

DECLARING INDEPENDENCE IN BERKELEY

BY SONNY KLEINFELD

At the Center for Independent Living in Berkeley, California, one encounters the revolution in microcosm. From a crowded storefront, handicapped people of all kinds agitate in the community for better jobs and housing. They also apply their talents to finding ways to help one another.

They make revolutions in Berkeley. This is where the Free Speech and the People's Park struggles found their momentum. The hotbed of liberal fervor. In more recent years, something new and positive has been happening here. The handicapped were clanking into town and living independent lives. The reason for all the action, I was told almost reverently, was the Center for Independent Living.

The center crouched low on Telegraph Avenue. It had the look of a lawn-furniture store from the outside, an unlovely affair with walls splashed with white paint, wedged between Pancho's Villa Mexican restaurant and a small parking lot. With a staff of 120 people half of them disabled, the center now serves about 5,000 clients on an irregular basis. Every conceivable degree of disability is handled, from the elderly who have mild mobility problems and need to be bused, to the totally paralyzed.

I walked inside. There was an imploded look to the place. Some individuals in wheelchairs jostled along the hallways. Several people at the reception desk were hugging phones and talking animatedly. The white hallway walls were scuffed from



Two members of the center dancing at the wedding reception of a fellow member.

wheelchairs whacking against them. They resembled retaining walls at auto racetracks, dirtied from cars slewing out of control. From an open office I heard a young woman, progressively going blind, tearfully unloading her problems to a counselor. I checked out some of the many notes

thumbtacked to cork bulletin boards in the corridor. One read: "Disabled man seeks companion for headtripping, studying together, Scrabble, etc. Ray." Another: "For sale, one chrome wheelchair. Used for three months. \$100. Call Peter." Another: "For sale. 1977 Dodge van. Built to drive from a

"Something new and positive was happening in Berkeley. The handicapped were clanking into town living independent lives."

wheelchair. Low mileage. Like new. Price: \$10,000. Call Mike." Another: "Self-defense course. Become familiar with your own areas of strengths and weakness and how to apply these to self-defense techniques. The course will concentrate on using canes, crutches, and wheelchairs as tools in self-protection. Starting March 6." If you were disabled and needed help, this seemed the place to come.

The mover and shaker behind the center was an outspoken and vigilant man named Ed Roberts. In 1962, Roberts, a postpolio quadriplegic, became one of the first severely disabled students to attend the University of California at Berkeley. Not only was Roberts confined to a wheelchair, but he also needed to spend most of his time inside an iron lung. He was put up at the Cowell Hospital on campus. Within a couple of years, Cowell became a haven for a dozen seriously disabled students in what had turned into a formal program, the Cowell Residence Program. The patients, however, found the hospital custodial in nature. They rarely ventured off campus into the community, the main reason being that the community was architecturally inaccessible to them. A unity developed, with a dim sense of purpose. They began to entertain the selfish, ambitious hope that they could get out of the hospital and live like the able-bodied.

They decided to whip up some alternative to the Cowell arrangement. With funds from the federal Office of Education, they created a Physically Disabled Students' Program in 1970. It was a sharp departure from past practice in medical and rehabilitation fields. The notion was to assume a hostile approach to society's limitations and to set up services directed at getting disabled people to live inde-

From *The Hidden Minority*, by Sonny Kleinfeld, to be published by Atlantic-Little, Brown & Co. in September. Copyright © 1979 Sonny Kleinfeld.

pendent lives. The philosophy of the nine founding members was: those who best know the needs of the disabled are the disabled themselves; comprehensive programs are urgently needed to meet those needs; disabled people must get out and get into the community.

As the founders began to sculpt and implement programs, they found the disabled student population steadily swelling at Berkeley; more and more of these students began to move from Cowell into the community. Requests for help rose at an astonishing rate. Rarely were pleas turned away, even when they came from nonstudents. By the spring of 1971, the amount of time devoted to community people began to impinge seriously on the program's ability to meet the needs of students. Thus was hatched the idea of a separate Center for Independent Living to serve everybody.

