

Chapter Three

Deinstitutionalization and Independent Living

THE TREND IN THE late 1950s and early 1960s toward deinstitutionalization allowed people with severe physical disabilities to begin entering the mainstream, bringing a new population to the developing disability rights movement. Nearly all people with serious physical impairments had trouble coping with a physical environment so ill-adapted to their needs, and many were spurred into activism by the discrimination and lack of understanding they encountered.

Deinstitutionalization

An early experiment in deinstitutionalization occurred at New York City's Goldwater Memorial Hospital, a long-term chronic care institution, where it was anticipated that people would remain their entire lives. Although hospital officials assumed that these individuals, most of whom had severe motor impairments, could not function in the mainstream, in 1958 a twenty-one-year-old quadriplegic wheelchair user, Emerman, was selected as a test case for independent living for this population. When she requested the opportunity to at-

tend college after graduating from high school, she was told by a social worker that "this idea is a fantasy, and fantasy can lead to mental illness."¹ Emerman, however, not only graduated from college and earned a master's in social work at Columbia University, but she also became a psychiatric social worker at Bellevue Hospital. By 1990, Emerman was a wife, a mother, and director of the Mayor's Office for People with Disabilities in New York City. Others like Emerman, who would become significant players in the disability rights movement, would follow this first test case out of Goldwater to live independent lives.

Among them was Marilyn Saviola, also a quadriplegic wheelchair user, who in her late teens organized a separate ward for young adults at Goldwater:

[Previously] a young person might be next to a dying octogenarian. "This was where the people the world wanted to forget about were thrown," Ms. Saviola said. Then she and other young people took the social activism of the 1960s to heart and pressed for their own ward. "We fought very hard to get that place," said Hermina Jackson, a quadriplegic who [also] later left Goldwater to become active in the disability rights movement. "I don't think a

lot of us knew how much potential we had until we moved over there."²

More like a college dormitory than a unit in a chronic care hospital, the young adults ward had brightly painted walls, "a recreation room with a stereo, a kitchen where residents pitched in to prepare dinners and [to arrange] expeditions to Broadway shows." Chosen for their compatibility with young people, hospital personnel in this new ward did not wear uniforms, and an elected council of residents advocated for the ward. Despite the many residents who used respirators or ventilators, the atmosphere of the unit was typical for coeds of the 1960s: "There was rock music, late night bull sessions and experiments with smoking and alcohol," as well as "romance." One of the young nurses in the unit, Deri Duryea, explained, "They were sent there to die, and suddenly they had life."

Saviola began her emergence from institutional life in 1965 by being the first patient to attend college while still residing at Goldwater.³ Because New York State Vocational and Educational Services for Individuals with Disabilities (VESID) claimed that she was incapable of working, she was unsuccessful the first time she tried to get financial assistance for college. Yet Saviola was not discouraged. As she explains,

I appealed to Senator Javits, and he interceded on my behalf, referring to the federal Vocational Rehabilitation Act. As a result, VESID gave me a semester's tuition on a probationary basis. After I got a bachelor's from Long Island University and a master's in rehabilitation counseling from New York University, I figured out a way to live independently. I rented my own apartment in 1973. Medicaid paid for my 24-hour live-in personal assistance services attendant, a van, and a driver, so that I was able to work as a rehabilitation counselor at Goldwater. But to keep Medicaid, I had to live at a subsistence level.

Still required to live at a subsistence level, ten years later, in 1983, Saviola became executive director of the Center for Independence of the Disabled in New York (CIDNY), the first independent living center in New York State.

Reflecting a new federal objective of including people with severe disabilities and expanding its coverage to include individuals who might not be able to secure employment, but who could live independently, the term "vocational" was eliminated from the title of new legislation, which when enacted was simply called the Rehabilitation Act of 1973. Advancing the deinstitutionalization process, this more expansive view of rehabilitation services focused on self-direction, rather than employment. Yet, as disability policy expert Edward D. Berkowitz noted, "By the late 1970s, those identified as severely disabled [people like Saviola] accounted for more than half of the vocational rehabilitation caseload."⁴

Many formerly institutionalized people with significant disabilities residing in the community lived in dread of being forced to return to institutions when their caretakers could no longer provide for them. Paralyzed by polio at ten years of age, Bernice White, a highly intelligent and beautiful woman in her early twenties, prepared a lethal dose of pills in the late 1950s to ensure that she would die before she would be institutionalized again. Although by 1960 she was married and living in her own home, she was not alone in preferring death to "incarceration" in a nursing home.⁵

In the late 1970s, Lyn Thompson of California, immobilized by muscular dystrophy, was told she was not disabled according to Medicaid law because she earned more than two hundred and forty dollars a month operating an answering service from her home.⁶ Consequently, she lost her income maintenance, her health coverage, and her personal attendant. Informed

that she would be forced to enter an institution (at a considerably increased cost to taxpayers), Thompson could not accept the loss of independence she had established with such difficulty. Despite her effort to be a productive member of society, Lyn Thompson, penalized by archaic laws, took her own life in February 1978. The September 30, 1978, CBS-TV broadcast of "60 Minutes" focused nationwide attention on this tragedy.

Thompson was not informed about a personal assistance services program evolving at that time in California that may have prevented her suicide. Ironically, on March 1, 1978, less than one month after Thompson's death, a new California law allowed people with severe physical disabilities to receive full support services while employed. Moreover, in 1977 after a reevaluation of a New York City program permitting employed consumers of personal attendant care to receive these services, the New York City Human Resources Administration decided not only to continue the program, but also to extend it to future consumers who would be employed.

