' movement starting in the years following World War II. Parents' groups formed mainly to obtain more social services for their retarded children, but also to protest the condescension of doctors and professionals who assumed these mothers and fathers were too guilt-ridden or inadequate to make proper decisions for their children. Those groups, including The ARC, which began in 1950 as the National Association of Parents and Friends of Mentally Retarded Children, changed the way professionals regarded parents, eventually leading parents and professionals to team up in their advocacy. Now self-advocacy is enlarging that circle. The parents' movement, says Gunnar Dybwad, one of its founders, is "getting tired," and the freshest thinking about improving the lives of people with retardation is coming from those with the disability. Jean Bowen,

an adviser to Connecticut People First, believes self-advocates will be more forceful fighters for their rights than their parents ever were. "Parents have been told to have such little expectations for their sons and daughters to contribute anything that they have been willing to settle for less," she says. Underpinning the self-advocacy movement is a faith that people with retardation—even the most severely retarded person—can be taught to make good choices. "This is a free country. You can talk for yourself" is the way T. J. Monroe explained it at the convention. "You might need some help, but you can talk for yourself."

As Monroe points out, however, if self-advocacy is a revolt against professionals and the nonretarded world, it also, paradoxically, remains dependent on people who are not retarded. Retardation means that a person has much greater difficulty learning than others. So people with retardation often need help in making the choices and judgments that constitute their own acts of self-assertion. Almost always, a self-advocacy chapter relies on a facilitator, a nonretarded adviser who helps break down complicated information but who, ideally, leaves decision making to the advocates. The facilitator treads a fine line. Usually a chapter's character is determined by the adviser. Some chapters are primarily places to socialize. Others press an agenda dominated by political activism. That is the case with Connecticut People First, whose chief adviser, Bowen, as director of the Western Connecticut Association for the Handicapped and Retarded, is active nationally on issues of the rights of people with mental retardation.

And if in Connecticut self-advocacy is a revolution, it is one that is encouraged, at least at arm's length, by the very regime that is being challenged. Speaking at the Connecticut People First convention, following a warm introduction by Monroe, is Toni Richardson, the state commissioner of the Department of Mental Retardation. "You are going to create a new world where everyone is included," she says, comparing the self-advocates to

Martin Luther King, Jr. "All of you are responsible for a new era and I take my hat off to you."

In the end, Richardson knows that self-advocacy will create more headaches for her. The people her department serves are being encouraged to complain about the way they are treated. But there are potential advantages, too. Richardson's department faces budget cuts in fiscally troubled Connecticut. The self-advocates could become effective political allies to help push for more money for, among other things, the new group homes she would like to open. But the biggest selling point for self-advocacy, says Richardson, is that it is the right thing to do.

Richardson has known Monroe since 1969, when, fresh out of college, she took a job at Southbury Training School, where he was then living. Working in one of Southbury's cottages as a residential aide, what she calls a "bottom of the heap" job, Richardson helped people eat, get to the bathroom, or get ready for bed. Later she became a teacher and then director of educational services at the institution. "A lot of the people who are part of self-advocacy now, I knew personally at Southbury twenty years ago. I remember what they were like, and what we, the staff, thought about their abilities. Now I see them in a whole different way, as colleagues and friends," says Richardson. "I'm not sure if they grew, or if we just grew in the way we looked at them."

Richardson was careful to stay at the edge of the conference, lest she seem to be co-opting or constraining the self-advocates. Her department, however, encouraged state-run group homes and institutions to let residents attend the conference, even making state buses available to transport anyone who needed a ride. This was crucial aid, since many of the self-advocates, particularly those in wheelchairs, would have had no way to get to the convention hotel in Middlebury, a small town in southwestern Connecticut. In addition, Richardson's department provided a \$5,000 state grant to finance the meeting, the biggest

single contribution. Another \$10,000 was raised with the \$20 convention registration fee and in candy sales by People First members.

People with retardation span a wide range of capabilities and experiences. This is reflected among the Connecticut self-advocates. Most live in group homes or with their parents, although a few live by themselves. Some, however, will return after the conference to a cottage at an institution that has been home for most of their lives. Most have mild retardation, which is not surprising given that 89 percent of the up to 7.5 million Americans with mental retardation are classified this way, according to The ARC. (Other experts, like Marty Wyngaarden Krauss of Brandeis University, say it is more helpful to consider a smaller population, the 1.7 million whose retardation limits their ability to live without help each day.) Some of the Connecticut self-advocates can read and write, while others have trouble making themselves understood. Most have jobs, although many are segregated in enclaves with only other disabled people.

The self-advocates run a model convention, starting with registration and coffee in the morning and concluding with a dinner-dance that ends at midnight. There is a seriousness to their work. The men come in coats and ties, the women in neat skirts and dresses. Monroe has worked for several months planning the conference, along with several self-advocates and advisers. He has carefully decided every detail, from not having a head table—to avoid putting "all the big people up front"—to the issues for the resolutions.

There are powerful moments when Monroe opens the floor to anyone who wants to speak. For two hours, two roving microphones are passed from one self-advocate to another. Most have never spoken before a crowd before. To do so is both nerve-racking and empowering. One man is so anxious that, speaking at hurtling speed, he lapses into the Sicilian dialect of his birthplace. The crowd applauds him wildly anyway, even though no

one has understood a word that he said. The self-advocates speak of their friends, their lovers, their families, about being married or wanting to be married. They talk about their jobs, about not making enough money, or about the pride they take in their work. Many share their pain of being considered abnormal and inferior. "We are human beings, not animals," proclaims forty-five-year-old Harriet Snurkowski, who recently moved into her own apartment after living in her mother's home.

Ultimately, self-advocacy comes down to the issue that has always been at the heart of how we deal with people with retardation: how much protection do they need? Is protection necessarily good, compassionate, and progressive? Institutions for people with retardation were first built in the nineteenth century by reformers seeking to help a vulnerable population. But today, these institutions are being depopulated and even shut down as professionals have come to agree that it is wrong to isolate people from the community around them. Today, such protection is seen as a paternalistic response that mires people in dependency, prevents them from learning how to take care of themselves, and, in the long run, costs society more than independence would by forcing government to continually look after a group made dependent.

At the same time, people with mental retardation, by definition, function at a significantly lower intellectual level than others, and that affects how they learn and how they make decisions. The Connecticut self-advocates are adults, but by virtue of their retardation they are sometimes vulnerable adults. This distinction is clear during two afternoon workshops at the convention.

A standing-room-only crowd of seventy attends a workshop titled "Doing the Right Thing: How to Flirt." A woman adviser to the People First chapter in New Haven shows videos of a party and then leads the group in some spirited role playing. You like someone you meet at a party, but how do you let the person

know you are interested? Among the tips are to compliment the person on the clothes he or she is wearing and learn his or her name and use it frequently in conversation.

Ten steps directly across the carpeted hallway is "Saying No: We Don't Want to Be Touched," a solemn session run by the director of a local rape crisis center. Again, there is role playing. Participants get on an imaginary bus and are approached by a molester who sits next to them. Among the tips for spotting a molester are that he compliments you on the clothes you wear, asks your name, and uses it repeatedly to win your trust.

Of the two seminars, the one on flirting succeeds precisely because it starts from an assumption that the people in the room are adults and, like others their age, are interested in flirting, dating, and sex. The antirape session misfires because the moderator assumes, correctly, that the participants are vulnerable but incorrectly that their vulnerability and retardation make them children.

People with retardation are thought to be more likely the victims of rape, because some people will try to take advantage of them. That is clear when the woman from the rape crisis center begins the workshop by asking for a definition of physical assault. Hands shoot up. One woman tells of being raped at an institution, but when she reported it no staffer would believe her. Another woman tells of being raped by a neighbor who, just a few weeks before, had knocked on the door of her group home when she was alone.

Thirty adults have come to the antirape seminar because they desperately want to exorcise their own bad experiences and to learn how to protect themselves. But the moderator does not address the personal tragedies of real-life adults who have had horrible experiences; instead, she keeps everything safely in the third person of role playing. She shows a video of elementary school children being approached by caricature-evil child abusers with arched eyebrows and smarmy smiles. She leads the

group in unison in shouting out how to spot danger ("You get that uh-oh feeling in your stomach") and then repeating what to do ("Say no! get away! tell a responsible adult!").

Ultimately, self-advocates are saying they are willing to take risks—like anyone else—to live like other adults around them. They want places to turn to for support, but they also want the feeling of respect and self-confidence that comes from taking chances.

Hard Choices

There is a delicate blend of success and failure in any person's life, but people with retardation are rarely trusted to handle either, complains Monroe. Self-advocacy is about taking risks. It is like, he says, "when a child gets on a bicycle for the first time and falls off and gets a little bruise. Are you going to keep that child off the bicycle? No, you let him get right back on. That's how people learn." His own life is full of success and learning from failure. Political leadership fits him neatly, as if it were his birthright. Wherever he moved at the convention, crowds of self-advocates seemed to form automatically around him. Physically, Monroe resembles Polish Solidarity leader Lech Walesa. He has the same bearish good looks, the familiar broad mustache—not to mention the charisma. He speaks emphatically, punctuating his remarks with sweeping hand gestures. Nattily dressed in a dark gray pinstripe suit, white button-down shirt, and a red tie, Monroe is expansive and open. He is a populist hero and role model to the self-advocates, who know the outlines of his story. From the age of eight, he spent eleven years at the Southbury Training School, a state institution where he says he was raped and abused, and then another dozen years living in a large group home.