The particulars were hammered out for more than a year. The group was officially formed in April of 1972. A roach-infested two-bedroom apartment was found with haste on, appropriately enough, Haste Street. The organization had one nagging problem: no money. Dollars were dug out of personal pockets, some benefit poker games were arranged, but not until July of 1972 was the financial squeeze settled. The Rehabilitation Services Administration produced a grant for \$50,000, enough to tide them over while other funds were secured.

Jerry Wolf, who uses a walker to hobble about because of the crippling effects of multiple sclerosis, coordinates the housing department. He was my first stop.

The purpose of Wolf's department is to act as a listing agency of accessible housing for the disabled and as an advocacy group to prod landlords into making their housing accessible. The

formidable hurdles it faces were in black and white on a tattered map of Berkeley tacked to the wall behind Wolf's desk. Shaded-in portions represented accessible housing. That meant six or fewer steps to get in. Most of the town, perhaps 90 percent, was unshaded. One reason was that a ramp to surmount just six steps could cost as much as \$1,000.

"The general vacancy rate in Berkeley is just 1 percent," Wolf said to me. "Finding wheelchair-accessible places cuts the supply down quite a lot. Anyway, rents are usually too high. They've gone up a good deal lately, so that a two-bedroom is \$200 on up. Finding a studio under 150 bucks is a feat of magic. We keep lists of people looking and try to arrange roommates. That's the only way some of these people can afford to put a roof over their heads." Wolf pointed out that although the disabled can apply for housing subsidies, they're tough to get and insufficient as yet to keep pace with demand.

Around 100 requests a month were streaming into the department, far too many to fill. "One of the problems we have is that Berkeley is being advertised as a Utopia for the disabled," Wolf said. "But not enough housing is available. People are literally flocking here from all over the country. They are landing at the airport and calling us up. About once a month someone pulls up outside in a taxi with all his belongings and says, 'Here I am.' One person showed up with an attendant and we had to put him in a hotel. His attendant left and he started asking bellhops to empty his leg bag. The hotel kicked him out. We finally found him a place with another attendant. People commonly show up with no money. One guy hitchhiked here with his wheelchair."

Wolf shook his head. "The truth is, we're placing about eight to 10 people a month, though sometimes I'm sur-

“A design engineer has built the perfect wheelchair—a ‘superchair’ with speed, reliability, and flexibility.”

prised that we place anyone at all.” I wondered how successful Wolf had been in convincing landlords to make the modifications that would render more dwellings accessible to the disabled.

“Mixed success,” he said. “A lot of landlords are reluctant to do anything because they think ramps look ugly. Then again, every so often we get a call from a landlord who wants to rent to the handicapped. He likes them because the turnover tends to be low. One of the big problems is that no one provides money for modifications. We try charitable organizations and private benefactors. We do get money sometimes, but not much. It’s a case of twisting arms.”

New housing, under law, is required to set aside a certain number of apartments accessible to the handicapped. However, the law is useless if no housing is going up. Berkeley hasn’t seen any since 1973. Land is expensive; nobody is buying.

I walked outside and meandered through the parking lot to a cluster of garages. This was where the van-modification and wheelchair-repair departments were housed. At the far end of the garages was a shop where wheelchairs were fixed.

“We can fix ‘most anything the same day,” one of the men in the shop said. “You go to many places and they’ll take weeks. Here, if we take any length of time, we have chairs to loan out so these people don’t lose their mobility.”

Eight repairmen work in the shop, three of whom sit in chairs themselves. The shop does about \$10,000 worth of repair work a month. Wheelchair frames break constantly. “We do a whole lot of welding work,” one of the men said. “A regular user may be in almost every week for repairs. These chairs are made terribly.”

In a small room off the chair shop

toiled Vince Grippi, design engineer. Since late in 1975, he has been working to build the perfect wheelchair, a superchair. If he has his way, extant wheelchair manufacturers can go into the lawnmower business. His chair will be the best. Taped on the wall was a gigantic artist’s rendition of it.

