

Our Man on the Moon



The first 'severely disabled person'
to attend a top ten university
was seen as both a hero and a freak

true stories of the
higher education of Ed Roberts,
as told by himself

It was a bitch to get in — I mean, they said, ‘Well, we tried cripples, and it failed.’ This was 1962. I had gotten my Associates degree from San Mateo community college in the meantime, with high grades, so they couldn’t legally refuse me, but ‘We tried cripples and it failed!’ I love that!

They told me there wouldn’t be anywhere for me to live, that my iron lung wouldn’t even fit into a dorm room. So I went to see the dean, Arleigh Williams. He was a little freaked out by me, as most people were then, but he sent me up to the Student Health Service at Cowell Hospital, to talk with the director, Dr. Henry Bruyn.

Bruyn had seen people with polio before, so he wasn’t frightened. And it occurred to him that there were probably a lot of young people like me, who had lived through polio and were college age. So he invited me to come live at Cowell [Hospital].

I insisted that I would be independent and not a patient — and he agreed. He said I could hire my own attendants and that the hospital staff would be available at night if I needed them. It was like a dream come true, and I started at Berkeley in the fall of 1962.

Once I got there and adjusted — and succeeded — the university was willing to take risks with other severely disabled people. John Hessler came in the next year. By 1967, there were eight or ten of us. I had to struggle so hard to do what I wanted to do that I just thought, ‘Why don’t we struggle together?’

*‘We tried cripples
and it failed’*

*My iron lung wouldn’t fit
in a dorm room so
I slept at the hospital*

It's always been easier
to be a freak in Berkeley

We were involved in the civil rights movement, the women's movement, anti-war and free speech. It was an exciting time, and we were well trained. We learned the theater of it, how to play good cop, bad cop. We learned the power of our disabilities. It was all theater. It worked with the governor, it worked with the janitor.

We had the usual extracurricular activities: sex, drugs, rock and roll. When people saw us do that too, it changed the attitude.

People in the other movements didn't always recognize that we were up against damaging stereotypes, just the way they were. We were in their movements, but they weren't in ours.

Once we established our credibility and proved our seriousness, the university began to change its whole environment to accommodate us, realizing that there were a lot more disabled people out there.

True: it has always been easier to be a freak in Berkeley.

It took me six months to fire my first attendant. One of the things Dr. Bruyn insisted on from the start was that I learn how to hire and fire my own attendants, as well as pay them. I wasn't being well taken care of, and the silence and anger in the relationship were awful.

Finally had to ask myself if I loved myself enough to make sure I got the care I needed. I decided I did, and fired that attendant the next day. That was a lesson we all had to learn.

When I approached people, they would deal with my attendant. Anywhere. For fifteen years, I was in a push chair, six years at the University. We'd go into a restaurant and they would say, "What would *be* like?" I was almost a nonentity, being pushed around.

We had tried a power chair, years before, and it

I was almost a nonentity,
being pushed around

didn't work for me. I had been told that I could never drive a power chair. The prevailing medical opinion at the time was that if you gave power chairs to people, even to quadriplegics, it would make them lazy.

If you find a way to make people mobile, it changes their personality. I've watched little babies, children who are a year or two old, who have never been mobile because they are paralyzed, get an electric scooter or something and within ten minutes, their personality has changed from being totally passive to being so aggressive you wonder what they're going to do next.

A young man, Don Lorence, who came into our program at Berkeley, all he'd done for fifteen years was sit in his room. And this guy was a genius with electronics and computers. He'd built all these things.

When he came to Berkeley, we could hardly hear him. You had to get real close because he wasn't used to talking to people at all.

We gave him a power chair the first day he got there. And we lost him! We couldn't find him. Finally, the campus police brought him back. They'd fished him out of the creek! Berkeley has a lot of hills. He was going to the top of the highest hills and putting his wheelchair on full speed. And that day, he came in and I could *hear* him. He was just totally exhilarated by the ability to move and to do things.

I had to fall in love before I learned to use a power chair. It was in 1967 or 1968 I think, I fell in love and it was wonderful, a great feeling. It became



ED ROBERTS, AT RIGHT, SPEAKS AT AN ORGANIZING CONFERENCE FOR DISABILITY RIGHTS IN AUSTRALIA IN THE 70S. PHOTO COURTESY OF THE MINNESOTA GOVERNOR'S COUNCIL ON DEVELOPMENTAL DISABILITY

If you find a way to
make people mobile, it
changes their personality

She's on my lap,
we're heading off
into the sunset

Those early power
chairs weren't the safest

ridiculously inconvenient to have an attendant pushing me around in a wheelchair. Real difficult to be intimate and to be alone.

