

Excerpt from Edward V. Roberts, oral history, University of California's Cowell Hospital Residence Program for Physically Disabled Students, 1962-1975: Catalyst for Berkeley's Independent Living Movement, Disability Rights and Independent Living Movement Oral History Series, online at <http://bancroft.berkeley.edu/collections/drilm/>

Henry Bruyn, M.D, and Decision to Use Campus Hospital as Residence

Roberts

But then, of course, when they sent me up there--I had to go to the hospital; that didn't sound very good to me. I didn't have high hopes about this. Then I remember meeting him [Bruyn], and I'm not sure if that was [the day of] the first meeting I had with Henry. But he was so friendly, and he had none of the things that a lot of the other people had. 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." I got encouraged, because I thought, Oh, well, maybe he's--

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 button and get help. We always have attendants there anyway, every shift."

O'Hara

Orderlies?

Roberts

Orderlies, they called them, yes. Basically, he said, "We can hire more." I think they had them every shift, but the nurses always like to have a man around. Nurses were always women, and the orderlies were always men, and they helped lift and do a lot of that kind of thing. I think they were a little worried that I'd take his time.

O'Hara

Did you already know about attendants? Did you have attendants at home?

Roberts

Yes.

O'Hara

And did you call them attendants?

Roberts

Yes, I called them attendants. For a while, I had an attendant take me to school and back. Mom did a lot in the beginning, and then for a while we hired an attendant through Rehab [California State Department of Rehabilitation].

5. The March of Dimes paid for four hours a day, five days a week, for household help thus making it possible for Ed to live at home and for me to function during the day--shop, take the younger boys to nursery school, et cetera. --Z.R.

I think it was Rehab that helped me pay for it, or I had some in-home support money. I started getting that in '58, I think. I was one of the first recipients that got the full amount. When the guy came and looked at me, he said, "I can't give you less." There was \$300 a month.

O'Hara

That was probably 150 hours of attendant time.

Roberts

[laughter] Yes. It seemed like so much more then. It was a little over two [dollars] an hour. I had to make sure I had an attendant that had a car. I remember I had this big guy with a little Volkswagen, but he could stuff my wheelchair behind the seat. That surprised me.

O'Hara

And you sat in the front, in a little Bug?

Roberts

In a Bug that went back and forth.

O'Hara

Incredible.

Roberts

He never hurt me; I don't remember him hurting me. But that was an important time, when I realized that I could have other people help me. My mother had helped me. Mother and Father had done most of that work. So it was like an indication that I could do that too, if I--and I didn't have any trouble giving directions.

O'Hara

So you intended right from the start that you would hire helpers, attendants?

Roberts

Oh, yes. It was a scary time when they said, "Okay. You're going to live at Cowell; you're going to pay \$300 a month for your room and board." I said, "Well, where will I get all--?"

They said, "Well, we'll talk to Rehab, and they'll pay part and you pay part." So I had to have enough to pay my own attendants, plus I got some money to pay for the hospital's--not really services, [but] food service, and that kind of services. Some people liked me there, and everybody was friendly, but some people were worried about the--.

What's most interesting is that there was a young janitor there, and he was probably my best friend in the whole place. He was a guy that actually was into music and a lot of things, culture. I can't remember. He was a well-educated guy, but who had come from Chicago and tried to work at--I think he started out as a manager-in-training at Marshall Field's, which is a big department store, and had a breakdown. He couldn't stand this horrible pressure to be a certain way. I'm sure he was gay; I'm sure there were a lot of other things. So he came to Berkeley and took this job at the university.

But Cowell had always very interesting people around. We talked earlier about Margaret Mead was there, and a guy named [William H.] Sheldon, who did the archetypes [somatotypes--connecting of physical characteristics with behavioral patterns] around people. Anyway, people had moved away from him [his theories], but he was very famous at that time. I can't even remember the other people, but there were several who used to come in and visit the psychiatrists. Other people who worked--there were some good people working at Cowell. But it was all set up to work with students, and then these folks would come in and stay for a few days when they were passing through, or working at the university.

This friend, Chuck [Sevier] the janitor, he loved Cowell because of these people. So he would do his job in a couple of hours, and then he'd come back and he'd play music for me or watch TV. He was my companion the first year I was there. And then he brought me a stereo. He had built this original stereo of his, and he bought one, and then he brought me it, and it was a monaural. It was a speaker with a turntable and a bunch of records. That's how I started to play--it's very unusual, you know. But he always kept me informed what was going on in the hospital.

