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Independent Living

IN 1962, ED ROBERTS, FINISHING HIS SECOND YEAR AT THE COLLEGE OF San Mateo, decided to transfer to the University of California at Berkeley. Because none of the dormitories were wheelchair accessible (and none could accommodate the “iron lung” he needed at night), Roberts moved into Cowell Hospital, the campus infirmary. His presence attracted media attention (most notably, an article in the *San Mateo Times* with the headline, “Helpless Cripple Attends U.C. Classes”), which in turn drew other students with disabilities to the campus.

Unlike the program at the University of Illinois at Urbana-Champaign, where students with disabilities were expected to define their disability in terms of the rehabilitation model, the students at Berkeley early on began to develop a political consciousness that redefined their issues as social, not simply individual, problems. San Francisco was, of course, the epicenter of the counterculture of the 1960s, with the civil rights and campus free speech movements feeding directly into the antiwar turmoil of the mid- to late sixties and early seventies. Throughout the last half of the decade Berkeley was the scene of student strikes, demonstrations, and civil unrest. It was not uncommon, as more than one disability activist remembers, to see police and students clashing on campus. In such an environment, it was perhaps inevitable that the students at Cowell would come to see their own issues politically.

One result of this new awareness was the formation of the “Rolling Quads”—an advocacy group pushing for campus and community access—and the opening in 1970 of the Physically Disabled Students’ Program (PDSP), a pilot project funded through what was then the federal Department of Health, Education, and Welfare (HEW). As word of the PDSP spread, people with disabilities in the surrounding community who weren’t Berkeley students began to avail themselves of its services, which included help finding accessible housing and personal care assistants, wheelchair repair, and rudimentary paratransit where no accessible public transit existed. In addition, students who graduated from Berkeley or

otherwise left school continued to need and use the PDSP. And so PDSP students began meeting with these consumers to plan the next phase, and in March 1972 the Center for Independent Living, Inc. (CIL), was established.

The Berkeley CIL was the spark for what grew by the end of the decade into a national movement with its own defined “independent living philosophy.” At its core was the then-radical notion that people with disabilities were the experts on their experience and could best decide for themselves what services they needed and how to use them. Many of its early proponents, such as Ed Roberts, Hale Zukas, Donald Galloway, Kitty Cone, Gerard Baptiste, Corbett O’Toole, and Mary Lou Breslin, became national and even international figures. Activists in other parts of the country, including Fred Fay and Elmer Bartels in Boston, Judith Heumann in New York, and Max and Colleen Starkloff in St. Louis, heard about the CIL and used it as a model for their own communities, or—as in Heumann’s case—moved to Berkeley to work with the center directly.

In 1977, Berkeley CIL activists carried out the most daring and effective civil disobedience action for disability rights of the decade—indeed, perhaps up to that time—the sit-in at the San Francisco offices of the HEW.

The CIL’s Disability Law Resource Center, founded in 1978, split off a year later to become the independent Disability Rights Education and Defense Fund (DREDF), cofounded by Patrisha Wright, Mary Lou Breslin, and attorney Robert Funk, its first director. DREDF in turn played a central role first in opposing the Reagan administration’s attempts in the early 1980s to scale back the gains made by the movement in the 1970s, and then in getting federal disability rights legislation passed in the late 1980s, most notably the Americans with Disabilities Act of 1990.

The independent living model fostered by the Berkeley CIL was so successful that by 1995 there were more than four hundred IL centers throughout the United States, as well as in Europe, Australia, Japan, Central and South America, and in several nations of the former Soviet Union.

Ed Roberts (continued)

“Within a day or so I realized, I can do this. I can be free.”

Ed Roberts, transferring to UC Berkeley, experienced all the trepidation and excitement of a young person leaving home for the first time, along with the

additional feelings that went with living those first weeks and months as the only student with severe disabilities on a largely inaccessible campus in a largely inaccessible world.

I totally surprised [my mother with the idea of going to the University of California]. Her thought was, “Whoa. Just going through the College of San Mateo was a remarkable feat.” And then she started hearing me say, “I don’t want to stop here; I have to go on.” I think I realized before she did that the path to my future and to my working was going to be education, totally. Because nobody was going to hire me the way I was. There was so much prejudice about disability.

The biggest obstacle became [obvious] real soon: where would I live? I think we almost gave up because of that. . . . [We had] a list of places, like the dorms, like International House, like other places. . . . I went to I-House, which was inaccessible, and Jean Wirth¹ went in. Now, you can imagine, this guy from Pakistan or somewhere just looked at her, this huge tall woman, and just kind of freaked out. “Oh, no, we don’t have any students who—Oh, no, we couldn’t have him.” And then he got the manager to say the same thing. It seemed like wherever we went, there was no opportunity.

I had to go to the [campus] hospital. That didn’t sound very good to me. I didn’t have high hopes about this. Then I remember meeting [Dr. Henry Bruyn, director of Cowell Hospital], and he was so friendly. He knew a lot about polio, and he looked at me, and he thought to himself, he said out loud—I remember it was one of the first things he said—“There must be a lot of people your age from these old polio epidemics that are ready to go on now to college, and they don’t have much help.”

He said, “Why don’t we open the hospital? You could live here,” and I started saying, “But I could live there like a dorm, right? I know about hospitals; I don’t want to live in a hospital.” He said, “We can work those things out.” I said, “I want to have my own attendants when I can. But I can’t afford to hire twenty-four-hour attendants.” He said, “Well, that shouldn’t be a problem. You’re just one person. If you need help, you can have a but-
ton and get help. We always have attendants there anyway, every shift.”

[The day I moved into Cowell, I felt] a combination of excitement and fear. I remember the first room I had was in the older wing. It was kind of dark. Most hospital patients’ rooms are dark. It was good-sized. The first few days, my mother stayed there with me, which was real good, because

it was scary. And my brother came each day, just to say hi and to help out wherever he could, feed me or whatever.

In the meantime, I was beginning to interview some prospective attendants. Within a couple of days, I found a guy that had been an orderly at Cowell.

[When my mother finally left Cowell to go home], it was scary. I just knew it was a monumental occasion, because we really hadn't been apart except for my being in the hospital. Within a day or so I realized—I could do this, I can be free, even though it was a halfway situation. The big skill I had to learn was how to hire [attendants, and] how to describe what I wanted, but I've always been pretty good at talking.

[My brother] was a very good attendant when he was ready. He'd always drink and come in late, so it would be a rush in the morning to get out. I'd be up and ready in fifteen or twenty minutes—washing and everything; it was amazing. So he was important. I could get him if I needed him. If I needed to go get booze or something, he could go get it, until John [Hessler] later came. We figured out all the stores that would deliver booze. That was pretty weird for them, because the hospital was not supposed to have booze. They brought it all the way up. Once in a while, some of the nurses would help a little bit, but it was a conflict for them.

