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Disability Rights and Independent Living Movement Oral History Series

UNIVERSITY OF CALIFORNIA'S COWELL HOSPITAL RESIDENCE PROGRAM FOR  
PHYSICALLY DISABLED STUDENTS, 1962-1975: CATALYST FOR BERKELEY'S  
INDEPENDENT LIVING MOVEMENT

Edward V. Roberts	THE UC BERKELEY YEARS: FIRST STUDENT RESIDENT AT COWELL HOSPITAL, 1962
James Donald	STUDENT RESIDENT AT COWELL, 1967-1968, ATTORNEY AND DEPUTY DIRECTOR OF THE CALIFORNIA DEPARTMENT OF REHABILITATION, 1975-1982
Cathrine Caulfield	FIRST WOMAN STUDENT IN THE COWELL PROGRAM, 1968
Herbert R. Willsmore	STUDENT RESIDENT AT COWELL, 1969-1970, BUSINESS ENTERPRISES MANAGER AT THE CENTER FOR INDEPENDENT LIVING, 1975-1977
Billy Charles Barner	FIRST AFRICAN AMERICAN STUDENT IN THE COWELL PROGRAM, 1969-1973, ADMINISTRATOR IN DISABILITY PROGRAMS IN LOS ANGELES
John "Jack" Rowan	STUDENT RESIDENT AT COWELL, 1971-1973, AND CHAIR OF CIL'S BOARD OF DIRECTORS, 1976-1982
Peter Trier	STUDENT AT BERKELEY: THE TRANSITION FROM THE COWELL HOSPITAL PROGRAM TO THE RESIDENCE HALLS, 1975

Interviews Conducted by  
Sharon Bonney  
Kathryn Cowan  
and Susan O'Hara  
1994, 1996, 1998-1999

Since 1954 the Regional Oral History Office has been interviewing leading participants in or well-placed witnesses to major events in the development of Northern California, the West, and the Nation. Oral history is a method of collecting historical information through tape-recorded interviews between a narrator with firsthand knowledge of historically significant events and a well-informed interviewer, with the goal of preserving substantive additions to the historical record. The tape recording is transcribed, lightly edited for continuity and clarity, and reviewed by the interviewee. The corrected manuscript is indexed, bound with photographs and illustrative materials, and placed in The Bancroft Library at the University of California, Berkeley, and in other research collections for scholarly use. Because it is primary material, oral history is not intended to present the final, verified, or complete narrative of events. It is a spoken account, offered by the interviewee in response to questioning, and as such it is reflective, partisan, deeply involved, and irreplaceable.

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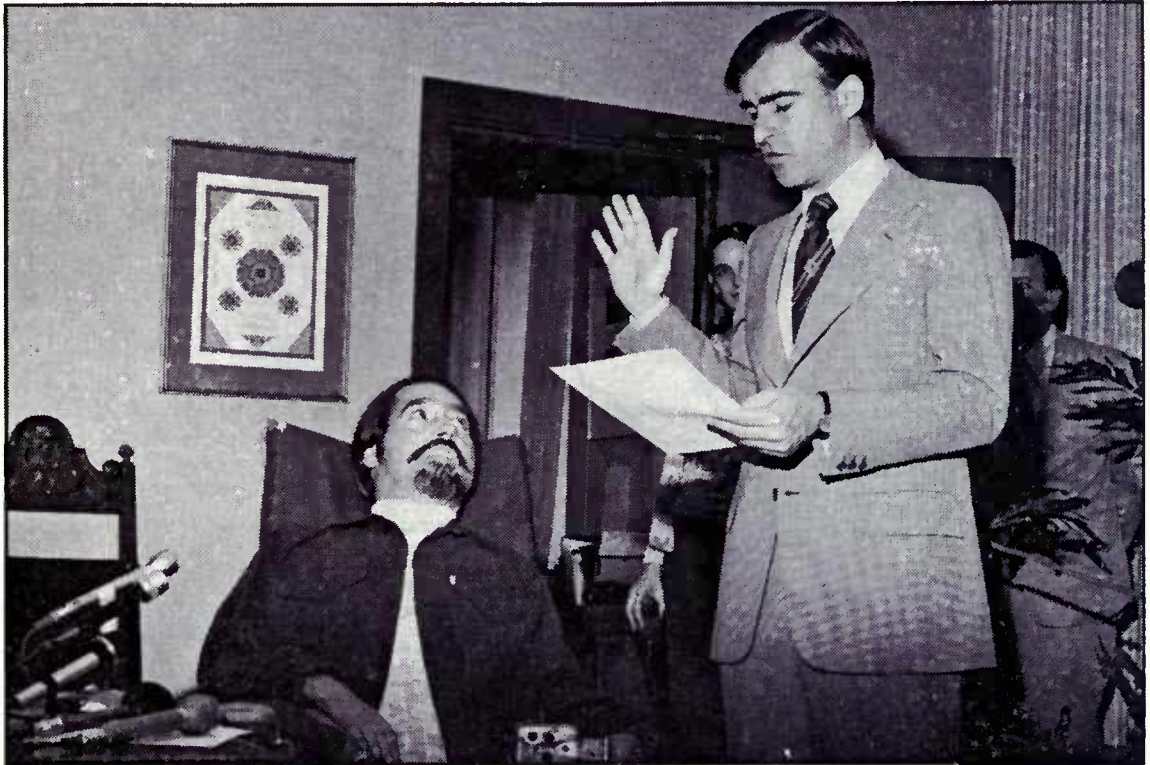
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Ed Roberts being sworn in by California Governor Jerry Brown as Director of the Department of Rehabilitation, 1975.







Don Galloway and Ed Roberts on the Berkeley campus, 1974.







Cathy Caulfield, 1966.





Cathy Caulfield, 1980.







Cathy Caulfield with daughter Julia, 1990.







Herb Willsmore, February 2000.

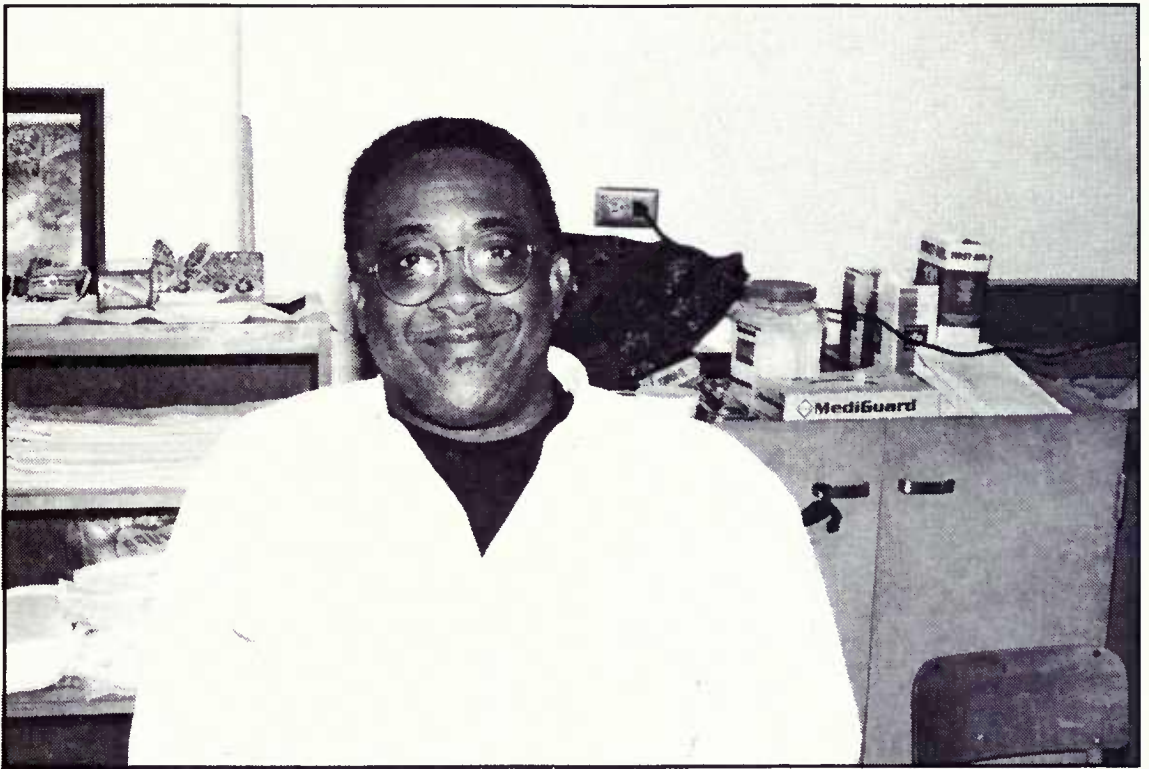
*Photo by Kathy Cowan.*





Herb Willsmore at the demonstration after Governor Reagan's veto of attendant care monies.

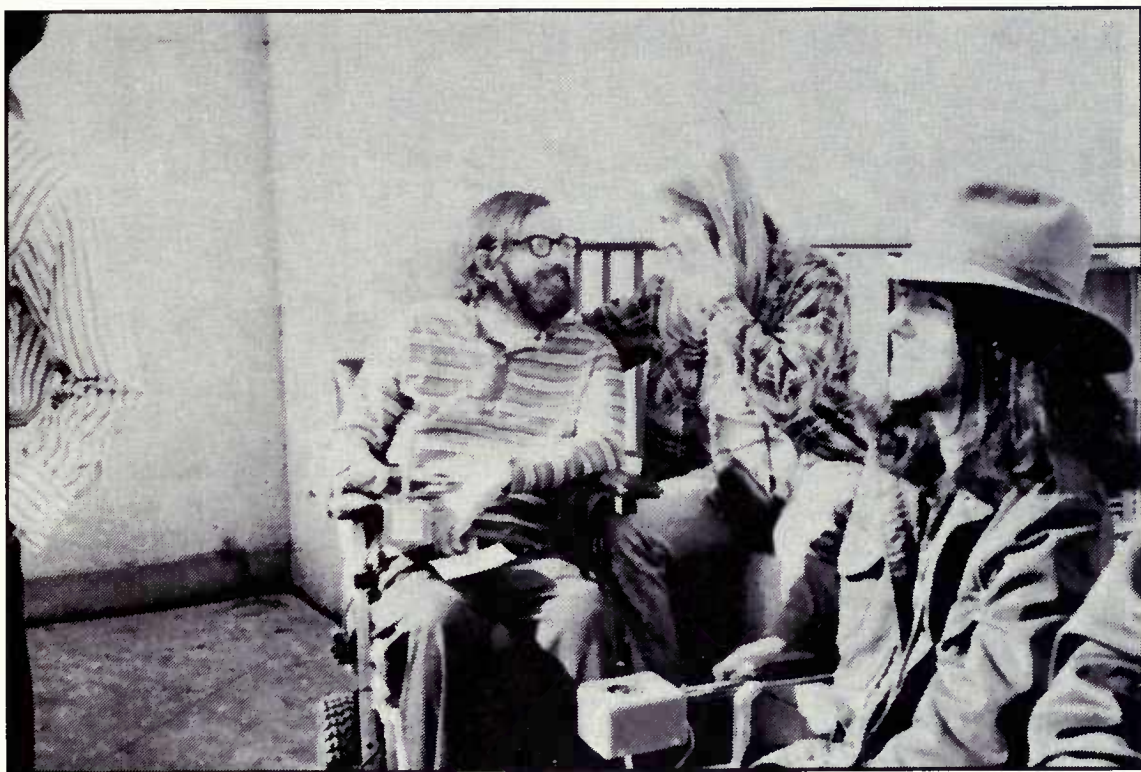




Billy Barner, 1998.



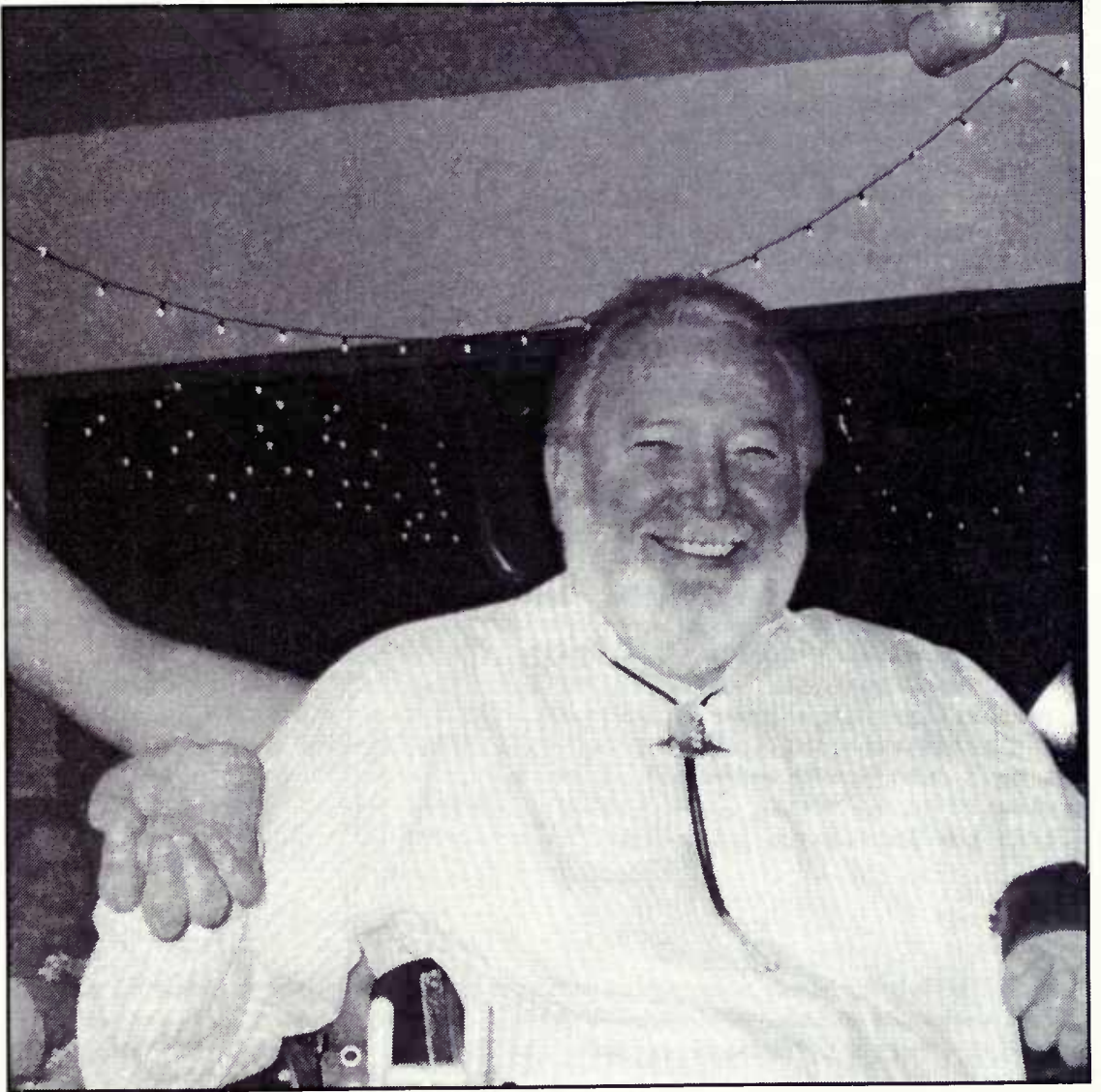




Jack Rowan, 1972.







Jack Rowan, wedding day and birthday, April 11, 1998.

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Edward V. Roberts (1939-1995), *The UC Berkeley Years: First Student Resident at Cowell Hospital, 1962*: role of Dean of Students Arleigh Williams, Dr. Henry Bruyn, nurses and attendants; fellow students John Hessler, Cathrine Caulfield; social life and political organizing at Cowell, media attention; relations with State Department of Rehabilitation (DR); genesis of independent living movement. James Donald (b. 1945), *Student Resident at Cowell, 1967-1968, Attorney and Deputy Director of the California Department of Rehabilitation, 1975-1982*: spinal cord injury at age 20; antiwar movement and other political activism on campus; UC Davis law school, 1969-1972; reflections on Ed Roberts and John Hessler at DR; legislation, access and transportation; San Francisco 504 sit-in, 1977; Disabled Peoples' International, Human Rights Committee chair. Cathrine Caulfield (b. 1948), *First Woman Student in the Cowell Program, 1968*: spinal cord injury and rehab; UC Berkeley student life; early days at Physically Disabled Students' Program (PDSP); travels and motherhood. Herbert R. Willsmore (b. 1946), *Student Resident at Cowell, 1969-1970, Business Enterprises Manager at the Center for Independent Living*: spinal cord accident, rehab at Kaiser Vallejo; power wheelchairs, attendants, Rolling Quads, and disability activism; lobbying in Sacramento; establishment of PDSP and CIL; career in real estate. Billy Charles Barner (b. 1949), *First African American Student in the Cowell Program, 1969-1973, Administrator in Disability Programs in Los Angeles*: football spinal cord injury; Rolling Quads' lobbying for attendant care money; independent living centers in Los Angeles; teaching special ed. John "Jack" Rowan (b. 1938), *Student Resident at Cowell, 1971-1973, and Chair of CIL's Board of Directors, 1976-1982*: older student at Cowell, Rolling Quads' lobbying efforts; CIL under Judith Heumann, Phil Draper, and Greg Sanders; Disability Law Resource Center; disability as a civil right; assistive technology. Peter Trier (b. 1950), *Student at Berkeley: Transition from the Cowell Hospital Program to the Residence Halls, 1975*: formation of Disabled Students' Union; leadership of John Hessler; political organizing and civil rights movement.

Interviewed in 1994, 1996, 1998-1999 by Sharon Bonney, Kathryn Cowan, and Susan O'Hara for the Disability Rights and Independent Living Movement Oral History Series, Regional Oral History Office, The Bancroft Library, University Of California, Berkeley.



## ACKNOWLEDGMENTS

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Special thanks are due to other donors to this project over the years: the Prytanean Society; Raymond Lifchez, Judith Stronach, and Dr. Henry Bruyn; and June A. Cheit, whose generous donation in memory of her sister, Rev. Barbara Andrews, allowed the Regional Oral History Office to develop the grant project.





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SERIES INTRODUCTION--The Disability Rights and Independent Living Movement, by Simi Linton

When I was asked to write the introduction to the Bancroft Library's oral histories on the disability rights movement in Berkeley, it reminded me of the summer of 1975, when I left New York City and headed out to Berkeley, California. For Berkeley was the place to be I told my friends, filled with hippies and free love. I would spend the summer, take courses at the university. I had been disabled just a few years and this was my first trip on my own, away from the tight circle of family and friends I had relied on in those early years.

Someone had told me that Berkeley was a center of disability activism, but I didn't tally that in my list of reasons to go there. I was a naive young woman in my twenties, and still new to disability. I "managed" my disability by keeping its profile low, and its needs in check. I use a wheelchair, and did then, and decided I would need to call the disabled students' office at the university to get help finding an accessible apartment near the campus, but also decided this would be the only concession I would make to my disabled state. I was fine, I told myself and my family, and by that I meant I could go anywhere, I could do everything. Disability would not bog me down and it would not mark me.

While bold on the outside, I harbored the deep fear that I might fail in my ability to keep disability in its place, that it would come crashing in around me and swallow me up. I, therefore, was completely unprepared for the headlong leap I made that summer toward disability, toward the people and the territory that I had shunned. I never imagined that I would move toward disability with interest and gusto. It didn't happen all at once in that brief summer, but I call that time in Berkeley my coming out.

I had arrived in a place where disability seemed more ordinary than it was where I had come from, where accommodations were apparent, where the curbscuts on every corner made it possible for me to go to the supermarket, to the bookstore and up to campus without having to stop someone at each corner, explain to them how to tilt my wheelchair back, take it down the curb, and lift it back up on the other side. Although Berkeley may not have had significantly more disabled people than other places, it seemed to. Maybe it was because I was out on the streets more than I was in New York. I saw people acting out the daily routines of life--going to the supermarket, school or their jobs--using wheelchairs or crutches, brandishing white canes, using sign language and all of the other indicators of membership.

And life started to become easier and more flavorful, not by avoiding disability but by living with it in a different way. The lure of the other disabled people I saw was great, and I learned that it was those people, most I never got to meet, who were responsible for the curb cuts, accessible bathrooms, the independent living center where I went for help, and the disabled students office that had found an apartment for me. I had never seen any place where disabled people were in charge and it thrilled me and made me optimistic about my life in a way that no other experience could.

I learned back then that it was not some benevolent church group that carved out those curb cuts, or a member of the town council trying to get votes who mandated accessible facilities, they were due to the deliberate actions and painstaking labor of members of the disability community who fought for the changes that were made. Their work set the stage for the ongoing struggle for rights and liberties that has engaged a nation of activists. Today, while discrimination remains a constant in disabled people's lives, the right to an accessible environment, to housing, employment, and transportation is governed by laws that are increasingly exerting influence on those who discriminate. Further, the idea of integration, in education, in public accommodations and in transportation, pervades the informed discourse on disability rights and is supported, again, by legislation that mandates desegregating society.

The Bancroft Library's Regional Oral History Office project, "The Disability Rights and Independent Living Movement: The Formative Years in Berkeley, California, 1960s-1980s," exposes the brick and mortar of these victories. Present in the narratives are major players and significant events, as well as the vital auxiliary figures and contributing influences that form the connective tissue of the Berkeley portion of these movements. The histories also reveal the dilemmas and roadblocks that halted progress and interfered with the integrated and equitable society that the framers of this political agenda envisioned.

It is a critical time to look closely at the progress that has occurred, and to study the impairments and deficits that remain in our not yet fully integrated and equitable society. Researchers, activists and those who write policy need, of course, to examine the present moment, and evaluate the necessary steps to take to move forward. Yet, just as important, is an examination of what led us here. How are present problems connected to past struggles? How do ideas that we act on today, relate to those formulated in past eras?

The oral history project provides detailed answers to those research questions. The material they have assembled will be of value to researchers, artists of all kinds, activists and policy makers. This endeavor is made possible now by opportunities afforded by the present moment that were not readily available before. The early activities and ideas have had the opportunity to grow and take root. There has been



time to evaluate their impact and to see the shifts in ideas, policy, and human interactions spurred by what at first glance might seem to be a random set of activities undertaken in reaction to specific concrete problems.

In addition, there have been a number of developments over the last three decades that have created both the need and the impetus for this work. I've grouped these into four sections that outline some of the cultural, scholarly and political activity that informs this work.

### The Social Construction of Disability and the Significance of Community

What I witnessed in the summer of 1975 when I came to Berkeley from New York was that disability could mean something different just by moving to a new location. I wouldn't learn the term "social construction" for another fifteen years, but I did learn through direct experience that disability is not fixed. I also learned that the disability community is a powerful and meaningful entity.

Fundamental to the Regional Oral History Office project is an understanding of the social construction of disability. The efforts begun in the sixties by the people interviewed here to reframe disability as a social designation and to conceptualize obstacles to employment, education and integrated living as a civil rights issue, rather than an individual problem of impairments and deficits, made it possible to understand disability that way. Further, an essential prerequisite for the progress of the disability rights movement was the organization of the disability community, a coalition formed by the discovery of each other and the recognition of our common social status. Although medical and educational institutions continue to categorize and divide people by impairment status, the formation and the formulation of the "disability community" has had a major impact in the social/political arena.

For all my early learning, and my ongoing study of disability, it is in reading these histories that I have begun to understand how profound and original the ideas are that drove the early activists. The voices that are heard here demonstrate the purposefulness of the activists and their comprehensive vision of an equitable society. If this research platform were to reveal nothing else, it would be invaluable as a means to contradict the stereotypes of disabled people, and of the disability rights movement as merely riding the coattails and mimicking the agendas of the civil rights and feminist movements.

Yet, not only does this collection of histories serve as an exemplar of social construction and the significance of community, it demonstrates the unique nature of the construction of disability and illustrates the struggle to define and assert rights as a minority group

in the face of powerful efforts to confine disability within the province of medical discourse.

### The Value of First-Person Narratives

A second domain that informs this project is the increased attention to the active voice of previously marginalized peoples. First person narratives, long discredited in academic circles, are now accepted by a wide variety of scholars and public historians as not only valid, but necessary research tools. ROHO's intent to bring disabled people's perspective to the forefront is consistent with that approach, and the nuanced and detailed data they obtained demonstrates again the value of the methodology. Disability has traditionally been studied as the effect of war or violence, the failures of medicine, or other causes. In these narratives, we see that what brought disability to the individual becomes much less important than what the presence of disability causes to happen. Significantly, the narrators show the ways that disability sets in motion certain social and institutional responses. As these histories reveal, a disabled person's presence in a school, a restaurant, a job interview, a social gathering, or other venue often caused events to unfold in particular ways.

While scholars outside of disability studies have rarely paid attention to disability narratives, this project provides compelling documentation of the place of disability within the larger social arena, and also demonstrates the ways that disability plays a role in shaping an historic moment. I believe that the rich insights of the narrators and their ability to reveal the complex consequences of disability oppression will engage scholars within disability studies as well as those outside the field. For instance, researchers might want to look at what the histories reveal about the parallels between the place of women in other early civil rights struggles and in the disability rights movement. They may want to examine disabled people's perspective on their exclusion from other social justice platforms or consider the obstacles that the disability community itself may have erected to coalition building with other disenfranchised groups.

### Complex Representations of Disability and the Social Milieu

The oral histories provide detailed descriptions of the lives of the narrators and others in their circles. These materials will be useful not only to researchers and activists but to writers and artists interested in portraying the lives of the people interviewed, or developing fictional representations using these figures as stimuli. For instance, writers can turn to these histories for background information for projects that dramatize events of the sixties. The projects might relate specifically to the events or the people described in the oral histories, or the research might be aimed at gaining more accurate information about secondary characters or events. A writer

might want to learn more about what the Cowell Residence really looked like, who lived there, what were the attendants like, some of whom were conscientious objectors doing alternative service during the Vietnam War, or what kinds of wheelchairs and other adaptive equipment were people using then. These histories are about disabled people and the genesis of the disability rights movement, but they are also histories of the period and will be useful in providing more accurate representations of both.

While mainstream cultural products continue to depict disabled people and disabled characters in inaccurate and narrow ways, a growing number of writers, artists, actors, and performance artists who are disabled or are insiders in the disability community are providing more realistic, interesting and complex representations of disability to a wider audience than the arts ever have before. Although the numbers are still small and the venues marginal, I expect that over the next decade, as increasing numbers of disabled people gain access to higher education and training in the arts, their ranks will grow and as they do, this material will continue to grow in value.

#### A Resource for Disability Studies Scholars

Finally, this project will be an invaluable resource to the growing ranks of disability studies scholars. Disability studies began to take shape as an organized area of inquiry in the early 1980s. Prior to that time, although there were isolated pockets of transformative scholarship in some liberal arts fields, the study of disability was housed almost exclusively in the specialized applied fields (rehabilitation, special education, health, et cetera). Disability studies came along and provided a place to organize and circumscribe a knowledge base that explains the social and political nature of the ascribed category, disability. The field has grown enormously, particularly since the early 1990s, as has the Society for Disability Studies, the organization that supports the work of scholars and activists interested in the development of new approaches that can be used to understand disability as a social, political and cultural phenomenon.

Certain ideas pervade disability studies. For instance, a number of authors have examined such ideas as autonomy and independence. The perspectives employed in a disability studies analysis of such phenomena afford a complex look at these hitherto rarely examined ideas. Scholars interested in the theoretical implications of these ideas will benefit from examining the ROHO histories. They will learn, as I did in a recent reading, how the early activists discovered that the surest route to gaining independence was to have access to attendant care. These young people, many just out of institutions, or living away from home for the first time in their lives, were creating a new type of community, one in which it was clearly understood that support and

services are necessary for individual autonomous functioning. They recognized the irony that what is typically thought of as "total dependence" was instead the ticket to the greatest freedom and autonomy they'd ever known. Rather than wait for the nurse or orderly in their institution to "decide" if it was time to get out of bed, have a shower, eat dinner or watch television, with personal attendants available and under their direction they could make these decisions on their own. Rather than wait at home for their mother or other relative or friend to bring them food or take them somewhere, they could lobby the university for a lift-equipped van that would be at their disposal and provide them with access to the kinds of leisure activities non-disabled students take for granted. They learned by setting up their own wheelchair repair services, and hiring qualified mechanics, they could keep their manual chairs, and the power wheelchairs that they also had lobbied for, in working order.

Through their lived experience they had the occasion to formulate a new way of thinking about such accepted ideas as what constitutes independence; what is freedom, equity, and integration; the ways that physical dependence and psychological independence are two separate and potentially unrelated variables. Disability studies, while dominated by theoretical formulations, social science research methodology, and modes of analysis employed in various areas of the humanities, will benefit enormously from the concrete examples given here of the abstract principles our work depends on.

The value of this project will ultimately be revealed as future research, creative endeavors, and policy initiatives are developed that have utilized this primary source material. Over the decades to come, researchers in all areas of inquiry will find within these documents numerous variables to be tested, relationships among people, events, and trends to be examined, cultural phenomena to be studied and dramatized, and ideas to be woven into theory or literature. The most exciting research opportunity that this work affords is the examination of the beliefs and behaviors of people whose demands for equity and justice upped the ante in the fight for an inclusive society.

The Regional Oral History Office staff are to be commended for their vision. They have brought us a vital piece of history, one that would be lost and forgotten if it were not for them. They have captured in these individual histories, a history. And a legacy.

Simi Linton, Ph.D., Co-Director  
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New York, New York  
April 1999



SERIES HISTORY--The Disability Rights and Independent Living Movement  
Oral History Project, by Ann Lage and Susan O'Hara

### Historical Framework

The movement by persons with disabilities for legally defined civil rights and control over their own lives took on its present framework in the 1960s and 1970s. Virtually simultaneously in several cities nationwide, small groups of people with significant disabilities joined together to change the rules of living with a disability. No longer content with limited life opportunities, nor willing to be defined solely as medical patients, they shared the willingness to challenge authority, discard received wisdom, and effect societal change that was the hallmark of the era. Not surprisingly, the disability movement paralleled other movements for equity and civil rights by and for racial minorities, women, and gay people. From our vantage at the close of the century, it is apparent that these movements, taken together, have changed the social, cultural, and legal landscape of the nation.

Berkeley, California, was one of the key cities where models for independent living were developed. A small group of young people, all wheelchair users, had one by one enrolled at the University of California in the 1960s. In an era prior to accessible dormitories or private housing, they were given living quarters in the campus's Cowell Hospital. In the midst of the campus maelstrom of free speech, civil rights, and anti-war protests, they experimented with radical changes in their daily lives, articulated a new philosophy of independence, and raised their experience to a political cause on campus and in the community.

By 1972, these students had created new institutions, run by and for people with disabilities, which soon attracted national attention. The first two of these organizations, the Physically Disabled Students' Program on the campus and the Center for Independent Living in the community, drew several hundred people with disabilities to Berkeley from across the United States. This early migration became the nucleus and the strength of the community that, for many, came to symbolize the independent living movement.

Political action kept pace with the developing awareness and institutional growth. In the early seventies, the Berkeley group successfully lobbied the city of Berkeley for curb cuts and the state legislature for attendant care funding. In 1977, scores of persons with disabilities sat in for twenty-six days at the offices of the federal Department of Health, Education, and Welfare in San Francisco, as part of a nationwide protest that eventually forced implementation of Section

504 of the Rehabilitation Act of 1973, often called the Bill of Rights for Americans with Disabilities. Many participants trace their awareness of disability as a civil rights issue and their sense of membership in a disability community to the 1977 sit-in.

By the 1980s, a number of other important organizations had evolved from the Berkeley experience: the Disability Rights Education and Defense Fund (DREDF), the World Institute on Disability (WID), Computer Training Program (later, the Computer Technologies Program [CTP]), the Bay Area Outreach Recreation Program (BORP), and others. All of these organizations shared the original philosophy of the Berkeley movement. Their example and their leaders have had national and even international impact on the quality of life and civil rights of persons with disabilities.

### Genesis of the Project

The idea for a project to document these historic events germinated for nearly fifteen years before funding was secured to make possible the current effort. In 1982, Susan O'Hara, then director of the Disabled Students' Residence Program at the University of California, Berkeley, contacted Willa Baum, director of the Regional Oral History Office (ROHO) of The Bancroft Library, suggesting that the genesis of the Berkeley movement be recorded in oral histories with participants in the campus's Cowell Hospital Residence Program. Mrs. Baum and Ms. O'Hara began planning, enlarged the project scope, gathered faculty support, and initiated the search for funding. Their efforts produced three grant applications, the final one in cooperation with Professor Raymond Lifchez of the UC College of Environmental Design, to the National Endowment for the Humanities, none successful.

ROHO then secured funding from the Prytanean Society, a Berkeley campus women's service group, to produce oral histories with Arleigh Williams and Betty Neely, both campus administrators who oversaw the establishment of the early disabled students' programs. Herb Wiseman, a former staff member of the disabled students' program, conducted these two interviews in 1984-1985. Later, the California State Archives State Government Oral History Project funded an oral history with Edward Roberts, the first student in the Cowell program and later the director of the California State Department of Rehabilitation. This initial support proved essential; all three individuals were to die before the current project was funded.

By 1995, as the historical importance of the events in Berkeley and beyond grew increasingly evident, the fragility of the historical record became ever more apparent. The archival records of key institutions that grew out of the movement and shaped nationwide events were not collected and preserved in a publicly accessible library. The



personal papers of key leaders of the movement were scattered in basements and attics. Moreover, the urgency of preserving the memories of participants through oral history interviews was underscored by the death of five pioneer disabled activists in the previous several years.

When Susan O'Hara and Mary Lou Breslin outlined the scope of the problem to The Bancroft Library, the then-curator of Bancroft Collections, Bonnie Hardwick, joined Willa Baum in support of the idea of developing a comprehensive disability collection at Bancroft. Baum, Hardwick, and Ann Lage, associate director of ROHO, worked with leaders of the disability community to design a plan for an archival collection at The Bancroft Library, to include both in-depth oral history interviews and written and photographic records of major organizations and activists. The Disabled Persons' Independence Movement collection was envisioned as "a primary historical resource of national significance, a research platform for future scholars, for persons with disabilities, and for public education." The National Institute on Disability and Rehabilitation Research generously funded the three-year project in 1996.

#### Project Staff and Advisors

The collaborative nature of the project--among the disability community, academic advisors, oral historians, and archivists--has strengthened it in every respect. The advisory board included three Berkeley professors: Frederick Collignon of the Department of City and Regional Planning, who has worked on disability issues since 1970; Raymond Lifchez, Department of Architecture, who has conducted research on environmental design for independent living since 1972; and William K. Muir, Department of Political Science, who has chaired campus committees on disability issues, and is a scholar of U.S. and state government and public policy. Paul Longmore, professor of history from San Francisco State University and a specialist in disability history, was crucial in defining themes and topics to explore in oral history interviews. Mary Lou Breslin, president and co-founder of the Disability Rights Education and Defense Fund, represented the perspective of the organizations to be documented as well as her personal experiences as an activist for disability rights.

Knowing that oral history is most often successfully carried out by persons who combine a compelling personal interest in the project with an ability to bring a historical perspective to their task, the Regional Oral History Office turned to the Bay Area disability community itself to staff the project's team of interviewers. Susan O'Hara became the historical consultant for the project and conducted a number of interviews as well as informing all of the project activities. All of the project interviewers had personal experience with disability. A majority had significant disabilities, several had participated in or

observed the historical events to be documented and knew many of the key players and organizations. Interviewers included Sharon Bonney, former director of the Disabled Students' Program at UC Berkeley and former assistant director of the World Institute on Disability; Mary Lou Breslin, who crossed over from the advisory board; Kathy Cowan, librarian for a public-interest nonprofit organization; Denise Sherer Jacobson, a writer and educator on disability issues; David Landes, a college instructor of economics and coordinator of student affairs for the Computer Technologies Program.

Joining the team to interview narrators in Washington, D.C, was Jonathan Young, a Ph.D. candidate in American history at the University of North Carolina who had conducted oral histories on the history of the Americans with Disabilities Act. When Mr. Young resigned to accept a White House appointment, Susan Brown, long familiar with disability issues and other civil rights/social movements, became the project's Washington connection. Ann Lage coordinated the interviewing team for the Regional Oral History Office, and the office's regular staff, coordinated by production manager Shannon Page, provided transcription and other clerical support.

Bancroft Library project personnel included Bonnie Hardwick, curator; Lauren Lassleben, supervising archivist; and Jane Bassett, the project archivist whose job it was to contact the disability organizations, project interviewees, and other activists and survey their records to identify historical material. Once records and personal papers were donated to the Library--more than 300 linear feet before the project's conclusion--it was Jane and her student assistant, Amber Smock, who preserved, organized, and made the papers accessible to scholars with detailed finding aids. The archival and oral history projects, though separately administered, were in close cooperation, with the interviewing team providing contacts with the disability community and leads on papers to collect and the archivists assisting interviewers in their research in the growing collection of written records.

### Interviewees and Themes

An overarching question for the project was to explore and document how this social movement developed in time, place, and context: how the movement in Berkeley was built, how it became effective, how individual life experiences contributed to and were changed by the movement. Lines of inquiry included identity issues and personal life experiences; social/economic/political backgrounds of individual activists; the roles of women and minorities in the movement; development of leadership; institution building and management; development of a disability community group identity; media, mythology, public image and the political process; impact of technology; the range

of efforts to influence disability law and policy and to embed disability rights into the canon of civil rights.

Interviewees (narrators) were selected for one of several reasons: the individual was a founder or recognized leader of one of the key institutions, made a unique contribution to the movement, was a particularly keen observer and articulate reporter, or was a sustainer of the movement who provided a unique perspective. We attempted to choose narrators who had a range of disabilities and to interview nondisabled persons who contributed significantly to events or institutions.

Interviewees fell primarily into two categories: either they were involved in the residence program of Cowell Hospital on the Berkeley campus in the sixties or they participated in the building of early organizations in the 1970s.

#### Group One--UC Berkeley's Cowell Hospital Residence Program

A wing on the third floor of Cowell Hospital was the site of the first housing for students with significant disabilities on the Berkeley campus. This cluster became a breeding ground for the Berkeley phase of the independent living movement. About a dozen students--mostly men, mostly white, mainly in their twenties, with more and more autonomy within their grasp--spent several years in this benign but nonetheless isolated hospital residence, in the middle of a campus exploding with student protest movements. Six of these students were interviewed, including Ed Roberts, who narrated several hours of 1960s memories before he died with the oral history still in process. The former students all refer to their sense of community, intense camaraderie, the thrill of independence, an atmosphere of an-idea-a-minute, and the politics of their involvement.

Also included in this first group were certain early university and State Department of Rehabilitation officials--the hospital director, the nurse/coordinator, counselors--who might be called traditional gatekeepers but nonetheless allowed the unorthodox residence program to happen and in some cases encouraged it.

The majority of the narrators in the first group stayed involved in disability-related activities for many more years. Their recorded histories include these later activities, overlapping with the events documented in the second group of narrators.

## Group Two--Builders of the Movement

The second group of interviewees are primarily founders and leaders who participated in the expansive phase which began in 1970 with the start of the Physically Disabled Students' Program (PDSP) at the university, followed by the founding of the Center for Independent Living (CIL) in 1972. These interviews reveal the grassroots politics, high energy, occasional chaos, unstinting belief in "the cause", seat-of-the-pants management, funding sources and crises, successes and failures of individuals and organizations. In the next few years a whole constellation of organizations evolved to sustain the independent living movement, including DREDF, CTP, KIDS, BORP, WID, Center for Accessible Technology (CAT), and Through the Looking Glass. This group of interviewees provide insight into the politics, leadership, and organization-building of both their own organizations and CIL.

Many key interviewees in this group are still in leadership positions and have had national and international impact on disability policy development. Also included in this second group are persons who were not in the top ranks of leadership but who were keen observers of the scene, could augment the basic history, and offer further points of view.

## Oral History Process

All of the project interviewers received formal and informal training in archival oral history procedures and met monthly as a group to plan and evaluate interviews and review progress. Interviewers prepared a preliminary outline before each interview session, based on background research in relevant papers, consultation with the interviewee's colleagues, and mutual planning with the interviewee. In-depth tape-recorded interview sessions were from one to two hours in length; interviewees required from one to fifteen sessions to complete their oral histories, depending on the length and complexity of their involvement in the movement.

Tapes were transcribed verbatim and lightly edited for accuracy of transcription and clarity. During their review of the transcripts, interviewees were asked to clarify unclear passages and give additional information when needed. The final stage added subject headings, a table of contents, and an index. Shorter transcripts were bound with related interviews into volumes; longer transcripts constitute individual memoirs.

More than forty oral histories are included in this first phase of the Disabled Persons' Independent Movement project. Volumes can be read in the Bancroft Library and at the University of California, Los Angeles, Department of Special Collections. They are made available to



other libraries and to individuals for cost of printing and binding. Many of the oral histories are accompanied by a videotaped interview session to document visual elements of the interview and the setting in which the interviewee lives or works. Video and audiotapes are available at The Bancroft Library. If funding for a second phase of the project is secured, many of the oral history transcripts as well as a representative collection of documents and photographs will be available on the Internet as part of the Online Archive of California.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. The office is under the direction of Willa K. Baum, Division Head, and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley. The catalogues of the Regional Oral History Office and many oral histories on line can be accessed at <http://library.berkeley.edu/BANC/ROHO/>.

Special thanks are due to donors to this effort over the years: the Prytanean Society; Raymond Lifchez and Judith Stronach; and June A. Cheit, whose generous donation in memory of her sister, Rev. Barbara Andrews, allowed the Regional Oral History Office to develop the grant project. The Bancroft Library's three-year Disabled Persons' Independence Movement Project, of which these oral histories are a part, was funded by a field-initiated research grant from the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education.

Ann Lage, Project Coordinator  
Susan O'Hara, Historical Consultant

Regional Oral History Office  
The Bancroft Library  
University of California, Berkeley  
September 1999





August 2000

Disability Rights and Independent Living Movement Oral History Series  
The Formative Years in Berkeley, California

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Billy Charles Barner, *First African American Student in the Cowell Program, 1969-1973, Administrator in Disability Programs in Los Angeles.*

John "Jack" Rowan, *Student Resident at Cowell, 1971-1973, and Chair of CIL's Board of Directors, 1976-1982.*

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Disability Rights and Independent Living Movement Oral History Series

UNIVERSITY OF CALIFORNIA'S COWELL HOSPITAL RESIDENCE PROGRAM FOR  
PHYSICALLY DISABLED STUDENTS, 1962-1975: CATALYST FOR BERKELEY'S  
INDEPENDENT LIVING MOVEMENT

Edward V. Roberts

THE UC BERKELEY YEARS: FIRST STUDENT RESIDENT AT COWELL HOSPITAL, 1962

An Interview Conducted by  
Susan O'Hara  
in 1994



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## INTERVIEW HISTORY--Edward V. Roberts

Edward V. Roberts was the first student with a significant disability to utilize Cowell Hospital, in 1962, as a residence on the campus of the University of California, Berkeley. This course of action proved to be the genesis of the campus Residence Program for disabled students. His pioneer political work earned Roberts the title of "father of independent living."

Roberts had polio in 1953, resulting in almost complete paralysis of all four limbs and the need for a respirator ("iron lung") to assist his breathing for part of each day. Later, while at Cowell, he and his assistants devised a way for him to operate a motorized wheelchair with his left hand.

Roberts was the second director of the Center for Independent Living, taking the reins in 1973, within one year of its founding. Roberts was the first significantly disabled director of the California State Department of Rehabilitation (1975-1982). In 1983, he co-founded the World Institute on Disability [WID] with Judith Heumann and Joan Leon.

Roberts enjoyed a relatively wide media coverage throughout his life; WID has placed a large collection of his papers in the DPIM archive at the Bancroft Library.

Three interviews took place in the fall of 1994; more were planned upon his return from a trip abroad. But that was all there were to be, as he died suddenly of a heart attack at age fifty-six on March 14, 1995.

The interviews focus on Roberts' recollections of his years on the Berkeley campus. He talks about his decision to apply to Berkeley, his life at Cowell Hospital and on the campus, fellow students, the Department of Rehabilitation. He recounts his oft-repeated favorite stories of those years, namely, on choosing stardom over embarrassment, on being arrested, and on fellow student Donald Lorence's first electric wheelchair.

The interviews were recorded in Roberts' home, a small cottage connected to his mother's house in a quiet neighborhood in southeast Berkeley. Interruptions were frequent--the phone rang, he and his attendant spoke of tasks to be done, his mother stepped in from time to time (her interjections appear in the transcript). On one occasion, Roberts fell asleep during the interview, a phenomenon well known to associates who sat through meetings with him. The interviewer and Roberts had been acquainted for many years.

The transcript was reviewed by his mother, Zona Roberts, after his death. She made a few explanatory comments, placed as footnotes in the transcript.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. Copies of all interviews are available for research use in The Bancroft Library and in the UCLA Department of Special Collections. The office is under the direction of Willa K. Baum, Division Head, and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley.

Susan O'Hara, Interviewer-Editor

December 1, 1999  
Regional Oral History Office  
The Bancroft Library  
University of California, Berkeley



## INTERVIEW WITH ED ROBERTS

Decision to Attend the University of California, Berkeley, 1962Meeting with Arleigh Williams, and Question of Campus  
Housing[Interview 1: September 15, 1994] ##<sup>1</sup>

O'Hara: Ed, we're going to start with the early sixties. Can you start by describing what made you come to the University of California at Berkeley?

Roberts: It's funny, Berkeley hadn't been part of the dream. I had always heard about UCLA [University of California at Los Angeles] being so successful, so I kind of set my sights to go to UCLA. It was built after World War II, and evidently a lot of disabled veterans went there. And for a variety of reasons, I had never thought about Berkeley. Until my brother got into Berkeley--he came here first.

O'Hara: Which brother?

Roberts: My brother Ron [Ronald W. Roberts]. But even when he came it was, "Oh, Okay. Maybe that's an alternative." But it seemed so, whenever I'd come to Berkeley, which wasn't very often, it seemed like it was not very accessible, as conscious as I was about whatever that was.

Then it was really going to the College of San Mateo [1959-1962] that I met and had a counselor named Jean Wirth. She was a remarkable person. She's six foot five. She was six foot five at twelve years of age, and her father was a famous cancer surgeon, so he had all these friends around who kind of examined her to see why she grew so fast. I think she went through a lot of similar things about being an object, in a way.

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<sup>1</sup>## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

I started off in English and literature [at San Mateo], and I thought I wanted to be a creative writer. Actually, no: technical writer, because I could make money at technical writing. That basically was, you write manuals for programmers. Didn't sound that challenging, but on the one hand, it sounded like it might be a thing I could make money in. I had learned how to dictate at San Mateo and to have things typed up. At the high school, I'd also learned more about writing. I did most of that with my mother. So I had some good skills.

Then I took a government class, American government. The teacher wasn't that great, the subject wasn't that great, but I loved it. I was excited by the government: How do you get things done, how do you make things happen through a government, and how do you deal with power and all. That was much more interesting to me than English literature, or than literature. I realized I was hooked, and so did Jean Wirth, I think, because I started talking to her about it.

She said, "Well, if you're going to be into politics, the only place to go is Berkeley." And I hadn't heard much about Berkeley. But she started talking to me about it, and the more she talked about it, the more I realized maybe that was the place to be instead. It was close to home. But growing up in the Bay Area down on the Peninsula, East Bay was so far away for me. I didn't even know much about Oakland and Berkeley and this. I had heard about them, but not much.

O'Hara: Berkeley was a quiet town at that point?

Roberts: Yes, it was, fairly quiet. We knew the university was there. I was probably a bigger fan of Stanford than Cal. [laughs] So I paid attention to them more athletically than anything else.

But she kept telling me, "You need to go to Berkeley. Let's go over." I remember when I came over, I came over first with her. I met [Dean of Students] Arleigh Williams the first time. The dean of students of the College of San Mateo came, and I can't remember his name right now.

O'Hara: Was that Philip Morse?

Roberts: Yes, that's right, yes. I know Mom will remember it, but anyway.

O'Hara: She's the one who told me a while back.

Roberts: Yes, he came too, and he was the vice president of the college. But I think we all kind of agreed that this was the place for me.

But it wasn't going to be easy. Oh my god. It all seemed sort of like a rough dream.

And then the biggest obstacle became real soon, where would I live. I think we almost gave up because of that.

O'Hara: Can we back up just a little bit?

Roberts: Yes, sure.

O'Hara: You came and talked with Arleigh Williams?

Roberts: Yes.

O'Hara: And do you recall that meeting at all? Did you feel--

Roberts: I recall the meeting. It was an interesting meeting, because--

O'Hara: Did you actually get in the meeting?

Roberts: Yes, I was there. I was there with Arleigh.

O'Hara: Was Sproul Hall--

Roberts: It was in Sproul, but I don't remember how, whether he came out to me or whether we went in.

O'Hara: I think your mother recalls that Sproul was not accessible then.

Roberts: It could be. But we did meet him in the hall down in the basement, or somewhere.<sup>1</sup> Because I remember it wasn't that long, but he was encouraging and discouraging at the same time. He said they didn't have much experience with somebody like me, but it was probably time for the university to do more. And how to do it, he wasn't really sure either.

He gave us a list of places, like the dorms, like International House, like other places, and it wasn't until we came back again and said, "Those places are too freaked out to deal with me."

---

<sup>1</sup>Philip Morse, Jean Wirth, and Zona Roberts came over with Ed to Berkeley to see where Ed would live. We pushed Ed up Bancroft and into a dorm where we were told, "Iron lungs won't fit into a dorm room." Phil knew Arleigh Williams and he went into Sproul to consult while we waited outside. Arleigh suggested seeing Dr. Bruyn at Cowell Hospital and we went to see him that day. --Z.R.

O'Hara: Did you actually speak with some of them?

Roberts: I went to I-House,<sup>1</sup> which was also inaccessible, and Jean Wirth went in. Now, you can imagine this guy from Pakistan or somewhere just looked at her, this huge tall woman, and just kind of freaked out. "Oh, no, we don't have any students who--oh, no, we couldn't have him." And then he got the manager to say the same thing. It seemed like wherever we went, there was no opportunity.

I remember my mother and I came up a couple of other times, and then we had a flat tire on the bridge. We just barely got off the bridge. Just all kinds of small vignettes.

O'Hara: What was your mode of transportation at that time?

Roberts: I was in a car. I had to be lifted in and out of the car, and I would every once in a while get hurt. My knees usually would get hurt. I was long, and--

O'Hara: And the chair--you were in a push chair, a manual chair, and that was in the trunk?

Roberts: The push chair laid back, yes. It worked for me, but I was used to being pushed around in it. I had no idea of how free I would be later.

But I knew I was ready to go on. I knew that. In fact, it was surprising to my mother when I graduated from the College of San Mateo [1962], and that was like incredible, and then she hears me saying--somebody said, "Are you going on?" and I said, "Oh, yes, I think I'll go to UCLA." And that's the first time she'd heard that, and that surprised her.

O'Hara: It surprised her?

Roberts: Oh, totally surprised her, and she thought, "Whoa. Just going through the College of San Mateo was a remarkable feat." And then she started hearing me say, "I don't want to stop here; I have to go on." I think I realized before she did that the path to my future and to my working or whatever was going to be education, totally. Because nobody was going to hire me the way I was. There was so much prejudice about disability.

---

<sup>1</sup>Philip Morse had lived at International House when he attended UC Berkeley and he suggested we look there as a housing possibility. --Z.R.

I remember coming over here [Berkeley] a few times, partly just to be with my brother a little bit.

O'Hara: And where did he live?

Roberts: He lived at a fraternity house, the Sigma Chi house, which is on the corner of Channing and College. So he was close to campus.

O'Hara: Was that accessible? Could you get in there?

Roberts: No, it wasn't accessible, but they could pull me--see, at this time, if I went at all, I got pulled up and down stairs. That was before I realized I was really risking my life, and that I had to do more about stairs. In order to go anywhere, I had to make sure the stairs were removed.

O'Hara: Were there any curb ramps at that time?

Roberts: No, there weren't any at all. Of course, when you're in a push chair, you just lean back and you tilt it. It jars you around a lot, but there were no power chairs at all. It wasn't until later.

O'Hara: When you say that the campus wasn't accessible, do you remember any specifics? Does anything pop up in your mind?

Roberts: I had to go to Sproul, and that was not very accessible. Anyplace I wanted to go, I had to send somebody into.<sup>1</sup> Even Dwinelle had stairs on one end and the other. I could go in to Dwinelle at different places. What's the big building in--

O'Hara: Wheeler?

Roberts: Yes, Wheeler. That's what I'm thinking about, Wheeler is the one that had--

O'Hara: With the graduated steps, kind of.

Roberts: Right. And Dwinelle I went in. I had a hell of a time finding the right rooms.

O'Hara: Everyone still does!

---

<sup>1</sup>On our second coming to Berkeley to plan Ed's classes, we were to meet with his advisor in South Hall, the political science headquarters then. His advisor came out to meet us. --Z.R.

Roberts: Of course, everyone found out that there were these multiple floors that had been mislabeled, I guess. But then I was in political science.

O'Hara: Were you in Barrows? Was that the--

Roberts: Barrows most of the time later, but I don't remember when Barrows was built. Maybe the second year I was there it opened, or so. I don't remember when I moved there. I remember most of my political science career was there. I was there later. So that was pretty accessible, because that was brand new, and there had been a '58 law that mandated some access, so the ground floor was pretty level. It had lots of elevators, because it's seven or eight floors high, but all my professors were in there, I remember.

O'Hara: So that worked fairly well.

Roberts: Yes, that worked out better.

O'Hara: On the same day that you met Arleigh Williams, I understand that he referred you to Dr. [Henry] Bruyn, and Dr. Bruyn was there, or was that another appointment?

Roberts: I'm not sure if he referred me. I kind of remember that as being another appointment, that Arleigh, after Arleigh got some pressure from the vice president of the college, Phil Morse, and he didn't know what to do. So I think it was at the last minute. Arleigh must have called Henry and said, "What do we do with this guy?" And Henry said, "Well, send him up to me; I'll tell him." I think he said, "I'll tell him that he can't come here."

#### 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].<sup>1</sup> 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.

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<sup>1</sup>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.

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.<sup>1</sup> 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.

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<sup>1</sup>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.

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]

### Three Favorite Memories

#### Being a Star

Roberts: But I loved Berkeley. I really got into it. I felt like a star at Berkeley. I was so different than anybody else, and I started feeling that at the College of San Mateo and Burlingame High School. I remember I had gone to Burlingame High School, at the beginning of the semester, students had come to me--

O'Hara: At home?



Roberts: And I was at home, I'd been virtually a shut-in for years. I remember when a social worker and my mother came to me and said, "If you don't begin to get out of here, you're going to stay here the rest of your life. I want my life, too." Not being cruel, but just started the re-incentive. Whenever I went to high school, I said, "Oh, God, no, it's such a hassle." I'm sure I was going to lay guilt on my mom, to show her.

So they loaded me up in the station wagon and took me to the school, and they started to unload me. It was lunchtime; there must have been 200 students, or it seemed like. They were all eating lunch around this court. So I started to get up, and every one of them turned to stare at me. My worst fear, and one of the reasons that I had not come out at all was that I was terrified of being stared at. That just indicated to me how awful it was and how ugly I was. I didn't want to put myself down in the process.

But I remember that day when they were getting me out of the car, and all of a sudden my worst fear came true: everybody was staring at me. And when I'd look up at them, they'd look away. And something remarkable occurred to me while I was there. The first thing was that it didn't hurt. For people to stare at me did not hurt me. It had been such a fear that I thought it would. The second thing that occurred to me was that maybe it wasn't all my problem, because when I looked back, they would look away. As I thought about that, why was I taking all this on as my problem when wasn't the fact they stared also their problem? It was an interesting feeling.

The third thing was, oh, it was like being a star! I think that was one of the more important times in my life, that I realized I could enjoy it. I didn't have to feel guilt or all those things that I was--anger especially. Actually, I could enjoy being stared at. If I thought of myself as a star, not just a helpless cripple. I think those things happened to me all through my life, these, "Aha!" The real "Aha." And I've talked about that a lot, not as much any more.

But why do we build the self-hatred around this stuff? Why do we accept all these old attitudes toward ourselves, and actually wind up being the people who put ourselves down? That's part of my philosophy. I began to see this whole idea of being a star as very important. It may or may not be true but--

O'Hara: That depends on what you do with the feeling.

Roberts: In many ways, I became a star. I just assumed that position.

[Interview 2: September 29, 1994] ##

O'Hara: [Showing Ed articles] So we've had a look at these few headlines which identify you as star and a hero. You had decided in high school maybe that would be fun. How did the press get hold of you?

Roberts: I think it was a combination of people who knew me from the area, from Burlingame and San Mateo, because I'd gotten some awards before I left high school, like I got the Soroptomists' award as the Youth of the Year, I remember. They also helped pay for my telephone link in high school that helped me go to school, so I went from my bed.

O'Hara: The Soroptomists helped pay for that?

Roberts: Yes. They're a women's club. So they took me on as one of their projects. Over the years, I had different articles written about me, but I think some people just kind of decided to get some articles in the local area. At first there were some written at the university and by local papers around Berkeley. There was the story in *Parade*, I think it's called *Parade*. That's the one with Ron and I; that's *Parade* magazine. So it was at least in the Sunday supplement all over. I think that exposure then led some others to want to do local stories around Burlingame and San Mateo about "local boy makes good"--here, "Local hero."

O'Hara: Did you get any response from the *Parade* or the national article?

Roberts: Yes, one of the things I got to do was, we got to--I told the reporter that I liked baseball and I'd never been to a Giants game, so he called the Giants and took the whole family to the game. We sat in this box seat up by the broadcast booth. I was in a push chair then, so I could be carried up and down a few stairs, at least; not too difficult.

O'Hara: This was at Candlestick [Park]?

Roberts: That was the only perk, I think. Yes, at Candlestick. I only did that one other time, and got so cold. Until they just did a story about me, it will be on PBS [Public Broadcasting System] next March, a series of three stories, they did a long one on me, and they as a reward took me to a Giants game. Candlestick is remodeled, and so this time I sat on the field right by the first base side. It was the best seat I've ever had at any athletic event--except my close encounters with the third kind, when I used to go to Harmon Gym and watch basketball.

### Arrested!

Roberts: One time I was there [Harmon Gym] with a reporter, and they wanted to take pictures and they kept moving me over so they could get shots of basketball players and me. They moved me too close to the court, and I remember Washington State [University] was playing. Washington State used to have these real big bully guys, 250 pounds, who used to play tackle on football and forward on basketball. My brother Ron kept saying, "Don't go any further." I remember looking up, I was talking to this reporter, and this guy had just taken a fast break, and he threw the ball and it landed on me. He wound up--I saw his face in the air. He went, "Oh, shit," and I went, "Oh, shit," and started thinking [Inaudible]. He landed on my foot pedals, which snapped back up. I thought for sure my ankle was broken.

That's the night I got arrested. That's the night as a reward after [the game], my brother and a couple of my friends and I went out to a bar, which I don't think is still around, but anyway it was a bar that had bluegrass music. I like bluegrass music a lot. Every crack in the pavement on the way there, my foot hurt. It hurt real bad. And I'll be damned if I wasn't going to go to this bluegrass thing.

O'Hara: You mean it hurt from being hit in the game?

Roberts: Yes. And I thought, Oh, it could be broken, but what the hell, I'm not--I didn't think it was, but I thought it would be swollen. We went there, and I remember drinking a lot, because I drank enough that my foot stopped hurting. We were drinking beer. I had enough beer to get paralyzed, but luckily I was already paralyzed, so it didn't matter. [laughter]

Then, all of a sudden, both John and I realized that we had to pee. John had a leg bag, and I had no urinal, so we grabbed the whole pitcher. The first thing, John went out and drained his urine bag. Then he came in and said, "All right, go on out."

Now, this all started because the bathrooms weren't accessible. So I went outside, and on the way out there, when I went to the back, somebody said, "Halt." There was a flashlight hit me in the face, and he said, "What are you doing? What are you doing here?" I said, "Oh, nothing, nothing." And of course, on the ground was this whole leg bag that John had dumped. He flashed his light there and he said, "Looks like you've already done something here." I said, "No, I can't go like that. It's probably just water. Somebody watered there."

So he let me go, and I went back in. I was totally bursting. I had to go so bad. I waited about five minutes, and then rushed back. We grabbed an old beer pitcher, and I really filled that beer pitcher up. Then we dumped it in the bush, basically. As I turned around to come back in, there was a, "Halt, you're under arrest."

I said, "What!" He said, "I warned you. You're under arrest." I looked at him, I said, "You get me, I've got to have an iron lung." He just looked at me like, What? I said, "I'll die in jail. You've got to have an iron lung." He looked at me with this look on his face like, Oh, shit. I was saying, "You've arrested me; now what are you going to do with me? Come on?"

He said--the funniest line was, "I've got to call my sergeant." So he called his sergeant. The sergeant came over, and I heard the sergeant saying, "You dumb shit. Why did you arrest him? That's foolish. We can't--it's not accessible. Our jail won't even take somebody in a wheelchair."

So then the sergeant came over and talked to me and said, "He's arrested you, and we know we can't take you, and we're going to let you go on your own recognizance, but we're going to report you to the university." I had no words. I remember at that time I was thinking a lot that I really wanted to have a political career. I didn't know how, but I really wanted to get into politics. And not just teach it, but really do it.

It's so funny, because two days later, Henry Bruyn pays me a visit and said, "We got this report that you were caught pissing in the street." I looked at Henry and I said, "Well, it's a slight exaggeration. The basic facts are probably true. But we were at a bar, we were drinking a lot of beer, I had to pee, and there was no way to get in the bathroom, and there was no place close, no accessible bathroom. There was a gas station close; we tried that."

I remember on my way home beginning to get a little bit more sober and hurting again, my foot. As I rolled across these cracks, the only thing I could think, and I said this to the guys that were with me, "Oh, my god, my political career is over before I started." Can you imagine, "Helpless cripple attends Cal and arrested for peeing on the street"? So I was drunk and kind of feeling like, well, that's the end of my political career. And then to have Henry come down and try to explain to him that, in fact, I didn't do anything real bad. We actually went out behind the bar.

It turned out when John had gone out there, he was a little noisy. There was an apartment next to there, and they called the police. That's why the cop was there when I got there. All this could have been prevented by--

O'Hara: Where was this?

Roberts: It had to be a mile away from the campus [in order to serve alcohol at that time]. It was past Ashby, so it was a pretty good walk from the campus. It was--I don't remember. Maybe I will in a bit, but I don't remember. It later closed.

O'Hara: It's gone now?

Roberts: I'm sure it's gone now.

O'Hara: Did they stop the game, or what happened at that moment when [you and the basketball player collided]?

Roberts: No, he went right on. The back of my chair flipped way up in the air. My brother Ron grabbed it, and I went, "Ohhh." I didn't know if I was hurt, but then it started hurting. I'm sure this guy landed on my foot pedals and flipped my chair in the back. Then when he jumped off, it snapped back up.

Well, that's the first story of my arrest. It was different than for political reasons, but I think Henry understood that the real problem was there was no bathroom. He still said, "I had to come down to tell you not to do this again."

O'Hara: Did this make it to the papers?

Roberts: I don't think so. I don't think I wanted it, and I don't think Henry wanted it. [laughter] It was around Cowell, though, about disabled guy, helpless guy, who'd gone out and gotten drunk, and then the cop--I never talked to him, but the sergeant told me that he was mortified. When I said I had to have an iron lung, he didn't know what to do. I guess he was more careful later in arresting people. Anyway, that was the whole thing.

#### Don Lorence and His Power Wheelchair

Roberts: Now, Hale [Zukas] came in '66, or '67. He came a lot later.

O'Hara: I think maybe even early seventies.



Roberts: Or maybe later than that, actually. What I did know is he wanted to be in the program and was rejected by Henry, because of the communication problem, I believe.

O'Hara: Oh, that was Hale?

Roberts: There was Hale, and there were a few other people, too.

O'Hara: Dr. Bruyn told me that he had rejected a student with cerebral palsy, and he regretted it.

Roberts: Yes. Well, Hale was so bright. He never should have rejected him; Hale should have been at Cowell. But Hale's family lived in Berkeley; he lived in Berkeley. So it wasn't as essential that he live at Cowell, although it would probably have been good for him and for us. They rejected a few people that I know of I met later. In a sense, when they began to reject Don, [Donald Lorence] and I told this story about Don when he first came. You could not hear him, his voice was so low.

O'Hara: You haven't told me on tape.

Roberts: Oh, really? Well, Don came about '68, '69, somewhere in there. And I couldn't believe when Don actually got in and I met him, I could not hear him. His voice was so low, and he was a nice guy, I liked him. But Don had lived in his room for years. His father was an engineer for Hewlett-Packard, and Don went to school basically from his room. He did a lot of work in electronics. Whatever his father was doing, he had parts of and pieces of. He learned how to solder, and he was almost like a partner with his father on electronic projects. So I guess he started off building radios; he built all kinds of electronic stuff. But he wasn't used to talking.

I remember when we first saw him, he was in this push chair and very quiet. John wondered how he would get along, being so quiet. He could be quiet; you could be quiet; I wasn't that quiet. And then, Donald, after being there a couple of days, one day he got a power chair, one of the old-fashioned six-volt chairs that had two or three batteries. It was relatively slow but had quite a bit of power. I remember the first day, they couldn't find him after he had this power chair, and we couldn't find him.

Finally, we started searching the rooms upstairs. By that time, we were on the third floor. Then somebody opened one of the doors, and there was Donald inside this room, exhausted, because he tried to yell, but they were pretty soundproof, these rooms, and [he] just didn't know what was going to happen to him.



He had gone--he could go in to doors, but the door closed behind him and he couldn't get out.

O'Hara: I remember.

Roberts: That's one of the reasons that on my office door, I insisted that they swing both ways, that I could be sure to go in and out alone. Interesting what these experiences teach you.

Then the next day, we lost Donald again and we thought, Oh, shit, he's locked [in]. We looked for him but we couldn't find him. Later, the campus police brought him back. They brought his batteries separate. We said, "What's going on? What happened?"

They said, "We pulled him out of Strawberry Creek." I said, "Well, how did he get into Strawberry Creek?" That's not easy. But he went up to the highest hill. There's a hill, I don't remember exactly where it was, but he was playing. He was so totally elated by being able to move where his whole life he'd not been able to move more than a few inches or a few feet because he couldn't push himself. With his muscular dystrophy, he was so paralyzed that he didn't have much strength to push himself. If you're living in your room, you don't go anywhere.

And then what they said was they fished him out of the creek after realizing they had seen him up in the hills rushing down, but somehow, he yelled and got a student, and the student got the police. Here was this mild, meek guy that you couldn't even understand when he spoke, unless you got real close to his mouth, and here he was a totally changed person. All this aggressiveness and all the feelings that he'd had about being blocked, not able to move, all of a sudden he could move. And he tried everything he could think of in that chair. It did scare him to roll in the creek.

O'Hara: Did he fall out of his chair?

Roberts: No, he didn't fall out of his chair. He was pretty lucky, actually, and that they got him. The creek was down low, and I guess it wasn't that--he just sank into some mud or something, who knows. I said, "Donald, did you actually do that?" He just got this incredible smile on his face, like, "Oh, did I love it too!" That's what he said. He said, "I didn't realize I could get into that much trouble that fast. I thought for sure I could stop, but the batteries bounced." So he lost his power.

So here was this Donald Lorence who was totally endearing to us, who had really showed us the meaning of freedom in power

chairs, from someone who never moved. John and I especially were just tripped by this. All of a sudden, he started speaking so we could hear him. A lot of the ways we knew him changed so radically in a few weeks. He just all of a sudden became--he was a student, and he was out, really out. He kind of tried to identify--later he decided he was gay, and all kinds of things came out of Donald that were there all the time, but he could never bring them out, I think.

He was just a wonderful example of how important it was for everybody to get a shot at--if you're paralyzed physically and you don't have mobility, you've got to have it. If you're a kid and you can't move, you've got to be able to move. So all these feelings, all these things came out of him. I got almost a better education at Cowell with my fellow disabled students than I did at the university. I felt that Donald, he was a real special person, real special, and a friend. I mean, I was more disabled in many ways, but not like he was in a social way. I had at least been out, I hadn't been isolated for years, and all kinds of things. But I had no trouble talking and being articulate. I couldn't imagine being shut in for so many years. I basically was shut in for five years.

O'Hara: During your high school?

Roberts: Yes, during those high school years, but I got away from it. But I never stopped talking and being very vocal. There were always people around me. Unlike Donald; he had no friends, nobody around him at all. His mother and his father, and maybe his brothers were--I think there was a brother and a sister, but I don't remember now.

Early Interaction with the California State Department of Rehabilitation [DR]

Conflict as Political Training Ground

Roberts: So Donald had been there for maybe a year or two years, and somewhere before, we had gotten a new counselor for the Department of Rehabilitation. Because Butcher--Butch as they called her--

O'Hara: Catherine Butcher?

Roberts: This Miss Catherine Butcher, she had been my counselor, and she was just wonderful. She had this faith in John and I both that we would succeed; it was a matter more of whether they helped us in the right ways. So she was an old-fashioned counselor who would say to you, "You know what you want; what can I do to help you get there?" It seemed later that counselors stopped saying that. But I think they still are awful in many ways, thinking they know more about what you want and need than you do, which I think is dumb. Nobody knows more. That's one of the reasons I don't choose a doctor unless I know they will listen to me about myself.

O'Hara: You know, there's a story that says that you were rejected [as a client] by the Department of Rehabilitation because you were not employable.

Roberts: That's right.

O'Hara: Now, did that happen before Catherine came on the scene?

Roberts: That happened when I applied to go to Berkeley, and when I was graduating from the College of San Mateo. I went to see a counselor when I started, and basically the first thing they said to me was--and the counselor had a limp, a bad leg. I went in, and they gave me some tests, and then within a couple of weeks they rejected me for service, saying that I was too disabled to go to work, and I was therefore infeasible. We said, "Oh, no you don't."

O'Hara: Who's we? Your family?

Roberts: My mother, myself, and Phil Morse from the College of San Mateo, and Jean Wirth.<sup>1</sup> At that time, the president of the College of San Mateo also knew me, and so this whole counter movement started. There were articles in the *San Mateo Times*, I think, about being rejected, but I don't know, because I think articles came out because we made it public that I had been rejected. And College of San Mateo said, "He's doing well. He can do all kinds of things. He can write. That's crazy." And this counselor, I

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<sup>1</sup>Jean Wirth and Phil Morse met with people from Vocational Rehabilitation (as it was named then) and discussed Ed's going on to college. Jean and Phil had Ed's grades and recommended support after Voc. Rehab. had turned him down saying they couldn't justify the expenditure as he was too disabled to work and earn money. Jean and Phil showed them his potential and they reversed the decision and did agree to support him financially at Cal. There was no newspaper publicity about this meeting.  
--Z.R.

remember him telling me that I was going to be rejected, and he believed it was important to reject me. His disability had hurt him a lot more than mine had hurt me, even though mine was a lot more disabled. He was a pretty down kind of guy. I think that it limited him more than it limited me.

O'Hara: What kind of tests did they give you?

Roberts: They gave me the Minnesota Multiphasic. They also wound up giving me tests--

O'Hara: Interest Inventory, or--

Roberts: Yes, and they gave me ink blot and some psychological tests. They said I scored off the top on aggression, and that I was too aggressive as well to be a client of Rehab. I scored real high. I turned around and I looked at this guy, and I said, "If you were paralyzed from the neck down and you wanted to do something in your life, don't you think being aggressive would make more sure that I would succeed?" He said, "Oh, yes, but you're way off the scale."

I said, "Well, I don't know, but I think it makes me more likely to succeed."

O'Hara: You said that you were eighteen, nineteen?

Roberts: Yes. Maybe twenty. But I said that. I knew he wasn't going to accept anything. But we got the department to change within a couple of weeks, the director--

O'Hara: In Sacramento?

Roberts: Yes, that guy. His name was Alan--Jeez, what was his name?<sup>1</sup> He was a real tall, good-looking guy, the image of a director. Only not my image of a Rehab director. Later, he was a head of INS [Immigration and Naturalization Services], which is immigration services, under [President] Ronald Reagan. Anyway. He became a kind of a friend, and he reversed the counselor's decision. One of the things I learned from that was that in dealing with bureaucracies like welfare bureaucracies and other bureaucracies, it helps when you have trouble with them to shine the light of

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<sup>1</sup>Under Governor Edmund G. Brown, Sr., the director of the Department of Rehabilitation was Warren Thompson (1963-1964); under Governor Ronald Reagan, Robert E. Howard was director and Elliot Allen was chief of Fiscal Services.

publicity on them. They got some pretty bad articles written about them. Here was this brave quadriplegic--

O'Hara: Hero.

Roberts: Yes, hero, whose only real future would have to come because of education, getting an advanced degree to make sure he was qualified to go to work, and they're rejecting him. This horrible department was rejecting him based on some weird standard called infeasibility. And when they decided two weeks later, I already had started school, but they decided they would allow as how they'd make an experiment. That's when I got Catherine Butcher.

O'Hara: Did you contact the director yourself?

Roberts: No, I didn't meet him until a bit later.

O'Hara: It was just the media exposure?

Roberts: It was total media, and people at the College of San Mateo calling. I think they had a little more knowledge than I did on how to make it happen.

#### Recall of Conflict with High School as a Civil Rights Issue

Roberts: So that was a good experience. It was another one like being told I was, I couldn't graduate because I had to have P.E. [physical education] and driver training. Did I tell you that story?

O'Hara: Not on tape.

Roberts: Oh. Well, I was in my senior [year in high school].

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Roberts: My whole attitude toward school had changed. I had gone from a bad student in grammar school, really not an F student but basically a C student, to in high school I had become a straight-A student. I was learning how to write papers and was doing all kinds of stuff. My mother was pretty smart and helped me do a lot of stuff. Basically, I learned through her tutelage, and other students, how to write and how to take tests and all kinds of things. I was pretty proud of myself.



I filed for graduation like my brother had, because by that time I'd missed two years of school and my brother's class was my class then by that time. So I graduated with Ron, but what happened then was almost immediately, the school came back and said, "You cannot graduate. You don't have enough required credits." We said, "What? I've fulfilled all my academic [requirements]. I've taken college prep, and done very well." They said, "But you have not had driver training and P.E., and these are state requirements." I said, "I don't think I'm going to need driver training." Later we said, "Well, I've had physical therapy," and they said, "No, no, that's not good enough." I remember my mother once, in a state of sarcasm, looking at the principal and saying, "Well, we'll put him in the seat, and I will get behind him, and I will drive him--" very sarcastical, and very--I laughed, because she made her point very clear, you assholes. [laughter]

They were still going to enforce it. I remember how I felt, really awful, like I was going to have to stay longer. I was twenty-one or twenty years old already, and now--I know I was totally age inappropriate. Things should be done when people's ages are relevant.

Anyway, so what we did was, we had a friend [of my mother's] who was on the school board. We picked up the phone and called Mimi Haas. She was a school psychologist, but she had run for the school board and was on the school board. She said, "The school board can make that decision, not the school."<sup>1</sup> My mother was--I didn't go, but she was so afraid and so--she was just scared to speak. Which is a little bit unusual, because she had been president of PTA [Parent Teacher Association] and all kinds of things, she was pretty well known at the school. But this was so serious, it was so emotional.

I remember she went to go up to the microphone, they called her. They didn't even let her say--they said basically, "We've talked about this, it's totally unreasonable, Ed will graduate." So she started crying. You'll have to interview her.

O'Hara: Oh, absolutely.

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<sup>1</sup>I met with Mimi Haas and we went over Ed's academic record at Burlingame to see if he had completed all necessary-for-graduation classes except driver training and physical education. Mimi assured me that he had taken and passed all academic requirements for State of California high school graduation. --Z.R.



Roberts: I guess they kind of got the message that she was so relieved. Then she came home and told me, and I was so glad. You know, for me, that was one of the most important fights of my life. Even though my mother actually did the fight, went before the school board, I was a part of that, and it was such a helpless feeling to feel rejected when I had done so well. I felt so vindicated. I also learned a lot from that fight. You don't let people walk all over you; you do something about it. You fight for what you believe is right, and that taught me that. I think that was the model that I followed ever since, and made me a lot of what I am.

O'Hara: And that influenced your reaction to the Rehab decision?

Roberts: Oh, absolutely. There was no question that after that, I fought. And I often did it on my own. Well, my mother did this one. We did it together, because I didn't go to the school board, but I was--I remember the assistant superintendent of schools, the number two guy in the whole district here, he knocked on the door and he came in, and we were talking. We didn't like him at all. This was my mother and I didn't like him much. Then he looked at me and he said, "Now, Ed. This won't take you long to do this, and you don't want a cheap diploma." Oh, my mother and I were so livid. After all, she was so proud, too. But I was so glad of what I did with the school.

O'Hara: What did he want you to do?

Roberts: He wanted me to continue in school for another year.

O'Hara: In high school, to make up for the P.E. and the drivers ed?

Roberts: Yes, that's what he wanted. We told him he could leave the house. My mother escorted him out the door; we were so glad. We were so happy to kick him out of the house. These guys had no concept of what it was all about. Now it would be a civil rights issue.

O'Hara: Sure, of course.

Roberts: It would be. So anyway, that was the most--the things I remember the most were going to school and thinking I was a star, and learning that I could be, and why should I put myself down so hard? And the second was fighting and winning this graduation. I think it just empowered me a lot. So by the fight with Rehab, we were ready. And by the fight to get into Cal, we were also ready. Although I thought I was stymied by the housing thing. They said it had nothing to do with my academics; I was qualified. When Henry Bruyn offered the hospital, that changed.

Can you imagine, if two or three things had been different, I might have had a whole different kind of life. It just makes me--I tell those stories to people, I want people to know about how important it is to fight for what you believe in, and to have the kind of confidence and empowerment to fight.

**DR Counselor Catherine Butcher, Advocate for People with Significant Disabilities**

O'Hara: And then Catherine Butcher came on the scene right after the fight to graduate from high school?

Roberts: That's when I got Catherine Butcher [as rehab counselor]. I was thinking about going to Cal. This was the second--well, that's when I got Rehab for going to Cal, was when I had to fight it out. I wish I had my records, I could look and see what year it was they rejected me. Because they did help me at College of San Mateo.

O'Hara: I might be able to get those.

Roberts: Okay, if you can, try.

O'Hara: I don't know if I have the authority to, but I could try. I'd be interested.

Roberts: But I wouldn't mind having them released to you. It would be very interesting to see what early writings they have.

I became a fairly notorious client, because very few clients fight to get into a system the way I did. Most of them went away. Eventually, when I won, that was a big difference. So Catherine Butcher was pleased to have me as a client. She liked the idea that I fought. She was very proud of that. She had to argue with the department for years to serve more severely disabled people. She was so fed up with the idea of creaming, which is taking those who are easiest to rehab and get them the eyeglasses or the hysterectomy or the whatever--

O'Hara: The least disabled?

Roberts: Yes, get them through, and then whether you're there or not, they'll succeed. So you close them [off the department rolls] as what is called 26 closures, which--and you get credit for that, and you're a better counselor if you have more of those. It's bullshit, but that was the way they judged.

Now, once I got into Cal and they agreed to sponsor me, then Rehab was pretty good. Catherine Butcher was phenomenal. My mom liked her, I liked her. She was so easy to work with.

O'Hara: What did she do for you?

Roberts: She got me a secretary, she got me people to push me to and from class, and all around, and then I hired my own attendants as well. She let me sign off so that I could get the money whenever, to pay people. There were a lot of things that she did that made the system--she did the system, and she got me everything I asked for, books, tuition. And when I wanted to buy extra books, she bought those. Set up accounts for me at the bookstore; that was nice. And that's what we did for all the students later.

O'Hara: Was she around for several years?

Roberts: She was only around for a couple, I think. I don't even know if John [Hessler] had her. She retired not too long after. Maybe four years. Then when the other students started coming in, she had retired, I think, during that time. She was so proud, she said. She came to me and said how important it was for her to work with me and with more severe, that those were the clients she always felt she had to work with and could work with, and be successful. By that time, we were kind of a model for almost the whole country in terms of severely disabled people, going through the process of rehab and through college.