Now, at thirty-eight, Monroe has acquired the symbols of success: his own apartment in Hartford, a Japanese-model com-

pact car with a sunroof, and a full-time job as a veterinarian's assistant, cleaning cat cages and giving flea baths to dogs. Monroe is a familiar figure, too, around the marble halls of the state capitol building, where he buttonholes legislators to urge them to spend more money on community group homes or to change guardianship laws. Several weeks before the convention, Monroe had been one of three thousand activists invited to the White House to witness the signing of the ADA.

But Monroe's own transition from institutional to community life has often been a rocky one, sending him from heights of self-confidence to suicidal feelings of failure. Reporter Kathleen Megan revealingly described Monroe's split public and private lives in a profile for *The Hartford Courant*. The public Monroe is the confident and effective activist who gets invited to the White House and is a commanding presence running the People First convention.

Monroe's private life is more troubled. There are bills past due, an unkempt apartment, a gnawing loneliness over scarce friends and lost family. Megan wrote of social workers from Connecticut's Department of Mental Retardation visiting Monroe's Hartford home to "dig him out" of trash and piles of mail scattered around his three-room apartment. "They scrubbed and scraped his kitchen counter and teased him gently about the 'science experiments' in his refrigerator. They helped him sort through the mountain of clothes—many of them too small or twenty years old—that covered his bed." Monroe sleeps, instead, on a "dusty, olive-beige bedspread that lies wrinkled on the living room floor." Sleeping in a bed brings back bad memories of life at Southbury—of being doused with cold water to wake up or of a teenage friend who died in a dormitory bed next to him. "When the social workers left, the apartment was serene, the rugs smooth, the bed clear, the kitchen tidy. T. J. should have been relieved, but he was not. 'I feel that I can't do it. They come in and they do it and then I feel like I'm supposed to do

it, but I can't. . . . No one really teach me how to do it." In the end, Monroe blames his poor housekeeping on his loneliness. "Why should I clean if no one comes?" he asks.

Loneliness throbs as a persistent unhappiness in Monroe's life. He does not curse the retardation that has made him an outcast, shunted off to an institution, and shunned by others. He is angry, however, about being given up by his mother and father. Monroe talks readily, and with deep sadness, of never having a family. It is a sense of loss, Monroe knows, that he shares with other people, not just ones with retardation who have lived in institutions.

When he was only sixteen months old, Monroe and his four-year-old brother, Raymond, were sent to live with foster parents. His foster father, however, did not welcome him, calling him "freak" and "moron." When he was six, Monroe was separated from his brother and foster family and sent to Southbury Training School.

Shortly after he arrived at Southbury, a social worker introduced him to an eleven-year-old sister he never knew he had. Peggy also lived at Southbury, then an institution of 1,700 children and adults, segregated for boys and girls. He would see her at movies on campus, and sometimes staffers would allow them to talk for a few moments or let him give Peggy a kiss and a hug. Six years later, Monroe learned about the existence of another sister, Mary Anne, after a social worker helped this oldest sibling track down her brothers and sister. (A third sister, whom none of the siblings remembered, called Monroe after reading about him in Megan's article.) Records from Southbury say that Monroe was "obsessed" with finding out anything he could about his lost family.

He had little success learning about his parents until one night in 1988 as he played video games at his favorite Hartford bar. The bar owner introduced him to a lost aunt. That night she took Monroe to another bar in Waterbury and led him to his

mother. She was distant and unexcited about this renewed contact with her son. Monroe felt let down. "I didn't kiss my mother, I didn't hug my mother. I shook hands with her," says Monroe.

A couple of weeks later, Monroe drove his sister Mary Anne back to Waterbury to meet their mother. She did not want to be seen with them and wanted them to leave quickly. She sat in the backseat of the car and told them about their father, who had abused her and had died drunk in a Waterbury alley. Now she had a new life: two children by a common-law husband. She had never told her new family about her other children. She wanted Monroe and Mary Anne to go away. "Didn't you ever wonder what happened to us?" Mary Anne asked. "No," said her mother. Confusion, hurt, and anger all bubbled up inside Monroe: "I wanted to say, 'Why not? We were your kids.'"

Self-advocacy was an import from Sweden. There the start of the movement can be precisely traced to a day in 1968 that Bengt Nirje, director of the Swedish Parents Association for Mentally Retarded Children had a routine conversation with a group of retarded young adults. Nirje was trying to develop programs to make sure that people with retardation experienced the same daily routine—working, relaxing—as anyone else. This was a simple, but then radical, concept known as normalization. Asking questions of a group of young retarded men and women, he realized they knew what they liked and disliked better than he or any of the social workers and other professionals did. From that meeting came an epiphany: that retarded people could and should have a role in their own choices.

That may seem obvious now, but at the time, psychologists argued that people with retardation could have no sense of self and therefore were incapable of making decisions. They were automatically placed in institutions, which were set up so that

doctors or other staffers could make all decisions. Those that lived at home with family relied on their mothers and fathers to make most decisions for them. Nirje realized that with support and teaching people with mental retardation could make decisions on their own. Nirje then led the creation of groups of disabled men and women, the first self-advocates, who met to discuss their choices in treatment and training. Says Dybwad, who was a key proponent of these ideas in the United States, "It was one of those occasions in history when the right man listened at the right time."

Normalization, promoted in the United States at an influential 1969 White House conference, would eventually lead to a revolution in the treatment of people with developmental disabilities. It was the philosophy behind the closing of institutions and mainstreaming people with retardation into regular schools, homes, and jobs in the community.

But it was parents and professionals who promoted normalization. It would be several more years before people with retardation began to advocate for themselves. The change dates back to November 1973, when a Canadian advocacy group for people with retardation, inspired by the first self-advocacy efforts in Sweden, held that country's first conference on how to set up such groups. The meeting took place on Vancouver Island in British Columbia.

Not too far away, in Oregon, a brochure about the conference landed on the desk of the administrator of the state's largest institution. Larry Talkington, director of Fairview Hospital and Training Center, was part of a new breed of institution directors who were carrying out state mandates to "downsize" their facilities. Talkington showed the brochure to Dennis Heath, one of his young social workers. Heath and three retarded men drove to British Columbia to check out what the Canadians were up to. Heath remembers the meeting as a flop. The social workers, teachers, and parents "stood up front and talked about how to

let people with retardation advocate" but did not let the one hundred people with retardation in the audience speak. Nevertheless, they returned to Oregon convinced that self-advocacy could be made to work. The following fall, the first state People First convention met in Oregon. Two hundred self-advocates had been expected. Some 560 showed up. There were workshops on how to get placed in the community and what to say when someone called them retarded. Most powerful was the chance to walk up to an open microphone and talk at the plenary session. "They were superstars and they were leaders," says Heath. "There's power in the microphone. Once they get the microphone, they have the power of being able to illuminate their voice to where everybody, for once, hears them. But now they had to share too, and they learned a whole new dynamic." They learned, he said, to listen, to share, to negotiate, to "disagree without getting angry."

It was during the planning of the 1974 conference, Heath recalled, that one of the pioneer self-advocates—who it was is forgotten—objected to the constant use of the words "retarded" and "handicapped." "I want to be treated like a person first," he said. From that came the group's name, People First of Oregon.

Spreading the gospel of self-advocacy was harder than those early advocates expected. It was the very beginning of deinstitutionalization efforts, and people in large facilities were not being given choices, much less the opportunity to protest and advocate. The idea of self-advocacy was still too new for people with retardation and too scary for their parents. Laws continued to restrict the right to basic choices. As late as 1980, thirty-three states still had laws prohibiting marriage by people with retardation, and not until 1974 did a U.S. District Court enjoin the federal government from providing funding for the then still-common practice of sterilization of women with retardation. Self-advocacy did not catch on in the mid-1970s.

Over the next fifteen years, however, the larger disability

rights movement began to grow. But because the increasing number of centers for independent living offered little to people with mental retardation, people with retardation were not immediately included in the larger movement. Self-advocacy, then, became an attempt to join as well as copy the growing disability rights movement.

Trends in the treatment of people with mental retardation also fueled the rise of self-advocacy. People who had grown up in institutions began moving to group homes or apartments. Children were staying at home with their families and going to mainstreamed schools. In the community, people with retardation became practiced at making their own choices. It was only a small step from learning to make their own decisions to political advocacy. There are signs of the growing influence of self-advocates. In 1992, the federal government began training the first two People First members to join teams of doctors and university researchers who do on-site review visits of programs that receive federal grants to provide services to people with mental retardation. The self-advocates, Nancy Ward of Lincoln, Nebraska, and Tia Nellis of Chicago, will not be expected to understand complicated scientific and medical work of these programs. That will be left to the academics and doctors. But the team members with retardation will judge whether the services provided are the type of thing that would help them and their friends, says Deborah McFadden of the U.S. Department of Health and Human Services, who is the woman who decided to include self-advocates. In addition, McFadden's department will provide \$1.8 million dollars between 1993 and 1996 to state advocacy programs that train either self-advocates or their parents in how to fight for services.