Earlier, in 1976, New York City established the Independent Contractor Home Care System, a program enabling self-directing consumers of personal assistance services to hire, train, supervise, and fire their own attendants.⁷ Because the program paid only the minimum wage without withholding taxes and provided no employee benefits, the Independent Contractor System failed to comply with various state and federal regulations. Furthermore, the system did not offer support to the non-self-directing and frail elderly. As a result, New York City initiated a "vendor" program in 1979—a new system in which the city contracted with nonprofit, community-based agencies to manage the employment, training, and supervision of home care employees—thus depriving self-directing consumers of their

previous autonomy. Implementation of the new "vendor" system galvanized these consumers into banding together to form a unique personal assistance program, complying with all government regulations, in which they maintain their independence.

Founded in 1980, this new program, Concepts of Independence,⁸ has grown from serving four consumers in the five counties of New York City to serving more than a thousand consumers in twelve counties, seven of which are outside the city. If these consumers had used traditional home care in 2000 rather than Concepts of Independence, the services would have cost the state an additional \$28 million. Joining with groups such as the Alzheimer's Association and Sick Kids Need Involved People (SKIP), Concepts of Independence began in November 1997 to include consumers who required surrogates—usually family members—to direct personal assistance services. To ensure that the program is appropriate for those who use personal assistance services, most board members are long-term Concepts of Independence consumers.

Chairing the board from its inception until her death in 1994, Sandra Schnur—quadriplegic as a result of polio and director of the New York City Office of Half-Fare Transportation for People with Disabilities—initiated and guided the program utilizing her organizational skills and political connections.

Marvin Wasserman, Schnur's husband, describes his wife:

In 1952, Sandra, a wheelchair user who had just graduated from high school, was advised by OVR [the Office of Vocational Rehabilitation, which later became Vocational and Educational Services for Individuals with Disabilities] to become a basketweaver. Considering that she had weak hands because of polio, this job was a poor choice, especially for a person with

her intelligence. When she asked to go to college instead, she was told that she was uncooperative, and her OVR case was closed. Thirteen years later, when OVR offered to send her to college, she needed two years of tutoring in mathematics, science, and foreign language to make up for the inadequate home instruction she had received. After graduating from college, Sandra earned her master's in rehabilitation counseling. Among her many accomplishments, she wrote *New York with Ease*, an accessibility guide for wheelchair users in New York City—maybe the first of its kind—published by the Easter Seal Society in 1963. But she considered her contribution to *Concepts of Independence* her greatest achievement.⁹

Programs like *Concepts of Independence* revealed that many people with severe disabilities could live independent, self-directed lives in the community more economically and productively than in nursing homes.

Early Accessibility Efforts in the Colleges

The story of Dr. John E. King—who in 1953 became president of Emporia State Teachers College, now Kansas State Teachers College—also illustrates how, when people with severe disabilities are given opportunities, common assumptions about their limitations may be dispelled:

Dr. King first seriously considered the idea of educating the handicapped at a regular college campus when he was the provost at the University of Minnesota's campus at Duluth. He recalls that a Hungarian English professor at the school discovered a youth in Duluth who was extremely able, but was almost totally paralyzed. Believing in the boy's mental ability, the school hired two football players to carry him, feed him, and tend to all his wants.

"At first we felt we were exploiting the boy," King said. "You know, helping a

person is sometimes almost an invasion of their privacy. But that boy did so well and turned out to be so fiercely independent that he made a believer out of me," he added.

King said he then began to realize the inadequacies of the educational programs for the handicapped. And, when he became president of the college here in 1953, he set about attempting to correct those inadequacies, at least at his own school. "We are blessed here with a campus without hills and not so large that the handicapped students can't get around," he said. "We'll gradually get this campus so that a student can go anywhere day or night whether he is blind or paralyzed." Years later, King said, "We've had no disciplinary problems with handicapped students except for one boy who ran his wheelchair too fast down a campus walk."¹⁰

After the first of these students graduated in the late 1950s, enrollment of students with severe disabilities steadily increased at Kansas State Teachers College.¹¹

One of the first college programs specifically geared for people with disabilities was established in 1948 on the wheelchair accessible campus of the University of Illinois.¹² Since in World War II paraplegic soldiers survived combat for the first time, they required accommodations never before provided, such as a barrier-free college environment, in order to participate in activities on an equal basis with other students. Because of the foresight of Tim Nugent, founder and director of the Division of Rehabilitation Education Services, the University of Illinois developed services and programs designed for students with disabilities. An accessible paratransit system—a method of transportation using lift-equipped vans—was devised for the limited area of the campus. Furthermore, Nugent initiated a sports program, which has evolved into a multi-faceted curriculum allowing students with a variety of disabilities to engage in athletic competition.

The University's acceptance of students with increasing degrees of disability necessitated the provision of independent living services. By the fall of 1962, students with severe disabilities shared responsibility for the operation of the newly established University of Illinois residence, the Guy M. Beckwith Living Center, renamed Beckwith Hall in 1992. Until the 1970s, the University of Illinois was one of the only major universities with both a wheelchair-accessible campus and programs specifically designed for students with disabilities.¹³

While the veterans' disabilities were all war-related, the reasons for civilians' disabilities varied greatly—from polio to cerebral palsy to accidents and innumerable other causes. Since they needed alterations for accessibility in the built environment, these individuals were motivated to seek alternatives to preconceived notions—for example, regarding transportation and architecture—as well as to consider legal and political tactics to accomplish these goals. Early programs developed on college campuses for students with disabilities were initiated by nondisabled people. However, by 1971 in Houston, 1972 in Berkeley, 1974 in Boston, and later in other localities, people with different disabilities would establish and direct their own centers for independent living—sometimes forming coalitions with like-minded groups—as they began to demand social change that would enable them to participate in the wider society.

