In the Beginning

Ed Roberts rolled onto the campus of the University of California at Berkeley (UCB) in the fall of 1962. Ed acquired polio as a teenager. He became a quadriplegic who used a ventilator to breathe during the day. At night he slept in an iron lung. He has long been considered the first person with this kind of severity of disability to attend an American college campus. When Ed enrolled at UCB the college administration did not know where to house him. After much discussion everyone agreed that Ed would become a resident of Cowell Hospital, the on-campus health center. From Cowell Ed attended classes. At Cowell he did homework and entertained visitors. While other students lived in dormitories, Ed resided in the hospital.

Two years later a quadriplegic named John Hessler became the second student with this level of disability to stay in Cowell Hospital. Ed and John became friends. During the next few years more students with disabilities came to UCB and joined Roberts and Hessler in Cowell Hospital. They lived together and studied together. They played and fought like other students in other group settings. Living in a hospital meant they were different than the remainder of the UCB student body. Though they were happy to be at UCB, they were not pleased with having to live in a hospital. How, they wondered, might they
change their situation? Living together at Cowell gave them the opportunity to talk with each other on a daily basis. The more they talked, the more intense their desire became to change their environment.

This group was not alone in this desire. In Berkeley, as on numerous college campuses in the 1960s, many students wanted to change the conditions of their lives. Students upset with the dictates of the UCB administration began to rebel. Their efforts became known as the Free Speech Movement. Other students participated in the Civil Rights Movement. Still others became involved with women's rights and Chicano rights. An atmosphere of activism and change saturated the Berkeley campus. The students with disabilities at Cowell participated in many of the other movements. They believed the issues they protested were important. But they eventually began to wonder about their own circumstances. They started to plan together to make change occur. They even gave themselves a name, "The Rolling Quads."

Learning About Each Other

The Rolling Quads questioned their living situation. Why were they forced to live in a hospital? There were many answers to this question. Dormitories on campus were not accessible to people using wheelchairs. University administrators expressed concern about students with disabilities becoming ill and needing immediate care. Where better to have access to medical attention than in a hospital? The Rolling Quads used personal assistants or attendants. There was no provision for personal assistants to share dormitory space.

The Rolling Quads also brought up other topics. They could not move freely around the city of Berkeley. There were no curb cuts to go from one sidewalk to another. No transportation existed to move wheelchairs from one destination to another. There were no apartments or houses available that could accommodate a wheelchair if a student wished to move off-campus. If a student's wheelchair broke down there was no place to go to get it fixed.

Talk Becomes Action

The Rolling Quads talked about all of these problems. They decided to work together to advocate for their needs. Meetings were arranged with University administrators. A decision was made to create a campus office to fix these
problems. The resulting Physically Disabled Students Program became the nation's first Disabled Students Office.

Talking about and working on these issues took several years. Many of the Rolling Quads were ready to graduate from UCB. They wondered what they would do after student life. To plan for the future they devised a course called "independent living." In this class they discussed how to improve conditions for people with disabilities in the city of Berkeley, just as they had done with the University. At the same time some money became available from the United States government to assist students with disabilities. The UCB students applied for the money. They did not get it. But they did not give up. They applied again. The second time they were successful. Building on their "independent living" course they started an off-campus office they called The Center for Independent Living or CIL.

Around The World

The Berkeley students acted on their own initiative, but they were not alone in their actions to champion disability rights. Similar groups were meeting all around the world. In Boston, Massachusetts, a group of students and community members started a self-help center for people with disabilities. In African countries, young people with disabilities began to meet with each other and talk about how they could improve their lives. In Helsinki, Finland, students formed Threshold, an organization which began to obtain services for students with disabilities. The same year the Berkeley students began CIL, Threshold also became an independent living center.

None of these groups knew about one another in the 1960s. They were all part of a worldwide movement to get equal rights for people with disabilities. In the 1970s they began to meet each other.

Peer Counseling

The Rolling Quads and the other groups around the world were peers. This meant they had similar life experiences. Quadriplegics in Berkeley faced the same kind of barriers that wheelchair users in Finland found. Blind students in the United States encountered similar difficulties as blind students in other parts of the world. People with lots of different kinds of disabilities started speaking to each other about their conditions. Deaf people learned that people
with mental retardation had communication problems just like they did. Some people had disabilities that could not be seen, like epilepsy or dyslexia. Barriers existed for them as well. For example, sometimes if a disability could not be seen other people did not believe it existed.

All these individuals with disabilities discovered that they had common stories. One of the most important conclusions resulting from these talks concerned who to turn to for advice. For years most people believed that doctors and psychologists and social workers and others in the "helping" professions possessed the best information about disabilities. They were the experts. Individuals with disabilities began to disagree. Did a doctor know more about the reality of their daily lives than they did. They didn't think so.

Doctors and the other "experts" knew about the condition of disability. But many times they knew little about living with a disability. The Rolling Quads and their peer groups around the world came to believe that they knew more about life with a disability than the experts. They decided that the experts about their own lives were really themselves. This viewpoint changed their way of looking at the world.