Still, some observers of self-advocacy, like journalist Victoria Medgyesi, are coming to believe the movement will succeed only when people with retardation join up with other disability groups and leave behind the nonretarded professionals who now

serve as their advisers. These professionals, argues Medgyesi, who wrote a handbook for self-advocates, will "never share real money, power and control." There have been a few tentative matchups between People First and ADAPT, the Denver-based disability rights group that uses civil disobedience tactics and mass arrests to fight for accessible transit and getting disabled people out of nursing homes. "I didn't know much about people with mental retardation," said ADAPT activist Stephanie Thomas after attending the second national convention of People First in 1991. "What I learned is that having mental retardation certainly doesn't mean that you're dumb." For their part, says Medgyesi, self-advocates have come away from ADAPT protests impressed to see other disabled people make their own decisions without relying on an adviser. In Tennessee, People First members, with guidance from ADAPT activists, took another step toward full independence when they sued the state to improve conditions at a state hospital. The Tennessee advocates were suing the same department of mental retardation that provided the bulk of their own monies. But after a lengthy and emotional debate about the risk to their own funding, Beth Sievers and the other self-advocates decided on their own that they had a moral responsibility to speak out.

Self-advocacy in Action

Self-advocacy has brought out wisdom and qualities of leadership from some unexpected sources. Nancy Cleaveland, the president of the People First chapter at the Southbury Training School, is such an unlikely civil rights leader. She has lived at the institution since she was nine. There, other people have always made basic decisions for her: what to eat, when to eat it, when to get up, where to live, where to work, when to watch TV, when to sleep. Even simple things that most people take for granted, like taking a shower, are regulated. Now, at fifty-two, Cleave-

land is demanding the right to make important decisions in her life. Most of all, she wants an apartment on "the outside" with her longtime boyfriend, Richard Carlson, another resident of the institution.

But the decision to leave is not Cleaveland's. It belongs to a beloved eighty-two-year-old aunt, Marion Mattoon, her only family, who is her legal conservator. Cleaveland, with Jean Bowen's help, has asked a legal service attorney to sue Mattoon for control over such decision making. To Cleaveland, it is an issue of her "right" to live with Carlson. "Nancy is being incarcerated," argues Bowen. "She is being held against her will, kept from her preferred place to live." Mattoon calls it foolishness to think that Cleaveland and Carlson can make it on their own. Her niece, she says, has been "brainwashed" by advocates and lawyers. "Everybody wants to paint the picture so rosy. But it's not rosy," says Mattoon, a retired special education teacher who taught people with retardation. She knows that a few previous attempts to move Cleaveland into a group home ended disastrously.

I returned to Connecticut two months after the People First convention to attend one of the probate court hearings that would determine Cleaveland's future. I wanted to understand the two seemingly irreconcilable images that had been painted of Cleaveland. There was the Cleaveland who was said to be easily led by others, and who, after a lifetime of retardation and institutionalization, had few of the skills needed to live successfully outside the protective confines of her cottage at Southbury. Then there was the Cleaveland who had become a stalwart self-advocate, a leader among her peers who had developed very strong ideas of what she wanted in her life. I also wanted to see Cleaveland in action, leading one of the weekly sessions of the People First chapter at Southbury Training School.

The Wednesday meeting of the People First chapter took place in the dining room of Cottage 15. A dozen advocates sat

around three dining tables as Cleaveland opened the meeting by holding up the front page of the local newspaper. It was the week after Election Day. At the previous meeting, Bowen had brought in pictures of all of the major candidates and talked a little about each one. "I did it as straightforward as I could," she said. But at the end, all of the advocates decided they would support Lowell Weicker, the independent candidate for governor. The advocates liked the fact that Weicker, as a U.S. senator, had been the first sponsor of the Americans with Disabilities Act and, partly because he has a son with Down syndrome, had been a leading supporter of disability legislation. A half-dozen of the advocates had gone into town to vote. Most, since they had limited reading skills at best, had asked for someone to help them mark their ballots. Now, ten days later, Cleaveland was holding the newspaper front page with a banner headline proclaiming, **NOW IT'S GOVERNOR WEICKER.**

"This is our new president," Cleaveland told the advocates, before Bowen, who sat next to her at the end of a table, corrected her. "I mean governor," Cleaveland said. Bowen then explained that there was a new state senator for Southbury and suggested that the advocates invite him to one of their meetings so they could voice their concerns, much as they had to his predecessor.

From there, Cleaveland took the meeting off on a rambling course. There was no set agenda, but those sitting around the table got the chance to speak up. The minutes of past meetings show that the group discussions often turn to familiar topics: moving out of Southbury, jobs, improving lighting and safety at the institution, ending the use of punishment by Southbury staff, reestablishing ties with lost family, relationships and sex. On this day, the talk turned to work and getting out of the institution. Mark, a handsome man in his thirties who had come to Southbury only a few years earlier, after sustaining a head injury, complains that his job in a sheltered workshop is boring and that he makes too little money. "I think you should speak

up for your rights," Cleaveland tells him, advising him to tell the Southbury work coordinator that he wants a different job, or to ask his parents to step in. "I don't want to ask for help. I want to take care of myself," says Mark. Carlson then explains how he "stood up for my own rights" to get his guardianship changed. Bowen notes that she helped Carlson get a lawyer and asks Mark if he, too, would like to talk to a lawyer. He agrees.

Cleaveland reported on her latest court appearance. "I came here when I was nine years old," she tells the other advocates. "I feel I need to get out with Richard in an apartment. I don't know how an apartment is gonna look. I feel Richard and I should look at it first." Then she asks Carlson to talk about what kind of apartment he wants. Carlson buries his face in his hands. "Don't be shy, honey, nobody's going to bite ya," Cleaveland coaxes.

Cleaveland is both loving and motherly toward Carlson. The two are "a very traditional couple," Bowen says. "Richard is very romantic, thoughtful and very gracious to Nancy," she adds. "Nancy's very jealous. She's protective of Richard and doesn't like other women around." She is also sentimental. Cleaveland keeps a stack of dog-eared photos of Carlson in her purse. Every night, she picks one of them to take to bed with her. Once, she saw the bedroom Richard shares with several other men at Southbury and was pleased to see that he has several pictures of her tacked to his wall by his bed.

But would the relationship between Cleaveland and Carlson flourish outside of Southbury? Cleaveland understands that living with Carlson, who is less capable than she, is fraught with risk. She has been hurt before when Carlson, who has a five-year-old child by another woman who once lived at the institution, flirted with other women. Mattoon doubts that her niece can count on Carlson.

A few of the students with mental retardation that Mattoon taught in her special education classes have married over the years. Some have even reared children. Mattoon runs into these

former students in the small town where she lives. Some have even dropped by with their spouses to visit Mattoon, in her large white wooden house on the town green. But Mattoon doubts that her niece can attain such a level of independence. Cleaveland has mild retardation. She can read simple sentences and writes letters to state representatives and social service officials in a girlish hand printing. Carlson also has mild retardation, but is less verbal than Cleaveland.

Ultimately, Mattoon worries that if living with Carlson does not work out, Cleaveland will have nowhere to go. She worries that, if Cleaveland cannot take care of herself, there will be no one to care about her after Mattoon dies. With her limited reading skills, Cleaveland, says Mattoon, goes to a restaurant and has trouble reading the menu. "She knows there's going to be a hamburger there nine times out of ten, so she orders a hamburger. Or she finds a picture on the menu and says, 'This looks good, I'll have this.' " Cleaveland copes creatively. But Mattoon sees her niece's serious limits.

Mattoon has been Cleaveland's conservator for twenty-five years. Cleaveland was sent to Southbury after her parents divorced. Her mother, Mattoon's sister, needed to work and could no longer care for her retarded daughter as well. When the mother died, Cleaveland was in her late thirties. Mattoon agreed to be Cleaveland's conservator. No other family member wanted the responsibility. It was not an easy job. Cleaveland would telephone her aunt often when she needed help with a problem at the institution—from dealing with noisy roommates to getting a job. On the decision that was most important to Cleaveland—whether she could live with Carlson—she and her aunt clashed. Cleaveland tried to explain why she thought she deserved a chance to live with Carlson, but Mattoon would not budge.

The case landed in the courtroom of Southbury Probate Court Judge Mary Kay Flaherty. From the beginning, Flaherty

was clear that Cleaveland did not need a conservator. That was an antiquated designation, once common for people with retardation but now used almost solely in cases where a person is in a coma. Cleaveland's status had never been changed, largely because the case had remained in the probate court in Mattoon's small hometown, where the judge knew Mattoon and saw no reason to challenge her control over her niece's life. Under current standards, Cleaveland should have a limited guardian, someone who would make choices only on important issues. Flaherty also had to rule on which decisions would be left to the limited guardian and which would be left to Cleaveland. Legally, the issues to be decided were: who would make her personal finance decisions? Who would decide if Cleaveland needed elective or emergency surgery? But choices such as who to live with would fall to Cleaveland.

An informal hearing took place around a conference table in the conference room next to Flaherty's office. Sitting next to Katherine Williams, her legal services lawyer, Cleaveland listened intently to the debate over her future. She leaned her elbows on the wood-and-chrome conference table, sitting forward on her chair with the tips of her toes pressing the floor. She looked younger than her age, betrayed only by a strand of gray in her short black hair. Despite the November cold, she wore a stark white cotton knit dress with a small flower print. She wore a string of costume jewelry pearls and matching earrings. Flaherty sat at the other end of the table. To her left was Diane Roy, Cleaveland's caseworker from Southbury, who, at Flaherty's request, had put together a report from a team at the institution that found Cleaveland "is functioning at the upper level of mild retardation." Williams argued that Cleaveland should be her own guardian and that she needed no limited guardian. "Part of being an adult," Williams said, "part of having control of one's life, part of having control, is being able to make your own mistakes and decisions."