O'Hara: And that was later to become one of your main themes as director of Rehab, wasn't it?

Roberts: Yes, send people on. Well, what I did was, I started cutting out the easy ones. I said, "Look, we don't need--if people have real heavy social problems from growing up poor, or some social milieu that will not allow them to get the kind of skills and things they need, then a small disability can be very large, but not in general." So we set up a system where we served more severely disabled. By the time I left, they were 83 percent severe, something like 70 percent. Of course, some of them monkey with definitions. But the department was really ready, I thought, to move into serving more severely disabled people.

O'Hara: Apparently, they're trying it again. [Rehabilitation Amendments, 1992]

Roberts: Yes, right now they are, yes. History repeats itself.

O'Hara: Did Rehab pay for the other students also, their tuition and some of their room and board?

Roberts: Yes, everything. Whatever the needs were for the people that came in, they were paid for. And we got a waiver at the state level so that any student that came to Cowell or the Cowell project automatically got the maximum of personal assistance, because they needed the \$300.

O'Hara: That would be from the county. Or was that from Rehab?

Roberts: They were all counties. They were all county departments of social welfare. Some of them would give the amount, and then we'd get fouled up because sometimes more conservative counties would give \$150 or less.

O'Hara: As far as the \$300 you needed for attendants, did that come from Rehab or from social services?

Roberts: Social welfare departments; that came from them. In a way, I was lucky, because Rehab was already paying out a lot of money. But they went and got a federal grant pretty quickly. I think it was \$50,000 at first, and then more, to sponsor us, and to use that money. Because we were fairly expensive clients, and they weren't used to that at all.

I remember later, when the counselor named Karen Parker--do you remember Karen? Topp was her last name, Karen Topp. I think she was Parker before.

O'Hara: Newsome.

Roberts: Oh, Newsome, Karen Newsome. Anyway, it's different now again, because she's married.

O'Hara: Goodwyn, it is now.

Roberts: But she was so wonderful. But her budget was like \$300,000, and she was buying vans and attendants.

O'Hara: She came on the scene much later, didn't she, more like '73, something like that?

Roberts: Much later. But she was the best in many ways. And I also remember that she struck me as being the kind that she could do that because we were so strong, as a group. But every year, they complained about her costs, because a lot of this was case service money out of Rehab. And the top people at Rehab, many of whom had been counselors at one time, it was unheard of to spend

that much money on clients. And yet, as you pointed out, how many were successful and went to work, how much they earned. That just proved how important it was to do that. But she was convinced it was--.

DR Counselor Lucile Withington, Catalyst for Student Power

Roberts: But by that time, she had a kind of freedom, because Rehab was afraid to take us on. That all started from when Catherine Butcher left, and they gave us--what was her name? I'm blocking it now.

O'Hara: Lucile Withington?

Roberts: They assigned Lucile Withington. Now, Lucile Withington in her best day may not have been a very nice person. [laughter] I don't have a lot of flattering remarks. But at her worst [she] was strictly an accountant who took seriously the idea she had to cut costs. Even though by that time, it was almost all federal money. Her job was to go in there and straighten these young people out, and make sure they got good grades and reported to her over and over. She came in and laid down all these rules. At the end of each semester she had to have all our grades, and all kinds of rules about money.

But it wasn't just what she asked for, it was how she did it. Because from the beginning, she started threatening: "If you don't give me your grades, I'll cut off your money. If you don't give me this, I'll do that." By that time, there were eight or ten of us, probably eight or ten. She became the real villain in this process. All of us realized we were well on our way to freedom and independence, and no one was going to stop that.

I remember coming together with the group, we called them in, and we said, "This lady is going to be trouble. We've got to be careful what we give her and make decisions together about what we will and what we will not." It's all right to give your grades, but she said if you don't get like a 3.0, we'll kick you out of school. And all of a sudden, she lays--you know, once we let her get away with a few rules, I think she got a reputation in the department that said good, and then she tried to be tougher on us, to the extent that I was working on my Ph.D. and she tried to give me subjects that I could write on. I said, "What qualifies you to--?" And by that time, we were a little alienated. And she knew she couldn't take me on, though. She was not going to try to--they'd already tried that.



But what she decided was that Don Lorence had to go. She had evaluated each student and decided that Don Lorence, and there was one other student that she decided had to go, too. I don't remember who it was. Jim or Larry or somebody.

O'Hara: Scott maybe? Scott Sorenson?

Roberts: Scott, yes, I bet you're right.

O'Hara: I don't know. I don't know the story.

Roberts: Anyway, she had decided that she was going to kick two of them out of the program. We said, "No, you can't do that." I said, "Don Lorence has already made phenomenal strides, and this guy will be employed and successful later, and so will Scott." It must have been Scott, yes. And, "You will not do this." And she said, "I am the counselor. I have the control of your money." Within a week, she kicked them out of the program, and made them leave Cowell. That was--

O'Hara: Clear out their rooms and everything?

Roberts: Yes, clear out their rooms and get out of there. We said enough, no, and we decided to fight her. The first thing I did was went to Henry, and he said there was nothing they could do. Rehab was in charge of it. I think in a way, he kind of agreed, but he talked with them, anyway.

O'Hara: He agreed with you or with them?

Roberts: No, I think he might have agreed with them, that they were not the strongest, but I said, "Henry, that's not the issue. These people deserve the opportunity. They will succeed. They're both strong individuals." Anyway, he kind of sided with Rehab. We called her supervisor and said, "This is not [Inaudible], and this decision must be turned around." He said, "Well, let's meet."

We had started a series of meetings with her. I thought we were remarkably patient. We never came to real agreements with her.

O'Hara: All the students gathered?

Roberts: Several of them, yes.

O'Hara: And met with her?



Roberts: Met in large groups with her, that's right. By that time, Eleanor Smith [first rehabilitation nurse in Cowell program] was our nurse on the floor, which was remarkable because when Eleanor came, all this medical knowledge came with her about decubitus ulcers, and how to get what you need out of Medicare and Medi-Cal.

O'Hara: She gave that information?

Roberts: Yes. She was real sharp. She knew that system. So we started getting power chairs, and we started getting about everything we wanted from the Medicare system. That's how I got my power wheelchair later, was that she knew the words, the magic words. "Medically feasible," all the right words. We got along great, she and I especially basically ran that program, and she was super.

But then, in the middle of this fight, she decided to side with Rehab. She'd already been there two or three years, and we were very close. She said, "They're my boss, they pay me, I have to." I'm sure Lucile Withington threatened her job. "You will be with us; we pay you." You know that message.

In the meantime, she had brought two or three people in that she was very close to before. She was a nurse before.

O'Hara: You mean students? Disabled students?

Roberts: Yes, students. A woman and a man. Which was fine with us. They were good. But in the middle of our struggle, the students she brought in sided with her and turned against us. There were eight of us. I think Jim and her, but all the ones that had come in. We couldn't let them get away with this. We saw loud and clear that we could be next. If we didn't get all A's, or whatever it was, we could be next, and there was no way. These other people that she brought in were more independent, often lived with her in her house and all kinds of things. And they basically turned against us.

If you've ever seen excommunication, we totally excommunicated them from our group, to the extent we wouldn't talk to them at all. They lived on the same floor, yet we thought they'd betrayed us. Of course, in the long run, they probably were thinking that they might get kicked out, too, and wanted to side with Eleanor, who had to win, may be fine. So I don't know.

But we had a series of meetings, first with her [Withington], where we were remarkably constrained. We tried to

work these things out, because we thought we could. And then with her supervisor, a guy named Rod, that always wore dark glasses. I thought he was smoking a lot or doing coke or something. By that time, I had experimented with drugs myself, so I kind of knew what was playing.

Then I called him and I said, "Look, she is not going to [Inaudible]. I want you to come in and work with us now." And he came in, he basically saw that she--we were being pretty reasonable, and she wasn't. And really, the solution we said, "She has to go." That was our bottom line. "She has to go, she will not threaten us again, and we will go to the wall on this." So my experience with the other issues with Rehab, I wound up calling the *Chronicle* and getting a reporter called, [Inaudible], and they did a story. Several of the papers did stories saying how awful it was for these kids to be kicked out, and how awful this department was threatening this program. It was the only one like it in the world basically, and where people were actually becoming independent and going to work and doing--these brave souls, these helpless cripples. And boy, did we play it up.

They got the stories in Sacramento, and it was hurting them. We turned the legislature loose on them as well. Like I went to a couple of our local assemblymen. I think even [Nicholas] Nick Petris was state senator.

O'Hara: That early? I haven't seen those articles; have you recently?

Roberts: No, I haven't seen them at all. I have no idea where they are.

O'Hara: I want to try to dig for those.

Roberts: Yes. And it vilified the counselor especially, but it vilified the department for backing her harassment of us. Within a short period of time, she was transferred to another district.

We didn't have a counselor. I remember they temporarily assigned a counselor. His name was Jerry Belchick; he's around. He now is retired. I don't remember if John [Velton, DR counselor] was involved in it then.

O'Hara: Soon after, maybe.

Roberts: He might have been involved in that. It turned out to be one of the first times in the history of the department that clients had ever forced the department to get rid of a counselor. We wanted her fired, but they transferred her, actually. And then retired her.

O'Hara: I think we're out of tape at this point.

Roberts: It's a good time to stop.

O'Hara: Yes, it's been a good hour. But I think next time, I would like to just have you reflect on that whole political process and the lessons learned.

Roberts: Oh, it's so important.

O'Hara: Because obviously, you were training yourselves to do some really interesting things.

Roberts: There's no doubt we were in training.

### The Exhilaration of Independence

#### The Power Wheelchair

[Interview 3: November 3, 1994] ##

O'Hara: Ed, do you remember when you first got your electric wheelchair and what was involved in that, and what the experience was?

Roberts: Yes.

O'Hara: What did it feel like?

Roberts: I'd been told my whole time that I could never drive a power wheelchair. I think I believed it. Maybe part of it was that the old E&J [Everest & Jennings] wheelchairs were very jerky. They were six volts, and they would have been very difficult for me to drive.

But about that time, a Motorette came out, it was called. The guy's name was Sean Solomon, I think. He invented this proportional drive. What he did was, he took the drive system for little electric cars and for gliders and planes, and he beefed it up and adapted it to be what was then called proportional drive. I think the Motorette was the first one to even have it.

But the most important factor of my learning how to drive a power chair was two things, I guess: one was seeing how free John

was, and wishing for that for myself, and knowing that it could make a big difference in my life.

O'Hara: Up until this point, you always had someone pushing you?

Roberts: I was always in a push chair. I was in a recliner, push chair. It was frustrating sometimes, but in one way, it was nice to have people with me all the time. In another way, whenever we went to a museum or a place that I wanted to look, I had to stop them. And the other thing that I noticed heavily was that when people would walk up to me, they would talk to my attendant. I was almost a nonentity, being pushed around. After I got my power chair, I realized that they had to confront me. All of a sudden, there was no one else there. That was very important for me to realize that and to--.

But what really happened for me was that--

O'Hara: I think I distracted you for a minute. You had two important factors, and one was John's freedom--

Roberts: One was John's freedom, and the other was I fell in love. It was a neighbor woman. Her name was Judy [Croxdale]; I still love her. But she had a son, and she lived in the apartments behind my mother's green house. That's how we met. Basically, my motivation changed. All of a sudden, I was highly motivated to get a power chair, to be alone with Judy, and to be able to go out and do things myself. And as I say, it's ridiculously inconvenient to have to have your attendant with you pushing you around when you really want to be alone with her, this woman Judy.

It was wonderful, so it was a combination of factors. I remember Eleanor Smith helped us find a chair in those days. I think it was Eleanor. It might have been after Edna [Brean] came, but I don't think so. So I kind of said that it's time I try again, let's try again. Let's see if I can't drive a chair.

One day, we got a couple of my attendants, and we put me in a chair. It was very awkward, but I discovered that with this Motorette idea, this proportional drive where the more you pull, the more you go, all I had to do was turn the controller around, because see, I couldn't push forward on it, but I could pull back. That made it even more complex, because when I pulled back and to the left, I went forward and to the right. If I pulled back and right, I went forward and to the left. So it was directly opposite, but I learned very quickly.

I remember them putting me in the chair, and I remember almost immediately crashing into the wall, but that was a thrill, because all of a sudden I could do it. And then we set my arm up in a way that I could get better hold, and pretty soon I realized that, boy, I can do this. I don't remember all the details, but I remember like Don Lorence going in a door and not being able to get out.

O'Hara: Were the controls set up that way, opposite of what you think they would be, for you specifically, or was that a standard way?

Roberts: No, that was only because we turned the box around. So I actually learned how to drive it with it turned around, and I didn't want to change it back. I could have switched the wires around and changed it. By that time, I was--and then we ordered a Motorette.

O'Hara: And you said this was the second time you tried? You had tried before?

Roberts: The first time. Well, I had tried it many years before, and I couldn't do it.

O'Hara: At a hospital or something?

Roberts: It was at Fairmont Hospital in San Leandro, which was an old polio hospital that I went to.

O'Hara: What was the difference? The Motorette and the motivation were different?

Roberts: Yes. I think the big thing was the Motorette. The second big thing was I was highly motivated. That was an important time, because I realized when you're highly motivated and have a lot of energy, you can often do things you never thought you could. I had never taken much energy towards it. I felt that I shouldn't put a lot of time and energy into it, because I couldn't do it. It's very interesting. In a lot of things I took the risk to try, this I never really did until things changed so much that I really had to, I wanted to.

O'Hara: Where were you when you tried this out the very first time?

Roberts: In Cowell.

O'Hara: In the halls of Cowell?

Roberts: I think we were on the third floor. I remember bouncing off the wall, but all of a sudden realizing, Oh, I can do this. It would

take a while, but once I got the Motorette and hooked it--see, that was a portable unit that hooked onto my push chair. They had real drawbacks. It spun a lot. It had direct drive right on the wheel, and if it got wet or anything, it would spin.

O'Hara: They had a reputation for being sort of bucking broncos periodically.

Roberts: Yes, they had a lot of power, but they also--in the very beginning, it would blow a transistor, and you'd go full speed on one side. I remember one incident a little bit later when I was way up on a hill at--you know the old school for the blind and deaf?

O'Hara: Yes.

Roberts: I was coming down, I was with my dog. His name was Tremor; he was a wonderful dog. A Malamute shepherd, but he loved to go for walks. I walked a lot when I came back here in, must have been '72, early '73. By that time, I had good control of the chair. But I was braking, coming down, and I blew a transistor. On one side was a creek, and on the other side was a big hole there. I remember riding that chair all the way down to the bottom of the hill, because it went full speed forward on one side, and crashing into a tree and finally stopping. That thing just burned a hole in the tire as it spun. So it really wasn't the safest chair at all.

Another time I blew a transistor and jumped into the street.

O'Hara: You?

Roberts: Yes, the whole chair jumped right into the street.

O'Hara: Over the curb?

Roberts: Yes, over the curb, and I didn't fall. I almost got hit by a car though.

O'Hara: When you came down the hill and it ran into the tree, were you all right?

Roberts: I stopped. Yes, I was fine. Also, I learned how to, if there was no one to help, I learned to have extra transistors, and I learned how to install them. So I could describe to somebody how to install them.

O'Hara: How did you get down--



Roberts: Donald Lorence was real helpful, because he knew how to do those. So he usually had some kind of electronic person around. It was hard to find those people here in the early days. I can remember going out on campus by myself, being just totally thrilled, taking Judy out, going out to eat or just being able to do things by myself. It was a total change in my life.

O'Hara: You know, your mother said that she moved to Berkeley in '67, so could it be that your chair came later than '67?

Roberts: It might have been '67 or even '68.

O'Hara: Wow. So you were five or six years in a push chair at Cal.

Roberts: Once I came to Cal, I was there mostly in the push chair. I think Judy didn't even--I think my mother rented a house and then took this house, and Judy moved in behind the house. We got together. I always wonder where she is now. I hear she got a Ph.D. and is teaching biology or something at the University of South Carolina.

O'Hara: What was her name?

Roberts: I don't know her last name. She got messed over by her husband, who she put through dental school, and worked, and then he dumped her after he left. After he set up his practice, he married his nurse or something. She was pretty badly hurt by that. I think we really loved each other a lot, but there was no way she was going to trust any man to support her. She had to have her--that's why she went back to school, so she could get a job. She was pretty sure by that time she needed to have a Ph.D. or at least a master's, and she was going to be self-supporting. That was the important thing. Eventually, I think that broke us up, because I was ready to do more at the time, and she just wasn't ready for it. It was just bad timing.

Then I started noticing things like, when I approached people, they had to deal directly with me. Whereas before--

O'Hara: You mean with the electric wheelchair?

Roberts: Yes. Before, I noticed they would deal with my attendant, and that wasn't unusual. Anywhere, you'd go into a restaurant, and somebody would say, "What would he like?" I'm sure you've experienced that; you don't get that much any more, but still, every once in a while--in fact, it happened in Germany with Otto [Ruderisch, attendant] just in the last month that somebody said, "What would he like?" and Otto turned to him and said, "Why don't you ask him?" I've always trained my attendants to say that.

"Don't speak for me, and don't let people make me invisible." But it changed my personality, and it made me more assertive. I was already pretty assertive, but it made me more assertive.

O'Hara: How about the hill going down from Cowell out the door and down into the campus? Could you do that by yourself?

Roberts: No problem. One day I actually blew a transistor, and I drove right into the ivy, but luckily I stayed there. I didn't go over the edge of the hill. So those are a thrill a minute, those chairs. They were bucking broncos. They had a high speed, and there would be times if you blew a transistor, it would pop you right in the air.

But I think it was one of the things for me that it was worth taking the risk. Actually they used the wrong transistors, so I went out and bought heavier transistors.

O'Hara: Have you had a series of chairs since then?

Roberts: Yes. Not too many, actually. I've only had--my second chair was built much more for the--it was a Motorette, a portable unit that was put on it. It was a much better unit than my first wheelchair. I think this is the third one. [tape static obscuring all speech; fast-forwarded to end]

#### First Students Move from Hospital to Apartments ##

O'Hara: You said that a few people moved out from Cowell. They were the first to leave.

Roberts: Jim [Donald] and Larry [Langdon], and I don't know who else. It might have been--that was the first group of us to get out. That made us begin to think about halfway houses. I remember John [Hessler] and I talking a lot about, if we were going to leave Cowell, we had to have some--what I guess would be called a--supported living situation. I remember we abandoned that; said, "No, we're going straight out," and my own idea [?], and we'll have our own attendants. For years, we talked about halfway houses.

O'Hara: That was all revolutionary.

Roberts: Oh, it was.

O'Hara: And what were the factors that made you decide to eventually move out directly to apartments?

Roberts: I think Jim and the group were very inspirational. They just went out on their own. They just decided--there were three of them, and I don't remember who the three--

O'Hara: Where did they live?

Roberts: In an apartment near campus. Turned out it had I guess an elevator, or--

O'Hara: Did you all visit them?

Roberts: I didn't. I wasn't--at the time, I don't think I was that thrilled by that. I knew I wasn't ready for doing it, but it was an inspiration, I think, in a way. It said this is real possible.

I don't know. I think it was almost surrealistic. I was working on my Ph.D., and working fairly hard, and I didn't keep a lot of--keep track. But John did, and John told me a lot about what was going on and how great it was.

O'Hara: Sounds like John.

Roberts: Yes, and was real interested in how they were doing it. They were paying for their attendants.

O'Hara: Were John and Herb [Willsmore] the next ones to move out? John must have moved out. Did he move out before he went to France?

Roberts: No. I don't think so. He didn't move out until later, until after the Disabled Student Program [at UC Berkeley] pretty much started. Then he moved into a small apartment, and then he moved to a back house, I remember. I've got a picture of it, but--

O'Hara: On Dwight Way, I think, maybe.

Roberts: Yes. It was his own little place, and he loved it. He was always talking about how he was cooking, and trying different ways so he could do more. John was more interested in being more independent than I was, although I became psychologically very independent. John was the one who thought through a lot of the basic issues of what would be the Disabled Student Program, what it would look like. We knew from our own services that helped us live that you had to have a personal assistance program, and a way to find them. You had to have money to do that, so you had to guarantee people would get enough help in the community,

transportation or what. There were a lot of issues that we began to put together, and that's when we decided how powerful a peer would be, too.

**Cathrine Caulfield, First Woman in Hospital Program**

O'Hara: Let's see. There were a couple other students: Cathy Caulfield.

Roberts: Yes.

O'Hara: Do you remember--was she around?

Roberts: Oh, Cathy, oh, I do. It had basically been an all-male place, and Cathy just was so--fit in. Cathy was tough from the very beginning. She was her own person, and she was so glad to get away from home. I remember one day her parents came to visit her, and she was in bed with Larry, or somebody--I don't remember--but she was more free in terms of sexual experience. By that time, we were all involved in this, getting our own experiences with partners and friends, and Cathy fit in so well with us. I loved her dearly; I still do. She became a very important, special person. We were very close. We were never lovers, but we were intimately sharing. She could always come to me and talk to me about what she was feeling, and I could tell her what I was feeling too. It was really wonderful.

She was the first woman, I think, that was at Cowell. Judy Taylor came along later, and then there were a couple of others, too, that I--

O'Hara: Sue Ward.

Roberts: Sue. Sue was one that kind of chose the wrong side in that struggle. Sue decided to stay with Eleanor and was excommunicated. That's what I remember.

O'Hara: Well, she was there when I came in '71.

Roberts: Yes. So she was there later.

O'Hara: You mean excommunicated from the inner circle?

Roberts: Inner circle. Partly because she was a friend of Eleanor's. I think she had lived with Eleanor for a while. I knew Sue, but I didn't get to know her real well. I left Cowell in '69. You came when, '71?

O'Hara: Yes.

Roberts: I don't think I really remember--I have to go see her [Cathy Caulfield], because she later had a kid, like I did, and she chose this kind of dorky guy, which was--by that time, I was off, had left, and we kind of drifted apart. We still love each other, we talk. John was a part of that, too. She was kind of the maverick. I remember her parents coming and going, "Oh, shit, she's in bed with Larry," or somebody, and they just rolled right into her room, and there--[makes snoring sounds]. They got very upset.

O'Hara: And I think they blamed the attendant, didn't they? I thought that was interesting.

Roberts: Yes. Well, they--Cathy complained a lot to me about her parents. It wasn't that they didn't love her; they did, but I think they always wanted her to be something else. She was just a beautiful person. She was totally wonderful. Easy to get along with. She fit in with all these guys real well, and strong friendship. She wasn't the best student in the world, but for her, it was very important.

She also broke her neck. She was standing on a beach, and a wave hit her and knocked her over and broke her neck. Very freaky. It was somewhere in L.A. [Los Angeles]. She got out of the hospital and she hadn't been too long disabled when she got to Cowell, maybe a year, year and a half. Actually, maybe two, but very--unlike the other people who had been born disabled, for a long time. She joined us--when we were fighting Rehab, and when we were fighting for our own rights, she was right there with us, helping out. She liked to drink, and she would--we all were drinkers then. We weren't into dope. That happened later.

#### Drinking, Parties, Drugs

O'Hara: Henry Bruyn told me that the nurses used to be sure that you were all smoking pot.

Roberts: We were, later. But I think people were smoking pot, and I wasn't. Yes, I thought I was going to be a teacher, and in those days, if you got caught smoking pot, you couldn't be a teacher. Because my brother Mark, and Randy, actually turned me on before I left Cowell, I'm sure. That's what I liked much better than booze. I thought if I wanted to get high, grass was a whole lot



better. I remember liquor being much more prevalent than smoking. And we tried acid--

O'Hara: So besides booze, you did try acid?

Roberts: Oh, yes, I tried acid. In fact, I always--

O'Hara: At Cowell?

Roberts: At Cowell, yes. In fact, I remember taking acid, the first time I took it, I didn't know what would happen, I didn't know if I'd lose my will to breathe, I didn't get out of my tank. But I had this wonderful time. At that time, I had an attendant who was with us, and he had a girlfriend named Stephanie, who's still a friend. They're both still friends. My attendant helped me take acid. I remember I'd forgotten that I had a meeting with Miss Butcher, and she was bringing up a couple of people, and I was stoned out of my mind. I only took a half of a pill; I didn't want to try the whole thing, but I was still very--she came in and I went, Oh, shit, I forgot about. I realized, even though I was stoned really [Inaudible], I really had to be straight. I remember having this huge shit-eating grin in my face, and laughing a lot during the time they were there. I'm sure Miss Butcher knew that something was going on, but I don't think the other two people she brought in knew.

The second time I took acid was also with my attendant, and this is how I got up in the wheelchair. He pushed me through campus, and I don't remember what year. I don't think I had my power chair then. I remember going down Telegraph Avenue and seeing these weird faces, and when people would have dogs, their face would look like a dog. And then there was a professor who went by. He was a professor who was burned by a student. His face was terribly misshapen, and he looked down and I went, Ohhh. Because Telegraph was pretty weird in those days. There were lots of hip people and lots of people who--of course, I had this shit-eating grin on my face. A couple of people looked at me and said, "Oh, have a great time." Because they obviously were doing it too, or they had been doing acid and they just knew that I was. Because if you really look at somebody's eyes, their eyes are totally dilated. You could tell somebody was doing it.

Then I got a little alarmed, because all these people looked so different. And I saw this professor who had a terribly burned face, he looked normal. And then four blocks in, there was a Pontiac dealership, and I looked--

O'Hara: On Telegraph?



Roberts: And I saw the Pontiac, and it was like normal. It was totally the way it should have been. It was totally relieving to me that I wasn't off. Then I went to a store; it was called Park & Shop. I forget what it's called now.

O'Hara: Andronico's.

Roberts: Yes. And I remember looking at labels. I mean, Twinings tea and these wonderful labels that were all different colors, but very similar. I got really caught up in all kinds of design things, features. And then I went to my friend Jeff's house and listened to music. The music sounded better than I ever heard it.

O'Hara: Did you feel like you were sort of initiated into the sixties by doing that, and part of the crowd?

Roberts: I think in one way. The revolution in Berkeley was my initiation more than--all the National Guard on campus, and Ronald Reagan was governor and being such an asshole. The political things; that was where I was initiated. Anti-war stuff.

O'Hara: I was thinking maybe next time we could sort of go into what was going on.

Roberts: That sounds like fun, yes.

### Employment at the University

#### Work with Dean Arleigh Williams on Building Accessibility

O'Hara: Can you talk a little bit about your job with Arleigh Williams?

Roberts: Arleigh Williams was my favorite person. It was Arleigh who didn't know what the hell to do with me, who referred me up to talk to Henry Bruyn, and I think called Henry and said, "Hey, this is a nice guy, I don't think we can keep him here." Arleigh got me to Henry, and Henry opened the hospital. He said, "Why don't you live here? We can make it work." He helped make a deal with me that it would be a dorm to me, I could have alcohol and--I don't think he realized to the extent--but all those things that I wanted.

Arleigh, I began to work with, around architectural design.

O'Hara: At what point? Had you been there a couple of years before that happened?

Roberts: Yes. I started teaching in--I came in '62. In '64, I entered graduate school. So in '65, I started teaching.

O'Hara: Teaching as a--

Roberts: A political scientist, teaching [assistant], T.A. In '64 and '63 I worked with Arleigh, before graduate school. I learned about a lot of things from Arleigh, because one of the first things we tried to do was choose buildings that should be made accessible, and made sure that new buildings followed the state codes. By that time, there were some state [access] codes, I think.

O'Hara: I think '61 there was an early code.

Roberts: Yes, for the university there was. Arleigh was always a very sweet man, and always on my side I felt. Like Henry, he was a benefactor. I did less and got more money for [from?] Arleigh, but he wanted me to work part time with him. Changing the campus, just look at things.

O'Hara: That was your principal job?

Roberts: My job was architectural consultant, and what they can do to include students with disabilities more. And I didn't know what a plan was. But I learned about how to get things done.

For example, the first year I was there, they have a priority system for reconstruction. Arleigh and I worked on it, and I remember we said--I remember that seventeen, eighteen, and nineteen was the priority for this first round. We didn't get it at all. Nothing happened. We didn't get it.

O'Hara: Do you mean the access was priority seventeen?

Roberts: But then I learned that they only funded the first five or the first seven priorities, and I insisted with Arleigh, "We won't do this again, we've got to be up in the top ten." He agreed, and it started to change then. I told Arleigh what I thought we should do, but he forced the university to put them up higher.

O'Hara: Do you remember some of those early, early changes that you actually saw happen?

Roberts: One was to Sproul [Hall]. There were ramps put in down below, underneath. Another one was to Life Sciences Building, so you'd

get in there. These were mostly entrance things. Another one was to Dwinelle, and another one was to Wheeler.

O'Hara: Underneath the stairs in the back?

Roberts: Yes.

O'Hara: That was not accessible before?

Roberts: It was partly accessible, but we couldn't get to everywhere. So we had to start charting out what we could do. Then they fixed the stairs in the front a little bit. If you rolled up to one end, there were no stairs. A small ramp in, so there was a little stair there. Pretty simple, but they were very expensive, I remember. The university does something, they do it pretty expensively.

And then there were buildings like South Hall, that were almost--that we just decided to leave alone. I remember there were classes that we agreed if we couldn't change the building, people could change the class. They'd move the class to a more accessible location.

O'Hara: Who did you--was it Arleigh that--

Roberts: Arleigh did a lot of it, and--

O'Hara: --was the intermediary in that?

Roberts: And what's the woman's name? She was a dean, too. She stayed later than Arleigh.

O'Hara: Betty Neely [Director of Student Activities and Programs]?

Roberts: Betty Neely was a part of our conspiracy. And Betty, I think, was smarter about things than Arleigh. She actually helped carry out a lot of the stuff. She was dean of women, I think, and I think she worked with Arleigh a lot, because--

O'Hara: She said she didn't really deal with disabled students until 1970, when she was sort of given DSP [Disabled Students Program].

Roberts: Yes. But I dealt with Betty early on. I think she was totally supportive, though; she was very supportive. Both Arleigh and Betty were like amazed by me and my [Inaudible].

O'Hara: Didn't you become an assistant dean, somewhere along the line, in title?

Roberts: Worked with Arleigh, that's right. He gave me that, an assistant to the dean. That was my role. That was my first job at the university.

O'Hara: Did you do site reviews, then, or where did you work exactly?

Roberts: I worked with Arleigh in his office.

O'Hara: I see, talking about it.

Roberts: I worked out of Cowell. I didn't really do site reviews. Arleigh had somebody that he trusted to do those.

O'Hara: Well, if they weren't accessible, it's hard to--

Roberts: Right. But I wasn't able to get into Sproul Hall, because they did that--right away they made, under the stairs, way in the back, there was a way in that we fixed up.

O'Hara: Where the police department is now?

Roberts: I think so.

#### Teaching Assistant in Political Science

O'Hara: And so your job with Arleigh lasted about two years, and then you became--?

Roberts: I think it was more like a year, year and a half. Because that must have been '63, and then in '64--yes. I remember going to the Political Science Department and a guy named [Professor] Aaron Wildavsky, who just died, who had a mentally retarded kid. He was more empathetic; he really tried to help me. I had finished my first year and master's, and I said, "I want to teach," and he said, "Oh, we can make that happen." So that must have been '65. So I probably worked with Arleigh in '63, '64. And I got paid, and that was wonderful.

O'Hara: Was that your first paying job?

Roberts: Yes. Well, I had been a paper boy.

O'Hara: It was your first paying job after you had had polio.

- Roberts: Yes, at the university. It was \$200 or \$300 a month. It was quite a bit for me at the same time. Then I became a T.A. and got more even.
- O'Hara: Can you describe a little bit how your teaching went, your second job?
- Roberts: It was like--it was wonderful, because I started in '65, I was finishing up my master's. I remember becoming a teaching assistant then, and meeting with the professors. Usually I was-- at first I was teaching Poli Sci 1, which is American government, but I liked it because I got the young students.
- O'Hara: Were these discussion groups? How did that work?
- Roberts: We did everything. We graded blue books, we talked in sections--
- O'Hara: There was no professor that taught--
- Roberts: No, there was. There was a lecture professor. There could have been 800 students in one class, and then they broke [them?] us up into sections, and I taught half time. I taught two classes. I remember the thrill that I got from working with these. It was Government 1. It was a required course, and I just was thrilled. They were mostly freshmen and sophomores, and I remember realizing, I can do this.
- O'Hara: How did they respond to you?
- Roberts: Wonderfully. I didn't have any problems with the students. I thought I might have, but students were--my fondest memories almost are of being a teaching assistant. I loved teaching half time and going to school half time.
- O'Hara: Were you surprised that you had the feeling that you could do this? Or were you surprised that you could do this?
- Roberts: I was surprised I could do this, but I was--I had been the kind of student that always felt I could do this better than they're doing it. A lot of professors were terrible. They simply gave their lectures. Some of them were very old lectures. I remember one, the Fybate notes were from 1948, and it was in the sixties. I don't know.
- O'Hara: Were you teaching in the classroom all the time? I think I heard that you sometimes had them at your house.
- Roberts: Small classrooms. Once in a while, I'd have them up at Cowell. I was still at Cowell. I took them outside whenever we could be

out. So I had some wonderful students. And every once in a while, I meet another one around somewhere in the world. "Mr. Roberts?" I'd go, "Yeah?" When I went to Rehab, several of my students were working in the legislature. Oh, it was wonderful. In the [next] six years, I probably taught 400, 500, 600 students. I became a very big veteran. I just liked the students a lot. It was a very important confidence-builder, and very important to me to earn some money, and also to be able to do something good like that.

I remember I had a group of students that were--in one class--largely engineering students. Now, I thought these were some of the worst students I'd ever had. I was discussing with them, because they obviously were taking this course as a lot of people did because they had some requirements. They couldn't write. I mean, it was like they were ignorant, almost illiterate. They could do math and they could do--I remember one day saying to myself, I've got to shake them up, I've got to do something.

That was when the Beatles came out with the song, "Nowhere Man." I brought that in and I played it for them. I looked at them and I said, "You're Nowhere people." It worked. I said, "Look, get with it. You're living in one of the most politically exciting times, the sixties, with the anti-war protesting. At least experience this; let it in." I remember, I didn't get them all, but several of them came to me and said, "You shocked us." A couple even read the books. I mean, they were that bad, it was that bad.

I taught with Nelson Polsby, and Aaron Wildavsky, and a lot of nice profs.

O'Hara: And [Professor William K.] Sandy Muir?

Roberts: Sandy Muir, I didn't teach with him. But I got to know him when he came to the campus. I taught mostly American government things, even those years. I did some T.A.'ing with graduate students later. But it was a very important time in my life. I really liked to work and do all kinds of things. The more education I got, the more open things were. I wasn't sure what I was going to do after. I'd given up my idea of being a technical writer. I knew I wanted to teach politics. Later I gave that up to do it.

O'Hara: To do what?

Roberts: To be a politician, and to be involved in--



O'Hara: Do you consider yourself a politician?

Roberts: I'm kind of more like a diplomat. More like somebody who understands a lot about politics but practices it as they get a little older. I don't see myself in the same way as the radicals in the streets. My job is to teach it in a way. Maybe I'll go back to teaching someday, but I like what I do now. I like traveling and being at WID [World Institute for Disability].

O'Hara: That's probably a good spot to stop.

Roberts: It's time for me to go to work.





# WORLD INSTITUTE ON DISABILITY

510 SIXTEENTH ST  
SUITE 100  
OAKLAND  
CA 94612-1500  
USA

## EDWARD V. ROBERTS

### CURRICULUM VITAE:

Born: January 23, 1939

Died: March 14, 1995

TELEPHONE  
510 763 4100  
FAX 510 763 4109  
TTY 510 208 9493

### HONORS

Fellow, John D. and Catherine T. MacArthur Foundation,  
1985-9  
Honorary Doctorate of Humane Letters, Wright Institute,  
1981  
N. Neal Pike Prize, Boston University, 1990  
Honorary Admiral in the Texas Navy, The State of Texas,  
1992  
Distinguished Service Award, President of the United  
States, 1991  
"Just Do It" Award, Administration on Developmental  
Disabilities, 1991

### EDUCATION

Ph.D. complete all but the thesis: five years graduate  
study in Political Science, University of  
California, Berkeley  
M.A. with Distinction, University of California,  
Berkeley, 1966 Major: Political Science  
B.A. University of California, Berkeley, 1964  
A.A. College of San Mateo, San Mateo, California,  
1962

### EMPLOYMENT

#### 1983-1995

President, World Institute on Disability, Oakland,  
California

Co-founder of the first non-profit organization which has  
as its goals the development and advancement of a unified  
body of public policy on disability issues and public  
awareness of disability. Responsible for setting goals  
and objectives, establishing the Board of Directors, long  
range planning and fundraising.

1975-1983

Director, California Department of Rehabilitation, Sacramento, California

Directed the principal State agency responsible for helping persons with disabilities reach social and economic independence. The department provides vocational and pre-vocational rehabilitation services to approximately 40,000 people a year. Pioneered in the areas of employment and rehabilitation services for people with severe disabilities, anti-discrimination legislation on both the state and federal levels, and developed Independent Living Program legislation. Responsible for an annual budget of \$140 million and directed a staff of 2500.

1972-1975

Executive Director, Center for Independent Living, Berkeley, California

Co-founder of the first Independent Living Program, the Center for Independent Living (CIL), and served as its executive director from 1973-1975. CIL is the international model of a community based self-help program that promotes and sustains the abilities of people with all types of disabilities to achieve economic and social integration. The CIL model has been replicated by people with disabilities in over 300 programs in the United States and internationally. The annual budget grew from \$40,000 to \$1,000,000 from 1973-1975.

1971

Dean of Students and Professor of Political Science, Common College, Woodside, California

Co-founder of a progressive educational institution for disadvantaged students. Serves as Member of its Board of Trustees.

1970-1971

Director, Project Handicapped Opportunity Program for Education (HOPE), University of California, Riverside, California

1964-1970

Co-founder and Instructor, Political Science, Nairobi College, East Palo Alto, California (1969-1970)

Consultant, Student Special Services Program, U.S. Office of Education, Washington, D.C. (1969-1970)

Assistant to the Dean of Students and specialist on removal of attitudinal and architectural barriers, University of California, Berkeley, California (1968-1969)

Teaching Associate, Political Science, University of California, Berkeley, California (1964-1967)

## APPOINTMENTS

Member, Board of Directors, World Institute on Disability, Berkeley, California (1983-1995)

Member, Board of Directors, IMPACT, An International Initiative Against Avoidable Disablement, Geneva, Switzerland and East Sussex, England (1986-1995)

Member and former Vice Chairperson of Disabled Peoples' International, USA. (1982-1995)

Member, Board of Directors, World Interdependence Fund, Sacramento, California (1990-1995)

Member, Executive Committee, Greenlining Coalition, San Francisco, California (1986-1995)

Member, Board of Governors, The Association for the Preservation of the Presidential Yacht Potomac, California (1991-1995)

Member, Board of Directors, By All Means, Berkeley, California, (1989-1995)

Member, National Advisory Board, Center for Children with Chronic Illness and Disability, Minneapolis, Minnesota (1990-1995)

Member, Board of Directors, Artship Foundation, Oakland, California (1993-1995)

Chair, Board of Directors, The Assistance Dog Institute, Rohnert Park, California (1993-1995)

Member, Advisory Committee, New Hampshire Self Determination, Monadnock Developmental Services Inc., Keene, New Hampshire (1994-1995)

Member, Advisory Board, School of Medicine Substance Abuse Resources and Disability Issues, Dayton, Ohio (1993-1995)

Co-founder and Board Member of the Wright Institute, Berkeley, California (1981-1984)

Member, Board of Trustees, Common College, Woodside, California (1972-1982)

Member, Board of Trustees, Through the Looking Glass, Berkeley, California (1983-1994)

Member, Board of Directors, The Association for the Severely

Handicapped, International (1990-1993)

Member, Advisory Committee, Richmond Unified School District Technology Task Force, Richmond, California (1991-1995)

Member, Advisory Committee, Pathways to Independence, UCP of Alameda/Contra Costa Counties, California (1990-1995)

Member, Advisory Board, Catholic Charities, San Francisco, California (1987-1995)

Member, California Commission on Aging, Sacramento, California (1983-1984)

Member, State Council on Developmental Disabilities, Sacramento, California (1976-1983)

Member, California State Council on Developmental Disabilities, appointed by the Governor to plan and coordinate all state resources to insure the legal, civil and service rights of people with developmental disabilities, in public, private, local and state agencies. (1976-1983)

Member, Board of Directors, American Coalition of Citizens with Disabilities, Washington, D.C. (1981-1983)

Member, Council of State Administrators of Vocational Rehabilitation (CSAVR), Washington, D.C. (1975-1983)

Member, National Advisory Committee on Vocational Education Models for Linking Agencies Serving the Handicapped, University of California, Berkeley (1980)

Member, California Interagency Council on Children and Youth, Sacramento, California (1981-1984)

Member, California Comprehensive Employment Training Act, California (1977-1980)

Member, Board of Trustees, United Way Area Crusade, San Francisco, California

Co-founder and Chairperson, Advisory Board, Disabled Students Program, University of California, Berkeley, California (1969)

Member, Advisory Committee, Disability Statistics Program, Institute for Health and Aging, University of California, San Francisco.

Member, National Advisory Panel, Public Advocates, San Francisco, California (1980-1987)

#### MAJOR SPEECHES



1995

Presenter, Partners in Policymaking Leadership Training, Colorado, (January 15), Illinois, (January 27)

"Empowerment and Civil Rights", American Medical Students' Association Conference, San Francisco, California, (March 11)

1994

"Civil Rights, Independent Living and the Role of the University", University of Colorado at Boulder - Office of Services to Disabled Persons, Boulder, Colorado, (January 19)

Presenter, Partners in Policymaking Leadership Training, Colorado (January 21), Minnesota (January 29), South Dakota (February 11), Delaware (February 26), Florida (March 19), West Virginia (May 20) and California (June 18)

"Aging and Disability: The Role of the Professional", Class on Aging and Disability, University of California at Berkeley, Berkeley, California, (March 10)

Address, West Virginia Assistive Technology Technician Conference, State of West Virginia Division of Development Disabilities, Charleston, West Virginia, (May 20)

"Speech Technology for the Disabled" Panel, Advance Speech and Applications and Technologies Conference, San Jose, California, (June 14)

"Leadership, People with Severe Disabilities and Community Based Rehab Agencies", International Association for Persons in Supported Employment Conference, San Francisco, California, (July 6)

"Opportunity to Work Together - Brotherhood and Sisterhood", Slovenia's Paraplegic Association's - 25th Anniversary, Slovenia, (October 12)

"Advocacy and Advocates - The Keys to Making Change", National Multiple Sclerosis Society Convention, San Francisco, California, (November 8)

1993

Presenter Partners in Policymaking Leadership Training, Delaware (January 29), South Dakota, (February 6), Minnesota, (February 23), Texas, (August 27), South Dakota, (September 3), Indiana, (September 11), Minnesota, (September 17), and North Dakota, (September 24).

"Independent Living and Personal Assistance Services Issues", Youth Institute, Moscow, Russia, (April 20)

Address, President's Committee on Employment of People with Disabilities' 1993 Annual Conference, ADA: Gateway to Opportunity,

St. Louis, Missouri, (May 13)

"The Power of Disability", Minnesota Summer Leadership Institute, Minnesota Planning Council on Developmental Disability, Bloomington, Minnesota, (July 18 - 20)

"Youth, Art and Disability", Share the Dream, World Interdependence Fund - New Mexico, Galisteo, New Mexico, (October 9)

"Civil Rights, Independent Living and Technology", Let's Put Iowans with Disabilities in the Drivers Seat Conference, Iowa University - Iowa Program for Assistive Technology, Des Moines, Iowa, (October 18)

"Personal Assistance and Health Care Reform", American Public Health Association's: Building Healthy Environments Conference, San Francisco, California, (October 26)

Address, Disabled Peoples' International Seminar, Disabled Peoples' International's Eastern-European Seminar, Prague, Czechoslovakia, (November 10)

"Foreign Policy and Disability" and "How to Change the Exclusion of People with Disabilities", The U.S.'s Role in International Issues on Disability, Washington, DC, (November 16 - 17)

"Strategies for Independent Living", International Healthy Cities and Communities Conference, Western Consortium for Public Health, San Francisco, California, (December 8)

#### 1992

Presenter, Partners in Policymaking Leadership Training, New York, (October 17), Minnesota, (January 18, September 19), Texas, (April 3, September 11), South Dakota, (August 21), and California, (March 20, June 27)

"The ADA - How to Effect Workable Solutions", Ability Center of Greater Toledo, Toledo, Ohio, (March 2)

Keynote, "Dreams, Diversity and Empowerment: Independent Living in the Heartland", Kansas City, Kansas, (August 11)

Keynote, American Association of Spinal Cord Injury Psychologists and Social Workers 6th Annual Conference, Las Vegas, Nevada, (September 8)

Presenter, American Paraplegia Society 38th Annual Conference, Las Vegas, Nevada, (September 9)

"ADA and Liberation", Hiring the Disabled Under the ADA: Second Annual Compton Community Conference, Los Angeles, California, (September 25)

"Empowerment and Possibilities", Family Support Conference, Denver, Colorado, (October 9)

Keynote, Building Partnerships that Lead to Supported Employment, RRTC - Virginia Commonwealth University, Norfolk, Virginia, (October 14)

Presenter, Community Living Issues in Traumatic Brain Injury Planning, Rehabilitation Institute of Chicago, Chicago, Illinois, (October 25)

"Supporting Youth with Disabilities", New Mexico Interdependence Forum on Youth and Arts, Sante Fe, New Mexico, (November 12)

### 1991

Presenter, Partners in Policymaking Leadership Training, Minnesota, (January 24, September 21), Illinois, (August 23), Colorado, (March 14, November 16), Louisiana, (April 26), Texas, (April 20) and Alabama (June 22)

"The Future of Independent Living In California", Chico Center of Independent Living, (February 13)

Keynote, Fund for the Society for Adolescent Medicine's Annual Meeting, Denver, (March 1)

Keynote, Enabling the Disabled in the 90's Conference, Durango, Colorado, (March 16)

Keynote, Touch the Future: Discovering Abilities Through Technology for Living, Learning, working and Playing, Atlanta, Georgia, (April 3)

"Consumer Empowerment", Developmental Disabilities Commissioner's Forum "Just Do It!", Washington, DC, (May 16)

Keynote, The Association for Persons with Severe Handicaps' Regional Conference, Atlanta, Georgia, (June 13)

Presentation, Independent Living: Preparing for the 21st Century Conference, Oakland, California, (October 4)

Keynote, Kalamazoo Center of Independent Living's Ability Conference, Kalamazoo, Michigan, (October 10)

Address, Public Citizen's 20th Anniversary Conference: "Taking Back America: A New Democracy for the 90's", Washington, DC, (October 25)

### 1990

Presenter, Interagency Conference, Denver, Colorado, (January 25)

Presenter, Commission on Quality of Care for the Mentally Disabled's Annual Advocacy Conference, Albany, New York, (May 15)

Keynote, Center of Independent Living of Central Pennsylvania's "Consumer Control: Becoming Your Own Advocate" Conference, Camp Hill, (June 21)

Presenter, Disability Rights Education and Defense Fund's Disability Law Conference, Berkeley, California, (September 8)

"Object of Charity to Civil Rights", Minnesota Partners in Policymaking, St. Paul, Minnesota, (September 15)

Keynote, Sonoma Developmental Hospital: "The Psychiatric Technician and The Disability Rights Movement", Sonoma, California, (October 10)

Presenter, Stanford University School of Medicine, Palo Alto, California, (November 5)

Keynote, Council on State Administrators of Vocational Rehabilitation, Charleston, South Carolina, (November 14)

#### 1988

Address, Disability Legal Education Clinical Program Conference, University of California, Berkeley, California, (January 16)

#### 1987

"How to Take Responsibility for Health Policy: Civil Rights for the Disabled", Stanford, University, (January 23)

Testimony, State of California, Commission on California State Government Organization and Economy, (Little Hoover Commission) Topic: Access to Substance Abuse Programs by the Disabled, (January 28-31)

Address, St. Paul's Episcopal Church, Oakland, California, (February 4)

Keynote, Independent Living Resource Center, Pleasant Hill, California, (February 7)

Keynote, United Cerebral Palsy of Indiana, Inc. "Living in the Community: Empowering People Who Have Disabilities", (March 12)

"Strategies for Affecting Social Change -- A Self-Advocacy Perspective", Partners in Policymaking Conference, St. Paul, Minnesota, (May 2)

Testimony, House Judiciary Committee, Fair Housing Amendments, Washington, D.C., (May 10)

Address, Center for Independent Living 15th Anniversary Dinner, San Francisco, California, (May 21)

Presenter, Communication and Handicaps Congress, Paris, (July 6)

"From Survival to Charity to Civil Rights", 12th World Congress of International Organization of Consumers Union, Madrid, Spain, (September 15)

Address, Quality of Life Conference, Washington, D.C., (September 25)

Keynote, United Cerebral Palsy of New Jersey, (October 23)

Keynote, Coalition of Texans With Disabilities, Houston, (October 30)

Keynote, The Association for Experiential Education 15th Annual Conference, Port Townsend, Washington, (November 12)

### 1986

Keynote, State of Washington, Department of Social and Health Services, "Making it Happen", Tacoma, Washington, (March 17-19)

Address, Western Social Science Association, 28th Conference, Reno, Nevada, (April 23-26)

Address, Rehabilitation Gazette's Third International Polio and Independent Living Conference, St. Louis, Missouri, (May 10-12)

Keynote, Pew Health Policy Fellows Conference, Philadelphia, Pennsylvania, (May 28-30)

Testimony, United States Commission on Civil Rights, Washington, D.C. hearing on "The Protection of Handicapped Newborns", (June 26-27)

Keynote, British Columbia Coalition of the Disabled Conference, Vancouver, B.C., (September 5-8)

Symposium, United Cerebral Palsy of NYC, "Innovative Methods of Community Based Approaches to Rehabilitation", New York City, New York, (October 5-13)

Keynote, The Developmental Disabilities Planning Council; Employment Conference: "Making It Work", Ellensburg, Washington, DC, (October 8-10)

Address, National Council for International Health, "Responding to Third World Health Issues: Assumptions and Implications", University of Washington, Seattle, (October 23-24)

Address, International House of the University of California, Berkeley, California, (November 16)

### 1985

Keynote, Staff Conference, St. Joseph's Hospital, Anaheim,



California, (February 6)

Address, University of San Francisco, School of Medicine,  
"Emotional Problems inn Physical Disability: Mind and Body",  
San Francisco, California, (February 16)

Address, Annual Convention, National Science Teachers Association,  
Cincinnati, Ohio, (April 19)

Co-Keynote (with Dr. Albert Sabin), Gazette International  
Networking Institute, International Conference on Polio and  
Independent Living, St. Louis, Missouri, (May 11)

Commencement Address, Department of Developmental Studies,  
University of California, Berkeley, California, (May 17)

Keynote, National Association of Protection and Advocacy Systems,  
(May 19)

#### MEDIA

Appearance, CBS's "60 Minutes", April, 1988

Interview, "Disabled in Action", WBAI Radio, February 15, 1992

Interview, "Sylvia Live", CNN Radio, October 27, 1992

Interview, "Health Care Reform", Larry King Radio Show,  
May 2, 1994

Interview, "Independent Living - Local Issues Around Las Vegas",  
On a Roll, KDWN Radio Show, July 10, 1994

Appearance, People in Motcion, "Ready to Live", KQED (PBS), April  
7, 1995

Appearance, "When Billy Broke His Head...And Other Tales of  
Wonder", KQED (PBS), June 22, 1994



**ED ROBERTS' AWARD LIST**  
**(UPDATED 4/96)**

**Certificate of Appreciation and Member of the National Advisory Committee on Accessible Environment, Architectural and Transportation Barriers Compliance Board, March 1979.**

**Completed Handicapped Affirmative Action Conference, Department of the Navy, United States of America, Pacific Missile Test Center, Point Mugu, California - November 5 - 6, 1980.**

**Resolution No. 1227, The Honorable Bruce Young, 63rd Assembly District and The Honorable William Campbell, 33rd Senatorial District, Sacramento, California, May, 1981. "Relative to the 1981 International Year of Disabled Persons."**

**Honorary Degree of Doctor of Humane Letters, Wright Institute, June 5, 1981.**

**Disabled Peoples' International, Vox Nostra, 1st World Congress, Singapore, November 30 - December 4, 1981.**

**Nominee - Annual Media Awards, California Governor's Committee for Employment of the Handicapped, February 1982. "Very pleased to honor Ed Roberts as a nominee in our Annual Media Awards competition for promoting an improved image and increasing participation of persons with disabilities both on camera and behind the scenes in the media industry - February, 1982."**

**Certificate of Appreciation for Contribution to Wellness Week '82, Governor's Council on Wellness and Physical Fitness, California Governor's Council on Wellness and Physical Fitness, Sacramento, California, March, 1982. "Your participation emphasizes your personal commitment to the promotion of health for all Californians."**

**Electronic Industries Foundation, Washington, DC, July 22, 1982, "This Certificate is Awarded to California State Department of Rehabilitation in recognition of outstanding leadership and participation in the Foundation's National Project With Industry Program to promote employment of handicapped individuals."**

**Certificate of Appreciation in recognition of policies instituted to increase opportunities for persons with disabilities. Governor's Committee for the Employment of the Handicapped, Sacramento, California, September, 1982.**

**Certificate of Appreciation, State of California Governor's Committee for Employment of the Handicapped, California, September 14, 1982.** "Presents this to Ed Roberts whose efforts have contributed to the Committee's goal of increasing employment opportunities for persons with disabilities."

**Certificate of Appreciation, Progress Through Unity, California Association of Post Secondary Educators of the Disabled, Los Angeles, California, October 21-23, 1982.**

**California Senate Rules Committee Resolution Relative to Project Interdependence, Sacramento, California, March 3, 1983.**

**Fellow, John D. and Catherine T., MacArthur Foundation, 1985 - 9**

**Center for Independent Living, September 26, 1985.** "In Appreciation for your vision - a vision you put into action so that thousands of disabled people may live independent and rewarding lives."

**XII Congreso Mundial De I.O.C.U. Solidaridad De Los Consumidores: Por Un Mundo Mejor Espana Madrid, 15 - 20 De Septiembre, 1987.**

**N. Neal Pike Prize, Boston University, 1990**

**Spirit of Michael Waxman, Partner In Policymaking of Alabama, 1990 - 1991 Class.**

**New York City Independent Living Centers, New York, May 10, 1990.** "Salute Ed Roberts with deep appreciation for all your efforts on our behalf."

**Americans with Disabilities Act Award, The Task Force on the Rights and Empowerment of Americans with Disabilities, October 12, 1990.** "Congratulates Ed Roberts on His Historic Contributions to the Enactment of The World's First Comprehensive Civil Rights Law for People with Disabilities."

**Certificate of Appreciation, The Association for Persons with Severe Handicaps (TASH) Executive Board, December 5, 1990.** "This is for leadership and service on the Executive Board of The Association for Persons with Severe Handicaps."

**Distinguished Service Award, President of the United States (George Bush), 1991.**

**JUST DO IT!, U.S. Department of Health and Human Services, Administration for Children and Families, Administration on Developmental Disabilities, Atlanta, Georgia, May 15, 1991.** "Presented to Ed Roberts In Celebration and Commendation pursuing a vision toward the American dream for all of this country's citizens; striving for a better quality of life for persons with developmental disabilities; offering inspiration

to coalesce and assert our common purpose; making the goals of independence, productivity, and integration into the community reality for and with people with developmental disabilities. Taking risks when others lacked faith and standing true to the ideal."

**PROJECT PATHWAYS TO INDEPENDENCE, Alabama, June 25, 1991.** "In Appreciation for Leading the People of Alabama in Promoting the Full Potential and Abilities of our Citizens."

**Bonnie Gellman Simon Award, Resources for Living Independently Center, October 8, 1991.** "Recognizes and honors Ed Roberts for your significant contribution to enhancing the lives of people with disabilities by influencing attitudes, Promoting equal rights and increasing public awareness of the Independent Living Movement, Annual RLI Awards Luncheon."

**Honorary Admiral in the Texas Navy, State of Texas, Austin, Texas, May 1, 1992.** "Senate of the State of Texas This Certifies that the Texas Flag herewith presented to Ed Roberts by Senator Chris Harris was flown above the State Capitol of the Sovereign State of Texas on April 30, 1992 in Witness whereof and pursuant to the authority vested in me, I have hereunto set my hand and official seal of office at Austin, Texas, this the 1st day of May, 1992."

**Models that Work: Partners for Independence, The Organizing Committee of the First North American Regional Conference of Rehabilitation International, October, 1993.** (Awarded to WID)

**Campaign Award, SDRAO of the College of Notre Dame, Belmont, California, October 1993.** " Gratefully presents this to Ed Roberts for his lifelong Barrier breaking advocacy for Students and Americans with Disabilities."

**Alumnus of the year Award, Burlingame High School, Burlingame, California, May 23, 1994.**

**National Institute of Art and Disabilities, San Francisco, California, October 22, 1994.**

**Slovenia's Paraplegia Association, Ljubljana, Slovenia, October, 1994.**

**CARF** "personal fulfillment and success is measured by the extent of positive impact one has on another. " (year unknown)

POSTHUMOUS AWARDS

**Courage Award, Courage Center, Golden Valley, MN, April, 1995**

**President's Award, Northshore Arc, Boston, Massachusetts, June, 1995**

**Lifetime Achievement Award, Westside Center for Independent Living, Los Angeles, California, June 23, 1995**

**Hall of Fame for People with Disabilities, Columbus, OH, October 14, 1995**

**Lanterman Award, California Association on Post-Secondary Education and Disability (CAPED), November 9, 1995, In Appreciation of Your Significant Contribution and Outstanding Service to Persons with Disabilities in California.**

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Disability Rights and Independent Living Movement Oral History Series

UNIVERSITY OF CALIFORNIA'S COWELL HOSPITAL RESIDENCE PROGRAM FOR  
PHYSICALLY DISABLED STUDENTS, 1962-1975: CATALYST FOR BERKELEY'S  
INDEPENDENT LIVING MOVEMENT

James Donald

STUDENT RESIDENT AT COWELL, 1967-1968, ATTORNEY AND DEPUTY  
DIRECTOR OF THE CALIFORNIA DEPARTMENT OF REHABILITATION, 1975-1982

An Interview Conducted by  
Kathryn Cowan  
in 1998





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## INTERVIEW HISTORY--Jim Donald

Jim Donald was invited to participate in the Disability Rights and Independent Living Movement oral history project because of his role as one of the first disabled students to attend the University of California as a resident in Cowell Hospital.

Mr. Donald lived in Cowell Hospital from 1967 to 1968 and then moved to an apartment near campus with another Cowell resident. He recalls the early days, his fellow students, and the political activism and turmoil on the Berkeley campus. He was a member of the Rolling Quads, the group of disabled students who were so influential in the formation of the Physically Disabled Students' Program and the Center for Independent Living.

Mr. Donald moved from Berkeley to get his law degree at the University of California, Davis. He was appointed deputy director for legal and legislative affairs, California State Department of Rehabilitation, by Ed Roberts. Mr. Donald recalls his work on disability legislation and talks of the events and policy changes at the department during Roberts' tenure.

The interview took place on January 23, 1998, at Mr. Donald's home in Sacramento, California. His dog, Gus, was present, as well as a pet parrot, who occasionally can be heard on the tape, screeching in the background. A noisy fax machine also is audible.

Mr. Donald did not edit his transcript.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. Copies of all interviews are available for research use in The Bancroft Library and in the UCLA Department of Special Collections. The office is under the direction of Willa K. Baum, Division Head, and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley.

Kathy Cowan, Interviewer/Editor

June 2000  
Regional Oral History Office  
The Bancroft Library  
University of California, Berkeley



Regional Oral History Office  
Room 486 The Bancroft Library

University of California  
Berkeley, California 94720

BIOGRAPHICAL INFORMATION

(Please write clearly. Use black ink.)

Your full name J Anne, EDWARD DONALD

Date of birth 9-7-45 Birthplace El Paso TX

Father's full name Donovan Lee Deane

Occupation \_\_\_\_\_ Birthplace Wichita KS

Mother's full name Grace Elaine (Johnson) Deane

Occupation \_\_\_\_\_ Birthplace Colorado

Your spouse Roger Grace (Laver) Deane

Occupation Administrative Birthplace Philippines

Your children 3

Where did you grow up? San Ramon, CA

Present community San Ramon, CA

Education High School

Occupation(s) Reading

Areas of expertise Reading, Writing, CA Poetry

Other interests or activities Travel

Organizations in which you are active \_\_\_\_\_





## INTERVIEW WITH JIM DONALD

## I PERSONAL BACKGROUND AND EDUCATION AT UC BERKELEY

[Date of Interview: January 23, 1998] ##<sup>1</sup>

Decision to Go to Berkeley

- Cowan: Jim Donald, January 23rd, 1998, Side 1. Jim, let's get started with some questions about your background, where you were born, your childhood, your parents.
- Donald: I was born on September 8, 1945, in El Paso, Texas. My folks lived there for a few years when my dad was assigned there by the telephone company.
- Cowan: Did you spend your whole childhood there?
- Donald: The first two years, and then we moved to Palo Alto. Then my family and I stayed in the house where my folks still are, in Palo Alto, until I left for college.
- Cowan: Did you go to high school in Palo Alto?
- Donald: I went to high school not in Palo Alto but in San Jose, at Bellarmine. It was a Jesuit high school. I took the train from Palo Alto down to San Jose, or Santa Clara.
- Cowan: Did you have some particular plans for where to go to college?
- Donald: No. I think my parents had more plans than I, but I knew I was just going to college somewhere, eventually. They wanted me to go to the Catholic college, Santa Clara, and I took the more economic and expedient route of going to Foothill College for a couple of years and then San Jose State for one semester and then on to Berkeley. Graduated from Berkeley.

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<sup>1</sup>## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

Cowan: What was the main reason you went to Berkeley?

Donald: Let's see. The reason I went to Berkeley was to get into a good, serious college. Foothill College was a junior college, and it was quite good. Good standards, and it had a good reputation back then. I assume it still does. San Jose State was kind of a one-semester fiasco, which I went to pending my financial loan approval at Berkeley. That eventually was approved, and I did go to Berkeley.

Cowan: Did you have brothers and sisters?

Donald: Yes. I'm one of eight.

Cowan: One of eight!

Donald: A big Catholic family.

Cowan: Did the Cowell program have any influence on your decision to go to UC?

Donald: It was probably one of the determining factors. I always had planned to go to Berkeley--not always, but when I left the junior college I was planning on going to Berkeley. I went to San Jose State to start my upper-division classes in the meantime. Between my San Jose semester and Berkeley--I had been accepted and everything was in place--I was in my accident, I broke my neck, so I became a quad at that point in time, which was 1966. I was planning on going to Berkeley in September of '66 and instead it was put off about nine months, and I went in June of '67, I guess it was. Yes, June of '67, after being in the hospital for a bit. I just didn't anticipate going to Berkeley in that fashion, but there I was.

Cowan: So your original plans were continued.

Donald: Yes.

Cowan: Where did you do rehabilitation?

Donald: I was at Stanford Hospital for rehabilitation. I don't think they have it there anymore, but they did in '67.

Cowan: How did you first hear about the [Cowell] program? Did the Stanford rehab department suggest it?

Donald: It was pure coincidence, actually. When I was injured I was twenty years old and I had quite a few college friends who were in the Palo Alto area. One of them had a friend--one of my friends

from college had a friend whose father ran Cowell Hospital. His name was Dr. [Henry] Bruyn, I believe. The word got passed down to me that the Cowell program was new and innovative and that there was possibly an opening and I should look into it. Looked into it, got accepted, and went.

Cowan: Was there a different admission process you had to go through because you wanted to get into the Cowell program, or was it just that you were accepted at UC so--

Donald: I already was accepted at UC and ready to go. Even with a financial package. But, of course, my finances were entirely different then because of the auto accident. By this time, about twenty years old, twenty-one I guess at the time, I was on welfare and Medi-Cal. That also assisted me financially to stay there. Let's see. I've forgotten the point of the question. The Cowell program enabled me to go there physically. Academically, I was already set. Financially, it was a combination of financial aid and welfare.

Cowan: And that made it a bit easier for you financially, the combination of welfare--

Donald: It made it possible. I didn't have any money. I had absolutely no money as a twenty-year old.

#### Life at Cowell Hospital, 1967

Cowan: Did you live at Cowell?

Donald: Yes. After rehabilitation I stayed at my folks' house for two or three months, as I recall, and then, when everything was in place and school was about to start, I moved to Cowell Hospital. There were only about three or four other people at the time. As I remember, it was a new program, maybe a year or so old, with the founding two or three.

Cowan: And that was John [Hessler] and Ed [Roberts].

Donald: Right. And I think Larry Langdon was there. I think he arrived the year before I did. It's hard to remember exactly. And there was a guy named Scott, who came the same time I did, Scott Sorenson. And so it was the five of us, as I recall. Larry Langdon was a little bit younger than I was at the time. I was twenty-one when I moved in, so he was about eighteen or nineteen. Scott was an older, more severely disabled fellow who didn't have

much of a sense of humor. And there was Ed and John. So, yes, I moved in and had my own room and hired my own attendants. You know how the system works.

Cowan: Yes, but did you know how the system worked?

Donald: Oh, that's right. You want my recollections! This was all new to me. I was young. I worked as a carpenter during the summer after school, so I was pretty outdoor-oriented. Being in a wheelchair was a totally new environment for me. And I had just been out of the hospital for just a few short months, so the system included living in a wheelchair, having an electric wheelchair for the first time at Berkeley, not before. And also living away from home, for essentially the first time. So a lot of new stuff.

When you ask if I knew how the system worked, the system in a lot of ways was new to me in terms of paying rent, living away from home, living in a wheelchair, and living on a campus.

Cowan: Who was helpful to you? Who helped you learn about using the wheelchair or just the daily things you were going to be doing? Did that happen at Stanford, or did that happen at Cowell?

Donald: Stanford didn't do too much at all for independent living aspects. They just taught you how to sit in a wheelchair to the degree they could. The person who facilitated my being at Cowell to the largest degree was my then-social worker, a woman by the name of Anna Bell at the time.

Cowan: Anna Bell?

Donald: Anna Bell, B-e-l-l. That was her married name. Her maiden name was Anna Klay, K-l-a-y. She was the one that made it possible for me to go there because she found the financing and did all the liaison work for me to make it happen.

Cowan: What about the staff who was at Cowell? Who was there?

Donald: Most of your focus seems to be on the program itself and how it worked. The Cowell program, as a program, I think, evolved later on, after I was there, if I recall correctly. The program as it existed then was a not a program. The program began by Dr. Bruyn allowing the unused third floor to be used by some severely disabled people who otherwise wouldn't be able to function on campus.

Ed Roberts had been there, I believe, for several years. As I recall, Ed simply went to Dr. Bruyn and said, "Why don't you let some other people stay here, too?" Because he had the whole floor

to himself. John Hessler came along a couple of years before I did. And then I came along eventually, probably a few years into the program. So as I recall, it wasn't a program. It was an event that later became known as the Cowell program that went well beyond Cowell Hospital.

Cowan: Was [nurse] Eleanor Smith there when you came?

Donald: As I recall, Eleanor Smith was there at a point in time when I was about to leave. There was somebody else before then. There was nobody else before then that organized it. But Eleanor Smith came in, and I remember she came in with a lot of rule-making that we didn't have before. That's my recollection of her. She was coming, and I was going.

Cowan: Her rule-making didn't sit well with the students?

Donald: I don't recall that. I recall her making rules. It didn't affect me too much. We were basically a bunch of college kids without supervision, as I recall.

Cowan: How long did you stay there? You came in '67.

Donald: I was there for less than a year.

Cowan: Is that unlike most people? Did most people stay longer than a year, a year or two?

Donald: Ed certainly did. And John certainly did. Larry Langdon and I moved out together. Scott [Sorenson] I think stayed. He stayed and moved in and out, and went in and out of the school. He eventually died while he was living with one of the attendants in town. His name was Dibner. Eric Dibner was the attendant that was living with Scott when he died.

Cowan: So when you were there, it was pretty service-oriented. You could go to classes, hire an attendant, but it had not yet become political--or am I jumping?

Donald: You're jumping a few issues here. When I was there, it was a place to live, and they provided meals, and you got your own attendant, and they had emergency attendants. I wouldn't call it "program." It was the availability of a dormitory situation. It later became, I suppose, a program.

Cowan: Did someone help you get your attendants? Or did you just advertise?

Donald: As I recall, we just put ads in the student placement, and they contacted us. I'm having a vague recollection on how. I think a lot of it was word-of-mouth. I know Eric Dibner worked for me, and his brother worked for me, and Ed Roberts' brother worked for me for a while. I can't recall any others, but a lot of it was word-of-mouth.

You mentioned political. It--and by "it" I mean let's call it the pre-Program, the pre-Cowell Program. The people there became political as the campus became political. Sit-ins seemed to be right down our alley.

Cowan: While you were still there, while you were still in Cowell, the campus began to produce demonstrations and things like that? Or was that after you left?

Donald: It seems to me demonstrations were a constant at that time, '67, '68, the two years that I was there. I don't remember the program itself being specifically political as a program. I remember Ed was active in his area. I don't recall any specific political involvement of the people as a group.

Cowan: Perhaps I misused the word. Was the group, the Rolling Quads--was that going on while you were still at Cowell? Or after you left?

Donald: I don't remember.

Cowan: Do you recall it at all?

Donald: I remember the newspaper calling us that. I remember we called ourselves that. But I remember the *San Francisco Chronicle* doing articles on us as a group once in a while, once or twice, and it was a big article. Have you run across those?

Cowan: I've read several of the history articles, yes. I don't know if I read the one you're specifically speaking of.

Donald: I remember it taking up the whole back page of the *Chronicle* on one occasion and slanderously referring to Larry and myself as being drunk.

Cowan: [chuckling] Oh, no!

Donald: Jokingly, you know. It was just talking about how we had a fairly easy-going life up there.

Cowan: But that's the group they were referring to? Or were they referring to just you and Larry?



Donald: Your questions are assuming that the program was in place when I was there, and it wasn't. It was a group of students that were taking advantage of a dormitory situation that served food. My involvement stopped in, I believe, less than a year, when Larry and I and this woman that I met, young girl, who became my wife later on, moved out into an apartment. We shared rent.

Cowan: Who was that?

Donald: Her name was Lillie Chan.

Cowan: So you were out of Cowell before it became a program.

Donald: Yes, I would say that, yes. Assuming it became a program at a specific time, it happened after I left.

Cowan: But you were still in Berkeley.

Donald: Yes. I graduated in '69.

Cowan: Do you have recollections of the changes that were happening there then, as it was changing from a dormitory situation to a program?

Donald: Generally. I was generally aware that there were a lot of other students coming in, and I remember that they had certain conditions. They had to stay in school. And I believe that there was a time limit, that you could only stay in for a few years. I may be wrong on that. I remember when I decided to move--this is an interesting fact, an interesting perspective--that it was before the independent living movement started, before it was even a concept.

### Living Independently, 1968

Donald: John Hessler, who was older than I, and a quad for much longer than I, had lived a few years in a nursing home before he went back to school. He advised me very strongly not to leave Cowell Hospital because I wouldn't survive on the outside. I would end up in a hospital and be sick and then my place would be taken and I wouldn't get back into school and I would just be in a nursing home, so I should not leave above all, if I knew what was good for me.

I left. And I got sick [chuckling]. And I got well again, and I learned how to take care of myself, which was a learning curve. But I made it. I think Larry and I are the first ones to

have moved out on our own without the support of some institution. We simply got a two-bedroom apartment and then hired our own attendants, and it worked well.

Incidentally, John is the first one to start one of these independent living programs off campus--and he's the one who advised me not to, so we were in a growing, evolving stage back then.

Cowan: You certainly were.

Donald: Believe it or not, there were no curb cuts in Berkeley. Not a single one. It was tough going down a couple of blocks.

Cowan: How did you find your apartment, you and Larry? Was it difficult to find an accessible place?

Donald: Actually, the three of us. Lillie, Larry and I went around. On a hilly campus there's usually apartments with one access, and we found one about five blocks from campus, a block off Shattuck. It was parallel with Shattuck, uphill. There's a Penny Saver market there, on Haste. Anyway, in the block just near Shattuck and Haste there were a couple of apartment buildings, and we stayed in one for a few months, and then we found a cheaper one around the corner. But they were reasonably accessible. I'm sure you're finding the term "accessible" has a lot of different definitions. It had functional accessibility. We made it in and out, and we made it work. Now, with all the codes that are in place that didn't exist then, accessibility has a legal, building-code interpretation.

Cowan: It might not be considered a legal place today?

Donald: No, it was just an apartment. There was no such thing as grab bars, as I recall.

Cowan: Did you modify it in any way to make it more functional?

Donald: No.

Cowan: So you were finishing up then. You were out of Cowell in your last year?

Donald: No, two years. When I moved to Berkeley, I moved into Cowell and I started with two classes in the summer, and then in the fall I took three, and then I worked up to a full load after I learned how to live in a wheelchair. So it took me from the June of '67 to '69 to graduate. It was about two years. Yes, that's about right.

- Cowan: Were you still interested in what was going on in Cowell? Were you observing that that was changing its focus?
- Donald: My only immediate interest was my friends. I'd go up there and visit Ed and John and Larry. Well, Larry was with me. So I went up there to visit my buddies.
- Cowan: Did it seem to you at the time that they were gaining stature in the community and beginning to develop some power?
- Donald: Well, I remember that there were a lot of new disabled people up there, and I also became acquainted with them. Not the close friendship, but they were friends. I can't think of their names [chuckling] right now, but there were two or three new ones. And every semester there seemed to be new ones. They're part of the old group that I run into once in a while. I didn't pay much attention to the program. I didn't have an interest in it. By that time, I got married and I was on my own and functioning. Cowell Hospital was something that helped me temporarily. This is, I believe, what it's intended to do, be a transitional situation. And just from my perspective, my recollection of my involvement in all this is that I moved out. There might have been some other people that started in Cowell and did not continue in school, so they had to move out of Cowell. They moved into the community there in Berkeley, and they wanted to stay in Berkeley because it was an exciting place to be.

#### Need for Support Programs Recognized

- Donald: So then the need developed for the community support system outside. I remember working with Ed and John and doing some grant proposals. I helped them write some of that, as I recall, to get funding for the community support system that became the Center for Independent Living and then later became the independent living movement. But that grew out of people dropping out of Cowell and living in Berkeley without the support system that Cowell had.
- Cowan: So you helped work on, or they asked you to participate in some of those original grants. Were those for student services or for independent living?
- Donald: The one that I remember working on was with John and Ed in the student services program. John Hessler, you may know, started the first student services program, I think while he lived at Cowell and then he went off campus. John was an institutional guy. He

liked Cowell Hospital. He started the student services program, which was just on Bancroft, off of campus, which was funded by the university, as I recall. As I recall, he was a university employee.

I recall that John asked me to help write a proposal for students who were not employees. What I mean is, disabled people who were no longer students who needed the support systems that weren't available to them anymore now that they weren't part of the students' program. And that became the independent living movement. It was community-based, rather than university-based.

### Role of John Hessler and Ed Roberts

Cowan: And John and Ed were the people who evolved this? Do you recall who said, Let's do this, Let's write a grant, Let's set up a student services program?

Donald: There were a lot of people on the periphery. Ed and John were the ones that stayed at the heart of these movements. And by "movements" I mean--forget the Cowell program. That's something that is a dormitory situation.

Ed was kind of the--I guess the big brother. He was always there. It wasn't so much that he was an academic or a philosopher. Well, more of a philosopher, I guess. He was the one that everybody went to, and he had the personality that accepted everything, so everything was a good idea. And he was also the good role model. He had strong leadership skills, and people came to him with the ideas and he embodied the ideas and he's the one that made it so it was really workable and useful. Without Ed's personality--and I guess it's more the personality--a lot of this stuff would not have happened because there wouldn't have been the cohesiveness and the focus of having somebody to carry the idea.

John was more the academic guy who wanted to put the program together, the functionary. I guess it was through John's effort that the independent living movement was given a direction toward Ed, who was just kind of hanging around, dropping out of his Ph.D. program and living in Berkeley with his mom.

Cowan: What do you mean by that, that it was through John that--

Donald: Well, John saw the need for the student services program, and he developed it into a program, and it was his student services

program that was the model for all the others now in the whole country. He saw the need for something beyond students, for students who were no longer students, and he probably--probably at least as much as Ed, and I wasn't directly involved in the genesis of this, but only on the periphery--pushed for the development of the Center for Independent Living.

##

Cowan: Interview with Jim Donald, Side 2. So you were off campus at this point but still on the periphery, observing what was going on.

Donald: Sure. I was part of the circle. We were the ones that watched the football games, went to the football games. We were all still in the same circle, but my involvement was more studies and married life off campus.

Cowan: So it was social.

Donald: Yes, social.

Cowan: Did you think a political component was beginning?

Donald: Back in those Berkeley days, you couldn't separate political from social because there was National Guard and helicopters with gas. Riots were so frequent there, I used to carry a gas mask on my chair just so I could sit and watch them.

Cowan: Did you really?

Donald: Oh, yes. It was great. It was like a tennis match, with the cops surging one time and then the students surging another time. But that's part of the story. To get back to the socializing with Larry and Ed and John, it was football games and sharing of attendants, socializing, drinking, hanging out, watching TV. In terms of the politics, they were developing programs and I was studying. That was basically it.

John was kind of--he had his master's, and he was looking for something to do with himself. Ed, I think, was kind of deciding whether he wanted to get his Ph.D. or not. He was teaching some classes on and off, kind of a waning Ph.D. candidate. I was still studying. Not that I was a serious student, but I was pretty serious. Good enough to be able to get into law school.

Cowan: Were you thinking at the time, Well, these two guys are going to go off and found big programs?



Donald: Those were concepts that weren't central to my life style because I was functioning well, and I knew that John and Ed were working in that area. I helped them--we talked about it, I recall, and I helped them with some grant proposals. But it wasn't the focus of my interest. Politics certainly was. We talked about that an awful lot, because it was back when Martin Luther King was shot and the riots were going on, and of course the Third World strike and that idiot, Reagan, as governor, who precipitated most of the riots. It's so clear that he did. All that was a highly politically charged time.

Cowan: Do you think that was a big factor in everything changing?

Donald: Absolutely. Timing was perfect, absolutely perfect because there was the Third World strike and minority rights, and here we were, disabled and couldn't get down the curbs and we had these fundamental unmet needs, like attendants, access. Transportation was a huge issue. And it seemed right to start doing sit-ins, so we did a few sit-ins.

Cowan: You did sit-ins before the big 504 sit-in?

Donald: Oh, yes. Oh, yes.

#### Political Activism and Turmoil on Campus

Cowan: Which?

Donald: As I recall, there were demonstrations to get funding from the campus, so I think we even sat in against Dr. Bruyn.

Cowan: Did you?!

Donald: Yes, as I recall. I have a vague recollection. He was always very supportive. I think he was instrumental in getting some of the university funds for John's program, the student services center. So there was that. And there was lobbying with the city that I wasn't directly involved with for curb cuts and that type of thing. So, yes, demonstrations.

And then the draft situation, burning your draft card. I recall one very comical situation. Hale Zukas--if you've heard that name--

Cowan: Yes, I have.



Donald: He was a crazy anarchist at the time. He probably still is. But he passed in his draft card. It was a 4-F draft card. And Hale-- just so you know on this record--is extremely, extremely disabled. He uses a head wand, and he can't speak, and he's very, very spastic, and he's in a power chair. And so the Nixon White House was saying they weren't punishing draft resisters by using the draft. Sure enough, Hale Zukas got a greeting that he was drafted, and so he said that he insisted on being taken. That was in the newspaper, of course.

Cowan: That's a wonderful story.

Donald: Oh, it's wonderful. Of course, they had to explain how they didn't punish him for turning in his draft card.

Cowan: Did they do that?

Donald: Of course not.