It's funny, because I started hearing a little bit about John. He was trapped in a county hospital. He was smart, he was going to school and was really ready to come to Cal, and I wasn't sure I wanted to give up my exclusivity. So I met John, and John was an imposing figure, let me tell you. He was six foot eight, and he had a huge wheelchair. He had a very slow power chair, but he had a power chair. It surprised me how large it was. I think we got along pretty much right from the beginning. He moved in right next door to me on the second floor there. . . .

By the second semester I was a veteran. I knew the campus, I knew myself more. I loved it, I loved the campus. I went to the football games. Every week, somebody would come and we'd sit out in the field. I went to Harmon Gym, although it was a bitch to get into. They had to carry me in. See, those were the days, my friend—It wasn't until later, after a couple of years, when I went to a history lecture—I think it was California Hall. I was getting pulled up the stairs, and the top part of my [wheelchair back] rest was removable. They grabbed that, and it yanked right out. I started to flip over, and some guys grabbed me and hauled me up. But I remember how afraid I was. I thought, I guess I'm going to survive, but I remember

later taking it a lot more seriously and always having four people lift me, always making sure that if I had to be lifted, it was safe.

I began to choose classes based on access. I remember I went to Dwinelle [Hall] and took classes in Scandinavian literature. . . . I remember learning about how to be a university student. My brother had learned a lot about it, but I remember also wondering how to take notes, and then discovering that if you gave somebody carbon paper, they would take your notes while they're taking theirs. Then I started making an announcement at the beginning of class, [asking for someone to make a copy of her notes] and could usually find a good-looking young woman. I'd get to know somebody that way, and they all loved it. Every day, they'd come by and give me the notes.

I had done most of my reading through high school lying in bed with a reading rack and a mouth-stick turning the pages. When I went to Cal Berkeley, I started using the reading mirror. You see this big mirror above me? If you flip it over, it's a reading rack. So I had a new mouth-stick made that was longer. But I had done some of this anyway, after I had my iron lung. So I got the rack from Fairmont Hospital, and we'd just put it up, we'd turn a mirror over, and it had these rubber bands that you attached the book with. They held the pages up there. Then I'd take out fifty pages at a time, and tuck it in. It took a little more time, but not that bad. I could be really free and independent with that, so I could read for an hour or two before I even got to the point [where I had to ask someone to turn the next batch of pages]. It was really nice.

I went all the through college reading [that way]. If you look at my bottom teeth, see how crooked they are, how they're pushed over? Mouth-stick. The mouth-stick did that, but it was worth it. So I could keep up with the reading, and I could keep up on all kinds of things. . . .

But I loved Berkeley. I really got into it.

Cathrine Caulfield

"Berkeley was the place to be."

Cathrine Louisa Caulfield was born on September 5, 1948, in Frankfurt, Germany. Her father was in the military but came from "dairy farmers and teachers in Minnesota," her mother "from railroad and medical people." The family moved back to the United States in 1952.

“I moved to California in 1964, the same year as my accident. I had been in California two weeks. I was playing in the water near the beach when a large wave hit me, knocked me off my feet, and my head hit the sand. The force of the wave crashed me on the beach. I had an injury to my fifth and sixth cervical vertebrae. This paralyzed me from the chest down.”

Caulfield went through rehabilitation at Letterman General Hospital at the Presidio in San Francisco, and then at the rehab center in Vallejo, California. “I did almost two years of rehab, which is unheard of now. But I kept progressing so I was able to stay. But as a teenager in a wheelchair, I kind of liked it there. There were other kids my age who were in the same situation that I was in.” Aside from the rehab regimen, which was often grueling, “We had bingo night. Then we changed it to beer and bingo night—much more fun!” How does one get beer to a group of teenagers in a hospital? “It takes one cool urologist, and a rumor that beer is good for kidneys, and voilà—beer and bingo night!”

Cathrine’s brother and sister both went to college (her brother became a doctor, her sister a teacher), so it was a given that she would go to school as well. Reading about the Cowell Hospital program in the *San Francisco Chronicle*, she decided in 1968 to go to UC Berkeley.

“I had an interview with Dr. Bruyn. At first he said he didn’t think so. There were no females in the program. The Cowell program was on the third floor of the hospital. If anyone needed anything—turning at night, help to the bathroom—the male orderly would come up from the second floor. They couldn’t let the nurses off the second floor. I assured him I did not need anything at night and let’s give it a try. Dr. Bruyn called in a week and said, ‘Yes, we will give it a try.’ Of course I was thrilled.”

Cathrine Caulfield died on December 12, 2003.

I moved into the Cowell program September of 1968. I guess that made it the first coed dorm at UC Berkeley. Just me and seven guys, like the Snow White story all over again. John Hessler, Ed Roberts, Jerome Frazee, Donovan Harby, Bill Glenn, and Scott Sorenson. I think Donald Lorence and I came at the same time. Herb Willsmore arrived a few months later.

I was very nervous. Moving in with a bunch of guys is a little nerve-racking. Everyone ate dinner in an old nurses’ station which happened to be right next to my room. They coaxed me out of my room after a few hours. We all became great friends very quickly. . . .

When I first met John and Ed we were basically roommates. I think they were happy to have a female on board. They were both smart, dynamic people. John was the tough and kind of grumpy one. He had a great sense of humor. Ed was the softer, kinder strategist. John got things done by hollering at you and Ed would charm the chicken off the bone. They were a lot of fun to live with and a major influence in my life for years. John was perfect for the director of Physically Disabled Students' Program, and Ed was incredible as the public personality needed for CIL. . . .

Ed introduced me to a friend of his, Linda Perotti. She was interested in working for me. She started working the next day. Linda's friend Barbara Karten was also interested. This was all new to me. But I quickly picked up on the attendant and disabled person relationship. I learned to hire people who could adapt to my needs. It's important to find people you are comfortable with. I was set up in no time.

Living at Cowell was very exciting and very busy. We were all going to school. In the evenings we would get together and discuss everything! We had to attend to our immediate needs, like privacy, curfews, attendants, and how to deal with the nurses from the second floor. I remember when I first moved there, if you came home after nine o'clock, you would have to climb the hill to the back of the hospital and be scrutinized by the staff (Nurse Benedetti) as to your whereabouts. Well, this didn't wash for long with us radicals from Berkeley.

We started organizing. The Rolling Quads were born. We spent many days and nights in Ed's room brainstorming. I remember a few nights breaking open a bottle of Chivas Royal Salute in Donald Lorence's room for his famous reality therapy sessions. This was a mix of how we could live together in harmony in this small wing of the hospital to who had partied late the night before and left incriminating evidence lying around. . . .

Of course, this was the late sixties, early seventies in Berkeley, and we were right in the thick of it. So sure, we might have indulged in a little bit of sex, drugs, and rock and roll. We partied hard but kept the ball rolling as far as the disabled movement was concerned.

We knew two people who were disabled, Jim Donald and Larry Langdon, who lived outside the dorm in their own apartment. They were both pretty low quadriplegics and were doing great on their own. Neither one of them [had ever] lived at Cowell as far as I know. They went right to an apartment. But anyway, we would go over and visit them, and they were

great. Then it started—“Let’s start looking around and see about accessibility.” Well, accessible housing was the pits. That’s how programs like PDSP started. If numbers of disabled people are going to live independently, where are they going to find accessible housing? Attendants to work for them? People to build ramps? All the stuff necessary to live each day. Would the landlord rent to you? Would they let you build a ramp? Could you get into the bathroom?