“You know, nobody has given a thought to the mobility of the handicapped,” Grippi said, playing with a pencil. “Nobody cares about building a better chair. Well, I care. We talked to a lot of disabled people and most of them were unhappy with what they were sitting in. The speed, the range, the reliability, the flexibility. They really had no voice in what they needed. ‘Here’s a wheelchair,’ they were told; ‘take it or leave it.’ Wheelchairs, understand, are their legs. We started with a clean sheet of paper.”

He pointed out some of the features of the superchair. It will have a cast frame that will be much sturdier. State-of-the-art technology will be incorporated. Grippi has designed an electric system that he claims will be much more reliable than conventional systems. “Most chairs will go four or five miles an hour and 10 or 12 miles before the battery needs charging,” he said. “Ours will go six miles an hour and 30 miles without charging. We’ve got a totally solid-state system, rather than a relay system.”

The chair will be adjustable to handle any size person. With a traditional chair, you have to pull the armrests out of the sockets and toss them on the floor to transfer out of the seat. In Grippi’s chair, the rests will pivot downward electronically. The wheels are sturdier. And the chair is being constructed out of standard equipment that you can get anywhere. For instance, it uses Schwinn bicycle tires and an ordinary automobile battery. Everest and Jennings has its own tires and batteries. The model is expected to be out sometime in late 1980.

That night, I ate dinner with Phil Draper and Judy Heumann—executive director and associate director, respectively, of the center. Both are quadriplegics. The typical discussion of where to go ensued. Everyone had a favorite place. A Chinese restaurant, Tung Yuen, was mentioned. Draper shrugged noncommittally. He said that would be okay, except he could fit under only one table there. Draper is tall. “Let’s just hope we get it,” he said. We were in luck. The table was vacant.

Heumann came down with polio when she was 18 months old; she has been paralyzed from the shoulders down ever since. Draper has lived with other demons.

In 1961, Phil Draper was a fun-loving, carefree 17-year-old, interested in the same things most young men that age are interested in: girls, cars, booze. So, it was not surprising that he and two friends set out in Draper’s car on a weekend jaunt to Fairfield, California, near where he lived, to see what was happening there. Nothing was, as it turned out, so the trio turned around and headed home. There was beer in the car. Draper had two cans. He says he wasn’t drunk; he could hold a lot more than that.

His memory stops three miles before the collision. He was later told that it had been raining that night, but he remembers no rain. He was doing 55 when he jerked giddily to the left, crossed the divider, and slammed head-on into the onrushing car. Draper’s neck was broken. He was left a quadriplegic.

Draper spent most of three years in hospitals. Having been a bullheaded individual, he reacted to his disability with a combination of bitterness, depression, and resentment. Once he was released from the hospitals, he didn’t get on with his parents, so he lived on his own with full-time attendant care. “This was back in the 60s.

"A class-action suit was being readied against an insurance firm charging the handicapped higher rates."

It had never been heard of. It was a new experience. A vegetable living by himself." It wasn't much of a life, though. "I was far from active. I was thrust back into society as a freak. I lived an active life of doing nothing." For the most part, Draper drank. Beer. Wine. Hard stuff. Whatever he could get his hands on. He was drunk most of the time. The moments he wasn't, he mostly spent reading. He remembers one day reading every single word in the morning newspaper, including every word of advertising copy. "It was possibly the most boring experience in my entire life." He came to Berkeley in 1970 for no particular reason, learned about plans for an independent living center, got involved, and abandoned drinking. He is now in his mid-30s.

The Chinese restaurant was a tiny, dimly lit place. A half-dozen young people were crammed into the small room, their leathery faces and rumpled clothes blending with the dun-colored walls. Because of its proximity to the center, the restaurant often was patronized by the handicapped, and so fellow diners paid us no particular mind. Draper used a fork that was strapped to his wrist with an Ace bandage. But he could shovel food down pretty fast. The wheelchair doesn't disguise Draper's owlish, rabbinical bent. He speaks, not with soapbox intensity, but softly, with an almost mournful tone.

