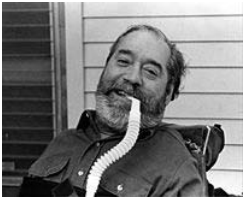


A CONVERSATION WITH ED ROBERTS

CALIFORNIA Q&A

by *Timothy Pfaff*



Berkeley alumnus who recently won a prestigious MacArthur Foundation Fellowship, the

so-called “genius award,” almost did not graduate from high school. Already two years behind at the time he thought he was ready for graduation, Edward V. Roberts was told that he still lacked his physical education and driver’s training credits – and was asked, “You wouldn’t want a cheap diploma, would you?” The incredulous former athlete had to go all the way to the school board (where the decision was unanimous) to get the principal’s decision reverse, and to graduate at age 20.

Quadriplegic (quadriparetic, technically; as he retains full feeling in his four paralyzed limbs) since the age of 14, Roberts could have had little use, let alone aptitude, for physical education and driver’s training, and even less use for the unconscionable discrimination implicit in the challenge to his diploma. He had contracted the dreaded polio that was sweeping the nation in 1953, two years before a vaccine was available. “When I do things, I do them well,” the 46-year-old disabled activist jokes now. “The damage done by the disease varied a lot from case to case. Some people got out of it with just a limp. But I got it pretty good. I had a really high fever and was put in an iron lung within three days.” More than three decades later, Roberts still spends as much as 18 hours a day in an iron lung – when he’s not traveling – and the rest of it in a custom-designed, motorized wheelchair equipped with a positive-pressure respirator. From the neck down, the only controlled movement he has is limited use of the fingers of his left hand, enough for him to drive his wheelchair safely. As a whole person, however – the way he insists you perceive him – he has remarkable power.

Roberts’ fight for the fundamental civil rights of the physically disabled, the

world’s most often overlooked and frequently invisible minority, dates back to the fight with the fever itself. “I was fighting a symbolic war,” he recalls, “and it came complete with rat-a-tat-tat, bang-bang-you’re dead sound effects. One of the special-duty nurses actually told me to stop, that I had to sleep, but she had no consciousness about what was going on. It was life-and-death struggle, and I was right on the edge. I won the war, and I lived.” In the meantime, doctors were telling his mother that his death might be preferable[sic] to what they perceived as his only other fate: life as a “vegetable.”

Roberts does remember a time early in his rehabilitation days when “I think I was trying to kill myself” by not eating. “It wasn’t a conscious effort, and the anorexia may actually have been a result of the disease. But the day they took my last special-duty nurse away, I started to eat again. Talk about symbolism! All of a sudden I was on my own, and I had to make my own choices. Again, I chose life.” The issue of eating prompted another important choice at the rehab facility to which he was next moved, San Francisco’s Children’s Hospital. Knowing that Roberts was not one of the “cases” that would eventually walk out of their facility, therapists there were determined to teach him how to feed himself. “The first time took me two and half hours, the food was cold, and I was exhausted at the end. I made a decision right then that I wasn’t going to feed myself. That made me a rehab ‘failure,’ but I knew that I had a limited amount of energy and that I wanted to go to school. It was one of the most important decisions I made, because education became my path to freedom.”

Not that it was an easy path. He re-entered high school by telephone hook-up to his bedroom and waited until he was a senior to return to the school itself. “I remember being unloaded from the car. Everyone was staring at me. I was so different. I knew that I could respond to their staring by feeling ugly, or that I could see that I was different

but that that was not so bad, that it could almost make me a star. I think that at that moment I began to understand that I could take all my self-hatred, and all the energy that comes from it, and destroy myself, or – and this is a very big ‘or’ – I could use that energy to do something with my life, to take the next step.”

At the College of San Mateo, where Roberts earned his A.A. in 1962, he resocialized himself after nearly six years of isolation, learned that he could compete academically if no longer athletically, and that political science was for him. He had planned to continue at UCLA, but an advisor encouraged him to try Berkeley instead, both because of the excellence of its political science department and for the kind of community it was.

“When I tried to get into Berkeley,” he recalls, “I was told, No. they had tried cripples before, and it hadn’t worked. I had high grades, so they couldn’t legally refuse me, so they told me there wouldn’t be anywhere for me to live, that my iron lung wouldn’t even fit into a dorm room. 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. He 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. I insisted that I would have to 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.”