Making Cleaveland's reach for independence more complicated was Mattoon's distrust of professionals who, to her, seem to jump from one fad to another. When Cleaveland was born, her mother was told it was best to put her daughter in the institution. Then there were attempts to get her into the community. The first, in the early 1960s, was a gloomy Dickensian horror. She was sent to work as a housegirl for a family in a small Connecticut city. But the family, which had promised her freedom, treated her like their indentured servant. She lived in a dank corner of the family basement, marked off by a sheet hanging on a curtain rod. Cleaveland remembers it as a painful, lonely period.

There had been a couple more recent attempts to put Cleaveland in a group home. The first was a large home, with some twenty people, where she slept in a room with several women. Rather than being comfortable like a home, it felt like just another institution to Cleaveland. The last attempt to move Cleaveland had come several years before. But there Cleaveland had a personality clash with a vindictive staffer.

These decades of stops and starts had left Cleaveland and her aunt skeptical of whatever was being hailed at the moment as the latest innovation. To Cleaveland, however, the bottom line was that she wanted out of the institution. But to her aunt, the institution had been the one constant. Although Mattoon thought it was silliness to talk about Cleaveland and Carlson living together like man and wife, she was willing to let her niece try living in a group home again. But she wanted assurances that Cleaveland would be allowed back to Southbury if the arrangement went awry.

Thomas Howley, Southbury's director, was not prepared to give Mattoon that guarantee. For one thing, the current policy of the state Department of Mental Retardation was to move as many people as possible into the community, and Southbury was slowly but steadily decreasing its numbers. A long-term state

plan called for reducing Southbury's population from 968 residents to 320 within twenty years. If Cleaveland left and her placement did not work, Southbury would take her back within "a reasonable length of time," a few months, for example, but not after, say, two years. Said Howley, "Once you've been out awhile, to come back is just as traumatic as it was at first to leave." This was not good enough for Mattoon, who wanted Southbury to be a guaranteed safety net. "Southbury has been good to her," she said. "Where else would she be? There's no other place for her to go."

By law, Cleaveland could not be moved into the community unless her move was carefully planned, with her input. She would go to a supervised group home or apartment. There would always be someone, a social worker and service providers, monitoring her. Almost certainly, someone would be living with Cleaveland, possibly on a twenty-four-hour basis, and at least several hours a day. She would be provided with work.

In the end, it was Cleaveland who steered a commonsense middle ground. She understood that there was risk if she and Carlson left Southbury together. It was Cleaveland who ultimately decided that she wanted to start out by living in a group home with Carlson and other men and women, or to have Carlson in a separate residence nearby. That way they could have their "privacy" but also time to work out being together. Finally Flaherty agreed, making Cleaveland her own limited guardian. Cleaveland turned down her first chance to live with Carlson in an apartment in Danbury, because it was far away from her aunt and Carlson's mother. It would take nearly a year to find a place that fit what Cleaveland and Carlson wanted. First Carlson moved out to live with a family near Danbury. Then Cleaveland moved to a similar house nearby. The move gave her new self-confidence. She loved her new job in a cafeteria. She called

Richard on the phone every day and was pleased when tensions eased with her aunt, whom she would once again call for advice. Eventually, Cleaveland and Carlson ended their relationship, which was doomed by distance. Cleaveland, however, thrived on her own.

Speaking for Yourself

Television has trained a generation of self-advocates. Walk into any group home or institution and a television screen is almost certain to be flickering. "These people now listen and see television. And there they get an introduction to civil and governmental affairs that you never had when you were a boy," says Dybwad. "They have time to listen. They know a lot about local politics. They hear the local political dialogue. They know how to express themselves because they learn it on television. You have to put this in consideration to understand why this movement is so effective today." David Beem, who ran for city council in Salem, Oregon, in 1988—collecting only a few hundred votes but getting national attention and an endorsement from civil rights leader Jesse Jackson—got little education during the ten years he lived in a state institution. "I didn't know that much about reading and writing so I watched TV and watched politics," he explained.

Television changed T. J. Monroe's life. It was from the tube that Monroe first made the connection between disability and rights. His inspiration: Raymond Burr from reruns of the old "Ironsides" series. "He got shot and was in a wheelchair and everybody wanted to feel sorry for him," Monroe explains. "But Ironsides did not want to be pitied. He wanted to do everything for his own. That popped something in my head." The Burr character, Monroe says, "would fight for a lot of people's rights. I decided to open up my eyes."

Another insightful self-advocate, Tom Hopkins, devotedly

watches the current affairs and cultural offerings of the Public Broadcasting System. Hopkins, a leader of Capitol People First of Sacramento, told me about watching a PBS show a few nights before. The documentary had tried to answer why the high school dropout rate was so high among Hispanics and blacks. "One expert who was interviewed said that teachers had low expectations of Hispanic and black students," Hopkins explained. "They didn't think they would learn. So they didn't teach them much. As a result, they failed and dropped out. And I was thinking, that's the way it was with me as a retarded person. People didn't think I could learn, so nobody taught me anything useful."

Hopkins graduated from high school with minimal skills in writing and reading. He went to a sheltered workshop run by some local charities, where he hoped he would learn carpentry skills. Instead, he was paid a piece rate for occasional tasks. (He has no concept of how much he was paid. "I think it was forty dollars an hour," he says. It was forty cents an hour.) He counted screws into small plastic envelopes. Other times he folded fiberglass insulation and would go home "itching like crazy." But most of the time there would be no work at all and Hopkins would sit around with the other men and play cards. "I became the greatest solitaire player the world's ever seen. I didn't learn diddly," says Hopkins. "It was day care for grown-ups. That's all it was."

After four and a half years and never being taught carpentry skills as he had been promised, Hopkins quit. "I got involved in People First and found out I wasn't the only one getting shafted. The system was set up to demean us, to exploit us and to treat us like slaves," he explained. "The workshop was segregated from society. Why were we separated? How come we were in the boonies? Other people worked downtown. How come we can't fraternize with other [nondisabled] people?" Hopkins talks about the social service system

as a "retarding environment" that does more to hold him back than his own mental limitations.

In 1985, Hopkins and one of his fellow advocates, Sandra Jensen, met then Vice President George Bush. What was supposed to be a two-minute picture-taking session in the vice president's office turned into a thirty-minute discussion of their self-advocacy activities. Hopkins talked thoughtfully about his disappointment in the sheltered workshop. Jensen, a woman with Down syndrome, spoke emotionally of how her parents had been told that, with an IQ of 30, she would never be able to live anywhere but in an institution, but now she lived on her own. Says disability rights activist Evan Kemp, who was present at the meeting, of Bush: "He never had his preconceptions about any group turned upside down so quickly."

A few years later, Bush got another explanation of self-advocacy, during the signing ceremony for the ADA bill, when T. J. Monroe self-assuredly walked up and presented him with a carefully printed letter. The president thanked Monroe, put the letter in his inside jacket pocket, and promised to read it later.

"Dear Mr. President," Monroe's letter began. "I am writing to you about self-advocacy. My name is T. J. Monroe. I am president of People First in Connecticut. What is a self-advocate? Self-advocate means knowing your rights and responsibilities. Self-advocate means standing up for your own rights. Self-advocate means speak for yourself and make your own decisions, being more independent, standing on your own two feet and sticking up for your rights as a self-advocate.

"We have to be happy. We are as good as any other person. Speak up and let other disabilities know we can help other people to grow and stand together on our big issues. People with disability can work hard for things they know are good for them."

"Sincerely,

"T. J. Monroe"

In 1993, Monroe took yet another step toward independence, leaving Connecticut, where he lived his entire life, to move to Knoxville to take a job organizing self-advocacy chapters for People First of Tennessee. "I'm on the other side of the desk. I'm a boss," said Monroe, noting that he was now a full-time professional community organizer, no longer simply a volunteer one. "I am still thunder. I make people think."

CHAPTER 7

THE SCREAMING NEON WHEELCHAIR

The story of the disability rights movement could be written about Marilyn Hamilton's impatience. It would start the summer day in 1978 when Hamilton crashed her hang glider nose down into the side of a California mountain. Her spinal cord was bruised and Hamilton became a paraplegic—a very impatient paraplegic.

Hamilton zipped through rehabilitative therapy in three weeks. Most people take at least three months. Then she was impatient with the bulky wheelchair—"a stainless steel dinosaur," she called it—that her physical therapist ordered for her. Hamilton loved sports but the wheelchair was too heavy to get back out on the tennis court. So Hamilton sought out her friends and fellow glider pilots Don Helman and Jim Okamoto. They had begun designing hang gliders from a shed on the farm near Fresno owned by Helman's parents. Build me an ultralight wheelchair, Hamilton asked them, out of the aluminum tubing you put in your gliders.

What they designed was light and sturdy, weighing twenty-six pounds compared to the standard fifty-pound wheelchair. It had a stunning geometry. Instead of being big and boxy like other wheelchairs, Hamilton's sky blue wheelchair was sleek and sporty, with a low-slung back and compact frame that looked as if it belonged to a multispeed racing bicycle. It was such an improvement over traditional chairs that Hamilton, Helman, and Okamoto went into the wheelchair-manufacturing business. They started selling their Quickie wheelchairs as fast as they could turn them out.

From the beginning, Hamilton had hated the "weird" way people acted around her in her first stainless steel wheelchair. "I knew I was the same as always," she says. "I just got around by a different means of transportation." But the gleaming hospital-issue wheelchair scared people, putting up a chromium wall of discomfort between her and the world. Even her doctor addressed himself to her husband, as if she were helpless or not even present. Friends saw her sitting in a wheelchair and their faces would cloud up, putting Hamilton in the odd position of always being perky and bright, the one to cheer them up.