Cowan: Any other sit-ins that you can think of, or demonstrations?

Donald: Well, I remember all of us being caught up in the huge demonstrations on campus because there were protestors and picketers, and if you crossed a picket line, the students would start yelling at you, and if you went in another direction, the police would be hostile toward you. I remember the police were extremely hostile toward everybody, anybody who wasn't in a uniform, in fact. The one thing that gives me the political commitment not to trust police and that police need to be controlled is my experience there, watching the police beat people and shoot people. One of my attendants was even shot, coming to work.

Cowan: Is that right! Shot?

Donald: He had long hair. Yes. I remember on my balcony on Haste I was watching the intersection of Haste and Shattuck. The police came in and blocked off the intersection, and there was one long-haired guy that was trying to get by, and the police attacked him, handcuffed him, knocked him down and kicked him in the stomach when he was handcuffed. I watched them knock over old people. Just really rude people.

Once I fell off the curb. My chair--electric chairs back then were really horribly inadequate, and I went off the curb and fell sideways and banged my head. There were two cops--this was right in front of the Student Union center on Bancroft. There were two or three cops sitting there, talking. They looked at me and laughed. Just started laughing. And then some pedestrians

came by and put the battery back in my chair and picked me up, and they just left. I dressed as I do now, with typically short hair. I wasn't flagging myself as a student protestor. I was just a student.

Another time I was at the steps at the Student Union center right there at the edge of Bancroft and Sproul Plaza, watching the riot, on a cold day. The students were across the street on Telegraph and Bancroft, and the police were sweeping the campus. They swept the campus periodically. I was facing it at the top of--there's four, five or six steps there that fade down into Bancroft. I had my hands in my pockets and jacket zipped up. Had my hands in my jacket pockets. And the cops were sweeping the campus toward Bancroft. There were about three or four of these jumpsuited, blue jumpsuited cops without badges, with gas masks and other masks on, and gloves, and clubs. They came up to me from behind and said, through their gas mask, "Rrrr Rrrr Rrrr. Get off campus." Basically, they were motioning toward the steps, toward Bancroft, for me to go.

I had my hands in my pockets, and I started to laugh at them. I said, "What do you want me to do?" And one of them whacked me on the back of my head, me just sitting in an electric chair. Whacked the back of my head. And another one grabbed my chair. I was doubled over by then. I couldn't get up. I was doubled over. The other one pushed my chair, and he was just about two feet from the edge of the steps, going full speed, and I looked up and I saw this student storming the cops. The cops let go of my chair, ran, and about five or six students carried me down and surrounded me.

Cowan: It just was chaos, wasn't it? Did you even know what was going on? Or was it just any time, anywhere, this could develop?

Donald: I saw it as a political riot and a police riot. And that's not an exaggeration. The cops took their badges off. They were shooting people, clubbing people. Again, like I said, I wanted to see all of this stuff because it was tremendously exciting, especially for a twenty-one-year-old. They were always out of control, the police. The Oakland police especially.

The National Guard were just kids, like ourselves, who were maybe indoctrinated against us. They had the bayonets against us, and they sometimes shot into the crowd. Once they shot into Bancroft. I was just below Bancroft, around those cement planters, if they're still there. There were about fifty to a hundred students watching the National Guard do their goosesteps across campus, with their bayonets out, and sweeping the campus of everybody. We were there, and all of a sudden some shots. I

heard the bullets, the buckshot, hit the trees just maybe fifteen feet about our heads. They were 200 yards away. How could they be so accurate and never inaccurate? Then they were sweeping, and then some stupid idiot National Guard put a bayonet against me.

Cowan: A bayonet!

Donald: In my chair. I was backed up behind--after the shots fired, I went behind the cement planters. And he put a bayonet on me and told me to go, and there was nothing but a cement wall behind me. That type of obscene--not obscene--but absurd, illogical, riotous type behavior. The point of all that was that the police were out of control, and it was a political riot. And Reagan as governor wanted to make sure that he kept the newspapers' headlines going for himself.

Every time the press started to wane, they found something out. Like, for example, on the Third World strike--it was one of several strikes down there--the marchers had been, say, they were a hundred strong, and after two or three weeks they're down to around four or five. And after they're down to four or five, Reagan called in the Oakland police, saying that the university police weren't obeying the law, allowing the strike to go on. And then, of course, they came in and everything broke loose. Everybody started fighting because they had the police and the soldiers attack students on campus. So that was the social life and the political life.

Cowan: So in this atmosphere, the idea of changing things was pretty prevalent.

Donald: Yes. It was changed. Everything was sit-in and make demands, non-negotiable. Good old non-negotiable demand.

Cowan: Think of something--

Donald: Yes.

Cowan: --and demand it.

Donald: There were so many social issues that had to be addressed. Ours was independent living.

Let me tell you one other story that's really interesting that's not directly related to disability, but to the turmoil on campus. During the Third World strike, of course, everybody wanted their classes off campus, and some of the professors accommodated by getting classrooms off campus wherever they could. I, as an economics major, was taking the economics of Marxism

course, a class you could probably only ever find at Berkeley at that time. My, of course, "leftie" teacher found a place right off campus, on Bancroft, just about a half a block west of Telegraph. The windows were high, maybe neck-high for people walking on the sidewalk from the campus.

So there was the teacher this one afternoon, in class with tear gas wafting through the windows and the soldiers, the National Guard soldiers, marching up and down the sidewalk with their bayonets and screaming and yelling outside. We were studying the theories of economics and Marxism, off campus. A wonderful setting.

Cowan: Well, what I was going to ask when you brought this up before was, since everybody was making demands, were you beginning to think of your issue as a civil rights issue at that time? Was that your thought? Or just something you thought you needed to have?

Donald: You're asking for perspective that evolved, and at what point in time did we start thinking of it as a civil rights issue. I remember thinking that I didn't want to become a professional cripple, as I called it back then. I didn't want to have my whole life centered around this new disability that I had. New friends with old disabilities and me with a new disability, breaking away from that advice that John gave me--don't leave the institution or you'll sink.

And so I--and Larry, who also had a fairly new injury, Larry Langdon--we were off on our own, and we didn't need the institution, so to speak. But we did have our old friends who were going in the institutional direction, like John and Ed. And that was fine. We just had different focus. My idea was to go off and do something else. My focus returned later on.

Cowan: But at the time it wasn't a civil rights issue in your mind that you can think of.

Donald: Yes. Personally, it was. As a movement, no. I remember when there was a reason for me to become involved, like grant writing, I would do it. Other than that, I was just studying and married life and socializing as a twenty-one-, twenty-two-year-old would do.

#### Moving to University of California, Davis, 1969

Cowan: So then you graduated and left Berkeley and went where?

Donald: Well, I remember that what I was going to do after I graduated was a big concern because my subsidy and my existence at Berkeley as a student, and life at Berkeley was a wonderful thing. It's something that you didn't want to be over necessarily. So I was in the process of changing my major to political science from economics so I wouldn't have to graduate, and my then-wife said basically, "I'm not going to put up with your extra needs if you're not going to do something with your life." So I figured, Well, I better do something with my life. I applied to law school, got accepted at [University of California] Davis, and rushed to graduate so I could go to school by next September. So that's what I did.

Cowan: Well, before we leave Berkeley and move on to your life in Davis and Sacramento, is there anything about Berkeley or the program or the people or anything that you think you'd like to comment on, that I haven't thought of asking you?

Donald: Well, I was always amazed at how the program was evolving under Ed and John. Mostly John at the time. And thinking that that's not what I wanted to do with my life. I wanted to be a lawyer or something other than a professional cripp.

Cowan: So you went off to Davis.

Donald: Yes.

Cowan: You went to law school and got your degree in Davis, and starting in 1972 you were the deputy attorney general of the California Department of Justice?

Donald: Yes. Let's see.

Cowan: After law school.

Donald: I remember I graduated, and I went to UC Davis.

Cowan: Were there any particular problems at Davis for a person with a disability? Was it an accessible campus?

Donald: It's flat. Very different from Berkeley. Yes. We got a nice, inexpensive apartment in married student housing, which was only a couple of blocks away from the law school, so I didn't have a need for a car. Well, I think I did have a car at that time. But I didn't need one for school. We just moved to Davis. The university put a little six-inch ramp to the apartment in for me, and that's all they did. The law school was new, and it was accessible.



Cowan: Was there activity on the Davis campus of students with disabilities? Was there anything going on?

Donald: No, there was none. None that I recall. One evolved when I was there. I met one or two other disabled people. I remember one specifically, who has been a friend. He was involved in the development, I think, of the student program on campus at Davis.

Cowan: What was his name?

Donald: Dave Rhodes, R-h-o-d-e-s. But when you're in law school, you have only time for eating and studying.

Cowan: That's what I've heard.

Donald: So that was my whole focus for the next three years, from '69 to '72. Access wasn't a problem; getting attendants wasn't a problem I mean, it wasn't an issue. Occasionally, it was a problem. But Davis is a non-automobile campus, so everything was right there.

Deputy Attorney General, California Department of Justice, 1972

Cowan: When you became an attorney, what did you do then?

Donald: Well, at about the time I graduated, one of my classmates told me about openings in the attorney general's office. I was very lucky in that I was reluctant to apply because I wanted to take some time off after the bar and take a trip, and I did. But I did the application, and they hired me. My one and only job application. And I got the job and started after my vacation. So that was fortunate. It was a very good job. I called it the boot camp for lawyers. It's deputy attorney general, where you learn how to write and research and get the basic skills down.

Cowan: Was there any activity in that office on disabled issues?

Donald: It was becoming a political issue because Ed Roberts was the chief plaintiff for all of the welfare cases. His attorney was Ralph Abascal for the CRLA [California Rural Legal Assistance Foundation]. Disability was becoming more and more of a political issue and a legislative issue because, primarily, of Ed Roberts.

Cowan: So you saw these cases coming through the office.

Donald: Yes. And they were of course the chief enemy of the attorney general's office, which was comical [chuckling], from my



perspective, because he was a good friend of mine. I didn't get involved in any of those. I was more in other areas, opinion writing and--I wasn't involved in any of Ed's lawsuits.

Cowan: At that time? Or ever?

Donald: In those arenas, in those welfare arenas. I was just a new attorney for the first year or two.

Cowan: Was this still the Reagan administration?

Donald: Coincidentally, it was just as Reagan left and Brown was elected. Brown, I think, was elected in '75 or '6, whatever it was. No, '74, I think. And all of a sudden it was a Democratic governor, and the disability issue was becoming prominent. The attorney general wanted to have a task force on disability issues. He had me establish that, and so I did within the attorney general's office.

Cowan: And who was the attorney general at that time?

Donald: Evelle Younger. A long time ago, huh?

Cowan: Yes.



## II DEPUTY DIRECTOR OF DEPARTMENT OF REHABILITATION, 1975

### Ed Roberts Era as Director of Department of Rehabilitation

Donald: And then Jerry Brown was elected, and he was kind of the kid governor who had all these new ideas. Disability was becoming a huge issue. And so I applied with the governor to become the director of rehab. And [chuckling] I forget when, but I applied, and then I called Ed and said, "Ed, I want your support. I want to be the director of rehab." And he goes, "That's funny. I've applied for it, too." And then he says, "Well, if you get it, you appoint me; and if I get it, I'll appoint you." [chuckling] So that was the deal.

Then, of course, Ed got it because he had all the political clout and he was the better person anyway. And so when he got it, he appointed me as the deputy director for legal and legislative matters.

Cowan: So you moved over from the attorney general's office to the Department of Rehab.

Donald: Yes. I was in the attorney general's office for about two and a half years and then I got the political appointment. So then I was back to being the professional crip. Which was a wonderful opportunity.

Cowan: It must have been an exciting time.

Donald: Tremendously exciting. It was basically a blank ticket for what we wanted to do. After we started wanting too much, of course, his people started reining us in, and we had fights, not ever with Jerry Brown so much but with his financial people and his legislative people. We had some huge battles with those folks.

Cowan: What do you mean by too much, "we wanted too much"?

Donald: Well, there were a lot of existing interests--Jerry Brown was a governor who allowed a lot of experimentation. He liked to get the two extremes together and let them come up with the solutions. That's why he appointed Ed--because Ed was a failure for the Department of Rehab. He was rejected for rehabilitation. Although I wasn't part of the appointment, his philosophy, Brown's, was to put the two extremes together and make them come up with a solution. So they did that with Ed. And then he brought in all these quads, myself and John--

Cowan: Hessler.

Cowan: Yes, John Hessler. My background with rehab--that became an issue when I got my appointment--was that when I applied for law school, my rehab counselor said, well, I want to see your grades to see if you're qualified, and I basically said, "I'm not going to. If I get accepted, you sponsor me because that's your job." I basically rattled him along those lines, made my demands, my non-negotiable demands, and I got him to reverse it. And so when I became the deputy director over all these people, they didn't like it very much. As well as Ed, because he was rejected, too. So they got all these rejects in there that were their bosses all of a sudden. I forget where I was going with that.

Cowan: I asked you what were some of the things that you wanted when they started to rein you in.

Donald: Yes. Ed started on the independent living program, and he reversed the history of rehab within Rehab itself by focusing on rehabilitation services for the most severely disabled first.

Cowan: Was that Ed's idea?

Donald: Well, it was Ed's idea to implement that. I think the Rehabilitation Act already required it, but nobody was paying attention to it because it was easier to get good successes with people who had a few fingers missing and get them a job, or maybe needed new teeth; you call them a rehabilitation, rather than taking a quad who had a broken neck and very limited function. So that was the battle within Rehab. They didn't appreciate it one bit. They saw us as the enemy for years. I mean, our department did.

Cowan: Really?

Donald: And that's not an understatement. There was tremendous, tremendous resistance. You don't know what institutional resistance is until you get into a situation like that. They just would not listen to Ed.

Cowan: It was an eye-opener for you, then.

Donald: Yes. One of the more comical situations was that I had a service dog back then. He was a young dog, about a year and a half, and I used to go in on the weekends to do work, and there were other deputy directors, the traditional bureaucrat people who were nice people but they were traditional Rehab folks. My dog had the run of the office up there, and he went in one Sunday into one of the other deputy's office and pooped in the middle of the office, and I didn't know about it. Monday morning, the deputy [smiling] comes in and says, "Next time, Jim, can you just send me a memo?"

Cowan: Well, do you think you got some of the things you got because of Ed's position? Ed was very much a media attraction. Did he have some power because he was famous?

Donald: Oh, yes. The only person that had more press in the papers back then was the governor. Ed had a lot of press in the beginning. It was kind of the honeymoon for disability, and we took advantage of that, and we started writing laws left and right. Every time we had a problem, we just drafted and pushed it into law if we could. Really fundamental, fundamental things were just popping up all over.

Remember, this was a time in the mid-seventies when the disability movement was just brand-new, and it was just breaking a lot of old molds that needed to be broken, and that's because disabled people were out there. They had their mechanical machines, like the electric chairs, and they were there. It was also after the Vietnam War, when there were a lot more of them, and, with the medical technology, they were surviving.

##

Cowan: Jim Donald, January 23rd, 1998. Tape 2. To get back to what you were saying, anything that came up you would write a law about it or regulate it.

Donald: It was wonderful experience because all of a sudden I embodied the problems that I wanted to solve. In a sense, it's a perfect political appointment because if I had a problem personally, I would try to legislate it, solve the problem, for everybody else. For example, I got a van that I could drive from my chair, which was one of the very first vans, in fact--I got a used van that was the prototype for driving from a wheelchair. I got it from an older quadriplegic who was moving up in the world. I got his old bread truck type thing, with the rope handles to close the doors and stuff. I couldn't get auto insurance because of my disability, so in a fit I went back and wrote a draft law and got

one of the legislators whom I was getting to know to sponsor it, and they just jumped on it. They liked this sort of stuff back then because disability was the new movement. And it became law the next year.

### Disability Legislation and the Legislative Process

Cowan: Who were the legislators who were particularly accepting of you?

Donald: Leroy Greene, who was I think an assemblyman, later a senator, from L.A. area. I'll think of names as we go along.

Cowan: But that would be the process. You or someone would think of something that should be legislated and take it to someone who--

Donald: Yes, but that process changed. In the beginning the governor--we just went, got the legislator to accept the law, and then somewhere along the process the governor's office would have to approve it as an administration bill. After a few of these, they said, "Wait a minute. You can't do it that way. You have to get approval from the governor's office before you do it, before you promote any of these."

So I tried that two or three times, and the governor had a new legislative coordinator called B.T. Collins. I don't know if you've heard that name. He became a very famous fellow after a while. He was a Vietnam-era veteran who refused to be recognized as a disabled person, even though he had one arm and one leg blown off from a land mine during Vietnam. He was an irascible, foul-mouthed, hard-drinking Irishman. After a while, I found out he wasn't going to let any of my ideas through because they conflicted with other loyalties that Brown had in various ways with other legislators who were against what we wanted.

Another obstacle I had in getting legislation approved by the governor's office was finance because it always cost money, and they always said no. Several times I had to deal directly--take it up to the governor and get his approval. I remember Brown was never on time, and we had to wait and wait, and one time I had to wait about six or seven hours to get this one program, bill, approved, and I finally got it approved. He never did understand it, but he approved it, in opposition to his finance director and everybody else.



He had a very short attention span. He'd ask me a question, "Is this this?" "No, Governor, it's this." And I'd start to explain it. "Is this this?" "No." "Aw, you can have it."

Cowan: Do you remember what that was?

Donald: That was a little later on in the administration. It was a bill to fund bringing a lot of different state programs in compliance with the new 504 regulations from the federal government. It had a multimillion-dollar impact, and he never understood it, but he approved it.

Cowan: And that was the process you had to use now, his approval first.

Donald: Now that he's not governor, I'll tell you how we did it [chuckling]. We learned that if we wanted to get a bill passed, we would get one of the local--I would write it or one of my staff would write it, and then we would take it to a community group, like CIL. Depending on what the topic was, we'd take it to a different group that had legislators here who had influence in that area. And then they would introduce it, and after it was introduced, we would seek to get administration approval, position, for an existing bill. And that's how we got most of our legislation passed.

Cowan: It worked.

Donald: Yes, it worked very effectively. So we got all kinds of stuff passed.

Cowan: Did Ed do any of this kind of work as well, or was this mainly--

Donald: Ed was the boss. But the boss was--he took on the character of Jerry Brown's administration, and that is, whatever you want to do is fine; just do it. I would keep Ed posted once in a while.

Cowan: What about Ed as the boss?

Donald: Let me tell you a little bit more about some legislation. I have some good stories. And then I'll tell you about Ed. There was a law I came across that said that to be a juror you had to be--it had the words that you couldn't serve if you were feeble, dumb, some archaic words like that, that basically excluded any disabled people, so we changed that. It went to the extent of prohibiting the exclusion of disabled people because of disability, which included deaf and blind, which was a big political plus in terms of being accepted. Educating the public in terms of the integration of the disabled was one of our major battles, and

getting laws like that passed was a big public relations type boon for us.

Cowan: Was that one of the ones you took first to a community group?

Donald: That was one of the early ones, I think, that we got through the administration. It was such an easy one.

Another one was a section--I think it's Civil Code Section 54.1; I'm a little rusty on the numbers now--that says that the disabled are entitled to access and use of public accommodations on the same basis as everyone else. I forget--it might have existed before we got there, but it was amended so many times--I forget now. But we expanded it to include public transportation and communication devices. Before, it had just meant that you couldn't kick people out because they were disabled. We expanded it to include that they're entitled to access on the same basis as other people, and it included specifically transportation and communication.

From that there evolved the requirement that the buses had to have wheelchair lifts, and that was a huge, huge battle. And another huge endeavor that wasn't so much of a battle was the communications for the deaf. That law resulted in the telephone company taking the initiative--they were pretty good at it--to developing TTYs and make them available for the deaf. And that's where you see that two cents on your phone bill. They took the initiative, I think because they wanted to get it paid for. And we didn't oppose that because not only it seemed fair, but also it was a good public relations thing, where everybody would see it on their bill every time.

### Effects of Proposition 13

Cowan: It sounds like an amazing time. You were just changing things right and left.

Donald: Yes. It seemed to be, there for a while, everything we wanted. Nobody would say no for a while. And if they'd say no, there would be ways around it.

Another good story on that one is a lot of good legislative battles with the governor. Remember Prop[osition] 13?

Cowan: Yes!

Donald: Where all of the local funding went out the window, and local funding was the source of a lot of the independent living programs and the student programs that we had established or that were being established. At the time, there was a big government surplus, \$7 billion, I think. And the question was what was the governor going to do with it? It was called the Bailout Bill. Prop. 13 came through, and the Bailout Bill was a list of items that were guaranteed for funding from the state to the local entities. The one we wanted was that the local entities had to maintain funding at the same historical level for all these programs if they were to accept any of this bailout money. There was a laundry list that the governor was putting together.

Couldn't get it through finance. Couldn't get it through. And, of course, there were bills already out there, and finance wouldn't approve it. And so the word was passed out to the community groups to do a protest and to picket the governor. So there were about--I think there were two or three hundred people that showed up to picket the state capitol and the governor directly, and a few legislators were giving speeches on the lawn. It was well-orchestrated through Judy Heumann, whose name you may have heard.

Cowan: Yes, I have.

Donald: A real dynamo. Phil Neumark, who was a part-time attorney with Rehab--and there are a lot of stories about Phil--and others. Ralph Abascal, I think, was involved in that one as well. The strategy was, well, we'll negotiate, we'll mediate between the disabled and the governor. Ed was sick that day, so I had the privilege of doing that. I went over to the governor's office and met with his chief of staff. "What do they want?" Of course, we had it all orchestrated. We want this and this and this.

And then the governor comes out. He says, "Well, what do they want?" And I said, They want this and this and this. "What do I do?" [chuckling] So I gave him advice. I said, "They think you're cold and impersonal, so what you have to do is call in five or six of the leaders, go around and shake their hands, and then listen. That's all." So he did [chuckling]. And it worked like a charm. He went in and shook everybody's hand. Basically, we got 100 percent of what we wanted.

Cowan: How did this legislation coincide with what was going on federally? The 504 thing?

Donald: I forget which came first, the 504 bailout--everything happened so quickly. This was more Prop. 13-oriented and the big government surplus on the state level that needed to be distributed. I don't

remember--these two events weren't necessarily connected. The 504 thing was--if you're referring to the demonstration in San Francisco, that was a different issue. Different time. Earlier, I believe.

Cowan: But changes were happening in Washington separately from changes here.

Donald: Yes. The changes in Washington basically occurred because of what was happening here. California was the one that started all of these concepts, and everybody said, "Yeah, let's do that." And they were good concepts and they seemed to be working well. A lot of it happened because of Ed's figurehead status and his visibility and his personal appeal.

Cowan: What do you attribute that to? Ed's fame and ability to attract the media?

Donald: Ed had charisma. Did you ever meet him?

Cowan: I didn't.

Donald: He had a non-judgmental personality. People just liked him. And he was there. And he had the type of personality where he didn't hide anything. He lived in his iron lung, and if you were there long enough and he had to get on the can, he'd do it in front of you. You know, that's just the way he was. So Ed was there at a good time, and he was a good figurehead, both statewide and national, and then later worldwide. And it was a time of protest and movement and social issues. It was just the right people at the right time. Ed was just right there.

Let me tell you a little bit about Phil before we forget about him. He's non-disabled, an attorney from San Francisco. He worked with Jerry Brown in the early, pre-political days as an attorney in the agricultural issues in the Central Valley, CRLA, California Rural Legal Assistance Foundation. Some of the big people there were Ralph Abascal, Phil Neumark, and Jerry Brown. And numerous others that later became his appointees. He got a lot of his appointees out of that same legal aid group. Like Marc [Marcel] Poche. Either that or Santa Clara University, where he went to school.

Phil is the classic brilliant--I call him the attorney's quarterback who doesn't want to work too hard. He always wanted to work part-time, so Ed told me to give him--after I had my political job--he told me to give him a part-time job. And so here was this non-disabled, strange guy that I never met before that Ed was telling me to get a job, so I put it off for six

months. Phil came back later and talked to Ed about the job, and Ed says, "I thought I told you to get the job." "Oh, yeah. Okay." So I got him a job, and he had to work with me.

Cowan: In the Department of Rehabilitation.

Donald: Yes. Phil just wanted part-time work, where he could make ends meet, so he wouldn't have to work too hard. Phil Neumark was Jerry Brown's chief assistant when he was secretary of state, before being governor, so they were buddies, and Phil left, as he has a tendency to do--on philosophical disputes. He just dumped Brown and went off on his own.

During this sit-in where we became the mediators, Phil walks in halfway through [chuckling]--

Cowan: These are the 504 sit-ins?

Donald: No, this was Prop. 13. And there was Judy Heumann yelling at Brown, and his chief health and welfare person, who was Mario Obledo, who recently was in the news--he just got that award from Clinton--so Brown looks up and says, "I should have known."

Let's see. Where was I?

Cowan: Well, you were still talking about the Department of Rehab and things coming through and things changing a lot, legislation happening. Did that change as Brown's administration went on? Did that willingness to pass things--

Donald: Yes. Another area was the access laws, the architectural barriers laws. When we got there, there were some fledgling laws that were permissive access laws that referred to some standards that were national. One of the areas that we saw immediately was that there had to be a need to make it mandatory and also more precise. So we--I forget whether we wrote the law or whether it was already existing. It gave to the state architect--appointed by Brown, of course--the authority to promulgate regulations in detail. Jerry Brown got this guy--his name was Sim Van der Ryn--as a state architect, who was famous for starting communes. His idea of regulation was that he didn't want to be bothered. So for a long time he didn't bother to promulgate the regulations, and we didn't have anything to go on except these old standards.

So I remember I talked to him, and he said, "Well, you just draft them and let me know, and I'll sign off on them." And so I started that process and then finance or somebody got involved and said, "Well, let's do it differently." So he took it back and started the ball rolling that ended up in a year's-long process,



very, very extensive. It takes up a whole catalog or two of state regulations now that detail every single aspect of building standards. And it's ongoing.

Cowan: That was a successful one.

Donald: Oh, very successful. It's very good. It was the model for the ADA standards, yes.

Cowan: Did John Hessler stay in the program at DR?

Donald: Yes, he was always there. Yes, he was there the whole time I was, the whole time Ed was.

Cowan: And how long was that?

Donald: It was about seven years.

Cowan: Then where did you go?

Donald: Don't you want to hear more about Rehab?

Cowan: Sure.

Donald: I haven't thought about these stories in a long time. There are some good stories.

Cowan: Please do!

#### Access and Transportation Issues

Donald: In the access law, one of the areas--there's an area of town here called Old Sacramento. In the seventies it was just beginning to be restored. The president of the senate, Senator [James] Mills from San Diego, was not a lawyer but an historian and a teacher. He, of course, had the interest of historical preservation paramount in his mind. I think there was federal funding for restoration back then, too. And one of the things that he did was that he passed a law--right about the same time we started--that exempted all historical buildings from access laws. So we saw that. Of course, immediately I drafted another one that put it back in. I got one of the groups to sponsor it.

I went to the governor's office for approval, and B. T. Collins, this irascible, foul-mouthed fellow, came in. They called me over to the governor's office, and they started talking



to me about how they didn't want this bill passed because the governor needed the president of the senate's support. And B. T. Collins comes in, and he starts yelling at me. For years--he and I were friends after a while--well, we were friends from the beginning, but he was always irascible. He never called me Jim Donald. He called me effing Donald. I said, "B. T., that's not my name!" Even on the sidewalk he'd pull over downtown and he'd yell out the window, "Hey, effin' Donald! What are you doin'?"

So at any rate, they wouldn't let me do it. I would have died for the bills that I wanted, so I just went to another group, and I got them to introduce the same thing, and it eventually passed. It was passed first--this was a political strategy on the other side. They thought they had us beat. They established a committee to establish separate rules for access to historical buildings, which was proper because they were existing buildings and you had to make different accommodations. So they established by legislation--I don't know--an eleven-member historical building code advisory board that advised the state architect on regulations for access to historical buildings, like Old Sacramento.

Then it got rid of that blanket waiver of access laws to historical buildings. Before that, they waived all of Old Sacramento on a block-by-block basis. Or any other historical area, like Old San Diego. So on the committee, the eleven-person committee, it had building officials, architects and historians, and one member appointed by the director of the Department of Rehab. So it was ten against one.

Cowan: And that one was?

Donald: Yeah, I was the one! Obviously, they were going to say--and they started to say--that disabled representative needs regulations that are being promulgated. I and Ed got as many disabled people as we could at these quarterly meetings, and we were very, very, very rude. Nothing--these people would fly in from all over the state. Nothing could happen. As soon as they hit the gavel to open it, there was protest, yelling, questions. And the first three or four meetings of its existence, nothing happened. And it became known as the Hysterical Building Code Advisory Board because I'd been screaming--and I mean screaming, yelling, accusations. Our purpose was to not let the first thing ever happen in that board until they started giving us proper attention because we knew exactly what they were going to do. This was a two-year battle.

So this went on. I was on a trip somewhere, so I got this other person in the architectural compliance board part of the

Department of Rehab, this one young woman in a wheelchair, very pretty blond girl, Hollynn.

Cowan: Do you remember her name?

Donald: Hollynn, H-o-l-L-y-n-n [D'Lil Fuller]. She lives in Sacramento now. Her last name keeps changing. So she went in my place. I said, "Don't let them get anything through. Your job is to not let them do anything." So she goes in there and they were so happy that I wasn't there. They said, "We'll work with you. Just don't let Jim Donald back here." So she used her charm, and she did such a beautiful job, she got a very strong set of regulations through over about a year's time. I didn't go back again. But it became a very successful one, to a point where she married the chairman [chuckling].

Cowan: Now that's successful.

Donald: And I told her that was really commitment. The funny thing is, he's non-disabled. He was a building official. And building officials were our arch enemy back then. They would not do anything for access. Literally, they were the enemy. So she married the enemy and got him converted. He was converted, and he became our choice for the state architect's appointment to promulgate these regulations.

Cowan: What was his name?

Donald: Jud. Jud, J-u-d B-o-i-e-s. [pronounced Boyce] He just retired about a year ago. He's done a tremendous job. Divorced. But he remained committed. In fact, he has become my expert witness in some access lawsuits.

Cowan: So these tactics came right out of the sixties in Berkeley.

Donald: Oh, yes. So we got historical access in, and we got Jud to do all of the regulations for the entire state, which became the model for the country.

Cowan: The ADA. Anything else that you did that became a model or a piece of the ADA that they looked to you for the model or the example?

Donald: Well, all of the ADA is modeled primarily on California's successes and failures, whatever the failures might be. Transportation was the other one. The law was passed that required all new full-size buses to have lifts on the buses as soon as there were two manufacturers of those lifts available. The transit district just was adamantly opposed to it, just

vehemently opposed to it. They were angry toward us. The unions were against this, and they said that they were going to get strikes because the drivers didn't want the extra responsibility.

I think it was AC Transit in Berkeley that did a survey to see if there was a need for it because they were still resisting it tremendously. They did a survey, and they put little survey questionnaires on the buses to see how many riders wanted it [chuckling], disabled access. Of course, we fought that one tooth and nail.

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Cowan: Jim Donald interview, Tape 2, Side 2.

Donald: On the transportation issue, the law was in place and we located manufacturers who were willing to bid on it. But the people in the state kept buying the non-accessible buses. So we found some pending purchases--I think it was SamTrans, San Mateo Transit District, and they had something like sixty-nine buses--maybe it was fifty-nine--a multimillion-dollar purchase. And they were about to be delivered from Detroit or wherever they were to the Bay Area, and we filed suit, an injunction, to stop it. The attorney general's representative in that suit, a friend of mine from law school, happened to be the deputy. Of course, Phil Neumark was involved in it. The deputy was John Davidson. He's still with the attorney general's office, the deputy attorney general.

We were successful in getting the injunction, and it became a huge issue in the newspapers, of course, because this idea of wheelchairs on buses was just a brand-new concept and how would it work and all that stuff. All of a sudden, millions of dollars were being wasted and SamTrans' whole system was turned upside-down because they didn't have the replacement buses they needed. They tried to negotiate with us. The legislators from that area came over to our office to talk to us, and we refused because we were philosophically bent. We were advocates. We just wouldn't bend for anything.

But then, about a month later, we saw the chance to get some allies on our side because Santa Clara County Transit and--an assemblyman--some guy that just resigned or just quit--they came over to my office and said that they wanted to buy the buses for SamTrans, Santa Clara County Transit, and that if we would allow them to take these non-accessible buses that they would promise to make them all retrofitted within a year, and they would promote the system and show how it worked positively.

It was a great opportunity. So we did it. And they did it. And that was the beginning of the change for accessible buses in California. It proved that it worked and that became the model for the rest of the country.

Cowan: There are still concerns on transportation, though. Does every county in California have accessible buses?

Donald: I haven't followed the law in the last ten years, and things have changed through the preemption of the federal law, which has different exceptions and exemptions. I remember in the process of negotiating it on the state level, they wanted to do the Dial-a-Ride. In other words, they said nobody is going to use the buses with wheelchairs on a fixed route, so if people wanted them, they'd just use a Dial-a-Ride call-up.

We knew at the time--and that has proved out--that funding first is to go to the special services and the special services wouldn't work anyway because even in Sacramento I know you have to call up twenty-four hours or forty-eight hours ahead before you can use their system, rather than just showing up on the corner for a regular bus. It just doesn't work.

Eventually, it played out to where we got both, and I think that the fixed route system is still evolving. Education is still an issue because when my van breaks down here in Sacramento occasionally, I need to use the bus to get down to the courthouse or whatever, and it just makes me so irritated because some drivers see you and they use any excuse to pass you up because they don't want to deal with it. That happened just a few months ago. It just makes me angry when they just see you and they pass you up. They pretend they don't see you.

Cowan: Any more stories of Department of Rehab or laws that were passed?

Donald: When we first got the access law passed, it was ignored for a few years and then we started hounding the local building officials and talking to them about having to enforce it. Of course, they didn't like these idiots from Sacramento telling them what to do. I remember one instance when I went to Napa County and met with their chief building official and their county counsel about starting to enforce the law or else.

Napa County, for some reason, just didn't like the idea of Sacramento telling them what to do. And they were yelling at me. And yelling at me. And yelling at me. "We're not going to enforce this law. We're not going to do it--." I said, "You've got to or we're going to make you." I was only a kid back then, just out of law school. I think I was twenty-eight, something



like that and had all these people yelling at me all the time. But I thrived on it, I think.

And so I was leaving this meeting downtown, and I went outside, and I knew that there was a new federal law, using revenue-sharing funds, if you remember that--

Cowan: I do.

Donald: One of the things that we got passed was--I didn't, but somebody did--I think Phil Neumark might have been involved with it--that to use revenue-sharing funds, you had to incorporate disability standards. They were renovating their courthouse across the street, I noticed. And they were in the middle of it at Napa County. I figured, Aha! I'll bet you that they're not complying with the access laws. And so, when I got back to the office, Phil--again involved in this--we called up the office of revenue sharing in Washington, D.C. "No, they're not. They're not doing it." We pointed out a few areas where they were deficient, and so we filed a petition to stop their revenue-sharing funds. And that was about a three or four million dollar project. I think Carter was in the White House then, so they were sympathetic.

Immediately, they stopped all funding for the courthouse [chuckling]. I mean, it really hit the fan. Letters went to the governor's office to get me fired, and I got calls from the governor's office--I think it was probably B. T. Collins--saying, "What's going on in Napa?" And I told them, and they said, "Okay, just keep us posted." So they tried to get me fired and all that stuff. But then they had to comply with the access requirements.

When I was a deputy attorney general, coincidentally in the Napa County courthouse, I had a hearing and I couldn't get into that courthouse, and we had to hold the court in the sheriff's office, down in the basement, where I could get in. That was just a historical coincidence, but boy, oh boy, were they angry.

And then, in that process, they had to comply with the state law. One of the requirements in those old standards, before the state architect passed those regulations, was that all levels on a given floor had to be connected by a mechanical lift or a ramp. All levels on a given floor. And this was a point in time when we were still trying to educate the people. We were still out for the shock value and things that would hit the newspapers.

So I went into the courthouse, and I said, "The judge's bench is not ramped. [chuckling] And therefore we want to hold up all federal funding." That was part of the revenue-sharing funds, and basically revenue-sharing funds said, "Satisfy Rehab

and you'll satisfy us." So we were the kingpin there. So I said, "It's not enough you've got to ramp the elevator; you have to ramp the judge's bench."

So I got a call from the two superior court judges. "Get down here right away." So I went down and met with these two superior court judges, who I'll never forget. I can't remember their names, but boy, talk about yelling. And it was just me with those two. And they're yelling. One judge, it turned out, had an artificial leg, and he says, "I can't walk up a ramp. I'm not going to walk up backwards, and I'm not going to crawl for you or anybody." His voice was shaking. And the other judge said, "I want you to know that I'm not going to enforce this law. If it comes in front of my court, I'm going to find a way not to enforce this law. And you in Sacramento aren't going to tell me what to enforce."

They're putting themselves above the law. I basically said, "This would really be good stuff for a law review article." And they were just livid. That battle continued.

At the same time, we did the same thing with a new courthouse in Santa Cruz County. I think it was the county. But they came up with a more constructive approach. They said that they had designed a mechanical device that fits under the platform that will come down, and they sent it to us and we approved it, and as soon as they get a disabled judge they'll put it in.

Cowan: Was that okay with you?

Donald: Yeah, because I was losing. But every day I'd collect these things. Every day in the Napa newspapers there was editorial after editorial condemning or praising. It was the big issue. They said maybe access to the witness stand; maybe access to the jury box; certainly access to the courtroom; access to everywhere. But not the judge's bench. I figured that was a billion dollars' worth of publicity right there.

Cowan: I think it must have been. Were you also starting to get resistance from the rest of the department, not you and Ed and John but the people who were there all the time? You said they were the enemy when you came in. Were you having problems?

Donald: That was a different arena. The legislative and the public arena didn't affect the professional rehab counselors. In fact, they probably appreciated it because they made their placements easier. That was an ongoing battle that evolved into personality battles and just bureaucratic resistance. It eventually came around after a few years.



Cowan: But you left after a few years.

Donald: We had to. Republican governor.

By that time, the whole fabric of society in terms of disability had changed. [Governor George] Deukmejian appointed a disability director. Ed was the first disabled director. The one before that was Alan Nelson, who was, I think--he was a friend of Reagan's, and he later became the immigration director under Reagan, Alan Nelson.

Cowan: And who did Deukmejian appoint?

Donald: I believe the next one was Bill Tainter, who was one of the directors of the independent living program in San Diego. I think I might be--oh, no, no, no. He appointed a political crony, an older Filipino woman, Cecie Fontonzo, who didn't do anything.

Cowan: Do you think during your time there that the department encouraged or supported CIL's developing all over California? Was that a part of what you did?

Donald: Sure. That was Ed's primary thing. He wanted to have federal funding for independent living centers based on CIL throughout the country, and he was successful in doing that. I think they call him the father of the independent living movement. That was his primary thing. Mine was more legislative, civil rights, access. And so a lot of overlapping, but we were in different focus in our work.

### Reflections on Changes in the Disability Movement

Cowan: So you saw things really change during the time that you were there, throughout California.

Donald: Yes. I like to think we were instrumental, but probably anybody in our role would have done the same. We were kind of on the crest of a social movement.

Cowan: In terms of discrimination or the public's view, did you feel that changed? Did you feel there was discrimination against people with disabilities, and did that change?

Donald: Oh, yes, tremendous. The institutional discrimination. Like the insurance. You couldn't get auto insurance because of disability, but that changed with law. You couldn't get into restaurants.

One of the laws that we got passed--well, we didn't get it passed. We implemented it. It was that you're entitled to go to places. You can't be kicked out because you're disabled. We embodied that social movement, and we did it aggressively.

I remember once I was not allowed to sit where I wanted to in a San Francisco restaurant, Castanoglas, on Fisherman's Wharf, if you know where that is.

Cowan: Yes.

Donald: They made me sit over by the coffee maker, and I said, "I'm going to sit where I want to." So she sat us there, and she left, so my friend and I went over and picked an empty table by the window. The waitress came over, yelling at us, "We told you you couldn't sit here." So we left. And we sued. And the newspaper called it the Out of Sight Lawsuit because we couldn't get the table with a view. We settled that one.

So, yes, there was a tremendous--one thing that really was demonstrated by this movement is that you can change, very fundamentally, public morality with law. If you get the law, society starts changing, and then it becomes the norm. Can you imagine now saying that the disabled aren't allowed into a public accommodation because they're disabled? You know, it's inconceivable. But it changed because of the laws. And maybe the laws were appropriate because of the changing attitudes. There's an interplay there. But it wouldn't have happened as it did without the law.

Cowan: Did you see the public support for this change in law change over time?

Donald: Oh, yes, yes. It's the public's opinions that changed because of the laws. When the ramps are there, some people might say, "Well, what an unreasonable expense. I don't want to be burdened by the 'x' regulations." But after you see them for a while, the public attitude becomes, "Of course. Why not?" And that's what it is now.

Cowan: Yes, it is.

Donald: It wasn't that way before. I think I happened to become disabled in '66 at the appropriate time for change. Because of Vietnam there were a lot more disabled people around, and because of the emerging technical improvements, like electric chairs.

When I first was injured, electric chairs were designed only for indoor use. That's another area. I'll tell you about some

engineers I met that designed a new type of wheelchair that helped contribute toward the innovation of outdoor electric chairs.

When I was first injured, it was still considered to be an unsightly thing, sort of a shame on the family, that old biblical thing that if you're disabled it must have been the sin of your mother type thing. Shut-in was a common term. I remember it was not uncommon to be in public and see the little kid, two- or three-year-old, saying, "Hey, Mom, look." And point. And the mother forcing the kid's face back so they couldn't, wouldn't stare, embarrassed, or they'd go another way to avoid the wheelchair.

So it's hard to say. It's not the laws so much, but it's the physical demand by disabled people to be part of society, to be enabled first because of medical stuff and second because of the technological wheelchairs. We're there. Now get us up on the curbs, get us onto the buses, and get us into the places, and get us into the restaurants and give us jobs. All of that happened at once.

I happened, fortunately or whatever, I just coincidentally happened to be there at the time when all this was changing. I recall being a spectacle. I recall gathering two or three people every time I got into my van because they were so amazed at the technology of a lift going into a van. I recall when we first got those special parking laws passed. They gave us special places. We always had places, and now it's so common it's hard to get the disabled spots now. So things have changed tremendously. People don't pay attention to me at all, even though I go around in an electric chair with electric doors and electric lift. They don't look. They don't even look twice. They don't even look. Which is fine.

One time [chuckling] I was helping an eviction. As a lawyer, I was helping somebody evict some tenants who wouldn't pay their bill, and it was a rough neighborhood. I remember thinking, I've finally integrated the disabled into the society because I went and this guy wouldn't--we were giving the eviction notice, and he came to me and said, "I'm going to ignore you." I said, "Ignore me, and I'll own your truck." He grabbed my shirt, and he was about to belt me in the mouth [smiling], and my immediate thought was not fear but "I've integrated!" He was going to hit me! I'm nothing special! [chuckling]

Cowan: That's a great story [chuckling].



III CHAIRPERSON OF HUMAN RIGHTS COMMITTEE, DISABLED PEOPLES'  
INTERNATIONAL, 1983

United Nations Committee

- Cowan: I see on your résumé that you have worked at the U.N.
- Donald: Well, participated.
- Cowan: Participated. Tell me what that is--the chairperson of the human rights committee.
- Donald: Let me back up a little bit and tell you what the organization is and how it evolved.
- Cowan: Is this what you went to from Department of Rehabilitation, or you went from there to private practice?
- Donald: It overlapped. Toward the end of the Brown administration, the disabled movement was well entrenched nationally, and certainly it was becoming strong in other countries as well. Again, it wasn't because of us. It was just because it was time.
- Cowan: Everything, yes.
- Donald: Technology, medical. And also the example of California. I don't want to underestimate that because everybody in the world came to California for advice on how we were doing it. In fact, '81--our term was up in the end of '82. '81 was the International Year of Disabled, the United Nations. That was brought on by Qaddafi, for some reason. I forget exactly why, but he did, and it was good. That put world focus on disability issues toward the end.
- Cowan: Can I just interrupt for a second? Did they come to California, or did they come to Berkeley? I mean, was Berkeley the big thing? Or was it California?

Donald: The Center for Independent Living was the primary paradigm for independent living, even though by that time they were all over the country. They were the think tank, so to speak. I remember, in preparation for the International Year of Disabled or participation in it, people from different countries would come, and also they'd invite us to go there. Ed went all over the place. I had the fortune of being chosen to do a speaking tour all through Australia, and I got to go to every country and meet their legislators and talk about the tenant program and the independent living program and the legislation that we had.

A few months later, one of the senators, one of their national senators came, and they wanted to see what we had, as a follow-up. He wanted to see the Center for Independent Living, and he wanted to see what we had in Sacramento. I forget where we were going with that, but certainly it was international by then.

#### Disabled Peoples' International

Donald: And then Ed somehow hooked up with a group in Canada who had the backing of the Mennonite Church and the Swedish government. They were starting an organization called Disabled Peoples' International. Their funding, through various sources, was dependent on involving the evolving countries, and so there were a lot of sponsors. The charter was written so I would especially be involved with the evolving countries, not just the western powers.

So Disabled Peoples' International's founding group involved Ed and a couple from Canada and a guy from Sweden and primarily that. There were a couple of others, as I recall.

Cowan: And they sought Ed out?

Donald: Yes. He's the grandpa of the movement. I was of course excited about it, so I went with Ed, and I was his alternate. Ed had a very well-earned reputation for being unreliable. He wouldn't show up most of the time, so I was his alternate. Got to do a lot of it.

Cowan: What year was that?

Donald: We were gone at the end of '82, so I think it started about '82. We had meetings, periodic meetings, about maybe two or three meetings, and they were at different places. I had so many of those meetings, I can't remember where they were. Somewhere in Oakland or Berkeley.



But that evolved into an organization that I was very intimately involved with for the ten or twelve years following. Of course, it was a non-paying thing.

Cowan: And that was?

Donald: The Disabled Peoples' International. The idea was to promote independent living throughout the world and to take the models and the information and successes that we had and take them to other countries, and to encourage and foster the development of independent living programs of whatever type--culturally--in every country.

For example, in Zimbabwe we were having some of these discussions about access, and this guy who didn't have any legs started yelling at us. I forget. It was a panel. "How can you be talking about ramps in the buildings? We don't even have any buildings. We don't have any pavement." And so he says, "Access is not ramps and not door widths or stuff like that. We don't even have--." You know, that type of thing. That's the type of thing in translating culturally into whatever it was.

Cowan: You're not part of that group any more? Is the group not existing, or are you just not part of it?

Donald: It's still existing. It has taken on kind of a western Europe flavor now because the personalities have changed and the sources of money have changed. But coincidentally, Ed was always central but always only there half the time, and we never had any money to contribute because all the money came from sources that required it to go to the developing countries. So the United States never had a real strong role other than Ed's and my own. There were efforts. It was mostly Canada because of the Canadian Mennonite Church and the liberal Canadian government and the Swedish government.

So that was going on, and it went very, very well. At the same time, I got a call from a woman who had just become an attorney, Karen Parker, who was a human rights advocate. She went to Boalt Hall and one of her professors was Frank Newman, a California Supreme Court judge who was also an international law professor who took his students to the United Nations to show how it worked. Karen was one of his students. She encouraged me to join with her to take California's successes to the United Nations. And I thought that was an exciting thing.

I was also involved with Disabled Peoples' International, so I jumped on the bandwagon and got funding, and Karen and I went to Geneva to the Commission on Human Rights meeting. I started

representing DPI, and I got a call from Stockholm, where they were having a DPI meeting--that I didn't bother to attend that year--and they said, "What are you representing DPI for?" Somehow, they heard what I was doing. I was making speeches at the U.N. Commission on--yeah, DPI. "You aren't authorized. You get your butt here right away."

So Frank Newman, the judge, was there in Geneva, and he says, "I'll give you the money," so my attendant and I--I always travel with an attendant--flew to Stockholm in the middle of the Commission meeting. Boy, were they yelling at me. All my friends from DPI, Disabled Peoples' International. They said, "You don't have the forum." They were really parliamentary-oriented. The chair of DPI comes from Singapore, was a parliamentarian type guy. So I said, "Okay."

So they had their meeting going on, and I immediately started lobbying all the different groups in the DPI meeting there in Stockholm. We were in some camp on the outskirts of Stockholm. And I got them to create a human rights committee and to let me chair. So after about four or five days, I went back to Geneva, and I had the credentials to represent DPI at the U.N. And that lasted for twelve years. And we had some tremendous successes.

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Cowan: Interview with Jim Donald, Tape 3, January 23rd, 1998. You were still talking about the international aspect.

Donald: Yes. Karen Parker was intimately involved in the disabled movement, although she wasn't disabled. She, as a lawyer, focused on international human rights law, so she was kind of the professor of our efforts there in Geneva. She was instrumental in formulating the agenda for DPI in the United Nations. The primary focus that we developed was to reinterpret or to interpret the Universal Declaration on Human Rights that I think Eleanor Roosevelt passed--she was instrumental in getting it passed--to include disability and disability issues as among those in the human rights. We worked for the first few years to get a resolution passed by the United Nations to include that. And we were successful.

Cowan: What year was it that you were successful?

Donald: Well, we started in '82, '83, and I think it took about three or four years to finally get the United Nations as a whole to get it past the subcommission on Protection of minorities to the Commission on Human Rights to the U.N. Body. So finally it was interpreted to include those rights.

And then, the next few years, we worked--in addition to developing our liaisons with other groups--to get a special investigator appointed to study the problem and report back findings to the U.N. That was an interesting process. We were successful in doing that. We took a fellow from Argentina, who was a lawyer, exiled lawyer. Went back after the military coup failed or was relinquished. And he basically said, "You write it and I'll sign it."

### Continuing Work on Disability Issues

Cowan: Does any of your work today, your personal work, include work on the part of the disabled community?

Donald: Some of it. I don't focus on it by any means. It's not even a major part of my work. It's an incidental part of my work.

Cowan: Any issues you think still need to be addressed?

Donald: Gee, I think with the ADA it's mostly implementation. I just haven't followed it as a professional so much. Whenever I get a new case in that area, I have to research to find out what everybody else has been doing, since I left that area. And I was not involved in the passage of ADA. I've seen the ADA as kind of an embodiment of what California has already done with quite a few variations. But I occasionally do have--well, I have one case now that's been going on for years, to do with the employment discrimination against a quadriplegic up in one of the northern counties. He was a probation officer for umpteen years, and they decided to get rid of him because of his disability. The ADA played into that, and that case just goes on and on. It has gone to the Supreme Court. I just got a note yesterday that the Supreme Court will not take a review. The other side lost on a review, and so now we get to go to trial.

I stopped doing the U.N. work because it was taking on a western European control rather than Canadian, and the people were changing, the board of directors, to a point where I wasn't close to them anymore, but also--equally important--I was just getting sick and tired of going to Geneva. After twelve years of going to Geneva and all your vacation time or available time was spent in one place--it's exciting to deal with those folks, but I just got tired of traveling, I guess. At one point I was gone as much as six months out of the year doing fact-finding tours and stuff like that.

Cowan: That's a lot. Was their point of view changing in a way you didn't like, as well?

Donald: No, not at all. It was great. But a lot of the stuff that we were doing--Karen and I were doing--we had pretty much accomplished. We got the report done, and we did a lot of working with other groups. One of the more interesting things was when we were there, a lot of the different special interest groups worked among each other in a supportive way, and after they got to know us a bit they would approach us with different issues.

Cowan: Such as?

Donald: There was an attorney from Japan who--this is one of the more striking examples--approached us and said he needed our support in his efforts to change national law in the way the mentally ill were treated in Japan. It turned out that the Japanese are horrible in the way they treat their disabled. There, they still see disability as a shame, and they hide the disabled and they institutionalize them without any right at all to rehabilitation or treatment. They showed me some reports. Of course, as an advocate, I took the report and I made a speech at the U.N. subcommission. One of the phrases I used, just off the top of my head, was that Japanese treat their disabled worse than animals. It turned to be a national insult [chuckling]. I'm not exaggerating any of this!

The next morning, it was in the headlines of the national Tokyo newspaper: U.N. Representative Shames Japan for Treating Disabled Worse Than Animals. It's a horrible insult. I don't understand the insult, but it's something you just don't say, and I was headlines. So the next day, I was inundated by about thirty Japanese reporters, asking me to quote it. Of course, I was an advocate, and I said, "Yes. And we will prove it if we have the opportunity." "Are you coming to Japan?" "As soon as we can arrange it." [chuckling] All of this was in two days. I didn't know what I was talking about!

So all of a sudden, the Japan Socialist Party, the local communist party, was giving us money to go to Japan to do a fact-finding mission. Anyway, it all fell together, and a few months later I was in Tokyo, interviewing all the prime minister's appointees on this issue. We got the tours; and boy, those guys are liars! It turned out that the Japanese have a private money-making system for treating their mentally retarded and their mentally ill. And that is that the government, to hide it, they just pay them by the head for any person that's institutionalized. They go into a private hospital, and they never come out again.

They get buried on the site. The doctors are on the site. And it's a money-maker. They just get so much money per person.

It turned out that the laws are such that you can declare someone in your family to be mentally ill. You go into a private hospital, with no right to an attorney, no right to any outside help. So if a wife wants to get rid of her husband, she says, "He's crazy," and he gets taken away for profit. And that's not an exaggeration. It's amazing.

Cowan: Still today? Is this recent?

Donald: It turned out that there were some changes in the law. They had to negotiate with DPI to get approval for some of their laws to be changed, except the Japanese just have a way of promising one thing and not following through, and so they made some token changes to their national law. We took that as a victory to some extent.

The backdrop, though, that made it really interesting was that one of the founding members of DPI, Disabled Peoples' International, is a Japanese fellow who is a national senator, Senator [Yashiro?]. He's a member of the ruling party, which is the equivalent of our Republicans, who are pro-business. And so when I did all of this, of course he called me in Geneva and he was yelling at me in Japanese [chuckling] with his interpreter, saying, "Next time you criticize my country, do it through me first so I know what's going on," because, of course, his party got mad at him for having his organization criticizing their constituents.

So when I did my fact-finding mission, of course, I was a guest at his house, and he got me the chauffeur and the car driver, and his assignment was to contain me as much as possible. I stayed at his place some of the time and in a hotel some of the time. At the hotel, I had these midnight visitors--other attorneys and other social workers--coming to tell me the real stuff.

Cowan: The real stuff. Japanese social workers?

Donald: Yes.

Cowan: Is their attitude toward the physically disabled similar?

Donald: Yes. Yes, it is. This fellow is a paraplegic senator, but he's there because he was kind of the Johnny Carson of Japan. He was a talk show comedian, and he broke his back during a live show,



falling off the stage. He was a very popular comedian in the country, so he was well-received.

Cowan: Would you say internationally, progress is being made in Europe but not elsewhere? What is your view on that?

Donald: Oh, yes, it's wonderful in the western countries. When I used to go to Geneva in the eighties and nineties, they have their blue curbs and they have--Geneva, especially, I recall because I've been there so often. They have subsidized taxi systems where there is a van taxi that has a lift, and you pay the exact same fare as you would for any regular taxi. Let them know you're coming, and they're there in an instant, and they pick you up and transport you anywhere you want. We don't have that here.

Cowan: That would be great, wouldn't it?

Donald: Yes. It's wonderful.



## IV REFLECTIONS ON INDEPENDENT LIVING MOVEMENT

Memories of the 504 Sit-in

- Donald: Let me tell you a little bit of a story about Karen Parker, the attorney in San Francisco. She's still in human rights work. When she called me at the end of the Brown administration to get involved in the U.N. work that her mentor, Frank Newman, got her involved with, she was an attorney. I first met her--I was casually acquainted with her before then, as a fellow advocate in California--I met her at the demonstration that we didn't talk about on this tape. I'm sure you've heard about it already, the 504 demonstration, where we sat in the federal building in San Francisco for about three weeks, I think it was.
- Cowan: Right.
- Donald: Karen was not an attorney then. Living in San Francisco. She was working in some capacity for mentally retarded. During the demonstration, she brought her crew of retarded people--about seven or eight or ten or twelve. At first they were there just for the day, as part of the demonstrators. They were a real animated group of people. Karen is a real high-energy person and totally committed to the idea that everybody is equal and they should participate equally. And so she had all her retarded people there, and she gave them jobs. Some were sentries; others were messengers. I forget exactly how many were involved, but boy, you gave them a task and nothing stopped their performance, whether it was a message or guard the door. Nobody got through.
- Cowan: As a matter of fact, I was going to ask you something about that demonstration. You were there. Were you demonstrating or actually one of the sit-in people, inside the building?
- Donald: This was in '77, as I recall. It was during the honeymoon era of the Brown administration. Because we started in '75. We were in the neat position--Ed and I and John--of participating in a sit-in

against the federal government while we were on state payroll. I remember a lot of frantic calls from Mario Obledo's office, "What are you doing?" Of course, we just didn't return the phone calls.

Cowan: It was his office that people were sitting in?

Donald: No. Mario Obledo was the state. We were in the office of Health, Education and Welfare. At the time, the director was [Joseph A.] Califano [Jr.]. But it was the local office here.

That was a unique situation, where basically the state government was sitting in on federal government--well, we weren't. It was mostly the disabled people. We were there; we were providing support. And Judy Heumann and Phil Neumark were primary players in that.

Cowan: Were they the ones who called you and asked if you'd come down and participate?

Donald: I wasn't involved in the organization. In fact, there was no planning on that. It was a rally. It just started as a rally, and it got out of control. There was a platform built at the U.N. Plaza. I remember everybody gave emotional speeches, and there was the usual motley group of disabled around. And Judy says, "We're going to turn in there--we're going to go in that building and we're not going to leave again until Califano signs those regulations." Everybody turned around and marched in. It was that spontaneous. And they just went from one thing to another.

Cowan: It was long.

Donald: Three weeks, yes.

Cowan: Were you in the whole three weeks?

Donald: I usually stayed at a hotel across the street [chuckling]. I stayed in the building a few times, and I went back to Sacramento, but I did spend my share of nights on a mattress in the hallway there. I remember that vividly.

Cowan: I have read that you were part of the group that went back to Washington during that sit-in. Were you?

Donald: Yes.

Cowan: What was that about? What did you do back there?

Donald: You've probably heard some stories already about the sit-in. Let me give you a little bit, building up to it. It was a long sit-

in. It had its ups and downs. It started with hundreds, and it dwindled down to just a fraction of that number. I remember it was approaching Easter, and Judy Heumann--always the dynamo--let's see. How did it work? I went to school with George Miller, the Congressman. He was in my class. She says, "Jim, you went to school with George. Call him and get him down here. We need some support." So I called him at his house. I think it was Easter Sunday, and he came over with his kids and his wife. Of course, Judy wasn't aware of it. She called the press at the same time. So George comes in. His kids bring in their Easter eggs because they knew the police were out there not letting anybody in. And the whole time Safeway and Black Panthers and everybody else was bringing food and stuff in.

And, by the way, the Department of Health, Brown's appointee, Jerry Lackner, director of health, was bringing in portable showers and mattresses for us. So we had all the state services supporting the protestors against the federal government. It was really an unheard of political fiasco. The cameras started rolling, and Judy starts demanding a Congressional investigation of Carter's administration. George says, "I'll see what I can do."

Phil Burton was a mentor of George Miller. They're on the same committee. So, to make a long story short, you probably heard that Phil Burton called a congressional investigation and conducted it in the middle of the occupied building and subpoenaed all the federal officials from D.C. So then we had all kinds of Walter Cronkite type coverage for weeks--not weeks, but for days and days. And then, from there, the money poured in and gave us funding through the labor unions and different churches and Black Panthers and--

Cowan: Funding for?

Donald: The trip to D.C., to picket the White House.

Cowan: Is that what the point of the trip to D.C. was?

Donald: Yes. To march and get Califano to sign the regulations that implemented the 504 regulations. I remember going to the airport. It was just amazing. So many electric wheelchairs, so many bizarre-looking disabled people en masse, heading off to Washington, D.C., going through the lobbies. I remember seeing Ralph Abascal there. That name will come up.

Cowan: It has. Yes, I've heard of him.

Donald: He just died in the last year. He was in the lobby, and he says, "Are you guys going to D.C.?" I said, "Yeah!" He goes, "I think I can come, too." He might have planned it. Knowing Ralph, he probably planned it. But he hopped on the plane with us and went with us. He's a master at public relations and strategy, like Phil Neumark is. We had labor unions meet us there with Ryder trucks that had the lifts in the back that transported--just packed us into these windowless vans and drove us all over the place.

We ended up picketing Califano at his house. Of course, Ralph arranged to have one of the local channels, Channel 4, whatever it is, follow us all the way through Washington, D.C. And so we went to Califano's house late one night. We were unloading the U-Hauls or Ryder trucks, and the police--we could hear the sirens coming through this posh neighborhood. They finally came to us, and the cops jumped out of the car, and they started running toward us, like they were going to club us or whatever. It's nothing unheard of after Berkeley days.

Of course, the TV cameras turned around and started taking their pictures. We, of course, were allowed to stay. We picketed Califano's house for hours and hours. It turned out he went out the back way. I remember it was hours. It either started before it got dark--no, I remember the police coming when it was dark, so it must have gone into the morning.

Cowan: Did you also picket at the White House or at Congress?

Donald: Yes, we picketed the White House. We had a rally at that park across the street from the White House. A few people went in to meet with some of Carter's people.

Cowan: Did you meet with anybody?

Donald: No, I didn't get to go in. I wasn't one of the chosen few. There were only two or three.

Cowan: Do you remember who they were?

Donald: Ed, Phil Neumark, probably Judy.

#### More Thoughts on the Movement

Cowan: Well, I've sort of exhausted my questions. Do you have anything further to say? Do you have any reflections on what disabled

politics are headed for, or what's going on, or how things have changed?

Donald: I don't see it as disabled politics. I see it as a battle that is won. I don't think there's any doubt we're integrated into society. Judges yell at me as readily as anybody. There's always the undercurrent of discrimination. I feel it by some judges, for example. They just don't like me, and I have to disqualify them. As with anybody. Maybe it's age, race, whatever. There's going to be biases against different people. But in terms of institutionalized, we are institutionalized. We're a part of the establishment. We've got our rights, and if they're violated we can sue for it, which we do all the time, with success and failure.

Cowan: Looking back at the impact--Berkeley and the Cowell program. You were there. It was a big influence on your life.

Donald: Certainly. It was the defining influence. It's hard to separate my age at the time from the place I was, Berkeley, to the movement that was evolving. With or without us, it was there. It's an event. It's not necessarily ongoing. It's a chapter that is passed, and we're into a different era now. Or else you wouldn't be doing this [chuckling]. You're documenting it. It's a unique point in time. But it was a tremendous experience to be an integral part of it, both on the local level at Berkeley and on the state level and national level and the international level. Now I'm just doing mundane practice of law. But I'm enjoying every bit of it because even some of the cases that I deal with are cited now as the old law, just in interpreting what the law is. I run across it. Even some of my opponents cite my old cases against me sometimes if it suits their purpose.

Cowan: It's hard to look back and remember exactly what you were thinking a long time ago, but did you have a sense of what was developing? Was it any part of your decision to become a lawyer?

Donald: No, it wasn't a part of--it was just a coincidental, concurrent thing. It was a need to do something that was suitable to my disability. People asked me why I became a lawyer. I usually tell them it's because I couldn't do anything else.

Cowan: [chuckling] Well, then. Any final thoughts on your part?

Donald: I've got to mention my dog.

Cowan: Oh, I wish you would. That's a wonderful dog, Gus.



Donald: He's only a shadow of the former dog, that was also named Gus. One of the spinoffs of this was somebody contacted Ed. It was back in '79, I remember, because that's when my first dog was born. She said, "I have this concept. I came back from the Peace Corps and I noticed how animals helped disabled people in different areas." There was this donkey that was helping somebody without legs or something. She goes, in her typical Peace Corps mentality back then, "I want to do something with that here." So she started something called the Canine Companions for Independence [CCI]. She developed this concept of having dogs serve disabled people like seeing eye dogs serve the blind. I'm sure it's a concept you're familiar with.

Cowan: Yes.

Donald: So Bonnie Burgin was the woman. She started this. She had placed one dog, I think, on an experimental basis, and she wanted Ed to take a dog because Ed was high profile. Ed was always on the speaker phone, and I happened to be at his place when she called. He just lived down the street from here. When he got the political appointment, I already lived in this house. And he says, "Help me find a house," so I drove around the block and I found a couple of houses for sale. Ed's house was there, and John's was about a mile in the other direction.

So I heard this, and I've always been a dog lover, and so I said, "I want one too." So she interviewed me on the phone. Believe it or not, this was the interview. "When were you born? I have to make sure you're compatible with this dog." So I got the dog, and he turned out to be an absolutely wonderful dog, and I had him for fifteen years. He died about two years ago.

She said that now that the program is institutionalized or established, she had to get the law changed, and so she came up and worked with me and Ed's wife at the time to get the law passed to where people with service dogs were not--you couldn't discriminate against them. She testified, and the legislation got passed, and called it the Gus Law. I don't think it's in the books that way, but everybody calls it the Gus Law. This isn't the original Gus. The other dog--he obeyed. This guy--

Cowan: More of a free spirit?

Donald: Bonnie took this one for six months, and she finally said, "He's just not suitable."

Cowan: [chuckling] Well, he's a suitable pet.

Donald: Yes.



Thoughts on Ed Roberts and John Hessler

Cowan: Both Ed and John are so prominent in this whole story. Do you have any final thoughts on either one of them, or both of them?

Donald: Well, let's see. John was kind of a primary mover and maybe the person who made Ed possible in terms of him putting together the programs and Ed saying, "Yeah, good idea. I'll be the figurehead" type thing.

None of it could have happened without Ed, either, in that he was accepted by everybody, and he's the one they went to when nobody else would work. Ed probably had more faults than he had attributes [chuckling], but he was a success in that he was there at the right time, and he was the one that everybody looked to. Not only all the disabled, but all the people on the outside, too, because he was such a shocking person to deal with, physically--reclined, little, slight, had a tube in his mouth all the time to breathe, noisy--but he was accepted by everybody, and he was non-confrontational. Everybody was okay type thing.

So the two of them together were--one wouldn't have happened without the other, I don't think. Not that they were such close friends. I don't know if they were that close as friends. They were not alike at all, necessarily. But their involvements complemented each other at the right time.

##

Cowan: Jim Donald, Tape 3, January 23rd, 1998. You were just finishing your thoughts on--

Donald: Well, both John and Ed are gone now, and they both lived in--well, John lived in Sacramento when he died. I dealt with him periodically. John was more of--kind of like an old friend that I didn't have a lot in common with toward the end. We both went our own separate directions. And, like an old family member you don't see too often and you don't go out of your way to see too often. Every time I'd see him we'd say, "Oh, we've got to get together and do something," but we never did.

I would deal with him on an issue basis. He would call me if he had something he needed some help or an issue that he wanted me to be involved with or something to let me know, something that was going on. In fact, I talked with him just a few days before he died. He worked here in Sacramento, to the end. And he lived just not very far at all from here.

Ed was more of a friend whom I didn't see very often, but we didn't deal with issues very much, mostly because he was off in his own world, doing things with the World Institute. The World Institute, by the way, came up when he no longer was involved with Disabled Peoples' International. He was off the committee, and he was looking for something else to do. One of his many admirers came along and said, "We'll give you funding if you start a think tank," and Ed did that.

Cowan: That's World Institute of Disability?

Donald: Yes.

Cowan: WID.

Donald: And that started, I think, on somebody's interest in seeing Ed take his leadership skills into an area where he thrives. And Ed wasn't the deep thinker--he was a deep philosopher type, where everybody was fine and everybody had a right to fit in, and he was the embodiment of all that. But he attracted a lot of good people.

One of the interesting things about Ed before he died is that he was one of my expert witnesses, and that idiot died three days before his deposition, and he was critical to my case, too. I won't forgive him for that. He had a stroke before he died, about six or eight months or a year before. I don't know if you're aware of that. Some sort of stroke. Clinically, I don't know what it is. But I saw him at a couple of funerals, one of which was the director that followed Ed at Rehab, Bill Tainter. Ran into each other at the park. I said, "Gee, Ed, I only see you at funerals these days. I hope we're both at the next one." We're both alive. Then he had the stroke. He was living in Berkeley. He sold the house down the street. And he just stopped by to talk a few months after his stroke, just to talk. I thought it was strange at the time, but we just talked about different things--about the fact that we only see each other at funerals, and he said, "See you later." And then he died a few months later.

Cowan: Too soon, really.

Donald: Oh, sure. At least three days too soon [chuckling].

Cowan: [chuckling] I hadn't thought of it that way.

Donald: So that's all I can think of right now.

Cowan: Okay. Well, I think we're done then. Do you feel done?

Donald: Yep.



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Disability Rights and Independent Living Movement Oral History Series

UNIVERSITY OF CALIFORNIA'S COWELL HOSPITAL RESIDENCE PROGRAM FOR  
PHYSICALLY DISABLED STUDENTS, 1962-1975: CATALYST FOR BERKELEY'S  
INDEPENDENT LIVING MOVEMENT

Cathrine Caulfield

FIRST WOMAN STUDENT IN THE COWELL PROGRAM, 1968

An Interview Conducted by  
Susan O'Hara  
in 1996





## INTERVIEW HISTORY--Cathrine Caulfield

Cathrine Caulfield was the first female student in the Cowell Residence Program (1968), participated actively, and was well-acquainted with other residents. In subsequent years in the community, she was involved in the early days of the Physically Disabled Students' Program [PDSP] and the Center for Independent Living [CIL].

The interview conveys Cathy's enthusiasm for her experiences in Berkeley--the daily conversations with other students at Cowell, the growing sense of community and empowerment, the embryonic thoughts that led to the founding of PDSP as well as the Disabled Community Health Clinic.

Cathy mentions other students who were in the Cowell program when she was there, and pays particular attention to John Hessler and Ed Roberts. She also describes the excitement of moving to her first apartment after Cowell.

The interview took place on August 1, 1996, in Sonoma, California, at Cathy's home, an open one-level house shared with her partner Andy and her seventeen-year old daughter Julia. Julia was present for part of the interview, in between trips to pack the van outside for a camping trip which was to begin immediately after the interview. The taping was interrupted occasionally with questions for her mother about packing details. Cathy and the interviewer have been acquainted since 1971.

Cathy reviewed the interview transcript and edited it extensively, adding more information after discussing the material with Herb Willsmore and her brother, John Caulfield, M.D., who worked as an attendant for students at Cowell in 1969. The final version of the transcript is now more precise, but with perhaps a little less of the spontaneity and flavor of the initial interview.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. Copies of all interviews are available for research use in The Bancroft Library and in the UCLA Department of Special Collections. The office is under the direction of Willa K. Baum, Division Head, and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley.

Susan O'Hara, Interviewer-Editor

March 15, 2000  
Regional Oral History Office  
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University of California, Berkeley



Regional Oral History Office  
Room 486 The Bancroft Library

University of California  
Berkeley, California 94720

BIOGRAPHICAL INFORMATION

(Please write clearly. Use black ink.)

Your full name Catherine Louise Caulfield  
 Date of birth September 5, 1945 Birthplace Frankfurt, Germany  
 Father's full name John Theodore Caulfield  
 Occupation SA Major Army Birthplace Byron, Michigan  
 Mother's full name Gladys Mildred White Paulson  
 Occupation Marshall Birthplace Enid, Oklahoma  
 Your spouse NA  
 Occupation \_\_\_\_\_ Birthplace \_\_\_\_\_  
 Your children Julia Morgan Caulfield  
Sacramento, CA - born 17, 1977  
 Where did you grow up? Berkeley, Ohio Alaska California  
 Present community Sacramento, CA  
 Education San Jose College  
 Occupation(s) peer reviewer, Director of  
Disabled Community Health Clinic, Home visit  
 Areas of expertise \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 Other interests or activities Cooking, Campfire Gardening  
Reading  
 \_\_\_\_\_  
 \_\_\_\_\_  
 Organizations in which you are active \_\_\_\_\_

SIGNATURE

Catherine Caulfield

DATE:

3-20-00



## INTERVIEW WITH CATHRINE CAULFIELD

Early Years: Military Family, Spinal Cord Injury, Rehabilitation

[Date of Interview: August 1, 1996] ##<sup>1</sup>

O'Hara: Why don't we start with where and when you were born and a little bit about your family?

Caulfield: I was born on September 5, 1948, in Frankfurt, Germany. My father was in the military and he was transferred there after World War II. We lived in the small town of Ober-Ramstadt and traveled through much of Europe. In 1952 we moved to Lima, Ohio. We lived on a 500-acre retired tank depot. It was a great place to grow up. Only three families lived at the depot. We had the run of the place. We played on the tanks, rail cars, and fished in the quarry. What more could a girl want? We had our own greenhouse and motor pool. Our home was next to the park with a tennis court. I learned to drive at twelve on a tank tract.

O'Hara: Did you go to school on base?

Caulfield: No, we went to public school, the base had been closed after the war. We left Ohio in '62. We were reassigned to Wildwood Station in Kenai, Alaska, and lived there for two years.

O'Hara: Do you have any brothers or sisters?

Caulfield: Yes, I have a brother, John. He is a doctor in northern California. He graduated from UC Berkeley and worked as an orderly at Cowell Hospital. He was also an attendant in Berkeley before attending UC Medical School.

My sister Marsha graduated from UC Berkeley and is a fifth grade school teacher. She lives in Tucson, Arizona.

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<sup>1</sup>## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

My mother is from railroad and medical people in Oklahoma, and my father from dairy farmers and teachers in Minnesota.

O'Hara: When did you move to California?

Caulfield: I moved to California in 1964, the same year as my accident. I had been in California two weeks. I was playing in the water near the beach when a large wave hit me, knocked me off my feet, and my head hit the sand.

O'Hara: A wave did it?

Caulfield: Yes, a wave did it. The force of the wave crashed me on the beach.

O'Hara: What was the result of the accident?

Caulfield: I had an injury to my fifth and sixth cervical vertebrae. This paralyzed me from the chest down. I function as a C7 quadriplegic.

O'Hara: So were some of your memories of your childhood pretty physical?

Caulfield: Yes, I was a very active kid. I liked to climb trees. We played tennis and swam a lot. It was a shock becoming disabled after such an active life.

O'Hara: What happened after the accident?

Caulfield: I was taken to a local hospital in Newport Beach and two weeks later transferred to Letterman General Hospital by military med-i-vac air transport.

O'Hara: Were you taken on a stretcher?

Caulfield: Yes, they had me all strapped onto this stretcher, and my mom and I flew to Travis Air Force Base, then in an ambulance to Letterman at the Presidio in San Francisco.

O'Hara: How long were you in the hospital, then?

Caulfield: I was at Letterman for about four months. Then I was transferred to a rehab center in Vallejo.

O'Hara: At Kaiser?



Caulfield: Yes. I did almost two years of rehab, which is unheard of now. But I kept progressing so I was able to stay. But as a teenager in a wheelchair, I kind of liked it there. There were other kids my age who were in the same situation that I was in.

O'Hara: What was there to do in a hospital? Future historians will wonder about that.

Caulfield: Well, first of all, they worked my tail off for six hours a day, mats, pulleys, and ice baths. This was the time when Maggie Knott started a new physical therapy technique. There were students from all over the world, Africa, South America, and Australia. The students were only a few years older than we were, so it was an interesting time. The occupational therapists were geared to teaching us to be as independent as possible.

O'Hara: Were there any activities?

Caulfield: Oh yes [laughter]. We had bingo night. Then we changed it to beer and bingo night--much more fun!

O'Hara: Now, how did you get beer into the hospital?

Caulfield: Well, it takes one cool urologist and a rumor that beer is good for kidneys and voila--beer and bingo night.

#### The Residence Program at UC Berkeley's Cowell Hospital, 1968

O'Hara: So when did you finish high school?

Caulfield: I did part of my schooling at the rehab center. When I moved home I tried attending Galileo High School, but it was much too difficult. The rickety old elevator and the hills in San Francisco made it very hard. I had a home tutor and graduated from high school in 1966. My parents bought a van and my sister and I attended San Francisco City College. Then I found out about the Cowell program.

O'Hara: How did you find out about it?

Caulfield: My dad showed me an article from the San Francisco Chronicle and said, "What do you think about this?" I said, "Yes, this sounds great! Berkeley? 1968? This sounds like a good idea!" [laughter]

I had an interview with Dr. Bruyn. At first he said he didn't think so. There were no females in the program. The Cowell program was on the third floor of the hospital. If anyone needed anything--turning at night, help to the bathroom --the male orderly would come up from the second floor. They couldn't let the nurses off the second floor. I assured him I did not need anything at night and let's give it a try. Dr. Bruyn called in a week and said yes, we will give it a try. Of course I was thrilled.

O'Hara: Then you applied to the university for admission?

Caulfield: Yes, my grades were good enough from City College. I didn't have all the prerequisites, so I was admitted under special circumstances.

O'Hara: Do you remember your first impressions of the program?

Caulfield: Eleanor Smith and Dr. Bruyn took me on a tour of the third floor, but it was during the day and no one was there. That was the first time I had seen Eleanor since rehab in Vallejo. She was rehab nurse consultant at the Cowell program. I'm sure Eleanor had something to do with my being accepted into the program. She was a major presence at Cowell. I liked her, I thought she was a smart, tough, no-nonsense kind of gal.

O'Hara: When did you move in?

Caulfield: I moved into the Cowell program September of 1968. I guess that made it the first co-ed dorm. Just me and seven guys, sounds like the Snow White story all over again.

O'Hara: Who was there when you arrived?

Caulfield: Well, let's see. John Hessler, Ed Roberts, Jerome Frazee, Donovan Harby, Bill Glenn, and Scott Sorenson. I think Donald Lorence and I came at the same time. Herb Willsmore arrived a few months later.

O'Hara: Do you remember the day you moved in?

Caulfield: That was a long time ago. I know I was very nervous. Moving in with a bunch of guys is a little nerve-wracking. Everyone ate dinner in a old nurses' station which happened to be right next to my room. They coaxed me out of my room after a few hours. We all became great friends very quickly.

O'Hara: How did you find your first attendants?

Caulfield: Ed introduced me to a friend of his, Linda Perotti. She was interested in working for me. She started working the next day. Linda's friend Barbara Karten was also interested. I was set up in no time.

O'Hara: Did you have attendants at Kaiser or at home?

Caulfield: No, this was all new to me. But I quickly picked up on the attendant and disabled person relationship. I learned to hire people who could adapt to my needs. It's important to find people you are comfortable with.

O'Hara: So what was it like living at Cowell?

Caulfield: Well, it was very exciting and very busy. We were all going to school. In the evenings we would get together and discuss everything! Living at Cowell we had to attend to our immediate needs, like privacy, curfews, attendants, and how to deal with the nurses from the second floor. I remember when I first moved there, if you came home after nine o'clock, you would have to climb the hill to the back of the hospital and be scrutinized by the staff (Nurse Benedetti) as to your whereabouts. Well, this didn't wash for long with us radical from Berkeley. This was the beginning of many more things to come. Living at Cowell gave us a great opportunity to be with people of like minds and bodies. Eleanor Smith, and then later Edna Brean took care of all those pesky medical needs, leaving more time for us to make the world a better place for our fellow disabled brothers and sisters.

O'Hara: So what came next?

Caulfield: We did start organizing. The Rolling Quads were born, Herb Willsmore was the president. We spent many days and nights in Ed's room brainstorming. The idea for our own disabled students' program grew and led to development of the Center for Independent Living.

O'Hara: Well, was there any time for fun?

Caulfield: Well yes, I remember a few nights breaking open a bottle of Chivas Royal Salute in Donald Lorence's room for his famous reality therapy sessions. This was a mix of how we could live together in harmony in this small wing of the hospital to who had partied late the night before and left incriminating evidence lying around. Life was tough...

Of course, this was the late sixties, early seventies in Berkeley, and we were right in the thick of it, so sure, we

might have indulged in a little bit of sex, drugs, and rock and roll. We partied hard but kept the ball rolling as far as the disabled movement was concerned.