Although other colleges had begun programs for the disabled by then, Berkeley clearly was the pioneer in opening itself to the severely disabled. Roberts did have a bout of pneumonia his first year. (from the same thing that

makes most new college students sick; not knowing your limits”), but the experiment was deemed enough of a success that Berkeley admitted another quadriplegic, John Hessler ’66, M.A. ’70, the following year. In a remarkably short time, an entire floor of Cowell Hospital became home for a group of severely disabled Berkeley students who, in the fashion of the time, organized politically, calling themselves “The Rolling Quads.” The Berkeley campus has neither been nor looked the same since.

Roberts took on his first paying job when Dean Williams hired him to research and advise on the matter of removing architectural barriers to the disabled on the Berkeley campus, one longterm result of which is that Berkeley now has, despite its daunting bills, one of the most completely accessible campuses in the world. (The job also, Roberts confides, taught him “the art of budgeting.”) After earning his B.A. in 1964, he went on to earn his master’s degree in 1966 as well as to complete all the work for his doctorate except the dissertation. Like many of his fellow graduate students, he worked as a T.A. much of that time.

Roberts’ history since leaving Cal is an extended refutation of the notion that “disabled” means unable. In 1970 he joined about a dozen colleagues to found the community-based Center for Independent Living (CIL), based on the University’s highly successful Physically Disabled Students Program, coordinating attendant care and helping to provide other services to keep disabled people active in their own communities and not confined to institutions or their own homes. Later that year he left the Bay Area to serve as a teacher, administrator, and consultant at a number of small, experimental California colleges and as director of UC Riverside’s Handicapped Opportunity Program for Education (HOPE). In 1973 he was invited back to CIL, where he served as executive director until 1975, proving himself a highly successful fundraiser along the way.

Incoming Governor Jerry Brown opened an important chapter in the history of the disabled rights movement with his appointment of Roberts as director of the California Department of Rehabilitation. The first severely disabled person to hold such a position, Roberts was director throughout Brown’s term, from 1975 to 1983, during

which time the department became a strong advocacy agency for some 40,000 disabled Californians. Shortly after that directorship ended, Roberts became director of the Berkeley-based World Institute on Disability, which he also helped found. The non-profit institute, whose presence is just beginning to be felt, seeks to influence public policy issues that affect the disabled around the world.

A phone call October 11 (he thought it was creditors) informed Roberts that he had won a MacArthur Fellowship, which would provide him with more than \$220,000 tax-free, no-strings-attached in monthly payments over five years. He was further told: “The Fellow’s Award is given in recognition of your accomplishments in human rights which demonstrate your originality, dedication to creative pursuits, and capability for self-direction. Our hope is that the award will provide you a period of greater freedom from financial and institutional constraints, during which you may devote yourself more fully to your own creative endeavors. Such a period, we hope, will lead to discoveries or other contributions to society that might otherwise not be made.”

In the manner of a practiced executive, Roberts ducked the interruptions of the constantly ringing telephone by telling his assistant he was “in a meeting” to give the following interview. The respirator on which his life depends interrupted him with an audible squirt of air every half sentence or so, but Roberts seemed almost unaware of it as he spoke freely about his past, present, and future.

Q: Congratulations on your MacArthur Fellowship. What do you think it will mean for you?

A: One thing it means is financial security for the next five years. It came at a time when I was completely broke, but then, I seem to have that kind of luck. When I really need something badly, I have to go through a little suffering first, but then it usually happens. Of course when I received the award, I lost whatever public aid I was getting. Luckily, this fellowship also comes with a marvelous comprehensive health plan, which will cover the costs of my equipment needs, wheelchair repair, and even my in-home attendant support. The fellowship also included \$15,000 for me to donate to the charity of my choice, which is the World Institute on

Disability. That will pay for an assistant to work with me, which will make me even more productive.

It probably also will mean more prestige, which will be helpful in my fundraising for the World Institute. While I’m already well known in certain communities, this should make me easier to trust with large amounts of funding. If the institute is going to do a world-wide job, we’ll need offices in other countries.

Q: Like a number of earlier fellows, you’ve expressed plans to use some of the money for travel. Pardon the boldness of the question, but how do you travel?

A: Not easily.

Q: Do you have to travel with the iron lung?