Hamilton's wheelchairs put people—users and those around them—at ease. Instead of chrome, Hamilton's chairs came in a rainbow of hot colors. The customer could personalize a chair in candy apple red, canary yellow, or electric green. Hot pink was added at a user's request. "Screaming neon chairs," Hamilton called them. A Quickie chair was fun, refuting the idea that the user was an invalid. (Quickie's biggest competitor today is Invacare, a name that is an abbreviation for "invalid care.") Quickie chair riders were neither sick nor objects of pity. They just got around a different way. "If you can't stand up," Hamilton likes to say, "stand out."

Hamilton's proud chairs struck a chord with the emerging disability rights movement. For one thing, there were more wheelchair users, up from half a million in 1960 to 1.2 million

by 1980, most of whom were no longer living in nursing homes or institutions as they had been just a couple of decades before. This new generation of wheelchair users was newly politicized and wanted maximum independence. They were demanding curb cuts, lifts on buses, and handicapped parking spaces. They had come to expect that they would go to college, take jobs, get married, and sometimes even start families.

Hamilton's brightly colored chairs tapped into this growing sense that there was no shame in being disabled. In a world where the workplace was often closed to a paraplegic and buildings were still inaccessible to a wheelchair, Hamilton's stylish product reassuringly said it was okay, it could even be cool, to be in a wheelchair. Even the double entendre of the wheelchair's name, Quickie ("You need a Quickie," goes one company advertising slogan) was a lighthearted mocking of the pitying "walkies," the rest of the world, who seemed to automatically assume that the loss of the use of one's legs must also mean the end of a sex life. Or that paralysis meant the end of a life worth living.

Hamilton had reinvented the wheelchair. She took a piece of medical equipment and made it fun and sporty. She took the universal symbol of sickness and turned it into a symbol of disability self-pride.

It was Hamilton's uncle who made her understand how a wheelchair represented her liberation. Bill Hamilton was a quadriplegic. When he was a high school student, Bill was thrown from a Model T Ford. His neck snapped on the hard road. Quadriplegics almost never lived in those days between the world wars. Rehabilitative medicine was just developing in a crude form in response to the return of paralyzed war veterans.

The wood-and-wicker wheelchairs then were rigid and rectangular, with high backs. They were too wide to get through most doors, a reflection of the fact that most disabled people then were considered useless members of society. Wheelchairs were made for people who were closeted at home or who lived

in institutions. Weighing ninety pounds, Bill's first wheelchair was too heavy to move far by himself. Wheelchairs then were still largely for those rich enough to afford to hire someone to push the cumbersome contrivances. The Hamiltons had the means to hire two attendants for Bill, who assisted him twenty-four hours a day. He went to college and law school in Los Angeles; then he returned home to oversee the expansion of the family orchard, successfully organizing other San Joaquin grape and fruit tree farmers. So, aware of how his family's support had allowed him to succeed as a disabled man, Bill Hamilton also welcomed this niece by marriage into the family fruit brokerage. The trade newspapers wrote about the "crippled" uncle and niece selling fruit out in California. Marilyn would work with Bill during the fruit season and spend several months each year traveling to events on the disabled tennis circuit, where she was an emerging star, thanks in part to her lightweight chair. The exposure the Quickie chairs got in the wheelchair sports world helped her new business thrive.

Wheelchair athletes—a community known for cleverly modifying chairs in search of a competitive edge—were the first to want a copy of Hamilton's featherweight wheelchair. Sales skyrocketed once a folding version of the Quickie was introduced in 1984. Then people wanted the chair not just for sports but for everyday use. Its lightness was liberating. It was light enough for a rider to wheel up to the driver's seat of a car, jump in, and then, unaided, fold the chair, pick it up with ease, and store it in the backseat. Within ten years, Quickie would grow into a \$40-million-a-year business and relocate to a 150,000-square-foot facility. Purchased by Sunrise Medical, a large medical equipment company, in 1986, Quickie's lightweight chairs were imitated by all other wheelchair companies.

To appreciate how the revolution in wheelchair design was tied to the revolution in disabled people's self-image, it helps to know some wheelchair history: A man who became a paraplegic

in a 1918 mining accident sought out a friend in California, an engineer, and asked him to design a lightweight wheelchair. In 1932, the engineer built one that could be folded and put in the back of a car. It was such an improvement over existing chairs that the two men started a wheelchair manufacturing firm. Together, Herbert Everest, the paraplegic, and Harry Jennings, Sr., his mechanical engineer friend, revolutionized wheelchair design, cutting the weight of a wheelchair from ninety pounds to fifty pounds. Their company, Everest & Jennings, dominated the wheelchair market for the next fifty years.

It is 1991, and Barre Rorabaugh, the new president and chief executive officer of Everest & Jennings, is sitting in his spacious office in Camarillo, California, late on a Friday evening. His wall-to-wall windows look out over the Ventura Freeway, an aquarium of colorful cars whizzing past, headed off for the weekend. E & J has hit on hard times, and Rorabaugh, a corporate turnaround specialist, is talking about how he plans to return the company from the brink of bankruptcy. E & J had lost over \$88 million the previous two years and laid off one-third of its local employees. Rorabaugh is retelling the story of the paraplegic who asked an inventor friend to design a lighter chair and how their creation revolutionized the wheelchair and led to the establishment of the hottest wheelchair company in America. Rorabaugh speaks in respectful tones. He could be relating E & J's proud story, but he is talking about Marilyn Hamilton. He is talking about how he will turn around E & J by learning from Hamilton's success: he will listen to consumers; he will seek to dominate the lucrative lightweight market with a new generation of wheelchairs made of even lighter plastic composites. (In 1992, after Rorabaugh brought back E & J from the brink of insolvency, the company was sold and moved to St. Louis for a fresh start.)

E & J lost its edge because the company got smug and stopped paying attention to what people in wheelchairs wanted,

says Cliff Crase, editor of *Sports 'n Spokes*, a magazine for wheelchair athletes. In the late 1970s, the Justice Department brought an antitrust suit, later settled, charging E & J with monopoly practices that set prices of wheelchairs artificially high and squelched competition and innovation from other companies. "People would suggest a change, something like a lightweight chair, and E & J would say, 'Fine, make it yourself,' " says Crase. Even when Quickie came out with its revolutionary chair, it took E & J several years even to enter the lightweight market. By that time, Quickie and other companies were battling for this fastest-growing share of the wheelchair market.

By the 1980s, the company that had made wheelchairs for FDR and Churchill, shahs and sheiks, no longer had strong disabled managers at the top to advise them. E & J missed the rise of a newly independent generation of wheelchair users who, with new jobs and less dependent on welfare, were emerging as a powerful consumer group. In some ways, it was easy to overlook this consumer uprising. Unlike virtually every other product, wheelchairs are not sold directly to users. Instead, they are marketed through occupational and physical therapists and medical supply dealers who recommend them to disabled clients and customers. But Quickie understood that, to make its mark, it had to reach beyond these usually nondisabled professionals and speak to the growingly self-sufficient wheelchair users. Their product brochures showed their chairs being used by active people, who were pictured at the office, on the basketball court, on the dance floor, and in wedding chapels. The E & J sales material, until recently, kept to the tradition of picturing their chairs in hospital rooms.

Another Hamilton accident, twelve years after the hang-glider crash, may lead to the next liberating design breakthrough: a lightweight power wheelchair. Broad-sided by a driver in November 1990, Hamilton's wrists and legs were broken in her crushed car. Within forty-eight hours, Okamoto had built

a streamlined power wheelchair. He simply rigged a motor to one of Hamilton's sportiest lightweight wheelchairs. At first, Hamilton was ashamed to be seen in a power chair. It suggested that her disability was more serious than before, even though her dependence on the power chair was only temporary. But during her three-month convalescence at home, she quickly came to appreciate the freedom it delivered.

There will be great profits for the wheelchair maker who can make an affordable power wheelchair light enough to be lifted. Today's models—which run on an acid battery, like a car, or are electrically charged—weigh hundreds of pounds. They cannot be folded or lifted into the back of a car. They are bulky, look institutional, and maneuver clumsily. They are slow on hills and lack the ability to speed up across the street when the traffic light turns yellow. Manufacturers have been slow to respond to consumer demands, says disability activist and wheelchair aficionado Mary Lou Breslin, because they fear legal liability if faster, forceful power wheelchairs lead to more accidents. But power-chair users for years have souped up their own by adding a second battery to double the voltage and with other modifications. Seeking to solve the riddle of how to build one that is light, stylish, fast, and powerful but not too expensive, the company now called Motion Designs/Quickie hopes to score with a version of Okamoto's prototype. It also hired Gordon Stout, a Berkeley inventor legendary for a handful of models he made in the 1970s that were designed more after cars than traditional push wheelchairs. California has been the fertile base of wheelchair innovation, due to the state's openness to new ideas, toleration of eccentrics, and clear, sunny weather that makes wheelchair use easy. But also in the hunt is Ohio-based Invacare, now the country's top-ranked wheelchair maker and the leading seller of power wheelchairs. Everest & Jennings, once the market leader (and the originators of the folding wheelchair), has continued to develop its power line, even while it paid a

heavy price for failing to acknowledge the lightweight market until too late.

