Independent Living: Born on Campus

the origin and the purpose
of Independent Living,
as told by Ed Roberts

ED ROBERTS, AT LEFT, SLEPT IN AN IRON LUNG. AT RIGHT IS HIS LONG-TIME FRIEND AND ATTENDANT, JONATHAN GOLD.

John Hessler was the second student to come into Berkeley. Whenever we needed somebody to stare people down, it was John. He was six foot eight inches, he had a huge wheelchair.

He went to France to study French. We got the county welfare to finance that. Then he decided he didn't really want to teach French. He came back and put the proposal together for the disabled student program. That document became the model on how to set up an IL program.

John was the one who thought through a lot of the basic issues of what would be IL. We knew from the services that helped us live that you had to have a personal assistance program, and a way to find [attendants]. You had to have money to do that, so you had to guarantee people would get enough help in the community, transportation, all that. There were a lot of issues that we began to put together, and that's when we saw how powerful a peer could be in the life of someone with a disability.

Our disabled student program at Berkeley was so successful. We taught people how to use the welfare system to survive and go to university. We got to know the welfare regulations better than the people who worked in those agencies. We knew all the loopholes.

We got a van. John Hessler by then was the director of the Disabled Students Program; he was a quad and he could drive it. We kept pushing the department of rehab to buy those kinds of things for people.

We made sure that our people got the maximum amount of attendant care. When we found it very difficult, we went to the state and got the regulations for it. We began to be perceived as political animals. That changes the perception of you to *powerful*.

As you begin to get more and more empowered, you see yourself as powerful too. We realized that the only way to change things was politics.

Always, other people had spoken for us. We were speaking for ourselves. We had lots of comments from legislators on how important it was to hear it directly from us. We had a lot of credibility.

We began to get involved in local elections, volunteering time to help politicians. We recruited friends and attendants to do that work, too. It gets you known in politics to do all that.

Our Disabled Student Center, we were the only people doing attendant services. This was during the Viet Nam war. There were a lot of Conscientious Objectors then, wonderful people. I talked with the [county's] head of selective services [the draft board] and suggested he turn those C.O.'s over to us.

We explained it so he could get it: that it would be punishment for them, having to scoop up our shit. We'd teach them responsibility, see? He gave us hundreds of C.O.'s for attendants. They were great attendants who were loyal, who stuck with us.

That was the only bad thing about ending the Viet Nam war. We lost our C.O. attendant pool.

The University finally said we had to stop serving non-students. So we moved out into the community with independent living services. It started in one room in 1972, then in a two-bedroom apartment. It struggled a lot just to get going.

I took over as director. We began to raise some money. We knew we had something important and it

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worked. We were very clear that if we were going to be politically powerful, we had to involve all people with disabilities, break down the barriers the charities had created between us.

An IL had to be an IL for all groups and all ages, not just for people with physical disabilities. This was clearly a political decision. We weren't going to get anywhere nationally or internationally unless we were together. The CIL immediately took off.

All of us who started the first Center for Independent Living were on welfare.

We made a conscious decision not to go off it.

We built that center on welfare. None of us could take a salary of more than $300 and still get the welfare, so that's how we did it. I didn't go off welfare until I became California Rehab Director in 1975. In 1976, we started twenty more CILs.

When an IL gets involved with a person with a significant disability, acute care costs go way down. It's links, some links to life. People who are going, who are motivated, don't get sick as much.

Even today there are 83,000 people with cerebral palsy locked up in nursing homes.* They're only in prison because of their disability. If you're going to get out of there, you've gotta fight.

> We built that first center on welfare

One hundred thousand people die every year from de cubiti ulcers — bedsores*. Most of them live in nursing homes. I thought by now, Independent Living would have put an end to that.

We can do *that* right now, get older folks, get everybody out of nursing homes.

What would I would do differently if we were starting IL today? First, I would do a lot more training, getting people in touch with the history and

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* *This interview took place in 1993.*

philosophy. Today we are not grounded in our own ideology.

Second, I would build more leadership as we go along. Give people the same basic activist training that we got in Berkeley [in the anti-war movement, the women's movement, the free speech movement, the civil rights movement] in the Sixties.