Ed Roberts and the Independent Living Movement

The counterculture activism of the stormy Berkeley campus of the 1960s and early 1970s resonated in Edward Roberts's energetic, anti-institutional biases. Severely disabled by polio at the age of fourteen and encouraged by a feisty mother, he overcame his

own self-doubt and the general skepticism concerning the opportunities that would be available to him.¹⁴ Roberts recalls:

I had a serious fever, and in twenty-four hours, I was paralyzed and in an iron lung. Within earshot, my mother asked the doctor whether I would live or die. "You should hope he dies, because if he lives, he'll be no more than a vegetable for the rest of his life. How would you like to live in an iron lung twenty-four hours a day?" So I decided to be an artichoke—a little prickly on the outside but with a big heart. . . .

The transition was hard. . . . Everyone made the outlook [seem] bleak. I decided that I wanted to die. Now it's very hard to kill yourself in a hospital with everything set up to save your life. But the mind is a powerful thing. I stopped eating. They started to force-feed me. It was really demeaning. I dropped to fifty-four pounds.

My last special duty nurse left, and the next day I decided I wanted to live. You see, that was a big turning point. Up until then, these nurses were available and doing things for me around the clock. I didn't have to make any decisions for myself because they were always there. When they all finally left, that's when I realized that I could have a life, despite what everyone was saying. I could make choices, and that is freedom. I started to eat again.¹⁵

Although Roberts completed his first three years of high school at home by means of a telephone connected to the classroom, both his mother and his social worker told him during his senior year that if he did not leave the house then, he never would. Roberts describes his first experience attending school with other students:

I had taught myself glossopharyngeal breathing—frog breathing, where you swallow air into your lungs, so I had been spending time out of the iron lung before. But I was scared to go out and be seen by people.

I remember that day very clearly. I arrived during lunch time. My brother lowered me out of the back of the station wagon, and it was like a tennis match—everyone turned

to look at me. I looked at someone, right in the eyes, and they turned and looked away. That was when I realized that maybe it wasn't my problem; maybe it was their problem. I checked myself out, and I realized two things. First, their looking at me didn't hurt, physically, and secondly I realized, hey, this is kind of like being a star—and I've been a star ever since.¹⁶

Deciding on a career in political science, Roberts acted on his mother's suggestion that he select a university based not primarily on accessibility, but on academic excellence in his field. "Armed with self-esteem and a portable respirator, [Roberts] broke the disability barrier to higher education, by insisting that he had a right to an education, by insisting that the doors to the University of California at Berkeley be opened."¹⁷ Roberts had to sue to gain admission to the University of California in 1962, just as in the same semester James Meredith required a lawsuit to become the first black person to attend the University of Mississippi.¹⁸ "When I first began talking with the administration," Roberts explains, "they told me, 'We tried cripples, and they don't work.'"¹⁹

After his successful lawsuit against the university, Roberts still had the formidable task of arranging for appropriate housing. Because of the severity of his disability, he was attended to at the Berkeley Infirmary, Cowell Hospital, by orderlies doing public service as an alternative to military service in Vietnam.²⁰ Steeped in the political milieu of this makeshift dormitory, Roberts recollects how he and the quadriplegics that followed him to the Berkeley campus created a spirited atmosphere on the third floor of Cowell Hospital.

They [the university administrators] didn't know where to put me. The dorms weren't accessible, and we had to find a place that would accommodate my eight hundred-pound iron lung. They finally decided that I could live in a certain ward of Cowell

Hospital, on the edge of the campus. Soon there were a bunch of us crips at Berkeley. It was an exciting time. The protests and student movements were rising all around us, and we were right there. John Hessler [another Cowell resident] and I used to roll right up to the front of the demonstrations and stare down the police. What could they do? When they threatened to arrest us, we just asked them, "How are you going to get us there? Do you have an iron lung in your prison?" That's one drawback of the Americans with Disabilities Act I guess, because they didn't have accessible jails back then, which meant they didn't arrest us.²¹

Influenced to some degree by the impact of the 1963-1964 Berkeley Free Speech Movement, Roberts and his followers were more profoundly affected by the eruption at People's Park in Berkeley in late 1964, as well as the students' reaction against the overwhelming police presence in the university town.²² Yet Roberts also acknowledges his debt to the Women's Movement:

I learned a lot from the Women's Movement. They used to let me go to their meetings; I guess they saw a connection between our experiences. I remember them talking about how to deal with stereotypes of weakness and passivity that society placed on them. I heard women talk about how they had manipulated men by capitalizing on these stereotypes. I realized that disability is actually a strength. If someone comes up to me and doesn't look me in the eye, if all they see is my ventilator and my chair, I can tell right away. If they don't see me as a human being, if they only see my equipment, I know that I can get whatever I want out of them. As long as this is not used pathologically, but to create beneficial change for others, it is a strength. Disability can be very powerful. We used the power of disability in political strategies many times.²³

As Roberts reveals, not all civil rights activists, however, recognized the connection between their causes and his cause: "I remember meeting with Leonard Pelletier [the Native American activist] before he was ar-

rested. I met with Stokely Carmichael and others in the Black Power movement. When I told them that we were all fighting the same civil rights battle, they didn't believe me; they didn't understand our similarities. I did. Even now, many people don't realize it."