O'Hara: What about when people started to move out? Was there an excitement about a new adventure?

Caulfield: Yes, and a little nervousness too. We knew two people who were disabled, Jim Donald and Larry Langdon, who lived outside the dorm in their own apartment. They were both pretty low quadriplegics (quads) and were doing great on their own.

O'Hara: They had lived at Cowell?

Caulfield: No, neither one of them lived at Cowell as far as I know. They went right to an apartment. Don't ask me how they came to Berkeley, I don't know. But anyway, we would go over and visit them, and they were great. Then it started--"Let's start looking around and see about accessibility." Well, accessible housing was the pits. That's how programs like PDSP started. If numbers of disabled people are living independently, where are they going to find accessible housing? Attendants to work for them? People to build ramps? All the "stuff" necessary to live each day. Would the landlord rent to you? Would they let you build a ramp? Could you find the right attendants? Could you get into the bathroom?

O'Hara: Obviously you did move out.

Caulfield: Yes, Linda Perotti and I found a place on Parker Street. Ed's brother was moving out. It was a downstairs flat with only three steps and the bathroom door was wide enough for a wheelchair, yes! The kitchen was awful but hell, who needs to eat?

O'Hara: Was that scary to move out from Cowell?

Caulfield: No, not really. I was ready. I had attendants set up, I knew the area by then, I knew where I was. I was close enough to school, I was used to being on my own. Since my accident I had lived in a hospital, a rehab center, with my parents for about a year, and then I moved into Cowell. I didn't have a car at that point, but you didn't need one in Berkeley, everything was so convenient. It was hard moving away from my friends, we were very close. Berkeley was such a small community then, we still saw each other almost every day. We were working on starting up PDSP.

O'Hara: What were your impressions of John [Hessler] and Ed [Roberts]?

Caulfield: Well, let's see. When I first met them we were basically roommates. We became close very quickly. I think they were happy to have a female on board. They were both smart, dynamic people. John was the tough and the kind of grumpy one. He had a great sense of humor. Ed was the softer, kinder strategist. John got things done by hollering at you and Ed would charm the chicken off the bone. They were a lot of fun to live with and a major influence in my life for years. John (the old man) was perfect for the director of PDSP, and Ed was incredible as the public personality needed for CIL.

After CIL: Physically Disabled Students' Program, Berkeley  
Community Health Clinic

O'Hara: What were some of the ideas and projects you worked on?

Caulfield: Well, we all agreed there were certain basic services that people needed as students and functioning members of the community. We needed a place to live, attendants to hire, a wheelchair that didn't break down all the time, and a place to get it fixed quickly if it did. We needed a central spot people could come to find services, PDSP for the students and CIL for the community. New students would come from all over to check out the Berkeley campus and we would show prospective students (Walter Wheelon, my first protege) around, exploring different avenues like "Telegraph."

O'Hara: Who hired John as the first director for PDSP?

Caulfield: Well, John was the obvious choice as he had worked hard getting it all organized. I was on the board of directors and I believe Dr. Bruyn was as well. There was also someone representing vocational rehab on the board.

There was so much going on at this time. People were working on the housing survey. They would go door to door, to every apartment building, evaluating accessibility. Others were working on funding for attendant care which was in jeopardy for a while. Chuck Grimes and Andy Lennox put together a wheelchair repair shop in PDSP; Zona Roberts, Ed's mom, was keeping the place [PDSP] together; Carol Fewell, my best buddy, was documenting everything, while trying to keep John calm. We had a lot of fun in that rickety old building, the smell of Top Dog coming through the window, maneuvering the old blue van in and out of the parking lot, and assuring everyone our ramp from hell was quite nice. While all this was



going on we had to stop the war in Vietnam and keep People's Park alive.

It was a crazy, exciting time and the disabled movement was part of that time. I remember passing out water to people marching against the war in Vietnam. Soldiers with guns were on one side of the street and we were on the other. One day Ed and I were coming out of our poly sci class (Ed was the T.A.). As we were leaving the building, tear gas was dropped on the campus. Luckily we lived at Cowell then, and we ducked in as fast as our chairs could go.

O'Hara: At what time did you begin to set up the Berkeley Community Health Clinic?

Caulfield: From the beginning, attendant and health care were of interest to me. I worked as the attendant referral person at the CIL on University Avenue. One day in the fall of 1972 Ed came to me and said, "Let's get the clinic going." I knew Dr. Wong and others were being overwhelmed by the number of disabled people needing services. The perfect place for it would be Herrick Hospital.

I contacted Dr. Wong. He had such a heavy patient load, he was all for it. I had a small room for an office, a part-time secretary, and the use of the physical therapy room once a month. Shelly Berrol was one of our important resources. At the beginning, we had a representative from social services available to help people get medical coverage if they were not already covered. I acted as an advocate for our clients. After each clinic, we held a meeting to determine if the person's needs had been met. Did they need to be referred to CIL, Voc Rehab, Social Security? I was the director for six months, and then I moved to Long Beach to get married.

O'Hara: What other projects did you work on?

Caulfield: For a while, a few of us put on seminars in nursing homes. We would inform patients of their rights. Many had been institutionalized since they were very young. We would tell them about the services and support systems available to them in the community.

I also participated in seminars to increase awareness for medical professionals. We would facilitate disability awareness groups for med students, physical therapists, occupational therapists, nurses, et cetera.



I was a consultant to the San Francisco Human Sexuality Project. We had discussion groups and held seminars on sexuality and disability. Dr. Robert Geiger and Ginny Geiger were facilitators for these seminars.

My last job at CIL, I was a peer counselor on the research and demonstration project. Sid Fry and Janis Kronis were there at that time. I liked that job, part counseling and part independent living skills. Unfortunately the documentation was horrendous.

O'Hara: Now, looking back on Cowell, did it influence your life at all?

Caulfield: Oh, definitely. It helped me realize a full and active life was possible. It renewed my self-esteem. I was living at home with my parents, attending City College, and that was as far as I could see. Moving to Berkeley gave me all sorts of energy. I no longer thought about "being disabled."

O'Hara: Was that because of the people you met, or was it the new mobility you had?

Caulfield: It was everything. Berkeley was the place to be then. We were attending one of the greatest universities in the world. My professors were incredible. It was an exciting time. Sproul Plaza was the Trafalgar Square of the West. We spent many afternoons at the outdoor cafe on Sproul Plaza breathing it all in.

#### Beyond Berkeley: Travels, Friends, Marriage, and Motherhood

O'Hara: You got married and lived in Long Beach; then you came back and worked for CIL. And then where from there?

Caulfield: I lived in Long Beach for a year, which is about how long my marriage lasted. Got out of that one alive too: "Had to get off of the L.A. freeway without getting killed or caught." I moved back to Berkeley and bought a great little International Harvester ice cream truck which was already fully modified so that I could drive it. I met a new, wild and crazy friend, Barbara Grand-Scrutton. Well, we thought it was time to get out of "Dodge." We decided to head north to Alaska.

Well, we made it to Benbow, California. I fell and broke my leg at our campsite. An orderly in the hospital agreed to build me a bed that I could transfer onto. We bought a great

tent and lived on the Van Deusen River for three months. Alaska was looking too far away, so we moved to the town of Bridgeville, which was a few miles from our summer campsite. We rented a cafe from the family who owned this little logging town. There were rooms in the back for bedrooms and the rest of the cafe was our living area. The whole set up was \$100 a month.

The next summer we spent on a ranch outside of Geyserville. Randy Turley, Barbara, Charlie Bulles, and I spent the summer swimming in the pond and soaking up the sun. My room was under the apple tree.

That winter, I moved to Cloverdale, where I met my daughter's father, Gary Westhoff. We moved to Sacramento where my daughter, Julia, was born November 17, 1979. She had a normal birth and came out kicking and screaming. While I was in the delivery room talking to the medical student assisting the doctor, come to find out he used to work as an attendant for Phil Chavez in Berkeley. Small world!

While I was pregnant I worked for Sacramento's Community Resources for Independence. Then I moved to Sonoma, California, in January 1980 and continued to live here since except for a one-year sabbatical in Florida to visit my old saddle pal, Barbara.

O'Hara: Now, this is the longest you have lived anywhere in your life. How does that feel?

Caulfield: Oh, it's fine. Sonoma is a great place to live. We lived in a converted horse stable for Julia's first four years, but then into a "real" house closer to town.

I've done a little bit of everything since I settled down. I love to go camping, and try to go for at least a month each summer. I take care of my daughter and watch kids for friends who work regular nine-to-five jobs. I drove people from a nursing home to their appointments for a while. I do independent living skills referrals when they cross my path. I love to cook and play house. I also love to garden. I had a large raised garden bed built. This year I had a salsa theme going: tomatoes, onions, cilantro, and lots of jalapeños. Mostly I love spending time with my wonderful daughter and watching her grow.

O'Hara: Is there anything I have missed? Is there anything you would like to add?

Caulfield: No, not really. I'm hoping, when Julia finishes high school, to start working again. I would like to contribute to the disabled community, there is still so much to be done.

O'Hara: Thank you, Cathy, for your input.

Caulfield: And thank you, Susan, for doing this project!



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Berkeley, California

Disability Rights and Independent Living Movement Oral History Series

UNIVERSITY OF CALIFORNIA'S COWELL HOSPITAL RESIDENCE PROGRAM FOR  
PHYSICALLY DISABLED STUDENTS, 1962-1975: CATALYST FOR BERKELEY'S  
INDEPENDENT LIVING MOVEMENT

Herbert R. Willsmore

STUDENT RESIDENT AT COWELL, 1969-1970, BUSINESS ENTERPRISES MANAGER  
AT THE CENTER FOR INDEPENDENT LIVING, 1975-1977

An Interview Conducted by  
Susan O'Hara  
in 1996 and 1999





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## INTERVIEW HISTORY--Herb Willsmore

Herb Willsmore was a student in the Cowell Hospital residence program and one of the first students to move from Cowell into the community. He was president of the Rolling Quads in the late sixties, participated in the establishment of the Physically Disabled Students' Program in 1970 and the Center for Independent Living in 1972, and managed the Business Enterprise division of CIL from 1975 to 1977.

In some ways, Herb Willsmore typifies the early students with disabilities at Cowell. He sustained a spinal cord injury in a car accident at age nineteen in 1966 and lived at home with his parents until he learned of the Cowell program at the university. He completed two degrees there, a B.A. and an M.A. in City and Regional Planning. He left Berkeley in 1977 and has been a commercial real estate broker in Santa Rosa, California, for many years.

The five interviews furnish a rich texture to the formative years of the disability movement in Berkeley. Herb describes the daily life of the students at Cowell, the development of a sense of community and political acumen among the students, the excitement of inventing new ways to live more independently and building organizations to sustain that life. He speaks of the new electric wheelchairs, the personalities, the campus in the sixties, lobbying with seven others in wheelchairs in Sacramento, the meetings that resulted in the establishment of CIL as well as his employment there.

Herb drove (his van is equipped to drive from a wheelchair) to the home of the interviewer for four interviews between July and December, 1996. A brief telephone interview was added in 1999. He reviewed the transcripts and made only minor changes. He and the interviewer have been acquainted since 1971.

Herb Willsmore donated a small collection of his personal papers to the DPIM archive in the Bancroft Library. A forty-five-minute video interview of Herb in his home in Santa Rosa was filmed in February, 2000, with Kathryn Cowan as interviewer. It too is available at the Bancroft Library.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. Copies of all interviews are available for research use in The Bancroft Library and in the UCLA Department of Special Collections. The office is under the direction of Willa K. Baum, Division Head, and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley.

Susan O'Hara, Interviewer-Editor

March 7, 2000  
Regional Oral History Office  
The Bancroft Library  
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Regional Oral History Office  
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BIOGRAPHICAL INFORMATION

(Please write clearly. Use black ink.)

Your full name HERBERT RICHARD WILLSMORE

Date of birth 3-6-46 Birthplace DEARBORN, MICHIGAN

Father's full name HERBERT GERARD WILLSMORE

Occupation SALESMAN; MACHINIST Birthplace MICHIGAN

Mother's full name GRACE EVELYN WILLSMORE

Occupation HOMEMAKER Birthplace PRESTON, MICHIGAN

Your spouse UNMARRIED

Occupation — Birthplace —

Your children —

Where did you grow up? DETROIT, MICHIGAN, 2 YRS; EL MONTE, CA, 5 YRS; SALEM, ORE, 2 YRS; SANTA ROSA, CA, 4 YRS

Present community SANTA ROSA, CA

Education BACHELOR DEGREE; 2 YR. GRAD. SCHOOL CITY & REGIONAL PLANNING

Occupation(s) COMMERCIAL REAL ESTATE BROKER

Areas of expertise FINANCIAL ANALYSIS, REAL ESTATE LAW, TAX ASPECTS OF INVESTMENT IN REAL ESTATE

Other interests or activities ~~SPORTS~~ BIBLE & SPIRITUAL GROWTH; CLASSIC CARS

Organizations in which you are active SPINAL CORD INJURY NETWORK INTERNATIONAL





## INTERVIEW WITH HERB WILLSMORE

## I THE EARLY YEARS: MICHIGAN TO CALIFORNIA

[Interview 1: July 27, 1996]##<sup>1</sup>

Family Moves: Arizona, Oregon, and California

Willsmore: I was born in Dearborn, Michigan, on March 6, 1946. My mother's family and my father's family lived there most of their lives. We moved from Michigan probably when I was about a year and a half old. We did a lot of moving early in my life. We moved to Tucson, Arizona, and my parents decided it was too hot there so they moved to Los Angeles. We stayed in Los Angeles probably until I was seven or eight years old. Then we moved up to Oregon and decided it was a little too rainy up there.

The reason we moved out of the Los Angeles area was my dad was an absolute addict on gambling. He used to go to the horse races all the time and blow a lot of his money. Even he realized it was getting too much, so he moved to Oregon to try and get away from that and also to kind of get out of the rat race. We got a little place up on the hill up there and country property. We stayed there about two years, decided it was too wet there; [laughs] we didn't like getting stuck at the bottom of the hill in our car because of the ice on the road--you couldn't get up the hill.

So we moved to Santa Rosa because my uncle had moved there. I basically grew up there most of my life from the time I was about nine or nine and a half years old until my accident.

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<sup>1</sup>This symbol (##) indicates that a tape or a segment of a tape has begun or ended. A guide to the tapes follows the transcript.

A Car Freak, Hot-rodder, Greaser

Willsmore: I did all the normal stuff that kids do. I was a car freak when I was young. Before I got interested in cars, I always used to--we lived in kind of a country place out of town, and so we used to go roaming through the hills and play army and those kinds of things. You know, normal stuff kids do.

O'Hara: What do you mean by "car freak"?

Willsmore: I just loved cars. My dad was a machinist and a very good mechanic, although his profession in life was salesman. He was probably the best salesman I have ever known in my life. [laughs] He could sell anything. People loved him. As soon as they met him they felt like they had known him for five years. He was that kind of a guy; he put people at ease.

Anyway, he had a lot of interest in cars and always did all the repairs on the family vehicles, and so forth. He always had a lot of unique vehicles. He bought a couple of Model A's, and even when we were up in Oregon he bought some old cars and just messed around with them. I guess that's kind of what got me and my brother interested in cars.

O'Hara: So he had quite an influence on you.

Willsmore: Oh, very much so, yes. He let us actually have a car before we were able to drive. Of course, we couldn't drive out on the road or anything but we had a pretty big place, and we used to drive around the property. [laughs] I would take engines and transmissions apart and put them back together--just anything on a car. I just used to love to work on cars. We would be out in the shed until three in the morning working on cars. [laughs]

O'Hara: So it's not surprising you built your own wheelchair.

Willsmore: I guess so, yes. Of course, back in that time that was the hot-rod era. Everybody customized their cars, different wheels, took all the molding off, and doing a lot of things to their cars to make them a little customized to your own taste. I really loved that. Had a '55 Chevy, and that's what I had my accident in. That was kind of my dream car: a little '55 Chevy two-door hardtop. It's a highly desired automobile right now. [laughs] They're just nice-looking little cars.

O'Hara: Did you go to the public schools in Santa Rosa?

Willsmore: Yes. I was kind of a kid that got in trouble a lot. Ever since I was in fifth grade, I think it was, from the time we moved over from one side of town to the other--and it wasn't the change in the area, I don't believe; I don't know what it was. It may have been something that was going on in the family; my mother and father weren't getting along too well. My father was not home much, and he was not very affectionate to us kids, to say the least. Anyway, I really got into a lot of rebellion, and I got in fights in school a lot. I started hanging out with some pretty tough crowds [chuckles] and basically became--as people look back on it--a greaser. A hot-rodder and a greaser. There were the jocks, you know, the people that were involved in all the school clubs and the athletes and all that, and then there were the rich kids, the kind where their fathers bought them cars and all that. And then there was this kind of a lower crowd, and I was more or less in the lower crowd. [laughs]

O'Hara: For the benefit of the younger historians, what exactly is a greaser then?

Willsmore: I'm not exactly sure where the name came from other than it may have been a combination of the fact that we used Vaseline on our hair.

O'Hara: Did you do that?

Willsmore: Oh, yes, absolutely. Vaseline petroleum jelly. That was the thing [laughter]. I mean, it would be held in place all day long; not one hair fell out. You know, pegged Levi's with white socks and black loafers. That kind of thing. That was the style back then. And black jackets. Just try to look a little tough.

O'Hara: Now this was the end of the fifties, is that right?

Willsmore: Yes. I graduated from high school in '64. So probably from ninth grade on is when I really got into the greaser thing.

O'Hara: And did you get in any really big trouble?

Willsmore: Well, let's see. I was taken in twice to the police department. Once was for siphoning gas, and another was assault with a deadly weapon [chuckles]. And that basically was--I guess it could have turned into something ugly--a couple of us, different groups, were always at each other. We were always challenging each other. I was out alone one night, and this guy and his buddies started following me, and basically got me cornered. I got out of the car, and they came after me,

and they had clubs in their hand. I happened to have a knife with me, and I pulled it out. So they turned around and went their way. [laughs] But evidently they told the cops. So the cops found me, pulled me over, and arrested me. Basically they dropped the charges, but they did that a lot with kids. You pull them in, scare the heck out of them, and then let them go.

O'Hara: So from an early age you were not afraid to stand up for your rights.

Willsmore: I guess [chuckles].

O'Hara: And you graduated from high school in Santa Rosa?

Willsmore: Yes, in '64, and by the skin of my teeth. I was probably a C or D student--right in that range. It was because I hardly ever went to school. I probably did the bare minimum of days of attendance that you need to do to actually graduate.

O'Hara: What were you doing?

Willsmore: We would cut school and just go out to the beach or just horse around and go to the river or whatever. Depending on the time of the year, of course. If it was wintertime we would just go over to one of the guys' houses and stay there.

I remember one time when we went over to my buddy Steve's house, and we were just bored and trying to think of something to do. We thought up this prank, and we called up the local newspaper and convinced them that we were representatives of this new car company. We told them that we had developed a three-cylinder car that got sixty miles to the gallon or something. [laughs] We told them that we were going to have it down there at a certain car dealer's showroom, if they would like to come and see it. [laughs] So they did actually go; we went down to see if they showed up, and they did. That was one of our greater escapades.

O'Hara: What happened after high school?

Willsmore: After high school I was just kind of floating along. I decided like most everybody else that I probably ought to go to junior college, and so I did.

Jobs and Life After High School

O'Hara: Did you have any jobs at this point?

Willsmore: Oh, yes. I always had a job. I started working when I was probably fifteen. Well, I started working when I was twelve, by picking prunes and doing various jobs around the ranches and so forth that were near our place. I worked in a convalescent hospital for a while; it was right across the street from us as a matter of fact.

O'Hara: What were you doing there?

Willsmore: Just general orderly work.

O'Hara: As a teenager?

Willsmore: Yes. Helping bathe patients and the whole bit and transferring them on and off the commode--just a little bit of everything, basically. Anything they needed you to do I did.

O'Hara: Did you ever work as a car mechanic?

Willsmore: In a gas station. Not a full-fledged shop per se, but I did simple things like changing starters and alternators and carburetors and that kind of thing. I never did much deep engine work or anything like that. I worked in auto parts, I worked in retail. I did a lot of different jobs [chuckles]. I worked in a bowling alley in the kitchen. I worked as a pin setter.

O'Hara: These are all in your teenage years?

Willsmore: Yes, from the time I was probably fifteen until the accident, which was just before I was twenty. And I worked as a carpenter out at a modular home builder. What else? A plumber's helper. I also worked with my dad; he used to have a water conditioning company, and we did installations on the water softeners and filters and things. At one time he also had a central vacuum business where he installed central vacuums in houses. I helped him do that. A lot of different jobs.

O'Hara: That's an impressive array of jobs. What led you from job to job?

Willsmore: I don't know if it was boredom, or what it was.

O'Hara: Opportunities?

Willsmore: Yes, a lot of it was opportunity. I maybe was doing a job and saw something a little better and took it.

O'Hara: Were you at Santa Rosa Junior College when you had your accident?

Willsmore: No, I think I had quit. I had enrolled in, first of all, just a general program there, just to kind of bone up on my skills a little bit, that I didn't do too well on in high school. And finished a couple of years there, I think--or at least a full year--and started on studying surveying. I actually had thoughts on becoming a civil engineer. I was trying to think of something that I could use, what I felt, was mechanical aptitude and interest, then gear that toward something I would enjoy doing. I was the kind of person that didn't want to be stuck in an office somewhere, or even in a drafting room or anything like that. So I thought of civil engineering, because it gets you outdoors to different sites and things. So that was the direction I was going.

But I was in with some pretty rough guys, and we did a lot of drinking, and I just didn't stick with the classes the way I should have. So as far as education, there was not a bright future there, at the time of my accident. I'm trying to recall the circumstances around my accident.

I had a high school sweetheart, and we went together for about three years. After I got out of high school, I became a little bit obsessive and jealous. She got a little scared and moved, for the summertime, back to her father's place in Utah. Late that summer, I followed her out there. I wanted to find out what was wrong and all that. I guess that whole thing was quite an event in my life, looking back on it. I really had a deep love for her. I think she was the only woman I ever loved.

But, anyway, then we kind of didn't hit it off real well when I went back there. I had wrecked my car on the way out there and ended up having to take the bus to get there.

O'Hara: You left your car somewhere?

Willsmore: Yeah. I was on the freeway at night, and I'm trying to remember how this happened. I don't remember if I was pushing somebody to get them started? Anyway, I was way over in this right-hand lane on the freeway and it was pitch black and the bright lights on the car weren't working, so I'm going along



about thirty, forty miles per hour, and all of a sudden I hit this thing that was in the road. It was this great big container that they used to put hot pavement in. They were repaving that portion of the freeway. They left it out in the far lane and I hit it. I bent the right wheel way back and tore the radiator hose. But it was still driveable and so I drove it to the next gas station, got a radiator hose and put it on. But the front end was so bad out of alignment. I had new tires on it when I left, and by the time I got from Vallejo to Sacramento, the right-hand tire was completely bald. So I knew it wasn't going to make it to Salt Lake City. And I knew it would probably be several hundred dollars to fix it, and at that time it was a lot of money. So I left it there, in Sacramento, and took a bus.

O'Hara: All the way to Utah?

Willsmore: Yes.

O'Hara: But this is not the accident where you were injured?

Willsmore: No. I had several before my biggie. And never really got hurt in any of them. I totalled that car--it wasn't really a total, I think you'd say--because it was not beyond repair. But I totalled two other cars that were beyond repair. I would get drunk and go out and just stomp on it and do really stupid things.

Anyway, I got back to Santa Rosa, after she and I had a falling out, and decided, Well, okay, I'll get back into the dating game and all that kind of thing. Just started living life again and trying to get my mind off of things. I had a pretty good full time job at a place that was a machine shop. They had just gotten a big contract to drill holes under this building that was used for refrigeration. The floor was buckling. We were doing a job where we were putting pipes under the floor, and they would run those pipes under there and then run warm oil through them to keep the ground from getting too cold and buckling.

#### Car Accident and Spinal Cord Injury, February 22, 1966

Willsmore: So I did that job for probably six months, and that was just about the time that I had my accident. Right about that time. And I had just--let's see--I'm trying to remember the circumstances around it. I had been drinking earlier in the

day. I went over to--this was just when the Vietnam War was getting cranked up. All of us guys of the draft age were quite concerned that we would be drafted. We had heard, me and my buddies had heard, that one of the ways to get out of it was to get a job at one of the shipyards. Then you're kind of a crucial employee of the federal government, and they won't pull you out of that. So that's what we did. That day that I had my accident, I went over to Mare Island to put in an application.

I got back to town, went over to my friend's house, probably drank about three or four beers. Then I went home, got cleaned up. We were going to have a party, that evening. Let's see. I went to the liquor store and bought a couple of cases of stout malt liquor, Colt 45, and put it in the back seat and went over to pick up this girl that I was taking to the party. I had never met her before. There was somebody who kind of put us in contact with one another. I went over and picked her up, and we were on the way to the party.

This was my '55 Chevy with a souped up V-8 and four-speed and the whole bit. I had these big meat tires and mag wheels--that I had on my car. This friend of mine asked me if he could borrow them, a couple of days before that. My tires and wheels--just for show, more or less--we used to love to do that. Maybe borrow each other's tach or wheels, something nice. In exchange, he gave me his tires and wheels off his car, which were kind of bald.

So that was one element, in the accident, overall. So we were on the way to the party and this girl noticed the four-speed and the tach on the dash and all this.

O'Hara: What is "the tach"?

Willsmore: It's the tachometer; it shows the engine speed, the RPM. It was kind of a showy thing that you would put up on your dashboard to show that you were into hot-rodding and that kind of thing. She said, "Hey, this seems like a pretty hot car--why don't you show me?" And just that evening, it was starting to mist a little bit, like the first rain of the season. That, combined with the tires--I put it into third gear--and I got going pretty well, and when I shifted into fourth gear, probably at about seventy miles per hour, the back tires lost traction, and the car spun around and hit a guard rail at an exit. You know how they have those big barrels of sand now? Well, they didn't have them then. And I hit that one and I went, basically, through the back window and on the way out, I hit my head on the window frame and broke my neck.

Luckily, she had her seat belt on, and she basically stayed in the seat. The front seat broke on my side, and I didn't have my seat belt on, and I went out the back. So she came out of it okay. She had a little bit of whiplash, but that was about it. Miraculously. I am so thankful for that.

Anyway, I ended up in Memorial Hospital. Finally, after about two weeks of a semi-coma, I came out of it and realized I was paralyzed. And what a bummer. [laughs] And you know, I thought, gee, life is over. That's all she wrote. Because I couldn't move anything. I couldn't move my hands, shoulders, nothing. Eventually, after about two months, I did get some feeling back in my shoulders and a little bit of movement in my arms and shoulders. So I was beginning to have a little bit of hope. There was a nurse or two there that kind of provided a little encouragement. They had seen a lot of adaptive devices and hand controls for cars. That was one of the things that I saw I was going to miss the most, was driving. I used to love to drive, and still do.

#### Rehab at Kaiser Vallejo and Living at Home

Willsmore: So I got out of the hospital there and got shipped down to Kaiser Rehab in Vallejo. There was a nurse down there that I met, and she was the one who was responsible for getting me into the program at UC, the Cowell Residence Program.

O'Hara: Who was the nurse?

Willsmore: Smitty. Eleanor Smith. She was kind of a consultant on bowel and bladder at Kaiser Rehab. She was an expert in the field, and she really is, too. [laughs] She just had an empathy and an understanding that those two things are two of the absolute tough problems in regard to spinal cord injury. And so she was just a registered nurse, basically, but over the years she kind of gravitated toward helping people with spinal cord injuries and severe disabilities, and learned an awful lot about bladder infections and catheters and those kind of things. And taught us a lot about it.

And even some of the stuff that was known at that time wasn't really quite as valid, now that we look back on it. They swore by irrigation, every day.

O'Hara: Who is "they"? The Vallejo Rehab people?

Willsmore: Her and the people--yes, the Vallejo Rehab people.

O'Hara: When you say "us", you mean other quads?

Willsmore: Yes, myself and other patients there in the hospital. But they basically taught you a little bit about what it means to have this catheter and you have to keep after it all the time. That kind of thing. At least the medical aspects of it. Not a lot of the practical aspects, like how do you empty your leg bag? [laughs] That's the kind of stuff we learned after we got to Cal. But anyway, I went through the Rehab program there and basically went back home.

I didn't know what I was going to do. I was thinking, well, maybe I should be going back to junior college. But, how do I get back and forth from school? And that kind of thing.

O'Hara: Did you need assistance, then, for daily living?

Willsmore: Basically, my family did it, at that time. My brother and my mother. My dad never really helped much in that area. He couldn't really accept what had happened to me. I was his namesake, basically, and he never really did accept it. I think, for a long time he thought that I just didn't have enough will power and persistence, and that if I did, I could actually walk again. You know, that kind of thing. He didn't really understand that it's a physical thing, it's not a matter of will power and all that, until he got cancer, something he couldn't do anything about--it was beyond his power. So he and I became a lot closer when that happened. That was in '73.

But, anyway, here I was stuck at home and about all I did was watch TV and read the newspaper. I kind of got interested in stocks. I had a little bit of money and invested that. I didn't do real well in it, and didn't really know what I was going to do. Thought I might like to be a stock broker, but I didn't see how I would get the training for that.

## II THE RESIDENCE PROGRAM AT UC BERKELEY'S COWELL HOSPITAL

### Applying to Berkeley, Spring 1968

Willsmore: I think Eleanor sent me a newspaper clipping on the program. It had a little note in with it that said, "You ought to check this out. It looks like a pretty good opportunity." So I did, I wrote to the university and they wrote back and said what all I had to do. I had copies of some letters that they sent me regarding how to apply for the program and so forth.

O'Hara: You said you had a "C" and "D" average. How did you get into Cowell?

Willsmore: Very much special acceptance criteria. I did have to take--

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O'Hara: I was asking you about your academic record and how you got into Cowell. How did you do that?

Willsmore: You tell me. [laughs] I was just reading this little letter they sent me when I inquired about the program.

O'Hara: Who is "they"?

Willsmore: This is the Disabled Students' Live-in Program, a letter from Dr. Henry Bruyn in March '68. It says, "Please complete the enclosed form as fully as possible and return to the above address. In addition, request physicians responsible for your care to submit medical reports as detailed and the questionnaire. An interview with the Director of the Student Health Service will be arranged. Academic acceptance for admission to the University of California at Berkeley is, of course, a prerequisite to joining the Cowell Hospital Program for Disabled Students. Admission is accomplished through the



Admissions Office." And how I ever got accepted, I will never know. [laughs]

O'Hara: You truly don't know? Did you have letters from people basically saying you had intelligence but hadn't applied yourself?

Willsmore: I think so, yes. I had taken various tests, aptitude and interest tests and things, and I even took a psychological profile when I was in rehab.

O'Hara: And you had a high aptitude?

Willsmore: I guess. I don't know. [laughs]

O'Hara: Had you seen Cowell before you inquired, or did you go on Eleanor Smith's word?

Willsmore: I went on her word that it was something that was worth checking out. She pretty much knew what was a good opportunity for somebody with severe disabilities. She had known many, many people with severe disabilities and seen them do a lot of different things. She knew me pretty well; we became pretty friendly at the Rehab Center. She was friendly with everybody, though. She is naturally that way.

It gave me some hope, you know. I knew that I couldn't make my living with my body any longer. So I thought, Well, this is an opportunity to use my brain. I had never aspired to the university prior to my accident. Never even in my wildest imagination, ever thought I would go to a university. Although I was thinking about the civil engineering. I was so nonacademically oriented at that time, that I didn't even know how you got into college, or what you do. I knew there were some special classes that you should take in high school to kind of prepare you for a college career.

Anyway, I did apply, I took the tests, I met a couple of the people--

O'Hara: At Cowell?

Willsmore: The counselor that was responsible for it, and, I think--you know, I don't even remember who it was now, that I first met with, as far as the Department of Rehabilitation. I had a rehab counselor in Santa Rosa because I was beginning to explore the idea of going to a junior college. One of the things the Disabled Students' Live-in Program advised me to do was make sure that I got my counselor in Santa Rosa tied in



with their counselor, there at the Cowell Residence Program. So if I was going to be able to go there, they would transfer all the records and that kind of thing.

O'Hara: How did you do in your classes at Cal? That's a pretty phenomenal leap, into the admissions.

Willsmore: Yeah, it is. I guess about a 3.7 grade [point] average. [laughs]

O'Hara: That is also phenomenal.

Willsmore: Some of that, I must say, was the times there at Berkeley, because a lot of the professors were very anti-establishment. They would just give you an "A" to spite the administration, or something. There was all the "power to the people" and free speech and all that going on, at that time. I guess that has a little bit to do with why our group became so political. It was just the nature of our society at that time. Especially the college environment.

O'Hara: So you came into the Cowell Residence Program in '69? In September?

Willsmore: In '69. You know, I don't remember--I think it was in the spring. We were on the quarter system. Is it still on the quarter system?

O'Hara: No.

Willsmore: So we went to school basically all year long, the people in the Cowell program. We took a little lighter load in the summertime, but basically we went to school all year long. That was basically because it was such a high expense. D.R. [Department of Rehabilitation] encouraged us to do that, so that we could get out of the program a little quicker. Otherwise, it would take too long. And much expense. [laughs]

O'Hara: D.R. was paying your tuition?

Willsmore: D.R. was paying the tuition and for some assistance like with taking notes, and they would buy tape recorders, and secretarial help to type out papers, and that kind of thing. Just various devices that we would need.

O'Hara: Did you use a typewriter?

Willsmore: Yes, they bought me a typewriter. When I was going through my stuff, I noticed a letter that was about conveyance of property from Department of Rehab. Yes, it was an electric typewriter.

O'Hara: Did you type with your fingers?

Willsmore: No, I used sticks that clipped on my hand. Those I kind of found out about at rehab. They put you into occupational therapy for an hour a day, and just let you try to do whatever you can do [laughs]. They show you whatever adaptive things they can show you, that they know about. That was, I think, one of the articles that I got in rehab, in occupational therapy, was some typing sticks. They made those for me when I was there.

#### Medical Professionals and Rehab Experiences at Kaiser Vallejo

O'Hara: In general, what did you think of the treatment by the medical professionals? Did it have any influence on you?

Willsmore: When I was going through it, I was kind of in a daze. I had just broken my neck, and here I was, a quadriplegic, sitting in a wheelchair. It was like, this wasn't really "me." You know? It was a very tough program they put us through. Therapy six hours a day, occupational therapy one hour a day. And in the personal therapy sessions, where you would have a one-on-one physical therapist working on your limbs and so forth, they put ice on you, crushed ice. They dipped these towels in crushed ice and put them on your shoulders. That was to stimulate blood circulation, and it sure did the job. But, oh, how miserable [laughs].

And that went on every day, for seven months. It was like being in--you know, you kind of felt like, my Lord, this is like being in a concentration camp or something! All this punishment you're going through, you know. But in a sense, after you get out and get through it, you thank them and you thank yourself for sticking through it. Because people who don't do it end up with contractions in their arms and are not able to do much at all. They warned us about that. There were a lot of elements of the rehab hospital experience that were valid and helpful, but a lot of it, too, was medically oriented. Medically modeled, like "We're the doctors, we know what's right." We really didn't have much say in matters of our own care.

Thinking about it after the fact--once a bunch of us got up there at Cowell Residence Program, we started talking about our rehab experiences, and the fact that they didn't teach us how to transfer in and out of a car, or how we were going to manage once we got home, and how to set up a room or a house to where it's workable for someone with a disability like ours, or how we were to empty our leg bags, or what it's all about, hiring attendants, how you interview, and all those kinds of things.

O'Hara: So occupational therapy didn't cover that? Was it more devices that might help you?

Willsmore: Yes, real basics. It was more clinical. Working on very basic things like just trying to see what kind of movement you still had left, and what you might be able to do.

The Cowell Milieu: Attendants, Students, Mealtimes, Power Wheelchairs

O'Hara: Do you remember your entrance into Cowell?

Willsmore: Pretty much, yes. They had things pretty well taken care of, as far as help for us. They had the CO program, the conscientious objector program. During the Vietnam War there were a lot of guys that didn't want to go to war. So they opted for other service. They were conscientious objectors, they didn't want to be involved in the war. And the government let them do something else, some kind of public service or something. So a lot of the attendants that worked there were COs. It was a great source of attendants, because they were wholly devoted, because as soon as they dropped out of that, they would get drafted. [laughs]

But I happened to get one fellow, Tom Wolf, and he was an exceptional guy. He was an English major there at the school, and also a CO. I guess he partly did it, too, because he needed the extra money. He was more or less putting himself through school. He was a great guy to know. Very intelligent, and he helped me a lot in English and writing and that kind of thing. He was very accepting of even the crummy duties that attendants have to do, you know, cleaning up bowel messes and all that kind of thing. Working with urine and whatever. But most of the guys, I would say all of the guys that worked there, and the girls, were just exceptional people. Really had

a feeling for others and enjoyed helping out. Enjoyed serving in that way.

O'Hara: Were these your personal hourly attendants, or were these orderlies, or both?

Willismore: Tom was my personal attendant, but I think he also worked on the floor for the whole group. They had an on-call attendant, I guess they call them orderlies, there at all times. Twenty-four hours a day. Before we were able to empty our own leg bags or go to the bathroom ourselves, or whatever, there was always somebody that needed something, some kind of personal help. The hospital had them there, just to make sure that there were no emergencies that happened, that would cause a liability, that kind of thing.

O'Hara: What did you think you were getting into?

Willismore: Well, number one, I was getting away from home and gaining some independence. I felt so stuck at home. I was trapped. I had nowhere else to go. It was almost like I was foisting myself on my family. My mother, thank God, was absolutely adamant about my not going to a convalescent hospital. She would just not hear of it. She did a lot, herself, and also my brother and my sister helped out.

But I felt, like a lot of times we do, like a burden on the family. And a young man likes to feel independent, strong. It's the last thing you want to be--a burden. So I saw it as an opportunity to relieve that burden on my family, and also to gain some independence for myself, and possibly to open up some kind of future. I didn't know what. I had no idea what I was going to go into, at that time. I had thoughts in the back of my mind about maybe a stock broker or something, but you don't go to a university to become a stock broker.

O'Hara: So you basically headed toward the university mainly because you were driven to want some independence? You didn't have some kind of driving academic goals?

Willismore: No, not at all.

O'Hara: Do you remember who greeted you the day you arrived? Do you remember that moment? Were you given a room by somebody?

Willismore: I think Lucile [Withington] was the counselor of the program, at that time. It was either her or Karen--I think her name was Newsome at the time [now Karen Goodwyn]. Those are the two

that stick out in my mind, of the rehab people that worked with our program.

O'Hara: Was Edna Breaun around at that time?

Willsmore: It seems like she came later.

O'Hara: Actually, she started in '68.

Willsmore: She did? Okay, then she was there then.

O'Hara: But you don't remember her presence at that time.

Willsmore: I didn't remember if she was there when I came; I'm sure she must have been.

O'Hara: So you had a private room, then.

Willsmore: Yes. We all had a private room to ourselves.

O'Hara: Who else was there? Who were the other students?

Willsmore: Well, let's see. At that time, Ed Roberts, John Hessler--Ed was in a room which we later turned into a pool room, where we had a pool table--Jim Donald, Larry Langdon. I don't remember if Don Lorence was there when I arrived. I think he was. Bill Glenn. Judy Taylor came just shortly after I did.

O'Hara: Was Cathy Caulfield there?

Willsmore: Yeah, Cathy was there. Jerome Frazee, Donovan Harby, and probably one or two more that I don't remember.

O'Hara: A full house.

Willsmore: Yes, quite a few [laughs].

O'Hara: What are the early experiences that you remember, or is it all a blur?

Willsmore: No. One of the greatest things about that was that we all got together for mealtime, in the dining room. That's where we did a lot of our talking and conniving and planning, and realizing that someday we were going to have to leave this sheltered, plush environment, and go out on our own. It was, relatively speaking as to what people came out of, it was paradise. I mean, we had power wheelchairs--I didn't have a power wheelchair at home. That one element in the program, when they started bringing out these better, power wheelchairs, that gave



us so much freedom, it was incredible. That was one of the biggest thrills that I remember, was being able to motivate yourself somewhere without having to have somebody to push you around or struggling for half an hour to get across the room in your manual chair. That kind of thing. So that was one of the most exciting things that I remember when I first got there.

O'Hara: Everybody was going through the same thing?

Willsmore: Pretty much, yes, came in there without any power wheelchairs of any kind.

O'Hara: So you have a bunch of twenty-year-olds, just really feeling their oats--

Willsmore: Yes, getting their mobility and independence, absolutely. We used to go out at night to a place kind of like Shakey's Pizza. That was our excursion, on a common evening, was go down to the pizza place and have a pitcher of beer. Sit around, just like everybody else. And that was very exciting, because up till that time, we were stuck at home and subject to whatever we were able to do at home. Or if we wanted to go out, we had to transfer into the car and go somewhere. A real hassle, and a hassle for everybody that was helping you out, too. But there at Berkeley, you could get around the community in your power wheelchair, and around the campus. It was a little hilly, in places, ran down a lot of batteries [laughs].

#### Adaptations for Classes, Studying, and Independent Living

O'Hara: Now, that was the evening. What did you do during the day?

Willsmore: During the day, it was classes. And we did the usual thing for registration and so forth. I think we even actually went down and stood in line. Although they did have some special accommodations for registration. But there were occasional times when we'd have to stand in line like everybody else. We were just students, the same way most students would be and do. And we usually carried all four or five classes. When I first started out, I think I carried three classes, and that was tough, when you first got going. You're not at all academically inclined. You have to change your whole way of thinking, you have to figure out a way to take notes or get down this information in the lectures, and so forth.

O'Hara: How did you do that?



Willsmore: At first I took a tape recorder and eventually I got to where I could write with one hand. Before I came to the university, I remember writing the letter to the university on this desk that I had set up at home. I had to use two hands to write, at that time. It was because my one wrist was just too weak; it was too jumbly to read. But over time I was able to strengthen that hand and it got to where I could write with one hand. I developed a lap board. I thought, Well, gee, I need something on my lap, to where I can hold a book on there and read or write something. So I just thought of what I needed, and I went down to the ASUC bookstore and bought some hardboard and some balsa wood, and had my attendant build me a lap board. And put some blotter material on top and some rubberized material on the bottom so it wouldn't slide off my lap. And I used that to do all kinds of things, eat, read books, write.

O'Hara: Had you seen anything like that before?

Willsmore: I had seen these lap boards that they had attached to the chairs, but they just seemed so confining. I didn't want that on my chair. Number one, I finally learned how to empty my own leg bag by bending over on my knees, but in order to do that, I couldn't have something in front of me. So I had to have something that I could take off my lap, and that's what I came up with. And refined it over the years to the thing you see here. [shows board]

O'Hara: Pretty slick. Did you have a desk set up? How was your room set up? Did you have any special features, gizmos?

Willsmore: Yeah, I did. I got ideas from John Hessler--learned a lot from John and Cathy. They were both quads that were about at my level and were around a lot and were friendly. We became real good friends. Some of the other quads that were there, Jim Donald, I never really became too friendly with him. He was a bit to himself. I don't know. He never really was a part of our group, especially. He was a friend of John's. He knew Ed pretty well, but he was kind of a loner. He was very much by himself a lot. But he had other friends, able-bodied friends.

But as far as the desk, John had used a door and put some cabinets or something under the door. So I got myself a door and set it up. Actually, at that time, I think the big thing was cinder blocks. We put cinder blocks under the end, built up a little platform on each end to hold the door. Basically, that was my desk. And I had one of the guys make a bookcase. I think Chuck Grimes made me a bookcase.

O'Hara: Didn't almost everyone end up having one of these door desks?

Willsmore: Pretty much. It was very common. You could put it at any height you wanted. It was plenty big. You could swing under it. You didn't have to worry about running into drawers.

O'Hara: It was also a very flat door. Big surface.

Willsmore: It was ideal, worked out great.

O'Hara: Could you get in and out of the door? Did you have any gadgets on the door?

Willsmore: Yeah. The door had kind of a--I don't know what you'd call it--not a loop handle, but just kind of a handle that came down and it was enough to get your hand under it and pull it open. So it was usable by a quad. They did have closers--no, they took the closers off, that's right--they would leave them on if you wanted. But it was easiest for quads not to have a closer on it. A big, huge, wide door--wide enough to get a bed through. So they were very accessible.

The rooms, you could paint them whatever you wanted. They were "our" rooms. And put up whatever decorations you want. We hired an artist to come in and paint the walls in our dining room. And she did this really exotic colors and something really unusual, very hippie style, back in those days. And we had a madras blanket hanging on the wall, also, in every room [laughs].

O'Hara: Hanging on the ceiling, or on the wall?

Willsmore: Well, some had them on the ceiling and some on the walls. Typically hippie-style, Berkeley-looking rooms. That's how we decorated our rooms. We all, eventually, found a way to manage in class and to do real well. So that aspect of it was great. I think the thing that most people were most excited about was the independence. The fact that we were around people that were like us, that understood what we were going through, and we would see others that were maybe a little further along on their coping with their disability.

### III ORGANIZING AROUND DISABILITY ISSUES AT BERKELEY: THE ROLLING QUADS

[Interview 2: August 3, 1996] ##

#### Access to Buildings on Campus

- O'Hara: At some point, this group became political. They have been known in the records as being the "Rolling Quads." Can you describe a little bit what kind of activities got the group organized into feeling some of their own power?
- Willsmore: I think the first part of that had to do with the fact that the university is a big bureaucracy, and not a lot of the university was very accommodating to people with disabilities, especially severe disabilities. There were a few disabled people there originally, but as far as any numbers of people and being able to get around the campus and maybe some special help when they needed it in terms of tutoring and that kind of thing, there wasn't anything really available. There was nothing in terms of services specifically for disabled people.
- O'Hara: What were those special services that people needed?
- Willsmore: Initially it was just accessibility to the buildings. Architectural barriers, really. We were trying to work with the university not only in terms of getting some more of the buildings accessible--the newer buildings, of course, were fine because they had ground-level entrance or a ramp and elevators and that kind of thing. But some of the older buildings where a lot of the beginning classes were held--some of the larger lecture areas--were not very accessible at all. Either they had no ramp or no way to get in there other than carry you up the stairs or something.
- O'Hara: Did that ever happen? Did you ever get carried up?

Willsmore: Yes. We did get some ramps, but I don't even remember what the names of the buildings were. For a number of the buildings we were able to get some additional ramps and accommodation for where a wheelchair could sit so a person could actually hear and be able to take notes. Then for getting off campus there were no curb cuts--

O'Hara: Did you ever get carried up the steps for class or anything?

Willsmore: I never did, no. I avoided taking classes in buildings that were inaccessible [laughs].

O'Hara: Did anyone agree to that? I know Ed said--

Willsmore: Ed got carried up. I know when he was going in his manual chair--and he did go in his manual chair quite a bit, and he was one of the last people to get a power chair because he didn't think he could handle a power chair. Then one of the guys that was real handy said, "There's no reason you couldn't drive a power chair." They knew his ability to use that one hand and so forth. All you need to do is the joystick.

#### Power Wheelchairs: The Exhilaration of Freedom

O'Hara: Were you around when he got his power chair?

Willsmore: Yes. He was crazy [laughs], just like all of us.

O'Hara: What do you mean?

Willsmore: It's incredible independence. All these years from age fourteen to--how old was he? Maybe thirty or thirty-five or something when he got his power chair. Before that somebody had to push him wherever he went; he had no ability to move himself at all. It was a matter of having somebody with you at all times. Once he got his power chair and got confident with it, he was able to go places by himself. He's told the story of how he even fell in love, and he used to go out with Cathy Duggan--the woman who bore his son--and all those kinds of things.

O'Hara: Did most people arrive with pushchairs?

Willsmore: I think they did, yes.

O'Hara: So one by one each person got a power chair.

Willsmore: Yes. It was either through Department of Rehab--I think Department of Rehab had one or two power chairs there on the floor as loaners or something. That's what I used when I first came. And then power chairs were just beginning to develop at that time. The loaner chair they had was the original E&J that did not have the real electronics; all it had was a switch, and you were either on or off [laughs], and it was very jerky. It would shake you all apart [laughter]. It was very easy to run into walls and such.

O'Hara: So this is what everybody started with?

Willsmore: Yes, pretty much.

O'Hara: And then when you got a new one it was the same style.

Willsmore: Yes. And then probably after about a year they came out with something called a Motorette. That was the new concept in power chairs. What it was is a unit that attached to a manual chair, and it was very fast, and it was smooth, and you could go as slow or as fast as you wanted by moving this joystick. It actually worked on electronics and a circuit board and all of that. So we all eventually had one of those. They were a little unstable for the hills because they were very easy to flip over. I think all of us at one time or another flipped our chair over backwards. In fact, Bill Glenn was down in the plaza one day, and some little kids came up and started playing with his joystick and flipped him over backwards and gave him a serious concussion. So we were always very leery when kids got around the power chairs [laughs].

O'Hara: But most times it was without injury?

Willsmore: Yes.

O'Hara: And what did you do when--your chair did flip over?

Willsmore: Just yell for a passerby, and they would come pick you up [laughs]. Mine flipped over once on the way home. Occasionally we would try and sneak a beer or two into the floor up there--alcohol was not allowed on the face on it, but we would always be able to sneak something in. I think really the people, the powers that be, actually looked the other way a little bit and allowed us to do some of that stuff. I was bringing home some beer in my bookbag on the back of the chair, and I forgot the fact that it would add extra weight and make it even easier to flip over. So I'm going up in front of Barrows Hall there where there's that real steep hill and sure enough, I flipped over backward. It was like one o'clock at



night or something [laughs]. There weren't too many people on the campus so I lay there for a while. That was kind of part of the adventures of being in a chair, I guess.

O'Hara: And someone finally came along?

Willsmore: Yes. Picked me up, got me back up, and pushed me up the hill.

O'Hara: You said everybody went crazy when they got these power chairs.

Willsmore: Crazy with exhilaration of freedom, basically. Being able to move yourself around and not having to depend on somebody else to help you out. That was just a great independence. We would go down to Shattuck Avenue to the pizza place or something and have a pizza or whatever.

O'Hara: You could do that independently.

Willsmore: Yes.

O'Hara: Did it change your relationship with walking people? Or with anybody?

Willsmore: I don't know. It may have allowed us to be viewed by others with a little less pity [laughs]. I mean, that was a very common thing and still is with able-bodied people that aren't used to being around somebody in a wheelchair. They just have this "oh, poor thing" attitude. They look at you as almost another species. Especially if somebody's pushing you around, that makes you look even more helpless. I'm sure the power chair did have some effect in that way. I don't know that it affected relationships or anything like that.

O'Hara: What was the reason that nobody had electric wheelchairs until that time, until they got to Cowell?

Willsmore: Probably cost. They were pretty expensive. And maybe also knowledge of the fact they were available. I never even knew there was such a thing [laughs] until I got to Cowell. They didn't have at that time--nowadays they do, in the rehab center--part of the job of the occupational therapist is to tell you what additional equipment is available or might be suitable for your disability. That's one of the things they help you with: to pick out a power wheelchair that fits, although they don't do a very good job [laughs]. At least they let you know they're there.

After the fact, looking back now, one thing we did get involved in in Cowell was talking about our rehab experiences



and looking back and having a feel for these folks that were going through rehab with a new disability and thinking they could probably benefit by seeing somebody that's been out for a while and is coping with their disability and that kind of thing. So we did a little bit of outreach to rehab centers from Cowell, just because we felt that maybe we could educate the doctors and the therapists a little bit, and also just kind of be an example for those that were in the rehab centers.

O'Hara: Do you remember any specific event in outreach or a specific hospital or meeting?

Willsmore: Yes. Kaiser Rehab--we used to go there occasionally.

O'Hara: And you met with doctors or patients?

Willsmore: With the doctors, and I think we would have group meetings--kind of a peer group meeting, where anybody that wanted to sit in could, and those who didn't, didn't bother. We didn't do a lot of that, but we did a little bit and got something started, and then got busy with other political activities and got distracted, so we never really carried that very far. But we saw it as a major need to improve the input of people that are successful in coping with their disabilities.

#### Working for More Accessibility on Campus and in the Community

O'Hara: It sounds like you, as a group, were certainly more enthusiastic about what you were doing, and actually it became a bit of a cause.

Willsmore: Yes, most definitely, it was a cause.

O'Hara: Which gets us back to the political question. You started talking about the first barriers being architectural barriers, and you succeeded--

Willsmore: That was our first group and our first attempt at using some influence by political means. It started with the university, and basically we just met with some of the administration. Ed was very instrumental because he was a political science major, and he kind of had a real good sense of how the system works and where the pressure points are [laughs]--you know, strategies and so forth. He was outstanding in that area.

O'Hara: Did he do the talking in these meetings?

Willsmore: A lot of it, yes. He also made the contacts and set up meetings and that kind of thing.

O'Hara: So this group actually got the university to spend money just because they went in and talked with somebody. That's pretty powerful.

Willsmore: Yes, things that never would have been done otherwise, I'm sure.

O'Hara: Why did the university do it so readily?

Willsmore: Maybe they kind of thought it was somewhat of an exciting program. And it was. It was groundbreaking; there was nothing else around that I knew of or that most people knew of. I know there were spotty things going on in Minnesota--that was probably the next most active spot for people with disabilities that I had ever heard of way back in those days.

O'Hara: At the university there?

Willsmore: Around the university, yes.

O'Hara: University of Minnesota?

Willsmore: It must have been, yes. It seems like it was in Minneapolis there somewhere.

Then we started reaching out because we needed to go out in the community. One of the obvious needs was curb cuts--ramps to get off of the curb at the intersection. So we started working with the city on that. We also used the Rolling Quads initially for political work with the Department of Rehab in trying to have more influence with them in terms of what they would approve for equipment and assistance and people to help you take notes in class and that kind of thing. It was kind of individual and kind of whimsical almost, or arbitrary, on the part of the counselor at that time. So we fought for a little more leeway in that area.

O'Hara: Now how did you do that?

Willsmore: Again, we met with the administration and--

O'Hara: There was always a group of Cowell residents--not just one person, but the group traveled together?

Willsmore: Yes.

O'Hara: Who was in the group?

Willsmore: Well, there was Ed, John, Cathy, myself, Don Lorence, Bill Glenn. That probably was the core group. Oh, and Larry Langdon. And Jim Donald occasionally, but he was not really involved heavily in the political aspect of it. There was a lot of political activity going on on the campus at that time. The Free Speech Movement, that phase had just passed, and now the antiwar movement was really gaining strength. Also, students were kind of in an uproar and trying to get the administration to be more responsive to student needs in general. So that probably had some influence on us because you're around it all the time, you read it in the Daily Californian about all the political activities of the student groups and so forth. That, I'm sure, influenced us in feeling that yeah, we could have some power too, with the powers that ruled over us or had the purse strings.

#### Fighting Cuts to State Aid for Attendant Care

O'Hara: In those days I doubt there had been many groups of six or seven people in wheelchairs requesting meetings with officials at the city or the university or the rehab. Was there any fear on their part?

Willsmore: There probably was. And they were confounded, I'm sure--"Now what do we do?" We also tried to use the media when it was necessary or appropriate and tried to save that as kind of the big guns and not to pull that out right away. But it did have an effect. If we had a really serious problem with--like when the attendant care cuts came down, that was a big war that we all fought statewide, and that was one of the things that we were involved in. Also the switchover from the old ATD [Aid to the Totally Disabled] system to the SSI [Supplementary Security Income] system. Those two things--and the fact that they at one point were seriously thinking about shutting down the Cowell residence program--were things that stirred us up and really made us political.

O'Hara: Were you all living at Cowell when the attendant cuts were threatened or was that after?

Willsmore: I think most of us were at that time.

O'Hara: Still at Cowell?

Willsmore: Yes.

O'Hara: The threat was by the state government, is that right? The county was not going to receive money.

Willsmore: [Governor] Ronald Reagan [chuckles] and his administration.

O'Hara: Did someone in the group call a meeting for that?

Willsmore: Yes, and we did personal interest stories about--we were in contact with other disabled organizations down in southern California, and I guess there was one--Joel Bryan's group in Davis--

O'Hara: The student service program there?

Willsmore: Right, student groups. And they were mainly centered around the universities or colleges. We basically tried to put out a concerted effort in outreach to the media, doing stories about how it would have an effect, and completely turn back progress for people with disabilities.

O'Hara: Was it true that John, in front of a TV camera, threatened to commit suicide if the attendant cuts--

Willsmore: I wasn't there, but I heard that that was true that he did say, "I have no reason to live; I'm not going back to County Hospital in Martinez," because that's where he spent an awful lot of his disabled life. I think he was there for like six or eight years, at Martinez County Hospital; he lived there. He said it was basically a hellhole.

O'Hara: Do you think that that statement was a certain amount of calculated strategy?

Willsmore: I think he meant it; I really do, because he talked to me about Martinez County Hospital [chuckles], and he said, "I will never go back there." Whether or not he would really commit suicide I don't know.

O'Hara: You mentioned John never wanting to go back to Martinez, and you mentioned that you had been stuck at home and had a feeling of no alternatives. Is that part of what drove this group forward, to push for the things that you needed?

Willsmore: It was survival, you know. Basic survival and self-interest. We were kind of working on behalf of all the disabled communities, but it was very personal too. We each had a personal stake in it, because if attendant care was cut in

half, none of us could function. There's no way you could get up every day and be in any way independent.

O'Hara: The attendant care money was not cut, is that right?

Willsmore: No, it wasn't. And it was only because of a lawsuit. We went to Sacramento a number of times, we lobbied the legislators, we had several that were very friendly and helpful to us: [George] Moscone--

O'Hara: Was he a senator at the time?

Willsmore: Yes, he was a state senator. I'm trying to remember--there was another one who did a lot working with the elderly. It was a Mc-something, I think. I don't remember his name, but he was very good. Also George Miller was Moscone's assistant. There was somebody in the Assembly that was very good too.

O'Hara: Was that one of the Burtons?

Willsmore: Yes, that was it. John Burton. He was one of the key people that actually wrote the legislation. There was a bill written in the Assembly, and that got passed pretty easily.<sup>1</sup> Then when it came time for the Senate to pass their version of the bill--and it basically was a bill that reversed and said, "No, Governor, you can't cut this in half."<sup>2</sup>

So afterwards there was a group we were working with, the California Rural Legal Assistance program, and there was a fellow named Ralph Abascal there. He brought a class-action lawsuit on behalf of the people that would be affected by this.

O'Hara: Now what was his interest in this?

Willsmore: I don't know. He was a very politically oriented kind of guy and very tied into the counterculture and the antiestablishment segment of our society.

O'Hara: A fairly powerful leader.

Willsmore: Oh, he was. Very influential. They had a lot of money at that time, too. They were free to bring lawsuits against the

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<sup>1</sup>The Assembly was always a little more liberal than the Senate. --H.W.

<sup>2</sup>We thought we had the support of enough senators to pass the Senate bill. But at the time of the vote a couple of those who said they were with us voted against it. -H.W.



government, which now they can't do. I think there are laws against it now, that they cannot actually bring class-action lawsuits--using federal funds that are supporting their program--to sue the federal government or state government. But back then it was allowed, and there were quite a few liberal judges too. Luckily we got a ruling by a judge that basically threw out the law and said it was unconstitutional.

O'Hara: So that the law that the Senate had voted against--

Willsmore: Yes. The judge said that because the legislation or executive order that Reagan was using to cut the attendant care program would cause irreparable harm to a group of people, it was set aside or overturned--whatever the legal jargon is. Well, they had to come to terms with it. So the governor and the conservatives came together with Burton and Moscone and basically worked something out to where there was money in the budget for attendant care as needed.

O'Hara: At what point were you the students influencing these legislators? Was it before the bills were written? How did the bills come up in the first place?

Willsmore: Yes, it was before the bills were written. First we just went to Sacramento and basically pleaded our case and said--

O'Hara: To people like Burton and Moscone?

Willsmore: Yes, and to all the legislators. We tried to hit every legislator's office and tried to meet them personally. Most of them we couldn't meet personally; we had to talk with their assistant. We left them kind of a position paper that basically stated what the problem was, what the action was that we were concerned about, and basically it was around the state budget. Especially the budget item that affected attendant care. Then wrote a couple of personal interest examples of what would happen if people got cut off from their benefits.

We gained a lot of acceptance and a lot of support from a number of the legislators, but it's a game up there. They all trade favors and all that kind of thing. When it came down to push and shove [laughs], we lost.

O'Hara: What is it that got you the friends up there? What do you think it was about this group? You had clear goals or was it the written material--

Willsmore: That helped, and also the fact that there had never been at the state capitol a group of fifteen people in power wheelchairs



running through the halls fighting for one specific cause. They could see in our eyes and hear from what we were telling them that these were life and death issues for us and people like us.

### A Growing Political Sense ##

- O'Hara: You said these were real exciting times, and I had a couple more questions about--let's take the Sacramento connection. Who, for instance, wrote the paper? You said you presented written papers to these people.
- Willsmore: Well, we all sat around in the dining room--maybe not all of us, just the core group--I think Judy Taylor was there by that time, and she was one that was very active and political and enjoyed doing this. We just talked about what we really wanted to say, and we wanted to be concise. Ed was good guidance in that, in trying to keep it as short as possible and say what we really mean so that somebody could read it in just a few seconds and get a feeling for what was going on. That's all you get with those people; they get so busy, so they don't want some four-page treatise.
- O'Hara: There was a political sense in the group.
- Willsmore: Definitely.
- O'Hara: Where did that come from?
- Willsmore: I don't know. Some of it maybe was common sense, but other of it was political tactics, and Ed was probably very influential, and also John. I think they had done a little work with the administration at the university before we got there and before we started the Rolling Quads. It just was easier to do and had more influence when there were more of us, and we had an actual organization. It started out as the Rolling Quads, but then it developed. We saw that we needed something a little more than just a campus-based organization. We needed something that could, from the perspective of the people that we were dealing with, seem like a pretty statewide or area-wide organization, so we came up with the name Disabled and Blind Action Committee of Northern California. One of Ed's famous sayings was, "You don't have to be a big organization. You just get yourself some letterhead and a telephone, and you got it made." [laughs] Basically, that's what we did. We just looked like we were a big organization and like we took in a large area and

represented a lot of disabled people. They don't know the difference [laughs]. The legislators and the administrators that we worked with don't know that we were just basically a small corps of people--although we did represent the interests of the broader disabled population. I'm sure they would have been right in line with what we were doing.

O'Hara: But you said that basically you had only really university groups connected at that point.

Willsmore: Yes. I think there were a couple of non-students that were also involved in this area, and I'm sure around the other campuses too. There are always a non-student or two that are disabled that also want to be involved in the activities. But yes, most of the effective political groups were centered around either the university or what were called colleges at that time and now are state universities.

O'Hara: While we're on this subject, do you think that the effectiveness of this group--because it sounds like this small group of eight or ten people that you were affiliated with was really very effective in achieving what they wanted--was it just a serendipitous group of articulate, bright leaders that came together? How did this group click?

Willsmore: We were always wondering ourselves, "How did this all happen?" [laughs] "How did all of this get to be so successful?" And we all decided and told one another that it's because it was so badly needed. Its time had come. That really is what it came down to. Society was maybe ready for it at that time, because society was going through a lot of changes and a lot of acceptance of new things and ideas.

O'Hara: Tell me a little bit about the Rolling Quads. What was it? Was it this group of people, and did they have a name all the time or was it just [inaudible]?

Willsmore: No, we didn't start out with the name, but we decided we probably ought to have a name and some letterhead so that we could communicate and be an organization that represented somebody. We didn't have a structure per se; we didn't have annual membership meetings and voting and all that [laughs]. We just winged it, and we had some letterhead, and we all kind of agreed on things. We were all going in the same direction, all working from the same page. We all had freedom to do our own little thing and yet use the banner, more or less.

Challenging Department of Rehabilitation Priorities

O'Hara: There was a fairly well-known incident where the Department of Rehabilitation wanted to eject Donald Lorence from the program. Were you there at that time?

Willsmore: Yes.

O'Hara: And was that a critical moment in the building of the group?

Willsmore: I think it was, but it wasn't quite as momentous as some of the other things that had gone on. There was something that went on with the Department of Rehab, and it's cloudy in my mind as to exactly what it was. I guess that was at that same time when they were thinking about ejecting Don because he hadn't really centered on a career or--. He was a little more "hang loose" with his academic preparation and such. He didn't like to follow structure at all, so I guess he liked to take whatever classes he felt like and that kind of thing, and that he didn't feel like he should have to have specific employment goals in the future and that kind of thing [chuckles]--like this was just a place for him to live, more or less, but the DR saw it in a much different way. Of course, we all knew that was DR's perspective, but we all also didn't want them pushing us out of the program so soon that we just weren't ready or weren't able to earn the kind of money that you need to earn. I guess for the most part we all felt that maybe we needed to go on to master's programs rather than just do a bachelor degree.

O'Hara: And many did get master's degrees, didn't they?

Willsmore: Yes.

O'Hara: And did you?

Willsmore: I went through the master's program at City and Regional Planning. I took my comprehensive exam, I was like three units short or something, and there was one class that I could've taken that I didn't take, and I never really made it up because I decided that it's not the field that I wanted to work in after all--after going all the way through that. I got into that field by default almost, and it had to do with somebody that Ed knew [Fred Collignon] that was in the Planning department and had helped us a lot with our political activities. He also was influential in putting us in touch with some people in Washington to eventually get the grant to start CIL [Center for Independent Living]. And that also is

where the money came from for the Disabled Students' Program-- from the Department of Education. There was a division there, but I don't remember what it was called.

O'Hara: HEW, I think. Health, Education and Welfare.

Willsmore: Right, but it was a special division of the Department of Education.

O'Hara: Oh, I see.

Willsmore: I don't remember what it was called, but it dealt primarily with minority programs--special minority programs on the university campuses.

O'Hara: The Trio program.

Willsmore: Yes. It had everything from Head Start and on up.

O'Hara: Upward Bound.

Willsmore: Yes, all those things. There was a category in there that also made it possible to fund programs for people with disabilities. But nobody knew about it. Somebody that Ed knew knew somebody in Washington, and somehow that little thing in the legislation came out, and we began to use it and get it broadly known that yes, there was money there. In fact, there were a number of other groups around the United States that wrote proposals for programs once that was discovered. So that was another part of the activities that we did.

O'Hara: You were in touch with other parts of the country.

Willsmore: Yes. And I'm not sure how that all came about. Part of it was the switchover from ATD to SSI, because that was a nationwide piece of legislation, although each state had what was called enabling legislation. But there were other disabled groups around that maybe were not quite as far along and sophisticated as our group out here because we were so political and had a lot of help from some of the university faculty and friends. Fred Collignon was actually very influential in helping us out.

O'Hara: From the planning department?

Willsmore: Yes. There was a lot of money in those days for research, so one of the things that we were also involved with was the idea that rehab counselors should have a greater sense of need to work with severely disabled people as opposed to just somebody with a minor back problem or very minor disabilities, which is

what primarily they worked with because they were an easy twenty-six closure [DR code for closing a case]. That's what they were looking for; that's what their numbers were geared toward: getting people through the program and employed. Taking a disabled person from the time they had their initial disability all the way through to employment is a much different scenario, a much different problem. It didn't seem like DR was concentrating very much on severely disabled people, which we felt was where most of the concentration should be, because that's where the greatest need was. But it's also the most expensive, of course, and DR fought it.

But one of the ways that we tried to attack that was getting, somehow, clients involved in evaluating the Department of Rehab. In other words, at that time part of the new trend in planning and public administration was evaluating programs from a consumer perspective and having more consumer input into the programs, and that was what ours was all about. That's what Disabled Students' Program and the Center for Independent Living were all about: consumer input--the people that received the services actually having an effect over the design of the program and the evaluation of the program.

We got involved in a little research project around evaluating Department of Rehab programs from the perspective of disabled people or from the perspective of clients of the Department of Rehab.

O'Hara: Is that the paper--

Willsmore: That's that paper that was written, yes.

O'Hara: The title was "An Evaluation of Rehabilitation Counseling Training Programs From the Perspective of Disabled Clients."

Willsmore: Right. So we were evaluating the training programs at the universities; they had about six different--they were state colleges at that time--that had DR counselor training programs. We traveled around the state and--

O'Hara: You actually did? Did you go down to Arizona? I noticed that was mentioned.

Willsmore: No, not to Arizona. I didn't go to Arizona. I went down to Long Beach and Northridge, where the earthquake was in 1994. Also, I think they had a program at UCLA and a couple other places. It's basically going into the programs, looking at what they were training on, asking a lot of questions of the faculty, and trying to figure out how their program might be



changed to make it more consumer-oriented and give the counselors a little bit of perspective of what it was like to go through the program from the perspective of the severely disabled person.

O'Hara: There were three findings that I read in that paper. One was "too much emphasis on psychiatric counseling." Now what was behind that? What did that mean?

Willsmore: I don't exactly know. I'd have to go back and review that. I think it had to do with--one of the primary things they do with you is they give you a psychological evaluation when they're testing you to become a client of DR. I guess they were trying to figure out what makes a disabled person tick, more or less. There were trends back in those days where they would view disabled people as an abnormal group, an aberrant group and/or behavior, I don't know how to explain it exactly. It's a psychological term, but it doesn't come to me at the moment.

O'Hara: Maybe it will later when you reread or something. It seems like that was a very strong feeling among the early community, that they wanted services in order to get on with their lives, they didn't want any kind of analysis.

Willsmore: Exactly. And the fact that we felt that people themselves would--once we got into some kind of a routine and training and maybe just beginning of schooling or whatever it is to prepare for some kind of career in the future--then you could begin to develop your idea of what career you wanted to go into and what was needed to do that. But there was an initial step that had to be taken first, and that was just getting out of your homebound or institutional-bound situation and into something where you were beginning to use your mind again, beginning to be active, beginning to be independent, and begin to think for yourself and gain confidence and all those kind of things that come first.

O'Hara: There was a sense then that Donald Lorence was right in his attitude of he didn't want to choose a specific career very early.

Willsmore: Right, yes.

O'Hara: Another finding was that there was too little emphasis on job placement skills.

Willsmore: Yes. You know, that was written so long ago, and that work was done so long ago, that I don't remember a lot of specifics about it.



- O'Hara: In their introduction, Fred Collignon and Mike Tietz, professors at City and Regional Planning, described you--the students--as "outspoken, confident, informed, increasingly militant."
- Willsmore: [laughs] Yes, I guess that would describe us at that time.
- O'Hara: Now, was there any incident that triggered this study of--why did you go into that? Were you having difficulty with the Department of Rehabilitation?
- Willsmore: Most severely disabled people were having trouble getting help in a long-term college kind of a program, that kind of thing. You know, DR was very geared toward wanting to move you through some kind of a six-month or one-year technical kind of training. Somehow that just didn't fit for most people with severe disabilities.
- O'Hara: So you had all individually gone, and you had individual counselors, and you were finding that they weren't disposed to pay for the tuition--
- Willsmore: Yes, and transportation and that kind of thing--the real basic stuff that you would have to have in order to really be successful in getting your training. But seeing that the Department of Rehab needed some changing, and that was one opportunity to approach having an input in that change. Maybe that was just some grant money that was available, and so we went after it and in the process feeling that maybe we can have some effect by doing this, even though it's not like you're getting inside of the administration and turning everything around. But at least maybe it would help the counselors themselves and the students that go through the programs understand what we felt was really needed in that area.
- O'Hara: It sounds like it was a very hopeful time and that the group was hopeful, that they had a certain faith that the system would change if they pointed out where it needed to change.
- Willsmore: Right, and just keep banging away at it.
- O'Hara: And it also sounds like there were successes--
- Willsmore: Yes, definitely.
- O'Hara: That must mean that there were people in administrations who were disposed to make some changes also.
- Willsmore: Yes.

- O'Hara: How much conflict was there? I mean real steely-eyed, desk-pounding kind of conflict.
- Willsmore: Well, that was more in the beginning, and that probably had to do with--they didn't know who we were, they didn't know how serious we were--the people in the Department of Rehab administration. And I don't think at first they really saw what the problem was and that yes, maybe this was an area that needed to change. But as time went on, and they were able to meet us and talk with us as people--and Ed was a very eloquent speaker and was able to convey the sense of what the goal was, what the mission was, and kind of got them to grasp hold of it to some degree. At first there was a lot of confrontation--
- O'Hara: Between?
- Willsmore: Between the group and the Department of Rehab, between the group and the Reagan administration. But we never really had much effect on the Reagan administration. They were going to do what they were going to do, and we were just a bunch of hippie students as far as they were concerned [laughs].
- O'Hara: What conflict were you referring to with Rehab, or do you recall?
- Willsmore: I guess part of it was trying to hurry us along in establishing career goals very early in the program.
- O'Hara: There were specific people who--
- Willsmore: That was an issue at the very beginning, and wanting everybody to have a clear-cut plan and career goal and have that all set out within the first year or something.
- O'Hara: It seems, if I recall, that some years later students just named a career goal and sort of let it go at that, and that seemed to satisfy the department. Is that a resolution that your group came up with, just name something?
- Willsmore: I think so. Well, I think individually we came up with that [laughs]. And a lot of us were reasonably serious about it, realizing that that could change at any moment, too, depending on what the reality was.
- O'Hara: But maybe in the beginning you took it seriously that this had to be it. Is that what caused the conflict? Or is that just in the mists of time right now?
- Willsmore: Yes, it is in the mists of time.

O'Hara: That's okay. I certainly don't want to put words in your mouth. Is there anything else about the--I mean, this politicization of the group is probably the most important thing that happened other than the changes in your own personal lives. I'd just like to know if there's anything else in regard to--were there enemies? Were there incidents?

Willsmore: Well, there was always a common enemy and a battle or a war. In the first instance it was the administration at the university. Next, it was the Department of Rehab when we were kind of defending ourselves within the residence program there.

There was a battle somewhere around Lucile Withington, and I don't exactly remember what it was all about. She was a counselor there.

O'Hara: Could she have been the one who wanted Donald to leave?

Willsmore: I think she probably was, and I think she was one that was sent in there to kind of put her foot down. As I recall now, Margaret Bewley was my counselor when I was first there at the Cowell residence program, and I think Lucile Withington came later. And then I think Karen Topp replaced Lucile Withington. Lucile was a very hard and by-the-book kind of counselor, and I think they sent her in there because that's the way she was and maybe she could whip these guys into shape. We all rebelled against it, basically.

O'Hara: Are you implying that the group was somewhat out of control?

Willsmore: Yes, there was some looseness there. I think in the eyes of the department we were, and in reality we probably were a little bit--

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O'Hara: You were talking about the group being a little loose and having a DR counselor sent in that was tough. Why was the group loose, do you think?

Willsmore: I think from our perspective we came there to live and be independent and eventually, probably, get a job. That was ultimately our goal because we all wanted to be self-supporting; that's a very worthy goal for your life. But at that time, none of us really had a sense of exactly what job or what career we wanted. If left to ourselves, we probably would have taken five years to make up our mind on a career goal. The Department of Rehab, it was warranted what they were trying to do because there is a budget and all those things, and we

understood that. But we just felt that it was a little too much, trying to push a little too hard. We all agreed that yes, we have to take a minimum number of units, and we all did our best to do that. I think we carried four classes minimum, each of us, and went to school during the summer quarter in order to get through as quickly as we could.

Things were a little loose back then in terms of students in general. It was like a rebellion in general, of youth, that students didn't like to be told what to do [laughter]. I think some of that rubbed off on our group. It was just a clash of two perspectives, basically: DR wanting to move us through quickly, and us feeling, Look, we need some time to--we just barely got wheels where we can get around and found out that yes, we can function and get up every day and spend eight hours doing whatever. Maybe that means we can have a job. But we were just finding these things out and just exploring and hadn't really come to the point where we felt we could think about career and how we were going to spend the rest of our lives.

O'Hara: And from DR's perspective, they were paying for the rehab nurse in the program and some of the other costs.

Willsmore: Tuition.

O'Hara: And some of the housing costs. Didn't they pay some of the housing costs?

Willsmore: Yes, I think they paid some of the--

O'Hara: So they figured that since their goal was employment, that was their perspective.

Willsmore: Yes. I'm sure we were very expensive cases, each of us.

O'Hara: Be that as it may, Lucile Withington left shortly after this conflict, didn't she? And why was that?

Willsmore: I think it was because we all wanted her out of there. We just were not happy with her. We felt we could work better with someone else. So Karen Newman came in. Was it Karen Topp or Karen Newman?

O'Hara: Karen Newsome.

Willsmore: Newsome.

O'Hara: So she was the next rehab counselor?

Willsmore: I think she was, as I recall. I'm trying to remember the dates on this, but boy, it's foggy. That was twenty-six years ago [chuckles], so it's tough remembering what happened when. But I think Karen Newsome was one of the last counselors of the program, at least when I was in it.

O'Hara: We'll be talking to her also, so she'll probably be able to piece some more of this together.





## IV LIVING INDEPENDENTLY IN THE COMMUNITY: 1970

Moving Out of Cowell and Managing in an Apartment

- O'Hara: You said you arrived at Cowell in '69. When did you move out and under what circumstances, and what was that like? Weren't you one of the first people to move out?
- Willsmore: I think I was. Well, Ed moved out first because he graduated, and it was time for him to get out on his own. I think he got a house with a number of attendants. I think Jim Donald lived with Ed when they first moved out. Then John moved out. I'm trying to remember if John and I had moved out at the same time. I think he had moved out and got his own place, and then I decided I'd move in with him and share the place because I saw he was doing okay and maybe I could survive out there too, you know. It was a little scary because if you've never lived on your own--the thing about the Cowell residence program is that you were in a hospital, so there's some sense of security in that, and the fact that they had someone there twenty-four hours a day. And it was actually the orderly that worked on the floor below and worked with the regular patients in the hospital, but was always on call--well, no, that was only in the evenings from like nine o'clock onward until daylight or something. We used the orderly that was downstairs that served the regular hospital population as an on-call orderly, so if we had some kind of emergency--. Basically we all had our own attendants, but during the day there was always an on-duty orderly. I don't remember if they called them an orderly or an attendant or what, but he was responsible for helping all the people in the program, emptying leg bags and throwing us in bed if we needed it, or whatever.
- O'Hara: So when you moved out, what were your concerns?

Willsmore: Concerns were, How would we get our meals fixed? That was also something provided by the hospital. They provided basically the hospital food from the hospital kitchen. Three times a day I got meals, whereas when you move out, quads don't have a lot of ability to do a lot of cooking. In fact, we didn't even think about cooking when we initially moved out. That came later.

O'Hara: What did you think you were going to do for eating?

Willsmore: Hire somebody to come in and cook meals. And that's what we did. Linda Perrotti worked for John and I for quite a while, just coming in and making dinner basically. As far as breakfast, I think we had our regular attendants do that. And lunch, I usually used to skip lunch.

O'Hara: Because you didn't have it?

Willsmore: I just never got hungry at lunchtime.

O'Hara: So that was how you solved that concern. Were there other concerns? How did you get in and out of your apartment?

Willsmore: It was a level entrance into the apartment. It was a three-story apartment building, but it had an elevator. But I think we actually lived on the ground floor, so we didn't even--I'm trying to remember if we had to use the elevator or not. I don't think we did use the elevator.

O'Hara: And you could get the door of the building open?

Willsmore: Yes. There was this little modification that you could do, and a lot of people use them still. It's a rubber thing that you put over the doorknob, and it's got like a lever thing on it. It makes the door easy enough to open for somebody with a disability. And we had a special flap fixed up for our key so that we could use the key and open the door.

Another concern was of course going to bed at night. For that we would just have to have an attendant come in and throw us in bed. John developed a way to get himself in bed and basically did his whole evening routine himself--except for bowel movement nights--then he had to have help. Eventually I did the same thing; I learned a lot from John. It was amazing. I don't know where he learned about the Balkan frame, but that was one of the elements that really made it possible for he and I both to put ourselves down at night.

O'Hara: What is a Balkan frame?