If people with disabilities were their own experts then they should be the ones to speak with one another about living with a disability. They believed they were the persons most qualified to teach about their experiences to other disabled people. They counseled other people about living with a disability. They began to call themselves peer counselors. Many believed that peer counseling established a foundation of their work to change the world.

From Peer Counseling to Peer Support

The Center for Independent Living in Berkeley became one of many disability rights organizations. In the late 1970s the United States government funded a group of independent living centers. All used peer counselors. Some people did not like this term. Sometimes counselors were thought to be people who had gone to school and earned a counseling degree. Other times people thought they or someone they knew needed a professional counselor to analyze complicated issues. These were some of the reasons that some independent living centers stopped using the term "peer counselor" and started calling the sharing of life experiences "peer support." Whichever term people used, sharing life experiences with each other continued to generate momentum to eliminate barriers.
Advocacy Oriented Peer Support

To advocate means to encourage change. The Rolling Quads and the other groups mentioned all advocated to make life better for people with disabilities. They chose to do so because they wanted to improve their own lives and the lives of those around them. They learned about one another's lives from sharing experiences. This is advocacy oriented peer support.

As these groups started organizations they developed models of peer support. Centers for independent living shared with one another aspects of these models. People taught courses about many aspects of peer support, including training to become a peer supporter and how to manage peer support activities. Manuals became available to help independent living centers create peer support programs. Training curriculum usually included information about different disabilities, how to communicate more effectively, and exercises to help people listen better to each other.

Three Examples of Peer Support as Advocacy

A southwestern center for independent living chose to make a one-day peer support training an example of how shared life experience could become a shared advocacy experience. During the first part of the day facilitators discussed communication skills, definitions of peer support, and the development of peer support. The attendees then broke into smaller groups where they talked about issues that bothered them. The smaller groups then each chose one issue. A facilitator then led each group somewhere in the community to advocate for change about the issue they had chosen.

One group traveled to a hotel that had installed a ramp with a killer slope. The hotel management tried to explain why the ramp worked. In exasperation one woman transferred from her wheelchair to another seat. She then asked the manager to sit in her wheelchair and use the ramp. He tried but could not do so because he was scared. He immediately began to work to modify the ramp.

Another group went to City Hall. They met with city management to request sign language interpreters at City Council meetings. They let the management know that if interpreters were not at Council meetings soon, they might use other methods, such as petitions or demonstrations, to continue to advocate for interpreters.
The second example begins with a group of citizens in the Denver area. They wanted to travel by bus but could not because the buses did not have wheelchair lifts. They began to demonstrate. They even sat in front of buses so the bus had nowhere to go without running over the disabled person. In a few years the city of Denver had wheelchair accessible buses. The group called themselves ADAPT, and they attracted people from all over the country--and then the world--who wanted to make change. They began to have street actions like the ones in Denver in other cities. Today ADAPT demonstrates to advocate for increased personal assistance services so people with disabilities do not have to live in nursing homes.

At an ADAPT demonstration, dozens and sometimes hundreds of people with disabilities get to share life experiences with each other on city streets. ADAPT demonstrators shout slogans about what they want to change and why. The immediacy of these demonstrations encourages people both to share life stories and to create them at the same time.

The third example occurred overseas. An American advocacy organization opened a sister office in Budapest, Hungary, in 1994. The two planned several annual conferences, beginning in 1996. At the first conference, Hungarians with disabilities were so reserved they barely spoke until the final day of the meeting. In 1998, the third annual conference moved to Gyor, Hungary. Conference topics included peer support and advocacy. Small groups met to discuss these concepts. The energy of the groups spilled over into the development of a spontaneous demonstration.

While touring the shopping plaza near the conference hotel, attendees discovered that there were virtually no accessible shops or restaurants. It so happened the conference coincided with the European labor holiday of the 5th of May. Conference participants decided to organize a demonstration. First, permission was obtained from the police, then the press was contacted. The group gathered first in front of Centrum, a chain department store, and asked to speak to the manager. He would not comply, so many wheelchair users wheeled over the one step into the store and started infiltrating both floors with their presence. Store customers expressed astonishment at seeing this group of customers. Demonstrators vacated the store, but not the plaza. Numerous pictures in front of other inaccessible locations were taken. For many the demonstration remained the highlight of the conference. In only a few years these Hungarians had evolved from not wanting to discuss their situations to bringing a group of people together for a mass demonstration.
These are only three examples of many that could be used to describe advocacy oriented peer support. They show what is most important about the concept. Life experience is shared and used to make change. Why else should a center for independent living exist?

The IL NET is a collaboration of Independent Living Research Utilization (ILRU) Program and the National Council on Independent Living (NCIL), and organizations and individuals involved in independent living nationwide. Now entering its second three-year funding cycle, the IL NET is building on its strong foundation to address the spectrum of needs expressed by centers for independent living and statewide independent living councils.

The mission of the IL NET is to provide training and technical assistance on a variety of issues central to independent living today--understanding the Rehab Act, what the statewide independent living council is and how it can operate most effectively, management issues for centers for independent living, systems advocacy, computer networking, and others. Training activities are conducted conference-style, via long-distance communication, through widely disseminated print and audio materials, and through the promotion of a strong national network of centers and individuals in the independent living field.

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