I asked Draper and Heumann how they spent their time. "The administration of CIL devotes most of its time to looking for money," Draper said unhappily. "It's a hard sell. It shouldn't have to be that way. We're not eating the money. This is a damned good cause. You find me a better one." The center was operating on a yearly budget of approximately \$1.2 million, money extracted from about 25 different sources. "We have tapped every conceivable source,"

Draper said. "One of the biggest problems is that we have no permanent source for funding. So it's soft money. Most places fund for a year and that's it. Social-service programs have a high mortality rate."

I asked them how the movement was going. "One thing that's very important," Draper said, "is the collectiveness, people working together. That's how they got their strength. Activism is found in only a few places in this country. We need more involvement. Too many disabled people are still sitting in their attics and reading old comic books. They've got to start shouting."

Heumann is a petite woman with a positive, earnest manner. She is 30. She was once arrested on an airplane for refusing to get off after she and her wheelchair had been cleared to fly. She went to court and won.

"I think the movement lies in the hands of disabled individuals," she said. "I am concerned that not enough people understand the independent-living programs. One of the reasons I think CIL is so successful is because it's run by disabled people. Our clients have hope when they see other disabled people managing their own lives. I don't know that the government is pleased that the disabled run these programs. Disabled people need to be much more militant about this. I think the next few years are going to be critical in the development of the movement. In a sense, the movement is just beginning."

Are more demonstrations needed? "More involvement," Draper said. "Just more involvement."

Heumann was crisp and downright. "We need more demonstrations. We still have many scores to settle."

The center's Law Resource Center is housed in a shopworn building across the street from the main building, and the next morning, I went

there to talk to the program's director. Mismatched desks and chairs and bookshelves were spaced around the room. The floor was much scuffed up; track marks from wheelchairs were plainly visible. Old Congressional Records and Federal Registers were piled high on the floor. Coffee was percolating in a percolator. A spider plant was hanging in the window.

The director of the law center, Bob Funk, is a lawyer, one of two in the department. We sat and talked in a small, airless room.

"Our goal here is to be a backup to a lot of community groups," Funk said. "We're agitating to get the disabled to be more assertive. To have them know they can raise hell."

A good deal of what the office does is to explain the laws and rights of disabled people. It will also file suits and negotiate settlements. Funk said three suits were in court at the moment, and six were about to be filed. Three previous suits had already run their course, all successful for the center. He said he was trying to help about 160 clients at the moment, the vast majority of them complaining about discrimination of one form or another. Funk rattled off some recent cases. Three local restaurants wouldn't serve customers in wheelchairs. A waiter at one of them flatly said, "We don't serve wheelchairs." The second restaurant said it would serve the person if he sat in an isolated walkway that joined the place to a coffee shop. The third place refused service because it said the person was too disturbing a presence. He was in a wheelchair folded out like a bed. "He would be disturbing," Funk said. "But that's tough. That's the law."

Complaints were reaching the center about auto-insurance firms charging the handicapped 30 to 50 percent higher rates than the able-bodied, though documentation makes clear they aren't greater risks. Funk said

“ ‘We need more demonstrations,’ ” stated Judy Heumann of the center. “ ‘We still have many scores to settle.’ ”

a class-action suit was being readied against one immense insurance firm.

“We are clearly in the right in almost every case we get,” Funk said. “They’re blatant cases of discrimination. Not even subtle discrimination. They haven’t a chance in court. Discrimination is such a traditional thing in this country that these people don’t even realize they’re discriminating. We can’t possibly lose most of these cases. In fact, we’re forced into court a lot more often than we should be.”

Funk laughed at the thought of how ridiculously simple most of the cases were. “What’s likely to happen is that, at first, all of the cases will be blatant. Then, they’ll get subtler and subtler. People will get more sophisticated in their discrimination. Restaurants will refuse to serve a handicapped person, but say the reason is that he’s rowdy or doesn’t have a tie on. The disability won’t even be mentioned. This happened with the civil rights movement, and it took 20 years to run its course. The same will happen with the handicapped.”

Anna Steiner is a beautiful woman with raised eyebrows and poignant circles of pure white skin around her eyes. Her only disability is a bad case of arthritis. She’s in her 30s and has an infirmity most people don’t get until their 60s. She heads the center’s job-development program, which faces the awesome task of trying to get jobs for the disabled.