Linda Perotti and I found a place on Parker Street. Ed’s brother was moving out. It was a downstairs flat with only three steps and the bathroom door was wide enough for a wheelchair. Yes! The kitchen was awful but hell, who needs to eat?

We all agreed there were certain basic services that people needed as students and functioning members of the community. We needed a place to live, attendants to hire, a wheelchair that didn’t break down all the time, and a place to get it fixed quickly if it did. We needed a central spot people could come to find services, PDSP for the students and CIL for the community. New students would come from all over to check out the Berkeley campus and we would show prospective students around.

John Hessler was the obvious choice as the first director for PDSP as he had worked hard getting it all organized. I was on the board of directors and I believe Dr. Bruyn was as well. There was also someone representing vocational rehab on the board. [And then] the idea grew and led to development of the Center for Independent Living.

There was so much going on at this time. People were working on the housing survey. They would go door to door, to every apartment building, evaluating accessibility. Others were working on funding for attendant care which was in jeopardy for a while. Chuck Grimes and Andy Lennox put together a wheelchair repair shop in PDSP. Zona Roberts, Ed’s mom, was keeping the place [PDSP] together; Carol Fewell [Billings], my best buddy, was documenting everything, while trying to keep John calm. We had a lot of fun in that rickety old building, the smell of Top Dog² coming through the window, maneuvering the old blue van in and out of the parking lot, and assuring everyone our ramp from hell was quite nice. While all this was going on we had to stop the war in Vietnam and keep People’s Park alive.³

I remember passing out water to people marching against the war in Vietnam. Soldiers with guns were on one side of the street and we were

on the other. One day Ed and I were coming out of our poly sci class (Ed was the T.A.). As we were leaving the building, tear gas was dropped on the campus. Luckily we lived at Cowell then, and we ducked in as fast as our chairs could go. . . .

Berkeley was the place to be then. We were attending one of the greatest universities in the world. My professors were incredible. Sproul Plaza was the [Speakers' Corner] of the West. We spent many afternoons at the outdoor cafe on Sproul Plaza breathing it all in. . . .

It helped me realize a full and active life was possible. It renewed my self-esteem. I was living at home with my parents, attending City College, and that was as far as I could see. Moving to Berkeley gave me all sorts of energy. I no longer thought about "being disabled."

It was a crazy, exciting time and the disabled movement was part of that time.

Michael Fuss

*"The disabled were very ripe for becoming
a liberation type of movement."*

"I have been involved with politics since I was probably twelve or thirteen," says Michael Fuss. "I was concerned about nuclear war, I was concerned about the inequality in the country . . . between blacks and whites." Fuss's concern led him to join the Congress of Racial Equality (CORE), to participate in sit-ins to protest job discrimination, and to organize for CORE in the Watts section of Los Angeles, "prior to the Watts riot."

Born in Brooklyn in 1945, Fuss was fourteen when his family moved to Los Angeles. After graduating high school he took a job at the Southern California Gas Company, where he ran their mail machine. He continued his political work however, recruiting for CORE among blacks at the company "who were basically in janitorial positions only." By 1964 he was also a member of "Friends of SNCC" [Student Nonviolent Coordinating Committee], "involved in trying to generate publicity" about the disappearance of civil rights workers in Mississippi. He also began attending night school, transferring to U C Berkeley in 1966.

Needing money, Fuss took a job as a "personal care attendant"⁴ at the Cowell Residence Program, where he met Ed Roberts, John Hessler, Scott Sorenson,

and others who would become principal activists in the nascent independent living movement. Fuss himself had a profound impact on the development of the “independent living philosophy,” helping to organize the Physically Disabled Students’ Program and serving as assistant director from 1966 to 1972. In the meantime, he graduated from Berkeley with a degree in anthropology. He did “a stint in the non-profit world,” teaching grant proposal writing, after which he earned an MBA and moved on to a career in small business management, fundraising, and consulting.

Over the years we talked more and more about the future, and as the program at Cowell expanded we talked about what should be done. I think that John and Ed and a whole number of other people up there felt grateful for the opportunity, but also very constrained by the limitations of living in the hospital and being under a medical model, and of being actively discouraged from attempting to live on their own. Nurses would come up from the floor below, and it was helpful to have the nurses if somebody was in trouble at night, but also they’d come up and tell people to be quiet or they’d start ordering people around like they were sick.

Well, these guys weren’t sick. They had disabilities of one kind or another. Most of them were quads—not all of them. They were healthy, late adolescent to early adult, mostly males—though we had two women eventually—who wanted to be like everybody else and explore their life, explore possibilities. Don’t forget the time: this is the middle to late sixties, and everything was exploding, everything seemed possible.

The first idea was more of a group home sort of thing to be run by the disabled themselves—by the quads in this case. Put people in apartments, with a place that they could come for wheelchair repair, and maybe a meal, and advocacy with the Department of Vocational Rehabilitation.

A lot was happening in Washington. There was money coming out, mostly for minority students to develop special services out of the Department of Health, Education, and Welfare. Its mission was to help develop programs across the country to bring people to colleges and universities, and to provide services for people who had not had opportunities in the past. There was a certain amount for Appalachian whites, and there were certain amounts for Puerto Ricans, for Mexican Americans, and for blacks. The original concept did not include disabled. My

understanding is that Ed had a lot to do with including the disabled in the program. So we had to figure out what we were going to do.

The first step was to set up independent student courses, one every quarter, so that people living in Cowell could work on this and get credit for it. Sometimes they would be in the sociology department, sometimes in political science. Ed was gone by this time. He and Jean Wirth got involved in setting up Nairobi, which was a two-year community college in the black ghetto in East Palo Alto. Most of his trips to Washington seemed to be around that.

John and I basically taught these classes. In those courses we went into things like self-identity, what does it mean to be stigmatized because you're in a wheelchair? How do people treat you? What do you feel about yourself? How did this come about? What can you do about it? What are the barriers in the way of you becoming more independent?

They were independent study courses, basically. We would approach a professor with a course outline and with books, and then John and I would do the research and tell them what we were doing, and they would say, "Oh sure."

The courses were just open to the disabled students. There were some who took advantage of it and didn't do much of anything, but a lot of people really participated, and I think this raised the awareness of what the problems were and created a lot of ferment in terms of the direction to take.

I think as this happened and people started living more independent lives—and in some ways doing riskier things, like trying drugs and having sexual partners—it started bothering the nurses downstairs at Cowell and, therefore, the hospital administration. They started trying to institute more restrictive curfews, and all sorts of things. There was more pressure from Vocational Rehabilitation on people not spending enough time learning or not taking schoolwork or the appropriate courses. There were basically two people they chose to come down on the hardest: one was John Hessler, and the other was Donald Lorence.