Willsmore: It's basically a frame that was used for people in traction. It attaches to the hospital bed, and it's just a frame over the top of the bed and runs the length of the bed. Now they don't use that; they use something a lot different nowadays. But it just so happened that that was very usable for hanging straps on in different locations so you could move yourself around. I don't know if John thought that up by himself or if he saw it somewhere else that somebody else was using. It was a pretty neat invention; I use it still on my bed.

O'Hara: It's just one more example of the creative thinking that was going on pretty well constantly. The door as a desk and the Balkan frame and the rubber levers and--

Willsmore: Yeah, you make do, I'll tell you. Then a number of other folks moved out in their own place, and it became pretty common. One of our major concerns was, Are we going to have wheelchair repair once we're finished being students? Are we going to have attendant referral? That was something we had developed with the Disabled Students' Program.

O'Hara: By this time you had gotten that grant from Washington?

Willsmore: Yes, I think right around '72 is when that happened.

O'Hara: PDSP started in July of '70.

Willsmore: Or '70, okay. Started back in that hole in the wall behind Top Dog.

O'Hara: And then Chuck Grimes was there for wheelchair repair. Was Cathy Caulfield doing attendant referral at that point?

Willsmore: I think she probably was. I don't remember. I remember Zona [Roberts] and John and Jan--

O'Hara: Was that Jan McEwen [McEwen-Brown]?

Willsmore: Yes. And she is up working at CRI [Community Resources for Independence] in Santa Rosa now. She lives in Marin County. She married a guy named Charlie, a paraplegic, and they're living happily in Marin County.

Don Lorence was working there at PDSP at one time. In fact, I think he took over as director when John left.

O'Hara: Yes, he did. Were you involved in the writing of the grant that sort of defined the PDSP and then was the basis for founding PDSP? Who wrote that grant?

Willsmore: John and I and Ed. Actually, Ed didn't do a lot of the real bare-bones work on stuff, but he did more of the political pushing and contacts and the influence-wielding kind of things.

### Accommodations for Survival

O'Hara: How did you decide what was going to go into the PDSP?

Willsmore: We decided what it was that we really needed to survive, and we all saw that we couldn't stay in the Cowell residence program forever, and that was probably the impetus for us moving out: DR was on our case all the time [laughs], wanting us to hurry through our program because it was so expensive. If you got out in your own place that kind of relieved that somewhat. We all wanted that new adventure anyway; we were young and foolish and adventurous at heart. We wanted our own place, and we wanted the additional independence and freedom because there were rules around the hospital and around the program there.

O'Hara: Were apartments hard to find for people?

Willsmore: Accessible ones were a little hard to find, I guess you'd say. But we always managed to build ramps or whatever. Some of the modern buildings were fairly accessible. The bathrooms weren't, but of course you can accommodate. A lot of us used commodes anyway instead of going in the bathroom on the toilet. That fact of not having a roll-in shower or something was kind of a problem. That was one thing we had at Cowell; that was a real nice feature that most of us used quite often. Rolled from our room all the way down to the shower on the commode [laughter]. Get a shower and go back to your room. That was nice to be able to have a shower.

O'Hara: I would imagine nobody had a roll-in shower when they moved to their apartments.

Willsmore: No way.

O'Hara: So did anyone ever get a shower?

- Willsmore: Very seldom. It's a matter of lifting, and some of us were pretty big. I rigged up something in my apartment when Judy and I moved in together so that I could get in a chair in the bathtub and get a shower. And we had one of those long hoses with a shower wand on it. But it was just such a hassle. It lengthened your morning routine by an hour, and it was hard on your attendant--you could see that. I just decided it wasn't worth it; we'll do bed baths. So that's what we did.
- O'Hara: Something like a shower would at least be a concern even though it got resolved in a different way. But there probably were a lot of little things. What about telephones?
- Willsmore: I think there was, even at that time, a program through Pacific Bell that provided speaker phones for people. It was through Pioneer Telephone or Telephone Pioneers or something. I forget the name of the organization, but it had something to do with pioneers. They were the ones that would actually come and install it, and they kind of put in volunteer time helping out doing this.
- O'Hara: Was that the kind with just a toggle switch and manual service? You just spoke to the operator?
- Willsmore: Yes. It had two boxes: one for talking in and one for the incoming speaker.
- O'Hara: Oh, the little one you talked into?
- Willsmore: Yes.
- O'Hara: That was a microphone. And what about beds? Did people use hospital beds?
- Willsmore: Most people used hospital beds.
- O'Hara: Where did they get them?
- Willsmore: From Medi-Cal.
- O'Hara: Oh, they purchased them through Medi-Cal insurance?
- Willsmore: Or whatever insurance they happened to have. Medi-Cal was a little better at that time; they were a little more liberal in what they paid for.
- O'Hara: Were these apartments furnished usually or did you have to get your own furnishings?

- Willsmore: Usually had to get our own furnishings, and a lot of us didn't have much furniture because it just gets in the way, you know? [laughs] Had a chair or two; that's about it. And a stereo, of course [chuckles].
- O'Hara: [laughs] Everybody had a stereo.
- Willsmore: Yes, a major stereo [laughs]. Played "Willie" by Creedence Clearwater Revival and the Poor Boys and all that good stuff back in those days [laughter]. Something Judy and I used to love to listen to was Hank Williams. We had a double album of his, and we'd sit around in the evening, have a beer or two and listen to Hank Williams.
- O'Hara: Now did you eventually set up your kitchen so you could do any cooking?
- Willsmore: Yes, I definitely did. I enjoyed that. But I still couldn't do a lot of the cutting up of things and whatnot, so we had a morning attendant get things ready and get it in condition to where Judy or I or John could pick up--Judy and I moved in together after a while. I moved out of John's place and moved in with her, and he got his own place somewhere else. But that was one other aspect of independence that was kind of nice: not having to worry about having somebody come in and cook dinner.
- O'Hara: So what did you do?
- Willsmore: Usually used an electric skillet or a little toaster oven. We didn't have microwaves back in those days. We just figured out things that you could make by using those two things. I think we even used the stove occasionally, but that was a little more dangerous, especially if you have any amount of liquid or anything like that.
- O'Hara: I personally remember visiting an apartment that you lived in--and I don't know if Judy lived there then or John; I think it was Judy--and being very impressed. I had not experienced this before. And I would assume that you played that role for a lot of people, that others saw what you did and then felt like they could do it themselves.
- Willsmore: We all learned from each other. It was incredible.



Friends and Attendants

O'Hara: Was there a lot of visiting back and forth?

Willsmore: Yes. It opened up your social life in that close, little community that was there. And we were friends with attendants. But basically our group of friends was other disabled people and attendants.

O'Hara: The attendants played a very critical role. You said you had your attendant cut things up for you. What else does an attendant do?

Willsmore: The real basics of getting washed up in the morning, bed baths, range of motion on your legs and things, taking care of your catheters, bowel movements, getting dressed, getting into your chair, getting breakfast in the morning, and keeping the apartment clean and whatever else.

O'Hara: Where did they learn how to do this?

Willsmore: We trained them for our particular needs.

O'Hara: So they weren't professionals. Who were they?

Willsmore: No, they weren't nurses or nurses' aides.

O'Hara: Where did they come from?

Willsmore: Most of them were either CO's--of course, the women were not CO's, and there were quite a few women attendants. Most of them were hippie types and didn't feel they needed a lot of money to live. They didn't have high expectations in their lifestyle and so forth.

O'Hara: What do you mean by "hippie type"?

Willsmore: Just a very casual lifestyle and did not have a need to accumulate a lot of material things and were just very "hang loose" kind of people. People like that, we found, were much easier to work with, much more accepting of some of the bizarre things that center around people with severe disabilities including bowel and bladder care and those kind of things. Throwing Judy in bed with me at night [laughs].

O'Hara: Attendants were part of a social circle then, too?

Willsmore: Yes, very much so.

O'Hara: They were employees and friends. Did that always work? Were there exceptions to that?

Willsmore: Well, some didn't really socialize a lot with the disabled people, but some of them felt very comfortable and enjoyed the almost different culture, really, in the disabled community. I had some of the attendants describe it to me as just an environment where people were real; you didn't have to go around putting on a front all the time or acting phony or be something they weren't. When you're disabled you lose your modesty and all of that phoniness; you are what you are, and you're dependent, and you're vulnerable, and it strips a lot of that away, a lot of that phoniness that goes on in our society, that layer or wall that most people keep between them and other people.

It's quite a phenomenon, that disabled community. It was very good, and I felt very at home, except I didn't always feel at home in Berkeley because there were so many strange people in Berkeley and so many strange lifestyles. I've very often felt like a fish out of water, although for a while I kind of blended in and grew my hair long and grew a beard. But I'm basically a very conservative person deep down inside [laughs], and eventually that came out, and I began not to feel at home in Berkeley. So I moved back to Santa Rosa.

O'Hara: Were you in school the whole time you were in Berkeley?

Willsmore: No. Got finished with my master's program in the summer of '75 and stayed in Berkeley until probably mid-'77. The reason I left was because my father was dying of cancer and I went home to spend his last years near him. We developed a much closer relationship after he had his cancer because that changed his outlook, I think, on my disability and all of that. He saw that there were things that happened to you that you have no control over. So it kind of gave us a little more in common, and we became much closer.

I worked at CIL for a while. I was head of the business enterprises division, which was basically the wheelchair repair and the van modification. That turned out to be a total fiasco. I was not ready for management at that time.

## V EVERYTHING HAPPENING AT ONCE: 1969-1970

[Interview 3: November 30, 1996]##

Lobbying and Lawsuit Against Attendant Care Cutback

O'Hara: You were saying that in 1970, everything seemed to be happening at once. What do you remember?

Willsmore: We were just finished up with the grant and had made lots of good contacts in state rehab and even at the federal level, and I guess we were just initiating what we called the Disabled Students' Program. The full name was the Physically Disabled Students' Program. That was the original name of it: PDSP. At the same time, Governor Reagan was governor. I guess he came in in '68. I'm trying to recall when he was elected, but I think it was '68. He was in there for a while, and then all of a sudden he handed down a dictum that attendant care--or his staff did, maybe he didn't even know about it--they came across with this cut for attendant care services, and they were just basically cutting the budget in half. They said that they were attempting to get at the abuses in the attendant care program.

O'Hara: Were you all as students getting attendant care money?

Willsmore: Yes. We were as though we were living in a private residence in Cowell Hospital. Our SSI check was evidently going--I'm trying to recall exactly how it worked--I think we gave everything but about a hundred dollars or something out of our ATD, which is what it [SSI] was called at that time. It didn't become SSI until '73. We were still receiving ATD and the attendant care money, which were two separate programs. The ATD was very small at that time; I think it was like \$170 or something. I don't really remember the exact level; it might even have that somewhere in here.

O'Hara: I was under the impression, and maybe it's very mistaken, that the residents in Cowell were some of the first people to hire attendants and use that attendant care money. But if the governor wanted to cut it, it must have been more widespread.

Willsmore: There were some people that were out in the community either living with their parents or on their own, and I don't think most of them were as severely disabled as the quads at Cowell. Maybe they were paras or maybe they were polio, walking with canes or crutches or whatever. I guess it was an attempt to keep people in their homes. I never did remember reading through the purposes of the program, which is one thing we did do with the ATD program when they did the switchover from ATD to SSI. That was done on the federal level; that came later.

O'Hara: ATD was the federal program administered through the state?

Willsmore: Through the state, through the counties, yes. The social welfare department. It's kind of the same way that attendant care is administered now. It used to be substantially federal money; I think it was two-thirds federal, and then the rest was state and county funds. Now it's shifting more toward where it's about half federal, maybe 25 percent state, and 25 percent county; that's the way that [Governor Pete] Wilson is trying to push it. I guess he's succeeding because there was talk of cuts and all that recently, but the counties were able to pick up the slack for the severely disabled.

At any rate, the idea of everything happening at once, this was kind of a life-threatening, survival-threatening occurrence--this whole attendant-care cutback--because there would be no way we'd be able to have enough attendant care hours to really live independently the way we were doing there at Cowell, with a 50 percent cutback. We were fighting it with all that we had. Most of the people that were being active in fighting this thing in Sacramento and with letters and so forth were student-based groups. There were some at the state university in Long Beach, and I think there was one at Chico and one in Sacramento and several others around the state where there was a core of younger folks that were severely disabled, using the program, and knew they wouldn't be able to go on the way they've been doing with those cuts. We were bringing the press and everything together to try and fight this, and I guess in a very short period of time we had quite an effect. I remember there were news stories on the local TV channel, it was in the newspaper a number of times, and so finally we got enough public support and people writing letters that at least the Republicans began to talk a little bit and negotiate. This was all being handled through a budget bill, I guess, that was

going through the legislature at that time. I think we had gotten John Dunlap involved in it, and [George] Moscone and [Leo] McCarthy were the main legislators that were involved in carrying the legislation for us to try and reverse these cuts. From what I recall, we spent one full day up in Sacramento. We organized a number of other disabled groups, got them all together, and kind of converged on Sacramento all in one day and basically went through the halls, and we had fact sheets and a position paper summarizing real quickly what was happening so that legislators could see firsthand that yes, it was really going to affect some people and that it was something that really needed attention. We were quite hopeful that we were going to be able to reverse it in the legislature. At the last minute, I think there were two Republican votes that swung the other way--they said they were going to vote with us, and they voted against us. So we lost it.

The last resort was to bring the lawsuit, and that was Ralph Abascal who brought that lawsuit. He was with California Rural Legal Assistance, I think it was called at that time. He brought that suit in the superior court or the federal court somehow in San Francisco, and we got a favorable ruling and overturned it. It said that it was just going to damage too many people. They were forced to go back to the table and work something out, which they did. So it turned out there were no cuts, and things just continued as they were. I guess they realized that that was one area that they weren't going to be able to really touch very much [chuckles].

O'Hara: Did you personally have anything to do with Ralph Abascal during that time?

Willsmore: I was in a number of meetings with him. John and Ed, I think, were the ones that dealt mainly with him, and primarily John, on a day-to-day basis. Ed was the one that knew him and was more political and tied in to the groups that were also being represented by him: poverty groups and minority groups and that kind of thing. I think John was the one that did the day-to-day, nitty-gritty work with him. He did have several meetings where he talked to a number of us and kind of got personal stories that he could use in his brief that he was presenting to the court. He was a good lawyer, and a very impressive person. He had quite a presence about him. He did a lot of good for a lot of different people.



Early Days of the Physically Disabled Students' Program

Willsmore: Anyhow, we resolved that crisis, and then of course the PDSP got going. It started in a little office that was off of Telegraph Avenue on Durant. You had to go down this driveway behind a little restaurant called Top Dog, a little hole-in-the-wall hot dog stand. We had to build a big, long ramp going up the back of the building because it was probably a good ten feet above the parking lot--the entry door. That of course wasn't very appropriate for a disabled students' office [laughs], but that was all we could find for the money that we had at that time.

O'Hara: And it was very steep.

Willsmore: Yes.

O'Hara: So you were involved in the design of that ramp?

Willsmore: Somewhat, yes. And Chuck Grimes--and I forget who else--was around at that time and helped to build it. I can't think of his name, but he had long, dark hair--Eric Dibner--he was very actively involved at that time as an attendant and also a friend of Ed and John and of everybody, really. He was always eager to help them. So I think it was he and Chuck Grimes that ended up building that ramp.

O'Hara: I always wondered why it wasn't a switchback ramp so that it would be longer and not empty into a driveway where you couldn't see who was coming [laughs].

Willsmore: I know, that was so crazy! And of course now they wouldn't even allow it to be built because there are standards now. But there were no standards then--or maybe there were, and we just kind of went around them. It seemed like all of the people that were there that were going to use the office could use it, and we knew it wasn't ideal by any means, and many people complained about it.

O'Hara: Now what did the office look like once you got to the top of the ramp?

Willsmore: It was basically an old house that was converted, so it's kind of like just any old house in Berkeley. I think we came through what used to be maybe a laundry room or something and then into what used to be a bedroom, and then there was a hallway, and you proceeded further. The first bedroom that you'd enter into on the right was where we had our meals. That



was a very unique part of PDSP, and every day at lunch one of the staff members had the responsibility of making lunch. And they made some pretty good lunches. They'd have chili or spaghetti or what have you.

O'Hara: And what was the rationale behind that--a university office serving its clients lunch?

Willsmore: It was kind of to attract people in to be sociable. We were very aware of the benefit of socializing or fellowshiping--I don't know what you want to call it--just kind of sitting around rapping and relaxing and talking among people with severe disabilities, sharing stories, sharing what was new if they had learned to do some new thing that they hadn't been able to do before, some new gadget they figured out and that kind of thing. A lot of that went on. Sharing resources. Of course, PDSP was trying to compile all those resources so it could be a referral source.

Wheelchair repair was being handled for the students by the staff there at PDSP. They actually had one room that was set aside for wheelchair repair; they had a bench and some spare parts and various things. Chuck Grimes, I believe, was our first wheelchair repairman.

O'Hara: Before we get too far from the dining room, what were the alternatives for lunch? I mean, if somebody didn't eat at PDSP, where would they eat?

Willsmore: Just from one of the vendors on Telegraph or one of the local restaurants. That was the thing about Berkeley: people were just so very accepting of people with a severe disability, whereas some of the small towns that we came out of, it was kind of a gawking type of situation whenever you went out into public [chuckles]. But somehow in Berkeley there was this feeling like you were accepted regardless of how you looked or how badly or severely disabled you were. Also people were kind of anxious to be helpful. We relied an awful lot on passersby helping us out doing things that sometimes you'd need--even down to helping empty the leg bags sometimes, if we got into a real predicament to where either we couldn't do it ourselves or an attendant wasn't around or something on that order.

O'Hara: Did the DSP look like an office? Somebody once described it as "funky."

Willsmore: It was very funky, yes.

O'Hara: And what would that mean, exactly?

Willsmore: It was not really that neat. You think of an office as being kind of sterile and everything neat and in its place, but it was more like somebody's house who had a lot of kids [laughter]. There was no way we were going to keep this place neat with all these "crips" coming in and dropping things or needing to move furniture around. Generally, the staff was occupied by meeting the immediate needs of the people with disabilities that were there. We didn't have separate attendants that kind of helped out--maybe helping people get their jacket off; when it was really cold, and you go inside, you don't need your jacket, so you need help getting it off. Just little things like that, the staff ended up doing those, so maybe they weren't as attentive on keeping everything else as neat as they could have. And of course the doorways were all gouged out by the chairs when they go through. There were old wooden floors--we didn't have carpeting because it's a lot easier for a chair to roll on just a plain floor, and this was a very old house, and a lot of the floors were all damaged or the stain was not real nice. But it sure did the trick; it served its purpose.

O'Hara: Who helped with the coats? Who was the staff?

Willsmore: Zona was there, and I think she was full-time.

O'Hara: And what was her job?

Willsmore: Just generally a helper around the office, helping John. I'm trying to remember who else was employed there. John was the director. I think Don Lorence was employed at one time.

O'Hara: I think you had also said last time Jan McEwen [Brown].

Willsmore: She was a full-time student, but she was there and employed part-time kind of to get the blind component of the program going--to identify the needs, to identify the people that were on campus with a visual disability and figure out how PDSP could address their needs, and being their advocate to try and get a share of the budget or a share of the attention for people who were visually impaired. She worked with another blind student named David Konkell. They were both very strong and outspoken personalities.

O'Hara: Was it mostly just wheelchair users and some blind students?

Willsmore: Yes, mostly. I guess people that didn't have quite as severe a disability as the Rolling Quad types really almost didn't feel a need for a special office to address their needs, although that later evolved, and there was more outreach to people with

less severe disabilities. At first it was primarily geared toward the severely disabled and primarily toward physically disabled. But the federal guidelines were such that they were encouraging in being inclusive of all disabilities. And of course the whole culture around that time was that the development of inclusiveness, open opportunities for everybody, and in this case it was all different kinds of disabilities. That was seen as a real need in the program, but the primary need was to meet the immediate needs of the severely disabled, to help them transition to the community. That was primarily why it was started, because people in the Cowell program saw that they weren't going to be able to stay there or didn't want to stay there in the hospital environment even though it was more like a dormitory environment, but it still had that institutional flavor to it. We wanted to get out into the community and have our own apartments and just be independent and just try and live as independent a life as possible. So that's why the PDSP really got started.

O'Hara: And what would you go there for? Either you or another student. What led you there? Were you there every day? [inaudible; crosstalk]

Willsmore: The primary services that I used were the wheelchair repair and the transportation before I got my own van. The van at PDSP was available to help people go on trips as common as just going shopping to get their groceries or something, or to go to doctor's appointments--just various living needs.

O'Hara: Did you use attendant referral or was there a lot of word of mouth in those days?

Willsmore: I did. I used the attendant referral quite a bit. I never advertised for attendants. Almost all of the attendants came through the PDSP. We had a system where the office advertised and did word of mouth and bulletin boards and those kind of things, and there was a source also through the draft boards that the COs--conscientious objectors that didn't want to go into the service and fight in the Vietnam War--.

O'Hara: Was DSP a busy place? Was it bustling or was it quiet?

Willsmore: It was quite a bustling place. It was either people with disabilities coming in and getting their needs taken care of or just coming in to visit and say hello or meeting other disabled people there. Also, it was used as kind of a staging area for the Rolling Quads, which later evolved into the Northern California Disabled and Blind Action Committee [chuckles]. We

realized the need to have a name and an image that was more broad than the Rolling Quads in Berkeley.

O'Hara: Geographically it had to be broader, and it sounds like the Committee included two types of disabilities.

Willsmore: Yes, disabled and blind were primarily what we were gearing toward initially.

O'Hara: Why the two?

Willsmore: Because the hearing impaired were kind of a separate community, we didn't know how to deal with them, it's hard for quads to sign [laughs], and a lot of the people that were involved in the administration of the program were quads. But the hearing impaired is really almost a segregated community, and they at that time preferred it that way--at least most of them. There were a few that felt there was a need to make coalition with the other disabled groups, and they slowly brought everything around, brought their own community around to recognizing that, and also made a way for themselves into the--like the Center for Independent Living. By the time it got to that stage, the hearing impaired were very much accommodated. That was, I guess, around '72 or '73.

Writing the Initial Grant Proposal for PDSP: Connection With Great Society Programs and the Consumer Rights Movement

O'Hara: Going back to the beginning of DSP, you said last time that you and John and Cathy, I think, wrote the grant--

Willsmore: And Judy Taylor was somewhat involved. Don Lorence was heavily involved.

O'Hara: Now where were you when you wrote this grant? Did you have a secretary or a typewriter? Paint the picture for me of what you're doing. You heard about the grant through Ed, I presume. And did the university have a representative in the writing of this?

Willsmore: We got the guidelines, and I think we really kind of took it on ourselves. We felt qualified to do it. We were young and very self-confident at that time.

O'Hara: You wrote a grant that would become part of the university budget.

Willsmore: Yes. I think John was quite heavily involved in it even though he was doing his master's thesis. So many things happened, like I said, all at once. Here John is doing his master's thesis, Ed was getting into teaching, and we were taking full loads as students, there were demonstrations going on on the campus [laughs], and cutbacks in attendant care, problems with the budget of the Cowell residence program, and problems with the change of the guard of the counselor of the Cowell program--so many things were happening together. It was a very busy time. I remember that.

O'Hara: But you stayed on top of it. You were managing every single issue.

Willsmore: Amazingly so, because we were just kids out of high school, really, and hadn't had any higher education until we got there--at least I didn't. I was kind of a D student in high school [laughs].

O'Hara: Were you all sitting around the room writing this grant or dictating to a secretary or somebody was writing--

Willsmore: I think we had some attendants there that were getting some part-time hours. We had some kind of seed money from something, and I think it was DR who gave us a little bit of seed money to pay for materials and maybe a typewriter and that kind of thing, just to see if we could get something going and actually put a proposal into the Department of Education. Ed had met a few people that were in the faculty there that were influential. I don't remember all their names. One woman, a very tall, powerful-looking woman--Jean something.

O'Hara: Jean Wirth was at the College of San Mateo.

Willsmore: Okay. Anyway, she was very helpful. She had contacts.

O'Hara: Oh, that's right. She was then a consultant in Washington.

Willsmore: Yes, she had a lot of contacts. And then a couple of other people in the university faculty had contacts of people that they had gone to school with or something that were back in the administration back in Washington. I guess that was [President Lyndon] Johnson's administration at that time.

O'Hara: Well, '69 would be [President Richard] Nixon.

Willsmore: Would it?

O'Hara: Didn't he resign in '73?



Willsmore: Yes, '73.

##

O'Hara: So you--or John or Ed or somebody--must have had phone calls back and forth to Washington, then?

Willsmore: There were some people who had come into the Department of Education--evidently there was some real growth in the Department of Education and in a lot of the federal departments from the time that Kennedy and Johnson came in, with the War on Poverty and the Great Society. Johnson carried on very strongly the whole idea that government could solve a lot of the problems, it needed to reduce poverty and help disadvantaged groups and all that kind of thing. And so there was a real outreach from the federal government and into the communities and the local organizations and state and local governments, providing money, there were programs--and there was a program that was primarily designed for minority students but somewhere in the legislation there was also a clause that it was supposed to be for people with disabilities. So that is the legislation that we wrote our grant under. I don't even remember what the name of the category was. There were minority groups on campuses at that time, like Afro-American Studies and all those kind of things--that was the same kind of legislation and money that was going to fund PDSP. Anyway, we found out what the keywords were and the jargon and how to write a grant--

O'Hara: How did you find that out?

Willsmore: By Jean Wirth and other people that had ties to people in Washington. They told us what they wanted to see in a grant. Using those guidelines and just our own heartfelt knowledge of what was absolutely needed--just real practical everyday living with it--we knew what was needed and so we designed these. We also designed them not only to have the services we needed, but to be run and influenced by the people that were going to be served by the program. So we made a very strong point that--and that was very much accepted at that time--the consumer-based idea, where the people with the problem or maybe that had come out of those kind of problems would be the best ones to run the programs to help other people that needed those services.



Insisting on Leadership by People with Disabilities

O'Hara: Did John Hessler subscribe to that philosophy also?

Willsmore: Oh, absolutely. I mean, so strongly--he was almost the philosopher and strength behind keeping it on track in that kind of approach, because it was very new for the university to have severely disabled people in any kind of administrative positions. So he had somewhat of a fight on his hands with some of the people in the university, but there were some that were very sympathetic.

O'Hara: A fight on his hands?

Willsmore: To maintain having the thing run and staffed by people with disabilities or people that were very familiar with the disability culture. That's what we considered, that it was like a culture. There was a black culture and a Chicano culture, and there's also a disabled culture.

O'Hara: What went into the culture? Commonalities of some kind?

Willsmore: Yes, just the commonalities of the way that people are responded to in the public eye, the way that the average person responds to people with disabilities is something that all severely disabled people have in common. And that is that people generally tend to treat you like a child. That's one of the primary elements. Also the "poor thing" aspect, and there were some with the feeling: "What are you doing out? You should be home somewhere!" [laughter] Also just the common barriers that you run into: you have to go do your errands and things, and all of a sudden you find out the office you have to go to has steps, and you can't even get into it. So you have to grab somebody on the street and have them run up in there. Those are all very common among people with severe disabilities.

O'Hara: Did a language develop among the students that was peculiar to them?

Willsmore: Oh, a little. We had our colloquialisms, I'd guess you'd call it.

O'Hara: Can you remember some of the colloquialisms?

Willsmore: Well, we'd call able-bodied people "walkies." We called each other "crips." There were probably lots of other things.

O'Hara: Those are two that stick out.

Willsmore: Yes. Those were two biggies.

O'Hara: Thinking back in this association with all these people with disabilities and thinking back even further to your earlier life, what was this like for you?

Willsmore: Well, it was like getting freedom. When I came to the Cowell residence program--I had been stuck at home for over a year. I was very restless and wondering if I was ever going to be able to do anything and trying to figure out how in the world would I overcome the aspect of--number one, if I wanted to go to school and get an education and get some kind of higher paying job, how would I get to a college? We had a junior college in our area. I was trying to imagine transferring in and out of a car several times a day and who was going to help me do all that. I didn't even know much about attendant care when I was home. The social workers were not prone to asking you to come on to the attendant care program; they very often wouldn't even tell you about it. They want to spend as little money as possible. I didn't really even find out much about it until I got to Berkeley. When we got to Berkeley we started realizing, Hey, we could learn all these regulations and know them as well or better than the workers that were in charge of our case. That's what we did; we got the actual manuals, studied them, and same with the Department of Rehab so that when they said no, we knew we had alternatives, and we absolutely took them [laughs].

The Protest Milieu: Free Speech Movement, People's Park, Antiwar Activities

O'Hara: The political savvy of this group amazes me.

Willsmore: I don't really know where it all came from, but I guess it came a lot from the environment of not taking no for an answer and asserting rights. That was going on in the general student community at that time. There was the Free Speech Movement, and then there was the anti-Vietnam War movement. There was People's Park and various political movements around at that time.

O'Hara: How was it manifesting itself? What did you actually see on the campus when you were out and about?

- Willsmore: We'd see demonstrations, we'd see people giving speeches, we would see sit-ins. The People's Park thing is where it really kind of got violent.
- O'Hara: Were you there at that time?
- Willsmore: Yes. That was just after I got there on the campus, and it was a very fervent kind of battling between the administration and the campus police and the Berkeley police and the Alameda County Sheriff's Department. Then finally they called in the National Guard.
- O'Hara: So was Telegraph just loaded with police?
- Willsmore: At times. There were episodes when the university was trying to take this vacant field ["People's Park"] that had been used by people just for casual use and for just hanging out in, and some people had started gardens there because it was vacant land, and it was kind of "power to the people" at that time, you know [laughter]. They just took it over, and then the university decided they wanted to build on it at some point, and they were trying to assert that this really is not public area, and all of a sudden the whole campus community and the whole Berkeley activist community got behind that and just refused to let the university take that away from them. I don't remember the exact things that started these real heavy episodes where we ended up having a helicopter fly over the campus spraying tear gas, but it was really something to watch.
- O'Hara: What did that feel like? Was it frightening?
- Willsmore: Not really, because if you were in a building you were all right. It was frightening to be on the street because there were times when people actually got shot, especially during one several-day period when the Alameda County Sheriff's Departments were called in. They came and they wore these blue overalls and blue helmets, and we called them the "Blue Meanies." [laughs] And they were mean, too; they wouldn't stand for anything. When people started throwing things at them, they started firing tear gas, and at some point somebody starting firing their shotgun, and they hit a couple of people. So people were wounded by that.
- O'Hara: Did you, in general, stay away from the centers of the action?
- Willsmore: From the major crowds, yes. When they started to move, they would be like--there would be a crowd gathered in one area, and then all of a sudden the police would come along and want to disperse them and get them moving so that they couldn't get

some kind of damage going or start breaking windows, because a lot of that was going on. The crowds would get all fired up, and there were these people out front that would be encouraging people to break windows or start little bonfires or something. So when cops would see a big crowd gathering, they'd come there, they'd call on their radios and get everybody else over there and try to move those crowds out of there. That's when it got dangerous because the crowds would start running, and running at full speed sometimes because they were firing tear gas at them and weren't sure whether they were going to start firing shotguns at them.

So we'd pretty much stay out of the way when that stuff was going on because it would have been dangerous. I got caught a couple of times in a little stampede like that. We had pretty fast chairs, and people were fairly considerate, but still it wasn't a pleasant experience.

O'Hara: How come you got caught? Were you just ambling along, or were you part of the crowd?

Willsmore: Just going from class to class or something.

O'Hara: Oh, this was on the campus and not on Telegraph?

Willsmore: Yes. A lot of it happened on campus. Some of it happened on Telegraph. But the parts I remember mostly happened on campus. Maybe because there was a little laxer policing on campus--they were just the campus police, and they're not quite as heavy-duty as, say, the Berkeley police or the Alameda County Sheriff. But I do remember times when Telegraph Avenue and Bancroft and some of the other side streets were actually lined with police or sheriffs. There were fires in the streets and various things. Lots of broken windows. That, I guess, went on for a period of a week and a half or two weeks--something like that. And then Reagan sent in the National Guard and really put a damper on things. They actually brought a helicopter over the top of the campus, swooping down over these crowds that would gather and just laying out a big cloud of tear gas [chuckles]. It was really something.

Finally, it kind of died down, and I guess they got the university to pull back somewhat to allow the area to continue to be used for public use. Then of course later--well, you know what's happened since then. They eventually did take part of that and build on it. I don't know if they've dedicated part of it or what.

O'Hara: People's Park?

Willsmore: Yes.

O'Hara: Well, they built--

Willsmore: Some dorms or something, didn't they?

O'Hara: No, part of it is the gardens, still the gardens with native plants, and then there's the sand-lot volleyball--and a big bathroom, and it's still very controversial. And I think they're going to make some more changes.

So this is the atmosphere that you were building your program in. From that, you got some kind of feeling that you could do this.

Willsmore: Yes, kind of an empowerment--that's the word that was floating around at that time.

O'Hara: Was the media at the campus demonstrations a lot? Did you see that too?

Willsmore: Yes.

O'Hara: So basically many of the things that you used you had seen from right in your own backyard.

Willsmore: Used by other protesting groups, yes. We were kind of helped along in remembering not to overuse or shoot all your guns at one time for little things, to save it for the really important stuff. That wears thin on the public and the media after a while if you call on them too much or send them too many press releases; it becomes mundane after a while.

So we held back on those kind of things except in the really severe circumstances, like the half cut in the attendant care services and the time when ATD was being switched over to SSI--that was '72 or '73. We were heavily involved at that time. We saw it as not only a fight to retain what we had, but also an opportunity to make the program a little better. And that's what we did with the attendant care. We got some legislation written into the enabling legislation that said there would be a special category of attendant care services, and that would be "severely disabled": anybody who used attendant care twenty or more hours per week, I think it was. Once that was established, it was kind of a special class of attendant care and wasn't subject to quite as much budget scrutiny because we tried to educate them to the fact that this was an absolute life and death kind of need. So they did give it special accommodation.



To get back to PDSP and such, the program worked really well, and it attracted--we also did outreach, you know, and of course it was written up quite a bit in newspapers and various rehab journals and all different kinds of things.

O'Hara: Were you employed by the DSP?

Willsmore: I don't think I was.

O'Hara: You just did things like these letters because you felt strongly about the program.

Willsmore: Right.

O'Hara: And did most people feel equally strong?

Willsmore: Yes. Well, there was a core group of maybe six or eight people that were very active, and Larry Langdon was one, and Judy Taylor, Cathy Caulfield, Don Lorence--you know, the usuals that you hear about.

#### John Hessler's Leadership of PDSP and the Idea for CIL

O'Hara: I started to ask you before about John. What kind of a director was he? What was his style?

Willsmore: He was a pretty strong director. He had his ideas of how the program should run. It wasn't like he came down on people or anything like that, but he commanded respect, maybe because he was so intelligent. He was also very personable. And he was very big [laughs], so he was a very imposing figure. I think he ran the program fairly efficiently and had a good sense of administration. It seemed like he was a pretty good manager. I don't know what you've heard about him.

O'Hara: I certainly have heard that, and also some people have said that there was kind of a love/hate relationship with John in a way. He was terribly strong [inaudible; crosstalk].

Willsmore: Oh yes, he was an absolute power; when it came to whose will was going to overcome, it was his usually.

O'Hara: There was a limit to democracy as far as John was concerned.

Willsmore: Right. Exactly.



O'Hara: Overall, was that good for the program at that time?

Willsmore: I think so. I think the university was looking for a strong leader and somebody that also had some kind of sense that there were bureaucratic things that needed to be done and some bureaucratic goals that needed to be satisfied, and he was good at doing that, at doing the numbers game for the university so that they could show they were achieving or growing or--a cost-benefit type of thing. He had a good head about that. He was a good bridge between a bureaucratic and rigid organization like the university and a real "hang loose" group like we were [laughs].

O'Hara: In something I read I got the idea that John, almost from the beginning of DSP, was thinking ahead to CIL.

Willsmore: We all were, actually. It didn't take long--I don't know if we really thought much about it in the initial stages when we were actually getting the grant together and so forth and thinking up the services that were needed for PDSP. But it wasn't very long after that that we started getting a lot of requests once the program was established. And even some of the students dropped out as students and just began to live in the community as non-students and sometimes called upon PDSP for services. Of course the university wanted to be sure that it was students that were served. Eventually that kind of service was needed anyway in the community; it just didn't exist. It was easier to do in conjunction with the university because DR had a very vocational orientation, and we didn't see any other place or source for the money for a community program.

So that's where we went for the money. They have always had a very vocational orientation, and they want people to be striving to become employed and have an outcome. And their twenty-six closure is what they call it when a person is successfully employed and steady in his job, and they pull out of it, basically. That didn't fit the model real well for a community-based program for non-students or people that weren't in some kind of vocational training, so we had to bring their thinking around to see that yes, it was a needed aspect of rehabilitation. Rehabilitation didn't always have to be vocational. It took a long time to get them to realize that, and to see that there was a real big gap between--they put you through a rehab hospital, and then they plunk you out in the community with nothing--attendant care, granted, but like we found out, many of the social workers didn't even tell people that they have attendant care available. It was just a very haphazard system where people fell through the cracks and usually ended up in institutions or stuck at home with their

parents. We saw that there was a need to reverse that and provide some kind of governmental support that would pick people up from the time they got out of rehab or pick them up while they were in their parents' home and had some kind of a goal to do something else besides that--to live independently in the community without their parents help or whatever. Just fill that gap. That was talked about a lot: gaps in services.

O'Hara: So it was just a natural evolution to renting the apartment--or am I jumping ahead too fast there?

Willsmore: The PDSP did operate for a little bit. We started to see a lot of non-students calling on the services and feeling like we wanted to help them out, and we did a lot of that in the beginning. But the resources just weren't there to serve the needs that were there, or the potential need that was there. So we thought it was time to get down to business and see if we can get something going in the non-student area. That was primarily done through--I guess it was the Oakland office and the district administrator here, and there was a fellow that worked in there, and I cannot remember his name. He was very helpful, very strong in advocating for us--he worked for the Department of Rehab. Boy, he was one of our strongest advocates, too. You know, that might be in some of my stuff here.

O'Hara: John Velton?

Willsmore: No, he was the district administrator, I believe. This was more of a floating consultant that worked in the department.

O'Hara: Gerry Belchick?

Willsmore: Yes. That was him. He was one of our strongest advocates and helped us probably more than anybody in gearing what we were trying to write in a manner that would be accepted within the department.

O'Hara: And this is for CIL funding now.

Willsmore: Yes. And John Velton was very influential and did help a lot and saw the need and wanted to see something get going. So he and Gerry and--I don't remember if Karen was involved; I think Karen was involved at that time--she was a counselor for people at Cowell and people that came out of Cowell.

O'Hara: Given the confidence that you all had that you could do anything in those days, was money the only reason, the major--

Willsmore: Obstacle?

O'Hara: Yes.

Willsmore: Yes. It was the money that would enable us to get a facility, an office. And although so many of the people involved were very committed to the "cause," the kind of program we envisioned could not be effective with just volunteers. We needed people who could commit fulltime, and even lots of after hours to make the program what it could be--and what it became--a powerful force for change. The other very crucial element was a pool of committed, intelligent and energetic "crips" to work there. One without the other wouldn't have done the job. But thank God both the money and people came together.



## VI EARLY DAYS OF CENTER FOR INDEPENDENT LIVING

[Interview 4: December 14, 1996] ##

Founding CIL and the Meaning of Independence

O'Hara: I think we're at the point where the Center for Independent Living was just about to form. I remember seeing you at those meetings, and I wondered if you could describe how they came to be.

Willsmore: There was a core group of people that were interested in getting this thing together, and it consisted of some of the students. John was willing to kind of help it along any way he could; he wasn't really involved in it all that much other than philosophically, keeping us on track, the whole idea of independent living. That became a real big phrase. Getting services constructed in a way that we could be pretty much independent from institutions and having a support network basically. That was the whole idea.

O'Hara: Can I interrupt you just for a minute? Independent from institutions, but obviously not physically independent totally. What independence is this?

Willsmore: Taking control of your own life. That was the philosophy. And making your own decisions about who you hired, where you lived, when you get up in the morning, what kind of career you're going to have, all those kinds of things--the same way that the average person makes those decisions. Whereas when people are receiving government funds, very often the government will tell you what you can do and what you can't do [chuckles].

So we fought for trying to give people choices and give them power in their lives to really be able to live as normal a life as possible and as active a life as possible and taking

responsibility too--not having the attitude that "it's the medical field's responsibility for making sure my health is maintained." Really getting in there and learning about your body and asserting yourself with your doctors and with your counselors or whoever else that was supposed to be helping you.

O'Hara: That makes sense. So getting back to the CIL--it was a group of students, John helped keep it on track. Do you recall who called the meetings together or who led them?

Willsmore: Larry Biscamp was very instrumental, as was Ed--although Ed did not put a lot of nitty-gritty grassroots time on it. I'm trying to remember how he all fit in there. He again was more of a philosophical leader for us and kept us on track in that direction. He was also the one that had most of the contacts and political savvy to be able to know who to call or where to look for an answer to a given question or how far to go in terms of putting pressure on various places in bureaucracies without being alienating or losing your entrée.

Larry Biscamp was very much in the philosophy aspect of it, and I think he envisioned himself as the first director. Don Lorence was much involved because he was becoming very near to graduating and was going to need some kind of a position.

O'Hara: What was your role in it?

Willsmore: Just wanted to see it happen, and it was a lot of self-interest--and for most of us it was. We wanted to see some kind of an orientation or a body or an entity of some kind to be there to fill the gap between the rehab hospital and out earning your own living. A lot of times it's a long trek between those two steps. The institutions that really were set up at that time--there was nothing to fill that gap. They'd put you out there--you know, when your time was up in the rehab center you were pushed out, and you either went home--if you didn't have a supportive family you went into an institution of some kind, usually a convalescent hospital or a county hospital. John spent I forget how many years--eight or ten years maybe--in the Martinez county hospital. He went to school out of there and was quite active, actually, but still it was an institution. He told me some of the horror stories about what went on in those places. If he didn't mind and do exactly as they told him they would take his wheelchair away, and he would be stuck in bed for several days or whatever [laughs]--I mean, it was sick. Things like that, where you were really under their thumb and had no choice. That was the purpose of CIL: to free people of those kind of things and to free people of dependency on family or parents. Parents are



great, and it's wonderful to have a supporting family, but it can be somewhat stifling too because mothers tend to protect and shelter their children and keep them from bumping up against some of the trials in life that make you stronger and allow you to go forward.

I guess those were the two that were mentioned most often as far as avoiding the institutional care setting and also the family care setting, where you were stuck in the family and really not going anywhere.

It was an attempt to help people to get from being totally stuck somewhere to a place where they could begin to see other options in their life instead of just staying home and watching TV or something. We saw it through the Cowell rehab program and through the PDSP--that just because you're very severely disabled, it doesn't mean you can't get out there and do things, you know. Really, if you have a sound mind that's how things are done--mostly by your mind [chuckles]. People get things going, and you can do an awful lot over the phone or if you have an assistant that can write for you or whatever--a lot of technology in it--and just a lot of things were evolving at that time too, as far as research--in the rehab area with new wheelchairs--that were making it possible for people to be much more mobile, including vans.

O'Hara: I saw Hale Zukas at those meetings. What role did he play?

Willsmore: Structuring things, helping us to conceptualize how the program would work, helping even to write some of the stuff. He was a pretty good writer. He was very slow, but we would each sometimes be assigned to a certain part of it--I took on the business enterprises aspect of it or the wheelchair repair aspect, because that was my interest; I love mechanics and things, and I was also being trained at UC. I got my bachelor's in economics, and I've always liked business and stocks and everything.

O'Hara: So what were you writing this for?

Willsmore: At first, we didn't even know where we were going to apply.

O'Hara: You're talking about funding?

Willsmore: Yes. We found out that there was seed money through the Department of Rehab, so we got a small grant that gave us the ability to have a place that was strictly for the group that was setting up the Center for Independent Living--or wanted to set it up. I don't think we even had the name at that time.

The name came up when we were sitting around--I think it was even up at Cowell--we were sitting around trying to think of a name. The whole thing of independent living was ringing very loud in all of our conversations.

O'Hara: I've seen references to there being a Center for Independent Living at Alumni House. Very short-lived. Do you recall that at all? It might have been a matter of weeks old, I don't know, but it seemed to me that at one point PDSP was named CIL.

Willsmore: I don't know.

O'Hara: I don't know either. Maybe before it became the official Durant thing.

#### Defining Programs and Clientele, Seeking Funding

O'Hara: So did you tell me--I think you did--that there was really no contentious discussion about this organization, but basically everybody kind of knew what was going to go in it, and the issue was where to get funding.

Willsmore: That's right. It was a very crying need that needed to be filled, and it was almost obvious what needed to be done, what services were needed. We were gearing toward severely disabled and kind of the blind and the other disabilities were peripheral in our goals, I guess you'd say.

O'Hara: So by "severely disabled" you mean people who use wheelchairs and need attendants.

Willsmore: Yes--adaptive devices and needed attendants and otherwise probably couldn't function out there in the work world or just in society in general.

O'Hara: Would it be correct to say that people with retardation were not included in the formula either?

Willsmore: Right. Part of that was because they had a whole support system of their own and a whole funding system which was far and above anything that we ever even foresaw for the severely physically disabled. And you know all about the developmentally disabled system, I'm sure.

O'Hara: Besides wheelchair repair and the van modification, do you recall what other units were to be part of the initial CIL?

Willsmore: Yes. There was attendant referral, information referral, and peer counseling. Peer counseling was one thing that we considered to be a major and important aspect of it, where experienced people could--but we never really did develop that probably as well as it could have been, probably because the other services were more needed than peer counseling. Of course, peer counseling happened whenever you get a bunch of crips together [laughs]. So it kind of happened on its own. In fact, we kept going back and forth about that issue--"Should we have designated peer counselors?" where they would sit down with someone, because each person is so individual in their disability and their needs for the adaptations to the disability. So no matter how expert you were in being able to kind of help people understand how they could do things by adaptive devices or doing things a different way, you'd never really be able to know how best somebody else ought to do it necessarily--but kind of just bouncing ideas off and being there as a model for someone else works real well.

So we thought that maybe what we ought to have is a meeting area or a lounge area where people can come in and feel comfortable and have all of this transpire. I don't know that that was ever carried forward very strongly, but it was seen as something needed when the whole thing was being conceptualized.

O'Hara: Do you recall who wrote the sections on the other parts--attendant referral, information referral?

Willsmore: And the transportation. I think Larry Biscamp--and Judy, I think, was very much involved in writing and helping to construct the way that services should work and how to seek out potential attendants and categorizing and all of that.

O'Hara: At that point were you meeting in a place that you had rented with DR seed money?

Willsmore: Yes. It was a one-bedroom apartment on Haste Street. It was in the same building where John Hessler and I lived. I don't remember if Judy and I had gotten our apartment by then or not. I think she was still living down on the end of that same block in a one-bedroom apartment.

O'Hara: That was near Haste and College, you said?

Willsmore: Right. I guess that was the cross street--College and Haste is where her apartment was, and we were just up the hill from that.

O'Hara: Once the papers were written, what happened next?

Willsmore: We started trying to get, first of all, [the Department of] Rehab because that seemed to us the most sensible place to find the money or to break apart a pot of money or get the administration to see that there should be a pot of money for this to get it going. Of course, their opposition to it was "it's not employment related." And our argument was that you can't even begin to think about employment until you get some of these things solved for people with severe disabilities. We were always concerned about how DR loves to concentrate on people with less severe disabilities because they have their numbers game. They need twenty-six closures; to them that's a success. And the more they get in a given time period, the better their figures look when they go and report to whoever it is that watches over things as far as budgets and so forth. We kept pounding on the fact that you're probably giving a lot of money to people that could rehab themselves anyway. Let's try putting some more money towards severely disabled and really get that going toward people that need it.

After talking to regional people, regional offices, and state offices--the regional and federal office is where we got probably the biggest impact, and then from there the people in San Francisco, the regional Department of Vocational Rehabilitation.

O'Hara: Do you remember any of the names associated with where you said you got a good response?

Willsmore: No. I really don't. I know that one fellow--not Gerry Belchick, but there was a consultant that worked with them. Boy, I wish I could remember his name. John would know it right off. He and Ed and a couple of other folks. You know who would know is your neighbor up the street here--Joan. She would remember him, I'm sure. He had gray hair and a mustache, he was kind of short, but real vigorous and energetic and really behind us 1,000 percent. If he were the administrator, we would have had all the money we wanted [laughs].

O'Hara: Did Rehab give money toward it in the end?

Willsmore: Yes, I believe they did. I'm quite sure that's where most of the money came from initially. We went for private grants also, and that was part of the deal when we went for the money through the Department of Rehab--we would have to have matching funds. So we were raising private money also. There were some foundations in the Bay Area here that were very receptive.

O'Hara: And were you personally involved in that too?

Willsmore: Some of it, yes. In fact, several of the foundations came to the apartment, and we sat down and talked with their people. At times it would be Ed going to their board meetings or whatever it was--their committee meetings.

O'Hara: Do you remember any names--foundations, people?

Willsmore: Sure don't [laughs].

O'Hara: Okay, that's fine. That would be asking an awful lot. So do you know the particulars of how much money CIL had to start with?

Willsmore: The figure \$125,000 rattles around in there.

#### Organic, Participatory Management

O'Hara: Can you describe any steps that you recall? We don't have a good history of those early, early steps of CIL, and if we could piece together everybody's memories--

Willsmore: We knew--and this was from intuition--that we had to get together some form of a guiding document or something that would keep us on track. In most organizations it's articles and bylaws. Those actually were developed pretty early on, with the assistance of people that were volunteering to be on our advisory board. I think we did establish an advisory board, and some of them were people from other nonprofit organizations and other radical organizations. We got ideas from them as to how to structure the articles and bylaws. We wanted always, at every step and level of the organization, to have majority participation by people with disabilities--severe disabilities if possible. So that was written into our bylaws.

We were also influenced by the Berkeley milieu, I guess you'd say, in trying to avoid the hierarchy idea of an organization or program. The word "organic" was used a lot; we want an organic organization, we don't want some guy at the top just telling his subordinates--and those subordinates telling other subordinates--what to do. We want people to have almost an equal share in the say in what gets done, in the goals. Really, I don't think it worked all that well [laughs]. We ended up having a lot of conflict and a lot of inactivity because of that. I think it later evolved--we realized we needed hierarchy, and we needed authority. But in the beginning that was the idea, and that was mostly the Berkeley



influence, I think. So it probably could have run much more efficiently the old-fashioned way [chuckles], but we had to go through that process.

And that had something to do with why I left CIL, too. One of the reasons I left was because of a hiring decision that I was overruled on. I was filling the initial positions on wheelchair repair and van modification. The van modification was pretty obvious because Ed knew a couple of guys that did machining and welding and various things like that. I can't remember their names, but they were mechanical type of guys, and they were the most appropriate for that, so they obviously got hired. As far as the wheelchair repair, we opened the job, advertised it, and put it out to different rehab offices and campuses where they had disabled programs. We did really want to try to hire some disabled people in wheelchair repair and every position in the organization.

At about the same time that we were doing the initial hiring for the Business Enterprises Division--that's what it ended up being. When we first went over to 2539 Telegraph Avenue, the Center for Independent Living's property had a big shop on it. When CIL first started providing services it only included wheelchair repair. The Business Enterprises Division was conceived about six months later. We saw a division of the organization that would hopefully make a profit and provide some money for other of CIL's services. We saw all this money being made by the businesses that sold all of us wheelchairs, vans, and disposable supplies like chux, catheters, gloves, et cetera. We envisioned CIL doing all that and keeping the money in the family, so to speak.

Additional seed money was found to start a Business Enterprises Division. It was housed in a shop building on the same lot the services office (main CIL) were located. The initial people in the wheelchair repair--was it Andy Cayting? He was one, and there was one other that was kind of part of the network of PDSP and the attendants and all that. Then there was an office with a couple of ladies in there--Lynn [Kidder] was one of the first people in the wheelchair repair in the Business Enterprises Division. She was doing the billing and so forth with Medi-Cal and such, along with a couple of other folks in there.

Anyway, we wanted to fill another position in wheelchair repair because we were getting a lot of demand, and the organization--wanting to be very organic and inclusive and all that--was looking to try and make it possible for existing staff to take any position that came open in the organization.



So rather than throw the job open and just hire the best person, it was written right into our policies that staff would be given priority. In fact, there was a big push at that given time to hire women and to hire them in positions that were not traditionally filled by women. Wheelchair repair just happened to be one of those. This woman that worked in the organization as a secretary--and I forget what department she was working in--applied. She decided she wanted to try for that job; I guess it paid more than what she was getting at the position she was in. We had been advertising it, and I had interviewed a number of people, and this one fellow that came over--he was not severely physically disabled, but he was a very severe stutterer; he almost couldn't talk. He convinced me that he had a sense about mechanics and could do things like that very well. I had him volunteer around the shop and do a few things, and he even did some repairs on the front door. I could see he was very well qualified and that he would make an excellent person for the job. I wanted to choose him. I went and met with Phil [Draper]--I don't remember if Judy [Heumann] was involved at that time or not--

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O'Hara: You said that Phil Draper was either director or assistant director at this point, and you met with him and possibly Judy.

Willsmore: And told them that I wanted to hire this gentleman. Of course the policy said I had to hire the lady that wanted the job, and she had never had any mechanical experience and was very--I don't know what you'd say--feminine [chuckles]. I didn't think she would really even like the job after she got it, but she wanted to try it, and they overruled me on it and said that this is the way the policies are written. So we hired her. Somehow that seemed to undermine also my authority in the whole business enterprises thing, and I think people lost a little respect for me as a leader, and I personally was very disappointed about that and felt that I was almost not in control of that function or division of our program. I just got fed up and quit. I resigned because I just didn't feel--it wasn't fun to work there anymore.

O'Hara: How long had you worked there?

Willsmore: Just about a year.

O'Hara: And was this--you were starting all these enterprises?

Willsmore: I was in the process, yes, with other people. Who's the blond fellow that lives in the East Bay now, I think? Orinda or

somewhere around there--Walnut Creek, maybe. He has a lip like Stacy Keach. Do you know who I'm talking about? He was one of the people that was helping to get things going in the business enterprises division, but he did it more as a volunteer than anything else.

O'Hara: And before your appearance there, there was no wheelchair repair. You actually started it, then.

Willsmore: No. I think the wheelchair repair aspect of it Ed got going through the two fellows that he eventually had doing the van repair and modification. I don't really think we ever got into doing much van repair and modification because it turned out that it was a little more of an undertaking than we were really ready to take on at that time. It required a lot of money and a lot of know-how. It involved a lot more resources than we could put behind it.

#### Herb's Training and Work at CIL

O'Hara: Did you start at CIL right at the beginning then in 1972 or was it a little bit later?

Willsmore: Right after I finished the master's program, I guess, is when I started there--in '75. I was very busy with the master's program in city and regional planning and really didn't have time to work from '73 to '75. And then in '75 I finished up there and was ready to look for a job. Of course Fred Collignon, who was one of the big people who helped us out politically and with connections in Washington, wanted Judy [Taylor] and I both to go into planning and maybe even work with him. [laughs] We didn't want to do that. After going all the way through two years in city and regional planning I decided I didn't even like that field. I just kind of happened into it because of Chuck Cole. I don't know exactly how Chuck Cole came into the picture, but he kind of drew Judy and me both into the planning department.

O'Hara: What was his association with PDSP or CIL?

Willsmore: Ed must have met him at some point--or John--and he became very excited about what was happening.

O'Hara: I think he wrote his doctoral dissertation in 1979 on this development.

Willsmore: Right. And he could see there was something big happening there. Very intelligent guy. And he was actually one of the people that helped us do a lot of the writing on some of these proposals--

O'Hara: For CIL?

Willsmore: Yes. And helped us to understand how these people that look at grant proposals view them and some of the jargon that they wanted to hear. We were just green, and we didn't know any of that. He was very good at that. So he would take what we wrote and take the basic philosophy of it and then help us to rewrite it and put in the buzzwords that they liked to hear.

O'Hara: Going back to your being overruled by people above you, did CIL struggle with the concept of decision making? On the one hand you said that--

Willsmore: I think they did, yes.

O'Hara: They didn't want a hierarchy, and then on the other hand you say you were overruled by someone.

Willsmore: We had a hierarchy. It was kind of like we didn't like a hierarchy and yet we had a hierarchy. I guess it depended on which way a person's decisions went--if they were a manager or a supervisor or something like that--whether or not they would find out there was a hierarchy [chuckles]. I mean, some were just left on their own, and some bumped up against the administration, so to speak. We had our share of problems all the way through the beginnings, the first few years.

CIL was going for two years by the time I got there. But my goal was to begin to do more than just the wheelchair repair--I was one that was very strong in trying to get the van modification going, not knowing that--in fact, it may not have been the right thing to do--it required almost a private enterprise kind of thing. Government-funded projects just don't have that profit motive, so they don't operate as well. But I wanted to also get us into selling some of the durable equipment that some of the other stores--equipment suppliers--were selling. We met with a number of various wheelchair manufacturers to try to get franchised and so forth. I don't think we ever did get a franchise for E&J Chairs because the existing vendors were heavily opposed to it. They did allow us to get parts and do repairs, but they never really allowed us to get authority to sell the actual equipment.

O'Hara: Who were the local vendors at that time?

- Willsmore: I think Robin Aids actually was doing some over in this area. And there was a Ron Hawkins that had a place.
- O'Hara: That was Berkeley Medical Supply or something like that.
- Willsmore: I think so, yes. And one of the girls out of the Cowell program ended up working there as a receptionist. I remember that. I don't remember if it was Susan--
- O'Hara: I think it was Linda.
- Willsmore: Linda, yes.
- O'Hara: What's her last name?
- Willsmore: I don't remember.
- O'Hara: Oh, Davis.
- Willsmore: I can see her now, sitting behind the desk with her headset on [laughs].
- O'Hara: That's a very good example, isn't it, of an early employment of a severely disabled person?
- Willsmore: Yes.

#### Dissension Over Issues of Control at CIL

- O'Hara: I had asked about the struggle with the hierarchy, and--
- Willsmore: And then there were later struggles too with--
- O'Hara: Yes, you were saying CIL had a variety of problems.
- Willsmore: Yes. We were also trying to kind of make it a compromise between a membership organization that really had decision-making authority--where members would come in, elect a board, and the board would be the one to set policy and do the hiring and firing and all that. We wanted the disabled population that was going to be served by it to control it. In trying to do that, I guess we ended up setting it up in a way that it didn't operate all that efficiently, and there was a lot of dissension and a lot of stress around which direction the thing was going to go.

- O'Hara: Were those the days of the caucuses at CIL? It seemed like there were any number of combinations of minorities, women, or--
- Willsmore: Yes, right. In fact, there were a number of lesbians, there were--and we were insistent, and Ed was real good about hiring minorities, and there were a number of minorities there. Each little group wanted to push harder for more concentration or more affirmative action within their certain group. A lot of that went on, yes.
- O'Hara: There was a general impression at that time that that consumed more time than perhaps work did.
- Willsmore: Yes, sometimes it did. The idea of the goal of trying to be inclusive and having affirmative action with respect to minorities and gays or whatever, to a lot of people it got in the way of hiring people with disabilities. In fact, sometimes those priorities were put ahead of hiring a person with a disability. I think that really is where the major conflict came, as I recall now. You know, I had forgotten all about that until you just mentioned it. I was one--and Phil Draper was one, and Judy Heumann I'm sure was one--that wanted to keep on the track of "No, I'm sorry, disabled people have priority, period. No question about it." Of course then later, federal regulations came in and there was a conflict around that-- federal regulations that say you have to fill the quotas and things like that in regard to minorities. The program ran into trouble with regard to that.

All in all it still functioned, and it still has done a lot of good and became a seed of many other independent living centers. Even though they don't get as much done, maybe, as they could, they do an awful lot of good in the communities that they're in because they are kind of the focal point for severely physically disabled people.

I know that in Santa Rosa when I moved back there--let's see, when I resigned from CIL I took a year--before I moved back to Santa Rosa--I took a trip around the U.S. for two months and then got back here to Berkeley, and my dad was getting pretty bad with the cancer that he had, so I decided rather than run home and visit twice a week or something that I would just move back to Santa Rosa.

O'Hara: By this time did you have your own van?

Willsmore: Yes.



O'Hara: How did you acquire that?

Willsmore: That came at just about the time that CIL was getting started. One of the arguments for my getting DR to buy a van was that I was going to be one of the employees at CIL, and I was going to be in an administrative capacity and needed a lot of mobility. So they did end up buying a van--one of the few they bought in those days.

O'Hara: Let me ask you--you said you were pretty busy with your master's degree between '73 and '75. I think Larry Biscamp came in as director in '72, as the first director. Is that correct?

Willsmore: That could be very possible.

O'Hara: He was the first director?

Willsmore: I think he was. I don't really remember, you know.

O'Hara: I think so too. And you don't remember Ed taking over from him?

Willsmore: Well, I do remember when that happened, but I was--like I said--not heavily involved in it. Once we got some money and the grant writing was over--the initial part of it was over--I went back to doing consulting work with Chuck Cole and Fred Collignon and doing my studies in the master's program.

O'Hara: What kind of consulting work?

Willsmore: Mostly with Department of Rehab, some with Department of Education, and just whatever happened to come up. We had fellowships too through the--Judy and I both got a fellowship.

O'Hara: What did it mean to work with the Department of Rehabilitation? Were you doing research or--?

Willsmore: Yes, we were doing research--one project, the main project that we really had, was trying to look at how counselors were trained and how they could be trained better so that they were more sensitive to the people they were serving.

O'Hara: I think we discussed that on one tape, and also the book probably will be--well, it's in the university library.

Willsmore: There's a paper that was written.

O'Hara: Yes, kind of a cardboard-bound thing.



Willsmore: I think Larry Biscamp was even part of that too.

O'Hara: I think so too. One more question about CIL: what was the atmosphere like? Was it a busy place?

Willsmore: Yes, very busy, and people always wanted to come and visit and take a tour through because this was a really new thing. People were busy because--you know, there were a lot of people out in the community that heard there was this new organization that maybe could solve all their problems [laughter]. So there was quite a demand on the services from the beginning. A lot of the demand actually came from people that we had not intended to target as our service population, namely--and primarily--the elderly. That became an issue at one point--how much time and effort do we put into people that call, that really should be being served through maybe the Council on Aging or one of those kind of programs. Most of the elderly people that called also had disabilities, so it was kind of a conundrum. We were oriented toward young and mature adults.

#### Moving Back to Santa Rosa, 1977, and Career in Real Estate

O'Hara: So you eventually then went back to Santa Rosa to be near your father, your parents. You had had an apartment in Santa Rosa?

Willsmore: Initially I did, until my father died. Then I moved in with my mother in the family house. It was kind of a symbiotic thing--she was not able to make it financially if I had not done that. It also made it much easier for me because she would be doing cooking and keeping the house up and such. She also helped me in the evenings--in fact, five days a week she would usually help me in bed.

O'Hara: At night.

Willsmore: Yes.

O'Hara: Was it different being in Santa Rosa then, from when you left to go to Cowell?

Willsmore: Big time different, yes.

O'Hara: So what was the difference?

- Willsmore: I was basically independent. I could do what I wanted to do, I had my own van, I had developed--once I was up in my chair for the day, I was independent. I didn't really need any help.
- O'Hara: So you had acquired a power chair while you were at Berkeley.
- Willsmore: Right. In the Cowell residence program.
- O'Hara: You hadn't had one before. And a van.
- Willsmore: And also learned a lot of little tricks that we all learned about how to do things.
- O'Hara: Had you been hiring attendants before you went to Berkeley?
- Willsmore: Yes. Wait a minute--no, I take that back. I thought you meant before I went to Santa Rosa. No, I think what we had there was visiting nurses, and that was the extent of our home care there. I wasn't even aware that there were was money for attendant care.
- O'Hara: So you learned a lot, you acquired a lot--
- Willsmore: Then after not working at CIL--after resigning there--and deciding that no, I don't want to do planning [chuckles]--I actually was still living here in Berkeley when I was really doing some research on where I could work. I wanted a job where you didn't have to show up at eight in the morning because I knew that wasn't real practical for somebody in a chair. I had saved up a big chunk of money, and near the end of my employment at CIL I was beginning to think that I was going to resign and do something else, and I also had saved up quite a bit of money in a PASS--a Plan for Achieving Self-Support. It was supposed to be used for purchase of a home and to modify the home so that I could be independent and function. I was looking for a place to buy, and I was dealing with this one real estate agent and he showed me a four-plex. I started talking with him about what it was like to be in real estate and if he thought I could do it--because I found it pretty interesting, the whole idea of selling property and especially the income property aspect of it. He said, "I think you can do it. I know this one fellow who's in a wheelchair that does it, and he does very well at it." He gave me his name and phone number, and I went and visited with him and interviewed him to find out how he did all this stuff. I went and talked with the Board of Realtors here in Berkeley, and I was getting excited about it. I felt it was really something that the Lord had kind of guided me into as an alternative to what I was doing

before. So that's how I ended up in real estate, and basically I got my training for it in Santa Rosa after I had moved there.

O'Hara: You didn't do any work here.

Willsmore: I didn't do anything here, no. I had an offer on a property, and that's about the most I did in real estate here. I pulled out of that at the last minute because I had resigned my job, and number one, I didn't think I could qualify for the loan, and number two, the future was too unsure to go into a major transaction like that. Anyway, I withdrew from that escrow and moved to Santa Rosa and went to junior college and did the classes there and bought a book and studied and took the license test and passed. I started talking to various offices and ended up at Century 21 because they had such good training.

The Department of Rehab did help me out a little bit at that time too, getting me resituated in real estate. They bought a set of ramps, they helped with transportation money for a while until I got going.

O'Hara: A set of ramps to get into properties?

Willsmore: To get into houses, yes.

O'Hara: Did you stay with Century 21?

Willsmore: For about a year and a half, and then I moved to Hurd Real Estate where I've been ever since.

O'Hara: And it's been a success?

Willsmore: Yes, very much so. I love it. I'm a numbers cruncher, so that's why I love commercial and income property.

O'Hara: I'm sure future historians will want to know when they read this document how you get into--how you actually manage.

Willsmore: Some I can get into, and some I don't, believe it or not. I've sold many properties that I've never been in. If I can't get in and if it's impractical--well, I can get into anything; there's always a way, but it just doesn't make sense to do it. As long as the buyer sees it and he's happy with it, and we have all our inspections and so forth, why do I need to see it?

O'Hara: How do you sell it if you haven't seen it?

Willsmore: Income property is pretty unique in that way, and that is if it's in a good location, if it looks okay from the outside then

chances are they've probably taken pretty good care on the inside. It's the numbers a lot, that's what investors rely on. Most of them, even though they say "I'll buy it" and it's in not so good a location, as long as it's making a lot of money--not really true. Almost every investor I've ever dealt with wants to be in the best location they can possibly be in--and of course have the property in the best shape possible. But it's extremely hard to sell property in bad areas. So I gave up on that. I just skim the cream; I work the areas where I know investors want to be. But you learn all these little things as you go along. You also learn that what people want--when I first started I thought like you were thinking there: "Oh, they're going to think that I'm not able to do a job for them." And that's not true.

Neil Smither, who is the fellow that I met who was in a chair and who was a very successful agent, ended up starting his own brokerage and had three offices. I don't know what he's doing now. He bought a lot of property at a very opportune time. He went into it, I think, in about '71 or '72, and it was just starting to really take off then. He pyramided--he was originally on SSI, and he made big bucks on the real estate that he bought. That became more of an income, of a moneymaker, for him than his sales of real estate.

Anyway, he was very encouraging and helped me to understand that people don't necessarily care if you don't have a lot of physical attributes--or abilities--that everybody else has. What they want is somebody that knows what they're doing and whom they trust. Basically that gave me a lot of confidence, because I got to where I knew what I was doing [chuckles]. And that kind of comes through when you're talking with people. They know immediately whether you know what you're talking about, if they're a smart investor. A beginning investor might not know, but most larger investors--which is the ones I like to deal with [laughs]--would know right away whether you know what you're talking about. So that's helped.

Community Resources for Independence and the National Spinal Cord Injury Association

O'Hara: Did you do anything with the--there's a center for independent living up in Santa Rosa, isn't there?

Willsmore: Yes.

O'Hara: And a Disabled Students' Program at the Santa Rosa Community College. Were you involved with either of those?

Willsmore: I did work with the initiation of the center there.

O'Hara: What's the name of it?

Willsmore: Community Resources for Independence--CRI. It was initially started by a fellow named Peter Leech. He was a post-polio quad, I think, but he had pretty good use of his arms and some use of his hands.

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O'Hara: Did you work there or volunteer?

Willsmore: I volunteered and was a member of the board. At one point I was vice president or vice chairman of the board. That's about as much as I got involved. I knew I didn't want to work there after going through my process with the Center for Independent Living. In fact, when I left Berkeley I said, "I am leaving the 'valley of the disabled'. The hell with that." [laughter] "I'm going to go into the real world." There was actually even almost an artificial work environment around CIL and PDSP and rehab type of jobs and those kind of things. It made accommodation for people and maybe didn't challenge them in their jobs as much as private industry would have.

O'Hara: You mean the accommodations were excessive?

Willsmore: I don't know. I don't think people were expected to work quite as hard as they would be expected to in private industry. Either you work hard and earn your keep or you're out, in business.

O'Hara: How did you get talked into or--let me rephrase that. What made you get involved with CRI?

Willsmore: I don't even remember how I met Peter, other than maybe he lived on the end of our street and one day saw me or something. I don't remember really, to tell you the truth. Or maybe I saw him uptown or something.

O'Hara: He was the director up there?

Willsmore: Yes.

O'Hara: Was his organization modeled after CIL?



Willsmore: Yes, very much so. It was right around the time when Ed was director in Sacramento, and he was beginning to develop the concept of other centers for independent living. There was some seed money that was going out to six or eight places around California that he wanted to get some other CILs going in other locations. Somehow Santa Rosa got in there, and Peter was very well connected also, through school--through Sonoma State University. That played a big role in it, I guess.

O'Hara: Are you still involved with CRI at all?

Willsmore: No. I left there again because of a hiring issue [laughs]. In this case it had to do with gays, and I have a moral aversion to that lifestyle and so it came down to--we were hiring some major position in the organization. The board was the one that hired--it wasn't always necessarily the director that made the final decision on every position; on departmental positions the board had equal say or actually overruling power. Anyway, we were interviewing for this one department head position. There was a lady who was gay and who had applied, and there was another party that I thought was better qualified. Somehow it came out of my mouth that all things being equal, if the two people had equal skills and abilities I would rather choose the one who was not homosexual. Because of all the political correctness and whatnot that was beginning to take hold at that time, that was very unpopular and I was actually asked to resign. So I did. They hired her--caused major problems [chuckles].

O'Hara: You mean she caused major problems?

Willsmore: Yes, she did. She turned out to be a real--she ended up suing them. I don't know exactly what those problems arose around other than I know that she had a lot of anger.

Anyway, so that was another putrid experience [laughs], so again for several years I didn't do anything in relation to disability other than I did volunteer with United Way. For a couple of years I was on their funding committee or something--I forget what they called it, but it was basically the committee that made the decision on who got money and how much and all that.

Then nothing for quite some time, then some woman sent me--somehow she got my name as being a quad--an invitation to a meeting of a group. It was the National Spinal Cord Injury Association. It was a chapter that was starting up in Santa Rosa, and so I got involved there. I was quite involved for about two or three years and then my interest kind of waned



because the woman that was running it was not disabled; her son was disabled. And I really felt that to make that thing go it needed somebody at the head of it that was disabled.

O'Hara: What was its purpose?

Willsmore: Kind of similar to an independent living center except it was specifically for spinal cord injury. There are real specific problems around spinal cord injury that all spinal cord people have, and they're pretty severe at times. The whole idea of peer counseling is very, very helpful in that area. Anyway, we kind of spun wheels for a long time.

O'Hara: Is it still in existence?

Willsmore: It's still in existence, but it's not doing what it really needs to do. The woman that's the head of it, basically the one thing that she has accomplished is that she has gotten together a very large resource library and video library. I think they still do send out videos to newly injured spinal cord--. That's a real helpful thing because knowledge is real helpful when you're first injured, because you don't know anything. I mean, you think you'd learn things in rehab but you didn't [chuckles].

### Religious Faith

O'Hara: Are there any other areas that we need to cover? One thing that we have not done is talk about or even mention the role that religion has played in your life, and that seems like it would be very important in looking back over the years.

Willsmore: Yes, my faith has gotten me through; I probably would have been dead by now without it [chuckles]. At the time that this whole fiasco at CIL happened, when I resigned and such, it also happened to be a time when I broke up with Judy--the woman I had been going with for about four years. She was also a quad. That was a real bad time for me. I had been a churchgoing kid--my parents sent me to church; they didn't take me to church. I got a lot of the Gospel when I was young, and as a matter of fact, when I was six years old I gave my heart to the Lord, and I really felt that something happened at that time. So I always had a love for God and for the Word of God. Of course, when I was a teenager--all kinds of influences come up and steer you away from those kind of things. But the spinal cord injury kind of brought me back to that, and I got into

reading the Bible again and reestablishing a relationship with the Lord. But then again, when I moved to Berkeley that kind of dissipated. I guess what I should have done was to find other like-minded people, but rather than do that I just fell in with the folks that were there and had fun--sowed wild oats, so to speak. When that thing happened at CIL I really reached out to God and He was there for me. And He's done a lot of things in my life ever since. I mean, He's made a way where there was no way. I still to this day--that's probably the most important aspect of my life, and it gives me great strength. A great deal of strength.

O'Hara: Probably a good place to end, isn't it?

Willsmore: Sure.

O'Hara: Thank you, Herb.

#### Addendum on the Cowell Program

[Interview 5: February 7, 1999] ##

O'Hara: This is Herb Willsmore on February 7, 1999, via telephone. Herb, in an interview with another one of our interviewees, we have run across some allegations that were very strong and very negative about the Cowell residence program, and we wanted to just check it out with your memory and see if you have some of the same memories, or if you have a different perspective.

Willsmore: Okay.

O'Hara: What we have been told is that there was "...a campaign of calculated viciousness," I'm quoting there, by Eleanor Smith, Lucile Withington, and Dr. Henry Bruyn, and that many of their actions endangered the physical health and the mental health of the students at the program. I wanted to ask you if you had some specific recollections of maybe about eight different things.

Willsmore: Okay.

O'Hara: One was, did anybody withhold medication from students?

Willsmore: If they did, I didn't have wind of it.

- O'Hara: Did you ever know of--and I'm not even sure what this means exactly--but did you ever know of any of those individuals removing a student's primary daily health provider? I think that might mean that someone's attendant might have been barred?
- Willsmore: I know there were a few attendants that were pretty heavy into drugs at the time, and there were some that I think the staff there, and probably Lucile, would have been against. But I don't know directly that that was ever done.
- O'Hara: You mean if anybody's health provider was removed?
- Willsmore: Right.
- O'Hara: I'm not sure what this word "health provider" refers to. What about removing medical records? It seems to me I have heard that one or both of the nurses up there took some records home. Have you heard that?
- Willsmore: Ah, no.
- O'Hara: Okay.
- Willsmore: I don't even know where the records were kept.
- O'Hara: There was another allegation that the three individuals played on the dependency of people with disabilities, and on the fears and self-doubt that our interviewee felt that most people with disabilities have.
- Willsmore: Hmm. Well, you know, if this stuff went on, it was not something I really was tuned into. I know there was a little tiff of some kind between Lucile Withington and Don Lorence, and that--in fact, my recollection is very blurry, but it seems to me like because he was not centering on employment-oriented education, there was talk about him leaving, and anyone else that wasn't moving along in their career goals.
- O'Hara: Tied in with that is the allegation that these three people attempted to have the University of California kick out selected students who were academically successful but identified as leaders. And I'm quoting on that one. Is that a slant that you were talking about, or were you talking about--
- Willsmore: No, I was talking more about the Department of Rehabilitation becoming a little uneasy about all the money that was being spent, and at some point, we had to kind of circle the wagons and start looking at what successes had been accomplished by

people that had gone through the program, and how near some were to getting a job, and kind of putting that in a summary or a study, and meeting with people in Sacramento to defend the Cal program, really. And to defend continuing to support severely disabled people that take a long time to rehabilitate.

O'Hara: So basically, are you saying that you didn't really see them picking off leaders? Their motive was not to do that?

Willsmore: You know, other than Don Lorence--but you know, Don Lorence did have a lot of dope going on in his room. And a lot of partying late at night. We all did, but I think he and his attendants may have been a little more oriented in that direction. Possibly Bill Glenn was on prescription medications, and if there was anybody that I would think there might have been some withholding of medications--but I never heard about it--it would have been probably Bill Glenn.

O'Hara: Could you elaborate on that a little bit?

Willsmore: Well, he was taking a lot of Darvon and other kinds of things. I think it was more for the high than for the pain. I don't know anything real detailed about it, but I do recall that he was kind of hooked on prescription drugs, I would say. I don't recall if there was any specific talk, but I know he had a problem with that.

O'Hara: But so--I see. We'll just let that go at that. Another allegation, I wondered if you remembered any specific incidents where confidential psychiatric information was used in public to humiliate and intimidate students.

Willsmore: Hmm. Well, I don't know what they mean by "in public." These are allegations that I--. We had our problems with the administration, but boy, nothing on the kind of level that I'm hearing from these questions. We had our battles, because of finances and tight budgets and people that weren't--you know, it was breaking new ground, kind of. So it was somewhat an uphill battle all the way, and including attendant care. When Reagan wanted to cut back one-half on the budget for attendant care, and that mobilized the whole state, basically.

O'Hara: What was the role of Withington, Bruyn, or Smith in that?

Willsmore: Oh, I think they were supportive in our fight, if anything.

O'Hara: I see. And there is also here the accusation that there were threats of removing students to back wards of county hospitals.

Willsmore: Huh. Well, you know, I don't know. That may have been something that--. I always thought that Ed Roberts was on very good footing with Bruyn and Eleanor Smith. He was one that came from a county hospital, and so did John Hessler. I do remember something about--you know, John every once in a while would say, "Before I would go back to that county hospital, I would die." So, I don't know.

O'Hara: And one last question: were scare tactics ever directed at students' families, in your recollection?

Willsmore: Not my family. Boy oh boy. No. And not that I know about.

O'Hara: I see. Well--

Willsmore: If this kind of stuff was going on, it's kind of news to me.





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Disability Rights and Independent Living Movement Oral History Series

UNIVERSITY OF CALIFORNIA'S COWELL HOSPITAL RESIDENCE PROGRAM FOR  
PHYSICALLY DISABLED STUDENTS, 1962-1975: CATALYST FOR BERKELEY'S  
INDEPENDENT LIVING MOVEMENT

Billy Charles Barner

FIRST AFRICAN AMERICAN STUDENT IN THE COWELL PROGRAM, 1969-1973,  
ADMINISTRATOR IN DISABILITY PROGRAMS IN LOS ANGELES

An Interview Conducted by  
Kathryn Cowan  
in 1999



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## INTERVIEW HISTORY--Billy Charles Barner

Billy Charles Barner was interviewed for the Disability Rights and Independent Living Movement Oral History Series because of his role as one of the first residents at Cowell Hospital and his participation in the development of the Physically Disabled Students' Program and the Center for Independent Living and his subsequent work in the field of disability in Los Angeles. Mr. Barner was the first African American to enter the program.

Mr. Barner received a spinal cord injury during a football game at Hastings College in Nebraska. He spent a relatively short time in rehabilitation, applied to the University of California, Berkeley, and became one of the early residents at Cowell Hospital. A member of the activist group Rolling Quads, Mr. Barner recalls the atmosphere and events that led to the development of the Physically Disabled Students' Program and the Center for Independent Living.

Upon graduation in 1973, Mr. Barner returned to Los Angeles where he has worked extensively in the field of disability, including fourteen years in the Los Angeles Mayor's Office for the Disabled. He now teaches special education classes for the Los Angeles Unified School District.

The interview took place in a single session on May 15, 1999, at Mr. Barner's home in Los Angeles, California. The interviewer lightly edited the transcript. Mr. Barner reviewed the transcript, making a few minor changes and adding a short paragraph.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. Copies of all interviews are available for research use in The Bancroft Library and in the UCLA Department of Special Collections. The office is under the direction of Willa K. Baum, Division Head, and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley.