A: No. I use a portable respirator. I have a face mask for it now, so I can breathe while I sleep. It’s harder on me than resting in the lung, but the benefits of travel make it all worth it – if a particular trip doesn’t go on too long. But travel for me is very expensive. Besides having to fly first class and take an attendant with me, I have to take a couple of back-up respirators, extra batteries, and my wheelchair. The respirator and batteries on my wheelchair will slip right out and fit under the seat of an airplane. One set of batteries will power the respirator for about 25 hours. When I flew to Singapore, it was about 23 hours, which basically means that there’s nowhere in the world I can’t fly. Now if I got hijacked or something ... But I’ve learned to take risks, within certain agreeable limits.

The point is that I like to travel, and when I travel I learn so much. And it’s remarkable the impression I make when I travel. In most countries, people like me are not alive, first of all. And if they are, they’re either in institutions, shut up somewhere with their families, or on the streets begging. I’m simply a good example of what’s possible. In Japan, they just couldn’t believe it at first. The disabled people there named me Edosan, which both sounds like my name and refers to a particularly wonderful period in Japanese history. I’ll be going back to Japan this summer, to help them set up independent living centers.

Q: What do you plan to accomplish with the travel opportunities presented by the MacArthur?

A: One of the things I most want to do with my MacArthur is help wipe out polio in the world. Last year five million people got polio. Fifty million have in the last ten years.

Q: Why?

A: There are many reasons, a lot of them political. The vaccine does need to be refrigerated, and there are other distribution problems. But it's a disgrace, when you consider that for 20 years or so we've had the technology to wipe polio out, that it's still a major world health problem. Cuba eradicated the disease in just two years. I plan to start my campaign in Mexico, which is currently having a polio epidemic.

Q: Why has Berkeley become the international center for the disabled rights movement?

A: Well, one reason is that I chose to come here. Once I got here and adjusted – and succeeded – the University was willing to take risks with other severely disabled people. We turned out to be fighters, and once we established our own 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.

Also, it's always been easier to be a freak in Berkeley. Even though we really were stared at at first, there's been a long tradition of the presence of the physically disabled in Berkeley, due mostly to the presence of the Schools for the Deaf and Blind here. Berkeley has long had a more willing, more experimental atmosphere. The extremes are more acceptable here. And being political is more of a natural life style in Berkeley.

Q: You were a student on the Berkeley campus during one of its most intensely political, some would say politicized, periods. What influence did the FSM and subsequent events have on you?

A: I couldn't have been at Berkeley at a better time for me, in terms of learning about political action, political organizing. It was a remarkable time. Although I wasn't a leader. I was part of the FSM, directly involved in what was going on. There are some things I couldn't do – Sproul Hall was totally inaccessible at the time – but other things I could. I got more involved when they brought troops onto campus, and I went through a couple of police lines in my wheelchair. It was scary, but I knew

that I was symbolic, that if they hurt me, it would be very bad publicity. If the Blue Meanies had done to me what they did to some of the other students, it would only have fueled the rebellion. The issues were being clouded by the brutality.

Of course it was a tremendously interesting time to be a political scientist. I had my students out doing surveys and really attempting to understand what was happening. And by the time of the campus strike, I was a leader, and actively involved in some for the alternative education efforts. All in all I learned a lot – that when you believe in something, you stick to it, and that you negotiate and compromise when you need to as well. I learned much of the art of politics in those days, probably as much as I learned from school.

I had been involved in the "other" civil rights movement, from even before my arrival at Berkeley, and I totally rejected segregation, including of the disabled. As time went on, it became increasingly clear how all those principles applied to us.

Q: Were there comparable battles in your group's struggle for independence as severely disabled students?

A: Oh yes. The one that sticks in my mind had to do with one of the counselors we were assigned by the state Department of Rehabilitation. We had had a wonderful one, and then they sent us one who was just a bookkeeper. She involved herself in many academic matters that were none of her business, which we all resented – and then she decided to expel three students in our program from school, having decided that they would never be able to work after graduation. She was wrong in all three cases, by the way. So the rest of us got together and fought it. We went to the newspapers, the University, and finally to the state legislature. Eventually, the department moved her to a different area. The incident taught me all over again how difficult it is to fight a bureaucracy.

Q: What were the more positive things your group did to achieve your independence and your rights?

A: As early as 1958, there were people who recognized that if severely disabled people were to reach independence, attendants were a key. When I got to Cowell, one of the things Dr. Bruyn insisted on was that I learn how to hire and fire my own attendants, as well as

pay them. It took me six months to fire my first attendant. I wasn't being well taken care of, and the silence and anger in the relationship were awful. Finally I had to ask myself if I loved myself enough to make sure I got the care I needed. I decided I did, and I fired him the next day. That was a lesson we all had to learn.