John at that point had two quarters left for his master's degree, and they said that they would support him for only one more quarter, and then he would have to leave. Since he already had a bachelor's degree, there didn't seem to be any sense in them supporting him to a master's.

Their issue with Don was his flamboyant lifestyle. He took on kind of a hippie air: he wore wild clothes and let his hair grow frizzy. I don't think

he was doing much of anything that other people weren't, but he didn't hide it. So there was an attempt to remove him from the program.

That created a reaction. The Rolling Quads were formed at that point, basically striking back about this. There were all these threats, for instance, of a medicine cut-off. "We're not taking care of you." The nurses from downstairs were told they had no responsibility up there, so they were not to come up.

I think that was kind of the key in terms of group cohesion. It took a little while, but almost everyone came over to supporting Donald and saying, "We've got to do something, we've got to set something up. This can't work this way." There were a few holdouts. A few people just wanted to be neutral and go to school, which was fine. And there were a few people who were very angry at what was going on. I think that gave it sort of the jumpstart—as a community—out of Cowell Hospital, because people started moving out.

At that point the idea of a group home disappeared, because people started moving out and surviving nicely, and it was great for them. The idea of taking the Cowell project and transplanting it out into the community, that just disappeared, because people took this next step beyond, saying, "I don't want to live that way; I want to live the way *I* want to live."

As things got really close to the point—remember they were going to kick Donald and John out—the Rolling Quads informed the hospital administration that they were going to have a sit-in in their offices. Donald showed them how he was going to do it [laughter]. It was the greatest thing—Donald just sort of collapsed in his chair. It was terrific to watch. We called Ed up, and he said he would be able to get media coverage. I was contacting the various groups on campus I had contacts in. We were going through Arleigh Williams [the dean of students], and Arleigh let the hospital administration and Voc Rehab know that he was not taking anybody out of school for non-academic reasons except for violating University of California regulations, which obviously no one there had done. We were working all the channels, which is a hallmark of how I like to operate, which is applying pressure inside the university, publicity, radical movement, the students themselves. The deadline got closer and closer, and they folded. The understanding that there was that kind of support from the university, from the media, from the student movement, and from themselves, I think just made everyone blossom. The idea that you really could fight city hall and win completely.

What did they win? All the threats were withdrawn. They could live their lives the way they wanted within the university regulations and within reason. The university took a more active role in helping develop the PDSP. There was a new nurse, Edna Breen, who was very sensitive to their needs, understanding that they were college students, they were adults, most of them older than most college students, and they should live their lives appropriately.

At the same time, we started writing a grant for this Physically Disabled Students' Program, or PDSP. Basically the writing turned out to be Larry Langdon, myself, and John, with Donald doing a lot of idea creation and help. It turned out that none of us had ever written anything like this before, and it had to go out in the university's name, and they wouldn't put it out. Arleigh Williams was very impressed with Ed, and John met him through Ed. John went down there and talked to Arleigh, and they went over it. Arleigh came up with this guy who was in public health, who was from New Zealand, and who had written a lot of grant proposals. He took our material, talked to us, and then put it into the right format and showed us how he did it. He was at UCB for only two years; he went back to take over the public health for a number of islands that New Zealand administered under U.N. trusteeship.

It was a good program. It was oriented toward the students, and we really felt like we could help students and bring students in from all over. We had money for recruiting. We also decided to put me in charge of non-university CIL type of activities: setting up advocacy sorts of things, political organizing, doing things in the city, doing things for non-students—all of that sort of thing.

John ended up being the director, I ended up being the assistant director, Larry ended up being the counselor coordinator. And we gave ourselves six months before the university cracked down. We said, "No one's going to notice us or do anything for at least six months." Full bore, out there for six months, then we'll deal with what happens.

Now this gets to the role of John as bureaucrat. John—deep, resonant voice—had a real presence. Very controlled. I don't think anybody in the university ever saw him lose his control. I have. [Laughs.] He's reasonable, forceful, very clear mind. We decided my role with the university was to continue as agitator. When we were having problems, I would go in first and ask for everything and be extravagant and crazy. Then John would come in with what we really wanted, as the peacemaker. It was

very effective. Behind me was the threat of students coming in in wheelchairs and sit-ins and all that sort of thing. Which they definitely did not want. They had enough problems with healthy people, physically whole people having sit-ins and being arrested.

After PDSP came into existence, the university really put its accounting [department] on us. We started understanding that you couldn't transfer between accounts except for minor amounts. We were all fairly naïve at this point. We were all griping that we didn't have free money—soft money I think it would be called today. I have no idea where the idea came up—but there had been an election—the student government was very big at that time, and the students had voted to tax themselves to support some program for blacks. So we said, “Hey, why don't we get some money that way?” Don Lorence was put in charge of that. So it was a Rolling Quad effort. The first slogan was “Nickels for Cripples,” and then “Quarters for Cripples.” I have some posters.

It worked. It passed. It was twenty-five cents per student, for close to 30,000 students. In 1970 dollars that's a lot of money. That money was soft money; it had no strings attached. It was basically used for starting the CIL. We made space in our office, bought office equipment, extra telephones.

At this point I'm living in a commune, with a total of seven adults. I'm living with my wife and a number of other people and two kids. People know my home arrangements and are curious, and I talked about it. There were a bunch of other communes around, and there were ways in which people were trying to say, “I'm supposed to live this way, but maybe I don't want to. Maybe I just don't want to go through the university, live in the dorms, graduate, get married, get a job, move to the suburbs and have kids.”

We started talking about how to do that and decided that we had to do it with community-based people. And so I made a bunch of phone calls. We decided to have a meeting—the royal “we”—John, Larry, and me. We each made up lists of people who we wanted for this meeting. Not just anybody, but people who could eventually be on a board or something like that. We didn't want it too large because then it wouldn't function. I remember calling Hale Zukas and a few other people. We gave them some material, and left, saying, “Here you go!” [laughter] John stayed. That essentially became a board meeting. I think it was Phil Draper who became the first chair of that.⁵

I think you can start seeing in the lives of the people on the Cowell floor, people choosing to live different lives. We had our hippies up there

who dropped acid and smoked pot. We had our beer drinkers who used to get sloshed and sing songs and chase each other and yell. We had our political activists—not that all these categories are exclusive. We had people who were much more like “let me get through, get a job, get married, and live in the suburbs.”

All this contributed mightily to the idea of, “They say I can’t do this [because] I’m in a wheelchair. Who says I can’t do it? What’s in it for them to keep me here? They’re getting lots of money at the hospital for keeping us, all this money from Voc Rehab, and they’re getting status for having this great program helping cripples. I don’t want to be helped; I want to live a life.” People started wearing their hair longer, and facial hair, and hippie-style clothes, and going to concerts, and doing all sorts of stuff like the other students and non-students around Berkeley.

This was an era of the liberation movements all over the world. Strong anti-colonial feelings. This was the start of the women’s movement, this was the start of the gay movement, a culmination in some ways of the civil rights movement, and the start of the black liberation movement. Attacks against any kind of hierarchy, attacks against patriarchy.