“Basically, we’re a placement service,” Steiner said to me. “Somebody has to come in here with some education, skills, abilities that could be translated into jobs. We’ve had lawyers. We’ve had a person who was a missionary. We’ve had a talented artist. We’re mostly working with the physically handicapped, but we’re expanding into the mentally handicapped.”

The program has a caseload of 125

clients, Steiner said. Since the program began in the fall of 1975, the placement rate has hovered around 40 percent, she said, though it had of late nudged up to 60 percent.

She spoke of some unusual cases. A blind janitor had been placed in a nearby town. “This was one of the cases where I said, no way, there’s just no way for this one.” The man told Steiner that he had experience scrubbing his father’s laundromat. He was totally blind in one eye and legally blind in the other. How would he clean a room? He said he would scout out the premises in advance until he knew the area by memory. How would he tell what was dirty and what was clean? He said he would assume everything was dirty and clean it all. Steiner said that a man with muscular dystrophy got a job doing drafting for the Navy. The only necessary concession was a lower drafting table.

“We work a lot with employers, too,” Steiner said. “Basically, we try to advocate for the disabled in general. We don’t go in and say, ‘Hey, you’re really stupid to have the kind of attitude you have.’ We’re subtler than that. We generally work with personnel people, who are sympathetic, because they don’t have to work with the handicapped people. We’ll do whatever is needed to help the employers. We’ll check out the work environment to see what modifications are necessary. We’ll help draft affirmative-action plans. We’re getting a lot more interest from employers worried about the law.”

Tanya Temporal, a counselor in the research and demonstration project, sat on top of a desk on the first floor, beneath the blind-services department. She was finishing a staff meeting. Temporal counsels severely disabled people. The project she is a part of hopes to prove that peer counseling of the handicapped works better than

any other kind. Her short frame and lean, cheerful face belongs in California; her hair, wild and electric, looks fine in Berkeley. She’s in her early 20s, and prematurely gray. Her conversation is a stream of information, a Niagara of words that, even so, somehow seems laconic. She smiles quickly and steadily.

“One of the main things we do is emotional counseling,” she told me. “Getting people to deal with their disability and to accept it. We have five part-time counselors, and each one handles about 10 clients. We have a caseload, altogether, of about 80 clients.”

She talked about her most difficult case at the moment: a 23-year-old girl afflicted with severe cerebral palsy who was living in an institution. Her speech is extremely difficult to understand.

“I’m dealing with her on an emotional level,” Tanya said. “I’m not really telling her. I’m allowing her to discover. A lot of time we role-play. ‘Okay, here we are in your apartment. I know you like to bowl. Let’s go over how you’ll set up a bowling appointment. Who are you going to call?’ I’ve got to get her to demand to go out and do things, not wait around for others to ask. She hasn’t really accepted her disability. She views it as a burden that God has placed on her. She believes that by God’s magic power she’ll recover some day. She’s very religious. I try not to discourage that belief altogether. I try to tell her, okay, for today you’re not going to get better. What can we do today?”

Tanya studied human development in college. For 13 years, she has suffered from rheumatoid arthritis. She has no idea why she got it. She has no pain, but has trouble walking and holding things. She occasionally resorts to a wheelchair. “I have accepted my disability,” she said. “I can’t say I don’t get angry when I

“For long distances, matters have improved. Airlines can no longer deny seats to handicapped individuals.”

drop something on the floor and can't pick it up. But I don't let anger overtake me. I'm not going to paint the picture of the Super Crip. Some people make it out that they're the Super Crip and it's wonderful to be disabled. Well, that's going overboard the other way. It's never wonderful to be disabled. But you can still be a whole person, still be a happy person.”

I went next to another hive to chat with Lon Kuntze. He, too, is in his early 20s, a big, broad-shouldered man with frizzy hair and a beard. Deaf since birth, he runs the deaf-services program. He nodded hello when I came by. Lynette Taylor, the center's staff interpreter, was to assist in our interview, though she was preoccupied with some phone calls. Kuntze suggested we begin by writing questions and answers on a legal pad.