Invited by his former college adviser, Jean Wirth, to assist her in developing a nationally-funded pilot project for minority university students, Roberts submitted a grant proposal for people with disabilities as a minority. After being funded, this proposal became known as the Disabled Students Program (DSP) at Berkeley. Establishing an agenda that suited these students' needs—wheelchair repair, accessible housing, attendant care—they formed the Rolling Quads, a political group that would make wheelchairs commonplace in the Berkeley community. Roberts comments:

My mother Zona managed the attendant pool. I remember we sent someone to visit with a high ranking military official who was responsible for the conscientious objectors. Edna Brean [DSP representative] met with him and told him about what attendants do for people with disabilities and that conscientious objectors would be ideal for the job. This official was enthusiastic; he thought this was like a punishment for these people who refused to fight. So, we got them signed up. These were the kind of people we wanted to work with. We were very lucky.

Struggling against the agency mentality that fostered dependence, the Rolling Quads worked toward achieving a barrier-free campus, one significant component of their effort to become self-reliant. Impelled by their desire to be in charge of their own lives, the Rolling Quads moved out of the hospital and into the Berkeley community. Spearheaded by Roberts, they organized an agency in 1972 governed *by* and *for* people with disabilities, the Center for Independent Living (CIL) that eventually gained na-

tional and even international prominence. Roberts explains:

Most people never thought of independence as a possibility when they thought of us. But we knew what we wanted, and we set up CIL to provide the vision and resources to get people out and into the community. The Berkeley CIL was revolutionary as a model for advocacy-based organizations; no longer would we tolerate being spoken for. Our laws said that at least 51 percent of the staff and board had to be people with disabilities, or it would be the same old oppression. We also saw CIL as a model for joining all the splintered factions of different disability organizations. All types of people used and worked in our center. This was the vision we had for the future of the movement.²⁴

Carr Massi, a leading organizer of the first independent living center in New York City, the Center for the Independence of the Disabled in New York (CIDNY), relates her impressions of the CIL in 1977:

The Center for Independent Living in California, which I visited in September, is an impressive operation. . . . Some people have the impression that CIL is a "village" of people with disabilities. It is not. It deals in services, counseling, and training. . . . There is peer counseling, legal assistance, job development, training in independent living skills, and health maintenance. The CIL degree program is the only one in the United States that focuses on the psychology of disability, using the peer counseling approach practiced at the center. All this is funded by private foundations and by the government.²⁵

Influenced by the CIL, Berkeley was referred to by the *New York Times* as the "mecca for the handicapped,"²⁶ the city where people with disabilities were accepted as an integral part of the community. Also, given the diversity of Berkeley, people with various disabilities looked just like one other unusual group that populated the area. Roberts notes:

We secured the first curb cut in the country; it was at the corner of Bancroft and Telegraph Avenue. When we first talked to legislators about the issue, they told us, "Curb cuts, why do you need curb cuts? We never see people with disabilities out on the streets. Who is going to use them?" They didn't understand that their reasoning was circular. When curb cuts were put in, they discovered that access for disabled people benefit many others as well. For instance, people pushing strollers use curb cuts, as do people on bikes and elderly people who can't lift their legs so high. So many people benefit from this accommodation. This is what the concept of universal design is all about. Now Berkeley is a very accessible city. We [people with disabilities] are visible in the community because we can get around everywhere fairly easily. . . .

I look around, and I notice that a lot of us are getting gray. As we get older, we realize that disability is just a part of life. Anyone can join our group at any point in life. In this way, the disability rights movement doesn't discriminate. So those of us who are temporarily able-bodied and working for access and accommodation now get older, and the changes they make will benefit them as well.²⁷

Two personal experiences evoke the atmosphere of the Bay Area in the 1970s.²⁸ Simi Kelley, a wheelchair user, describes her summer in Berkeley in 1975:

Rounding the corner to my street, I see three or four beautiful, blond California women surrounding a young handsome man sitting in a wheelchair. They're out there on the street throwing yogurt at one another and laughing like they'll never stop.

I go out to the store. I don't stop and think about it; I just go. There are curb cuts on every corner, so I don't have to deliberate over every maneuver.

There are many disabled people in Berkeley (often called Berzerkeley), and they are such an outgoing, active group that the ground has been broken. A whole different attitude

toward people, and therefore toward disabled people, exists.

I found people helpful but not over-solicitous. In restaurants, hotels, and shops, people are more used to seeing people in chairs and understand how to best serve their needs.

Jane Wipfler, a founding member of the New York Metropolitan Chapter of the National Paraplegia Foundation, expresses her feelings about living in northern California, where she moved to from New York City in 1975:

The most exciting news I have to share is the attitude of people out here. Everywhere I go, I see "wheelies"—rock concerts, flea markets, movies, grocery stores, on the streets. . . . Many buildings display the wheelchair accessible emblem, and the front seats of all buses are reserved for the elderly and the handicapped. I've seen quadriplegics literally fly down some fairly steep hills in Berkeley without attracting much attention. It really heartens me to see the handicapped as part of the community.