Kathy Cowan, Interviewer/Editor

March 27, 2000  
Regional Oral History Office  
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Regional Oral History Office  
Room 486 The Bancroft Library

University of California  
Berkeley, California 94720

BIOGRAPHICAL INFORMATION

(Please write clearly. Use black ink.)

Your full name Billy Charles Barner  
 Date of birth 5-9-49 Birthplace Jacksonville, Texas  
 Father's full name Connie Barner  
 Occupation Tile Setter (Deceased) Birthplace Henderson, Texas  
 Mother's full name Bennie Ola Barner  
 Occupation ~~Custodian~~ Custodian Birthplace Henderson, Texas  
 Your spouse Carol Mercedes Barner  
 Occupation Data Entry Operator Birthplace Los Angeles, CA  
 Your children Aaron Charles Barner

Where did you grow up? # Los Angeles

Present community Southwest, Los Angeles

Education Masters Educational Psychology

Occupation(s) Special Education School Teacher

Areas of expertise Disabled Rights, ADA, 503, 504,  
Substance Abuse Administrator

Other interests or activities Disabled Advocacy, Chess

Organizations in which you are active Youth Motivation Task Force,  
City Mayors Office on Disabilities, County Commission on  
Disabilities



## INTERVIEW WITH BILLY BARNER

## I EARLY CHILDHOOD, FAMILY, EDUCATION

[Date of Interview: May 15, 1999] ##<sup>1</sup>

From Texas to California, 1963

Cowan: Billy, let's get started with some questions about your early childhood: where you were born, your family, where you went to school.

Barner: I was born in a small town called Jacksonville, Texas. I'm the eighth child out of a family of nine. I moved to California when I was twelve years old. I attended junior high school and high school in Los Angeles.

Cowan: What made your family move to California?

Barner: It was kind of a strange incident. My dad was self-employed in the lumber business. His brother passed away in Los Angeles, and my dad came to his funeral. After he got here, my brother found him a job as a ceramic tile setter. So he called home and said, "We're going to move to California." In about two months, we moved from Jacksonville, Texas, to Los Angeles.

Cowan: What year was that?

Barner: June, 1963.

Cowan: So you switched schools. Where did you go to school here?

Barner: I went to John Muir Junior High School, and Manual Arts High School.

Cowan: What kind of kid were you?

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<sup>1</sup>## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

Barner: Well, California was kind of a culture shock because when I left Texas I'd never seen a freeway. When I got to California, I was on the freeways, and all the hustle and bustle. It was pleasant. I think I adjusted very well. My old school in Texas--I think there were 300 students. When I got to Los Angeles, the junior high school had about 2,000, so I had to make those adjustments. But there wasn't any problem. I was a little apprehensive, but it went away very fast.

Cowan: Were you a good student? Did you like school?

Barner: Oh yes, I enjoyed school. If you ever knew of anyone from the South, their parents--that's the first rule: do good in school. So I did very well in school.

Cowan: Were you active? Did you play sports?

Barner: Oh yes, in junior high school, I played basketball and track after school. In high school I played football.

Cowan: Football--and is that how you were injured?

Barner: No, not in high school. I played football but I did not get injured. After I graduated I had a number of different scholarships--academic and athletic--to different schools. In fact the first school I received a scholarship to was William Jewell, that was in Liberty, Missouri. But there was a school called Hastings College in Nebraska which I had been looking at and I liked. The representative came to our school, Manual Arts, and offered me a full scholarship. I chose to take it. However, my mom and dad did not want me to play football. In fact, my dad would not sign the release for me to play, and my mom had to sign it.

### Spinal Injury Playing Football

Cowan: It was a football scholarship? That was going to get you there?

Barner: Yes. I went to Nebraska in August, and I was injured November third. So I was only in school approximately three months before I was injured.

Cowan: Was it a football accident?

Barner: Yes. I dislocated a cervical vertebrae--C5,6--in my neck, which totally paralyzed me. I was injured in Lincoln, Nebraska. We

played a homecoming game at Nebraska Wesleyan University in minus zero degree weather. I speared a player on the other team with my head, and fell to the ground paralyzed immediately. It was a common football tackle!

### Rehabilitation and Return to School

Cowan: What happened after that? Did you go to rehab then?

Barner: I stayed in Nebraska for thirty-two days. At one point I could not move anything but my eyeballs. They did surgery and my mom flew back that same night. After thirty-two days, I came back to Los Angeles on a train. I came to Los Angeles Orthopedic Hospital, right here in Los Angeles--2400 South Flower St.--and that's where I did my rehab. I was in L.A. Orthopedic for approximately three and one-half months. I was back in school within four months.

Cowan: That was fast.

Barner: Yes, because of my condition for playing football, the doctor said that I really recovered fast. I just applied my athletic abilities that I did to football to rehab, and I was back in a junior college, just taking classes to see how I could adjust. I was back in school within four months.

Cowan: That's really fast.

Barner: It usually takes eighteen months, eighteen months to two years, for someone to recover from this type of injury.

Cowan: How did you make the adjustment? What were your feelings?

Barner: I never was bitter or angry because I loved football, and my brother, who is now Dr. Robert Barner, was a senior at the University of Redlands, and I went to stay with him. That was very vital in helping me make the transition, going back to school and staying with him on campus. I had already been accepted to the program at Cal--the PDSP, the Physically Disabled Students' Program--but I didn't want to go jumping back in by myself. So I decided to go a semester with my brother and live with him. That was really beneficial.

Cowan: They were a big influence on how you felt--your brothers?

Barner: Yes.

Cowan: In what way? In what way were they helping you make that adjustment?

Barner: They were family, and there's nothing like a family. Staying with a family is a whole different story. At the hospital and even in Nebraska, I was like a stranger. But living with my brother--it made me feel like I was at home, so that was a major factor. And my mom was a major factor: three months I was in the hospital, and she never missed one day visiting me.

Cowan: That's wonderful--moms. How did you get some training for living your daily life? Did rehab help you with that, or was it mostly your family?

Barner: No, I got the training through orthopedic, through occupational therapists as well as the physical therapists. They let me go with all kinds of splints, braces, apparatuses, and so forth. They also trained my mom and my family how to take care of me, but that wasn't very difficult.

Cowan: When you left the orthopedic rehab, did you have a wheelchair or a power chair?

Barner: That's an interesting question, because I was able to push a wheelchair almost like a "normal" person. But my doctor said he didn't want me to have a power chair because I would lose a lot of my muscle tone. He wanted me to stay in a push chair. I had to convince him that by going to school at Berkeley or University of Redlands where there's a lot of hills, I couldn't make it all day long, I would be tired out. He finally broke down and ordered me a power wheelchair.

Cowan: And was that wonderful?

Barner: Yes, it was good because that way I could do as much as I wanted to, go any place that I wanted, and not worry about being exhausted at the end of the day. I would also still on weekends get in my push chair and wheel around just to keep up my cardiovascular.

Cowan: Did you do any kind of sport things?

Barner: Yes, I played poker.

Cowan: [laughs]

Barner: No, I played pool, table tennis, chess, and things like that.

Cowan: To keep your athletic interest up?



Barner: Yes.

Cowan: What were you studying at the University of Redlands?

Barner: At the University of Redlands I was just getting my prerequisites out of the way. When I was injured at Hastings College, I got all withdrawal passing, so I hadn't acquired any units. So at the University of Redlands, I took the prerequisites--math, English, whatever.

Cowan: What were your plans for the future when you went to Hastings?

Barner: I didn't really know. Football was my life. My mom cried when she signed the papers. I said, "If you don't let me play football, I don't see any need to go to college." When I got to college, I was there to play football. But as time went along--even though I was only there three months--I begin to feel like I was getting into the real world, and I began to think about possible majors. I thought about psychology and sociology.

Cowan: So that's the direction you decided to go?

Barner: Yes, I thought about that very briefly. Three months is not a real long time.

Cowan: No, it isn't at all. When you were at Redlands were you still thinking along those lines of psychology?

Barner: I thought about psychology. That was my major course, Psych 1, and I started to psychoanalyze everyone after that [laughs]. But now I'm in physiology because I wanted to learn as much as I could about my own disability, about the spinal cord and how it functions, the physiology of the central nervous system.



## II THE COWELL HOSPITAL PROGRAM AND PDSP, 1969-1973

Enrolling at UC Berkeley, 1969

- Cowan: You were at Redlands, but you had already applied to Berkeley?
- Barner: Yes, I'd already been accepted.
- Cowan: How did you hear about that program?
- Barner: From a very close friend of mine, who was a nun, Nancy Ellis. She came in one day when I was in orthopedic, and she said, "Bill, I heard about this program up at Cal Berkeley, and it's for disabled students. They make arrangements for you to live, and get attendants, and the whole nine yards." So I applied. I had to go through a battery of tests because in 1968 or '69, they felt if you had a spinal cord injury, it somewhat affected your cognitive ability. So I had to take a battery of tests, and I scored in the 90th percentile on all the tests. Berkeley accepted me, but I told them I would not come--I think it was a quarter later, maybe two quarters later before I would come. They said fine.
- Cowan: You took the test down here?
- Barner: Yes, I actually took the test through the State Department of Rehabilitation. They paid for the test.
- Cowan: Were they also going to pay for your tuition at Berkeley?
- Barner: To get accepted into the program, you automatically became a client of the State Department of Rehabilitation in the Bay Area, so they were just transitioning me from L.A. to Berkeley. So I transitioned to the State Department of Rehabilitation in Berkeley from L.A.
- Cowan: That's a big leap, isn't it? What did you think about going to Berkeley? What were your plans then?

Barner: I went to visit Berkeley before I attended school there. I went up approximately five or six months before I was going to stay. For lack of a better word, a little culture shock [laughs]. Telegraph Avenue was full of dogs and strange looking people. But I really enjoyed it; I always relished a challenge. I didn't have any fears. I knew I was leaving home, and I was really looking forward to it.

Cowan: That fit in with your ideas of moving on?

Barner: Exactly.

Cowan: Do you remember what quarter you moved up? I think they had quarter system then.

Barner: I went to Berkeley in August of 1969, and I was going to start school in the fall quarter of '69.

Cowan: Did you have to choose a major?

Barner: No. I didn't choose a major, but I did start taking psychology courses, prerequisites, lower division psychology courses.

#### Early Days at Cowell Hospital Program

Cowan: Tell me how it was to come to Cowell Hospital. Was that where you came when you first got to Berkeley?

Barner: Yes, this is an interesting story. My brother drove me up in a Volkswagen van, and we got into Berkeley about six o'clock in the evening. My brother dropped me off, and I already had my room set up. It was funny because when he left, I said goodbye. That was it, and the rest is history. Everyone was so cooperative. I think there were seven people in the program at that time when I went into Cowell Hospital.

Cowan: Can you remember who they were?

Barner: Yes. There was Jack Rowan, Donovan Harby--there was more--Judy Taylor, Gwin Hinkle, Herb Willsmore, Jerome Frazee.

Cowan: Can you recall that first moment you were there, what that was like? Were you nervous?

Barner: No, not at all. The students in the program were just so cordial and so friendly that I didn't have any bad feelings. Really, I

was happy. I was thinking, "This is your chance now, you're on your own." I'd always wanted to be on my own. I just said, "Now you're on your own, just in a little bit different manner--you're in a wheelchair." It was really delightful.

Cowan: Can you remember what things looked like?

Barner: You mean in Cowell Hospital?

Cowan: Yes.

Barner: I saw six or seven disabled persons. They were all quadriplegics, but they all had their own different personalities. It was interesting because at that point I started to learn how--we all discussed how we all had become disabled, what was the nature of our disability. It was interesting--they were all interested, they all thought it was just fantastic that I was injured playing football. This is something that still goes on now--when you meet disabled people and they find out you were injured playing college football, they think that there's some kind of accolades that go along with that that you don't get when you're injured in a car accident, diving accident, et cetera. My answer to that was that we're still quads, so no matter how we got there, we're there.

Cowan: What about the physical layout itself? Did everyone have their own room?

Barner: Yes, we had our own room, and we shared a bathroom. Gwin Hinkle was in an iron lung, so he had his own restroom, but the rest of us had our own room and we shared a bathroom. We had a common dining room that we all used.

Cowan: What was your room like? Just a bed, a desk?

Barner: It was large. I had a bed--later on a friend of mine, Greg Sanders' brother, was a carpenter. So he made me a beautiful desk. It was six to eight feet long, six feet high. It was very nice. They called me Mr. Neato because I kept my room almost immaculate, really. I really kept my desk neat, I kept my bed made-up, nice bedspread. So I got a few laughs with that, it was just kind of funny.

Cowan: So that wasn't typical?

Barner: No, not at all [laughs].

Cowan: Did everyone's room appear individual? Did they have their own posters on the wall?

Barner: Yes, we all had our own personas. They had their posters. Jack Rowan came along later on, and Jack had a waterbed. Judy, as a female, she had her room set up the way she wanted it. Everyone had their own personas, and that was the interesting thing about it. You get to see how the different rooms were set up, and you get some ideas from the other people. It was different, but it was very interesting.

I'd never been around disabled persons before. I had seen disabled persons in wheelchairs, but to be right in the midst and being disabled myself, that was a great revelation to me. I really took advantage of it because it made me a better person. I feel as though I was already a good person, but just maybe a better person.

Cowan: In what other way was it a revelation to you?

Barner: I was quite mobile and able to do a lot more things than most of the persons that were there. Matter of fact, they gave me the name "superquad." We had some straps and I could do fifty pull-ups and things like that. It was just a whole different sphere of life that I hadn't experienced. A lot of the other ladies and guys--for example, Gwin Hinkle was in a wheelchair--Gwin was really just ecstatic about my football career. He wanted to know all about my football career, so I would tell him all about that. It was just a whole different life. I actually divorced myself from the L.A. scene; this was the world to me now.

Cowan: It was a new identity.

Barner: A new identity, exactly. This is where I was going to have to be for a while.

Cowan: Did you encounter any resistance from the university in terms of how you were living up there, decorating your rooms and things like that? Were you just regular dorm kids?

Barner: No. The only problem that we got from the university was that we used to pull practical jokes all the time. One time we flooded the whole third floor and water went down to the infirmary. They didn't think we could do it, but they just came up and said--they used to refer to us as "you people." We always had a saying that three quads could make one "normal" person.

Cowan: [laughs] How did you do it?

Barner: We had ways of doing it. We used our wheelchairs as bulldozers, and we turned the water on and stopped up the sink.



Oh, by the way, I was the first African American student in the program. It was ironic because a few of the people did have questions, but I could tell that they would try to feel me out. As a matter of fact, at the time that I was there, there were a few little racial slurs; but if they'd say them, they weren't around me. I just laughed because I adjusted to it so well. I just really laughed and let it go by. It was never a problem. Only if I beat them really bad shooting pool or one-on-one on poker night, when they would say something insulting about buying me a watermelon or something like that.

### Memories of Staff and Students

Cowan: [laughs] What about staff? Who was there?

Barner: Ms. Edna Brean was the nurse. She was really great. She brought all of my medications and made sure everything went well. I went there with the same attitudes I did before: I was there to get an education. She would come in around nine, and I was very glad to see her. She was great; anytime I needed anything she was always there. She was a nice lady, very nice.

Cowan: So her role was--?

Barner: I guess you'd call her the nurse, the floor nurse.

Cowan: Did she help you with physical problems, or any kind of issue that you felt you hadn't learned how to do or needed help with?

Barner: I think Ms. Brean was really learning herself. At that time we'd already adjusted our learning how to deal with our physical conditions or problems. I think I did one thing that made Ms. Brean very happy. When I first got there, being the athlete, somehow I got the athletic department to donate some wall pulleys to the floor. Also, I helped the program get a pool table.

Cowan: That was your influence.

Barner: Yes. Ms. Brean really got in touch with that, she really liked that. We would just be sitting around on Saturdays after class, and we would shoot pool, and we'd use the wall pulleys. It was really fun.

Cowan: I was going to ask you about that, what you did in the evenings.

Barner: We would come in, have dinner--at that time we were having dinner from the cafeteria. They would bring it up to the third floor, and we would eat. Don't ask me how the food was; I remember it wasn't very good. We'd always look forward to steak because steak was once a week, so we'd look forward to that. After that, we would shoot pool.

Cowan: Did you all eat together, or in your rooms individually?

Barner: Yes. Donovan Harby stayed in his room, and his attendant would come and feed him in bed, but the rest of us would eat in the cafeteria.

Cowan: You ate in the cafeteria?

Barner: It wasn't the cafeteria, it was the lunchroom. We called it the lunchroom. We had a six-foot diameter table, and we'd all come in and eat, tell jokes, and laugh. Most of the time we'd all eat down in Sproul Plaza.

Cowan: [laughs] It was a social event.

Barner: It was really kind of fun because as the program began to grow, we would begin to come in together and tell jokes. We'd spend an hour and a half, two hours at dinner--throwing jello, having food fights, whatever.

Cowan: College kids. Was it what you expected?

Barner: It was more than what I expected. First of all, I'll say it again, the people were so nice. It was like it was a home away from home.

#### Hiring and Training Attendants

Cowan: How about attendants, did you have an attendant by then?

Barner: Oh yes, as a matter of fact, I had four attendants. When people would come into the program, they always called me "Mr. Surly" because I was very strict about my attendants.

Cowan: Mr. Surly?

Barner: I guess you could use that word because everything was quite rigid. You had to be on time. I always scheduled my classes--the first class would be nine o'clock in the morning.

But it got to the point where I was one of the ones who would help my friends screen attendants. Some of the attendants wouldn't show up on time, and if you're lying in bed and you need to go to class, or you may have to go for your bowel or bladder treatment and nobody showed up--. I took on a lot of different faces when I was there, and that was one of them. A lot of people would come ask me and say, "Would you please interview this person for me before I hire him?" I had two attendants who stayed with me the whole four years I was there.

Cowan: Who were they?

Barner: Bob Zlomke, he was out of Rice University. He was a graduate student in German. Alene Levine--she was a young lady; she worked for me. Dave Ceponis--he rode a bike all the way from Philadelphia; he was a student at Carnegie Mellon. They stayed with me for many years. If I was gone to Los Angeles in the summertime, we'd connect back in the fall.

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Cowan: Billy, you were just starting to tell me how you got started in helping other people train and hire their attendants.

Barner: A lot of the students that came in after I was there, they were very submissive. They'd just come from home or wherever, and they were afraid to reprimand their attendants. If you really got on the bad side of your attendant, they'd come in late sometimes, or they wouldn't show up. I just told them that if it didn't work out, just fire them. There were a lot of students on campus who wanted jobs. Most of our attendants were students.

#### Reviewing Applicants to the Program

Barner: Even then, too, I was on the panel who would choose the new students to come into the program. They would have to be interviewed by people already in the program to come in.

Cowan: People who applied for Cal? I didn't know that.

Barner: You just couldn't come in because you were disabled. You had to commit to taking the same academic standards that everyone else did.

Cowan: What were some of the qualities you looked for? Assertiveness?

Barner: Yes, and self-esteem. I don't recall turning down very many people, but we looked for those persons who really wanted to do something for themselves. It was hard. I remember my best friend, Greg Sanders, came in--his parents brought him in--and you know, to suffer a traumatic injury at age nineteen is kind of tough. He was a little quiet, but something I saw in Greg, I said, "Let's give him a chance"--you can't ever tell. So he was just one that I can recall, and we let him in. I guess they respected me on that.

Most of the other gentlemen, other students that came in, we'd ask them questions like, "How would you feel staying away from your parents?" Susan Ward was another student who was there, and she lived in Hayward, so that was right close to the campus. So those were some of the things that I looked for.

Cowan: Can you remember hiring your first attendant? What that was like?

Barner: My first attendant, I think Ms. Brean sent the person to me. I didn't hire him; he was waiting for me when I got there. The person worked out, but I can recall hiring attendants after that, though. But yes, this individual was a pretty good attendant, so he worked out. Because when I was dropped off, like I said, on that Saturday afternoon, I didn't know anybody, and I was just waiting for that guy to come in; he came in, and we worked out real well.

Cowan: Was he someone with a little experience already?

Barner: No, he didn't have any experience. I always felt better to take those who didn't have experience than have those that had experience because if they did have experience, they always wanted to see things their way--in other words you could say, "I need my pants adjusted," and they'd say, "Well, it looks fine to me." But if they didn't have any experience before, you could tell them and they knew exactly how you wanted things done.

Cowan: Did attendants take you to class?

Barner: No, not at all. Attendants would come in for me in the morning, get my breakfast, get me dressed, get my bath, get me in my chair, and that was it. I wouldn't see them anymore until ten, twelve, or eleven o'clock at night.

Cowan: How about class? Did you have difficulties taking notes, or did you have any gadgets that helped you? Did you tape?

Barner: We had splints that we could write with, but it wasn't that beneficial. What we did was, the State Department of

Rehabilitation paid for note takers. I went to class I always looked around to see if I saw someone--usually it was some young lady that could write really well, because you know guys, they just scribble. I'd always look around, and I'd ask them if they would like to take notes and get paid. They said yes, so that's how I got my note takers and people to do my typing.

Cowan: So DR paid for both of those services?

Barner: Yes.

### Experiences on Campus as an African American with a Disability

Cowan: Did you experience any difficulties in class? Was there resistance from other students? Did other students resent having a person with disabilities in class, or was there any kind of reaction from the students or teachers?

Barner: No, at that time Berkeley was a place where everything went well. It was just like: love, peace, and happiness. I can't recall one bad moment. The only--I won't call it a bad moment, but I was going in Wheeler Hall, and there was a big heavy door at Wheeler Hall where I couldn't open it. When I left Cowell Hospital, it wasn't raining--but in winter quarter it starts raining overnight --it rained for two days at a time. When I got to the door, I was sitting there, but I couldn't get in. This gentleman came by and he was going in, so I said, "Can I follow you in?" He said, "No," and went in. I don't want to call it unpleasant, but I said, if that's the way you feel, that's fine. It didn't bother me.

But the students were great. Myself and friends of mine--well, yes, I did fall out of my chair a couple of times. One morning I was inebriated and I fell out of my chair Sunday morning, fell in the middle of College Avenue. Some college guys stopped and put me back in my chair.

Cowan: You didn't have experiences of discrimination or rejection?

Barner: No.

Cowan: You are kind of a double minority, both a person with a disability and an African American. But that was not a problem?

Barner: One thing I found when I got to Cal was that I thought more--well, I'll just tell you the incident. I didn't see any African American students. This was right before the fall quarter



started, so I said I would go out to Sproul Plaza and look around. One day I saw these six African American young ladies, so I said, Oh, I see some African Americans, I'll go over and get acquainted. I went over and I said, "Hello," and they just fled like you'd throw a rock at a flock of quails. I said, "Oh, what did I do?" That was one experience I had. Then come to find out that the next quarter, they all were on academic probation, and they were no longer there. That was kind of strange--that was a weird feeling, because it seemed like they were the ones that most scrutinized my disability, but I know they didn't have two words to say to me.

Cowan: They were young too.

Barner: That's true.

#### Beginnings of the Physically Disabled Students' Program

Cowan: I wanted to talk some about the forming up of an organized group in PDSP. At this time was it PDSP, or was it the Cowell Hospital program?

Barner: It was called the Physically Disabled Students' Program. Well, I guess they had a dual name: with the University it was PDSP, and it was also called the Cowell Program. The PDSP was an office over on Durant, behind Top Dog.

Cowan: But that hadn't quite formed up yet when you got there--is that right?

Barner: Somewhat--it was there, but it wasn't as active as it got to be, no, but it was there. It wasn't quite formal.

Cowan: I understand you and John Hessler were great friends.

Barner: Yes, we were very close.

Cowan: What kinds of things did you guys do together?

Barner: Played poker, drank a lot, ate pizza--just did the normal things. Also we worked on making the PDSP better.

Cowan: Was John living at Cowell when you got there?

Barner: No, John had moved out of Cowell, but he was up there almost every day.



The Rolling Quads: Organizing Politically, Lobbying in Sacramento and on Campus

- Cowan: Those meetings at night and when you talked around the dinner table, were you thinking of a program or thinking of things that needed to be done? Were you becoming a group?
- Barner: We were becoming cohesive, but we weren't really talking about anything of any substance. We were just talking about what went on the day before, when the next poker game was. It didn't really get serious until--Ronald Reagan was governor at the time. Ronald Reagan decided he wanted to close the program down. Somebody in Sacramento felt that the Cowell program or PDSP wasn't standing up to whatever the standards were.
- We all got together, and I was the one that was to go around and interview every student in the program--I think there were about nine of us at this time--and find out where we would be if we were not at Cal. I can't remember exactly, but over 75 percent said they would have probably been in a convalescent home. We got in touch with Sacramento, and Reagan said he would speak with us. So we all got together--a few guys had cars: one guy had a car. Jack Rowan had a van--you could see the highway down through the floor, but it was a van. So we all got together--I can't remember what day it was--and we went to Sacramento, to the capital.
- Cowan: Who do you mean by we?
- Barner: I think we were called the Rolling Quads at this time, so there was myself, Greg Sanders, John Hessler, Herb Willsmore, Judy Taylor--as many as we could get into the vehicles we had. We got to Sacramento, and we went in this room; we had to go through the service entrance because it wasn't accessible at the front. We went in this large room, and we said, "We're here to see the governor." This gentleman walked in with a large tape recorder and said, "I'll put your testimony on this tape." And that was kind of a big blast; but anyway, we talked and he reinstated the program.
- Cowan: Was that the program or was it a threat to cut attendant care?
- Barner: No, that was to cut the program, and that would also cut attendant care.
- Cowan: What was the issue over attendant care? I heard there was an issue that he had wanted to cut attendant care as well. How were attendants paid?

Barner: We paid attendants through what they called then ATD.

Cowan: What does that stand for?

Barner: Aid to the Totally Disabled. We got \$333 a month from the state. We would pay our attendants from that money. At that time we were paying--I think it was something like--three dollars an hour, two or three dollars an hour. If you found a really good attendant, you would pay them maybe four. But since you mention it, I do recall something about that, but I can't remember the exact specifics about it. I remember the attendant care thing came up.

Cowan: Attendant care was available not just to students but to everybody who was disabled?

Barner: Yes, once you got accepted to the program, all these amenities were available to you.

Cowan: Back to the Rolling Quads that you mentioned. I have heard that that group formed up and became an organized political group. Tell me how you think that happened.

Barner: There were issues that--the answer is we were just looking for anything so we could get in trouble [laughs]. Berkeley was very political in those days. Let's see if I can recall one specific issue. It had something to do with the program, and we all circled Sproul Hall. Ed Roberts was there; we were going up and down Sproul Hall; we went to San Francisco. I can't remember the exact issues, but whatever came up, we would get as many wheelchairs as possible and usually there were more than fifteen to twenty wheelchairs. We just encircled the buildings, carried posters, we all wore the army fatigue jackets and early twenties hats, and we would just protest. But it was really for a good cause. We didn't really do anything just to be doing it; we fought for our rights.

Cowan: Were you thinking of yourself as a group at that time? As a group that had political issues?

Barner: Oh yes.

#### Developing Leadership and a Political Sense in PDSP

Cowan: Did you have issues with the university? Do you recall any meeting with any of the university officials?

Barner: The university was great. If I'm not mistaken, Betty Neely was there to help us disabled students. I do recall one issue that came up. Even though we were a close knit group of people--I've mentioned Greg Sanders' name and Jack--the university decided to take twenty-five cents from each student to put into a fund to help assist the disabled population, because some of the people that moved out were having trouble with rent, utilities, and so forth because it was hard to make it on \$300 per month.

They said it would be twenty-five cents every quarter from each student. That came to something like \$15,000 to \$20,000, so it was a nice sum of money. But all the disabled people wanted to put the signature power in John Hessler's hand, and that's when we became a little divergent. While there were just the three of us --myself, Jack Rowan, and Greg Sanders--we decided that that wouldn't be very good.

Cowan: I don't know what you mean by put the signature power in John Hessler's hands.

Barner: The money that would be accepted from the students at Cal Berkeley, twenty-five cents per quarter--I can't remember what that would come out to, but John Hessler would have signature power over that money. If I came in and said, "John I need \$500, I'm moving;" "I need \$500, I didn't make my rent this month"--he could just sign it over. We felt as though that was not fair to John and not fair to us because he was too close to us.

We met with Ms. Betty Neely and some of the administrators, and we won it, that Ms. Neely would have the signature power. We thought that that wouldn't be fair really to him because how could he turn down a friend. But believe it or not, there were no bad feelings. No one disliked us; they just knew that we did something--that if we didn't like it, we would deal with it.

Cowan: You mean no bad feelings between the residents.

Barner: Right, so they would just deal with us. Maybe about twenty or thirty saw it that way.

Cowan: Would you say that you were the leadership? Who would you say were the strong leaders in getting this group together?

Barner: As I said, John Hessler was there--not living there--but John would come up there quite a bit. I learned a great deal from John, from Herb Willmore, and also Ed Roberts--Ed was such a great guy. It didn't take very long before I began to get into the swing of things and see what was going on. It's like the baton was passed on--myself, Jack Rowan, Greg Sanders, Judy

Taylor, and Mary Ann Hiserman--we decided to take up were John and Ed had left off. We were always in contact with Ed and John.

Cowan: What do you think made Ed and John the leaders to start with?

Barner: First of all, Ed was the first student in the program, so he had a jump on it. He knew what was going on, how things worked. John came along, so they both just jelled; they knew all the ins and outs.

Cowan: Were they forceful people?

Barner: No, but very political, though.

Cowan: What was the difference between the two?

Barner: Forceful--to me--is when you try to make someone do something. They never tried that. They would never force you. They would say, "This is what we're going to do. If you have your feelings about it, say it, you don't have to do it." They just let us use our own minds.

Cowan: Do you think that your group was developing the idea of PDSP? That you were creating it?

Barner: Yes, PDSP was developing from all of that--anything that helped or affected the program. It was growing because we would counsel students in the city who were disabled. Whenever students were having trouble with classes, they would come to PDSP. John wanted to put me on payroll, but I never accepted a salary. I would go over there after classes and work there, but I never accepted a salary. I knew some days I'd have to take a test, and I wouldn't be there in time, so I volunteered time there.

Cowan: So you did work there, but not on a paid basis?

Barner: Yes, I volunteered there.

Cowan: On Durant.

Barner: Yes, behind Top Dog. I would eat Top Dogs for lunch [laughs].

#### Working for Accessibility on BART and in Berkeley

Cowan: How did the ideas of what services were needed--is that something that developed out of your discussions at Cowell?

Barner: PDSP kept a file of attendants--about this same time CIL came along--Center for Independent Living. I remember, it was John--Ed Roberts was there too. As they say, necessity is the mother of invention, and a lot of people wanted to move out of Cowell Hospital and become independent in the community. At first a few persons moved out of Cowell Hospital, but they had to move back because they couldn't maintain in the community. So that became the CIL movement. As memory serves me, I think it was about a \$10,000 grant. I think Larry Biscamp had a lot of work to do on that. That was just about the time when I--I was in my senior year, but I remember working on the proposal to get the program funded.

Cowan: For CIL?

Barner: Yes.

Cowan: In creating the ideas for PDSP--say, to decide you needed a wheelchair repair, do you recall having that kind of discussion go on--say, What do we need, what do we have to offer?

Barner: Yes, they did set up a wheelchair repair shop in the PDSP office on Durant. That was one of the primary things. It's kind of difficult for me to recall all that, but whatever you needed, PDSP was there--like I said, problem with getting classes, wheelchair problems, medical problems. We did a journal--I don't know whatever happened to it--we went through all of downtown Berkeley and found doctors, dentists, gynecologists, whatever--we found out whose offices were available and accessible for disabled services. Earlier, we met with the city council to help get BART [Bay Area Rapid Transit] accessible for wheelchairs.

Cowan: By we, who do you mean?

Barner: If my memory serves me right, it was Herb Willsmore, myself, Jack Rowan, Greg Sanders. That's all I can remember. We were very proactive as far as getting things set up in Berkeley.

Cowan: Tell me about the meeting to make BART accessible. You met with the Berkeley city council?

Barner: They wanted to know why we needed this, what was the purpose of making it wheelchair accessible. Even at this time, even though Berkeley was very liberal, they were not aware of the needs of the disabled population. I remember we had to submit something to them in writing stating why we felt as though we needed the Bay Area Rapid Transit accessible. I was afraid to ride it myself, but a friend of mine, a disabled student, Bill Glenn, rode it and it broke down, and he stayed in there one summer day for three



hours. I don't know what it was, but we submitted the document-- why we needed it, why we wanted it, and why it had to be.

Cowan: Were you guys feeling pretty powerful now?

Barner: Yes, powerful but not obnoxious.

Cowan: You thought you could get any changes you wanted.

Barner: Basically, yes.

Cowan: What was the reaction of the city council when you guys came in?

Barner: They were listening because we dropped a few names. Ron Dellums was very active at that time. It's hard for me to really pinpoint exact conversations or specifics, but they knew we had other pipelines. They accepted us with open arms.

Cowan: Did you ask for other things from the city? Accessibility issues?

Barner: Curb ramps began. We began some curb ramps. Because at one point you could only go from Bancroft to Durant. But after that they went all the way down to East Oakland. That's about as far as my memory serves me.

Cowan: Curb ramps were an enormous step forward, don't you think?

Barner: Yes, very much so. I'm trying to think about restaurants. I know we approached a few restaurants, but I can't recall any changes. Giovanni's was a nice Italian restaurant--it was upstairs. Trader Vic's, Spenger's, I don't recall which ones we'd challenge to make any changes, but it was brought up quite a bit.

#### The Impact of the Program: Empowering Students ##

Cowan: Anything to finish up about the Rolling Quads and testing your political muscle? Were there other issues or demonstrations that you can recall?

Barner: Yes, if you ask me a name, I have to say I can't remember. I can recall fighting tear gas and several instances, but I can't remember specifically what really went on. I recall that one night, Arthur Jensen spoke on campus, and the campus police were all up in arms. We had to stay in Cowell Hospital for about two



weeks--we couldn't go out. Jensen felt as though blacks were inferior to whites.

One thing that impressed me about the Berkeley scene, no matter how much protesting or rioting was going on, the halls of academia never stopped. If you didn't go to class, you flunked. I remember one time they protested in the hallways, the garbage was literally two feet thick, but you had to go to class.

Like I said, for the four years I was there, there's no way I can recall everything that we really got involved in. But the things that we did get involved in were basically to make things better for disabled people and to help make the people who were non-disabled become more sensitive to the needs of the disabled. One of the primary things you asked me--what I got out of the program--the program empowered me to feel like I had the power over my life. When I left Berkeley I left there knowing that I had the knowledge academically and the knowledge civically to make a difference in this world. That was one of the great things Berkeley did for me, and that was something I see the stronger people--myself, Herb Willshire, Greg Sanders, Jack Rowan--we tried to instill in the other students that came in to the program. That you're not just a person using a wheelchair, you are an individual, you have rights, you have the ability to make a change. I think that was one of the greatest things that went on with that program.

Cowan: Do you think it took the four years that you were there? Can you look back over it and say, "Year by year I gained strength or belief in myself"--just looking between your freshman year and your senior year?

Barner: No, I'd always believed in myself. I had that when I went there. It's just that when I got there, I began to see some of the things I could do myself. I had no idea that I could live on my own or the CIL [Center for Independent Living]--those were the things that I begin to see. Like I stated about the university: the university was there to do everything they could to enhance what we were doing or to help us. That's why I look at Berkeley now, and it was a major turning point in my life. When I came away, I can't tell you the feeling, and I still have those feelings. You can probably tell in my speech. It was just an experience that it's hard to even put in writing or to talk about because it was deep down inside.

Cowan: Were there instances while you were at Cowell of strife on the floor and difficulties between the staff and the students or between the students and the students?

Barner: One thing comes up. We were living in Cowell Hospital, and the hospital was going bankrupt, so we had to go out and hire our own chef to come in and do cooking and bring it in. So that was just one of the minor things I can recall.

Cowan: You all chipped in?

Barner: Yes, we paid fourteen or fifteen dollars a week. Don Pierre was his name. He was a French Canadian guy. He would come in, and he would fix dinner. He would cook it outside and bring it in and serve it to us.

Cowan: That sounds great.

Barner: Yes, I can recall--there was a doctor--I can't recall her name, but it was so interesting because when I came there I was the first person in the program that had an athletic injury--football. Right after we met she wrote a book, and I got an acknowledgment in the book. It was called How to Watch Football. She was a football fanatic--how to watch football for wives, lovers, whatever. Ms. Brean and I wanted to get together and write a book on isometrics and women sitting at their desks all day.

So they really tried to utilize my athletic knowledge and what I knew about sports, exercising, and all that. It really felt good when I sat at that pool table because everyone was buying new pool cues, everyone was shooting pool, everyone was using the wall pulleys. It was a great program, but the program allowed people that were much more severely disabled than the initial group--myself, John, Greg, Jack Rowan--to enter the program. They were bedridden and we'd spend a lot of time trying to empower them to get up and do things for themselves. There was nothing I can ever think that really caused any problems among the group. We pretty much stayed together.

Cowan: That's great. You never moved out of Cowell. Did you ever have the urge?

Barner: Yes, I did. Several times I thought about it, but the thing is I could not have afforded it. I think rent for a one-bedroom apartment one block from campus was like \$600. So I couldn't afford to do it. There were some students there, their parents were subsidizing their income, but I didn't have any subsidies. There was a friend of mine, Greg Sanders, he had a house, and he thought about fixing it up so I could move into his garage. It was really nice, but it never happened. So I just said, "I'll just stay here and move on."

Cowan: Were you sorry about that?

Barner: No, I loved it. I enjoyed it. I spent most of my time out of Cowell Hospital because when I'd get up in the morning sometimes I wouldn't get back until nine-thirty at night, so it was a place to sleep and eat.

Cowan: What major were you in by now? What did you graduate in?

Barner: I graduated in psychology, August 1973.

Cowan: You stayed with that major.

Barner: Yes, I stayed with that major.

Cowan: Is there anything else you want to say about being at Cowell and what that program and those people were--not only an influence on you, but an influence on becoming a movement?

Barner: To sum it up, I think that the Cowell program, the PDSP program, and the CIL program, did a lot for the people from the time I came. It just continued to grow. I think what it really did was, it empowered a lot of people who felt their disabilities would not allow them to survive in life, but they did.

Cowan: It was student-run? Students themselves did that--you didn't have administrators coming in or teachers?

Barner: No, but we did have periodic checks from the State Department of Rehabilitation. Gerald Belchick would come around every month. He was the one who would come around and sign off on our room and board. He would come around and just see how things were going.

Cowan: What was he like?

Barner: Oh he was great; he was a nice guy. He was serious. But we had two or three rehab counselors out there--they kept changing them.

Cowan: I've think I heard that there were some problems with DR and people choosing majors. They made people choose a major instead of changing their major all the time, to stay in school.

Barner: I don't know if you want to call it a problem, but I do know that some people invented their own majors. Cal being a school of this size, they would allow you to make your own majors. I know a friend of mine came up with a major: the ego system versus self. I'd never heard of it, but they let him go through with it. I think at one point they did say--as I said before, you just couldn't come in and sit on your duff and not do anything. My last three quarters--I carried eighteen, nineteen, and twenty-one units, respectively, to graduate.

Cowan: No wonder you didn't get home until eleven-thirty at night.

Barner: The quarter I took twenty units I thought it was bad, but the quarter I took twenty-one units, I didn't even have time to eat. The university was very understanding. I know a lot of times--and this is something I went through--probably a lot of students, they would get sick--they would in general be ill. After they got well, they would still say, "I can't come to class; give me my notes." So people would use the system every now and then, but no; I myself, I went to class rain, snow--it snowed once when I was at Berkeley. To me that's the way I wanted it. I remember one time I got a small decubitus from sitting, and I had to take a course--I was out of class maybe three weeks. But the minute that healed up, I was back in class full time.

Cowan: Looking back on it, it sounds like you see it more as a student program than a political organization.

Barner: Let's say, how about student/political. You had to be political because if you didn't, we would never have evolved to where it was at this point. If we hadn't got up and fought--Reagan tried to cut it out--it would have been abolished.

Cowan: Would it have not become political except for a few people? Would you say there were some people who were the reason it became political?

Barner: Ed Roberts was one. Ed didn't take anything off anybody. Ed rubbed off on John, then Ed rubbed off on myself, then Greg Sanders, Jack Rowan. So we felt like we had to fight--not literally fight--but we had to dig in the trenches for our rights.

Cowan: So you guys supported each other?

Barner: Yes. There was never a dissension among us--only during a poker game [laughs].

Cowan: [laughs] Do you think it might not have happened if Ed had not been there, or John had not been there, or you had not been there? Do you think that some of you guys were so important that without your presence it might not have become political?

Barner: I think after Ed came through and John went through, it was going to be--because they were still within the Berkeley area--so I don't think that would've resolved--the baton was just passed on to us. Herb Willsmore was kind of a quiet guy, but Herb was very political also. But I began to think--look up at the sky and I was saying, "What's really going on?" I found out that we could not just let things be. You mentioned things about the attendant

care. I vaguely recall that--I can't recall any specifics. But whatever it was we would come to deal with issues whatever they may be.

Cowan: I should have asked you back then--did you ever get any response from Ronald Reagan from your tape? Did he ever write a letter and say, "I'll listen to your tape" when you went to Sacramento to--

Barner: What he did, he just wrote a letter to the Regents and said, "Let the program continue." We never saw the letter; all we got was news that the program would continue. As a matter of fact, we had two weeks--we stopped going to class, because we had to get documented why we were there, where we would be if we weren't there, and what we would be doing. We jumped on that; that was a big deal. That would have affected a lot of people--a lot of people got very frightened around that time. As a matter of fact, I got a little frightened myself because I knew if they abolished the program, I would come back home, but a lot of people didn't have homes to go back to.

Cowan: Institutions?

Barner: Right, exactly. I can't remember exactly how long it was after that, but somehow he--and I say he, but I don't know if it was he himself or some administrators in his cabinet--but they told the program to continue.

Recalling PDSP on Durant Avenue: "Typical Berkeley"

Cowan: If you are okay with it, maybe we could move on to PDSP as its own program on Durant. It sounds like you were very busy as a student, but people will want to know things about it. What do you remember how it looked?

Barner: It looked like a hippie hang out [laughs]. There was a long ramp, and if you weren't careful you'd fall off the ramp, to get up into the place. No carpet on the floors. It was typical Berkeley--no drapes. It was a building.

Cowan: It was upstairs?

Barner: It was upstairs, because you had to use the ramp to get up to it. It was a typical dive, really. But that's the way it was: nobody was into this materialistic scene. It was just typical Berkeley. You go in there, you'll find five or six wheelchairs at one time, you'll find hot dogs on the floor. We used to have a funny saying



in Berkeley: when you got a hot dog or hamburger, we used to set them on our hands and you only got one bite because a lot of times, you'd bite into it and it'd squirt out of your hand. So we had a saying, when you take that first bite, that's it, because you may not get another bite [laughs]. So you may go to PDSP and there may be a hot dog on the floor or a hamburger. But that's what it was all about.

Cowan: Who was at PDSP who wasn't at Cowell? John was the head of the program, is that right?

Barner: Who was there that did not go through Cowell?

Cowan: Who do you remember working at PDSP? I have heard Zona Roberts.

Barner: Zona was one incredible lady. Zona was everywhere. I first met Zona about a month after I got to Berkeley, and we hit it off like peas and carrots. Zona loved everybody. There were a couple of students who came in to Berkeley from Minnesota. One guy came in from Minnesota with just the clothes on his back. Zona took him in. This was one incredible lady. But I can think of several cases where people heard about the program, and they would come in. They thought it was just a program that they could just pop in to, but they couldn't. They would also get services from the Physically Disabled Students' Program, and apply to the university.

Cowan: You mean these were non-students who would come in?

Barner: Right. This one guy I remember, he came in from Minnesota. He had hitchhiked in a wheelchair and came into Berkeley. He wanted to get in the program, and he didn't have the academic background. I don't think he even graduated from high school. But the bottom line was that he wanted to get into the program, and he couldn't. But Zona took him in, and I think he stayed with Zona for over a month or so. Zona would not let you go lacking. I think she had about four sons. Like I say, this is one incredible lady.

Cowan: I've heard she cooked lunch there. Do you remember that?

Barner: That's right, she sure did. Usually I got there after lunch because my classes were running like one-thirty. When I got there usually all the food was gone. Zona was all over the place. Wherever someone needed anything, she was there--unconditionally, no reservations. Carol [Fewell Billings] Langdon worked at PDSP, Larry Langdon worked at PDSP. I think Larry has passed on, but Carol worked there.



- Cowan: Why would people come in to PDSP? What sorts of problems would bring people in?
- Barner: Basically, I need my wheelchair fixed. Secondly, I don't want to take this class, and I'm flunking, and I want to get out of it. I want to change classes. I'm looking for a house; will you help me find an apartment?
- Cowan: Oh, there was housing?
- Barner: Yes, they had [assistance finding] housing. PDSP did a little bit of everything. Whatever an individual needed as a disabled person. They would try to help with accommodations. John was really good with that. He would sit there all day long and sit by the phone.
- Cowan: You felt John was an effective manager?
- Barner: Oh yes.
- Cowan: I've heard he was very strong.
- Barner: John was the sort of person if you--he was strong--but if you confronted him, he was the most diplomatic person in the world. We got along real well because I was strong too. If something came up, then we'd just have to discuss it.
- Cowan: Did you feel that PDSP served everybody? Do you think everyone felt comfortable coming in to PDSP for services who needed them?
- Barner: Yes, I think everyone felt that if they came, they got something.
- Cowan: No need for outreach?
- Barner: PDSP was outreaching, if you know what I mean. Whatever you needed they would try to procure it or find it for you.
- Cowan: Were there students with disabilities on campus that didn't come through the Cowell program that just came there that lived independently from the beginning--that you knew of?
- Barner: There's a name--I'm going to call it--his name was Alan Fabyancic, and it's amazing that I can recall that name. Alan Fabyancic was a law student. I don't think he was in the Cowell program. A couple of times I did see him at PDSP, but he was one of these kind of guys that was--he thought he could make it on his own--that he wasn't really disabled.

Cowan: So PDSP offered housing services, or help in finding housing, and help in finding attendants?

Barner: Mostly attendants. Because housing wasn't something that a lot of people liked doing initially. During the last couple of years I was there accessible housing became an issue.

Cowan: When you went to visit people who were living by themselves, like Greg, how had they made their housing accessible and usable for themselves? Were there gadgets?

Barner: I got some funny stories. We used to call John cheap because John put two wing nuts into the wall, and hooked his pants loops in them. What he would do is drive up to the wall, take the strap and hook it to this loop on the sides of his pants and back up and pull his pants off. So when his attendant got there, he'd be ready to go to bed. Oh, we laughed about that, that was so funny.

Donald Lorence had the scariest ramp you'd ever seen at his house. You'd be like at a thirty-degree angle going this way, and oh God. Along one side he had about sixty candles, and Donald would let anyone come in his house. He would just let them come in. That's how Berkeley was--just like "love, peace, and happiness." It was great.

Cowan: How about cooking for themselves?

Barner: At one point a lot of them that had moved out on their own would just eat at Cowell Hospital. Most of them would eat at PDSP. If that didn't last them overnight, they'd order pizza. We did a lot of fast food ordering. I guess you got the story of Susan, right?

Cowan: Not necessarily, let's hear it.

Barner: I don't want to be redundant.

Cowan: No, it would be fine, even if it was repetitive.

Barner: Susan was a very special person to me.

Cowan: Susan O'Hara?

Barner: Yes, you know Susan?

Cowan: Oh yes, I do.

Barner: I was coming through Sproul Plaza one day, and Susan's sister walked up to me and she said--I can't recall specifically, but something to the point of, "Are you going to school here? How do

they manage, how do they take care of you?" I said, "I'm living in Cowell Hospital, through the Physically Disabled Students' Program." So I took her up to the hospital where we lived, and we had four or five vacant rooms. I took her up and showed her the rooms. She said, "I have a sister who lives in Chicago, and she's a school teacher." She said it's cold and she needs to get away from there--it's hard in the winter time.

So I went to Ms. Brean--and I can't trace it all the way down to each step--but I mentioned it to Ms. Brean, and then I went in to the PDSP. To make a long story short, I got it set up so Susan would get to come and spend one summer in Berkeley.

Cowan: That's great.

Barner: I'm not saying this to brag about it, but I'm happy I could do that. I think she got there when I was home on vacation. I'd never seen Susan; I just talked to her sister. When I got there, there she was there in bed. "Oh," she said, "so you're Billy Barner." That was the most wonderful, really proud thing. She came here, and then she went back. The next year she came back and stayed.

Cowan: And became director of the PDSP program eventually?

Barner: Yes, Susan is a great person. I hold her in high esteem.

#### Remembering John Hessler ##

Cowan: Billy, I think we were talking still about John Hessler's leadership style. I've heard that if John wanted it, he got it.

Barner: I beg to differ. A couple instances--because John was powerful and John had one thing on everyone else: he had experience, he had a lot of knowledge of the system and what was going on. But I was telling you about the money the university was raising which was allotted for the disabled students. John wanted signature power of that money, but John did not get it. I don't know if it was because he knew it would not be right for him to have the power or because it would be too subjective, but he didn't fight back. He spoke about it, but he didn't fight back; he did not get it.

But as I stated earlier, I think John was a very diplomatic person. If you did not know--if John wanted to get something over and you didn't contest it, it was gone. But if you would confront him--he was one of the nicest persons I've ever known. I think

that's how John and I really got to like each other because we respected each other. We didn't argue. I can't recall specifically, as I said earlier, but he realized that I wasn't a weak person and neither was he. So we decided to compromise on a lot of issues.

### Need for Non-Student Services

Cowan: We're talking about PDSP again and when it was located on Durant-- John was the director. Did you begin to see the need for this to expand into the community to serve non-students?

Barner: I don't think I saw it, but I think what happened was that in 1970, '71, the word was getting around that there was this fantastic program in Berkeley. People were coming from all four corners of the United States, literally, to visit the program and try to get in. What John would do--John would assist them in, like I said, attendant care, housing, and if they were eligible, help them to get into the university. But there weren't very many people that were successful.

The program was reaching out into the community because there were a number of people that were in the Berkeley community that were disabled that did not even know about the Disabled Students' Program. They were either elderly people, or they had become disabled before the program was in existence. They were persons that were in maybe their fifties or sixties. But I know the PDSP, the Physically Disabled Students' Program, did as much as possible for anyone that they could. John did a great job for the program. I have to give him credit for that.

I really wanted to work there when he offered me a position to work there as a counselor. But I really wanted to get my degree and move on, so that's why I volunteered. But I did spend a lot of time, I'd say four to five hours out of a week, I was there at least three or four days.

Cowan: Seeing these people come in who were not part of the university, do you remember discussions about how the program could be expanded into what became the Center for Independent Living? Did people talk about the need to provide these same services to non-students?

Barner: I can't recall any specific conversations about expanding the program. I think they did on an as-needed basis. I think if someone came in and Zona didn't put them up for a while, I think

that John and the staff at PDSP would do whatever they could to assist them. But I think the people that were really coming into the program were really coming into the Cowell program. Therefore, they didn't have a need to look for housing or for attendants immediately.

But the PDSP was always there for the attendants. The program did grow, for example: when I went there in '69, there were seven, and by the early seventies, there were approximately thirteen or fourteen in the program; when I went back approximately six years later, there were maybe over 150 people. A lot of them did live in the community, and were now students at the University of California.

Cowan: So that was probably CIL then?

Barner: Yes, CIL was really blooming then.

Cowan: Do you recall what Ed Roberts was doing at this time?

Barner: Yes, Ed was working in San Diego. Ed was specifically doing, if I'm not mistaken, some lobbying in Sacramento about disabled rights. I don't think it was too long after that he got appointed by Governor Brown to the directorship of the Department of Rehab. But after that he started to work in the independent living center. He was all over the place; he was very busy. I'd be doing you and myself an injustice if I tried to put that in chronological order.

Cowan: Did you hear about similar programs starting anywhere else?

Barner: No, not at all.

### Minority Students

Cowan: Did you see an increase in minority students coming into the program? You said you were the only African American.

Barner: That's a good question because I graduated in '73, but when I went back in '83--

Cowan: For the reunion?

Barner: Yes, for the reunion--I think I saw maybe four or five, but there was still a lack of minorities.



Cowan: So that's where outreach might have been useful too. Was there any suggestion of trying to increase the number of minority students?

Barner: I don't think--no one thought about it, in my opinion, when I was there. No one ever mentioned the racial imbalance. No one ever thought about that. They said, whoever applies, we'll evaluate them and try to put them in. But no one ever mentioned the racial imbalance.

Cowan: Did you think about it?

Barner: To be honest, I didn't really think about it until I went back to the reunion, and I saw that there were more minority faces there. Then maybe it did make me feel a little bit better. But even the time I was there--I would come home on Christmas and vacations, and I would try to find disabled people, minorities, and try to get them to apply to the program. But it wasn't something that--the program was so lucrative and to me such a good program that you didn't really think about this. You just thought about whatever--if a person was an eligible person, or if you found a person that wanted to get into the program, you would try to help them. But the racial thing wasn't a big factor.

Cowan: That's interesting.

Barner: Yes, now that I think about it, it is interesting.

Cowan: Do you have any final thoughts on PDSP--the program and how it served the community?

Barner: When you went to PDSP, you didn't have to worry if your wheelchair broke down or if you dropped your food on the floor. We were all like a family. People loved to stay there. I loved to hang out at PDSP if I wasn't in class. Everything was just so smooth. To roll in and look at the place, you'd think that it was a juke joint. But it was a really good program; it provided a lot of good services. But the main thing I think it added was people that were reclusive, quiet--when they went to PDSP, they would open up because there wasn't a stigma. We all were one; we were all the same. There was not a stigma of "you can't do this, you can't do that." Or, this thing about Zona's cooking; Zona would fix a meal for anybody that came in. There was no discrimination. It was just a great place.

Cowan: Did it lend a sense of empowerment to everybody, then?

Barner: I think so.



Influence of the Berkeley Campus Setting: Political Protest and Academic Standards

Cowan: One of the things I wanted to go on to is Berkeley itself. One of the major questions everybody has is, "Why did this happen in Berkeley?" So I wonder what you recall of Berkeley's campus--the city and the campus scene? What was going on when you were there? You mentioned earlier some demonstrations and protests--.

Barner: When I went to Berkeley, I really didn't know what Berkeley was all about. I didn't know what the academic standards Berkeley had set for years, the Rhodes scholars, anything about Berkeley's legacy, and the Nobel Prize winners. But the bottom line was that when I got there, I began to get--you hear people talking about, "You know this is one of the best schools in the nation, universe, or whatever."

But I do remember going to some protest because Berkeley at that point in '72 had to drop its standards to let minorities in. But what it was doing was it was letting minorities in, and they were flunking out after their first quarter. I can remember my first quarter, I couldn't even eat before I took my finals because being only the first black in the program, I felt if I didn't make it, I couldn't set a precedent for anyone else.

But that's when I realized what a great school Berkeley was. Not only was it a great school, but it also lent that air of comfortability--people came there, everyone got along with everybody, even the dogs were congenial. You'd see dogs or cats playing together. It was just a fun time. It was a city that--I won't say culture shock affected you because you would see different people: the mimes, the hippies, and all the different dress codes. But it wouldn't bother you; after one month you ignored it.

Cowan: Earlier in the sixties there had been many violent political protests over the Free Speech Movement, civil rights, and then the antiwar movement in the later sixties and into the seventies. Was anything like that still going on when you got there?

Barner: The People's Park riot happened when I was there.

Cowan: Say a little about that. Not everyone knows what that's about.

Barner: There's a park right off of Haste and College, and it was an asphalt basketball court. The Vietnam War was going on, and the students got up in arms--I can't remember the specifics. But I was out goofing off--when I say goofing off, I mean just cruising

around campus. All of a sudden I smelled tear gas. I thought I was dying; I thought it was a nuclear war because this tear gas hit me, and I'd never felt it before. All of a sudden you see five or six thousand people come running from campus. They tore up asphalt; they just destroyed it. That was one of my first experiences.

Another experience was the Armenian students were protesting some academic rights or standards that they didn't agree with. I saw this physically. The campus police came out with riot gear: I saw them beat people; the blood was gushing. It was just incorrigible; it was just a ridiculous thing. At that time, that's when they shut the campus down. I went back in Cowell Hospital; they told us not to leave for weeks. So I stayed in the hospital over a week, but I had to get out. Then again, [Arthur] Jensen came on campus; he spoke. He was saying that the minorities were less intelligent than the whites.

Cowan: Who was that?

Barner: Jensen. Jensen was a professor in the UC Department of Education. Arthur Jensen.

Cowan: Oh yes.

Barner: But the funny thing about it, they would never let the black students know where he was speaking. He spoke in Hildebrand Hall, and we knew he was in there but nobody knew what room he was speaking in. So those were the kinds of things that you would see protested, and I was the type that--because I was in a wheelchair, I would stay far away; when five or ten thousand students come rushing at you, it's hard to get out of the way. But every year, there was something going on. As I stated--ourselves, we would get together--fifteen or twenty wheelchairs and ride around Sproul Plaza, ride around Ludwig's Fountain in the middle. So we had our protests too.

Cowan: What influence do you think that it had on you to see that there were protests and people were taking a stand? Do you think that influenced the people in Cowell, thinking that they could do the same? Do you think there was a connection?

Barner: I saw it as something that we had to do. To get what we wanted we had to do it, otherwise if we didn't--because once you got into the program, you really became a part of it. I can't think of anybody that really was in the program--that didn't have a vested interest in the program. So we saw that after a while if we didn't stand up and speak for what we wanted, we wouldn't get it.

Cowan: Did that example--look at those guys, they're doing that, and we can do the same--was that--?

Barner: No, that was not a part of it. But we did get a lot of "normal" people--walkies, we'd call them--that we got in our protest with us and say, "Hey, do the right thing." Berkeley was such an amicable, open environment.

I can tell you a funny story. I was down in Sproul Plaza one day, and I was sitting with my army jacket on--I never spent a day in the army--that had all these patches and badges and everything on it. This gentleman walks up to me, and there was a little hole cut in the asphalt and there was a tree in it. I guess the tree was about the size of a broomstick and six feet tall, and he walked up and said that he remembers where I got shot in Vietnam, the hospital I was in, and when I got shipped in. [laughs] I'm just saying, "Okay, you don't need to do that." He asks me, "Would you like to go behind that tree over there and smoke a joint?" [laughs] I said, "No, I don't think so." But I was there when they passed a law that said you could smoke marijuana legally. It lasted about a month.

Cowan: [laughs] When was that?

Barner: I think that was in about '71. You could go in a restaurant and light up a marijuana cigarette and smoke it. It lasted about a week. The thing that really fascinated me about Berkeley--I always tell people for every minute or hour that you protested, rallied, or partied, you'd have to study ten times that much for your studies. If you had to ask me what I really wanted to do and what I'm most proud of, I'm most proud of the education I got from Cal.

Cowan: It sounds like you were a really serious student.

Barner: Yes, I was.

Cowan: I've seen people who were more interested in the program than the studies, but it seems like you were a really serious student.

Barner: I gave--I won't say half--I spent as much time as was needed with both, but my primary thing was to get my degree. I was the type of student--I know that the school was so liberal that they would let you take a quarter off or semester off, but no, once I got my head straight, I said, "I'm going to go do this." That's why I was telling you I took those three quarters, nineteen, twenty, and twenty-one units. I did that because I wanted to graduate. It didn't preclude me from getting involved in anything that would come up.

Cowan: When did you graduate?

Barner: August 1973.

Cowan: In psychology?

Barner: Yes, in psychology.

### III CAREER, FURTHER EDUCATION, AND REFLECTIONS ON THE DISABILITY MOVEMENT

#### Career in Los Angeles with Two Independent Living Centers and the Mayor's Office

Cowan: So, what then?

Barner: That's very interesting. I had applied for graduate school, and there was a program when I graduated that you could take three classes and get a master's degree in public health. A friend of mine from L.A. did that and went on to get a master's. But I was offered a job here in Los Angeles at Martin Luther King Hospital in the neuro-psychiatric ward. So when I graduated I immediately came home to take the job. But when I got here, the job and the money didn't come through from the feds. So that made me a little distraught. Then about six months later I got married.

Cowan: That summer, after you graduated?

Barner: No, I didn't; I take that back. I came home, and I started looking for jobs. 1973 I was 22--

Cowan: That's when you graduated.

Barner: Anyway, the job was available. I must have gotten married. I got married. The money never came through. I started working for Kedren Mental Health Center. I was working there in the child-parent training program. I was working with kids with disabilities from ADD--attention deficit disorder--to schizophrenia to burn victims. I worked with kids and their parents. I worked there for six months. I moved on--that program got defunded, so I went into substance abuse. It's called Kazi House, and it's still in existence now. I got promoted to coordinator, and we worked with hard core heroin addicts--PCP, crack wasn't out then. It was either cocaine or heroin. So I worked there for eight years.

Cowan: Eight years?

Barner: Yes, approximately eight years. Then I moved on to the city--no I moved on to the [Good Shepherd] Center for Independent Living. I worked there for one year.

Cowan: So you worked for the Center for Independent Living. What was that like?

Barner: Yes, in L.A. It was good; it was interesting, finding housing and being an advocate for disabled persons.

Cowan: How was it similar to the Berkeley programs?

Barner: By that time it was more evolved, it was larger, we had more staff, and a more spacious area. So it was like working in a regular office. But we provided the same services.

Cowan: As far as you know, had they looked to the Berkeley example to found the Good Shepherd CIL here?

Barner: Yes, by that time, yes. By that time--by '73, '74--people were flying to Berkeley to look at the program, from all over the United States, to see what it was all about, to visit it. Matter of fact, when I applied for the job at the Good Shepherd Center for Independent Living and they saw that I was one of the co-founders who worked on the proposal for the Berkeley CIL and worked at PDSP, they hired me right off the bat.

Cowan: And that was about 1978 or 1979?

Barner: Going on 1979 because I went to work for the mayor in 1980. I went to work for the mayor, Tom Bradley, in Los Angeles--the Office on Disabilities. I worked for Tom Bradley there for almost fourteen years. Also, I was in contact with Ed because Ed was the director of the State Department of Rehabilitation, so our grants came through Sacramento. By then, Ed, John, and I met at several conferences here in L.A. and around the state. I worked there for fourteen years. I didn't have civil service protection, so when Tom's term was up, my term was up also.

Then I went into work in the Regional Center with basic developmental disabilities. I worked there for almost two years. Then there was a Center of Independent Living that had been started up in the state three times and it failed. I got a call from a friend of mine that worked in Sacramento, and he said, "Would you like to be on the board to help develop this Center for Independent Living?" I said, "I don't know right now." After a while I said yes. So I got on the board to help to develop it.



We kept trying to hire a director and couldn't find a director, so I took over as associate director. I worked there for three years; that was from 1993 to 1996.

Cowan: What was the name?

Barner: CRS was the umbrella--Community Rehabilitation Services. They had the money--but the center was called the Independent Living Center, L.A. I worked there, and I got the program started; it was booming. When I went there, they had twenty-six consumers; when I left there, we had over four hundred consumers. We covered the area from Hollywood to Carson, which is approximately, as the crow flies, twenty miles, but it's basically all of Los Angeles. Once I felt like I got the center going--I was working eight, ten, twelve hours a day--I decided to go into teaching. I had been in a wheelchair for almost thirty years; it was hard to work those long hours. So I started in teaching in the beginning of 1998.

#### Master's Degree and Special Education Teaching

Cowan: Did you go back to school during any of this time?

Barner: Yes, I went back to school in 1976 when I was working with the drug program--at Pepperdine University. I worked on my master's degree in counseling psychology. I went for about a year, and I was going on Saturdays but I was working six days a week. I was actually working seven days a week, but I was taking off to go to school. I stopped that program because I found out that--when I was in that program--I learned more at Cal as an undergrad than I did in the graduate program. Just two years ago I finished up in a global university, American World University.

Cowan: What was that?

Barner: I finished up my master's at American World University. I got my master's in educational psychology. I had to work there for about two years. Working and going to school at the same time is kind of difficult.

Cowan: Yes, it is.

Barner: Now that I've started teaching, I'm teaching special ed, teaching to orthopedically handicapped. I found out once I started teaching, I found I had to go back to school to take all of these classes in special ed--and that I did not plan on. But that's what I'm presently doing now. I'm presently in a dual credential

program: I'll have a special ed credential, a regular ed credential, and I have the option of going for a master's if I want to. But I don't know if I'm going to see all that through.

Cowan: A second master's.

Barner: This year I took ten units. When I get off from work, I leave school at three, be in class at Cal State University, Los Angeles, at four, stay in class from four to nine. In this context--I get up at five in the morning--from five to nine, that's ten to twelve hours.

Cowan: Where do your students come from that you're teaching?

Barner: L.A. Unified School District.

The First Proposal for the Center for Independent Living in Berkeley ##

Cowan: You had quite a career and stayed in the field of disability. Do you have any regrets about leaving Berkeley and not staying there?

Barner: No, I don't have any regrets, but I would be remiss if I didn't say that I--hindsight is 20/20--and I usually don't like to say if I could do it all over again, but I would have liked to stay at Berkeley and gotten my master's degree and gone a little bit further. But I had that job offer, and I was engaged at the time. I wanted to get home, and I had a job offer. That was the primary thing, that I had the job offer. I figured if I spent these four years studying it was time to use all of this knowledge.

Cowan: Just to get started--

Barner: That's right, because I was back in school, back in Pepperdine University, a year after I graduated, so I didn't waste any time as far as getting back into school. But I just found out that working and going to school was pretty taxing. But yes, I would've loved to say that I have an M.A. behind my name from Berkeley.

Cowan: I think I heard you mention--I don't think we got it the first time around. You said when you had worked on the proposal for getting money for PDSP--

Barner: No, CIL.

Cowan: CIL--I didn't ask you about that.

Barner: Let me explain that. I'll be as detailed as possible. John Hessler and there was another psychologist named Peter Leech. But he worked in the city of Berkeley, and he got to meet with us--he came up and got into the PDSP program working with us. He was doing therapy in Berkeley; he was a wheelchair user. We started thinking about getting out into the community. I recall several nights we set up over on Haste Street--I don't know how the apartment got rented. Someone rented an apartment on Haste Street, a two-bedroom apartment. We had a table and a couple of chairs, but we didn't need furniture because our wheelchairs take up a lot of space. We started writing up this proposal to submit to Sacramento for an independent living center. I think Herb Willsmore may have been there.

But to make a long story short, this work got initiated. We wrote it up for what we wanted to do: we wanted to find accessible property; have a center to help people find jobs, houses; advocacy; whatever. So that was submitted. I gave my input on the initial part of that, and after it got implemented. I didn't spend that much time working on the proposal, but I know what we did to get it started. I can't recall what happened after if it was submitted, but I did find out from Greg Sanders--a friend of mine told me about this. I left and came to L.A., and Larry Biscamp had gone back to Washington to help get the money to finance it. CIL came out of that. Actually, we had CIL set up in that two-bedroom apartment, right there on Haste Street.

Cowan: Was Ed involved in that?

Barner: I'm sure I saw Ed there because we used to meet there in the evenings. A lot of faces start coming back; I remember them quite vividly.

#### Peer Counseling at CIL

Cowan: I understand that peer counseling was a unique feature of CIL. Do you remember anything about that?

Barner: It wasn't called peer counseling then--maybe now. Peer counseling just became a core service of independent living in the past five, six years.

Cowan: Would you describe what peer counseling is?

Barner: Peer counseling is--you find a person who is disabled or has become disabled, and the person may have become a little bit reclusive, a little bit introverted. There's actually a paradigm set up for peer counseling: 1) active listening; 2) experience sharing; 3) empowerment. To be effective, you want to sit down and discuss what the life changes are that a person must encounter. You can sit down and take a tape recorder and have them say something about what they need to do in life and then have them repeat it back to you.

There are four different steps to peer counseling: basically, letting them know what they have to do or trying to get them involved in how their disability will affect their livelihood. Peer counseling is really beneficial because a lot of people that become disabled don't know how to deal with their disability. So you find veterans like myself who can tell them things that we've been through, or what they're going through, and just try to empower them to get involved in the Physically Disabled Students' Program and how to go about getting the things they need, and how to become self-advocates.

Cowan: Have you done some of that?

Barner: How much?! As I stated when I was doing it in Berkeley twenty-five years ago, we didn't call them peer counselors. If a student would come in--someone would come in who was disabled--we would just sit down and just talk to them about their disability, and how they were going to make different changes. Now, there's actually a set of rules, a whole program of peer counseling.

Cowan: Are you finished up with that?

Barner: About the peer counseling?

Cowan: Or your jobs and what they've meant to you since you went to Berkeley?

Barner: I basically stayed within the disabled realm because I know I have a lot to offer in that area. I wrote a paper for one of my graduate classes at Cal State L.A., and I basically said, the world has dwelled too much on normalcy. Even in the medieval days, if someone was born with a disability, there was either euthanasia or they were ignored. I wrote it really strong. I don't know where the paper is but my professor put on the paper, "strong." I feel like people deal with normalcy too much--I'm "abnormal" to them. They can learn from it, but they don't understand it and they don't want to know about it.

Another example. I have been asked to speak--in every class I've taken, either undergraduate or graduate, they've always asked me to speak to the class on how it feels to once have walked and now be a wheelchair user. I went from running on the football field to stopping still in my tracks. It's hard for people to identify with that. The basic thing I tell them is that I don't have any regrets. I love football, and I was injured doing something I love, so why should I be bitter? That's the major thing--you speak about peer counseling--because if you can share your experiences, then you get people to realize that there is a life in a wheelchair. That carries a lot of weight.

Cowan: A valuable service. We've already said your experiences at Cal helped you get the jobs that you got.

Barner: Yes.

Cowan: It was important to have that connection.

Barner: The academics I got at Cal, I wouldn't just say the name Cal. I got jobs--I didn't have that many jobs, really--but it works both ways. Most people if they see you going to Berkeley, they want to know if you graduated, and if you did you were probably intelligent.

Cowan: But also your experiences at PDSP and CIL at Berkeley were valuable.

Barner: Yes.

#### Influence of Fellow Students and the Berkeley Community

Cowan: Who, looking back, would you say were your really big influences in Berkeley?

Barner: You mean persons who influenced me?

Cowan: Yes, or events.

Barner: That's a difficult question. I'll tell you why. I've always been really independent, and I can think of a lot of people that I mentioned before--Jack Rowan, Greg Sanders, John Hessler, Ed Roberts. But if I had to, I would say Ed and Gwin Hinkle. Ed and Gwin were two guys that really empowered me, because when I looked at my disability and my adversity--they were in iron lungs, and they never stopped. So if I was going to name two people--but



like I said, I was pretty independent and I still am on my own. But I looked at those two guys and I said, "There's no reason why I can't go to the top."

Cowan: Yes. Do you have any thoughts on why--Berkeley was one of the very first programs--maybe not the first--but one of the very first PDSP programs. Do you have any thoughts on why so much happened in Berkeley?

Barner: I always presumed the fact that Berkeley was such a liberal city.

Cowan: So it was the city?

Barner: I always thought that it was because Berkeley was such a liberal city. I don't know how Ed got into that program when it started, but I know that Berkeley was such a liberal city when I got there. When you get in that environment, you see and you feel how comfortable and how congenial people are. You start a center in L.A.--because I started the Center for Independent Living in L.A., you don't get the same cooperation as you did in Berkeley. Berkeley was such a liberal city. That's how I looked at it. That's my personal opinion.

### Looking Back at the Movement

Cowan: Looking back over these twenty-five years, what would say has changed? Personally, what do you think has changed in the disability community?

Barner: Do we have two weeks here? The pertinent thing is that more disabled people have become self-advocates; more disabled people have become empowered to do things for themselves; you find more disabled people working; you find more disabled people living normal lives--as "normal" as possible. I find that the law is changed. A lot of people don't know that when Joseph Kennedy had a child that was born with a disability, he talked to John, Jr., and John began the President's Commission on People with Disabilities. All the politics have been involved and funneled down through the years. All of that has come to play in the twenty-five years.

I tell people now--I use this quotation: I say I fought my battles years ago, I don't fight now unless I have to. Now I see youngsters, they say, "We need this, we need that. Can you help us out?" I say, "I'll tell you how to do it," but I tell them, "You're going to have to do it because I fought my battles."



A very interesting comment--we were having a SILC [Statewide Independent Living Centers] meeting. Jim Donnely, the director from CIL, was there. (Jim, if you hear this, don't take it personally.) I went into a meeting out in Downey--and I can't recall the lady's name--but I got there late, and she said, "Billy should introduce himself because Billy brings a very interesting background with him." I found that most of the people in the independent living centers have only been in there five or six years and don't know what the movement is all about. When she said that, Jim said, "Oh, what the hell, don't we all bring an interesting background?" So I didn't say anything, but I told him when we took a break--I said, "Come here, Jim. You see the center where you're working and you're the director of in Berkeley? Have you ever heard the name Ed Roberts or Billy Barner?" He said yes. I said, "I was in that movement." He offered me a job to come back; he said, "We have job openings." I said, "No, you can't even pay me enough." [laughs]

That's why when Susan told me about this interview, I was really elated because there aren't too many of us dinosaurs left. I don't think this should die. This movement was really a fantastic movement. It lasted a long time. I could talk here for days on the things we did. That city of Berkeley will live in my mind forever because I don't think I knew anything about Berkeley; I didn't know where Berkeley was; and when I got there the city was so receptive to the changes--to find a major university like that to do what they did. The director out here at UCLA, Doug Martin, he's the director of--it's not the Physically Disabled Students' Program, but the Disabled Students' Services at UCLA. But none of them are the same as in Berkeley.

Cowan: Not the same openness?

Barner: No.

Cowan: How about technology? How has that changed and contributed?

Barner: Then again, do we have two weeks? The wheelchairs have changed. There used to be an old wheelchair called the motorette. If it blew a fuse, your wheelchair would just take off full steam ahead and you'd run into whatever. Now the chairs have braking systems; they stop. They have voice drag and dictate; you talk to computers and they print. We could go on and on; so much has changed. We saw change; we made the change. In other words, if you want it, you got it. You can do whatever you wanted to do. I have a van that works by remote control--I press a button and the door opens and the lift lets down and up and the doors open and close automatically. It's a Ford van.

Cowan: It would have been harder to become so independent without technology changing at the same time the movement was changing.

Barner: Most definitely. It would have been impossible.

Cowan: Impossible?

Barner: I think so. Because people like myself and other people that went through the program, we needed certain things. Different people needed different things. For example, Michael Pachovas was so large that he had to sit and take this arm out and tie himself into the wheelchair. That's when the guy invented or came up with the chain-drive chair that could carry Mike, who weighed 350 pounds. He came up with the chair that could carry Mike. So all these things come into play, if the need was there.

#### Thoughts on Discrimination

Cowan: Anything else about the changes over the last twenty-five years?

Barner: I'll be remiss if I didn't say this: I think that the technology, the physicality, and all those changes have been great because what they do--if you have a person that's not strong-willed, they can make it. But I think that the discrimination is still there.

Cowan: Is it? Why do you think that?

Barner: People will never accept that we're not normal. I don't want to say "never." We've come a long way, but we've got a long way to go.

Cowan: Say more about that.

Barner: I'll give you an example. At the school where I worked--74th Street school--I wore my different outfits, and they always say, "Oh, your outfits are so cute, you look so cute. Who dresses you?" They want to treat you like you're a little kid, and that's just because you're in a wheelchair. They think because you're in a wheelchair that somebody must do everything for you, which you do need assistance.

Another example, I carry my keys on my wheelchair--the keys to my van. One of my assistants, she said, "Who brings you to work and takes you home?" I said, "I drive myself." This young lady, she was a cook and she said, "I never thought about your disability." I said, "Don't even say that because there's no way

that you can't see me without seeing me in a wheelchair. The bottom line is that if you see a nice looking guy that's standing up walking and another one in the wheelchair, which one would you choose?" She started to laugh. That's people's preference. The old saying, "If you can't say something good, then don't say anything." But don't patronize me; I don't like to be patronized.

Cowan: So that hasn't changed a lot over the years?

Barner: No. They were shocked. Once you become paralyzed, many people think you don't have kids, you don't have sex. You don't have a sex life.

Cowan: In terms of discrimination between being disabled or being a minority person, which one has been more manifest in your lifetime?

Barner: I'd say being in a wheelchair, being disabled. [pause] I thought about the question before. I'm very much a people person, but people look at this wheelchair, and it's a barrier. You can do a lot of things in the world, but it's still a barrier.

Cowan: Can't get past that?

Barner: Not yet.

Cowan: What do you think will help that to change?

Barner: I think that one thing that's happening now is that more and more people are being born with disabilities and more and more people are becoming people with disabilities, so the whole world is beginning to see that it can happen to them or anyone else. I say this reluctantly because people ask me why I don't revere Christopher Reeve. As a matter of fact, somebody gave me the book; but I didn't read it because I didn't feel I could learn anything I don't already know. But now when there's movie stars or actors who become disabled, people want to put money into disability research. But before, they don't. He gets \$100,000 just to speak. I did more speaking for independent living for years, for free. So it's all about who you are and how much money you have, and that's something that perturbs me. But it's good because the money may help someone, someday. This is good.

Cowan: Do you think it might help change people's ideas the more they see people with disabilities--the celebrity makes a big difference in how they think about it?

Barner: I don't think it's going to make any major difference. I think it's just going to make them a little bit more aware. I think

that Christopher Reeve, those two movies he made--this is just my opinion--they did just because he's Reeve. I think in a couple of years it will fizzle out. I think people have to realize that they don't want to face anything that's not pleasant, and can happen when you least expect it.

Cowan: People often don't want to admit that to themselves.

Barner: Exactly. Even people with eating disabilities and diabetes.

Cowan: What do you think needs to be done now? What are some things that you'd like to see happen?

Barner: I always tell people that each day when I inform or enlighten someone about my disabilities that it helps bring down the barrier that disability is not a death sentence. I have lots of friends who are disabled. The disabled barrier runs from those with congenital disabilities, like muscular dystrophy, to traumatic injuries, like myself. I had good friends in Berkeley who had muscular dystrophy. With MD you can almost count your days. Therefore, they wonder why anyone would want to help them. This causes an attitude problem, contrary to a person with a traumatic injury who could live as long as anyone else. However, the attitude situation is not as prevalent with all congenital disabilities. But if I take care of myself, I might live a normal life. Each day, if I can enlighten someone, if they say, "Why are you so happy?"--when I speak in my classes they say, "You seem to be so positive." I said, "What do I have to be negative about? Sure, I'd like to stand up and walk, but as long as I can't walk, being negative isn't going to make it happen sooner."

Cowan: So you think that your self-example is important?

Barner: Yes.

Cowan: How about advocacy and public education?

Barner: Advocacy is doing nothing more than helping people get their rights, but I think that peer counseling should be administered to a lot more--even to people in rehab. They don't understand the ideology of different disabilities--even in special ed. Each school I go to, I like to put on seminars and in-services on disabilities, to make them more aware of the disabilities they're dealing with. A lot of teachers are dealing with kids and are not aware of what the disabilities are. Osteogenesis imperfecta--what's that? That's brittle bone. Let's say you've got spina bifida--what's that? I think that if the teachers and educators became more aware of the disabilities--I've always had this

saying: if people could experience for one day what it's like, then it would change their whole world.

Cowan: It would.

### Summing Up ##

Cowan: Did you want to finish up, sum up, or have any final thoughts?

Barner: I want to say that I was happy to do this interview. I feel like the change is already made, and now I would like to see more changes as rapidly as possible. But I know that people must really reach down deep within themselves, because nobody can give it to you, nobody can tell you, nobody can make you do it. For those people or students or whoever may read this book or read about these interviews, you can learn a lot. But until you actually enact that, you really haven't done yourself any service.

Cowan: Actually, that brings up my question again about "Why Berkeley?" Do you think students that are more self-reliant are more likely to come to Berkeley than they were to go elsewhere? Do you think Berkeley had some particular attraction for people who were inherently self-reliant, assertive people?