And I remember being like that where I was before.

6. Ed had a remarkable facility with people and knew lots about the lives of many of the hospital workers after living with them even a short time. --Z.R.

I remember always getting to know the janitors.

Living at Cowell Hospital on Campus in the Sixties

Moving in and Getting Settled

Roberts

Where were we?

O'Hara

The early days. Do you remember the day you moved into Cowell, and what it was like?

Roberts

Yes, I do. It was a combination of excitement and scary. I remember the first room I had was in the older wing. It was kind of dark. Most hospital patients' rooms are dark, although they can be--it was good-sized. I remember I had to--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.

O'Hara

Did you find him by just talking around, and asking questions?

Roberts

Actually, we got a list of the people who had applied to Cowell. I began to interview people that had applied to Cowell.

O'Hara

Oh, for some kind of staff position?

Roberts

Right. And I think that this particular guy was referred to me by somebody at the hospital itself. He was a black guy, obviously gay, but a very sweet man. A little burned out by the time I got him. Took me six months for me to fire him. It wasn't that he was terrible; it was a time when I was going through a lot of stuff myself, trying to figure out my own capabilities. I can remember my mother leaving, and that was kind of scary. It was nice to have the hospital people there if I needed them.

O'Hara

Were you on the third floor?

Roberts

Second.

O'Hara

Second floor to start with. That was the actual hospital part.

Roberts

Yes, it was.

O'Hara

And so you had--

Roberts

After the first week or so, I was moved to the new wing on the end.

O'Hara

On the second floor?

Roberts

On the second floor, where I was--the third floor was closed off, basically. They didn't use it. They only used the second floor.

O'Hara

So if you wanted to talk to somebody, there were people up there?

Roberts

Yes, and I had a telephone.

O'Hara

What kind of phone did you have?

Roberts

It was a phone that had a pad that I could hit the pad, and it would--it was like a nurse's call bell, except it was hooked on to a telephone, so when I hit it, it would dial the operator. So actually, what I wound up doing was dialing outside the hospital, calling into the hospital, calling the second floor nurse's station, and getting them that way. It seems complex, but it worked very well.

Managing Personal Assistance

O'Hara

Did you have several attendants, then?

Roberts

Yes, I had. But first I only had that one guy that worked a lot. I think then I had another guy who worked in the evenings, who got me back in the tank. I remember meeting some really nice people. One guy was a graduate student who was married; I don't think he had any kids. I've since lost total contact with him, but I really liked him, because he was somebody I could talk to.

O'Hara

Why did it take you so long to fire the burned-out one?

Roberts

I think I was a white liberal, and I wanted to really be good to the guy. I kept wondering if it was my problem, not his. One day, I remember--a lot of times this happens in my life--I get to the point on an issue where I go, "Wait a minute, this [Inaudible]." I said to myself, "It doesn't matter whether I'm wrong or right. I'm not getting the care I need from this guy because it's so difficult for him and I to be together. Do I love myself enough to take better care?" I remember, saying this to myself shocked me. [tape interruption]

It took me a while to finally say, "Hey, I can do this." So I had to talk to him and let him go, and it worked fine. He was ready to go, too. It is much gentler that way, without having a lot of anger and hostility and things behind it.

O'Hara

And you said when your mother left, it was scary.

Roberts

Very. Yes. But there were people around, so I wasn't afraid. I just knew it was a monumental occasion, because we really hadn't been apart except for my being in the hospital. My parents would go away a couple of times on vacation. [tape interruption]

Anyway, it was a good day, though. Within a day or so I realized I was--I could do this, I can be free. And even though it was a halfway situation, I knew that they [Inaudible]. My big skill I had to learn was how to hire, how to describe what I wanted, but I was pretty good at talking. I've always been pretty good at talking.

O'Hara

Had you hired the attendants at home?

Roberts

I did mostly, but my mother helped, too. We did it together a lot.

O'Hara

So you had some experience.

Roberts

I had some experience, but not so--this was important for me to do it for myself, and I realized what an important skill that is. It took me months to be able to let go of a person. After that, it was never so difficult. It wasn't easy at all, because you get so close to people, negative and positive.

O'Hara

Did it change your life at all to be away from home and hiring your own attendants? For instance, did you hire them at different hours than you would have at home?

Roberts

Yes. Well, let me think. Because when I was going to school, I hired them for the school hours, because they had to push me around. Through Rehab, I got money to hire people to be my secretary and also push me around.