As founder of the Berkeley CIL, Roberts became the embodiment of the principle of self-determination for people with disabilities. Roberts indicates how he harnessed his anger so that it fueled his creative energies:

Most psychiatrists and service professionals who work with us tell us that anger is a bad thing—a stage to get over or something that we need to overcome. But anger is a powerful energy. We don't need to suppress or get over our anger; we need to channel it into making change for the greater good. We need to make sure that we don't turn our anger in on ourselves or our loved ones, but focus it on removing obstacles and making things happen. . . . I get angry all the time. I'm angry that people with disabilities are second-class citizens in this country. I get angry at how 97 percent of the billions of federal dollars spent either perpetuate our dependency on the system or increase it.²⁹

In order to foster independence for people with severe disabilities, the original CIL

was the model, not only for the satellite agencies in each of the twenty-eight California counties, but also for the hundreds throughout the United States and in other parts of the world. Assistant Secretary of Education Judith E. Heumann, who in 1978 was senior deputy director of the CIL, relates the accomplishments of members of the CIL by engaging in an imaginary dialogue between observers of the CIL and CIL representatives:

"There's something that's going right. They're producing more rehabs than rehab, and why is that happening?" We are saying it is very simple: Disabled people know what disabled people need and want. (That is not true for all of us, but it is for many.) As a result of that, we are able to help people move on. We are peers. We are role models. That is critical. When we go into most "establishment" organizations, we hardly meet any disabled individuals; there are no peers that we can look up to. I never met a disabled professional until I was in my twenties. I had only nondisabled role models—who are not role models to me because I am not nondisabled. That oppression, which goes on, on a day-to-day basis, is something that we in the independent living programs have been able to change.³⁰

Acquiring his bachelor's and master's degrees, as well as an appointment in political science, at the University of California at Berkeley, Roberts struggled against the prevailing assumption that his disability negated his intellectual capacity and his employment potential. When Jerry Brown was elected governor of California in 1975, he appointed Roberts director of the State Department of Rehabilitation. Roberts recounts:

When I finally met him [Governor Jerry Brown], he asked, "Are you one of the leaders of this [the landmark disability rights sit-in of 1977]?" I told him that I was, and he listened. Not only did he hire me, but he never cut program funding for people with

disabilities while I was there. If he ever had a question, he would come to me directly. . . . I went straight from being on welfare to this state government position. People asked me if I was going to become a bureaucrat. I told them, "No, I think I'll be an 'advocat.'"³¹

In this position, which he held for eight years, Roberts was responsible for twenty-five hundred employees and a budget of \$140 million. Robert Levine, San Francisco Bay Area Accessible Transportation Planner, who contracted polio when he was fourteen, remembers Roberts:

When Ed became the head of the Department of Rehabilitation in California in the seventies, he was like a kid who had slipped into the establishment. The faithful would go up to Sacramento and talk about how it was to be on the inside. Ed developed countywide CILs around the state, such as the San Francisco one at 812 Mission Street, where many of us joined together to discuss issues and plan strategies.

I also remember Ed speaking in New York in 1991. It was the annual meeting of disability organizations held at the Republic Bank, and Ed gave a great speech on why we should be proud to be disabled. It was a rousing tour de force. Later he was asked to name the three things most important to the disability community. He answered, "Advocacy, advocacy, and advocacy." When I saw him at Gracie Mansion the following year, he was, as usual, seeking money for the World Institute on Disability. "Hi Bob, how are you doing?" he said, and I was impressed. Ed hardly knew me, and if he remembered my name, he must have remembered thousands of others. A good trick if you're trying to get money.³²

In 1983, Roberts and Heumann founded the Oakland California World Institute on Disability (WID), a nonprofit public policy, research, and training institute established to achieve independence and improved quality of life for people with disabilities. WID works collaboratively with a local, national, and international network

of people with disabilities as well as policy-makers, corporations, and nonprofit organizations.³³ In order to raise public awareness of disability issues and the independent living concept, Roberts traveled to Russia, Australia, Japan, and France. His 1984 MacArthur Foundation Award helped fund many of his WID activities.

A unique and innovative force in the modern disability rights movement, Roberts was mourned throughout the world by many people, including the disability community, when he died at the age of fifty-six of cardiac arrest in Berkeley, California, on March 14, 1995. Although several independent living centers (ILCs) were initiated before the Berkeley CIL, Roberts deserves credit for being the founder of the ILCs because of his success in establishing a nationwide, and even a worldwide, Independent Living Movement. Dr. Frank Bowe, professor at Hofstra University, tells about Roberts's effect on people:

I think Ed had a "visionary" bent that people found inspiring. He had the ability to think in very broad terms and to speak in an all-encompassing way so that everyone who listened to him felt included in what he had to say and encouraged to do more and better. He was one of the first to get the idea that it was not just his job to "deal with" his disability; rather, society had some obligations, too. In the 1960s, the very concept that the University of California at Berkeley and the City of Berkeley had responsibilities to accommodate for Ed's needs and for those of other students like him was radical. Certainly, it never occurred to me in four years of college that Western Maryland College should accommodate my needs [as a deaf student]. I just never thought of it that way. I saw a college that worked the way it worked, and I thought my job was to adjust to that way—or get out. But once someone like Ed introduces a new way of thinking, it can spread—as it did! I was one of many who benefited.³⁴

Lucy Gwin, editor of the bimonthly mag-

azine *Mouth: The Voice of Disability Rights*, remembers Roberts as the person to whom she was directed when she had questions about disability rights history. She was told that "Ed Roberts has all the answers," but she did not see him that way:

Ed didn't, as he was the first to admit, have all the answers. But there was genuine treasure imbedded in his tales of the early days of IL [Independent Living]. He had stories enough to make me wish, today, that I'd recorded every one of them. Both Billy Golfus [writer and director of the well-received documentary film about the disability rights movement, *When Billy Broke His Head*] and I say we miss him most late in the evening. That's when Emperor Ed the Head held phone court from the iron lung where he spent his nights.