I remember them putting me in the [power] chair, and I remember almost immediately crashing into the wall, but that was a thrill! All of a sudden, *I could do it*. Sometimes I'd go through doors and not be able to get out... lots of things I had to learn. But I learned how to drive a power chair in two days. Two days, she's on my lap and we were heading off into the sunset. I tell you, that was motivation.

When you're highly motivated, you have a lot of energy. You can often do things you never thought you could. After I got my power chair, I realized that people had to confront me. All of a sudden, there was no one else there. That was very important to me.

Later, it must have been '72 or '73, I was with my dog. His name was Tremor; he was a wonderful dog, a malamute-shepherd, and he loved to go for walks. By that time, I had good control of the chair. But I was braking, coming down a hill, and I blew a transistor. On one side was a creek, and on the other side was a big hole. I remember riding that chair all the way down to the bottom of the hill, because it went full speed forward on one side, crashed into a tree and finally stopped. So those early power chairs weren't really the safest chairs.

I learned how to have extra transistors, and how to install them, so I could describe to somebody how to install them.

The battle [that brought The Rolling Quads together] had to do with the second counselor we were assigned by the state Department of Rehabilitation. At first, we had a wonderful counselor, and then they sent us a bookkeeper type, Lucille Worthington. Lucille Worthington on her best day may not have been a very

nice person. But at her worst she was an accountant who wanted to cut costs. It was all federal money by that time, but she still wanted to cut costs.

From the very beginning, she started threatening: 'If you don't give me top grades, I'll cut off your money.' I was working on my PhD and she tried to give me subjects that I would write about. We were on our way to freedom and independence, and nobody was going to stop that.

Some of us had been locked up all our lives, in nursing homes or state homes. She decided to expel three of them from school! She had decided that they would never be able to work after graduation. (She was wrong in all three cases, by the way.) The rest of us got together and fought it.

We went to the university and finally to the state legislature. We talked harder and longer to the newspapers. Several papers did stories saying how awful it was for these kids to be kicked out, and how [VR] was threatening this program. It was the only one in the world! One where people were actually becoming independent and going to work! These brave souls, these helpless cripples... Boy, did we play it up.

A few weeks later, our friends were reinstated at the university. It turned out to be one of the first time in the history of state rehab that clients had ever forced the department to get rid of a counselor. We wanted her fired, but they transferred her, and then retired her.

Like Saul Alinsky says, it's really important to win that first battle.

People expected us to fail. That didn't happen. We became powerful. We stuck together, we worked together, we drew the line of what was unacceptable. There were times when the word 'no' was unacceptable. There was no question we had control of the program.

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these helpless cripples...'
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The first curb cut in Berkeley

We got the city to do the first-ever curb cut, on Telegraph Avenue. The city wanted to know why we needed curb cuts: 'We don't see you people out there.' — you know that Catch-22 thing they do.

So they put in the cut and old people liked it and then women pushing baby strollers liked it and they put in more cuts and more of us were out there.

We had this political clout with the city. They had to listen to us in a much more realistic way. All things change when you get political power.

We just got stronger and stronger as more people came in. People came from all over the U.S. to see how these severely disabled people were going to school. The university found it a matter of prestige to back us. They began to see that the future was in serving more disabled people.

What was to become the first CIL, that started on campus. I worked with the federal government as a consultant about that in 1968. It was my first trip to D.C., my first plane trip, the first time the government had to pay for an attendant to accompany anyone.

We had to go through a few bureaucrats to get that accomplished. They were saying: 'Why are two people coming when we only invited one?'

They brought me in to work on a special student services program for racial and ethnic minorities. As that bill was going through the House, one guy threw in a clause that ten percent of it had to go to the disabled. I helped write the guidelines for that.

We used that to set up a program that had to do with self-help, with an attendant pool, with working with peers.

Our job was not to control their lives but to help people take control over their own lives. It works fantastically, as you know. It works like crazy.

Whenever we start by believing that people can't do

The first attendant travels at government expense

it, we set up all these systems to do it for them. Charities do that. At Berkeley in the beginning, it was the attitude of people that I would get my PhD and then go live in a nursing home. Society's expectations of us — very low expectations — have tremendous power over us. Our helpers, for instance, were so fearful that we would get out in to the world and die.

IL is something else. IL is independent.

We were very clear philosophically. We were beginning to talk about disability issues as civil rights issues. Ø

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tremendous power

*For Ed's memories of the first Center for
Independent Living, see page 42.*



ED SPEAKS AT THE FIRST CONVENING OF A PARTNERS IN POLICYMAKING TRAINING. PHOTO COURTESY OF THE MINNESOTA GOVERNOR'S COUNCIL ON DEVELOPMENTAL DISABILITY.