“The biggest problem for deaf people,” he wrote, “is, of course, communications. The deaf are the only disabled group that can't regularly use the phone.”

The only way the deaf can talk, Kuntze explained, is by use of what are known as TTYs. Basically old teletypewriters that, by use of a jack, can be hooked to a phone line, they clack out in written form what conversation is to be exchanged. They aren't cheap and they aren't readily available, so even if a deaf person could get hold of one, he couldn't call very many people. Some federal offices have installed them, as has the phone company at a few of its service centers. One of the troubles is that it's an agonizingly slow way to talk, yet anyone talking over a TTY pays standard phone rates. A popular deaf person can run up staggering bills.

Lynette finished with her calls, and came over to interpret. Her mother was deaf, so she picked up sign language early on. Kuntze was relieved; he was getting a writing cramp.

“Deafness is a disability on the communications level, whereas other disabilities are on a physical level,” Kuntze said. “The deaf can't deal with people who don't know sign language. The best remedy for the communications problem is interpreters. The biggest trouble is there aren't enough interpreters, and there's no money for interpreters. They cost up to \$10 an hour. Most of them get \$7.50. Court work costs \$15. The money, from their standpoint, is terribly low. It should be equal to foreign-language interpreters, who get \$15 to \$35 an hour. That's why more interpreters haven't been attracted to the field. Deaf interpreters simply don't get a decent wage.”

My last visit was with the community affairs department. Its aim is to address community issues and to inspire demonstrations when it senses the need. I spoke with Kitty Cone, who has muscular dystrophy, and with Hale Zuykas, whose cerebral palsy is so severe that he has but limited use of his hands and can barely utter intelligible speech. When he gets bogged down, he spells out his thoughts with a brisk tapping of the pointer. The back of his wheelchair sports a button reading: “ACCESS AMERICA.”

Of late, the department had been working at mobility and architectural issues. Thumbtacked on the wall were two immense maps, one of Berkeley and one of Oakland. Black dots were inked in where ramps or curb cuts had been made. Berkeley looked pretty good, but Oakland had a long way to go before it could be called an accessible city.

“We are working quite a bit on transportation issues,” Kitty said.

Hale began to struggle, wanting to say something. I couldn't understand his grunting. Saliva drooled down his beard and onto his clothes. Kitty had

to interpret. “Hale says, ‘Boy, do we work on transportation. We're suing everybody in the world.’”

Paramount to all severely disabled people is the issue of getting around. For long distances, matters have improved since the Federal Aviation Administration ruled in May of 1977 that airlines can't deny seats to handicapped individuals. It had been common practice for the airlines to boot disabled people off planes, contending that they might hamper evacuation procedures should there be an emergency. Now, all airline personnel are required to be properly schooled in ways of handling the disabled. Several cruise ships have started to take wheelchair travelers. The first ocean liner so designed, the *Queen Elizabeth II*, boasts nine staterooms that were made for the disabled, with 12 more that are accessible to them. Thirteen elevators are on the ship. Some of Amtrak's trains can accommodate wheelchairs in certain bedrooms, and these trains offer accessible bathrooms. Stations are being built barrier-free. Hertz and Avis have hand-control cars at some of their locations, and the newer highway rest areas accommodate the handicapped. For lodging, Holiday Inns is making one in every 100 rooms accessible to the disabled population.

Local travel, though, is something else again. Wheelchair users can't very well hop into taxis. Subways, with the exception of the San Francisco, Washington, and Atlanta lines, aren't available to the severely disabled. And no available evidence suggests they ever will be. Elevators would be needed, and the cost is prohibitive. Public buses aren't much better, since their floors are around 35 inches above street level. A protracted battle, involving a spate of suits by handicapped groups, resulted in an order in May of 1977, from Transpor-

“The handicapped must scream at their legislators to start moving. The laws are sending us to psychological deaths.”

tation Secretary Brock Adams, requiring that buses with 22-inch floors—called Transbuses—be produced by 1979. Twenty-two inches is about as low as buses can be made without having them scrape the ground when climbing hills or going over bumps. The buses would also have to include ramps that would shoot out from underneath to allow wheelchairs and mobility-hampered individuals to come aboard.