Ed sent me a video about the first Center for Independent Living, the CIL in Berkeley that he helped to found. That video was a sixties period piece showing the IL guys wearing so-stylish bell bottoms and stringy long hair. The founders of IL were bright white male students of a prestigious university who grew up in homes where families could describe themselves as "comfortable." In the '40s and '50s, polio had knocked down those families' most-likely-to-succeed kids like bowling pins. America's best and brightest . . . had been transformed over night into second-class citizens by a microscopic organism with a long Latin name. . . .

What caused them to question their second-class status? They'd hatched out of privilege and protection into a world that was changing radically. A people's cry for liberty and justice was visible, audible, and haunting America on its nightly news. The nation sat witness while solemn black people stood their ground as sheriffs set dogs on them for having the nerve to sit down at lunch counters, go to schools, or both. . . . Black pride arose from white oppression and black poverty.

The independent living revolution arose from among privileged white boys. And, bless them, those boys stormed the barricades to free us [people with disabilities] from *the medical model*. They fought tooth and nail for curb cuts and restaurant access, and a new,

improved vocational rehabilitation system. . . . Ed Roberts did, later, rise above his privileges to spend the last years of his life touring the country for Partners in Policymaking. He spoke then of freedom for *everyone*.³⁵

Proliferation of the Independent Living Concept

Berkeley was a harbinger for what was to come, and what is still in the process of happening, as other cities become increasingly accessible, though the climate, transportation, and culture may not be as hospitable to people with disabilities in other locales as they are in the Bay Area. The Boston Center for Independent Living was established in 1974 by Fred Fay, a quadriplegic disability activist and a Ph.D. in psychology; Paul Corcoran, a physician in rehabilitation medicine; and Robert McHugh, a rehabilitation counselor.³⁶ After Fay broke his neck in 1960 at the age of sixteen as a result of a fall from a trapeze, he spent two years rehabilitating at Warm Springs, Georgia, where he experienced people with disabilities serving as board and staff members. Fay received his undergraduate and graduate degrees from the University of Illinois, an institution noted for being receptive to and accessible for students with severe disabilities. With his vision of the potential of disability independence encouraged by Warm Springs and the University of Illinois, Fay initiated a halfway house in a Boston nursing home for people with severe disabilities who had no family or friends to provide care.

Perceiving these nursing home clients as people who were "incarcerated against their will," Fay indicates that "their only crime was needing attendant care in the morning and at night; otherwise they were pretty much independent for the rest of the day." Disillusioned by this experience, Fay obtained funding from the State Rehabilita-

tion Agency to cofound the Boston Center for Independent Living (BCIL) in order that people with severe disabilities could function autonomously outside an institution. Like the Berkeley CIL, BCIL provides peer counseling, personal care attendant services, advocacy, and employment referrals, as well as information regarding community-based housing and assistive devices.

Experiencing disability discrimination after he broke his neck in a 1967 car accident, Lex Frieden became an advocate for disability rights and independent living.³⁷ When Frieden, a wheelchair user, was refused admission to the completely wheelchair-accessible Oral Roberts University in 1968, he indicates how he became aware of the similarity between racial prejudice and prejudice based on disability:

The school was built according to 1960s architectural standards—level with wide doorways—so although wheelchair accessibility was not deliberate, it seemed a good place for me to go to school. When they wouldn't accept me because they said my presence in a wheelchair would be an imposition on the other students, at first I was disheartened. But in a few days I realized that this was discrimination—just like the discrimination people of color had to deal with—for a characteristic over which they had no control and for which there was no logic.

The next school I applied to, the University of Tulsa, was built according to 1930s Ivy League standards with many steps, so the dean of admissions had to meet me in the parking lot. He told me that the new building would have level entrances, and if I would plan my schedule early, all my classes would be in that building until other buildings became accessible. This was reasonable accommodations before the term was invented. Then he said that the University of Tulsa would be honored to have me. After I filed a 1976 complaint against Oral Roberts, I received an apology and an invitation to attend the institution. Some of my colleagues suggested that perhaps Oral

Roberts University had originally rejected me because I would have been an embarrassment considering Oral Roberts's reputation as a faith healer.

While at the University of Tulsa in 1968, Frieden helped organize a disability rights organization, Wheelchair Independence Now (WIN), but the name was soon changed to Win Independence Now: "We realized that not all people with disabilities were in wheelchairs, and we shared common issues." About the same time that Roberts founded the CIL in Berkeley, Frieden organized Cooperative Living, an independent living center in Houston, Texas, "that attempts to bridge the gap between hospital and community by means of a six-week program that teaches independent living skills."³⁸ In 1975, the same year that he was elected as the first secretary of the national disability rights organization, the American Coalition of Citizens with Disabilities (ACCD), he formed the Coalition for Barrier Free Living, an organization focusing on accessibility issues.

Founded by Frieden in 1977, the Independent Living Research Utilization (ILRU) program, the think tank for the Independent Living Movement, defined the concept of independent living.³⁹ Serving as a national center for information, training, research, and technical assistance in independent living, ILRU incorporated independent living provisions in the Rehabilitation Act of 1978. ILRU's staff, mainly people with disabilities, develop techniques for accumulating, synthesizing, and distributing information concerning independent living for national and international rehabilitation and educational agencies and institutions, consumer organizations, and other independent living centers and councils. Similar to the World Institute on Disability, ILRU's goal is to increase and disseminate knowledge and understanding of independent liv-

ing, as well as to advance the use of research project results.