Barner: You mean disabled or normal people?

Cowan: Disabled. Probably everyone, but in particular, disabled people.

Barner: Yes, I think so. Yes, you have to be a strong person to live in Berkeley. Even though it was nice, you have to be strong to make it here. You had to make adjustments to different sectors of people, so you had to be self-reliant. It was the strangest feeling when my brother dropped me off and said, "See you later." But I said, "Hey, I'm on my own," but I thought about it for only one minute, did I want to call him back? I was ready to meet the challenge.

Cowan: I think I'm out of questions, but were there any questions that you expected me to ask that I didn't ask?

Barner: No, I think we could have gone into a lot of scenarios that happened around campus, but I think we covered the meaty things as far as what the program was all about, what people would really need to learn about what went on, how different things manifested themselves, and how the program operated. I think that's the main thing, and I think we covered that. You mentioned Cowell

Hospital. When I went there, Ms. Brean was another powerful source because whatever we needed, she would get it for us. All we had to do was roll right down the hallway to her office, and we got it. We always set the program up, we were very adamant about it. I won't say it couldn't have been set up better, but the way it was set up, we were able to function and make it. I made it, and I think that I did really well.

Cowan: You did. Anything more to say?

Barner: No, I think that's about it. Except that I miss Berkeley.

Cowan: It's a wonderful place to be. I thank you for the interview.

Barner: Thank you.



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Disability Rights and Independent Living Movement Oral History Series

UNIVERSITY OF CALIFORNIA'S COWELL HOSPITAL RESIDENCE PROGRAM FOR  
PHYSICALLY DISABLED STUDENTS, 1962-1975: CATALYST FOR BERKELEY'S  
INDEPENDENT LIVING MOVEMENT

John "Jack" Rowan

STUDENT RESIDENT AT COWELL, 1971-1973,  
AND CHAIR OF CIL'S BOARD OF DIRECTORS, 1976-1982

An Interview Conducted by  
Sharon Bonney  
in 1998



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## INTERVIEW HISTORY--John Rowan

John "Jack" Rowan was invited to participate in the oral history project because he was a student in the Cowell Hospital Residence Program for physically disabled students, worked at the Center for Independent Living (CIL) as a peer counselor, and served as chair of CIL's board of directors. Jack was in an auto accident in 1957 when he was a college student at the University of San Francisco and sustained a spinal cord injury. He spent time in a rehabilitation hospital and ten years in a bedroom in his parents' home before re-entering society. He moved into the Cowell Hospital program in 1971 and describes life as a Berkeley student during tumultuous times, a student with a disability who has attained new-found freedom, and as a person who has discovered a supportive "disabled community."

Mr. Rowan talks about the Physically Disabled Students' Program, about his involvement as treasurer of the Rolling Quads and their political organizing and lobbying efforts in Sacramento, about life in the city of Berkeley before curb-cuts, and about the interactions the students had with the Department of Vocational Rehabilitation.

In the late 1970s and early 1980s, Mr. Rowan was a staff member at the Center for Independent Living where he began peer counseling people with disabilities on eligibility for Supplemental Security Income and Social Security Disability Insurance, and on using Plans for Achieving Self Support (PASS) to exempt income or resources toward a goal of self-support. He observed the internal workings of the Center for Independent Living and the relationships among people who worked there.

At the same time that he was an employee at the Center for Independent Living, Mr. Rowan was the chair of the board of directors for six years. He describes the problems created by being a staff person and a board chair who was involved in trying to resolve several staff strikes and in trying to create a holding company to protect the center's assets. The center was a lively, busy, disorganized, political, and fast-growing organization, which Jack discusses in detail.

The interviewer and Mr. Rowan have known each other since 1979 when he was doing peer counseling at CIL and while he was the chair of the board of CIL. Two interviews were held in Mr. Rowan's living room in Cedar Crest, New Mexico, just outside of Albuquerque, on October 3 and October 4, 1998. He had been in bed over a month at that time with a severe skin breakdown and was on an air bed. The sound of the air bed can be heard on the tapes. He had a sipping straw in his mouth attached to bottled water, and Mr. Rowan would drink water as the interview progressed. His wife, Mary Ann, repositioned Mr. Rowan every two hours, and fed him meals. She can be heard in the background preparing meals and doing dishes. Sounds of nail pounding and wood sawing can be heard as a friend was building a greenhouse on the back of the living room as a wedding present to Jack and

Mary Ann. The interviews were conducted in two parts each day, a morning segment and an afternoon segment. The transcript was lightly edited by the interviewer and by Mr. Rowan. He donated an original tape of a Center for Independent Living board of directors' meeting from the early 1980s to the archival portion of the project.

Copies of interview tapes are available for listening in the Bancroft Library.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. Copies of all interviews are available for research use in The Bancroft Library and in the UCLA Department of Special Collections. The office is under the direction of Willa K. Baum, Division Head, and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley.

Sharon Bonney, Interviewer-Editor

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Regional Oral History Office  
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BIOGRAPHICAL INFORMATION

(Please write clearly. Use black ink.)

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Areas of expertise SYSTEM TECHNOLOGY COMPUTER TRAINER,

Other interests or activities MUSIC, MOVIES, WRITING, READING AND COMPUTER

Organizations in which you are active \_\_\_\_\_



## INTERVIEW WITH JOHN "JACK" ROWAN

## I THE SON OF IRISH IMMIGRANTS, A STRONG WORK ETHIC, TRAUMATIC INJURY, COLLEGE, AND TEACHING AT CHRISTIAN BROTHERS

[Interview 1: October 3, 1998] ##<sup>1</sup>Growing Up in San Francisco

Bonney: Jack, let's start out with your early background. Tell me when and where you were born and a little bit about your family.

Rowan: Born and raised in San Francisco. One of five children, all boys. Mother [Mary Schofield Rowan] and father [Michael Austin Rowan] met in San Francisco, both immigrated from Ireland--my father from the Dublin area, my mother from a little island in the Atlantic off of the Shannon River named Innishbuffin, which means "The Isle of Buffin."

I was basically raised in the same neighborhood in San Francisco. I lived half a block from the church and school that I attended through eighth grade. All my brothers and I went to the same elementary school: St. Anne's, in the Sunset District of San Francisco. I started my work career as a paper delivery boy probably in like the sixth grade. I delivered afternoon newspapers in San Francisco. Then, I think, in the seventh grade or maybe eighth grade, I started morning delivery routes, which meant getting up at five a.m. and delivering all the papers and then going to school all day. I did that all through high school. In my junior year of high school I also picked up a job working in a bakery on weekends. So I'd get up to deliver newspapers from five to seven, finish my route, and then work seven to nine scraping ovens and floors in the bakery. Then I'd go home and it was time to play and do things.

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<sup>1</sup>## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

In my junior year of high school I got a job working in a gas station. I started out just pumping gas and cleaning the gas station. My whole last year of high school I was still doing my morning delivery route at five, finishing at seven-thirty, and hitchhiked to school every morning to save bus fare. After school I got involved in track, so I ran cross-country and the regular track season. I did the 440 and the 880, pole vaulting, discus, and high jump. I would then hitchhike home and study. I went to St. Ignatius Preparatory High School, which was a Catholic high school run by Jesuits. It was quite demanding. I would usually stay up until about midnight or one o'clock doing homework and still would get up at five and do the newspaper route.

In my senior year of high school, I quit the paper route and went into almost full-time work at the gas station. I bought a used car, repaired it myself, got it going, and I would go to school, run track, come home at five or six o'clock, grab a quick dinner in a bag, go to the gas station between five-thirty and six, and then I would manage the gas station and close it at eleven-thirty at night. I would clean it all up and do all the books and inventory. I would usually be home around midnight and get up and go to school.

Bonney: You say you bought a car. So you stopped hitchhiking somewhere in there and started driving yourself to school?

Rowan: I hitchhiked all through high school, so after high school I went to the University of San Francisco, which was literally across the street from the high school. It was also a Jesuit institution. All through high school and college I paid all my own tuition, books, clothing, everything. My father's point of view was that children, once they were able to work, were supposed to bring money into the house, and if you wanted anything you paid for it yourself. I used to work like forty- or fifty-hour weeks all summer, making money, making car payments, at the gas station. And then when college started, when I went to USF, I always scheduled my classes to start at eight a.m. I would go to the library, bring my own lunch, do homework until about three o'clock, go home and change and be on duty at the gas station at four or five o'clock and then close it up at eleven-thirty.

Bonney: Was your family poor?

Rowan: Poor is a relative term. My older brother was born in 1937; I was born in 1938. My next brother was born in '40, and the next child was born in '42, and then the fifth and final surprise came in '48. So within that short period of time there were five children. The basic comment from everybody was, "How many

children?" "Five." Then you'd say, "All boys." And the standard comment was, "Your poor mother."

The first jobs I remember my father having were--his history was that when he came to San Francisco, he got involved in the union movement, and he was instrumental in setting up the Hospital Workers' Union in San Francisco. He started out, I guess, with nothing by the time the union was actually functioning. My father was not one for systems. In Ireland, I would imagine my mother had little or no formal education. The island she lived on, one of my brothers has gone back and visited, and it's literally like a flat rock off the coast. You can only get to it by boat. They were little boats, and you were born on the island and you died on the island. You could go around the circumference of the island in about a four- or five-hour walk. My father was in Dublin. They both left Ireland in their teens. My father at best had the equivalency of an elementary education. And my mother worked primarily as a domestic. My father and his Irish friends--San Francisco was a very political city. He knew a lot of people, and he was very well-spoken, he got along and had lots of friends. The union position--he told me stories that they were just a lot of internal politics and he got caught up in the middle of some mess. He decided it was time to get out of that, and he picked up various jobs. They were usually all blue-collar.

Bonney: Did he work in a hospital?

Rowan: I don't think he ever worked in a hospital. He got in it more on the organizing end of it. The first job I ever remember him having--and again, my parents were both from Ireland, and at this point my mother is still alive at ninety-two. My father died five years after I broke my neck, so I guess he died in '64 or '65 of a heart condition. But whenever any of us inquired about any of our past history, it was none of our business and that was that. I picked up little bits and pieces here and there from parties. The Irish tradition was everything occurred in the home. You never went to restaurants--men might go to bars for short times--but primarily it was always friends; we'd go from house to house to house to these big parties. Sometimes during these parties, as a kid, people would be playing cards, and music, and people with fiddles and accordions and roll up the carpets and dance. That just happened a couple of times, but you'd go visit other people. So as little kids you'd be dragged along and laid down on a bed or a couch somewhere and go to sleep.

Bonney: What about your other four brothers? Were they as hard working as you were when they were growing up?

Rowan: No, I was the worker guy. I was the one who was always interested in working with my hands. I really enjoyed mechanics and tools and things. As a supplementary sideline, my father got a real estate salesman's license, and in the course of that, I think there were five different times he purchased wrecked or burned buildings, and we would build them. His source of labor was his children. He had no real formal training as a carpenter or anything. His buddies from Ireland were plumbers and carpenters. A buddy would pick up something from somebody. But probably starting in the seventh grade I was doing electrical wiring and plumbing and sheet rocking and pouring cement and crawling under buildings and tearing out roofs. In between that you would try to go play. My father would drive around the neighborhood in his car looking for us; all the playing then was in the streets. The street above our house we had even marked off with white paint; every five yards would be a marker for our football field.

Bonney: What street did you live on?

Rowan: We lived at 924 Judah Street, with a streetcar going by. The home I was born in--a little neighborhood--that I just went back and looked at a couple times: a place called Mangles Avenue. We moved from there to the house on Judah Street, which was literally--San Francisco blocks are short. We were on the middle of the block between 14th and 15th Avenue. And 14th Avenue was where the St. Anne's Church and elementary school was. So we would wait to hear the church bell go off at eight-twenty-five while eating breakfast. Everybody would grab their brown bag and run out the door. And we had five minutes from the time the bell rang to the time the nuns rang the bell at the schoolyard for eight-thirty, when everybody would line up in the schoolyard in cadres. Every class would be formed in a square, military style, and they would do a headcount then. You'd all be lined up alphabetically, and we would all repeat the national anthem out in the schoolyard and we'd raise the flag. Class by class you'd march into the school building and then up into your classrooms.

Bonney: What did you like best in school? What kind of courses?

Rowan: I never really liked elementary school at all; I was always scared to death of the nuns. The parish was run by Monsignor Moriarty, a very strict old Irishman. As I was raised, God was fear and the nuns ran the place, and you had better not do or think anything wrong. I was more susceptible to being good than most people. The only thing I really enjoyed was math because it was easy, I could do it. Most of the whole structure of the school was very regimented. I found that I don't like that, across the board. It was always a very oppressively restrictive kind of emotional and mental atmosphere.



Bonney: Did it get better in high school?

Rowan: Well, in high school my family really never discussed anything. It was one of those stereotypical closed-family systems with very little communication. Everything was understood. Upon graduating it was kind of understood that I would go to a Catholic high school. There were two: Sacred Heart and St. Ignatius. My older brother and I were in the same grades together all through elementary school. My first experience with school was going down to the convent with my father and sitting quietly in a chair while my father dealt with the Mother Superior, explaining to her that I was already doing my older brother's homework, and he could see no reason in the world why he should have to pay thirty dollars to send me to kindergarten, which was foolishness, when I should be able to skip that foolishness and go into the first grade. So my older brother and I went through school in the same class. But I was like one year out of sync. At elementary school that's a lot. So he was always like in sync and I was always out of sync with the group. We would do things together, but mostly he was primary and I was secondary, so I got real used to just watching and listening. He was much more outgoing and personable than I was. I was more into working and he was more into socializing and playing.

All my brothers went through St. Anne's elementary school. When it was time to take the exams for high school, literally my brother and I were on the same bus in the city going to take the exams for high school. The first stop was to let people off for a long walk up to St. Ignatius High School. We never discussed it, we never thought about it. At that bus stop, here are all these guys from the eighth grade of St. Anne's elementary school, practically all in the same bus, all going to take the exams for either Sacred Heart or St. Ignatius. St. Ignatius was like the prestigious school and Sacred Heart was like the blue-collar school, run by the Christian Brothers. The bus stopped and I remember sitting in the bus watching who was going to get off. Two guys that were more like closer friends than some of the other group got off at that stop, so I literally got up and got off at that stop, and the bus continued on. My brother Tom went to Sacred Heart and I went to St. Ignatius. As the two big primary Catholic high schools, there was a traditional rivalry in sports and everything. Yet he was going to one and me to the other.

Bonney: Did you have rivalry between the two of you?

Rowan: Oh, we couldn't care less. To me it was all a joke. I've never seen sports as anything than--I really enjoyed being in them, I enjoyed track. I went out for track because my father refused to sign a release to play football. I didn't need one for track so I

went out for track. My youngest brother Jim also went to St. Ignatius. When it came time for him to sign the release to play football, he just forged my father's name. He played football. He was our family's black sheep. He was very sociable, very personable, very much on his own. He got kicked out of the school for playing too much and not keeping his grades up and not being respectful enough. So he ended up finishing his high school in a public high school.

Bonney: Tell me a little bit about your years at the University of San Francisco [USF]. What did you major in and what kind of a college student were you?

Rowan: I went into USF just because it was across the street from S.I. [St. Ignatius] High School. It was a continuation of the same kind of education. I went with a whole mass of other people to take the entrance exam for USF. It's the only college I ever applied for; I never thought of going anywhere else. The alternative was City College, and that was like very non-status. I wasn't so much into status as into being somehow good, which was like the subliminal message that permeated everything without anybody saying it. So doing the right thing was always going for the challenging thing.

I remember I sat in this huge room with hundreds of high school graduates, taking the exam. I passed the exam to the point where--that was 1957--they were starting to eliminate and colleges were being forced to start "bonehead" English, where if you didn't score well enough on the entrance exam you'd have to take these remedial courses. So I didn't have to do that. A couple of guys that I graduated with also got into USF. I went there as a freshman.

I also picked up a little martial arts along the line; I was very much into being independent. The few kind of physical fights I got into in high school, it never lasted long; I was just always working hard my whole life, and I was tall and thin, but then I met this guy who was a paratrooper and he was trained in judo and jiu-jitsu. He had some books, and I'd read the books and learn from that. He'd show me some stuff and I'd practice a little bit. People would start something and I'd finish it real fast. Nobody ever got hurt; I had this mental attitude of feeling I was always doing the right thing. Following all the rules. And anybody who crossed my trail was wrong, and if there was a dispute one of us was going to die and that was all there was to it. Apparently I had some kind of attitude, people told me, or a look in my eye that people would just say, "Okay, never mind."

So I went into USF and they started all the freshman indoctrination and you had to wear this beanie and do push-ups when upperclassmen came and requested it and all that. I thought, "The first guy that runs that on me, we're having a conversation." So I never wore my beanie and never partook in any of that; none of it made any sense to me. I thought it was all quite silly and I went about my business. I was still working full-time, paying all my bills, and getting money together for the car and the insurance and the tuition and books and clothes. I was pretty much on my own, and then would try to contribute anything left over into the house.

Bonney: So you lived in the family home while you went to college.

Rowan: Yes.

Bonney: What did you major in?

Rowan: I didn't know what I was going to be and didn't have any idea about anything in particular. So at the end of senior year you take vocational testing. I scored good in science and math, so they said, "Good, be an engineer." I had no idea what an engineer was except it had something to do with building things, and I liked doing that. So I thought, Okay, I'll be an engineer. I went into USF and signed up as a major in engineering. I was taking physics, chemistry, calculus. In high school I had had three years of Latin, which was required. My first semester in USF I failed calculus, so that was like a real disgrace, so I signed up immediately to take it again.

#### Auto Accident and Rehabilitation in Vallejo, 1957-1959

Rowan: I was just starting my second semester when I got in this big car crash and broke my neck.

Bonney: What year was this now?

Rowan: That was March 11, 1957.

Bonney: Tell me what happened.

Rowan: I was still working in the gas station and trying to work all the hours I could. I would study at the USF library on the upper floor, and the library was this big study lounge. So I would do all my classes in the morning, go up there and eat lunch and study. Then I had some science or physics class in the afternoon,

at three-thirty; I had to take the lab. Just to take a break, sometimes I would get into my car and drive out to the ocean. I always liked the ocean. I would find a parking spot where I could sit there and watch the waves and do my homework. So I would just sit in my car and read and do homework and watch the waves and relax.

One day I thought, I have a half hour or forty minutes here. I'm just going to take a break and drive down the highway and look at this new construction they were doing over the airport. They were doing some new subdivisions south of San Francisco. I drove down there and found this place to park; it was overlooking the airport that was still under construction, and this big pre-development layout where the streets were in and that was all. I just parked there and watched the planes land and thinking and taking a rest.

Then it was time to head on back to the city for my afternoon physics lab. I was on a freeway heading toward town, and I forget the intersection, but it was three lanes each way, developments going on alongside both, a lot of construction. I just remember driving down this long thing, heading for the city, seeing this whole group of cars way out in front of me. I had a four-door '54 Ford that I had bought from the mechanic at the gas station about five or six months previously, when he bought a new car. I bought his other car. I used to polish the inside of the fender wells. I mean, I had this thing tuned and cleaned, and I was very proud of it. Driving along, I remember cars along to my right, and looking to my left and looking out in front of me, and there's a cement mixer crossing the freeway. They didn't have any overpasses or stoplights, so all the construction vehicles would wait for an opening in traffic and cross the freeway.

I spent a whole lot of time going over this because I was involved in a lawsuit over the accident, and--

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Rowan: --and I remember processing it at an incredible rate of speed. Reading about sports car drivers, and to me personally, and doing athletics, a couple of times I remember getting into what they now label "the zone". Basically it's a super-hyper mental state where everything processes so rapidly it seems as though it's in slow motion. The other thing I remember specifically was no auditory--no sound at all--just hypervigilance visually and probably hyper-reflex. I remember processing it, watching this big cement mixer truck, the barrels still going around on the back of it, and knowing that if I went to my right, I might hit this other vehicle, lose control of the car, or end up going between



the front wheels and the rear wheels and being decapitated. On my left was one lane and then a bunch of sand and then the traffic going the other way. I thought that if I got in the sand I might flip and roll.

So I remember processing all this and going into this super mental state of focusing totally on the front corner of the bumper and front wheel of the cement truck and just praying and praying that he would stop. If he would stop, there may have been enough room for me to do a left swerve, stay on the asphalt on the crossover section between the lanes and get back in again before hitting the sand. I remember stepping on the accelerator and it kicked right into passing gear, and I was doing about fifty-five or sixty when I saw the truck, and I remember seeing if I could crank that baby as fast as I could to get by the front of this truck. I just took off to the left, trying to keep control of the car.

Photographs that were taken of the accident afterwards-- apparently I had--I remember the last point of consciousness, still watching the front bumper and the front wheel, and it never stopped. It never stopped. I kept praying that if it stopped I would have a chance. But it never stopped. Apparently I made on the right front of the car a slight little curve in the front fender right above the right wheel, and then it gradually, very slowly went in, and apparently the bumper hooked at the seam of the car, between the end of the front fender and the right passenger door. The rate of speed I was going at that time literally just ripped the car apart.

From one side of the car it looked untouched. The other side of the car, the roof was gone, the windshield, side doors, trunk, everything was like ripped off in a piece. The back of the front seat was impaled on the bumper of the cement mixer, sticking perfectly horizontal, still with the blanket that I used to use to cover it. So apparently whatever happened upon impact, I found out later the driveshaft had snapped, the universal joint popped, so I had basically gone into neutral and the car just drifted down into the sandy part and came to a stop. I was lying on my back across the front seat, with my head hanging down over the edge of the front seat.

I remember my first conscious memories after the impact were like wind on my face and this pain in my neck. I was just moaning, "Oh, my neck." I remember people talking. I remember one guy yelling, "We'd better get him out of here before it catches on fire," and someone else yelling, "If you touch that kid I'll break your arm! Don't move him. He's got a neck injury."

The next thing I remember was a priest bending over me giving me the last rites. He would start the words and I would just repeat them after him. Before the priest arrived, I remember somebody saying, "At least let's get him off this broken glass." So apparently the speed or the dynamics of the impact, I was actually lying on top of the windshield that was on top of the front seat. Mentally, I just remember setting myself for the impact and saying, "Hold on to the steering wheel." There were no seat belts at that time, or very few. I wasn't belted in in any manner. Afterwards when they were analyzing the accident for the trial, which I never went through, they said if I was belted in I'd be dead for sure.

So anyway, I had the last rites because this priest told me later--I met him in the hospital--he was in traffic behind me when they had to stop the traffic to clean up the accident. He came forward and saw my University of San Francisco book covers on the books that I had in my trunk and in my back seat that I was studying from. He knew I was probably Catholic so he gave me the last rites. The only time I would become conscious after that would be if there was any movement. I would come to and fade out.

They took me, I found out, from the car wreck to a little emergency hospital that was right down the road, close by. Because my father worked for the city then--he was driving city buses--I was under Kaiser Permanente health plan. Their rule was if you were within twenty miles of a hospital, you had to be taken to one of their hospitals. So even though there were several hospitals close by, they let me lay in this emergency place until seven or eight o'clock that evening until Kaiser could send an ambulance to pick me up to bring me to their hospital which was newly built on Geary Street. Afterwards I found out I was the first spinal cord injury patient in the hospital.

I remember being interviewed by a highway patrolman in the emergency room. I remember when they had to move me to cut my clothes off. I remember every time I would wake up would be during the ambulance ride to San Francisco--whenever the ambulance would decelerate--my neck would hurt. I was wearing this plastic neck collar, and I would just go, "Oh, my neck." I remember the sensation. It was curious because I remember this one movie I saw years later, a Western, and the guy is shot in the back, he's paralyzed, and whoever wrote the script knew the background of it. This guy kept saying, "Straighten my legs out for me, will you?" When I was in the hospital and in the ambulance I kept saying, "My knees are bent. Can you straighten my legs out?" Apparently that's some kind of neurological message out of a spinal cord injury.



In any event, I finally got to this hospital, and the only time I'd wake up after that would be when I felt this weirdest noise in my head and this sharp pain, and that's when they were drilling holes in my skull to put in the Crutchfield Tongs. I remember I would come to, and literally one guy was reading a book on drilling. Or they would catch a piece of my flesh in the drill and it would wake me up, and I'd hear all this crunching going on and ask what they're doing. They'd say, "We're drilling some holes in your head to put these tongs in." Then I'd go out again and I'd keep coming in and out only when the pain in the skull would bring me back. I would wake up and say, "You're not going to drill too far and get into my brain and kill me, are you?" They'd say, "No, no, no, we're measuring, we're measuring." I found out later that they put the thing in the wrong place. They put it in my temples; it should have gone on the upper part of the skull. So as a result, where they drilled one of the metal prongs going in there locked my jaws. So I was on a liquid diet the whole time I was in traction because I couldn't open my mouth to chew.

It was like one fiasco after another. Both myself and my parents were unfamiliar with hospitals and never had anything much to do with them. There was a whole series of bad news. I've never done well in hospitals. I have a bad record in hospitals. So anyway the next thing was my father got a hold of a lawyer and we starting a legal suit. I was kind of out of it. I had turned nineteen in April; I was eighteen in March when I broke my neck. I was still a minor at that point, until age nineteen. I was still covered under my father's hospital coverage because the accident occurred before age nineteen. They had to continue my care under his plan. So I stayed in Kaiser.

I was three months in San Francisco, in traction, on a hospital bed. Every three hours they would get four or five people together: one would hold my head, one would hold my shoulders, one my hips, one my legs, and they would go, "One, two, three, flip!" and put me on my side. There were some guys that would come in on night duty who were moonlighting from the military base in San Francisco, from the Presidio. I think it was Fort Miley. I remember one night laying there, and this guy came on duty, Sergeant Jimmy Neeley. We kept in touch for several years. He came in, looked at me, and just started cursing. He opened a door yelling, "Who's in charge of this patient?" He was a master sergeant. Out of the hallway there was all this ruckus going on. There was himself and two other guys that would work night duty, that were moonlighting, and who were corpsmen out of the Presidio. They knew their stuff. They said, "Why isn't this guy on a Stryker Frame?" A Stryker Frame is what they used for spinal cord injuries for years. They said, "We don't have one."

He was saying, "I'm going to get one; I'll be back in two hours. I'll go over to Fort Miley, and by God, I'll get one and bring it here." They had this big discussion and had to call doctors and restrain him.

But they never, ever changed me from a hospital bed in three months. They put a heating pad on me once because I thought I could feel something in my hip. They changed shifts, left it on, someone came in and smelled burning flesh. They found this heating pad that cooked its way through into my hip.

I went blind for about a week. I had been watching television--they taped a hand mirror onto the head of the bed--and I would just watch television by staring into this mirror. Apparently it burned out my eyes. One day somebody came in and I told them to turn on the lights and they said that the lights were on. I said, "No, they're not. Turn on the lights." Then up came the doctors, and I was blind.

So it was three months laying in a hospital bed with these traction things in. This was in 1957. I never had any surgical procedures at all on my injury. Part of it may have been my father, who was basically an alcoholic, and his way of dealing with bad things was to get drunk. He would come in drunk a lot. Whether or not he refused to give permission to the doctor, or I was in such deep shock--in the beginning I could hear people talking--and I wasn't expected to live, so it was like "Why bother doing anything for the guy?" In that three months, I didn't find out until later when I was going over my own medical records preparing for this trial that never happened--it was two years in preparation--as a standard procedure then, the deal was to never tell anybody the truth because it would be too hard. So nobody would ever tell me why I couldn't walk or when I would walk. Everything was "You'll be okay," and "You can never tell," and "There's always recovery." Anyway, I set my whole mind that no matter what anybody said I was going to walk again, and that was all there was to it.

So I used to lay in bed trying to wiggle my toes and move my arms, do anything. I got a little bit of movement back in my arms. I kept pulling my arms up because that's all I could do. So as a result of being in a hospital bed for three months with my arms lying primarily on my chest I ended up with contracted biceps. To this day, besides all the other limitations, it really limited that too. I've got about a forty-five degree ability in the arms and that's it.

Bonney: When you were first injured were you totally paralyzed then?

Rowan: It's what they call an incomplete spinal cord. Completes almost never happen unless they do it surgically. So basically what happened on the x-rays was that the whiplash at the scene of the injury--they say your head is like a twenty-pound bowling ball bouncing on this little stem of bone. The x-rays show that literally the fifth cervical vertebra had totally disintegrated. So the whiplash was like real severe. I got a little bit of C-4, disintegrated 5, and also got 6. I basically had like a C-5-level injury. But then later I found out that they had me on Demerol every four hours around the clock. That was at that time, quite a procedure to keep you calm and keep you from realizing what had happened to you and blah, blah, blah.

After three months there I went up to their rehab facility in Vallejo, California. That was the first time I had seen myself. They had me on a hospital gurney, and I was down at floor level with the guys pulling the grips on either end meant for transporting down these long corridors, they just collapsed me down to low and just pulled me along. They were pulling me along through these long, long corridors. It was a long, one-story, sprawling rehab facility that Kaiser bought from the government for like five dollars at the end of World War II. It was a rehab facility built for the navy, and then he [Mr. Kaiser] bought it for his coal miners.

When I moved in there, there were still some guys living there from the old coal miner Kaiser rehab days who decided to live in the facility. It was just like the military, one-story, rambling wood structures connected by these long linoleum hallways. We made this turn, and at the end of this hallway--I guess for gait training--was this great big huge mirror. It was a big, full-size, corridor-wide mirror. As we went around the corner, I looked sideways and there was somebody I had never known. There was me lying on this gurney being pulled, and looking back at me from the mirror was this super-thin, totally pale, hair-sticking-out-all-over person I had never seen before in my life. I was just shocked. It was the first time I had seen myself in three months.

I went on to the ward, and they were doing the intake. I remember the intake doctor pulling the records out and yelling at the nurse, "I don't care what this guy says, he gets nothing. Not even an aspirin. Nothing for pain." It made no sense to me. For whatever reasons I never experienced any withdrawal or anything at all. I had never, ever requested a pain med. I had no knowledge I was on round-the-clock Demerol.

It was a peculiar beginning from the get-go. I went in that rehab hospital three months after injury, after living in a

hospital room--during which in '58--there was a big earthquake. The whole hospital was shaking, I'm laying in bed and the fifteen-pound weights suspended off my tongs were rattling on the bed. I thought, "What if it's going to fall down?"

I was two years in Vallejo. My family wasn't ready for me-- I didn't know, they didn't know, nobody knew what to do with me. Because I was still a minor in '57, '58--the legal age was twenty-one--my father was running everything.

Also while I was at rehab, during physical therapy, I broke my right femur. They told me it was a bursitis. They were shooting pain meds into my hip and stuff. I didn't know what was going on. It wasn't until years later that I saw x-rays and got totally mad because these physical therapists and nurses that I considered my close friends after living there two years and seeing these people every day, everybody covered up for everybody. That injury has kind of caused complications over the years, but by the time I discovered it everybody was gone and moved and the lawyers pretty much told me, "You'll never get any witness around to say when and where and how this occurred."

I would go home on weekends. I would live there for a solid year, and after a year they would let you go home on weekends now and then, trying to prepare the family to get organized. So we lived in San Francisco then, at 21st and Pacheco, in a three-story house on the corner. San Francisco houses usually have parking areas down at the bottom, and then the house level above it, and then if it's more than that your bedrooms are above that. So it was a great big house my father had bought all run-down and beat out. It was one of the houses I had helped him rebuild. He had added on a room on the second floor. He always did things a little off. Smart guy, but with alcoholics things never go right. Instead of putting it on the ground floor he put it on the second floor. Instead of stairs he just put in a ramp, but the pitch on the ramp was so steep it took two people to push the wheelchair up and down. So I hardly ever went anywhere. Two years in rehab, the only time I ever left was to go home on the weekends, and then I'd stay sleeping in this bed in the front room until the room was added on in the rear.

My father's idea of a weekend at home was to have a party: invite everybody and every relative and everybody in town to come see Jack, the poor guy. It was always just weird. Then because I was involved in this lawsuit, and everybody was looking at all these potential riches, at that time in '57 and '58, suing for half a million dollars was an astronomical amount. Nowadays it's like nothing. We entered a suit for half a million. The company that hit me, their insurer paid off within months. They had no



problem; they paid their limit of \$200,000 and were out of it. So the lawyers said this company was underinsured and this and that. He investigated this and that and found out it might have been a little underworld front operation. They had everything covered and he couldn't find any assets.

I roomed with a guy who got a huge award after breaking his neck up in northern California playing football. They gave him a \$600,000 settlement against the school district, because they had picked him up off the playing field and brought him to the sidelines to continue the game. It went to the Supreme Court, and I roomed with this guy for about a year. I still maintain contact with him to this day. From his experience and talking to him about lawyers and lawsuits and judgments and jury awards and appeals, it became quite clear to me that we could probably get the jury award but we'd never get the money. I talked to the lawyer about it and he kind of agreed with me.

Bonney: Who was this guy you roomed with?

Rowan: His name was Tony Welch. He lives down in Los Angeles. I was visiting California in July of this year, and I went and saw him. He's still around and operating. One of the few guys I've kept in touch with from the rehab days. There's one other person I used to keep in touch with, she was a Native American. She was twelve or thirteen years old, one of eight or twelve children. She was riding in the back of the pickup truck on the reservation, and it flipped over. She was tossed out and she broke her neck. These last two years are the first two years I haven't heard from her. I don't know if she's still alive or not.

Bonney: You were in the rehab center for two years?

Rowan: Yes.

Bonney: What happened at the end of the two years?

Rowan: I turned twenty-one. My father and lawyer came to visit me on one of their periodic visits. My father had worked out some kind of a deal with the hospital there, that they would give us a break on the price or whatever to stay in there. The lawyer felt that it was better to stay in there for the trial rather than to be at home, in order to build up a documented medical and financial record. They came to visit one day and I had turned twenty-one. We went over the case and my father was like, "No, we're going to trial, we're going to trial. That's all there is to it." The lawyer turned to my father and said, "Mike, you're out of it. He's twenty-one, he's now in charge of his own case. I now work for him. So Jack, what do you want to do?"

I said, "Let's settle. Settle for all you can get. Let's settle, because going to trial looks like a--." I had no doubt, the lawyer had no doubt, that we would get the award, and the lawyer when I spoke to him agreed with me that we'd probably never collect it. All this company had to do was go out of business, change their name, and set up again down the street, and that's the end of it. So I thought I'd cut my losses and just go home and figure out how to make a living on what I got left after paying all the legal and medical bills.

### Returns to Parents' Home for Ten Years, 1959

Rowan: Shortly after that I returned home to live. Basically, home was another version of rehab. I literally lived in three or four rooms for about ten years. I learned about investing, read about stocks, read about real estate. My father had a sales license. We were using what capital I had in buying and selling real estate and making second-mortgage loans, a couple of third-mortgage loans, and bought a few stocks here and there, but they didn't go very far. Mostly it was real estate.

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Rowan: My story: I'm now at home in San Francisco. I'm living in this room, my father dies in '64. I'm in real estate, very few visitors. And my solution to survival--I was in a pushchair--but I couldn't push. My mother and my brothers did most of my attendant care. I would hire people to come in in the morning and at night. They would get me up and come in and put me to bed. I would sleep on my stomach on stacks of pillows all night.

I was going through strange things, one of which was I got this tremendous pain going in my right foot that I couldn't figure out. It turned into this horrendous deal where we'd go to the doctors and the toe would be inflamed. They would look for an infection, but no infection. Remove the toenail, because it must be an ingrown toenail, but I shouldn't be able to feel it. I would get spasms from it and I couldn't sleep at night. So they prescribed all these pain meds for me and at one time I just Nebutol-ed myself into an overdose and almost died. An attendant came in in the morning, and he had some experience dealing with drugs. He went to rouse me, and I couldn't be roused. He got on the phone and the ambulance got there, and I was back in rehab in Vallejo over going to Kaiser in the city for a while. I was in there on a psych entry. They had me down there as "suicidal/psychotic" because I tried to kill myself by overdosing on



Nebutols. All I knew was I still had this terrible pain in my foot.

I had a long series of misadventures, and one retired navy doc on staff said, "Take this white pill." I said, "What is it?" He said, "I'm not even going to tell you. Just take this white pill." So I took it, and in a couple days the pain started to go away. I saw him three days later and I was happy. I was able to sleep for the first time that I could remember in a year. I told him it was great, that it worked, and he just sat in his chair and laughed. He said, "That pill is only good for one thing in the world, and that's gout. You had gout, and for some reason that pain track works." Every now and then it flares up, and I just manage it by cutting down on my acidity.

But weird little things like this would happen at home. Various attendants. My biggest outing, through a lot of goofiness, I ended up owning this great, big, huge old house up on the Russian River seventy miles north of San Francisco. I ended up rebuilding that--not by hand--but by money. My father had picked it up and I had bailed out of it. I took over the title and such. I still have that house today; my mother's living in it. I gave it to her. That was like the first property I had ever bought. That was in 1960.

The first item I ever bought when I went home out of the hospital was--I had these two friends that were down in Santa Clara University, they were both into engineering. In 1960 they went out and bought me the fanciest, high-priced, hi-fi stereo setup in San Francisco. These huge monster speakers in my little bedroom. I bought the Great Books of the Western World. A salesman came by, I talked to him, and I still have the set over there in the bookcase. I started reading volume one. By mail I would belong to all these book clubs, and I would order books. My day for years was reading U.S. News and World Report, Time, Newsweek, real estate journals, the newspaper front to back, and just read books. I did that for ten years along with drinking wine.

I went through three severe depressions. The third depression, when I felt it coming on, none of them were clinically treated, it was just that in retrospect I knew what they were. I just kind of worked my way out of them. I remember on various occasions realizing that instead of one empty wine bottle there were two or three empty wine bottles at the end of the day. I thought, "Uh-oh." So I just stopped drinking. Everybody, especially my mother--my father was an alcoholic--she was used to it. Whatever Jack wanted, Jack got. What's a little more wine, and I'd still just read.

Around 1968 I went into business with a real estate broker I met down south of the city. I sold all my property in San Francisco and was going to go into business with him in San Mateo County, which was developing. I bought and had a brand-new home modified at the blueprint stage for wheelchairs. Left San Francisco and went into this fully accessible house with a nice view. I was half a block from a shopping center; my mother could walk to do all her shopping. My brothers had all left home. I figured I'd be near a junior college.

Part of the move was that I'd been ten years paralyzed at that point. I was about breaking even and maybe doing a little bit better financially. My medical overheads were running about \$20,000 to \$25,000 a year, between attendants and this and that, because I was not eligible for any coverages. Also supporting the family and bailing a couple of brothers out of trouble that they had gotten into. Everybody was expecting that Jack should be this incredibly rich guy, that he was going to make all this money in real estate. It dawned on me, "Why should I make all this money, living in these three little rooms, die, and then someone else spend it?" So I thought, "No, I'm going crazy. I'm getting depressed and out of things to do. I read myself to death. I've got to get out of here; I've got to do something."

So I decided to move down to San Mateo. They had just built a brand-new junior college system down there. So I bought this home that was like a quarter mile from San Mateo Junior College. I thought that this made sense. I'll be near a junior college, watch the students, advertise there, find me a student to do some attendant work, get a driver, be able to drive up and down and go to classes. It should all work. Well, it looked good on paper. Finding help doesn't have much to do with logic and reason. I got all that situation together, and the business thing turned bad. The guy didn't work out.

From there, I had read in the newspaper about the [Physically] Disabled Students' Program at Berkeley. There were some articles in there. So I started inquiring around. I thought, "This would be good. I got this brand-new house down here, my mother's set up, the stores are close by, she's taken care of, and my brothers are on their own. It's time to take care of Jack. Let's go back to school." I figured I had to make my living out of my brain and my mouth. Psychology. I'll become a psychologist.

The other place that was close by was Stanford. I phoned up the Division of Vocational Rehabilitation in San Mateo and said that I wanted to go back to school. I said, "I'm self-supporting. I'm living off of my money. I don't have that big a budget, I'm

going to need your support and whatever help I'm eligible for through DVR. I read about this program at Berkeley, but I am also close to Stanford. I'd like to go to one or the other." They said, "Well, if you go to Stanford you're own your own. It's a private college and we're not paying that tuition." I said, "Okay, then it looks like Berkeley. What do you know about it?" They told me about the Disabled Students' Program there, and then I phoned relatives in the city who had kids going to college and I said, "What do you guys know about this program at UC Berkeley?" They said, "All we know is that there's a bunch of really crazy guys in wheelchairs. God, they drive around town like maniacs and drunk and roaring around. You'd be in different places and you'd see like these three or four guys in wheelchairs zooming around in these power chairs. It's kind of crazy."

So I wrote a letter to the Disabled Students' Program and got a letter back. At that time I used to write a lot of letters to a lot of people. I'd use a Rapidograph engineer's graphic pen because I really liked the way it would write. I had all this time on my hands. In the meantime I had learned meditation on my own, just for survival. So I wrote this letter to the Disabled Students' Program and gave them a little biography and the story of my life and where I was coming from. At that time I thought entrance to UC Berkeley through the Disabled Students' Program was entrance to UC. So I talked to DVR, and they said they would sponsor me to UC. I was communicating with the Disabled Students' Program, and at that time Don Lorence and John Hessler, I think, were head of the group. I went over there one day and met with them all up in Cowell Hospital in the lunchroom around this big, round black table that when I lived there became where we would eat lunch and play cards in the evening. I talked to them and they said, "Okay, we agree that we'll let you in." I was just starting to use a power wheelchair at that time.

A little footnote here: I started going to San Mateo Junior College. I went there for two years. I had a major in psychology and also business and real estate. So I would take courses in the evening in business, depending on when I could get a driver and put all this stuff together. I had a little Corvair van for transportation, and it blew up. After that I bought a '68 GMC panel truck with just a manual ramp on it with tie-downs. One of my brothers was working night shift in the city, and he would come down in the morning, drive me up to school, and drive back home and go to sleep. My mother would wake him up at three o'clock, he'd go back up to campus, pick me up and drive me back down home. I was still in a push chair.

I would get students to push me from class to class, because meanwhile I was trying to get this business together to build my

own power wheelchair; I didn't like the ones that were on the market. E&J [Everest & Jennings] had one, and I thought that for the amount of money they want for that I'd build my own.

So I got involved with the Stanford engineering department, and they had some students working with me on it, working on designing this wheelchair. In the hallways at the junior college, I bumped into this guy that I was in rehab in Vallejo with years before in '58. Lo and behold, he had a home close to there, and he was going to junior college, and at the time he had a serious skin breakdown and he was in the local hospital for treatment. So I would go and visit with him.

He said he was just going to the junior college to keep DVR --because he needed the support--to pay for a few bills. He was a spinal cord quad [quadriplegic]. He was married, had a house, had his attendant. One day I bumped into him in the hallways again. I asked him how it was going, and he said he was back at home. But when he came home he found out that he had no furniture and no wheelchair, no car and no wife, no attendant, and no dogs. The wife and the attendant had been having an affair, and while he was in the hospital they sold everything they could get a hold of, took off, and when they arrived at the door with him in the ambulance to return home, there was nobody there so he went back to the hospital. He said, "I'm starting out from scratch again."

I said, "Look, I've got this project ready to go. I've been working with DVR and trying to find funding. I don't really want to get into the wheelchair manufacturing business. What I want to do is go to college and get a psychology degree." He said, "Well, I don't want to go to college; I want to get into the business factor." So I turned it all over to him and told him, "I'll make a deal with you. You get started, and I will buy your first power chair." In the meantime, he said, "By the way, I have an old electric one." He was a real small guy. He lent me his old electric one that I put an extension back on and stuff. That's the one I went to Berkeley in, waiting for this other chair to get developed.

### Living in the Cowell Hospital Residence Program, 1971-1973

Rowan: Anyway, when I went over to Berkeley, school started and I arrived. I went into the Cowell Hospital, moved in, was assigned a room, everybody unloaded everything, and I was there in my chair. Then I went down to the Disabled Students' office, at that time, which was over Top Dog off of Telegraph [Avenue] and met



Zona Roberts. I'm talking to Zona and she's saying, "Okay, where's your registration and your numbers? We've got to get you into classes." I said, "What registration?" She said, "Wait, what are you doing here?" I said, "Well, I wrote to there and went to the group, met here and I'm here in the Disabled Students' Program. Doesn't that mean I'm in the university?" She went, "No."

So a call went out to Gerry Belchick, who was the DVR counselor monitoring the Disabled Students' Program. I think it was Gerry at that time. So Zona got hold of Gerry and said, "We've got another one." Apparently I was the second person to have done this. The other one was Judy Taylor. She arrived from Texas and thought that being accepted in the Disabled Students' Program meant you were enrolled in the university. So anyway, in one day I got enrolled, registered, they got the whole thing together, and I was a student. And I started classes.

Every now and then, my friend would bring over a prototype that he had been working on, and it had go-cart tires with chain drive with two quarter-horse electric motors with electric brakes on it. It would go. So all the other guys in the program using power wheelchairs were all like, "Oh, man, this is like hot rod from outer space." [laughter]

Bonney: What was the name of the guy building the chair?

Rowan: Don Chisholm. He's dead now. The hospitals started a logical response to the situation of spinal cord injuries. Very few people knew anything about spinal cord injury. Anytime I needed to go to a hospital for anything they never knew what to do with me. I had no sensation, I had no accurate feedback, I knew I was sick, didn't know where, didn't know what hurt or where. So basically they started saying that these guys who have been disabled a long time know what they need, know more about their bodies, and we'll go by them. Don had this feeling that he had an impaction. This was after the wheelchair business had gotten started up. I heard this story from a good friend of his that he had gone into the hospital, and they were doing these enemas to clear and he just said, "No, no, it's still there; I can feel it. I know it's a block." One person giving him the enemas finally said, "No, I've given you too much water. I'm not going to give any more." He goes, "No, you've got to put more in." He refused to do it, so they assigned someone else to do it, and they burst his lower bowel and he died.

The company went into a receivership and someone else took it over and manufactured the chair for several years. It's the same chair that Ed Roberts used. He kept his until his last day.

I had mine up until--I guess I got it in the early seventies--and I finally had to stop using it because I couldn't put a proper back seating system on it in 1990.

So there I was in Berkeley as a student.

Bonney: Tell me what it was like to live in the Cowell Hospital program.

Rowan: When I went into the Cowell Hospital program it was kind of strange because here I was back in the hospital. Once I got this more powerful wheelchair, the campus was a delight. To be able to cruise around that campus with all these beautiful buildings, trees, and landscaping, I've always loved architecture, and in my bones, choosing what I would want to be in life would be an architect. It was just a wonderful experience. It was also an experience of liberation. Not an unusual disability syndrome since I had been living in a very restrictive environment since breaking my neck--and also a very isolated environment. I had very few peers. I was kind of at home with the folks and taking care of business.

When I arrived there I was one of the oldest guys in the program. I was twenty-nine. And here were all these people of various disabilities, and in Cowell Hospital everybody was in a wheelchair. The Disabled Students' Program itself, dealing with people who were deaf, blind, post-polio, ambulatory, some using wheelchairs, some canes and crutches, it was kind of like being back in rehab. On like a physical rehab, social rehab, intellectual rehab, and I think underneath it all--for myself for sure, and I think for most of the people I met in the program--a total psychosocial rebuild. Some people arrived there and literally went crazy with liberation: drugs, alcohol, sex, your own hours. It was out of jail.

The climate at the time I got there--which was '71, I think --and I had gone to this junior college from '68 to '71. The junior college was just straight scheduling, go home, sit up, handwrite all my papers, all my reports. A lot of younger students. Junior college was not highly motivating. The classes I truly enjoyed in junior college were the night business classes I went to with adults who were working. They came prepared and they were ready to go. Whereas during the day classes I would go to, professors would ask a question and there would be no response, no hands up. The only activity that went on was between classes, everybody trying to make connections and dates and party schedules.

A few classes that I was in I did very well in. I was only there to go to school. A couple of the profs I got close to. One



of them even would come to my house now and then to visit. I did very well. I did well in the business courses and I did well in the academic courses. It took me more than two years there because of trying to get my transportation and attendants going. One woman who drove me to classes then in '68 and '69 I'm still in touch with to this day--her and her family up in Wyoming. We're still friends.

So from there off to Berkeley. A whole other climate. All my relatives in San Francisco were scared to death for my safety, because the news coverage out of Berkeley at those times were the anti-war riots, tear gas, police, students burning and pillaging, closeups in the news. It looked like on TV that Berkeley was on fire, that there was like guerrilla warfare on every avenue because of the way the news coverage was on the events. They were all afraid that Jack's going to go over there and get killed in all this madness.

While I was there, there was still the residual of that going on. There were several instances where all the Oakland police with their shields and blue helmets were coming across Sproul Plaza in a line with their batons up and students yelling at them and tear gas fumes going through the air, and I'm just driving around in my wheelchair going to class. A couple of classes were canceled. Some classes would have a little tear gas come in them.

And the other thing was that living in Cowell Hospital, all of a sudden they're going in and out of the building and up and down the elevator, and maintenance was all busy one day. I remember when [Governor Ronald W.] Reagan decided what a great idea it would be to have the National Guard helicopter fly over campus and tear gas the whole place. The students that had the tear gas on them would be admitted to the hospital, and the tear gas would still be active and it started affecting all the patients who were in the wards. So they had to build this outdoor shower in the back to where they could wash down and rinse off the students coming in for treatment from the tear gassing, before they went into the hospital where it was affecting the atmosphere in the hospital.

It was really weird: it was going to school, being independent, hiring your own attendants, making your own schedules, going to these classes, being overwhelmed with intellectual challenge, trying to take a full academic load, trying to keep the wheelchair going, trying not to have skin breakdowns, and at the same time having at my disposal this huge social calendar of parties and people to meet and places to go. Time-wise and physical-wise, you couldn't do it. People with

different amounts of personal discipline did well, and others self-destructed. I think everybody found their own way through. There were a lot of rumors, a lot of heroes, a lot of stories that may or may not have been true about various adventures that people would have, and yet also there was like this bond of people that were really tightly centered around--

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Rowan: --their family with disability. The fact that the office was off campus in this converted apartment, going up the back ramp was one of the first challenges. It was this really steep thing. It was a test of courage, really, to go down that thing in your chair, until you figured out how to slide and use reverse and slow down and hope a car wasn't coming through the underpass out of the street and into the parking lot in back.

It was all like being involved in--especially looking back at it now--the feeling of experimentation in the most positive way--that it was hard work and totally challenging and open-ended. It was open-ended, down, up, and sideways. You could go through it in a destructive mode, in a creative mode, in a survivalist mode. One of the good things that I got out of it was being in a group, sharing the same experience in similar ways, and people were able to cross-feed information. Everybody was into trying to find bigger, better, faster wheelchairs. More comfortable things, how to handle pressure sores, attendant seeking and training. Everything was shared information. It was like one very loosely constructed kind of think tank.

Ed Roberts had been living in Cowell Hospital and had just left and gone out into the community just before I arrived. One of the things I remember was Cathy Caulfield. Going there, I was so nervous and uptight and scared and brave and all these things at the same time. Cathy Caulfield, I remember, was like a semi-hero. I haven't seen her for years. I saw her up in northern California in the late eighties or middle seventies. Her brother was going to medical school and Cathy was really out there: she wasn't afraid of anything, and she was out doing it.

She was one of the first people to move out of the hospital. Her motivation was living with all these creepy males that were just making her crazy. She was the only female, and she was getting a lot of harassment. She was one of the first people to move out, and that was a big deal. I remember it was this really big deal among the disabled students and also the university hierarchy that this quadriplegic woman was going to be attending classes, but living in the community and actually going across streets and curbs. There were no curb cuts. You'd find a

driveway somewhere. And I remember when John Hessler moved out--his brother worked for the city--and John was telling me one time that there were a couple of intersections he had to cross where there were no driveways for like half a block. Somehow, accidentally during the night, the city truck dumped its cement--poured a little ramp [laughs]--on a couple of these corners that John would use on his route to the university. That was the beginning of curb cuts. The university was putting in curb cuts on campus.

One of the stories was Cathy--I think it was Cathy; I don't think it was Judy Taylor--was going to classes one day and there in the "No Parking" curb cut ramp area somewhere on the university--it was also part of a parking lot--was this very nice fancy car blocking the ramp. She reached in her bag, pulled out her handy-dandy marker, and wrote a very nasty note on the guy's fender. Well, it was a prof, I think, or someone at the university. The campus police were at the dorm. Everybody was investigating as to who did some significant, costly damage to this guy's paint job, writing this message with this highlighter marker pen on his fender about blocking wheelchair curb ramps. That was one of the first real punitive blocking-the-curb-ramp stories I ran into [chuckles]. She never did suffer any consequences, but the campus police started really enforcing it after that. Things like that made the days interesting.

#### The Rolling Quads, Disabled Leaders, and the Political Climate

Bonney: As you said, you all lived together at Cowell Hospital and you sort of had shared information on how to do things and you had a great social life and all of that. Who were the ringleaders when you were there? And what did they do, and what did you hear and see? I mean, you just gave a great story about Cathy. Who were the ringleaders?

Rowan: I was treasurer of the Rolling Quads. Herb Willsmore was president. Herb, I last heard, was selling real estate in Santa Rosa.

Bonney: He still is, yes.

Rowan: He helped me sell my van. We were going to keep in touch, but we kind of fell apart. I'm glad he's still around. Herb was one of the few guys who had use of his triceps. He could extend his arm up over his head. When I got there what Herb was famous for was that in his room he had his stereo on a shelf up high that only he

could reach the volume knob. He would run off to classes in his chair and leave the stereo blasting and bothering everybody else. The other thing was the university pretty much left us alone on that floor, as long as we didn't do anything to disturb the rest of the hospital. It was like they really respected the privacy of living up there on that floor.

I remember we would have our meetings around that big custom-made, black top table in the lunchroom. Don Lorence was this very peculiar person who always reminded me of a character out of Alice in Wonderland. When he moved off campus, he invented this little gadget for opening his door with a key. He had this metal rod, and on the end of it it had like a S-shaped piece of metal so that he could lift this little rod out of this tube that was alongside his leg rest. I forget what Don's disability was. I think it was muscular dystrophy, and one of the things about living in that group at that time was meeting all these people with different disabilities. Everybody's an expert on their own, and you kind of get a closed focus of what disability means when it's just locked into your own.

One of the really broadening things was meeting all these people dealing with these different "disability issues." They were similar but different. There was kind of this strange reverse hierarchy when it comes to disability. At least when I got into--I tend to analyze things a lot. It's like the more disabled you are the higher your status as a disabled person. One of the stereotypes was spinal cord quads had it rough, whereas paraplegic spinal cord injuries didn't have any problems at all. And post-polio were lucky because they could still feel and enjoy sex. Different disabilities had these different tradeoffs. We'd get into these discussions sometimes as to who would trade what for what [chuckles] and what were the pros and cons of this and that.

The thing I remember primarily was that so much of my time and energy was taken up on just trying to keep attendants together. That's like a lifetime situation. At Berkeley, what was really neat about that time was the Vietnam War was still winding down and there was a load of conscientious objectors [CO]. To keep their CO status, they had to do some kind of civilian employment bordering on social work. The goldmine of attendant care, in my experience, was in that period of time. We could hire these guys that were bright, intelligent, healthy, strong, motivated, who wanted to be attendants. Not only wanted to, they needed to be. You've got to do this job and they want to do this job, and we worked out a deal. These were people who were of all kinds of different political and social persuasions, and it just



opened your mind to all these aspects that one would not ordinarily come into in your own chosen social circle.

Then on top of that, the UC medical system--to get into med school--started putting a value on any prior hands-on experience in the medical field. We had these beautiful, young, intelligent, attractive college coeds that wanted to get into med school and all of a sudden realized they needed some hands-on thing to put on their résumé to get into it, and all of a sudden they "needed" to be attendants. It was great. That part of it made life a little bit easier.

But still trying to get someone to come in, many of them students, all overstressed already in their usual academic pursuits, to show up at the same time every morning--how late could you stay up? Most of the students would be like, "Look, the latest I could come would be nine to ten o'clock." So one of the really frustrating parts for me on being a student was that I had to get somebody in early in the morning to get me up out of bed at six o'clock, grab breakfast, run off to class, come back, and then in the evening you'd just be getting into things, things are quieting down, and you had to go to bed.

Once I was in bed I couldn't do anything. Some guys were able to crank up in bed, sit up in bed, and do some reading and writing, but I couldn't. Once I was lying down my arms wouldn't function hardly at all. There were really no devices out there that were going to allow me to operate in that position. My time to study was really limited. It was really frustrating. So you'd spend a whole weekend trying to catch up all the time. And even then feeling like going to classes with half a deck, never able to keep up with the required reading.

Bonney: Were you there during the Lucile Withington era?

Rowan: The name's familiar.

Bonney: She was the rehab counselor that authorized services for the students in the program.

Rowan: Yes, and then there was a younger woman that came in and took over.

Bonney: Karen Topp came in.

Rowan: Karen Topp. Lucile was just before Karen.

Bonney: Right. Where you there when the Lucile flap happened?

Rowan: Just a little. I was so preoccupied with other things--all I wanted from DVR was for them to pay my books and tuition--and I was doing everything on yellow writing tablets. I got an IBM Selectric with pegs on my hand and I'd type on that. Then I'd just get someone to retype it all. When I came into the program, I think there was a student revolt against the DVR, against the way they were running things at that time. Lucile Withington's name I remember just a little bit. They also put an RN [registered nurse] to kind of oversee the ward.

Bonney: Edna?

Rowan: Edna Brean. She came in pretty tight and then gradually loosened up. Edna did okay, but I had very little to do. All I wanted was, you guys do the paperwork, pay my funds, I'm in here and I'm out of here. I was up to my ears, and my main focus was study.

The political part of it, the thing I remember the most, was everything about Ed. And the other thing hearing that he was one of the big LSD dealers [chuckles] on campus while he was getting his Ph.D. I really didn't see much of him; I mostly saw a lot of John Hessler. I didn't get along with him too well personally.

Bonney: With John or Ed or both?

Rowan: Ed's a very likable guy. Very charming personality. Hessler was very smart. We had a big chess thing going for a while, and Hessler was real good at chess. I remember John Hessler mostly; he was more involved in the Disabled Students' Program after he and Ed graduated. I remember one of their great things was, I just heard the story, of their study in France to learn French or something. The two of them went together and had this great time going through. Apparently for both of them and especially for Ed that really opened up world travel and what was going on out there internationally and everything.

In the Rolling Quads, I remember politically we would have these meetings, and at that time DVR had a policy that they would not allow anyone--they would not even sponsor anyone with spinal cord injury until two years after injury--because there was this statistic floating about that there was a high rise in suicide two years post injury. So their way of getting around wasting money on people was to wait for this two-year period to go by. If the person hasn't committed suicide, they probably won't. This item caught my attention, and I got really furious at it.

There were a couple of students that were trying to enter the program right out of rehab and get going again, and they ran into this block. So in the Rolling Quads I remember we got



together in this meeting, and some of the professors--this one woman, I can't remember her name--but she was really good. She got involved in the program; she was out of the Department of Social Welfare. She was helping us get it organized structurally, and the paperwork and the process, and how to approach the problem and hit Sacramento and legislate.

We were meeting one time and I put forth my opinion on this subject, which was, "Well, of course. If you're a young person and you're going through life full-bore and you get this broken neck, then you're in rehab, and six months later you're out of rehab, and they tell you to go home and live with your parents for two years, of course you're going to get depressed. So the thing is let's get back as soon as possible." This met with unanimous approval, and they all agreed that I should speak this in our meeting in Sacramento. I thought, "No, no, I'm the treasurer, Herb's the president. Herb should do the talking." I kind of gave him the words and he did the talk. I remember going up to Sacramento and meeting with all the DVR people in this big meeting, and then they changed the policy and let these two guys in.

Bonney: Do you know who those two guys were?

Rowan: I think one of them was Wally Whelan, and I don't know remember the second.

You asked me earlier about the movers and shakers. There were the political movers and shakers, there were the social-political movers and shakers, and then there were the "notorious" movers and shakers.

Bonney: And who was what? [laughs]

Rowan: I remember one of the notorious ones--Larry Langdon--was a real low quad, right on the border of quad and para [paraplegic]. Larry was famous for doing drugs and getting drunk. There would be these Larry Langdon stories, one of which was when they were putting in the BART [Bay Area Rapid Transit] stations down on Center Street in Berkeley Larry was zooming along late at night in an altered state and went right through the barrier. In the morning the crew came on and looked down the hole and there was this wheelchair all smashed up at the bottom of the hole--oh, my God. He was uninjured.

Another time we used to play these poker games up at Cowell Hospital late into the night on the weekends, and Larry left one night--he had been drinking a lot--and one of the fun parts was there were certain really smooth asphalt streets on campus, and

the hospital was up high right below the stadium rim. So you'd have these long hauls down where you could really fly. Larry had this lightweight powered wheelchair and he was flying down this one street and apparently lost it. The campus police were driving about late at night and found this empty wheelchair at the bottom of the street on campus. They thought, "Oh, my God. Where's the owner?" They went looking about and found these two shoes sticking out from under a parked car on the side of the street. It was Larry. They hauled him out; he was fine [laughter]. There would be these little stories that would go about, and I'm sure some would get exaggerated.

When the professors from the social department got involved in it--I didn't talk to Ed that much. I'd meet him over the years now and then and we'd talk a little bit, and he said they helped out a lot. They were really helpful with paperwork and processes and where to go and how to aim it.

Bonney: You mean this was in terms of grant writing or something?

Rowan: In grant writing, and when they landed the money that changed it from where the only thing in the whole community was the Disabled Students' Program. The big fear was it was this wonderful thing to get into, it was this wonderful thing to be under and supported by as a student, but then upon graduation there was nothing. Basically you were on your own. The idea of disabled people--it's funny, because even now it's like you're disabled, you get all the support--like right now starting in special ed, through high school and even through college. After that it drops off. It just drops. As long as you were in an academic pursuit of some sort, the society and the tax bases and the funding is there to support you. But upon graduation it's like you're off the cliff. You're on your own and you're disabled.

Depending upon the degree of your disability the support system you need--like for me one of the things that used to really get me over the years after I had lost all my own money and had to go on benefits was that my attendants were getting paid more than I was. The amount I had to live on, my attendants were living better than I could, yet their job was taking care of me and I was the guy with the college degree. But the employment opportunities available to me, if I took them I would lose my benefits and I couldn't survive.

That's when all the work incentive legislation started going through. That all started--like if I look back at it historically--the Disabled Students' Program at Berkeley led to the Centers for Independent Living, and the people that came out of the Berkeley situation. Again, after World War II there were a

lot of disabled student programs set up for paralyzed vets. But somehow no political change came out of that. They were under the VA [Department of Veterans Affairs], they had their medical lines, they had their support systems as veterans. But if you were a non-vet there was nothing.

So somehow out of the Berkeley experience and the Disabled Students' Program there--started by Ed Roberts getting in there with his mother Zona and his brothers and being the first disabled student trying to go through a university in a severely physically incapacitated manner. Then upon graduation, like with what Ed said, he's about to graduate and as long as he can stay in the doctoral program and stay a student he was still covered. But whereas in the ordinary course of events people go through the college experience as a grudge, a task, to graduate, and upon graduation you now had your certificate for employment, money, gain, and a life. The reverse psychology that happened in the Disabled Students' Program was that as long as you could maintain your student status you had this great life. But upon graduation was disaster.

Bonney: How did the Berkeley group become political? What was it about them that was different than these other college campuses?

Rowan: Looking at it now, I think one of it is what I just said: you're civilians. You have no social supports out there. When I was injured in '57, and probably even in the seventies, even though there was the Department of Voc Rehab, Voc Rehab was primarily set up for people injured on the job, primarily doing blue-collar work, and who would then need some retraining to reenter the workforce. But the idea of dumping onto this department people with severe needs and very limited physical abilities with a college degree, find me a job. Nobody knew. What it did is it came upon invention. And I think what became clear--I think looking back--what made it was the whole political-social milieu of the university along with the City of Berkeley clicked. The university was willing to support and sponsor this "impossible experiment" and to give people with severe disability situations--primarily physical and not so much mental or emotional--a chance to get a college education. Then upon graduation, DVR had this problem.

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Rowan: Why in Berkeley? The academic department, intelligent, motivated people. Really a great deal of the credit falls on Ed Roberts, but with Ed, his mother Zona. Zona is an amazing person. Hooking up and networking with other people of intelligence, ambition, and drive, different motivations for different purposes. Ed Roberts

came from a very supportive family structure, went through elementary school with a lot of kindness and support. Got polio as a young child. The adjustment to disability, the onset of disability, the younger it is the less impact it has on your personality structure because you end up intact. Your personality, your experience in life, is a continuum.

Traumatic injury later in life blows your whole psychological structure, your image of yourself, your abilities, your capabilities, your careers, your ambitions, they all have to be restructured and rethought. In my experience, people with an early onset in childhood or a birth situation have "more pleasant" personality structures. People like myself with a traumatic spinal cord or head injury is like a whole class to itself almost. But some sort of really debilitating amputee or bone crushing or something that really imposes major physical limitations upon your lifestyle that you had been accustomed to makes a lot of anger. Anger and depression are soulmates.

I remember John Hessler telling me his motivation toward establishing "independent living in the community" was the fact that after his injury--and this was a man six-foot-seven--when you can't do your own moving around when you're six-foot-seven, it's a real chore for other people to move you around. Beds, wheelchairs, nothing fits. When the political arguments were starting around seeking funding and legislation and support for severely disabled people living in a community--because at that point it was live at home or live in a nursing facility. The Disabled Students' Program at Cowell Hospital was somewhere in between a hospital/nursing situation, independent living, student dorm, but in a way it was like the perfect environment for this thing to grow because the college years are like an artificial environment.

The stereotype is you don't work or you work part time. Your identification in society is "student." In Europe there's tremendous privilege given to anyone in a student status; they're given all kinds of breaks for being a bit crazy or bizarre or extreme, as long as you're identified as a student. In America it was more like you were isolated. These campuses would be like worlds unto their own, especially if there were dormitories. You're living in this totally small world, and generally your academic load is so high you're not aware of world events. You're cut off from your family, and it's your first time to experience independence, individuality, and at the same time the responsibility of just academic pursuit but not so much making a living and money and paying the bills--even though that's part of it; a lot of people have got to do both. But your primary focus is graduation.



That was kind of like a mixture of it all. And then when the war movement hit, and the students in Berkeley got involved in politics outside the campus, and the studies and the relevancy and the life goals of the "student" as to national policy, war, death, killing, weaponry, military-industrial complex--this very concentrated group of people at the most prestigious university in the land, chosen from the top 20 percent of the high school population throughout the state, and also students from all over the world, and suddenly to get blown out of your tightly focused academic pursuit and expand it into--my God, what's going on in the world and in my country? Being subject to the draft and being told that upon the whim of a number, you're yanked out of your pursuit as student and privileged person and thrown into G.I. Joe out there killing people you don't want to kill. All this was happening.

In the city of Berkeley itself, even politically down to the city council and the mayor, world events were involved in city decisions. Discussion would go on where the university--it's funny, it's like a little war zone that occurred: all the things that were covered on the news were all within a three- or four-block area of Sproul Plaza down Telegraph Avenue. That was it. Yet the national local news coverage made it look like a citywide guerrilla warfare. Television likes flames; they look pretty on TV. A house catches on fire, it's on TV. Newsradio was different: newsradio, you had to have content rather than visual. TV was discovered, and the war was on television and Berkeley was on television. All of a sudden these disabled students were running around in wheelchairs.

Hale Zukas got a brand-new wheelchair out of it when a news van backed over him. Because he had to be in there [chuckles]. They backed up, and Hale was behind them. He didn't get hurt, but his wheelchair got tweaked.

I went down to take a look myself. I'd watch, and I'd go, "It's not a good place for a guy in a wheelchair." Other people in wheelchairs decided, "I want to go out there and run head-on into this." There was also the idea that because I was in a wheelchair, you couldn't hurt me. It was socially unacceptable to hurt somebody in a wheelchair. I remember when I was working at CIL [Center for Independent Living] there was the time when there were a couple of women in wheelchairs that were involved on campus. They were pulled out of their chairs and raped when there was a lot of activity. It was the Free Speech Movement, and it went into the civil rights movement.

Berkeley was a very turbulent, exciting place to be. I don't remember fear as an element. I remember excitement, I

remember change. The expression was "blowing your mind." It's like expansion of parameters of right and wrong, of acceptable and unacceptable.

We were involved with DVR a lot because DVR was the only source of money. DVR was the source of funding. There was SSI [Supplemental Security Income], there was social security disability insurance [SSDI] if you were eligible under your parents' account. California was just starting the attendant care program, and that was it. The thing was, you were stuck in this terrible bind. If a job were offered to you, and once it went over a certain amount of money, you lost all your benefits and you couldn't survive.

So people had to start looking for and I think this is where the political/social/economic and I think the academic/intellectual resources available through the university supported the whole enterprise. There were people you could call and talk over things with. People who knew about legislature and knew about economics and knew about processes and knew what was going on. You could get hooked into the power structure, and then operate in the power structure.

When the first grant was written, I think it was like the opening of a whole concept no one had ever thought of before. I think it was Ed and John Hessler and a couple of other guys--I wasn't involved in it--along with some of the advisers out of the university who wrote up a grant. All of a sudden there was grant money from the federal government to start up this independent living center. You could stay on benefits and work in this position doing this work that impacted immediately on your own life. Then tangentially, almost incidentally, it impacted on the lives of disabled people throughout the United States.

Greg Sanders was a really smart guy. I always wanted him to go to law school but he didn't want to. I did advocacy with him; I got trained under him in advocacy with him doing SSI and when we discovered plans of self-support. He could literally read a manual of regulations and memorize it, and then quote reg and number.

Bonney: Now when did you go to CIL? First of all, did you graduate from Cal?

Rowan: No.

Bonney: What happened? How did you make the transition from Cal to CIL?



Rowan: I'm going to the university, I'm working, I'm getting near graduation, I'm thirty-one years old, and all of a sudden I meet this young lady who thinks I'm just wonderful. We start having my first real relationship. She's in her twenties and she's a liberal radical. Her parents have to come out from the East Coast to meet me, and it's like my last quarter at Berkeley, and it's like this whole other affair opened up, and time and energy is going, and school work was kaput. It was doing reconstruction at the university.

It was during the Free Speech Movement under Mario Savio. One of the issues that the students brought up to the university was this issue of taking an incomplete, and that it had to be finished within a certain period of time. One of the things that went through at that time was that if you took an incomplete you would have an open-ended period of time to complete it, because most of these things we're involved in having attended all the classes, done all the work, but simply not have written the paper. So in this spirit, I ended up with I think three incompletes, having my social love life going so well. Okay, I'll finish it during the summer. Well, it never got finished. There were, I think, three courses I took incompletes in, and that didn't give me enough units to get my degree.

Moving to Christian Brothers Catholic Monastery and Teaching Adolescent Boys, 1975-1976

Rowan: At that time, I guess it was '75, I decided it was time to go live on my own, this girl, Laurie, and I. She started working for me as an attendant. She said we could work out a deal: "I'll be your attendant, we'll get paid with that, and I've got the house up on the river rather than going home and living with my parents." I'll stay on benefits and she'll do the attendant thing. I had been at it on a nonstop thing my whole life. I guess I started working the paper routes in sixth grade. I had been working in college when I broke my neck. I did basically two years in rehabs and I was running my family, then I was doing business, then I went to junior college, then I went to Berkeley, and I had never had a break anywhere. So I was tired. I thought it was time for a break. I said, "Let's go up and live in the woods and enjoy and play." So I did.

During that same period of time my oldest brother had joined a Catholic religious teaching organization, the Christian Brothers. He was principal of an elementary school in the Napa Valley. I was having a nice restful year, and during this whole

year I was always saying, "Well, I'll finish these papers." Now and then I would drag out all my notes and my materials and start writing my papers. Then some party would happen and something else would happen and it never got done. Then my brother, Tom, one time said, "Look, it's a private Catholic school, we're short on teachers, I need somebody in there. I could get you in there if you want to teach these kids." It was a boarding school from fifth through eighth grades. They'd send all the children home on the weekends to keep in touch with their families. It would be a residence thing, so I thought what the heck, because by then it had fallen apart with this relationship, and then in and out of a couple of other ones and it wasn't going anywhere. I thought, "I need to pull myself out of this. It's unraveling and getting too loose. Teaching little kids, that'll be fun."

So off I went to the Napa Valley and lived two years in a Catholic monastery on top of a mountain in the Napa Valley. The Christian Brothers were still maybe involved in the winemaking process. There were 500 acres of vineyards all around me. Gorgeous, beautiful spot. For two years I taught fifth through eighth grades, various subjects. I would learn them before I taught them. I ended up getting along well with the students because I wasn't one of the strict Christian Brothers. I ended up running study halls and ended up putting together a math tutorial program that one of the old retired brothers told me he had used in New York. I reworked it a little, and that worked out very well. It brought the scores up for a lot of kids.

Basically I would get up at exactly six-thirty every morning, go have breakfast, hit the classroom at exactly eight o'clock, have lunch at exactly eleven-thirty to twelve o'clock, monitor the hallways from exactly twelve o'clock to one o'clock, teach from exactly one o'clock to three-thirty, take a break from exactly three-thirty to four-thirty. I monitored the hallways and recreations from exactly four-thirty to five-thirty, at which time everybody would have dinner, students and staff included. Then from exactly six-thirty to eight-thirty I would monitor the hallways in the school building for recreation, plus run the study hall. At nine o'clock my day would be done. This was on a monastery school schedule.

On the weekends we would play cards in the residence that the brothers had. Some of the brothers that worked in the winery and the old retired guys. So I'd hear all these stories about school teaching from these old guys. Guys involved in the winery and the wine business, I'd learn about wines. I'd have dinner with the guy that would have his name on all the labels, and I learned a lot about wines and the history of the order, and a lot about theories and methods of teaching kids through strict

Catholic doctrine and things I found hard to agree with. After the first year I thought, "I'd better find out how I'm doing." So I taught one year, and then that summer I went back to Berkeley and took educational classes all summer.

I stayed at Rochdale, at the dormitories there. I made my connections again, got hold of attendants, and ended up taking post-grad ed classes for a summer, where I was trying to learn how to teach reading and math, and educational theory. During that period of time I was working with CIL to find attendants. They were started up, but they were growing, and they were talking about some of the plans that they were having. I would meet people here and there, some I knew from the Disabled Students' Program. At that point, I think Ed Roberts was running the center.

Bonney: Now this is about 1977?

Rowan: Earlier--I guess 1974-'75. I think '75 was the summer I was down there. I'm not real good on dates.

Then I returned to Napa, taught another year there. At the end of that year it was real neat, they gave me this plaque that I still have: "Teacher of the year." All the kids and a couple of the teachers put it together, and in the yearbook they did a little spread on me. It was real nice. And the brothers really liked the way I was operating, and they offered to keep me on there if I wanted to. I thought, "I've been living two years as a monk. [chuckles] Either join the order or get out. It's time to leave." My brother likes this lifestyle, that's nice. Nothing I ever wanted, and I enjoyed the work, but it's like, No, thank you, I like girls too much.

My financial situation had hit the skids. During all this time I was still trying to manage my finances. I had a bunch of real estate I had bought down in San Mateo County, I had gone through three different business associates, and one guy ended up embezzling a bunch of money from me. It cost me \$100,000, and that really put a dent in my capital. After that I knew I was on a downhill slide; I didn't have enough capital to live off the investments. Whatever work I could get, I thought I had about five years' money I could live on plus my SSDI, and I'd better figure out something to do fast.

So I had a talk with my mother--who I was still supporting--and gave her the choice of what she wanted to do and where she wanted to live. I had to sell off some property, combine everything. I was also involved in a lawsuit. This one guy that embezzled money from me set up all these false contracts, and they

were then trying to sue me for recovery. I had to get hold of a legal firm to get me out of that. I got hold of another guy I knew for years and who was also in real estate, in land development. Then through my brother, Tom, through fundraising for this school, he knew this guy who was a millionaire businessman. I got together with him and got some legal advice. He tapped me into his legal firm. All this was all going on.

I finally bailed out of all of that. My mother decided she wanted to live in the house up on the Russian River, so I sold off everything else and got that house fixed up for her. I put her in there and figured that takes care of me living there. It looks like I'm going to make a life for myself in Berkeley.

## II THE CULTURE AND PREVAILING ATTITUDES OF THE CENTER FOR INDEPENDENT LIVNGING

### Attending Antioch College and Working Part Time at the Center for Independent Living in Berkeley

Rowan: So I moved back to Berkeley, got involved with CIL, got a job there part-time as an advocate doing SSI with Greg Sanders. I met Sue [Susan] O'Hara when she came to Berkeley and she was at Cowell Hospital. She and her sister arrived, and they were all strung out, and I went back to my room and got a bottle of scotch to calm them down a little.

Bonney: She talks about that [chuckles].

Rowan: Meeting her and her sister, I went, "Oh, my goodness, these poor girls are in for a hard time. They're from the Midwest; they're in for something." [laughter] A little schoolteacher from Chicago, oh, boy.

Then at that time CIL was working with Antioch College [West] on trying to develop a specialized degree in counseling and psychology for disability. That sounded attractive to me, so I went and checked that out. I got involved with that, got accepted into that, and told them I never really received my certificate. They said, "Okay, we'll take you in pending." I said, "Okay, I'm still working on it; want to do it?" So I got into that psych program and got a master's in psych, and they were trying to also work out a legal situation with the State of California that would lead to a license in disability. I was involved in that through CIL and through Antioch. Meanwhile I was working at CIL part-time and I was going to school at night at Antioch. We had a trailer set up in the lot at CIL with offices and classrooms, and we used one of the larger rooms so that Antioch would hold their classes over in Berkeley to save the commute.



I was working during the day and going to school at night. Around that time Ed got appointed to head of DVR under [Governor] Jerry Brown. What was funny was that I went to high school with Jerry Brown. I knew of him; I really didn't know him in high school. I just saw him around. He was a cheerleader.

Then CIL was going through all these grant-writing expansions. Things were just happening real fast. It was politically positive. It seemed like any grant that would be written would be approved, there was all this money coming in. They were trying to figure out people to handle it, they had a lot of people that were put into--

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Rowan: --level of disability and their political ax to grind than on any skills of management or processing or whatever. Yet the whole thing was just growing and growing. I remember being in some kind of community meeting we were holding in the back. The first office CIL had was down on the big main street coming into town off the freeway--[University Avenue]. I think I was in that building only twice. But there was a minor fire there one time. The fire department showed up, and there were all these people in wheelchairs on the third or fourth floor. They had a heart attack; they were trying to haul these people downstairs. People who were there at the time working were telling me about it. The firemen were trying to carry these people who were incredibly fragile and they couldn't breathe if you turned them the wrong way. They had to get them down four flights of stairs or something, and all the smoke, and there were no elevators, and plus they're in wheelchairs and they wanted to stay in their wheelchairs. After that the city said, "That's the end of that. You guys are on the ground floor."

However Ed did it, through lease or rent--I think it was a lease thing--we rented the old BMW sales lot on Telegraph. It was a victim of the "Berkeley riots." Apparently a lot of expensive cars got dented, broken, burned, or busted, and they had abandoned that dealership. So here was this one great big huge classroom, and behind it a bunch of service garages still with the hydraulic lifts in it and everything and the overhead chains and lube racks and everything, and then this big parking lot. So they went and subdivided it up in a classroom and in a back room they used to have these big meetings.

I remember I was on staff, and we were having some kind of a political community meeting in the back, and off in the corner in the other area of this big back room there used to be the auto maintenance racks. There was a board meeting going on. It's like



everybody was in everybody's business all the time there; it was all one sponge of information. There were rumors of all the financial troubles, audits, grants, this and that and everything going on. I think at that time Ed had left. When he left he had put Phil Draper in charge.

I remember sitting on the back porch at PDSP [Physically Disabled Students' Program] on top of Top Dog when Judy Heumann showed up. Judy had left whatever she was involved with in Washington and came to Berkeley, and the story I heard was that she was under the impression she was coming in to take over, to follow Ed as executive director. When she arrived, lo and behold, there was Phil Draper as executive director, and she was to be assistant executive. She was quite unhappy. A bit mad. Yet it was a done deal. Sue O'Hara was on the board at that time, and I was over in my corner with this other group doing some kind of self-support plan or advocacy training--I forget what--and I remember the board was meeting in this one great big open area way back in the corner.