Hamilton's own understanding of the changing world of wheelchair users has paid off handsomely. She lives a good life now, validated by the little "presents" she has bought for herself: the ultrapowered red sports car with a ten-disc compact disc player, a vacation spot big enough for fourteen family members to spend Christmas, and a new house of glass and steel so unconventional that she had to find a commercial builder to construct it. (She and her husband divorced, more due to her emergence as an entrepreneur than for problems resulting from her injury.) Hamilton spends weekends at a soaring stone-and-wood-beam condominium on the top of a Sierra mountain ski resort, where she is a familiar figure on the slopes with her specially designed sitting ski device. The condominium with its elevator is wheelchair accessible, unlike the homes of her family members. So she invites everyone to spend weekends and Christmas with her there.

On the way to the resort and back, the road winds past Tollhouse Mountain, the scene of her hang-gliding accident. Its peak rises arrogantly in the distance. But she speaks openly of the accident. For the first five years after the injury, Hamilton was convinced she would walk again. At first, she mastered a way to take "steps." Putting all her weight on a short leg brace, she would plant one foot, then throw the opposite hip to send the other leg swinging forward, repeating the painful process, literally a form of self-torture, for hours during morning physical therapy sessions. Even today, when she dreams, she is not in a wheelchair.

It is not uncommon for paraplegics to believe they will walk again, despite all evidence to the contrary. It is a way to hide from the stigma of disability. There are daily reminders of the shame of not walking—from telethons seeking to cure "crippling" paralysis so that pitiable poster children can take steps

again to inaccessible homes, stores, offices, and buses that admit only those who can walk. But today, years after her disabling accident, the woman too impatient ever to take no for an answer finally accepts the fact that she will never walk again. It is only right that Marilyn Hamilton, who took the stigma out of using a wheelchair, should be so at peace.

Assistive Technology

Hamilton's Quickies are proof that, in disabled people's quest for independence, technology can be the great liberator, by making physical and even mental limitations largely irrelevant. A wheelchair is freeing, not confining (the reason many users hate to be described as "wheelchair-bound" or "confined to a wheelchair"). It is a device that supplements lost leg muscle exactly as eyeglasses replace lost vision. The right "assistive device" can turn passive patients into independent consumers, able to go to school, work, rear families, and live on their own.

Machines now speak for the voiceless, see for the sightless, and move and touch for those who cannot move their own muscles. The late Stanford University professor Cal Pava was able to resume a career as a highly regarded teacher after brain surgery to remove a tumor wiped out his memory of how to read. Instead, he learned to use a Kurzweil Reader, a machine that scans printed text and reads it aloud with a voice synthesizer. Technology helped rhythm and blues singer Teddy Pendergrass work again, too. When an automobile accident left him a quadriplegic, he learned to use similar voice-activated computer technology to compose music.

High school student Stacy Bibb is unable to talk as a result of cerebral palsy, but he can control his tongue. A wireless transmitter was fitted into the roof of his mouth, like an orthodontic retainer. With his tongue, Bibb presses buttons on the retainer, which emit a radio signal that is picked up by a control-

ler box. That way, he writes out messages on a computer, which then speaks for him. He can also turn the television or the room lights on and off with this system. The technology allowed Bibb to communicate with classmates at school and promised a lifetime of unexpected independence. Machines can break down the natural walls of discomfort. Alan Brightman of Apple Computer tells how the world opened up to another young boy who was unable to talk until a \$99 voice synthesizer was mounted on his wheelchair. "The other kids had no incentive to get to know him. But with an inexpensive speech synthesizer, he can tell a joke out loud and the whole dynamic changes," said Brightman. Not only did classmates interact with him but teachers expected more of him, too.

Such marvelous breakthroughs are coming at an astoundingly rapid pace. Some devices are simple, others futuristic. Computers have led the revolution. Hundreds of companies, from computer giants to attic inventors, have produced thousands of software and hardware aids that can mitigate the problems posed by even the most severe physical disability. There are computer monitors with magnified, large-type letters; keyboards with oversized keypads; and printers that print in Braille. Someone unable to grip a pen and write can use a computer. If fingers lack the muscles to type, a computer key can be struck with a mouthstick clenched between the teeth or with a headstick strapped to the forehead. There are light-sensitive keyboards, too, which can be stroked, not by a finger but with an infrared beam strapped to the typist's head. The light from the beam, instead of a finger's touch, engages the key.

More sophisticated are several versions of eye-gaze computer systems, in which a user can stroke a key simply by looking at it. The technology, originally created for Israeli and U.S. jet fighter pilots, was a godsend to people with severe disabilities who do not have the muscle control to use a keyboard. An even more sophisticated twist on the eye-gaze system involves im-

planting tiny electrodes in the scalp that determine where that person is gazing by tracking brain waves. This device was first used by an Oregon doctor with amyotrophic lateral sclerosis (ALS), a degenerative nerve condition better known as Lou Gehrig's disease, who was then able to resume part of his medical practice.

Equally amazing are computers combined with robots. Computer programmer Jeff Doran, a quadriplegic who cannot move even his head, instead uses his voice to control a computerized PRAB Command work station programmed to respond to the sound of his voice. With a few basic voice commands—that take as much time as the keystrokes his colleagues use to operate their computer terminals—Doran can make his computer and robotic arm do virtually anything his coworkers at Boeing in Seattle can do, including pick up a can of soda or take down a ten-pound book from a shelf. Says Walt Weisel of PRAB Command, the Michigan robotics firm that developed the system, "If you or I saw a person in a corner with no legs, we would know automatically to get that person a wheelchair. I want people to see this system as an extension of a broken body. If a person can't move, but can still talk and has a good brain, then this is something we should get for them."

Such technology will revolutionize the workplace, predicts Rachel Cox of the Seattle Resource Center for the Handicapped. "Now it's not surprising to see a black or a woman in a high business position. In the nineties, we hope that it won't be a big deal to see a quadriplegic near the top of a Fortune 500 company," says Cox, who trains disabled workers to use new devices. "And it's technology that will have made it possible."

Some such instruments are highly expensive. Jeff Doran's system cost close to \$50,000, which Boeing was willing to pay as a codeveloper of the technology. But the devices with the most promise to create a space-age workplace are those that will be affordable or, even if expensive, are useful to all workers, not

just a handful of disabled ones. For example, computer companies are perfecting machines like Doran's that can recognize speech and transcribe dictation. A device invented to meet the needs of severely disabled workers may one day be a fantastic convenience for all. In the workplace of the future, computers that transcribe dictation may make the keyboard, and even typists, obsolete.

With prostheses, too, there are awe-inspiring wonders. New plastics have made artificial legs, feet, and arms stronger, more flexible, and, most important, more comfortable to wear. Today's prosthetic gloves are far more realistic than metal hooks, which can be off-putting, and refined enough to pick up a piece of paper off a desk top. Inventor John Sabolich has created a system that when placed in the sole of a prosthetic foot can pick up the bioelectrical signals from the wearer's remaining muscles and send these impulses to the brain, as if they were coming from the natural foot. It is a trick on the brain, but it enables an amputee's foot to sense when it is stepping on a stone. Chuck Thiemann, who lost his right leg after touching a live electrical wire, uses the Sense-of-Feel (SOF) System to play softball, and he can run and even slide into base. A similar myoelectric arm can pick up signals from a wearer's skin surface and then amplify them 300,000 times to control a prosthetic glove. Right now, such systems are experimental, expensive, and consequently available to a few. But "one does not have to have been a fan of television's 'The Six Million Dollar Man' or 'The Bionic Woman,' " says sociologist Irving Kenneth Zola, "to realize that we are entering an era where almost every human body part and function becomes replaceable, or, at least, assistable by some technical device."

Disabled athletes helped propel such advances, just as they did wheelchair designs. Today there are so many types of prosthetic legs and feet that athletes change them for different activities, just the way other athletes wear different shoes for

different sports. Amputee Jim MacLaren, a professional triathlete, used to use one artificial leg for the biking events and then put on another for the running segment. Now a new prosthetic ankle allows him, within seconds, to move the same foot from a walking position to an extended swimming position or to a free-flex position for rowing or skiing. The device was designed by Albert Rappoport, a California prosthetist who lost a leg to cancer, and Mike Ross, who lost both legs in a boating accident. Paraplegic engineer Peter Axelson has taken the concept of a prosthesis further to build sports equipment. His monoski is a prosthetic ski. Its hinged, fiberglass seat, custom molded to fit the skier's body, is attached to a ski on a springed aluminum frame. This allows the skier to shift weight with his upper body to ski. Axelson, who has been timed at sixty miles per hour downhill, used his invention to win the gold medal at the first World Disabled Skiing Championships in Sweden. He has also designed a cross-country skiing device and a "dance orthosis."

A False Cure

Faith in technology can play into the hated images of cure and pity that the disability rights movement has sought to erase. No two devices have held the public and the media more in awe than the Functional Electronic Stimulator (FES) and the cochlear implant. FES, which has been featured in breathless reports on CBS's "60 Minutes," ABC's "World of Discovery," and other television shows, promises to let paraplegics stand up and walk again. Cochlear implants, similarly hailed in numerous newspaper features, promise to let the profoundly deaf hear sounds, speech, and music. The realities are often less rosy.

To some, cochlear implants are a miracle. To others, they are an instrument of cultural murder. That such an advanced device can be held in such disparate regard shows the depth of the

qualms over assistive technology's power. The clever hearing technology implants a tiny computerized hearing aid into one of the ducts of the cochlea, the spiral-shaped section of the inner ear that contains the auditory nerve endings. The implanted electrodes electrically stimulate the damaged nerves and then send the vibrations to the brain, which interprets the sound to give hearing. Thousands of profoundly deaf adults and children are thankful to have hearing restored with the implant.