Two accessible apartment complexes—Creative Living I and II—built in 1974 and 1986 in Columbus, Ohio, served as temporary independent living environments for young adults with severe physical disabilities who were pursuing educational or vocational training or beginning employment.⁴⁰ These programs, funded by the Department of Housing and Urban Development (HUD), prepare quadriplegic wheelchair users for self-sufficient futures. However expensive the cost of subsidizing these residents may appear, approximately thirty thousand dollars a year for six years per person, the investment is prudent because of the long-term dividends. If recipients of Creative Living Services become gainfully employed rather than totally dependent on Medicaid, society benefits by both their professional and economic contribution.

When the Rehabilitation Institute of Chicago organized an independent living committee in 1978 in order to set up an ILC, the institute's plan was to establish transitional housing for recently-disabled people who had completed rehabilitation.⁴¹ A member of the committee, Marca Bristo, newly rehabilitated following a spinal cord injury, asked a provocative question: "Where do we go after we leave transitional housing when there's no accessible housing?" Having just attended a conference in Berkeley on sexuality and disability, Bristo was keenly aware of the variety of disability accommodations being provided in the San Francisco Bay Area. Supporting Bristo in her concern, other members of the committee pointed out that what was really needed was accessible, affordable housing, where people with disabilities could live independently alongside nondisabled people. "We don't want to live in segregated, special housing," asserted Bristo, expressing the sense of the

committee. Responsive to the committee's recommendations, the institute abandoned its original plan, and instead in 1980 established Access Living, the independent living center of Chicago.

President and CEO of Access Living since its inception, Bristo has helped to create a model independent living center that serves all of Chicago.⁴² Access Living provides the four core ILC services: information and referral, peer counseling, independent living training, and advocacy. Unlike many of the other centers, however, Access Living treats litigation of disability lawsuits as a significant aspect of advocacy. With a civil rights team consisting of two staff attorneys and two technical assistants, Access Living deals with a variety of disability issues including access to transportation and to schools, discrimination in housing, availability of home services, and denials of sign language interpreters for the deaf. With the exception of housing cases, the center's focus has been on large-scale cases to achieve systemic change.

Consistent with its initial purpose, Access Living supports lawsuits filed against violators of the federal Fair Housing Amendments Act of 1988, which not only protects people with disabilities against housing discrimination but also requires that housing developers comply with the principles of "adaptable design."⁴³ Developed in the mid-1980s by the disability community in conjunction with architects, adaptable design incorporates certain fixed access features but allows others to be added to existing structures as they are needed. Thus, this design enables all people to remain in their homes if their physical conditions change as a consequence of disability or age.⁴⁴

Adaptable design, however, applies only to newly constructed multi-family dwellings with four or more units that were ready for first occupancy on or after March 13, 1991. In addition, Access Living supports city and

state legislation mandating "visitability"—basic access to newly-built single-family homes for which owners receive financial or other assistance from city or state government.⁴⁵ Known across the nation for its pioneer work in fair housing,⁴⁶ Access Living also provides technical assistance on the Fair Housing Amendments Act to over five hundred organizations across the United States.

Characteristics of Independent Living Centers

Certain services are basic to all ILCs, yet they vary in their programs, staffing organization, and funding sources, as well as the consumers they target. Some ILCs are associated with uncommon services; for example, one of the first services offered by the Berkeley CIL was wheelchair repair. Two early ILCs founded in New York City—the Center for Independence of the Disabled in New York in 1978 and the Brooklyn Center for Independence of the Disabled (BCID) in 1979—include personal attendant, deafness and blindness services, as well as housing, benefit, and transportation information. In addition, CIDNY, in partnership with Tisch Hospital (one of the facilities at New York University Medical Center), provides primary care services to people with disabilities. While Bronx Independent Living Services helps crime victims with disabilities, Queens Independent Living Center (QILC) includes the Cork Art Gallery, which displays the work of artists with disabilities. Because people from ethnic and racial minorities were underserved by ILCs, Harlem Hospital—in conjunction with QILC and Sylvia Walker of Howard University—created the Harlem Independent Living Center (HILC) in 1991, the last of six ILCs in New York City, all of which remain in existence today. At the same time

QILC, like many other ILCs, developed minority outreach programs to deal with multicultural disability issues.

An ILC in a state where disability activists are well organized has an increased probability of receiving state funding, allowing it to join with other ILCs from that state to form a network. Some states with effective ILC networks are California, Illinois, Massachusetts, New York, and Pennsylvania. Not only do the ILCs in these states share information and innovative approaches, but they also gain considerable political clout. Despite their efforts, disability rights activists did not succeed in getting federal subsidies for independent living services until the 1978 amendments to the Rehabilitation Act of 1973.⁴⁷ Although disability leaders requested funding for a variety of ILC programs, by 1978 ten ILCs received only start-up money. With the passing of the 1986 amendments to the act, additional federal funds were provided for establishment and operation of ILCs as well as legal services.⁴⁸

The 1992 amendments to the Rehabilitation Act of 1973 increased consumer control of ILCs, for with this new legislation federal subsidies were allocated directly to the centers rather than funded through state rehabilitation agencies.⁴⁹ These amendments also mandated that each state establish a Statewide Independent Living Council, primarily to prepare and monitor a three-year plan for independent living services.⁵⁰ In addition, these amendments were designed to motivate ILC participants to advocate for equal access to health care, housing, public accommodations, communication, and transportation, and for equal opportunity to education and employment. Since enforcement has not kept pace with the existing laws dealing with many of these issues, ILCs are faced with a significant challenge: to educate people with disabilities, as well as businesses, government, and

the general public, regarding disability civil rights legislation.