Perhaps even more important was learning how to drive a power wheelchair. The prevailing medical opinion at the time was that if you gave power wheelchairs to people – even to quadriplegics – it would make them lazy. I had to fall in love before I learned how to use one. When I realized how ridiculously inconvenient it was to have an attendant along to push my chair when I wanted to be with my special someone, I became highly motivated – and learned to drive a power chair in two days.

It was like being reborn, and the other disabled students who followed me had the same experience. So we began to insist that new students in the program get power chairs if they didn't already have them. The results were sometimes dramatic. I remember one student who was so withdrawn when he arrived in Berkeley – he had lived just about his entire life in his room at home – that you could hardly hear him when he talked. When he got his power chair, he changed completely, and became a veritable daredevil. It seems the campus police were forever fishing him out of the creek. But when he got control of it, he also got self confidence.

Q: You've long been a pioneer in the area of independent living for the disabled. Is the idea catching on?

A: Definitely. There are now some 200 independent living centers in this country, modeled mostly on the one in Berkeley. And when I was director of rehab in California, we got a federal law passed, one whole section of which, Title VII, is on independent living. So for the past six years, the federal government has put up money for independent living centers. That steady funding source has made a big difference.

Q: Do you think new federal budget cuts will imperil that money?

A: I doubt it. The good thing about our cause is that it appeals to both left and right. There's nothing more conservative than bootstrap theory, and that's what we're all about. Ronald Reagan has become a supporter of independent

living – but while he has made some gains in that area, he’s cut some other programs so substantially that it has threatened our lives.

There are substantial cost benefits in taking people off welfare and putting them back in their own communities. More than \$200 billion annually goes to services and things like social security that directly benefit disability. But it’s mostly spent in ways that perpetuate the dependency of the consumers. Only a little more than \$3 billion goes to independent living programs, integrated special education, and the more progressive programs of the rehabilitation department. The rest is caught up in the institutions, the workshops – in maintenance at the most. What’s interesting is that it is in times like this, when budgets are tight, that we can often make the most progress in reallocating the funds.

Q: Governor Brown certainly made waves appointing you director of the state Department of Rehabilitation. How did that happen, and what did you make of the opportunity?

A: Because Governor Reagan threatened us so much, he helped us come into our own as a group. Many of the people I worked with over the years, fighting the Reagan cuts, were close to Brown, and together we decided to get me appointed. So for months, everywhere Brown and Mario Obledo went, they kept hearing about me. Soon they started asking, ‘Who is this guy?’ And when they came to CIL, they found out. They’d never seen disabled people working like that.

I made no bones about the fact that my loyalties were not to them, but to the disabled. And I told them that I would probably get them into a lot of trouble, that it would mean shaking up the old ways. I did get Brown into some trouble. But, to his credit, while he did ask a lot of questions about what I was doing, he let me do what I had to do. I called myself an advocrat, half advocate and half bureaucrat. You’ve got to be a bureaucrat, too, to keep things moving.

We got a lot of disabled people to work. We helped write national laws about disability. We helped write state laws about building accessibility, transportation, and architectural barrier removal. California is the farthest along of any state in the nation, because we were active. It’s the only state that has legislation mandating accessible buses. That’s one area in which the disabled

are conspicuously discriminated against. Blacks may have had to go to the back of the bus, but we couldn’t even get on the damn thing.

Q: What’s the single most difficult thing to confront in the fight for civil rights for the disabled?

A: Attitudes. And they’re clearly reflected in the language. “Invalid” somehow says in-valid. “Disabled” means unable to many people. And “handicapped” has in it the notion of cap in hand – begging. I’ve played with the language myself. I’ve always hated the word “crippled,” so I decided to transform it into a loving word, “crip,” just for us, the way black people use “nigger” as a term of endearment among themselves.

We don’t understand how we inculcate prejudice in people, but we do it. And prejudice is the worst thing around. In my case, I call in “handicapism.” It’s an -ism like sexism. It puts you apart, makes people think that you’re something other than what you are – that you’re weak, sick, and unable.

Q: Another prevailing attitude is that the disabled are not sexually desirable – or, for that matter, sexual at all. Care to set the record straight?

A: It’s true that most people don’t see people with disabilities as sexual people, but it’s totally a myth, and a particularly devastating one. I’m always surprised that people are shocked to hear that my son Lee is my natural son.