But the device is called a form of "genocide" by many deaf people. While hearing people usually think there is something regrettable in deafness, many deaf people abhor the operation as suggesting that deafness is a pathology, something to be corrected or eliminated. It is as threatening as Alexander Graham Bell's eugenicist recommendation to stop the genetically deaf from marrying. Instead, critics of the cochlear implant say, deafness is an identity to be adopted with pride. Tellingly, in England the sign language symbol used for cochlear implant is the same one as "to kill." When the Food and Drug Administration approved the implant for children in 1990, five years after it had been permitted for adults, the National Association of the Deaf condemned it as "invasive surgery upon defenseless children." The advocacy group recommended a ban on the operation in children, so they could grow up and then decide to choose a deaf identity or a hearing one.

Despite all the hype, the cochlear implant is an imperfect operation of limited benefit. The device and surgery are expensive, costing \$20,000 to \$40,000. Wearers hear an imperfect version of sound, making others' voices sound like the scratchy talk of Donald Duck. Fewer than 1 percent of the 22 million Americans with hearing impairments can benefit from the operation.

FES is part of an expensive long-term research venture to re-create the act of walking. Scientists from Case Western Reserve University and the Department of Veterans Affairs are

seeking to unlock the precise movement sequence of some nineteen interacting leg muscles involved in walking. When some fifty electrodes are implanted or attached externally to a paraplegic's legs, a computer can be activated to generate an electrical impulse that, in the correct sequence, jolts damaged muscles. The result is a jerky, torturous version of walking, in which the test subject holds on to a walker to keep his balance. Despite progress made on the system, it may never prove practical beyond the walls of a laboratory. Unlike nature, the artificial machine overstimulates muscles, leaving users exhausted even after short distances. Yet FES technology continues to fascinate a society that equates using a wheelchair with tragedy.

To wheelchair innovator Ralf Hotchkiss, FES is an impractical folly. It unrealistically buys into the Hollywood fantasy version of spinal cord injury: that with enough determination and pluck, the person with a spinal cord injury will overcome paraplegia and one day walk again. Better, argues Hotchkiss, would be to take the money spent on FES research and study ways to build better wheelchairs or to replace architectural barriers. These are low-tech fixes and not nearly as sexy to a high-tech-adoring society as a machine that proposes to make people stand up and walk, but there is more bang for the buck, Hotchkiss argues, in low-tech solutions for the nation's 450,000 paraplegics, quadriplegics, and those with muscular and neurological diseases such as multiple sclerosis.

Hotchkiss has proven with his own inventions the utility of simple design. He has invented a wheelchair that can be reproduced cheaply with simple tools and materials available in even the most impoverished Third World country. On a 1980 trip to Nicaragua, Hotchkiss, a paraplegic as a result of a college motorcycle accident, found there was an acute shortage of wheelchairs for the Central American nation's war casualties. At a rehabilitation hospital, three or four men shared one broken-down wheelchair. It would cost millions of dollars to set up a wheelchair

factory like Hamilton's Quickie plant, and the new lightweights that so benefited American wheelchair users would be too expensive and not durable enough for use in poor countries where the terrain is rugged and there are few sidewalks, much less curbs cuts. So Hotchkiss came up with a sturdy design that could be replicated in small, local workshops by anyone with the tools to bang out a dented fender. Each chair costs about \$250-\$300, compared to the \$1,000 sticker price on comparable factory-built models.

Hotchkiss, who won a 1989 MacArthur Foundation "genius" award, has traveled from Sri Lanka to Siberia, setting up workshops in remote corners of the world. Scores of Third World and American students have enrolled in the Third World wheelchair construction class he now teaches at San Francisco State University. Many, like Dwight Johnson, a retired IBM engineer, and his wife, Vivian, then go overseas to spread the Hotchkiss method.

Reliance on technology can be risky. Machines can close off worlds to disabled people just as quickly as they can open them. Not until nearly one hundred years after the telephone's invention, for example, would deaf people begin to overcome the technology gap it created; in 1964 Robert Weitbrecht, a deaf American scientist, invented the TDD, or telecommunications device for the deaf (sometimes also referred to by its original name, TTY, or teletypewriter). But even then, TDD owners could talk only to people who also had the machine. They remained isolated from everyone else. The first relay system was a short-lived operation. The idea was to create a central operator who could take a TDD message from one party and then translate it by voice to a second party, or vice versa. A St. Louis family, working out of their home, set it up in 1969, charging a flat fee of \$2 per month. But the operation was so overwhelmed by demand that it was forced to shut down within six months. Some thirty states set

up relay networks of their own before 1993, when under the Americans with Disabilities Act, such a relay system became required on a national basis. For the first time, people with speech and hearing impairments were guaranteed full access to the telephone, from the ability to call an emergency 911 number to the right to order a pizza.

Technology can threaten once again to isolate deaf people and others with disabilities, warns Deborah Kaplan of the World Institute on Disability. Emerging devices are often incompatible with existing ones, in effect erecting "electronic sidewalks," she says, that close off technology as surely as a sidewalk with no curb cuts limits the access of a wheelchair user. A new design in telephones suddenly made hearing aids incompatible with the new phones, so hearing aids could not pick up the sounds on those new models. It took an act of Congress in 1989 to create "an electronic curb cut," notes technology consultant Jay Brill, to force telephone manufacturers to include both the old and new systems in their phones.

For 13 million people with blindness and low vision, reliance upon technology has created an epidemic of illiteracy. The invention of tape recorders and then computers with voice synthesizers that can read a printed page have been great aids in educating blind students. But the result of reliance on such devices is that few people with visual handicaps bothered to learn Braille. Today, only 12 percent of visually handicapped students read Braille, far below the nearly 50 percent in 1965, according to the American Printing House for the Blind. And there is an acute shortage of teachers trained to teach the system of reading the raised dots that was invented in 1829 by blind Frenchman Louis Braille.

Today, many blind people and educators of the blind consider Braille obsolete. But some blind adults, like Kenneth Silberman, an administrator at the Goddard Space Flight Center in Maryland, are rethinking their failure to learn it. Silberman

needed to know how to read to keep up with the increasingly technical field of aerospace engineering. It was impractical to play back a tape recorder to find the information he had dictated to himself. It became impossible to carry off his old trick of memorizing what he needed, as "the work was getting steadily more sophisticated." Learning Braille, he says, allowed him to stay in a technical job rather than quitting work and living on Social Security disability benefits.

Literacy proposals have split the blind community. As usual with such disputes in the disability community, this is not just a fight over education but over rights. The National Federation of the Blind, a strong rights advocacy group whose officials are all blind, is pushing for state laws to require all legally blind students to be taught Braille. Marc Mauer of the Federation says they need to know how to use written words in order to get good jobs and notes that 70 percent of working-age blind adults are unemployed.

Other groups that represent blind people, however, say it is often inappropriate to teach Braille, since 85 percent of legally blind persons have some useful residual vision and can read large type. These groups, like the American Foundation of the Blind, are run largely by people without visual handicaps or, like the American Council of the Blind, by a combination of disabled and nondisabled officials. Susan Spungin of the American Foundation for the Blind speaks of her "amazement" the first time she saw a legally blind child "reading, by sight and not touch, the white Braille dots on the white paper." Mauer, however, notes that some forms of blindness, like retinitis pigmentosa, are progressive, and the student who can read large type today may have no vision tomorrow. Those who refuse to learn Braille, he says, are often ashamed, because of the stigma of being disabled, to admit the extent of their visual limitation. Dick Edlung, a state representative who sponsored a successful mandatory Braille bill in Kansas—one of five states to have one—says the

most resistance came from parents. "A lot of parents don't want to have a blind kid," says Edlung.

Yet just as technology once threatened to make Braille obsolete, it may now turn the tide and launch a Braille revival. Inexpensive Braille printers and computer programs that translate print into Braille have made it easier than ever to get a wide variety of texts in Braille, including complex technical or scientific material. In some cities, even the daily newspaper can be translated into Braille by calling a computer bulletin board and downloading articles into one's home computer.

Random Access

The hardest part of the technology puzzle has been simply to get new devices to the people who need them. Making the technological breakthroughs—what would logically be the hard part—has proceeded at a brisk pace. Making those devices available—which should have been the easy step—remains the barrier. "It's cruel," says Dr. Barbara Boardman, who studied assistive devices for the congressional Office of Technology Assessment. "We hold out technology to people as a little shimmering dream and then we don't deliver."

British physicist Stephen Hawking is the shining example of how technology can dramatically improve the lives of people with disabilities. Bob Magee, a retired U.S. Air Force photographer when I first wrote about him was, unfortunately, more the rule.

Both Hawking and Magee were battling amyotrophic lateral sclerosis (ALS). Both men had lost the ability to speak or walk. Hawking's story is fairly well known by now. Widely considered the world's most brilliant theoretical physicist since Albert Einstein, Hawking does his talking—even conducting seminars at Cambridge University—through a computerized voice synthesizer. He picks out words on a computer screen, and an electronic voice "speaks" what he writes. This high-tech wizardry allows

Hawking to continue probing his theories of the universe and black holes, work his peers expect will one day win him a Nobel Prize for physics. Says Hawking in *A Brief History of Time*, his nonfiction surprise best-seller: "This system has made all the difference."