Independent Living as an Extension of Rehabilitation

Independent living centers were an extension of the concept of rehabilitation in a civilian context. The convalescent project in the military hospital, the forerunner of rehabilitation, originated as a halfway program between the hospital and the battlefield. On the other hand, ILCs complement civilian rehabilitation, offering support to enable people with disabilities to become integrated into the mainstream. Rehabilitation refers to a medical field; independent living denotes people with disabilities relying on their own resourcefulness to acquire the social services they need in order to participate in society. "It [independent living] is deciding one's own pattern of life—schedule, food, entertainment, vices, virtues, leisure, and friends. It is the freedom to take risks and the freedom to make mistakes."⁵¹

Gerben DeJong succinctly describes the differences between the rehabilitation and the independent living approaches to disability.⁵² While the rehabilitation model locates the problem in the person with the disability, emphasizing fixing the individual, the independent living paradigm places the problem in the attitudes of society and stresses changing the environment. The language of rehabilitation uses expressions such as "patient" or "client," connoting dependence on authority, whereas the vocabulary of independent living employs the term "consumer," suggesting control by the user of the service. The purpose of the rehabilitation prototype is to enable the person with the disability to be as physically and economically self-sufficient as possible. The objective of the independent living construct

is to fully integrate the person with the disability fully into the social, economic, and political fabric of the community.

Evaluation of the Independent Living Movement

In the late 1970s, Sandra Schnur, a quadriplegic wheelchair user who would become chair of the board of Concepts of Independence in 1980, expressed concern that the ILCs would become another self-perpetuating, bureaucratic layer between the disabled consumer and the provider of services.⁵³ Suggesting that ILCs encourage preservation of the status quo rather than social change, *Mouth* editor Lucy Guin asserted in the late 1990s: "The ILC movement still hasn't caught up with him [Ed Roberts]. He was a gentle and a patient man. But he would have howled if he heard ILCs say, 'We'd love to get people out of institutions, but we aren't funded for that.'"⁵⁴

Yet however cautious some ILCs may be, others have engaged in controversial activities. For example, four New York City ILCs provided funding for two buses of disability activists to travel to the demonstration organized on January 8, 1997, by Not Dead Yet, the disability organization protesting against physician-assisted suicide in front of the U.S. Supreme Court. Patricio Figueroa, the director of the CIDNY, pointed out that ILCs were the appropriate resource for people with disabilities because the service providers, themselves disabled, had lived with the same problems and frustrations confronting their clients.⁵⁵ Tom Agency, NYU computer programmer and a two survivor, urged the disability community to protect Ed Roberts's concept of the ILC as an organization of people with disabilities, advocating for and empowering themselves.⁵⁶

Independent Living and the New Disability Activism

The emergence of people with severe disabilities from institutions, in combination with the strategies for independent living that allowed them to participate in the community, was a pivotal force in the evolving disability rights movement. At a previous time, many of the individuals who would become prime movers in the ongoing civil rights struggle for equal rights for people with disabilities might have remained hidden away in institutions or confined in their homes. Edward Roberts, founder of the worldwide Independent Living Movement, had to sleep in an iron lung. Assistant Secretary of Education Judith E. Heumann, who founded Disabled In Action and, with Roberts, established the World Institute on Disability, requires attendant care for activities of daily living. By the late 1990s, Boston Center for Independent Living and American Coalition of Citizens with Disabilities cofounder Fred Fay would be lying on his back "all day, every day in Concord, Massachusetts, operating not only his home but also state and national political campaigns and international [disability] advocacy through an economical combination, which he developed, of personal assistance and three computers."⁵⁷ Leading disability advocate Justin Dart added, "Our society [still] puts people like Fred into nursing homes at far more cost than would be required to empower them."

The Independent Living Movement reflected a change in social perceptions about disability as illustrated in the difference between two popular Hollywood films, *The Men* (1950) and *Coming Home* (1978). At the end of *The Men*, the hero, a World War II veteran in a wheelchair, asks his wife for assistance in getting up a step. This scene signals to the audience that the disabled veteran will be all right because he is finally

able to ask for help—something he often will have to do to survive in a society with so many obstacles. A fitting finale for a film of that period, this scene would not have been consistent with the 1970s sensibility, a time when architectural and attitudinal barriers were no longer deemed unalterable by the disability community. Unlike his counterpart in *The Men* who deals with the necessity of acceptance and adjustment, the disabled Vietnam veteran hero of *Coming Home* learns the value of protesting social injustice and educating a misinformed public.

The prophetic language of the 1970s disability rights activists, many of whom benefited from deinstitutionalization and independent living, is reminiscent of the rhetorical exhortations of the 1960s civil rights orators inspiring listeners to fight for racial justice. For example, at "The Psychological Impact of Disability," a conference held at the New York University Medical Center in New York City on October 5, 1977, speaker Tom Clancy, a quadriplegic wheelchair user and

a former resident at Goldwater Hospital as a chronic care patient, roused the audience with a challenge. Echoing images of Martin Luther King's "dream" and James Baldwin's "rainbow sign" and "fire next time," Clancy invoked a new age that would supplant the Age of Aquarius:

Look out America, because I'm coming. I have always had my dream and my rainbow, but now the picture is clearer and the colors are brighter. I have tried and failed, cried and raged in silence. I have sat and watched because I could not keep in step with you, but I never gave up.

You have not heard the last of me. In fact, you have not yet heard me at all. Until recent times, you kept me out of sight and sound. Now as you begin the search for a moral answer to the materialistic chaos which you now have created, my voice will rise. For I am the living proof that physical and mental perfection are not the answer. It is the inner fire that will not accept the "impossible."

Move over Aquarius! There is a new dawn coming.⁵⁸