O'Hara

So you had quite a few people.

Roberts

I had a few people by that time. I was lucky that they were willing to do that, because I couldn't have made it otherwise. Ron, the first one, not my attendant, but soon became my attendant, he was so quick and so fast.

O'Hara

Your brother?

Roberts

Right. He was a very good attendant when he was ready. But I had other people. I remember him being able to--he'd always drink and come in late, so it would be a rush to get out. A rush in the morning. I'd be up and ready in fifteen or twenty minutes. Even washing and everything; it was so amazing. I think he still holds the record for getting me up--for getting me up too fast. 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. [laughter] Until John [Hessler] later came; because I wasn't into booze at all. We figured out all the stores that would deliver booze. That was pretty weird for them, coming to a hospital. Booze, that became an issue, because the hospital was not supposed to have booze.

O'Hara

Did they deliver to the front door?

Roberts

No, they brought it all the way up. They knew they had to, because I--once in a while, some of the nurses would help a little bit, but it was a conflict for them, it really was. Because they knew drinking wasn't a good idea around.

O'Hara

Now, you're obviously referring to John Hessler [the second physically disabled student resident of Cowell]. Can you describe--do you remember when you first met him?

Roberts

It's funny, because I started hearing about--because I was the lone guy, it was kind of nice being there. 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. [laughter]

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.

O'Hara

A manual chair?

Roberts

No. He had a very slow power chair, but he had a power chair. He was used to having 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. It just seemed very natural to be--

O'Hara

That was one year later?

Pneumonia and Fears of Dying

Roberts

Yes. Now, I went through a lot of other things. I know that at the end of my first semester, I went home, I was sick. I got worse. I wound up having double pleurisy pneumonia, which was painful. I remember I was hallucinating a lot. I

was in my room at home watching television, and my brothers would bring their friends in and say, "What are you watching?" And the TV wasn't on. It was like a tape that I had inside my tank. So I got pretty sick.

They decided to get me back to Cowell. So I went back in an ambulance.

O'Hara

You mean when you were sick?

Zona R.

You went back in a station wagon, Jeff Littke driving.

Roberts

Oh, the station wagon.

Zona R.

We felt like an ambulance.

Roberts

Laying down. I wasn't able to sit up.

O'Hara

Why did you go back to Cowell? Because it was a hospital?

Roberts

Yes.

Zona R.

Well, that's where he--they were set up over there. They were expecting him. They had a whole medical staff, you know.

Roberts

I was pretty sick.

Zona R.

He had pneumonia.

Roberts

They were worried about me. I didn't know what was happening. I remember the doctor coming in assuming I was spinal cord injured, and saying that we should catheterize me. I said no, no, that's not what I had. "I pee fine, leave me alone."

Zona R.

No, no, up in the neck, the--

Roberts

Oh, trach; they were worried about tracheotomy.

Zona R.

That was always the first reaction to any kind of thing when he was sick, like, "Let's give him a trach."

Roberts

And this was something I hadn't had at all. I was so much better off because I hadn't had a trach. So they kept, "Well, if he gets more sick, they have to do this." And I wasn't getting better. I remember something happened, it was one of the first times, I remember the middle of the night, I was terrified to go to sleep, that I'd die. Here I was, really just beginning my life, and I'm terribly sick. One night, I had this apparition. I still to this day think it was Henry Bruyn, but he denies it.

O'Hara

You mean somebody came into your room?

Roberts

And told me that I was dying, but that I was actually killing myself because I was so afraid of death, that if I would just relax, my body would take--they were doing all they could. They had given me antibiotics. I was terrified. And this was not a heart-to-heart; this was like telling me, "You better stop this or you're going to die." It was so vivid, I remember. I remember right after going, "Ohhh." And actually going to sleep for the first time. I woke up in the morning and felt a whole lot better.

Now, if this really happened or not, I don't know, but it was perfect. It was exactly what I needed to hear. I've always remembered it, always. Because the more uptight you are about your own sickness, you create more tension in your body, and it's more difficult. It's an interesting phenomenon.

O'Hara

So that was a rather critical moment, whatever it was.

Roberts

Very, yes. It was very lifelike, and I'm sure it was Henry. But I think I'd heard he'd done that before. But I don't know for sure; he says no. I woke up the next day feeling a whole lot better, and knowing that I'd recover, and that was such an important issue for me, life and death. It taught me that you can actually kill yourself and your zest for life you want so much; whenever you want so little to die that you can push yourself over the edge. And I think I came to terms with death that night, in a very interesting way. It was probably the most important lesson I learned at Cal. I'm sure there were a lot of other great lessons, but it helped me take control. Because I was very--.