The disabled were ripe for becoming a liberation type of movement, wanting to define themselves and live life as they wanted, being people who were more hemmed in than most because of their physical disabilities, because of the medical model, and because of society’s view of them. So the time was very critical in terms of the individuals feeling that and the society around them—Berkeley—being very supportive. The idea of people in wheelchairs having sit-ins or people in wheelchairs dancing and partying was a gas. That was just obvious, wasn’t it? How come we never thought of that before?

Kitty Cone

“This is the most wonderful thing.”

Kitty (Curtis) Cone first became active in the disability rights movement in 1972, when she moved from Chicago to Berkeley. Only twenty-eight at the time, she was nonetheless by then a seasoned political organizer, active since her college days at the University of Illinois in the civil rights, antiwar, and women’s movements. Like Michael Fuss, she was perhaps typical in that she, like many activists of the seventies and early eighties—Mary Jane Owen, Bill Bronston, Wade

Blank, for example—cut her political teeth in movements other than disability rights.

What was perhaps less typical was Cone's evolution across so much of the political spectrum. Coming from an affluent and influential family, as an adolescent Cone was a self-described conservative Republican, entering an American Legion essay contest, writing to the FBI for help with an essay on the dangers of communist infiltration. By the time she arrived at Berkeley, Cone was herself a committed communist with several years' experience in the Socialist Workers Party (SWP), a leader in the Students for a Democratic Society, an editor of Left publications, and among those brutalized and arrested during the "police riot" at the 1968 Democratic National Convention in Chicago, where she lived and worked for several years.

"The undercover cops in Chicago were just notorious. There later was a grand jury investigation into the cops, because they were working hand in glove with the right-wing Legion of Justice that was a very racist, violent group that was attacking the different radical organizations. The SWP was under constant harassment by this right-wing group and by the cops as well."

Cone was born in April 1944, and was diagnosed with muscular dystrophy at age fifteen, though she'd been having symptoms for years. She and others around her considered the diagnosis tantamount to a death sentence, and this added an intense sense of urgency to her quest for social justice. Once in California, Cone offered her commitment and her highly honed organizing skills to the Center for Independent Living.

I moved to Berkeley in the summer of '72. I came out to California because I had friends out here. I said to the guy who was the secretary of the SWP at the time, "I'm miserable in Chicago. I'm having a nervous breakdown." He said, "Where would you like to go?" I said, "What about California?"

I was the assistant organizer of the [SWP] Oakland/Berkeley branch for a number of years. I worked in this office on Telegraph Avenue that had one room downstairs. I got this Advanced wheelchair. It was the best wheelchair they ever made. So I had this super chugger wheelchair that I loved, and I lived about a mile away from the branch, straight down Telegraph Avenue. I would leave my chair at the bottom of the stairs, and the organizer, who was a very strong guy, would transfer me into my pushchair I had there and haul me up this flight of stairs into the regular branch, and that's how I dealt with that. I remember that I was very upset

that there were no curb ramps on Telegraph Avenue. So I would drive my chair home in the street, and a comrade would follow me home in the car to make sure I didn't get run over. . . .

My wheelchair kept breaking down. I had bought it through Thrifty Rents, and the guy at Thrifty Rents said, "You shouldn't have to wait while we send this piece back to the factory every time," because then I wouldn't be able to use my wheelchair; I'd have to use the pushchair. He said, "Why don't you call up the Center for Independent Living?"

So I called, and someone came down and jacked my chair up and replaced the part. I thought I had gone to heaven. "This is the most wonderful thing. This is the way it ought to be."

I started doing volunteer work at CIL because I was so appreciative of the wheelchair repair shop. So I decided, number one, that I wanted to be involved with this organization, because I thought they were doing good services. Number two, I wanted to earn money—the SWP was paying me forty-five dollars a week or something, and then I had trust funds from my family, which were not enough to pay for attendant care. I wanted a paying job at CIL. I went to Ed Roberts, who was the executive director at that time, and said, "I really am impressed with your organization, and I would like to work here. Do you think that you have a place for me?" He said, "What do you like to do?" I said, "The only thing I know how to do is political organizing." He said, "Well, then you can be a political organizer. Go work with Hale Zukas."

I reported in for work, and Hale was at that time handling everything for CIL from benefits, SSI, the Homemaker Chore program—which was what attendant care or personal assistance services was called in those days—architectural barriers, mobility barriers, anything like that. Hale dealt with all of it. My job in the beginning was to interpret for Hale. He would take me to meetings with him, and I would translate for him.⁶ So I would travel to Sacramento with Hale and whether we were lobbying or just meeting with agency officials or developing testimony or whatever, I learned a great deal. Hale knew more than anybody about all of those issues. As a result of working with him, I learned them as well.

Hale was just a genius on transportation. I remember once going to an APTA [American Public Transit Association] conference with him. I believe it was in 1979. And we were going around to the different open houses that were being hosted by different vendors there. And we went to one that was General Electric, I think. Hale got into this technical discussion with

somebody who at first probably wasn't going to pay any attention to him. Then they got totally entranced by him because they got into this discussion about what kind of glass there is in the Amtrak train windows, the history of that type of glass and why they chose to use it. I was trying to translate, and I didn't have a clue what the next word that was coming would be.

A whole variety of issues would emerge, some of which I knew very well because I was working on them regularly, and others which I didn't have any knowledge of. I would be told, "Take this on as a project. Organize around it." This has been a positive thing and a negative thing for me. With the exception of the transportation issue, I didn't have a very consistent job. I'm a fast learner, and I can articulate issues well if they're explained to me. So I would be told, "Okay, this is happening; we need to organize around it, we need to have a demonstration. They're going to cut the county funds, or they're going to take the agents out of the BART stations," or whatever. "Go do something." And I would collaborate with Hale or with Judy Heumann or with Greg [Sanders] or whoever.

I loved the CIL from the minute I got in there. I liked everybody a lot and I felt like they all had a lot to teach me, because they had been living independently, in a way that I hadn't, because I had had this built-in support system through the SWP. I was definitely out there in the world doing my thing and making changes; but I didn't have full control over when I was going to take a bath, when I was going to do whatever. And here were these people choosing and hiring who the people were who were going to be assisting them, and really managing their own lives.

The other thing was that it was a coalition. It was people in wheelchairs, people who walked, who used canes, crutches, and people who were blind or vision impaired—so it was not just all people in wheelchairs. And there were people who were severely disabled like Ed Roberts or Greg Sanders, not just people who could push their own wheelchairs. And there were people who depended on personal assistant services, not people who would spend an hour trying to sit up in bed because they were being watched over by the Rehab Center [at the University of Illinois]. People thought of it as a cause—not just a service, and I think some of the friendships that got forged in those early days, even though people were very, very different, had a great deal of meaning.

The staff was so small that we could all fit into this fairly small conference room. Oh, God, when we had staff meetings! I had come from an organization that had these very structured meetings—which I really

prefer. People would give reports on their work, and then you'd discuss it and decide where you were going, and then you'd vote to carry it out or whatever. Ed would call these staff meetings, and would just start talking, and he would just roam all over. I would always come with a report on what we were doing, and half the time I never got to give my reports [laughs]. So I would just butt in and say, "We're having a demonstration. Will people please come? See me later."