In the United States, Magee of West Valley City, Utah, could not get the computer that had proved so liberating to Hawking. Instead, Magee's days were spent in a nursing home bed. His wife, Claudia, had fashioned a crude device for communicating—a lined, green piece of writing paper, like what an elementary school child uses to practice his letters, with the alphabet written out in large block letters. Claudia would point to each letter until Bob blinked his eyes or gave a jerking shake of his head for "yes," eventually spelling out words and sentences. In this protracted way, Bob could get across a few basic needs and feelings. Often these sessions would end with Claudia and Bob crying in frustration. After one struggle to make himself understood, Bob painstakingly spelled out, "I feel like I'm living in a coffin. I want to die."

Developing a technology is one thing, but for those who need it, affording it is quite another. Hawking could purchase his system because he makes enough money and companies donated the software to the famous man. Claudia Magee priced a computer talking system for her husband that would have allowed him to operate the computer by moving his head to aim an infrared beam at a keyboard. At \$4,500, the system was out of reach for the Magees. They had been living comfortably before Bob's illness, diagnosed in 1986, forced him to retire as an industrial photographer for the U.S. Air Force. Claudia quit her job as a company credit manager to take care of Bob. The costs of long-term care quickly ate up the \$17,000 nest egg they had put aside for vacations and emergencies. The couple quickly went into debt, with an endless stream of medical bills looming long into the future. "I can deal with the disease. But what I hate

most is that Bob can't talk," said Claudia. "I would dearly love to talk to him, but we can't pay for it."

A bigger problem is that assistive technology generally is not covered by insurance. Bob Magee's private insurance reimbursed the first \$3,000 of his nursing home stay but would not pay for a computer talker. Drew Batavia, formerly of the National Rehabilitation Hospital in Washington, D.C., says private insurers usually deny claims for such devices out of fear that paying for expensive systems would force them to raise premiums. That could make them less competitive with other insurers.

Access to technology can turn on something as whimsical as what state one lives in or what public funding system one qualifies under. The Department of Veterans Affairs provides some of the most comprehensive coverage of technology but only for those with service-connected disabilities. State vocational rehabilitation programs, another important source of money, are often underfunded. Many school districts provide devices to children but only during class hours. Complains Dr. Howard Shane of Children's Hospital, Boston, "I've got children who can communicate from eight to three, Monday through Friday."

Equally frustrating is working through what Stephen White of the American Speech-Language-Hearing Association calls the "amazing maze" of federal reimbursement programs. Medicare will compensate "medically necessary" expenses, such as devices that replace body parts. Conventional hearing aids are excluded. But a cochlear implant—because it is not worn externally but is a surgically inserted hearing aid and therefore considered a body part replacement—is covered. Even more confusing are Medicaid rules, which vary from state to state. In Massachusetts, for example, Medicaid will pay for one hearing aid. Next door in Vermont, only a hearing aid for a minor is covered. Cross the Massachusetts border south to Connecticut, and Medicaid will pay for hearing aids in both ears until a person is twenty-one, but

only for one ear after that. "The rules make no sense," complains Alexandra Enders, an assistive technology policy expert at the University of Montana.

Even for the disabled person with money, finding out what exists is a time-consuming, hit-or-miss exercise. Claudia Magee learned about the computer-synthesized talker only by accident, from another spouse with a similarly disabled husband. "There's no effective center for information," says Judy Heumann of the World Institute on Disability, who points as an ideal to Sweden's fifty-two government-sponsored technical aid centers where disabled citizens can test devices before buying them. Some new resources are springing up around the United States. IBM's Atlanta-based National Support Center for Persons with Disabilities records nineteen thousand queries for information a year. In Berkeley, California, Jacquelyn Brand, with help from Apple Computers, set up the Disabled Children's Computer Group, a resource center filled with the latest in assistive devices for parents and their children to try out. Brand, whose original quest was to find technology to allow her multiply-disabled daughter to attend school, later established the Alliance for Technology Access and built 45 other centers around the country.

Ordinary market forces that can spur development of traditional products have tended to hold back most disability technology, which is usually expensive and used by a small number of people. "It's a catch-22," says engineer Walt Woltoz, owner of Words+, who got his start, like many in the adaptive technology business, by trying to invent something for a disabled relative. "The prices are high because the volume is low and the volume is low because the prices are high."

Not all helpful devices are expensive and high-tech. Theaters and conference rooms can be equipped for a few hundred to a few thousand dollars, depending on their size, with an FM, infrared, or audio loop system that transmits sound to a receiver worn by

a hard-of-hearing listener. A hearing aid can cost just a few hundred dollars. A lightweight, portable TDD can be purchased for a little over \$100. And in 1990, Congress passed a law requiring all new televisions sold in the United States to come equipped with an inexpensive "decoder chip" so that deaf viewers could watch closed-captioned shows and videos. A light that flashes to let a deaf person know when the phone is ringing or someone is knocking at the front door can cost just a few dollars.

Traditionally, the devices that do best tend to have an appeal beyond the market of disabled consumers. The Jacuzzi, with its warm swirling waters, was invented by a man in search of something to relieve his eight-year-old son of the pain of his rheumatoid arthritis. Today the son, Kenneth Jacuzzi, runs the company. He compares the Jacuzzi to curb cuts, which were created for wheelchair riders to cross streets but have become a convenience for bicyclists, mothers with baby carriages, and pedestrians who do not want to negotiate a curb. "We invent technology that we think will help somebody with a disability, but time after time it ends up helping all of us," noted Mary Pat Radabaugh, who before her death to cancer in 1991 ran IBM's technology center. Also among history's examples: the first successful typewriter, patented by Charles Thurber in 1843, was conceived as an aid to the blind.

Consequently, universal design—the idea of making things simple to use by disabled people and nondisabled people alike—is newly in vogue among designers and architects. Lever handles were created to make it easier for a person with a disability, such as arthritis, to open a door, but they are appreciated, too, by those with arms full of groceries or wet hands. Large numerals on a clock or a microwave oven are a boon to people with low vision, or others simply trying to read in the dark. Architects are including design features in houses—from stairless entries to adjustable shelves—so that aging no longer threatens one's ability to live at home.

Often technology developed for the general public—especially what the University of Montana's Enders calls the "yuppie market"—has applications for disabled people. Environmental control systems, built around a computer that can be programmed to turn on or off a home's heating and air-conditioning units, lights, televisions, and other appliances, are particularly convenient to a person with a physical disability who cannot move around a house easily, and just as attractive to a nondisabled person looking for a time-saving device. One such environmental control system, called *Butler in a Box*, can be programmed to recognize speech and will respond to commands by saying, "Yes, Master." But the voice-recognition characteristic, a novelty for most, is particularly valuable to quadriplegics and others who cannot push buttons.

Sometimes technology does not get used because people are uncomfortable with or scared by machines. Some fear the stigma of being disabled—of being old, dependent, not normal—that can come with using such devices. It is not uncommon for elderly people to refuse wheelchairs and walkers, even if it means never leaving home. Everest & Jennings and Invacare sell a popular line of three-wheeled motor scooters, most of them to elderly people, who fear being devalued once they depend upon a wheelchair. Others are technophobic, again particularly older people from a precomputer generation. Singer Stevie Wonder was one of the first musicians to experiment with electronic keyboards and synthesized sounds, so it is not surprising that he also was one of the very first people, in the early 1980s, to buy a Kurzweil reading machine to scan fan letters, books, and business documents. Ray Charles's singing style is more traditional. He stuck with grand pianos and generally stayed away from electronic gimmickry. It took Wonder to buy Charles his first Kurzweil Reader, as a present for the singer's sixty-first birthday in 1991.

Government, charitable groups, and private businesses have

set up innovative programs to deliver technology. There are federal tax breaks for companies that adapt offices for their disabled employees. Because banks generally refuse to grant loans for assistive technology, states including New York, California, and Maine, and groups such as the United Cerebral Palsy Associations have set up low-interest loan funds for disabled people to use, rent, or buy equipment. Pennsylvania lends assistive devices outright to disabled students. The National Easter Seal Society created an assistive technology grant program for farmers, who face a high rate of disabling farm accidents. Car companies, such as Chrysler Motors, have offered rebates of up to \$1,000 to people with disabilities to modify cars and vans. The National Christina Foundation, The Amyotrophic Lateral Sclerosis Society, and other groups donate computers no longer used by businesses to people like Magee who need them. Both IBM and Apple have discounted computer prices to disabled buyers.

Bob Magee got a talking computer a few months before his death. Walt Woltosz, who had set up Hawking's computer, flew from California to Utah with one for Magee. It used an infrared pointer that Magee could aim with his head. "He could talk again," recalls Claudia Magee, and that made him happy. When his muscles continued to weaken and even typing out letters became difficult, he could still play an Airplane Bomber video game that Woltosz had installed in the computer. Claudia would get into his bed and play it with him. "It was a stupid game but it was something he could do better than I could, even in his condition," Claudia remembers sadly. "It was therapeutic. It was marvelous." With the computer, Bob Magee made his peace, saying what he wanted to get across before he died.

Claudia Magee gave the computer to a Utah man whose wife was also dying of Lou Gehrig's disease. They, too, had struggled to find a computer that could help them. When that woman died, Magee sent the device to the ALS Society so that it could

be passed on to another family. Her only regret is that she had not known how to get the technology sooner, so that her husband could have used it more.

Since Bob Magee's death in 1989, there has been a new, more militant attitude by disabled people in need of technology. "Most disabled people are beginning to believe they have a right to technology," says Karen Franklin, formerly of RESNA, a technology policy group. "It is no longer a luxury." The newly militant attitude, says Franklin, reflects the emerging rights-based thinking of disabled people. They have come to see barriers—from inaccessible buildings to inaccessible computers—as violations of their right to basic equality.