I’m convinced that the experience of disability can make you a better lover and partner. Disability forces you to confront things. One of the things I discovered when I came to Berkeley and got into serious relationships, and sexual relationships especially, was that many women are not looking for the kind of macho guy who can pick them up and throw them into bed. Instead they’re looking for gentleness, someone who can listen to them, and touch them in ways that are important to them. And it gives some women the chance to be more aggressive in sexual relationships, which I encourage.

When you’re paralyzed from the neck down, you have to learn how to talk, and one of the most important things in creating a good sexual relationship is being able to talk about what you want and what you like, what feels good to you – and being receptive to what the other person is saying about what they need and want. When you’re paralyzed, sexuality can be very creative. Disability

allows for experimentation and can result in exciting things that make a relationship stronger.

Q: What about marriage and parenthood?

A: They pose the same opportunities and problems for the disabled as for the non-disabled. I was married for four years, and my ex-wife and I are still close, still friends. We have joint custody of our son Lee, and we have no trouble with the exchange. We seem to have worked out a relationship that works well for all three of us.

When Lee was born, at first I was worried that I wouldn’t be able to hold him, that I wouldn’t be able to participate. But I learned that I could. And Lee taught me a lot. He taught me that when you’re Daddy, it doesn’t matter who or what you are.

Q: Michael Pachovas, another disabled rights activist, described the physically disabled as the “equal opportunity minority.”

A: Yes, anyone can join us any time. Some people are born with their disabilities, but by far the most become disabled at some later point. I’ve come up with the phrase “temporarily able-bodied,” which I think gets the same point across. In fact, the World Institute is going to give out an annual TAP Award to the temporarily able-bodied person who has done the most for the movement.

On a slightly more serious note, we have to recognize that the elderly make up a large share of the disabled population throughout the world – and that as a nation we’re all growing older together. We have to deal with the issue of long-term care for all disabled people, and that makes a powerful argument for the benefits of independent living. Why should people have to leave their homes and their communities just because they grow older and develop new needs?

Q: Is there a danger that medical technology will create new disabled populations beyond what existing social services and awareness can handle?

A: Yes, but of course it’s a complicated social issue. Forty years ago, spinal cord injured people simply did not survive, except for a few paraplegics who had unusually strong constitutions. Now we can keep all kinds of people alive with machines, which I think is disgraceful for those who would rather have some dignity in their deaths. But I talk about this very gingerly, because

there is a fine line. The first people Adolph Hitler killed were the disabled, starting with the mentally retarded.

We have largely depended on the medical profession to decide who should live and who should die, and that's been a mistake. Medical people see us at our worst, when we're sick or hurt or for some reason not making it in the community. So medical people often feel that death is preferable to disability. And there isn't often a lot of informed choice on the part of parents; they're still told what's best. Think of the Baby Doe cases, who are left to starve because they are born disabled. One baby girl in Indiana was so strong it took her seven days to die. This has become a very important issue in our community. The essential thing to know is that disabled people can have real quality in their lives, and can do much more than had been thought.

Q: What do you mean when you talk about the power of disability?

A: It's a power that comes from being stereotyped, from being perceived as crippled and unable to do anything. When people look at my respirator and don't see me, it gives me a tremendous amount of power. While they're staring and thinking I can't do anything, I can manipulate the hell out of them.

One thing disabled people can do to change stereotypes is to be themselves. Disability has nothing to do with whether you're happy or unhappy; and there's a lot you can learn from disability. At the age of 14, I was concerned with life and death matters. I wouldn't want that for everyone, but it helped me understand a lot. And it helped me gain my values quickly.

Q: You've often said that you want to be seen as a person and not a disability, but it's equally clear, as you yourself have pointed out, that when you got polio, you also found a cause. How do you reconcile the two?

A: It's another fine line. Making disability my cause just seemed natural to me. I had to struggle so hard to do what I wanted to do that I just thought. Why don't we struggle together? Many of us have made individual changes in our lives that have ended up affecting thousands, even millions, of people. It's true. I'm always the quadriplegic. I'd like to be Ed Roberts, not Ed Roberts the post-polio quadriplegic who sleeps in the iron lung. But that's my business. I don't feel sorry for myself, and, in the

end, celebrate difference. It's something to be cherished, because you can learn from it. I guess that's one of the things I like about California, that difference is appreciated here.

*Retyped 7/03
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by the Minnesota's Governor's Council on
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