So when there was an issue, like when the federal portion of the Homemaker Chore money had run out and the state and counties were not willing to pay the whole amount—CIL always took the leadership because they could say to clients, "Your attendant care money is going to run out. We're going to organize a demonstration. We will provide transportation, we'll help you get to Sacramento." So we would just organize caravans. Nowadays things are very different—nowadays people are working regular jobs. Young people get rehabilitated and go out in the world and take advantage of all the gains that we've made. They're not around and available to take their van off to demonstrate in Sacramento, and the will doesn't seem to be there either.

The early seventies was still a period of radicalism in Berkeley. There was this group of people who were real pioneers and considered ourselves a movement. We hung out and socialized together a lot—we were younger—we were in our twenties. You went into CIL, you got your wheelchair repaired, you talked to people, you found out what was happening in the community—like maybe there was going to be a demonstration around attendant care or so-and-so was having a poker party at their house. . . . It was a happening thing.

Carol Fewell Billings

"Being rebellious in an extremely productive and positive way."

Born in 1949, Carol Fewell Billings was a self-described "walky" during the early days of the independent living movement, arriving in Berkeley in 1969. Soon after arriving she married Larry Langdon—then a student at the university and one of the early Berkeley activists—whom she had known since high school in their home town of McKinleyville, California. Like Michael Fuss, she worked as a personal care "attendant" for residents of the Cowell program, and as staff at the Physically Disabled Students' Program. She was there when

the CIL went from being “a closet” at the PDSP to occupying a two-bedroom apartment on Haste Street in Berkeley.

Billings and Langdon eventually divorced, and Billings left Berkeley to return to McKinleyville in 1977, where she became a teacher. Now retired, she has visited Berkeley from time and time, and “there are people in wheelchairs everywhere! And we used to remark on that: ‘Look at all the crips! Where’d they come from?’ Now there are even more, so I think that shows that if you build it, they will come.”

I started working at Cowell as an attendant. I can’t remember who I first started working for—probably Cathy Caulfield or Judy Taylor. They were my main people.

It seemed pretty hospital-ish, except there were people buzzing around having a good time or studying. I think the rooms were fairly personalized, but I don’t remember to tell you the truth. We’d play music or hang out.

It was a job, and it was people I knew, and it was money, and I had worked in Berkeley as a nurse’s aid, at a convalescent hospital. So I knew the attendant kind of stuff, bathing and getting people dressed and how to lift and all that. I’d done it. People in convalescent hospitals are fairly passive and it’s basically keeping them clean and maybe moving them some. With active people you’ve got a lot of stuff that—in terms of catheter care or just in terms of getting them dressed—people want to get dressed a certain way and so there was not the passivity that there was in that other kind of place.

I believe Ed Roberts had gone to Palo Alto by then, or maybe to Washington. I don’t remember the first time I met Ed, but he was always a presence even before I met him, because he was the guy who started it.

It was like a subculture of Berkeley. I’ve thought a lot about how much trouble I could have gotten into at that time in that place. I know a lot of people who went down to the Bay Area and got involved in drugs or crime or different things as a way of working against the system. I feel like I was in the best of all possible worlds because I got to have that experience of being rebellious in an extremely productive and positive way and learned so much about so much.

The students at Cowell eventually got a place, and money from the university to start the disabled students’ program—the PDSP. You came

up the ramp and went into this little small receiving office and then into a large common area which I think of as the lunch room because that's where we always ate. And then there was a little hallway into the kitchen, I believe, which was a very important room, and then into one of the main offices. If you went through the doorway, to the right, the wall on the right was the walk-in closet where CIL started. . . .

I remember thinking that this is so great to work here, because it was almost like not work. I mean, it *was* work: there were things to be typed, there were phones to answer, and people to call and so forth. And during grant-writing time it was always crazy and long hours and cutting and pasting and typing on my old Selectric. I thought I was in heaven! An electric typewriter!

Lunch was the pivotal point of the day. We all gathered. There was a communal atmosphere, because the walkies would cook and the crips would put in money. We ate together and someone had cooked the food and it really added to the feeling of community that we had. We would take turns cooking—each person had a day. And I really loved that.

We must have advertised for assistants. And Zona Roberts [Ed's mother] was really active in the CO thing—the Conscientious Objectors—so she would get people. In fact, she had people living in her house who were COs and it was like this conduit to the disabled community, because they needed service work and here was the perfect work.⁷

A lot of what we did, or a lot of what I remember doing as I became more competent, was working with students who were coming into the university. You've got people coming into Cowell or into the dorms—that's the first place you would look for housing. And we must have had listings or other ways to find it, too, or just to help them if they were looking for a house—help them to get a ramp put in or to modify the place in some way or other—because there were people out there who were willing to do that kind of thing. Maybe they weren't attendants, or maybe they were attendants, but they also would build a ramp, or come in and fix shelves or whatever it was. There were just so many people who were not into working nine to five but who needed jobs.

I started working at CIL when they had moved from the closet up to Haste and College, their first apartment. There was a living room, and I believe there were two bedrooms. We weren't there very long. . . .

There was definitely a need for the CIL, partly because PDSP was doing such a good job of serving the disabled community. At least that

was our feeling—that here was a place where people could come, they could live independently, they could be mobile, there would be people to accept them, they could be visible; and so more people would come in and they weren't students. . . .

When I first got to CIL I was married to a disabled man and there was a lot of discussion within the community about personal relationships and how you deal with the different problems. And one of the problems was the way people would look at you and view you as a couple or as a person. And I think as more people became visible as independent human beings or powerful human beings or human beings with purpose or whatever—things sort of organically started to change. Just by being around it, you can't but see things differently.

And then as PDSP and CIL became more of a force in the community, always with the idea that the leaders were the physically disabled and blind and deaf themselves, that was another way of changing people's views. And the other thing was keeping in mind that there are these people who need certain things so that whenever new streets were built, ramps were put in. It seems like a really small thing, but having that in the consciousness in the community was pretty important. . . .

I remember a party at John's where they played this song called "Don't Stop the Music" over and over and over. It was a country western song. People drank like crazy. There was a lot of marijuana. Ed always had the best dope in the world. People would have parties, they'd go places together, we'd hang out together, you know. . . .

It wasn't [just] another job. It was exciting to be working in something on the cutting edge. That was just part of the whole thing. It was like the social life was integrated, the movement was integrated, everything was integrated as far as I was concerned.

Donald Galloway

"We would draw from the civil rights movement . . . but we were not actively involved in the black movement."

Donald Galloway had a different perspective on the early days of the CIL. An African American, he was among the first to call out the CIL specifically, and the disability rights movement in general, on its lack of racial diversity.