The handicapped, however, aren't exactly ablaze with enthusiasm over the Transbuses. For one thing, the low-floor buses won't start rolling down city streets until 1981 or 1982, and a complete transition will take a good deal longer. The old buses must first wear out. What's more, how are the handicapped people going to get from their homes and offices to the nearest bus stops?

The center was in the midst of a suit against AC Transit, the biggest bus line in the Berkeley area, for failing to order accessible buses, as required by a California law, as well as by the federal order. AC owns a fleet of about 800 buses. As I talked with Kitty and Hale, a big AC bus rumbled past.

“Let us ride your bus,” Kitty shouted out the window.

Hale laughed loudly and nodded his head in agreement.

Another transportation issue had to do with BART (Bay Area Rapid Transit). One of the three accessible subway systems in the country, BART was planning to automate a lot of its stations by withdrawing agents and monitoring stations through closed-circuit TV. The disabled were aghast at the prospect. They sometimes needed help to pay their fares, and if someone has an epileptic seizure or a blind person falls on the tracks, no agent would be available to assist. The main issue is safety, though, since the disabled fear that muggings and rapes would climb at an alarming

rate. So Kitty and Hale were orchestrating protests to pressure BART into abandoning the idea. Pickets and rallies were being planned.

“We don't want to badmouth BART, because they are accessible to us,” Kitty said. “But this just isn't going to happen. No automation. Automation is for the birds.”

Kitty then related a horrifying story that illustrated the inequities in the benefits system for the handicapped. A 27-year-old woman named Lynn Tompson, afflicted by muscular dystrophy, lived with an attendant in Los Angeles. The pain from her disease was so bad that her legs had to be disconnected from her hips. Most of her medical expenses were being picked up by Supplemental Security Income payments. In general, Social Security laws define a disabled person as someone who can't engage in “substantial gainful activity.” Such activity, according to these laws, is any enterprise generating an average income of \$200 a month over a nine-month stretch.

That means, in effect, that someone who can't budge a muscle below his chin, but who holds a job paying a mere \$200 a month, isn't disabled in the eyes of the law, and thus isn't eligible for the SSI program or for Medicaid and other benefits. It's a rotten system, the handicapped agree.

Without paying staggering premiums, severely disabled people can't get conventional medical coverage. The architects of the welfare laws plainly never imagined that severely handicapped people might earn a salary. Under current laws, they would have to either make a pretty scant income and get benefits to help out, or else earn a fairly hefty salary.

Lynn Tompson wasn't happy sitting in her apartment and rotting away. So she started working as a dispatcher. She enjoyed hearing other people's voices and felt good about

accomplishing something. Eventually, she worked her way up to an income of \$500 a month, hardly enough to meet all her bills by itself, but she was gaining some freedom. Social Security people stopped in one day to check up on her and discovered her extra income. She hadn't reported it to them. Her payments were immediately cut off. What's more, she was notified that she owed \$10,000 in back payments that had been made to her. The only way she could live would be to go to a nursing home. Instead, in February of 1977, she committed suicide. She left a note saying that her death could be blamed on Social Security.

One of the cruel ironies of the case was the fact that, unbeknownst to Lynn, California had recently passed a measure allowing handicapped people to draw medical coverage, as well as funds to pay for home nursing care, while they're working. The law established a graduated scale so that, beyond a certain income, a person chips in part of his expenses and the state furnishes the rest. Handicapped groups are trying to persuade other states to follow that precedent.

“The tragedy of this story,” Kitty said, “is that Lynn Tompsons can be found all over the country. California has done something to rectify the benefits problem, but what are other states doing? The handicapped must scream at their legislators to start moving, because the laws are sending us to psychological deaths.”

Early the next morning, I caught a plane out of San Francisco, leaving the center behind. Beyond doubt, I had returned to the “real” world. I checked carefully the passengers aboard my crowded United Airlines flight. Not one was disabled. □

Sonny Kleinfeld is a reporter for the *New York Times*. He is presently at work on a book about AT&T.