I went from there, and I started getting better and better. I was able to go back to school the next semester. I think I had not finished all my classes, because I was sick, so I wound up taking the finals. I remember not doing quite as well as I thought. I got two A's and two B's, or something like that. Which was fine, but I was used to doing better.

Inventing Ways to Manage Student Life--Classrooms, Reading, Notes

Roberts

I was a veteran by that time; the second semester. 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 in the field. We sat out in the field. The athletic parts of the campus were real important. I went to Harmon Gym, although it was a bitch to get into Harmon Gym.

O'Hara

How did you get in?

Roberts

Well, 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, it was a history prof. It's now the administration [building]. I was getting pulled up the stairs, and the top part of my brace was removable.

O'Hara

The top part of your--?

Roberts

The extension on the wheelchair.

O'Hara

The backrest?

Roberts

The backrest. It 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.

O'Hara

So you were lifted to some classes regularly?

Roberts

Yes. But it was not accessible. And then I began to choose classes based on access. I remember I went to Dwinelle and took classes in Scandinavian literature.

O'Hara

Because it was accessible?

Roberts

Well, I was carrying four classes, twelve units. I looked for one that was different, and usually very easy. I had other classes. The football team had all easy classes. So I got to meet the football players, and all their girlfriends, and I would go into these classes. They gave me a whole list, and I took a lot of them. It turned out Scandinavian literature was wonderful.

Zona R.

I think your brother Ron turned you on to those.

Roberts

I think, yes. One was about Strindberg, and the other was--what's the other guy's name?

O'Hara

Ibsen?

Roberts

Of course, Ibsen, yes.

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 their notes while you're taking yours. Then I started making an announcement at the beginning of class, and usually find a good-looking young woman. Because I'd really look at their writing, so I'd get to know somebody that way, and they all loved it. Every day, they'd come by and give me the notes. And then there were what were called Phi Beta Kappa notes. Do you remember those?

O'Hara

Yes. Fybates.

Roberts

Fybate notes, yes.

Zona R.

You also learned that at College of San Mateo, having the lovely young ladies take notes for you.

Roberts

Yes. I actually did that first at CSM, yes.

O'Hara

[laughter] That tradition continues, by the way, the lovely young lady idea. Many men after you thought it was a great idea.

Roberts

Well, it's such a simple way to take notes. And of course, to meet people and get them involved with you. So there were all these little gimmicks. I never bought Fybate notes in big supplies, because even though it was '63, '64, they were the exact notes of 1948. It just blew my mind how a professor could have the same class that many years in a row, you'd get the same notes. And of course, then you bought some packages, but you could also buy them single every day. For me, they were real helpful. I didn't read them all. Having my own notes and those really helped.

O'Hara

How did you do your reading?

Roberts

I had done most of my reading through high school lying in bed with a reading rack and a mouthstick turning my notes, 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 mouthstick made that was longer. But I had done some of this anyway, after I had my iron lung. I don't remember when I--I must have got it during the College at San Mateo.

O'Hara

So you'd attach the book to the mirror with some--

Roberts

Yes, with big rubber bands in the back. You'd have these things from--did you ever see--it said "O. T. [Occupational Therapy] Fairmont." 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. Then I'd take out fifty pages at a time, and they had little adjustable--they held the pages up there. I could take it out from behind the pages 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--it was really nice.

I went all the through college reading--if you look at my teeth, see how crooked they are?

O'Hara

Bottom teeth?

Roberts

Yes, how they're pushed over? Mouthstick. The mouthstick 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.

O'Hara

Did you have exams? How did you take them?

Roberts

I took them. I always the first thing sat down with the professors and said--I always assumed that I was going to take the exams, and how could I do them. Some professors would say, "I'll give you one of my T.A.s and you can dictate to him," or, "my secretary," or, "I'll give you a test to take home, and you have whoever you use." So it was really a variety of things. There were very few professors who weren't flexible.

O'Hara

You always handed in a written piece, then? You didn't use a tape recorder?

Roberts

I didn't use a tape recorder once, at all. I always did blue books, I wrote them, with somebody. It's just the same, basically. And if I'd studied well, I usually was very good. Usually there was one class that was, like Scandinavian literature, that was easier. And I read them, because I enjoyed the books and the plays, and learned a lot. I don't think I was expecting to learn a lot. [laughter]