Galloway was born in 1938 in Washington, DC, and disabled at age thirteen after being struck in the eyes by an arrow. Lack of proper medical care led to the wounds becoming infected; he was left totally blind. Galloway subsequently spent three years in a residential, racially segregated school for blind children in Overlea, Maryland.

Galloway's first involvement in politics came after his family moved to California in 1954. In high school he became vice president of the local junior branch of the National Association for the Advancement of Colored People. His first efforts in disability rights activism, understandably, were in the blind community, as a junior member of the National Federation of the Blind (NFB). Galloway graduated from high school in 1958, attended college for a short time, and then left school for a career as a folk singer. He returned to school in Los Angeles and San Diego to earn his BA in science and sociology and his master's in social work. From 1969 to 1971 he traveled throughout Latin America, researching the social, political, and economic status there of people of African descent.

Galloway was introduced to the IL movement in 1974. By then he was living in Berkeley and disillusioned with the factionalism inside the NFB. Ed Roberts invited him to work with the CIL as its director of services for blind people. Galloway left the CIL, and California, in 1977.

Galloway became director of Peace Corps programs in Jamaica in 1978, helping to remove barriers to disabled Americans wishing to volunteer overseas. Returning to the United States in 1980, he coordinated Peace Corps efforts worldwide in connection with the United Nations International Year of Disabled Persons. From 1982 to 1987, Galloway served as director of the District of Columbia Center for Independent Living, and from 1987 was the manager of the Special and Demonstration Programs Division at the District of Columbia Department of Housing and Community Development.

Donald Galloway died in October 2011.

When I first got to CIL, I was fascinated by the repair shops that they used to have. They used to have a wheelchair repair unit. I thought that was a great idea, to have a portable unit that would go anywhere in the community and fix people's wheelchairs that would break down.

I had to experience working with people that I couldn't understand initially, like Mr. [Hale] Zukas. I couldn't understand him. Ed Roberts would be talking to him, and I just couldn't understand how could Ed be talking to this man, when all I could hear was "Mmmm, mmmm." Then

I found out that Zukas had a PhD in Russian history or something. My whole attitude about people with cerebral palsy or speech impediments changed drastically. Before, I had the same attitudes that other people had, that if you didn't speak well, you were not educated, you were mentally retarded or whatever.

Then I started running into a blind woman named Janet [McEwan Brown]. She ran the newspaper there; she did all the publications; she was totally blind and did all the editing. I started running into people doing all these wonderful things.

I didn't see very many black people. I was the first black person that I knew of at the center, hired on the staff, full-time. Ed was a very casual guy. He was a strategic planner too; he would put people into positions that normally they wouldn't have thought of. He said, "Now that you've got the blind component started, would you be interested in heading up our research team on independent living standards?" So I became the director of the peer counseling research component of the agency.

That was very interesting. I had PhD's working for me, and people that were very skilled in doing research. [But] that was [also] kind of a bummer period, because I was the only black, and I started bringing black people into the center as drivers and attendants, and bringing in professional types. . . . There was just a handful of us that came in, but we came together and decided that we needed some input into this system. . . .

We were in a predominantly black community. The city council was predominantly black, the whole area was predominantly black. The movement was predominantly white. We needed to reach out to the black community in Oakland, get the Black Panthers involved, and any other group that would like to be involved.

So I went to the board of directors and said, "We're going to start a black caucus to make sure we get our voice heard." That went over like a lead balloon, because the attitude was, "We're all one, and there's no need for it. That would be like a blind group trying to say that we wanted the blind to be paid attention to more." It was part of the whole attitude that no special group should be dominant. Although the people in wheelchairs, the people that were physically disabled, basically ran the joint. I don't think it was consciously said, "We run things, and we're not going to let you disturb that," but I think we knew that the emphasis was with people that were physically disabled.

The process was we would meet as a caucus and then the issues would

be brought to the board and then it would be shot down. Like, “We are not racist, [but] we do not think we need to change our system to accommodate any particular group.” Basically: “Be quiet.”

It was ironic. You had the center identifying with the university more than it did with the community, although it was a community-based organization. Most of the funding for the center was because of the black influence on the city council, on the mayor.

All of Berkeley was very radical at the time. We were involved in a revolution not only with disabilities, but that whole drug culture, that whole hippie thing. If you wanted to start a group in Berkeley, right on. It was a place where new ideas could get a real good start. The city council was controlled by blacks, it was responsive to our needs. For example, there was an effort to restrict people in wheelchairs to [the first] floor of buildings, because of fire dangers. The Center moved from a three- or four-bedroom apartment to a small unit on the second and fifth floor of a building. The fire department wanted to move us all down to the first floor, and the disabled community went and testified before the city council and said, “No, we want to take the same risks as everyone else,” and they understood it. They said, “You can’t restrict people with disabilities to the first floors of buildings.” There was a lot of tolerance of our differences in Berkeley. There was a whole bunch of white people who were disabled coming into the city, and people were like, “That’s cool, we’ll make space for you.” The city opened up.

I didn’t see a lot of black people being served. I saw a lot of people coming in from Chicago and New York, and all over the country, coming in to go to school. You could come into the center, and 90 percent of the people being served were white. I don’t think that was deliberate; it’s just that a lot of the people that came in were college students. They would come into the community, and there would be accessible places for them to live, and there was a center, the streets were becoming accessible. It was kind of a mecca for all of America, for people to come in, and most of those people that came in were white. It wasn’t that we would go out to the NAACP and talk to them about disability groups or go to the different black groups, churches, and talk to them. That wasn’t the emphasis. The emphasis was with the university, with the rehab centers, with the bureaucrats, and with the consumers that were coming into the city.

There was a severely disabled man in the Black Panther Party named Brad, and Brad was our link to the Black Panthers. We would go and

provide him with attendant care and transportation because we had a small transportation system going, a fleet of vans going out to the community. Ed made a decision that he wanted us to get more involved with the Black Panthers and with Oakland. So we would go to some of their meetings and explain our programs. Because Brad, one of their members, had a severe disability, we were quite accepted. This would be in the mid-1970s—1975, 1976, somewhere around there.

I think because of Ed having a political science background, he understood that the black movement was very similar to what we were trying to accomplish in the disability community. But most of the people there didn't have that same level of consciousness. I think the consciousness was that we're starting a disability movement, and our main focus was disability. We would draw from the civil rights movement, some of the principles of nonviolence and advocacy and protest. We would borrow some of that, and we would appeal to the black politicians on those levels. But we were not actively involved in the black movement, in a conscious way, other than to use the similarity to bring about some empathy for our struggle.

To be realistic about it, the organized black community did not really identify with the struggle of people with disabilities in the same way. The black movement, in some instances, did not want to include people with disabilities because they thought it would disperse the power, the emphasis on black history. In fact, Senator [Hubert] Humphrey, even back in 1964, when the Civil Rights Act of 1964 came up to be voted on, wanted to include people with disabilities, and the organized black community said, "No, this is a civil rights bill that is going to have to be limited to the minorities. We don't want to include people with disabilities." So, yes, the emphasis on our side was to try to touch base and identify with the movement. But I don't think the black community at the time, the black movement across the country, identified with the independent living struggle.