When you look at too many CILs, you see white middle class

All too often, people make IL their career. Originally, it was this: We go in, learn to do jobs, move on in another few years and let other people get those jobs — while we move on and take over government agencies, take over those old-time charities, and take the IL philosophy to them.

Third, the leadership would be around political advocacy, around political change rather than around one advocate working to get services for one person.

We discovered that over and over. All things change when you get political power.

Politics changes lives.

CILs should be the leaders in a national campaign against sheltered workshops. We should be doing that *now.*

A person with a disability should be running the center. Yes, we should include parents and friends. I'd like to see much more teamwork at CILS — under disability leadership.

We should be helping parents get kids into regular schools. We should be making a commitment to a generation of young people with disabilities, that they know their history.

CILs don't do enough teaching or our history, our ideology. Too many teach us to suppress our anger, not to use it! If anything, we're too passive. Anger is wonderful if you get energy out of it and *learn*. It's terrible when you take it out on yourself or the people you love. Yes, I'm still angry. Lots of professionals make me angry. They're too much in control of our lives. People with disabilities are aging. I see them putting their own parents into nursing homes — parents who took care of them all their lives! This has to stop. We have not aligned ourselves with the elderly strongly enough. They are written off, written off.

When you look at many ILs, you see white middle class

We are still a long way from working equally with people with mental disabilities. We need attendant programs for people with emotional and cognitive disabilities. It could work great. Nobody's doing it.

We were strong integrationists and inclusionists [in early IL].

When you look at many ILs, you see white middle class. I'm glad there are a lot of women in it — that grew out of the women's movement.

CILs don't do enough recruiting from Asian, African, Hispanic communities. There are starting to be a few CILs on Native American reservations, that's good.

We would never do a government agency's job. We didn't want to set up a segregated transportation system. Getting people places is the transportation system's job! *Our* job is to hold them accountable.

I watch CILs who are doing transport or building houses or delivering services — instead of holding agencies accountable, we take over their services.

If we are co-opted by the system, we are in trouble. More important than being service deliverers is being advocates. We're too heavy into social services. Yes, it's easier to get money that way, but it's harder to get advocacy. We're losing the ideology of independence.

Voc Rehab
is killing IL.
They're killing it.

Voc Rehab has totally failed. Either they shape up or we shape them up or we get rid of them. CILs get their money from Voc Rehab and Voc Rehab is killing IL. They're killing it. [*See pp 48-49 — editor*]

CILs should be separated, away from Voc Rehab.

The IL movement is at a crossroads. It's growing internationally, but not very much here at home. A lot of centers are not in touch with their philosophy or their meaning. IL looks a lot like UCP and MDA.

Because Gov. 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 [Jerry] 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.

[When Brown appointed Roberts head of California VR] 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 in 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.

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.

Through all these experiences I learned that if I was to be free, if I was going to be independent, if I was going to lead my own life, then I had to fight for it.

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For 'The Tao According to Ed,'
see page 24..

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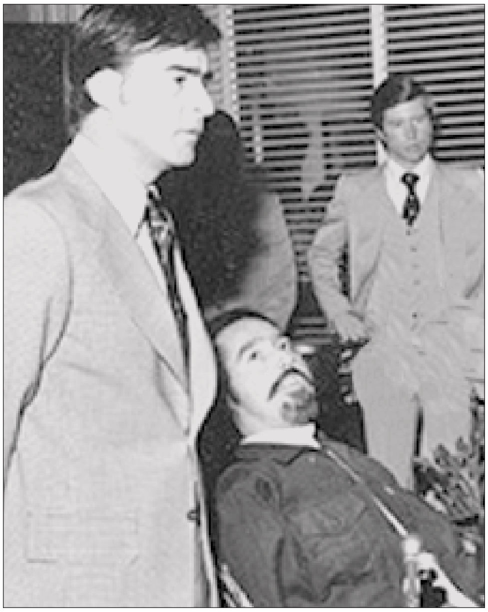

AT LEFT, THE YOUNG GOVERNOR BROWN. WITH HIM, THE EVEN YOUNGER ED ROBERTS