Corbett O'Toole (continued)

"We're all branches off of the same tree."

Moving in 1973 from Boston to Berkeley, Corbett O'Toole soon made connections with the disabled women's community, and then the Center for Independent Living. In 1974 she got a job at the CIL, working in "attendant referral,"

helping to link up people with disabilities who needed help with day-to-day tasks with able-bodied people (like Fuss and Billings) looking for work as personal care assistants.

What was CIL like? It was a cross between a party, a job-training program, and an office. It was sort of like all three at once. Everybody was a client of the agency. I mean, we didn't have that concept of clients. Almost everybody that worked there was using the services of the agency in one way or another, and the non-disabled people that worked there were people intimately connected to the community. The same people you worked with or the same people that came in for services were people that you partied with and that you hung out with and that you were friends with.

So it was a very free-flowing environment, which I think allowed a lot of things to happen. First of all, it allowed a lot of disabled people that had never thought that they were ever going to be able to work to come into an agency where other people that looked like them were working. There was like a lot of that kind of social hanging around so that people got to see what it meant to be in a work environment. And it allowed people to help out and try out and learn some basic skills—because for those of us that grew up disabled, there was no McDonald's, there were no entry-level jobs for most of the people—certainly the people in chairs that came up to CIL. This was the first time they ever saw people in wheelchairs working, and so it was a really good experience for people to have.

In those days there was no public transportation. BART was not accessible and the buses were not accessible, so CIL also ran a transportation service. It ran a van repair shop and a wheelchair repair shop, so lots of people in the community got to know each other by using those basic services for people that used chairs. Blind folks came to use blind services. That was the only place in town that had a free braille writer and material in braille and information about how to get books on tape. It was the Information Central for the blind folks in town.

So the combination of the services for people in wheelchairs and the services for the blind meant that it was really like a community center, like the way some senior centers function now—the good ones, where people are really involved. There would be classes on independent living skills, classes on basic sign language, but they were informal classes taught by your friends, more or less.

There were parties—every holiday was a party. We were all young in those days, so nobody thought too hard about dying. Nowadays, I'm going to more funerals than parties some years, but in those days you were just going to parties. People got to be outrageous. I think that's the thing that was wonderful for me about being there. I had always been really closeted about my disability because it was not an okay thing to be disabled, and here I was hanging out with a bunch of people like quads who couldn't hide their disability, couldn't pass, and we were just getting crazy.

What I'm remembering was the Halloween parties, particularly, where the wheelchair repair guys hooked up a power chair to be operated by remote control and they put a stuffed animal in it and it started driving around the party. Or Dale Dahl, who was at that point dating Maureen Fitzgerald. Maureen worked at the Berkeley Women's Health Collective, and Dale showed up with a speculum, a surgical mask, latex gloves, and a surgical gown, and then went around to all the women and said, "Oh, you want a free exam?" It was just outrageous, very funny and very silly and very wonderful—just people with disabilities being really off the wall crazy and changing the world.

In a traditional funding sense, we were not fundable by anybody's stretch of the imagination. Yet, the work that we were doing was really important and making a difference. We helped people make the transition from no access and no independent life—living with their parents, or living in an institution, living in a nursing home—to believing that they could make the transition to having their own life, defining their own destiny and then actually helping them to accomplish that. It was not the agency that did that, but it was the act of having a central place for information and resources and community. People could just essentially show up at our door, which they did rather frequently, and sometimes too frequently, and we would help them. The whole community would pull together to help each other, so there was a sense that we were in it together.

There was a real sense that we were doing something that had never been done before, that there was no other model, that we were in a struggle essentially for our survival. A number of people that had come to CIL, especially spinal cord injury people—quads—had already been in nursing homes. Some of the old polios had also been in nursing homes as kids or spent their whole childhood in hospital-schools. And there was a

real feeling that they knew what would happen if we didn't succeed, if we didn't create alternatives—that disabled people were just going to end up in nursing homes, or that the people that could pass and survive, would pass and survive in isolation. They were going to do just what they did before—live in isolation, live in their parents' house, depend on other people to get them in and out of a building, out of a home, and not be able to work or have a sex life—not be able to do anything.

We would literally get calls from the San Francisco airport police saying, "We have this person. They're in a wheelchair. They say they're coming to CIL. Could you please come get them?" This was like Friday afternoon, they'd flown in from New York, and we didn't know who they were! They thought that if they physically just got themselves on the plane, we would figure out how to take care of them. And usually they were right and usually something happened.

I came out as a lesbian in late '74. CIL was a place where there were a lot of lesbians. There weren't very many gay men but there were a lot of lesbians and so it was a place where I felt pretty safe. Even the straight men were not particularly homophobic because, like I said, we were all in it together. Although there were lots of things that could have divided us about age or race or income or whatever, we just chose to be in it together and see each other as mutually helpful. So that was one thing it gave me—it gave me a sense of home.

It also gave me a lot of information, stuff that was not available in books. I didn't know anything about spinal cord injuries before I started working there. I didn't know anything about muscular dystrophy. I didn't know anything about deaf people, about blind people. I had gone to camp with disabled kids, but that's really different than hanging out with people and dealing with leg bags, or Braille, or sign language, or going with them to the grocery store and the coffee shop.

It was hanging out with people where you really got to experience in a much more direct way what their lives were like. How did people who were quads physically manage in the kitchen, how did they manage in the bathroom? How do you manage attendants? What's the role of an attendant, how do you balance that? How do you have a sex life? What kind of sex do you have? How do you find partners, how do you communicate about it? How do you have kids? I mean, all of that stuff—because somebody at CIL was doing all of it. Judi Rogers was having

babies, Janice Krones had already had a couple of kids. Certainly closer to the beginning of the eighties there was a whole disabled baby boom, but in the seventies that wasn't as true. Certainly people were having lots of sex—I mean, there was lots and lots of sex going around. Kitty [Cone] was having sex and I'm like, "Well, if she can have sex, I can have sex" [laughs].

So there was a feeling that anything was possible because the jocks were off being jocks, and the eggheads were off being eggheads at school, and the teachers were off teaching, and the parents were off parenting, and everybody was crippled.

So it was very educational. You also got the negative ways that society tried to stop people from making choices—how they tried to not give birth control information to people with certain disabilities or tried to take their kids away. You kind of got the whole spectrum.

By the time I left CIL, I felt like I had value as a person, I felt like I had value as a leader. I had had opportunities to plan events, to figure things out, to write. I had done a lot of training, particularly within the non-disabled women's community around disabled women's issues with other disabled women. I had also kept the Disabled Women's Coalition alive and ran it as an office out of UC Berkeley. I was able to work. I had a career.

The reality of my life, now twenty years later, is that many of the people I was friends with in CIL in the old days are the people I'm still friends with. It became a base that's essentially lifelong, even though a lot of us went off in different directions professionally. Because we came through the same door and because we see all the work as intrinsically tied together, it doesn't matter whether people are doing computers or parenting or school work or whatever, it's all the same root, we're all branches off of the same tree.