All of a sudden there were all these rising voices and people were angry. We were trying to listen in on what was going on and quieting down what we were doing. It got more and more heated. All of a sudden all of these people got up and left. We found out that seven or eight board members resigned on the spot. Several of them were attorneys, people that were totally supportive of the organization and willing to go out on a limb. Apparently they had told them they simply cannot do this or that because it's illegal or improper and it was still being done to meet whatever financial needs there were to be covered. Legally, I now know more and I know why they had to do that.

Activities as Chair of the Center for Independent Living's Board of Directors, Strikes, and Restructuring, 1976-1982

Rowan: But then after that there was this huge meeting. At that time they needed board members, so people said I should run for the board. I said I didn't want to be on the board. "No, no, we need you; you've got to be on the board." I said, "Okay, I'll put my name up, but that's as far as I'm going." The bylaws of the organization at that time were that you could be on the board and be an employee. Phil Draper and Hale Zukas were on the board; they were all working for CIL and they were all on the board. Then they'd have these people from the community that would also be on the board that you needed for advisors and fundraisers.

But at that time the political attitude, and people said it to me quite openly and sincerely, was that anybody who was a professional could not be trusted, that being professional was bad, and that these businesspeople and bankers and people with wealth were not to be trusted. They were the enemy. This was our Berkeley radical political perspective. I was there coming from a background of business and having made money and lost money, and I was thinking this was all nuts. This was crazy. And then trying to survive myself on just SSDI and attendant care and using related work expenses and learning all the regs. I went through a plan of self-support to get myself through my master's program, get my licensing, and another plan of self-support to get me a van that I was able to drive. That really changed things when I could drive.

So anyway, they had this big meeting and they were doing it, and boom, I was elected on the board. All of a sudden I'm on this board of directors at this place I'm working in, and it's got this huge pile of problems, and that's when I started getting into the deeper end of all the political and economic part of it. After one year on the board, I was chair of the board for six years. I was on it for seven years. For six years I was chair of the board.

I was just trying to clean it up. When I came on I said, "Where's the personnel policies? Where are the books? How are you keeping them? Where are the annual reports?" "I don't know." "Where's this? Where's that?" "We don't know. Oh, here's a copy we dug up." The personnel policies were literally cut and paste; people had found paragraphs of stuff in different documents they had been reading through, and they cut them out and xeroxed them and put them together. Some of it was sideways and some of it was at an angle, and they were all different typefaces [laughs]. I was like, "Oh, my God, I can't do this."

Yet there was no money to do it. There was money to do all the grants, but when they wrote the grants no one ever put in administrative, or they put in the 15 percent, but 15 percent didn't cover anything because there was no other money anywhere. Everything coming in was going out on grants and salaries. Many of the people working there were maintaining their benefits by working part-time, but they were really putting in full-time hours. But they couldn't go full-time because they would lose their benefits, and they couldn't lose attendant care if they needed attendants. That was the real crux of it: keeping your attendant care and keeping your Medi-Cal. You just had to.

When I was on the board, I think we had three strikes. One of them was really severe. The entire staff was out picketing

their own organization. Because I was both a staff member and chair of the board, I was trying to play both ends all the time. People would complain to me sometimes, "Jack, you're always on both ends of everything." "You have to be around here."

Meanwhile, I'm still trying to get my master's degree in psych at night.

Bonney: What were the strikes about? What was the first big strike about?

Rowan: The first big strike. Ed had these friends in town that he got involved in CIL on the, we put up a wheelchair repair and van modification business, we wrote up a grant, and there were these two really neat guys who were total, full-blown communists from A to Z. I mean, that was their whole thing. This one guy used to always have this little cap on, he was tall and thin. Really neat guys.

But they were into making the organization a totally socialist organization. There was the whole social/political thing on equality, where there should be no bosses. Everybody should be equal in running the organization. Structurally that's real hard to put together. Phil was a really nice, likeable, pleasant guy, terrible administrator. Judy was an incredibly powerful political force, but totally disorganized. She would just be into so many things that she would need a staff of fifty behind her just to keep all the parts together, kind of. And things were always moving fast, just a lot going on, and everybody wanted to do everything. And we were landing all these grants that had to be put together, that required accounting and structure and business, and at the same time--in a way it was like trying to manage this super--when I came on the board I think the budget of the place was around \$400,000. In two to three years to was \$2 million.

The first strike, I think, happened out of two guys in the shop and the people around them, and it started out with equality, trying to restructure the management, and the board was selling out to business interests or trying to structure it on a business thing. It was one of these things that occurred that you couldn't really get a handle on it. We ended up calling in lawyers from the Department of Labor. DOL was called on, it might have been like a wrongful termination suit. Then other people went out on strike to back up this person's suit. Then that came into labor practices and where we were in compliance or out of compliance and what you could do and couldn't do and all this was like news to everyone.

I had tried to restructure the organization. I had talked to Phil and Judy, and both of them agreed that management was not something that they were really interested in or good at or that was happening well. At the same time, they both wanted to be in the organization. I had gotten some advice and some connections with the retired executives of volunteer organizations. There's a group out of San Francisco of retired execs. Some of their guys came over and they would meet with us. I'd be chair of the board, and so somehow everything always got aimed at me. I'd be meeting with these guys in this room, and they'd go, "Oh, my God, this is not right, and you can't be doing this, and this isn't set up right, and yet these are "professional businessmen" and lawyers and guys that were not "right" to the movement."

The phrase that's still thrown about is "the movement"; you're either with the movement or against the movement. Somehow the movement takes on this life, rules and parameters of what's right and wrong and acceptable. So I'd be listening to these guys about what they found and what they saw as the areas and what we needed to do to correct it. At the same time, I'm thinking of my fellow disabled people working with and associating with and going, "It's not going to fly. Oh, my God, I can see this one now. This person has already told me that if this comes down they're going to raise the roof over it," and on and on.

Then there was another kind of strike craziness that occurred. When Phil Draper was still there, he met some guy who wanted to restructure CIL, to computerize the whole thing. This guy basically had a little Radio Shack computer and this great idea. He came in and worked with Phil and Judy, and he was put in charge. This big audit came in from the federal government, and after it we ended up having to hire literally ten or fifteen people just to do accounting. Just to go back over all the records and papers. There was no money for it; it all had to come out of all these administrative things and all the other budgets.

He ended up in charge of this department, and he was a very bizarre personality. He ended up with everyone in the place absolutely hating him. I mean, like pure, unadulterated hate. This individual, I can't remember his name, became like the focus of this entire thing. Draper had put this guy in charge of this thing. He was running this incredibly complex audit, paper chase, and at the same time trying to write his own program for nonprofit organizations to track their funding.

Somehow in the midst of trying to backtrack this audit, doing all this paperwork, Mary Lester probably knows all the real ins and outs of this; she was all involved in it. She would keep Phil organized. As chair of the board, we would have these board



meetings with 100 or 150 people attending, a rabid lynch mob. They were out to get rid of this guy. This guy by then was so deeply involved, and no one else knew what he was doing, and how it was going, and if we dropped this guy we'd be back to ground zero, and I didn't know what he was doing.

Phil was working with him, and Phil had appointed him, and finally it came to this board meeting, and it was so hot. We used to have them in the back room at CIL, and I finally decided it's just too nuts. We work all day in this building, we're in the office, everybody goes out to all the little local restaurants, has dinner, comes back at seven o'clock to start these board meetings that would go on until midnight. My butt was breaking down, and my deal with my attendant was that if I don't show up by eleven o'clock, you're free. My time to go to bed was ten o'clock, and my attendant would be there at ten. One hour to go to bed and get everything done. So I'd be running these board meetings, it would be hot, and people would be into staying up all night. I had to get home so I could go to bed [chuckles]. You get all these bizarre pressures going here and there in my own brain. So I'm trying to run these board meetings like a shot, boom, boom, everybody else wants to talk for hours about every issue on their mind.

I found these rooms around town in the local libraries. So I moved them off site onto neutral territory where I thought we could get more done. We're in this library room once and I'm out in the back parking lot, and this one guy on the board finally brought it up. I told him not to, and he did. The audience got into it and open to discussion. It was on hiring or firing this guy. This guy literally got fired at a board meeting. So many people on the board voted yea or nay to terminate him. I'm out in the parking lot during a break, and this guy comes up to me and says, "You're the chair. You can't let this happen. I can't be fired by a board. I mean, Phil is my superior and he hasn't fired me." I said, "You saw the vote, you saw the thing, it's done." The next day the guy comes in, takes all his records and leaves.

Bonney: Why not? [chuckles]

Rowan: Then a really big one occurred while, as I started to say earlier, I decided on the advice of the retired executives to break up the organization. They said that one of the things that's right here is that you're liable in all these areas. Legally liable for suit. Anyone who puts a suit against any individual in this organization--right now it's against CIL and everything you own including the typewriters and the door stop--what you should do, structurally, is have a separate holding company that would do all your fundraising and hold title to all your assets.

I got to thinking about it, and I thought, Great place for Phil. His personality, spinal cord quad, well-known about town. I'll get the lawyers to help us create a foundation, and we'll set that up and put Phil and Judy over there. They can do their fundraising, and social and political stuff there. It's not involving any kind of a legal liability situation in dropping someone off a lift or breaking their wheelchair or tripping on the front door coming in. That would be the asset holding company, and give us a position to actually start doing some discreet fundraising to get some discretionary money coming in the place.

They agreed that it was a good idea. About the same period of time, we went on a hunt for a new executive director. We hired a woman that was running a volunteer organization out of Hawaii.

Bonney: Marilyn Thornton?

Rowan: Marilyn Thornton. We went through our national search flying people in and this and that. We put her in. I was working with her, and from my own point of view it became apparent real quick that she was over her head. She had been running this little volunteer thing, it sounded good on paper, and people liked her political perspective and all the rest but--[sighs]. She was in charge during the great strike caused by the two guys that were running the van repair shop. They wanted to restructure the place on Department of Labor and socialization and such.

Halfway through the strike I would come into the building and, I remember I was coming through the picket line at one time, and there were these signs, "Jack Rowan hates disabled people." [laughter] This is funny. I went in there, and she was in the office furthest back from the window, way in the back of the building, with three or four people gathered around her, this pile of cigarette butts on her tray, smoking constantly, drinking coffee, and literally trembling and shaking. The phone would ring and she would be like [in a paranoid voice], "Who is it? What do they want?" I thought, "Oh, my God. The woman is totally panicked, scared. This is just not going to work."

I went home and started phoning all the board members and saying, "Look, we've got this problem." Because I was told by the lawyers that as a board member I could not advise, participate, speak to anyone about any issue at all except to the board. I couldn't get involved in this; this was a labor dispute. So even though I was still working there as staff, legally there were a lot of restrictions. I phoned all the board, and I was telling them the situation. I said, "There's one guy I know that I could stick in there that I think could handle it. That would be Greg Sanders." I had great respect for Greg's intelligence. He knew



the people, he knew the organization, and what I knew about the guy was that if you put a bunch of things in front of him and he read them, he could comprehend, memorize, and digest them. He was neutral to a lot of parties. So I took a phone call and they all agreed to terminate Marilyn and put Greg Sanders in as an acting director and find the next person. And that occurred.

The strike finally resolved somehow, and then it was time to start a search for a director.

Administration of the Center for Independent Living Under Judith Heumann, Phil Draper, and Greg Sanders

Bonney: What were Phil and Judy's relationship towards each other?

Rowan: Phil always had the same demeanor: he was always calm and pleasant and talked to you. You'd talk to him and he'd be kind of nice, and Mary Lester would be knowing where all the paper was, and it would all be filed, and she would have it under control. I had a lot of respect for that woman. She did a lot. I think she was like in a "secretarial" or administrative assistant position. But she did a lot of running the place. She kept it going. She did a lot of work; I had a lot of respect for her. She was very good. She was totally dedicated to doing whatever needed to be done.

Bonney: Was Phil an effective manager?

Rowan: No, he was much too nice. He couldn't make a decision that might possibly offend anyone in any way, at least in my relation with him. Again, he was a guy who was a quadriplegic, broke his neck at an early age, was not real intellectually self-motivated.

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Bonney: Did Judy focus on the internal workings of CIL or was she an external type of person?

Rowan: Judy, in my experience with her, was always orientated more toward the political end of things. She was much more looking toward the national. I mean, the nickname given to her even in news articles was "The spokesperson of the disabled." She had an incredible memory, and she could just rattle out names and bills and contacts. Her orientation was always political. Even in the city, for a time her goal was to get a seat on the city council. I think her eyes were always on Washington. She was, if anything --from my perspective of someone who wanted to have an

organization--like for me, my problem with getting involved with the Center for Independent Living was that I came and kind of looked at it, sized it up, and I had my own vision of what it could be, which translated out to "what I wanted it to be."

What I saw was this incredibly unique opportunity in time. Historically it was just the right time at the right place to form a strong community-based organization, totally supported and networked into the city and into all the citizens of Berkeley, and to use it as an agency that would provide support for anyone with any kind of disability need, individually or within a family, from transportation to counseling to employment to resources to social activities.

I saw it as becoming an integral part of the city of Berkeley. To keep it autonomous--have it as an integrated structure within the city culture--but autonomous and run by people with disabilities or experience with disabilities, focused on the unique needs and supports of people with disabilities to function and get to the point of being a seamless service. Where rather than being an exclusive kind of place you'd go to only for something that was specifically related to disability, it could branch out into things that might be tangential to that: aging, general accessibility, elevators, ramps, architecture, public transportation, politics. To really integrate it into the financial/business/social organizations of the city, to where people could go there, get what they need, and leave.

I also saw it as a unique opportunity for people. I was disabled when I was nineteen; I had started to work, I was starting to go to college. All my life plans changed. It's a tough thing. Working there, I met people who were congenitally disabled or disabled at an early age, who literally were very, very sheltered and "protected" by their family systems. This would be a unique place for them to come as like an intern shop. To be able to come there, work at a job, learn professional skills, learn how to operate in a professional manner, and move on and up and out.

One of the psychosocial problems that I was always bumping up against myself was coming across people that saw it as a unique and separate entity that they wanted to keep that way as "our private turf." People that would come and see or have the idea or the attitude that the only place they could ever be employed or the only people they could ever socialize with were other people who were also disabled, because it was only a disabled person who could fully understand or relate to a person with a disability. If you were not disabled yourself or had some very close experience with it you were "not one of us." It was like a

separateness. There was strength in it and there was bonding in it. That was a psychological thing that I was always bumping into.

Bonney: Now CIL did not get integrated into the city of Berkeley's culture. Were you unable to make that happen? What happened to that concept?

Rowan: I spent six years of my life trying to make that happen. The last time I ran for the board and was not elected, it was both a relief and a sadness. When I went back to town to see somebody maybe six months later, I went over to CIL and I looked around and talked around and I left. When I got into my van to drive away I thought, "Six years down the tube. It's back exactly where it was when I found it." So what I learned from that was that this is how "they" want it to be. I wanted it to be elsewhere and I tried to get it that way.

Two of my most painful, angry memories I have of that period is I was trying to restructure the board to get a balance of votes on the board that would be professional people outside of "the movement," per se, of disability: people that were more in business and such. We were starting to get leads from businesses locally, where as part of people's growth in their own areas it was kind of required that they do community service. One of those things was to sit on boards of nonprofits and charitable boards and such. So we started sending feelers out. A lot of the people in the agency and on the board didn't want to do this. They wanted to get politically correct people, in their opinion.

After about five years I had finally gotten the board make-up--first of all---reducing it in size. I think it started out with like seventeen board members. We'd have these horrendous meetings, and trying to have a quorum out of that many and such. Nobody trusted anybody. You'd make a committee and somehow or other everybody had to grill the committee on everything they wanted; they couldn't make a decision or report. It was all mixed up. I wanted to try to get things done efficiently, quickly, and delegate. If someone recommends this, you go with their recommendation.

Judy tried to control everything from the background. Phil was the executive director, but Judy really tried to run everything politically. It was quite disruptive, because she would come into a situation and want to know all about it, want all the facts, and investigate everything. Who said what, why did they do it, I want to know this, I want to know that, who voted this way, who voted that way. She would come up with a bunch of

recommendations, ideas, names, phone numbers, people to contact about this and that and leave.

She was a great traveler. She was all over the place. Phil stayed in the city, and I stayed in the city. I didn't travel; it was too expensive, and I had great concerns after hearing about other people getting their wheelchair smashed in the baggage compartment, getting your butt scraped on an aisle chair. I didn't want to take the chance. I had too many other things I wanted to get done, primarily finish my psych training, get my master's degree and my licensing. This was just something I was doing on the side.

Bonney: Do you consider yourself a political person? Were you comfortable in that role?

Rowan: I was good at it, but it became real obvious to me early on that the people that I saw being "successful" in the political arena, it was their life. It was a twenty-four-hour, seven-day-a-week job. They were on the phone, they were with contacts, they were in meetings, they were staying up late, they were going here and there; I decided very early on it wasn't what I wanted to do. I could handle the information, I could run meetings, I could discuss, I was pretty good at mediating and compromising, but I had no intention whatsoever of getting into the demands of political life. The people I saw doing it, who were good at it, it literally was their life. It's not what I wanted.

At one time when it was all agreed that we would look for another executive director, several people on the board said, "Why do we need to look? You're the man, and we want you in there." I told them no. I'm just doing this because I'm doing it. My main job is to get my degree in psych, and if I get involved in this job, it's a full-time job, and it would end my academic pursuits. I can't do both. If I'm going to do something, do it right or don't do it.

Bonney: You talked about Marilyn Thornton being a bad match for the job, and that she needed to go. Who succeeded her? Who did you get to take her place?

Rowan: Temporarily it was Greg Sanders, and then we started advertising a nationwide search. That's a whole story there too [chuckles]. We started getting résumés in by the pound and we were going through them. We finally boiled it down, I think, to five finalists. Toward the end of it, Judy started campaigning for Michael Winter. Michael was, I think, working then at CIL. I didn't like his politics. He was very radical, he would go to the city council meetings and just take over the microphone and be quite, let's



say, rough. Impolite. He had just accepted an ILRC [Independent Living Resource Center] position, I think, in Hawaii. He had been in Berkeley and then he had gone to Hawaii. Judy was saying, "Have you got a hold of Michael Winter? Is he on the list?" I really wasn't keen about even interviewing the guy, and then Judy was saying, "No, no, we've got to get Michael Winter on the list." Okay.

We set up this thing that first I wanted to set up a nomination committee, have them go do preliminary interviews, and get it down to about three people. Then we'd select three to five members of the board to do the interviewing. A lot of funny things started happening after that, and afterwards I found that board members were changing their minds on things we had agreed on.

The whole thing got changed around to the entire board interviewing all the finalists. We rented a big room at the Claremont Hotel, flew people in--an expensive undertaking. We were firm that it was the board's place to do this hire. It was out of the realm of administration. At that time the foundation was set up. Phil and Judy were over there. Bob Funk had been involved in CIL for some time. So we finally sent out all the notification of finalists and set up the interview times at the Claremont Hotel and had flown people in that needed to be flown in.

After going through the applications there was one applicant in particular who looked really well qualified, and she herself was not disabled. I was on the position that this is an expensive proposition that we're going into; it's important. The law says no discrimination either way. The person most qualified for the job gets the job. Are we going to go by this or not? Because if we're not, I don't see why we should involve this person. "Oh, no, no--." Okay. Go ahead and do it.

We were sitting in this big room in the Claremont Hotel with our schedules, with our résumés, with our discussions. The entire board was, I think, at that time eleven people or so. It was a good-sized group. We set aside our whole day. As we're interviewing the first person the doors of the room burst open and in comes Phil Draper, Judy Heumann, Bob Funk and at least one or maybe two other people. They sat themselves down and said, "We are here to observe." I was stunned. I mean, just the inappropriateness and disrespect. Any word you want. I was chairing the meeting, and I said, "We're stopping this meeting. We are not proceeding until you leave."

Well, the board got all upset, Judy started talking, and it turned into this big harangue and discussion, and the majority of the board finally voted that they could stay as long as they did not interrupt. Judy thought this was unfair and unjust, that she should be able to ask questions whenever she wished. I stated, "No way. If you ask a question you're out of here." The board finally agreed that yes, that would be just too inappropriate. So we did these interviews in this situation.

We did our interviews of all the people involved. When it came down to picking the executive director and we're going over it, my choice was for the non-disabled person. At that point, meeting in private and with the board, finally the board just overwhelmingly agreed that symbolically the organization couldn't possibly be represented by someone without a disability. I was just, "Why did we bother?" Even the woman, while we were interviewing her, was saying, "I really don't know why I'm here since all I know about this organization is that it's really orientated toward disability, and it's very politically active and it seems like the spokesperson or leader of this thing should be disabled. So I don't even know why I'm here." I was just going, [utters low growl].

Another person who was a really good contender got disqualified because we found out they had falsified information on their application. The field narrowed. I guess that's when Winter got it.

Bonney: So Judy won [chuckles].

Rowan: Yes.

Bonney: When did you first recognize--or did you recognize--that you were in an independent living movement?

Rowan: When I was going to school in Berkeley. Being a student, going to school, being disabled and suddenly making trips to Sacramento and dealing with Voc Rehab--higher echelon people--and all of a sudden being part of the Rolling Quads. Just this little group. Going through the Capitol, the first time in my life I had gone into that kind of situation. I'm just this guy in a wheelchair trying to get through school, and I'm like wandering around almost in a movie. Then meeting people like Ed Roberts or Hale Zukas or Judy Heumann, who would off to Washington at the drop of a hat, and this committee and that committee and Senate bills and House bills and this and that, and hearing this like a day-to-day conversation.



Everything was political. The Vietnam War, the Free Speech Movement, the Civil Rights Movement, Kennedy, Martin Luther King. Prejudice as a fact. Going from hearing remarks in the family over the years about blacks or niggers or Jews as jokes or comments or ways of labeling or classifying people, and then getting into situations where I would be sitting on a board going over issues of disability and sensitivity training for medical students at UC or something. It's like, my goodness, one side of the brain is saying it's really awful that this has to be done, and it's really strange to be put in kind of this elevated--if you care to put it like "hero" or out-of-the-ordinary platform--for doing these things that in my opinion "anybody" should be able to do. I had no great unique bit of wisdom or insight to offer that other people could not equally offer. Yet I was put in situations a lot of times: "Jack, you go out there and do this and that."

I'm good at speaking my own thoughts and feelings, but I'm not real good at parroting, and I'm not real good at memorization. I'm not real good at being politically correct. The people I would meet would talk about the "movement", in quotes. Even while they're saying it; you could feel the quotes. There was the Civil Rights Movement, the anti-war movement, there was the Free Speech Movement; there were all these movements. To me, all I wanted to do was to be able to make enough money to pay my bills, to take care of my medical situation, and be able to do something I enjoy. That's all I want. That's what I'm going for. I have no interest or desire to "make history." The people that I associated with that seemed to be in the movement and in the disability movement were people that seemed to want to "make history", to make a contribution to history and see themselves in that kind of a context.

Bonney: So did you ever feel as though you were in the movement?

Rowan: No, as a matter of fact I kind of made like a conscious choice not to. I'd say, Hey, I'll do whatever I can to help better things and to try to do what I need to do for me to get where I want to go. But I don't see myself being on the phone eight hours a day and writing letters and going to meetings and flying all over the place and keeping track of people's names because they may be somebody I need to schmooze with later. But I was very aware of the power of it. As a matter of fact, I invented my own thing called--

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Rowan: --not only that, but with it was a sense of invulnerability. But it was all like a reverse negative. It was almost a double bind. It was "my power comes from my ineptitude," or "my lack of being

able to do something is your fault, and you owe me for it. Therefore, I can not be held responsible." Crip power, that's what I called it. Crip power.

For instance, one of the scenes is that there was even a photograph in the paper. There was a demonstration in Washington, when Judy and a whole group of people went back trying to get the 504 regs implemented under [Secretary of Health Education and Welfare Joseph A.] Califano. They were passed, but the regs were never implemented. There was a meeting going on at some big hotel or something, and they had all the police out there to keep these disabled demonstrators from crashing this meeting. I saw the photo in the paper, and I talked to Judy about it sometime later when I met her.

So Judy thought, Well, I'll zoom around and go down the parking ramp and get in the elevators and go up the elevators. They had a police line across there too, making sure who was going to go down into the parking lots under the building. Well, Judy in her wheelchair--this little tiny woman in her little tiny power wheelchair--rammed this policeman in the ankles. Ran right into him. The guy told her, "No, ma'am," and she runs into the guy. You can really wreck somebody hitting them in the ankles with your pedals. She thought it was funny, and in my mind I thought, "Anyone else doing that would be in jail."

Bonney: That's assaulting an officer.

Rowan: Yes.

Bonney: You don't get away with that lightly.

Rowan: No consequence.

When I was on the board or just before I got on the board--it was right in that period of time--when we were being audited, in came all these auditors, and I'm meeting with Phil and Judy. I'm going, "Oh, my God, we're getting audited." We were running these grants out of a checkbook. Everybody hired a friend. The only people you could trust were your friends, and your friends were the people you partied with and whatever with. I think it was Eric Dibner--I'm not sure--who was the accountant, and he had a little room in a trailer at the parking lot of CIL and a bunch of books, and basically he was working out of checkbooks. He'd write checks and he'd enter in the stub. The auditors came and were, like, "Oh, my God!" [laughter] "Let's see your records." There's this grant, and this grant, and this grant for hundreds of thousands to do this and that, where did it go? "Well, here's the

checks." [laughter] "Do you have any bookkeeping experience?"  
 "No."

I'm talking to Phil and Judy, "God, they could close this place down. We are out of business." Judy said, "They'll never do that. They wouldn't dare touch us." I thought, "Huh?" She was right. She said, "They wouldn't dare close this place down. There would be so much fallout from Washington they wouldn't last a minute." So she made phone calls or whatever. To me, from where I was at, it was like these people were really going out of their way bending over backwards to help us survive. We should cooperate with them, not make them into fools that we control. Somehow I was always in my own thought field on that. Some people I had met over the years that I would talk to privately, they'd say, "Yeah, me too." Other people would go, "That's wimpy thinking; that's not the way to go." Other people you could never even get that far into a conversation. Everything was straight-ahead power play.

San Francisco 504 Sit-in, 1977 .

Bonney: You mentioned 504 and Judy going back to Washington. Tell me what was going on at CIL and with you and the board during the 504 demonstration.

Rowan: Sit-ins were used very well in the civil rights movement. Again, you talk about crip power, to me this is the ultimate example. Judy is politically active; I mean, she's now employed by our government in Washington. You change things a little bit, she'd be in jail. There was always, always activity going on besides just trying to serve the clients, as it were. Then on top of that there was a whole other equal--if not more active--strain of thought and energy going on politically all the time.

Somewhere in there the 504 legislation had been passed but it wasn't being implemented; it was being stalled. I think Judy was a main mover in this, because a lot of times events start and then they take on a life of their own. Even a couple of times clients I was working on--Social Security was giving this guy a real bad time on trying to give him a decision on a plan of self-support--and he went down in his wheelchair to the Social Security office in Berkeley with a big chain and a lock. He wrapped it around his wheelchair, wrapped it around a desk and locked it, and put the key where it couldn't be gotten without disturbing him a lot [chuckles]. He refused to leave until he got a decision. They got security guards. I mean, Joe Blow tries that and you're

gone. Well, he was there for about a day and a half. They couldn't close the office and they couldn't leave him without medical assistance and this problem and that problem.

Anyway, it was decided to go over to the Federal Building in San Francisco and go up to the office responsible for this legislation and the processing of it, request a meeting with these people, and we're not leaving this meeting until we get a decision. Simple enough. Well, the group of people that went over there, said, "We're not leaving. It's a big political issue and it's in Washington and we're not leaving until we get a decision." Well, five o'clock came and it's time for the federal employees to go home, and they left, and these people stayed. Then the guards came, and the guards weren't about to throw all these blind, deaf, and wheelchair-using people out. I guess everyone thought that they would get tired and go home.

One day led to another day, led to another day, and meanwhile we're back at the office at CIL and half the staff is over in San Francisco in this office, and we're trying to carry on business. So phone calls are going back and forth. People would always stay in the office in the Federal Building and take messages, and other people would go out and use the pay phones. We need this, and we need that, and we need this faxed off to this, and we need copies of this, and we need brochures now, and we've got to start educating the public, and we've got to start contacting the news media. Then the TV and newspapers were in there reporting, and pretty soon it kept getting bigger and bigger.

I went over there a few times, and I'm out in the plaza because they were restricting access to the building unless you were an employee. All the employees of the building were getting really mad at this bunch of people: it was making their life quite difficult. Eventually it ended up where it's like--can you bring over bedding? We need places to sleep. It was turning into this major camp-in situation. The police weren't going to allow it, and then people started claiming medical situations, and they needed their attendants and this and that. They had to be allowed in on a medical basis. It just grew on itself.

I was out on the parking lot out in the plaza a few times and got interviewed a few times on camera, but I never saw myself on the news. I was mostly staying in CIL trying to keep the doors open and run business. I was still doing my job as an advocate, and I had cases to write up and things to do and phone calls to return and keep other things going.



Meanwhile, everyone over there was still getting paid [laughs]. I'm on the board and I'm looking at the finances, and I'm thinking of the legal end of it, and these people are over there doing this sit-in for like three or four weeks. They were all collecting their pay [chuckles]. The work isn't getting done at the office, but it's this huge political news event occurring. And it's in the Guinness Book of World Records as the longest sit-in in a federal facility. I remember even the mayor went and visited and offered to set up a shower because people were getting a bit ripe. Then the media blasted him for supporting these lawbreakers.

Bonney: What was it like back at CIL?

Rowan: Very quiet. It was very, very quiet, and there were very few staff. Phones would ring, and everything was like hush, hush, and there was paranoia that the FBI and the CIA and people were tapping the phones and they were trying to get evidence on things that could be brought to charges later. Things had to be done in code, and couriers were in and out of the building and they would carry papers back and forth. It was this big super-adventure, and at the same time knowing that you're playing with powerful forces. The people that I spoke to that were in the building--CeCe Weeks was in there; this neat lady who was blind, I think her last name was Owens--

Bonney: Jan McEwen?

Rowan: She might have been in there. Don Lorence was in there or was available. I remember Don's big deal was that he was trying to put together a scrambler code on this radio that the CIA might not bust because he could see their antennae on a truck across the way. He was going to try to put together a secure scrambled communication thing or something.

Bonney: It wasn't Jan McEwen. You're thinking of M.J. Owen?

Rowan: Yes. Tall woman. She told me a story of how she would be going up and down the elevator and the employees would all back away from her, because she had such strong B.O. or maybe because she was "one of those illegal people disrupting things". She's blind, but she's very aware of everything going on and could pick up on their movements.

Bonney: Did you get any feedback from CIL clients at the time who weren't getting served? Or did they get served?

Rowan: They weren't getting served but there weren't complaints because it's like whether you were in San Francisco in the building, out

of the building, or in Berkeley, everyone was behind it. Whatever sacrifice, whatever needed to be done, was worth it to get this passed. This was a very unified political front. If there were any complaints, it would be like, "We're working on it," and then they'd be like, "Oh, yeah, we know you guys are all doing a job; you're doing great. Keep it up and don't quit."

I remember I was over there one evening when I was leaving San Francisco Plaza late and they were locking the building, and there was this man with cerebral palsy. He was out in the plaza because we were still keeping the demonstrations going outside for the media. This young man with cerebral palsy--he might have been in his middle or late twenties--was crying, "I need to be in there. I want to be in there; I got a right to be there!" He started trying to run toward the front doors when they were locking them. He tripped and bashed--he was ambulatory but the spasticity--he fell over and really scratched himself up. We were helping--I was there just watching from my wheelchair--but other people were helping him up, and he was just crying, "I need to be in there! I want to be in there! I need to be in there!" That was kind of like the feeling of the place.

One of the fallouts from that sit-in was the staff of CIL got a free seminar from Erhard Seminars Training, Inc. [EST]. [Werner] Erhard came to the building and thought it was one of the great, positive, motivated events of this era and did an EST training for the staff, for anybody who wanted to at CIL in Berkeley. I missed that training.

#### Articles of Incorporation of the Disability Law Resource Center and Bob Funk's Role

Bonney: Let's talk a little bit about more about your work at CIL. While you were president of the board I think you signed the articles of incorporation for DREDF [Disability Rights Education and Defense Fund]. Can you tell me about that?

Rowan: Bob Funk showed up in Berkeley. He was an amputee out of the Peace Corps. He was a lawyer. He had joined the Peace Corps, gone to Africa, and gotten this slight thorn puncture in the leg and it turned into this infection. The native population, I guess, are immune to the vegetation, and he was not. It got worse and worse. They ended up flying him out of Africa into Europe. I think he said into Germany, in a military hospital. They could not stop this infection, so they ended up amputating his leg. It



also had a systemic effect on him; he had to be careful of his diet.

Bob showed up at CIL. He's one of the bright, high-energy people I've met in my life. Very pleasant. Really liked him a lot. He looked over the place, and for whatever his personal reasons, he saw CIL as like a tremendous esteem builder for disability all over. He threw himself into it unconditionally. He was a lawyer, so he started writing grants. I think his first shot out, he wrote like twenty grants. An amazingly productive man, really. He landed fifteen of them. All of a sudden, the federal government gives you this grant announcement, you send it in, it gets approved, they approve them all at the same time, you send them all out at the same time, and you've got thirty days to get it up and going [laughter]. So part of the things he wrote grants for were for disability legislation support systems. Several of those grants came through, and all of a sudden we had a legal arm. That was the beginning of DREDF.

Bonney: It was called the Disability Law Resource Center [DLRC] when it started, wasn't it? It wasn't DREDF originally.

Rowan: Right.

Bonney: So we're talking about DLRC now.

Rowan: Yes. Because we had to do something with these grants we got all of a sudden, and Bob was the lawyer, and he wrote them, and he was the only guy that knew law. Go hire people and get this thing up and going. We rented a little mall/restaurant area right across the street from CIL, and in came carpenters and gutted the place out from the stores and tried to turn it into a bunch of offices. It was all stained glass and wood and tile floors. Somebody's idea of a little unique multi-store mall. That started it out, and then it got a little bigger, and Bob Funk really put it together well and ran it well and hired some really good people. It was moving along. Then it got big enough to where he saw he'd have to incorporate it as something else.

We did a lot of business in the parking lot. I never did have an office; I just had a desk I worked at. The rest of it was in the back room and parking lot, meeting people here and there. Bob came to me and we were talking about it. He said he had been talking to everybody, getting ideas. He had been talking to Ed in Sacramento, who was then head of DVR, and Judy and Hale and various people. He asked my opinion also. I said, "Bob, to me CIL is about as big as we want it to get. I see what you're doing and how you're doing it, and you're doing it really well, and you've really got a good thing going here. My concern is if we

keep you incorporated as part of CIL, you're going to get caught up in all the inefficiency craziness and money management problems and administrative problems. I suggest that you go set it up yourself. Run it yourself. Make it a separate entity and cut yourself off." He thought, "I don't want to do that. I owe everything to CIL. I got started from here and I've got all the connections from here." I said, "This is how I see it." So he went and did that.

He incorporated separately. Sometime later Ed was visiting Berkeley, and we were rolling through the parking lot and talking about this and that, and he let me know that one of the things he was really aggravated at me about was letting DREDF get out of CIL.

Bonney: So you did sign the articles of incorporation?

Rowan: Oh, yes. Bob and I worked together. He didn't want to do it; he felt like a traitor to the cause by separating out from the Center for Independent Living, which was to be the keystone of everything.

#### Relationships Among Staff at the Center for Independent Living

Bonney: Another question I have about CIL is what were the race relations like at CIL?

Rowan: CIL was one intense melting pot of everything. There were primarily Caucasian people working there. A few African Americans came in down the line. One of the early guys, I can't remember his name, he was blind. He always used to knock me out because he was one of the most sharply dressed guys--every day--that I had ever come across. I thought, This guy's blind and he dresses so sharp. He was just into clothes, he and his wife had this whole trip going, and he knew what he wanted and how he wanted it. Apparently he had some vision in his youth; he got hit in the head with an arrow and lost his sight as a child.

When we were trying to set up--he was head of blind services--and when we were running into money/grant problems, that was the first overt racial thing I ever remember coming up at CIL. Somehow he or somebody was putting it across that it didn't want to make the blind service unit grow bigger simply because we didn't want a black person running it. The thought had never even entered my mind. I thought, Where in the world is this coming from?

There was another guy that we hired who was African American, and he was hired under an independent living grant. He was just a flaming, outrageous, gay dude. Also more happy-go-lucky than hard-working, politically motivated. Those things kind of clashed with some of the staff. Then a couple of Asian women. But I don't ever remember any kind of racial discussions or slurs or hostilities coming up; it was more like this huge experiment.

The big issues I remember were for gay men and women. We had a big influx in the ratio on the staff of gay men and women. The gay rights movement was just starting out hot then, too. In San Francisco the gay men's movement was strong, and in Berkeley and around CIL there started to be a real strong gay women's movement that seemed to be more Berkeley than San Francisco. Then the disabled, gay women's movement was even more strong and very active and very overt to the point where it got to be like a joke, if you will, or a syndrome. Every disabled woman that showed up in Berkeley from elsewhere would right away get hit by the welcoming committee on--if you want to be really liberated--you need to be a full sister. This indoctrination committee would be out there. "Have you been hit by this squad yet?" [chuckles]

We had Hispanic guys working there. I don't remember. So much of it was disability-focused, and it was like there were people who were blind, people who were deaf, people who were post-polio, there was multiple sclerosis, and everybody was trying to relate, to fit, to cope with, assist, be sensitive. The big deal was to be sensitive. At the same time the women's liberation movement was hitting. I remember when I was a student at Berkeley it was at the point where you couldn't ask a female student for a date without getting slapped as a male, chauvinist pig. This was all going on at the same time.

Bonney: Hard to know what to do [chuckles].

Rowan: Oh, yes. Like the joke about the woman--it wasn't a joke; it was an article in the newspaper--who was changing a flat tire on this street, and some guy stopped to help her and got cussed out for it.

Service Delivery at the Center for Independent Living

[Interview 2: October 4, 1998] ##

Bonney: Jack, let's start today by talking a little bit more about CIL. Could you give me your perspective on service delivery at CIL around 1976?

Rowan: When I was working there my job was primarily advocacy, dealing a lot with SSI and SSA [Social Security Administration] and really starting for the first time to use and implement plans of self-support, which were not clearly defined and were merely on the books. I think Greg Sanders was really the first guy to discover this vehicle laying around in the regulations. We developed that to the point that Social Security and SSI put a whole team on it, and over the years they have really developed, refined and restricted the range of it. I went to a seminar about six or eight months ago and the new regulations for plans of self-support are so incredibly limited now and regulated and they're really hard to use. But in the early days they were quite flexible and we used them to really help out a lot of people with benefits, to get education, to get vehicles, to get mobilized, to get a lot of things. It was really exciting and creative.

At the same time within the agency all the thrust of thinking was grants and going over the Federal Register and using whatever political information we could get on available funds. It was pretty much a catch-all kind of thing. Anything at all vaguely related, it seemed, to any kind of independent living, which would include a lot of different areas depending on how far you wanted to stretch it, would get a grant in. Suddenly we'd have a grant that may have been written as a response to an RFP [Request for Proposal], and then we'd get it and all of a sudden "Whoa! Now we have to go do it."

I think the organization started out really as a spinoff of the Physically Disabled Students' Program at UC. The people involved in it and starting it and running it were people dealing primarily with issues of physical disability and limited mobility. Then it started gathering into meeting the needs of all different disabilities. A lot of people initially involved in it, even out of UC, were visually impaired. So we were trying to develop blind services.

Financially, usually someone who was legally blind, they were pretty good: they didn't really need attendant care and wheelchairs and things. The funding under SSI for blindness was pretty good. People involved in that were, as we used to say,



kind of symbiotic: they would be around, and they'd help pull wheelchairs out of the dirt. It was kind of like a team tradeoff on skills and abilities and knowledge, and a lot of people that were totally blind especially, and yet able to get a college education or be able to read and memorize Braille--quiet high-functioning and mentally alert people, and very much involved in the political and grant-writing end of it--and at the same time starting to expand into political activity.

I think one of the big splits in consciousness, from my position--especially being on the board and being an employee--was the split between the political activity, the social activity, and the fulfillment of basic needs. It was pretty much agreed that advocacy as relating to benefit eligibility, ongoing support, plans of self-support, attendant care and Medi-Cal as just survival mechanisms, along with attendant referral, were always seen as like the real foundation of the service delivery to the community.

The other end of the spectrum was trying to get funding to do real research into getting statistics and information on what a person with a disability really needed to get through education and employment. Yet in my experience there, it seemed that the whole idea and thrust of the organization became quite thin and really not focused on employment per se outside of any area not directly impacting on disability. The support, the need for grants, the need for expertise or support in getting into the private sector in the beginning was almost seen as anyone with that skill and ability would be betraying the movement and would even be like a loss to the "movement" if they left the "disability arena" and went into private employment. Those people that chose to do that seemed to have little association with CIL, unless they needed attendants or something. To me, looking back on it now, it was an area that got very little attention.

Bonney: Could you briefly describe what a self-support plan is?

Rowan: Originally in the regs when we got it going, it was just in there as a device within the regulations that would allow an individual who was on benefits to write up a plan that would exempt earnings, income, or resources toward achieving a goal leading to self-support or financial independence. I would get them off of benefits, and you could write up the plan for a period of eighteen months and extend it another eighteen months. If you were still in a training or educational situation, it would cover a four-year period during which time a person could maintain their SSI eligibility, maintain their SSI income or their SSDI income and be exempted from the limits of earnings and resources that would otherwise make you ineligible. You'd still be susceptible to the

"substantial gainful activity" criteria, which in the beginning was the ability to earn more than \$300 a month. So you had a lot of people restricted, and for their survival and their medical needs they would profile themselves to take part-time work.

Also built into the regulations was that if you purposely manipulated the regulations just to maintain your eligibility, that could be seen as fraudulent. So there was always this very peculiar relationship in how far can we go with this without it rebounding and costing us and be penalized for it? At that time, people who were unable to fulfill their goals under their plans to achieve self-support [faced] no punitive damages as long as they could account that the money set aside actually went toward what they were trying to achieve.

I personally used that device to finance my master's degree and to work out a deal with DVR and a plan of self-support when I was able to put aside enough money to actually purchase a vehicle. Then DVR, once it was purchased under the plan, did all the modifications on it so that I was able to drive. I got that achieved in '76 or '77, I think. I also used it to finance my licensing in California--marriage, family, and child counselor--which was quite expensive because I had to pay supervisors and go to trainings and such. Without that device I couldn't have done any of that.

Bonney: Overall, why was advocacy so important for people with disabilities in those days?

Rowan: There were instances where, I remember two occasions of people literally arriving on the doorstep of CIL who had hitchhiked or gotten transportation. I remember one person used a wheelchair for cerebral palsy. He literally got his SSI check at home in a state in the Midwest, went down and cashed the check and hitchhiked his way to Berkeley. He never informed his parents; he just left town. Just wanted to get free. He had heard that Berkeley was a total support system for anybody with a disability. He was sitting in his wheelchair on the front doors. We came to open the place up and he said, "Well, where do I live?" He was expecting a full residence program, and that was a conception that was quite widespread.

People would arrive in Berkeley on SSI eligibility and literally expect the Center for Independent Living to have a full-support, resident, attendant care full-spectrum service. Everybody would have to get quite active and get him signed up for attendant care. We were always involved in that. It was never enough money. There was Section 8 housing, which was limited. We had to learn all the regs, had to do everything we could to get



people involved in that. On top of that there was the whole idea of people coming to town simply on an SSI eligibility. We had to immediately get them signed up with the county for in-home supportive services, then had to help them find attendants, then had to help them find an affordable place to live, and get people into shared housing situations.

What we were doing was case management. No one called it that, but everyone was pooling all their resources. The bottom line of everything was money. Nobody, somehow, would seem to be focused upon money as an employment goal. Generally it was seen-- at the very best people would have maybe a high-school situation, maybe junior college--but even with a bachelor's degree the salary levels at that time were not equal to what you needed to even pay for an attendant. Attendant costs in California at that time--the county started out spending around \$800 or \$900 a month, I think-- and went up to \$1,200 a month for attendant care if you were severely disabled. Then if you included wheelchair maintenance, your overhead just to get going could be between \$1,200 and \$1,500 a month. If you were in a wheelchair interviewing for a job, there were still huge accessibility problems. Hardly any buildings were wheelchair accessible. Then if you did get in, it was just non-accessible bathrooms. There was just many, many issues.

To me, what sparked and what drove the whole thing is the things that the University of California had done for the disabled students on campus in the way of curb-cuts and bathroom accessibility, accommodations for moving classrooms around to ground floors or into buildings where you could access the elevators and little things like Braille signs showing up here and there. Once people left that university campus setting, [these things] were totally nonexistent once they were literally across the street. The frustration and anger and need for survival drew a core of people that were motivated by lots of emotion and lots of energy.

The other thing that was very, very exciting to me and I think to people involved in it at that time was that you could almost see the results of your activity quite quickly. Things would start happening. Physical things would occur. Elevators would start to be put in, curb cuts would be put in. You could now go into a restaurant or go shopping without people turning and staring at you. It became commonplace to see someone touring about in the course of their activity in a wheelchair. Movie theaters voluntarily started pulling a couple of seats out in the back row because they said, "You can't sit in the aisle; you're a fire hazard." Well, we don't want to sit in the back and look through the glass window. Little things that some people did

voluntarily later became goals, I think, and functional methods that came under a lot of the ADA stuff about getting ideas about what you really needed and what was practical.

Then it became legal; you had legal clout behind you. Some people went to all kinds of lengths with wanting to sue everybody in the place. Again, there were people that were using it as "how can we work on this together?" kind of situation. I found a lot of the people that had a tremendous energy and drive were motivated more by anger than by trying to work more slowly with less tension for more concrete goals. That was more like the way my personality was. Yet the people that were using their drive and anger and frustration and whatever catharsis, the result was a tremendous activity and a lot of information, a lot of attention. Results. There were results.

#### Recognition of Disability as a Civil Right

Bonney: When did you personally see the legal issues and the things that people were fighting for as a civil rights issue?

Rowan: As a civil rights issue, to me, it really came out of the civil rights issue under Martin Luther King and out of the south on the civil rights movement per se. When I would be in discussions about what we were doing and where we were and why were we doing it, and the future and the past, people would really see it as a link of social issues being addressed. There was a racism focused primarily at African Americans. The Asian discrimination has always been very low profile. Native Americans have kind of come in recently. It was almost like you could see this pyramid of concerns as to what degree of the population was getting more frustrated to the point of action. Who's next? What's the next group to break the ice, to hit the barrier of frustration that's severe enough to make you want to go out and put your life energy into doing some changes? It was the turn for the "disabled."

Within the disabled there was a hierarchy. There were some organizations that had funding sources available to them. In California there used to be a thing called the Crippled Children's Fund. There was a lot of state money available for children who were disabled. It was named Crippled Children's Fund. Then it became all this socially and politically correct language, and that was bad. Yet there was the March of Dimes for polio. There was United Cerebral Palsy. There were these various organizations.

There was really nothing for spinal cord injury. You're out there on your own and nobody knew what to do with you. If you were injured it was kind of your own fault, and one of the stereotypes always was, "What were you doing wrong to cause this injury?" Whereas something like polio or cerebral palsy would be visited upon you through no fault of your own. When I was getting my psych training in disability, even in the middle and late seventies, there was still a fairly prevalent social attitude that there was something that the family or the parents or somebody had done to bring this curse from God upon you. Somehow it was always deserved through someone's fault. With spinal cord injury it was generally, "You were reckless," or "You were drunk." You've done something to deserve this.

Also, the survival rates of spinal cord injury, until after World War II, were like three to five years; you usually die of bladder or kidney complications until the antibiotics came along. Paralyzed Veterans of America started getting organized. But then anything above a paraplegic or quadriplegic was kind of like you were nursing home material and there was really no concept of potential employment. It wasn't even out there. It was like, "How can I maximize the benefits I have to live on?" That's where advocacy became so important. It was really the only financial support--especially someone with a spinal cord injury--could look at, because you could never see the potential for getting employment that could meet all your ongoing expenses. So it's like you were locked in on benefits for the rest of your life, so how could I maximize and retain these benefits? Otherwise it was off to the nursing home.

Bonney: When did you see it as a civil right? You said it was sort of tied in with Martin Luther King.

Rowan: I think through peer support, began to see the word discrimination as a civil violation of your personal integrity. I think it came out of these civil rights movements for the African Americans, to where you kind of saw your physical condition as this total medical problem. I think everybody would treat a lot of situations as purely medical situations. To see it as a social/political situation, as a civil rights focus, didn't occur until people started getting into--oh, I remember we'd have all these sensitivity and consciousness-raising things and going through literature, teachings on stereotypes, literature and films and drama. Expressions of the spastic and the evil, deformed person. Physical deformity are differences, or even being in a wheelchair somehow made you threatening or sinister or taboo. People, I think once they had enough support to get an ego and to get self-esteem, I think it was like, "How dare you treat me as inferior or second-, third-, fourth-, or fifth-class?" Or as an abhorrent

idea. Something children weren't allowed to talk to. Parents would drag their children away lest they be contaminated.

I remember this one woman I was counseling, and the trauma she incurred after getting over polio. One of her great therapies that she enjoyed was swimming. She had learned to swim in rehab. The first time she went to a public swimming pool in Berkeley, as she got in her wheelchair and went to start transferring into the swimming pool, mothers were running and pulling their children out of the pool lest they catch polio.

That kind of attitude, once you sniffed it, once you got an idea of it, I think that's what I and other people with whom I associated--and again politically--we found that to have power, again out of the civil rights movement, and seeing ourselves as disabled people in a civil rights movement, we weren't out there just crying and begging for more money. We were out there demanding equality in the eyes of other citizens, of other people. I may look different, I may be different, but I am a citizen, I deserve rights and respects. That's when a whole lot of the ADA came in on the accessibility issue. For the first time it was like pity and sympathy and sacrifice were all kind of changed around into a focus of anger and oppression and demand. By law I have a right to be able to go in the front steps and not the freight elevator. Once a few people had achieved and experienced it, it was incredibly contagious. People were energized by it.

Once Ed Roberts--and Judy Heumann came out of the East--and Hale Zukas were doing all these trips to Washington and coming back and finding out how this "system" worked and where the money really came from, and the legal, legislative means toward achieving funding to keep the place going and to do things, a lot of it came down to civil rights. It came down to law. It came down to legislation and all that. It went from kind of begging and keeping a low profile and hoping to get whatever you could get without anybody really noticing, to demanding and requiring and even upping the level of demand. We wanted full accessibility to all phases of society, from economic to sexual to religious to even the right to be crazy, to be improper, to be drunk in public, to no longer being on the ivory tower--a hero, saint--but to be human.



Comments About Ed Roberts and Jack Rowan's Disappointment With the Center for Independent Living ##

Bonney: Jack, is there anything else you'd like to say specifically about CIL before we move on to some other topics?

Rowan: Right now I'm living in New Mexico. Recently the local Independent Living Resource Center moved in next door, sharing the same building. It's really mind boggling to think about Ed Roberts. One of Ed's great strengths was his personality and charm. He had the ability to really draw people to him and to really support him and to dedicate themselves toward achieving goals he would define, a lot of very, very powerful and intelligent people. He had a real cadre. He had a way of attracting people. He was very charming, a very clever guy. I guess if I wanted to stretch out the analogy, I guess to the disabled population he's kind of like what Kennedy was politically, nationally. He had that charm and that wherewithal to carry that off, along with a really innate ability to organize.

CIL started out as this little group of five or six people with very little money, most of them living on SSI, getting grant money that opened an office. I think it all started out just really renting an apartment: a place for people to get together with a phone. From that, nationally, there are centers for independent living all over the place.

The social and cultural changes in the nation are amazing since the fifties. Disability per se is in a way a "common" and "normal" part of the social fabric rather than some taboo tragedy visited upon individuals or families. You're watching television and having National Football League commercials with this huge, big athlete out there talking about having a son with autism or cerebral palsy, and please support United Way or something. This could happen to anybody for any reason, for any cause, and it's an issue that is commonplace. Christopher Reeve is now the big, stereotypical image. Look at Christopher Reeve against Ed Roberts. Ed started as a post-polio living and sleeping in an iron lung and learning to breathe on his own and really coming out of a little family situation and a little suburb outside of Berkeley and decided he didn't want to end his life with high school.

It was really civil rights. It was social, political, economic rights as opposed to now like under Reeves it's back into a medical situation and looking for a cure to "make me normal." It's a whole different thing. It's like living with a severe or incapacitating injury or socially unacceptable surface laid upon

your soul or your heart, as opposed to "No, I cannot stand this insult, and the only way I can function fully in society is to not have this overlay upon my soul or my spirit." I think with Ed it's like, "This is my soul and my spirit, which is full and complete in itself. This overlay is simply an overlay. Let's deal with the spirit within and move on from that." There are two really different ways of looking at it. I think what Reeves is running is kind of back to sixties and fifties. Cure me or kill me.

CIL was a thing I fell into almost accidentally. I used it to achieve personal goals. While I was there I got involved in it through my six years on the board of directors, and it was a terribly difficult time. I put a tremendous amount of my life energy into it. I guess one of the difficult parts for me was I ended up making decisions everyone complained and griped about but didn't want to do. Replacing the executive directors. Even when it came to selling off part of the property, everyone on the board bailed and it came down to people looking at me and saying, "Do we keep it or sell it?" Selling the parking lot to help pay off some debts. The residual attitude was that what we are doing is so good and wonderful and proper that we should not be financially responsible; we should be financially exempt. A lot of people gave me trouble for that.

The thing that really saddened me was after I left my position on the board and I had gotten my degree and finished my counseling and I had gone to live up in northern California outside Santa Rosa, one day in the mail arrived an invitation to an awards dinner being held in Berkeley. It was an R.S.V.P. That's all I knew about it. At the time I was quite tired and defeated, seeing the goal I had for CIL and how they let it slide, disintegrate after I left. I thought I might as well go down; maybe the only thing I'll really ever get out of this place is this free lunch.

I went down, and it was a big, huge hall that they had rented, and I was sitting at a table in the audience. I was speaking with people I hadn't seen for several months and visiting. As part of the awards dinner they gave an award to Phil Draper for all his years of service: a big photograph of "wheels in motion," they called it. Two weeks later a friend of mine called from Berkeley, we were talking, and I was saying, "Yes, it was nice." He said, "Oh, by the way, do you know what was behind all that?" I went, "No." He says, "You were also supposed to get an award for all your years on the board and the work you had done. But because you had been instrumental in removing Marilyn Thornton and restructuring Judy and Phil's job, Judy was really



still angry at several things and had refused to allow you to have the award." I still remember that. That was unpleasant. Small.

Bonney: Yes.

### More on Relationships Among Staff

Rowan: I was really hoping that they would get rid of the adversarial attitude toward "non-disabled" people. Earlier, one of the questions was racial differences. In CIL, it was funny: it wasn't racial, it was disability. It was blind, deaf, spinal cord, polio, multiple sclerosis. Differing disabilities kind of had differing value judgments as to ability or competency or tragedy or something. It was a kind of subliminal attitude.

Disability per se was the topic, the overriding flavor in judging or evaluating almost everything. Even this past two years I had met a couple of people here in Albuquerque that were involved in ADAPT [American Disabled for Attendant Programs Today, now known as American Disabled for Acceptable Public Transit], which is a fairly "radical" disability organization. They were using terms that I hadn't heard for years, like you were an AB, which meant able-bodied. Somehow that was a negative. If you weren't disabled you were an AB.

Then the other one was "everyone is only temporarily able-bodied [TAB]." Underneath it--I tend to analyze things a lot--but the statement was that the only good people were disabled people [laughter], and if you're not disabled you're not enlightened and you don't know and you're not qualified. That little flavoring caused CIL to really miss an incredible window of opportunity through the seventies and even into the middle of the eighties to really grow, expand and become a fully integrated part of the Berkeley community.

### Completion of Clinical Practice and Granting of Counseling License

Bonney: Let's go on to something maybe a bit more pleasant for you. During this whole time you were going through school trying to get licensed. You did get licensed, we know that. Tell me how you did it, what happened and when you got your degrees.

Rowan: I left Berkeley, and I really still do, to this day, want to get my degree out of Berkeley. If it's still on the books where I could complete some "X" courses and do it, I'd still like to do that; it's still important to me. But I ended up getting a master's degree in psych.

I would be working really full-time and getting paid half-time doing this incredible learning curve on Social Security, SSI, not only for myself but a lot of the people I was working with. We were working on cutting the fine edge on self-support plans and earnings and money and eligibilities and keeping attendants together and at the same time getting involved in all these local, political activities. CIL's board meetings would go on until--oh, God--eleven o'clock at night. That's it--I've got to be home. Goodbye. Close the meeting. Management by crisis was the modus operandi. Then three times a week going to night classes in a little trailer--a classroom set up in the parking lot of CIL--rather than transporting over to San Francisco to the Antioch campus over there. And I was doing all that homework.

After doing all that, psych learning, then going for my license and getting together supervisors and getting the funding through another plan to achieve self-support and paying them and trying to come up with my 5,000 hours of counseling. All the while, still working at advocacy. All the time trying to learn all the changes in the regs, all the time doing a whole lot of freebie counseling. Somehow people would come to me a lot with problems and issues and spend an hour or two here and there with somebody. Then doing it officially and clinically and documenting it and trying to set up a space in my apartment and also seeing what space was available. One of the terrible issues at CIL was space. There was never any privacy. I literally did counseling with people between parked cars at the end of the parking lot, below a cement wall where there was a little bit of activity. I remember dealing with a couple of people that would come to the agency out of the Disabled Students' Program at Berkeley. They'd be in tears, weeping over issues. We're out there in the parking lot going over this stuff because there was no private space.

Bonney: You did your practice work then at CIL?

Rowan: Only part of it. I would see some people at CIL that I would sign up and who were willing to go into long-term counseling over issues and I would also see people in my apartment. I set up my front room. We did group therapy out of there, myself and, especially, Pat Bentley. She was going for her license also. We would do group therapy there. Peter Leech was one of my supervisors, and he was trying to establish a bona fide peer counseling program out of CIL. There was a peer counseling

program there, and it was based on the kind of revolutionary, socialistic "we're all equals," and if you were disabled long enough that entitled you to counsel someone else with a disability. Training was a nice frosting but not necessary.

One of the people I really enjoyed was Dr. Sheldon Berrol. He was running the spinal cord center down at Santa Clara. He was also on the staff at Antioch. He was my instructor for several classes. He was also on the board. So I got to know him on several levels. He went from spinal cord injury to head injury, and I followed some of his interest into that area. He was trying to establish a real kind of treatment for traumatic head injury in rehab, back into society and such. I think he died of a stroke or a heart attack--one or the other--while he was still in full power and still moving ahead in a lot of areas.

Getting the license, getting the eligibilities for it, applying for it, then going up to Sacramento, taking the exam, getting the license. Then once having the license, I started to try to develop a private practice in Berkeley. One of the expressions was, "In Berkeley you could find a licensed MFCC [Marriage, Family and Child Counselor], at least one or two, living on every block in the neighborhood in the city." [laughter] The town was full of people that all wanted to do counseling. My special was physical disability, and the need was great. But the thing is, no one had any money to pay the going rates. There was one person who got their license and started doing it. He made quite an example because he tried running it through Medi-Cal, and it was against the regulations. He ended up doing jail time, I think, and he lost his license.

I was still working at CIL, still trying to develop private practice, still trying to keep things together. I investigated several situations in Berkeley where I tried to get on staff in counseling clinics. Volunteer work they were willing to accept. Salary work on a part-time basis wasn't there. Then to establish your own practice, everyone said, you've got to have an office. You've got to come up with the rent, you've got to come up with the tools. I wrote up a plan, I submitted a plan of self-support, it got denied. I wanted to set up a model office based upon something I picked up out of Stanford that they had started down there in their family therapy sessions using a lot of videotaping and such.

Some personal relationships in my life got stressed out at that time and fell apart. Then I met this woman and got involved in a relationship with her down in Palo Alto. She was involved with the Stanford Research Institute. So I left Berkeley and moved down to Palo Alto and interviewed for positions as a

counselor in some agencies there. Whatever reasons, I never got hired. Then when that relationship fell apart I decided to go back up to my house on the Russian River. I kind of holed up there to regroup.

I always had the thought it would be nice to go back to Berkeley. At the same time it felt like it was like a definite going back. People I had known over the years that had stayed in Berkeley seemed to stay in the same strata. They seemed to get into this routine, this niche, and stay there. It wasn't something I wanted to do; I wanted to get up and out of there.

Ten Years in San Diego, Meeting Wife Mary Ann, Career Services Job in New Mexico

Bonney: What were your subsequent moves? I know you were in San Diego at some point.

Rowan: Yes, I was living at the river for a while. Then this business acquaintance I had ten years earlier--I had gone into an investment property with, it had gone bad--and he finally improved his situation to the point that he sent me a whole bunch of money that he had owed for ten years. I thought, "Oh, how nice." So I used it to help repair the house a bit.

At that time there was a big, huge conference going on down in San Diego. Because of my license I would get all this literature in the mail all the time: seminars in counseling and all these things going on all over the place that I couldn't afford to go to or didn't have the travel to get there. Something came up in San Diego: it was the Tenth Annual Mandala Conference, and it was a big international spinoff, New Age, psych situation. One of the people working for me at that time as an attendant in the area used to live in San Diego. She was all keen on going back to San Diego and seeing things. She was in for the trip. I had the money to fund it, and I had some friends in San Diego, and they said I could set up camp in their front room and save some money there. I added it all up and so off I went to San Diego for this two-week training, Health Optimizing Institute.

I signed up for all the courses. They had a lot of the New Age, new wave people whose books I had read, and they were there presenting. It was a very, very enriching experience. Here I was, this whole group of people that were Ph.D.'s and clinical psychologists and psychiatrists and MFCC's and licensed clinical



social workers [LCSW] and psychic readers. You know, a whole mix. Lots of excellent presenters and seminar leaders and such.

There I was tooling around in my wheelchair, a spinal cord quadriplegic, with all this wellness and wholeness going on all around me. Nobody knew quite what to make of all of this [chuckles]. At the same time, I ended up doing counseling on a couple of people there that were using wellness and wholeness because they were terminal cancer. Because of my obvious disability they had picked me out to counsel them kind of on the cuff. This is something that seems to occur to me a lot all the time. At the end of the conference it was quite an experience because on the last day a lot of people at the conference, in their evaluations and discussions, were all sharing on how much they had learned from sharing the experience with Jack Rowan, this spinal cord quad in a wheelchair who had a different kind of slant or look on a lot of things that they had been gathering on.

From that experience of living in San Diego, two weeks, it was incredibly busy. Up early--the thing started at eight--and it would sometimes run through seven in the evening. It was on the San Diego-La Jolla campus. Beautiful. My friends were in San Diego, and this woman who came down with me--with her teenage son --after being there for the two weeks says, "You know, I think I'd like to come back here." So we talked about it and I said, "Okay, I'm kind of tired of living with my mom at the river with no job opportunities popping up for me there. It's still within the state of California. Okay, I'll cut you a deal. You guarantee that you will work for me as my live-in attendant for one year and we'll cut expenses three ways." Since she had a son, she was divorced, she had child support and alimony, I said, "I will give you the full attendant check every month, you take care of the house, cook, do the whole thing, and we'll split the rent, one-third utilities, the whole deal. All you've got to do is get me up in the morning, put me to bed at night, pick up another job somewhere else." She had training as a nurse, she was in a hospice, she was in different things that she picked up. She felt she could get back into hospice care in San Diego.

I said, "Okay, I've got to head back. I have attendants lined up there. You drive back with me." We were in my van, and we had to go together; I didn't want to drive that far on my own. I always did the driving because I was the only one who could drive the van. She would sleep, and we just drove nonstop from San Diego to San Francisco. I would just stop to fill up the gas tank because I was in a wheelchair that I had to be sitting up in all the time. So I would just wait until the last minute and she would get me out of bed, I'd get in my chair, and the van would be loaded. Off we would go. We would take off and she

would crawl in the back with her son and they'd go to sleep. I would just drive all night and drive straight on through. I did that five times.

So we drove up there, and then she jumped in her car and drove back down to San Diego. She stayed with friends, she'd phone up, and she found a three-bedroom home for a pretty good rental price. She signed a lease and I sent her the check and packed up and moved to San Diego. I ended up living down there for ten years [1984-1994].

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Bonney: Jack, how did you meet your wife, Mary Ann?

Rowan: In San Diego, there was a lot of New Age, new wave and psych things, and I would be working down there at the CSCD [Community Service Center for the Disabled], an independent living program. I would branch out and entertain myself, go into all these different New Age churches on the weekends. There was a woman down there, and we even made Time magazine. She had a church that was getting a lot of attention. We used to go out there, and they were involved a whole lot with New Age and psychic, and I was always interested in psychic, Eastern meditation hypnosis stuff. I got involved in this little group that I would just go and hang out in different places and pick up what they were doing. I would always feel like I was kind of observing through the glass, as it were, rather than being involved in this world. I always found it interesting and curious to explore. So there was this little spiritual psychic church. I used to go there for readings just to see what they were up to. They were a neat group of people; I befriended several of them who used to show up there now and then.

In the course of my work I got a pressure sore, so I went into Sharp Hospital and had surgery there. I was in bed for eight months before I was allowed to get up for about four hours. On one of those four-hour get-ups on a Sunday, I decided to jog over here and catch the little church and see what's happening. I was sitting in the parking lot waiting for them to unlock the doors, and the first car to drive up, out steps this woman with an attaché case. I was sitting in the sunlight on the cement platform by the side door that had a ramp onto it. That was Mary Ann. I met her and we were talking for about ten or fifteen minutes, waiting for the hour to arrive for people to show up to unlock the building and go in. I found out that she had just started working for the Association of Retarded Citizens [ARC] in San Diego and really hadn't had any background or experience and was having a lot of problems trying to find out and relate and deal with all the different disability types that she was dealing



with. I told her I was a counselor and I had some of my cards with me. I gave her my card and told her that anytime she wanted any information I'd be glad to help her out. She thanked me, and that was that.

A few weeks later I was returning to work and started to get some bad symptoms. I went back to the hospital and found out I had a lot of subcutaneous tunneling of fluid in a wound that wasn't drained properly and didn't heal. They had to open it all up again and ended up doing nine months more in bed. During that period of time every now and again, Mary Ann would phone up and say, "I've got this client I'm dealing with, that I really don't know what to do with." She was handling staff. She had just arrived in San Diego after living for twelve to fifteen years, I think, in Hong Kong as a Catholic nun. Before that she had taught in England and Italy. So I thought this was great. I thought an ex-Catholic nun is about the last person in the world I'm ever going to have to even consider having a relationship with; just help the poor girl out.

There were occasional phone calls, and I was just stuck in bed the whole time. I had a really hard time finding attendants because part of the deal was I was lying on an air bed in open drainage trying to get all this fluid out. It's supposed to go from wet- to dry-packed sterile dressings around the clock every four hours on attendant pay [chuckles]. So I ended up with one person who was on speed, one person who was a thief, one person who was a child molester, one person who was an ex-convict doing rehab. I said, "You treat me straight, I'll treat you straight. Keep it clean." After the first person, I had an ongoing police investigation trying to get this woman imprisoned, and I could never do that. I had to deal with all these credit card debts and canceling them out, and lawsuits. It was a mess.

So all this time I'm laying around just trying to heal up. Through one thing or another and seeking all sources for attendants, I ended up with this one guy who was a political refugee from Poland. He had a background in psychology; he was a psychologist in Poland. He had lived two years in Italy waiting for his visa to get into the United States. He learned to read and write English listening to BBC [British Broadcasting Corporation] broadcasts in Poland. I had to meet with him for two or three interviews before he agreed to take the job as a live-in attendant. He was pretty short, and I got him through this refugee placement organization. He turned out to be a real good friend. His concern was that I might be in trouble and he would not be able to speak properly to me in English enough to handle the medical situation. I said, "You take care of me, and I'll teach you English." We did that. Marian Krzysztan. A good man.

In that same period, Mary Ann would start showing up now and then. A couple of times she even brought her entire staff over. I'd be laying in my bed in my bedroom, and she'd be there with these six people under her and herself. They'd all be basically doing an in-service on disability, psychology, social issues, SSI, Medi-Cal, plans of self-support, education. It was a whole new arena to me, too, because it was the first time I really got into all the issues of mental retardation and group home living and the issues of that, using all my training in psychology, disability, group dynamics, communication theory, and family therapy. Her visits would be erratic, and now and then she'd call and then she wouldn't.

She was raised here in Albuquerque, and the family that raised her owned a beauty shop. So she was also trained as a hairdresser and beautician. She finally came over one day and said, "I just can't stand looking at the way you are anymore." [laughter] She cut my hair and my beard, trimmed me down, cleaned me up [laughs], and cut all my nails. Then it got to the point where she would phone me with a case issue or a work issue, and then it would go into talking. We would be on the phone for three, four, or five hours. Longer and longer.

So I knew her this way for about two years. At that point I was just getting to where I was able to get out of bed again. By then I was so debilitated my blood pressure, heart, and everything were just shot. I would sit up and just keep passing out. Marian was still working for me, and right about then he wanted to move up to San Francisco and see that part of the world. Mary Ann was living alone in her apartment, and we decided to combine finances. It happened that between rent and overhead and finances, the money that I was getting for live-in attendant care would about break even with what she was making working in a supervisory capacity. By then she was a supervisor for ARC. We decided to give it a shot on that logical, rational basis. Also the word used was that we were getting more fond of each other. So we got fonder and fonder.

Then a situation evolved where I was going back for treatment at Sharp Rehab and got to know a man there named Richard Green, who was running the outpatient clinic--an LCSW--and he asked me if I would be interested in working part-time. I said, "Yes, I think I could cut part-time but not anything more than that." Mary Ann said, "Need any assistance?" She would be there to help me. She is incredibly proficient in paperwork. I said, "Okay, let's give it a shot."

So I went back to work, and I was the first disabled employee they hired there. All the rest were LCSW's, and I had my

little MFCC. So I was there with all the social workers doing social work part-time and still maintaining my medical coverage and my attendant care. I got into doing counseling and running groups there and getting involved.

By that time I had found this really neat low-income apartment complex. It was real small--just eight apartments all by itself--built right into Old Town in San Diego right by the freeway. Palm trees, brand-new apartment, custom-built, full wheelchair accessibility, roll-in shower. Perfect. Money was working out, everything was working out. It was working out for both of us. I was still pretty weak. Mary Ann for a while thought I'd never be able to sit up. The only way I could sit up was she would throw me in the shower chair, or on a lift, roll me in the roll-in shower. I'd sit in there under full cold water just to keep from passing out, trying to build up my blood pressure and sitting tolerance. It was a real difficult year.

Even on Saturdays we used to go over to Sharp Rehab Hospital and pull all the medical records, and working off my quick notes, I'd have to do all the docs [documentation] and bring up everything and have Mary Ann handwrite everything in. Even though it was a rehab facility, they had never set up any of their departments to have a disabled employee. So there were medical records, the charts, the docs, the tables, none of it could I get under in my power wheelchair [chuckles]. The good thing I like is, because of a family situation that came up, Mary Ann and I talked about it and decided to pack up our San Diego thing and head back up to northern California. My mother had a health issue, and one of my brothers was in a real serious legal and financial problem. Things looked tough and it looked like she might need some help. I always loved living in that house; it was in the Redwood Forest. Mary Ann and I could live up there the rest of our lives, no problems. We'd get set up, see if I could find some work.

So we packed up and headed up to northern California again. For some strange reason my mother took an incredible dislike to Mary Ann. Probably because I told her she was the one I was going to be with the rest of my life. My other brothers had been married, some divorced and remarried. But for me, I guess one of the things about being the disabled person in the family is you are the one who could be depended upon to be there with the parents forever, and the parents would be your caretaker and you would be their job. I wasn't into that.

After a while it got so uncomfortable--I had been quite frugal and got into some other business things and found some other people that I knew from the area that were then in business.

We rebuilt the house a lot, restructured it for myself to live there the rest of my life, and it got so uncomfortable--the dynamics between Mary Ann and my mother.

In the meantime I had picked up a position on the advisory council up in Sacramento. I was going up there right after Bill Tainter had died and Brenda Premo had taken over then. She was an assistant under Bill. She had white hair; a friend of mine in San Diego had the same disability. It's kind of an albinism. The funny thing was that after being in Berkeley all those years, after the severe liberal Democrat as-far-left-as-you-can-go wing, there I was sitting in Sacramento under this Republican administration, with Premo and all these meetings. I was there as a civilian advisor and picking up my per diems and travel pay and hoping I could make a connection out of there to a job somewhere else that would pay enough to do rent and travel. Nothing was really coming forward. I made connections with Herb Willmore in Santa Rosa again. This man that raised Mary Ann here in Albuquerque said, "Hey, why bother? Come to Albuquerque. I'm retired, got lots of money, I'm rebuilding my house, I'm going to change the design on the house to make it wheelchair accessible. You guys come and live with me. You can find a job here or not; it matters not."

So we came, and anyway a lot of problems between he and Mary Ann that were buried from way back all surfaced. That got quite unpleasant. In the meantime I passed my résumé around and picked up a part-time job here in Albuquerque. One of the depressing enlightenments was that New Mexico has little or no social programs. They do on the books; they just don't fund them. So when I came into the state they said, "Yes, you're eligible for attendant care and Medicaid, but we have a two- to four-year waiting list." I said, "That's nice. What do I do in the meantime?" They said, "That's not our problem. Our funding is maxed." That was the end of the story, so one of the things that happened in New Mexico was that I got liberated from my tie to attendant care. Basically I was on my own financially. I told Mary Ann, "Let's try it for six months. We either make it or not. You go to work, I go to work. You do my attendant care. Nobody gets paid for anything." We go earn it. It's a low-wage state, but it's low rent. Then it turned into a boom state, and all the rents start going up.

I finally went into full-time work, something I never really wanted to get into because I thought the spinal cord injury and the time demands were just maxed out on my sitting tolerance. I'm now sixty years old. When I broke my neck they told me I'd be lucky to live to sixty or sixty-five. Skin problems, muscle atrophy--the normal aging process--would be somewhat accelerated



through the paralysis. Then in San Diego in '84 I had a minor surgery and something went wrong the night before and my heart stopped. So I went into clinical death and they brought me back. Did the blue light and the tunnel. It does change one's attitude. Heart's been on the blink ever since. I'm on heart meds. So energy was always kind of a problem.

So anyway, now I'm in bed for about another two months. And Mary Ann and I got married last April, after living together for ten years. We figured we're in New Mexico, we had bought this house here, we're not going to move unless someone offers me a tremendous amount of money. Here we are, so we might as well get married and make it legal. This friend of mine, as a gift, offered to build me this greenhouse that I just had as kind of a theoretical fundraiser during the wedding. People kept asking if we were registered anywhere. "Contribute to our greenhouse please." So it's being built now as we speak. It'll be really nice, and this is my home, and it's all wheelchair accessible. And Sharon Bonney's dredging up all these memories from way back.

CIL in Berkeley, at that time in my life--and that was in the late sixties to early seventies--it was for me and probably for a lot of other people in the United States dealing with disability factors that had maxed out their coping skills and family finances and their ideas about what was achievable--it gave me a life. It changed my life. I'm sure it's done it for a lot of others. It continues to do so on a lot of different levels.

Bonney: Let me change the focus of the discussion just a little bit. You're working now at a career placement center? What is it?

Rowan: It's called Career Services for Persons With Disabilities. It's been in Albuquerque for a little over twenty years, and it's vocationally orientated. It was something I again had little or no practical experience in aside from my own vocational needs. I started out being hired under a Dole Foundation Grant where we got \$55,000 worth of computer equipment. My job was to write, design, create, and teach a one-week intensive program that a person with a disability with little or no idea or experience in employment could come and start out with basically, "What is a job? Where do you look? How do you find it? How do you present yourself?"

I used videotaping for interviewing skills and taught basic computer skills. The goal was to have everyone who went through there with whatever level of disability to use whatever assistance or equipment that we had available to generate and type their own résumé on a computer, put it on a disk, be able to update it, and access it for different jobs. Once I was done with the training part of it and getting them ready, then the agency itself was

experienced. Its background was dealing with employers throughout the city on job carving, job accommodations. Their heaviest unit involvement was in supported employment dealing a lot with mental retardation. Not a sheltered workshop; that was like a total non-starter. It was full employment as a full employee doing whatever jobs with whatever support and assistance one needed on the job. Then I designed and taught this course for about three years.

Another grant opened up and the person who hired under that grant to do the computer training and the assistant technology training--and he had gotten some more grant monies for some pretty high-tech stuff for computer access--he had gotten a better offer, so he went. By then I knew enough about computers and Windows and a little bit of DOS and doing the résumés. I always liked gadgetry anyway. I picked up enough on the side to where they put me on that grant, and I did a steep learning curve on AT [assistive technology], and someone else filled in behind me on the program I had developed on the interview and job seeking and retention.

What I was doing was primarily assistive tech training. Again, that was all primarily on vocational rehab referrals, private insurance, Workman's Comp. I'm working, also, now a lot with the Albuquerque public high school system on a work-to-school transition, dealing a lot with young adults coming out of special ed that have had assistive tech provided through the schools--primarily Macintosh-based, Apple-based or software written primarily for special ed students--but there's no crossover to it into the general economy. So retraining, restructuring, trying to identify the hardware and software crossovers and training these people up. Once I'm done with my part, working in conjunction with them and then handing them off to job developers, job placement, job coaching, and then getting them into employment.

#### Assistive Technology: From a Selectric Typewriter to Computerized Voice Recognition

Bonney: I want to ask you about computers personally. They've certainly changed a lot in the last twenty or thirty years. How has access to a computer changed your life? What systems do you use? What kind of adaptive equipment are you using?

Rowan: For a long time I would just use two typing sticks. I went through college typing on an IBM Selectric and just using a writing splint on my right hand on yellow legal pads. Once I started learning, I had my own Macintosh computer that I had



bought on a PASS, that I was going to use in my counseling practice for records and data storage and such. Macintosh has very limited use out in the work world, so I started learning DOS and Windows 3.1 and then Windows for Workgroups, and now Windows 95. The main access with the computers and the whole computer industry now is that for better or worse--it's recognized that the workforce coming out on minimum wage for service jobs--everything is tied to computers. Cash registers are all computerized. Everything goes into databases for inventory. The level of technology, like when Bush went out and discovered an infrared checkout device. Poor man! They're finding that the literacy is terrible across the board. Everybody wants voice recognition.

Bonney: Do you have that on your computer?

Rowan: Yes. Right now there are three big contenders. There's Dragon Dictate, IBM Via Voice, and now there's a new one coming out through L&H called Voice Express. Voice Express has just hooked up with Bill Gates and Microsoft. L&H is a European software company out of Belgium, and they're building a voice recognition based more on semantics than on straight algorithm recognition patterns. In addition to that, I've worked with real high spinal cord people on vents using reflectors, either infrared or sonic. A reflector dot placed anywhere on their body activates the mouse on the screen. There's a Sip and Puff head mouse.

Then there are software solutions where you can put an on-screen keyboard, and you can configure it any way you want and make it any size you want. You can put the cursor by aiming your head around. The most far-out one is a thing called Eye Gaze, where literally it focuses a camera on your retinas, and it follows your eye movements around. I tried that once for a short time at Sharp. Oh, it's just so demanding trying to control the movement of your eyes. It's incredibly demanding. Some of the systems require that you have to learn to think on two or three levels. Then they've got word predication and word expansion things now, where you could make up coin phrases, and through a couple of clicks on letters it'll punch them in. You can use all these different kinds of mice: anything from Glidepoint, where you just use your fingertip on a plate--

Bonney: Which ones do you use?

Rowan: I'm using primarily voice actuation, so that I can literally tip back in my chair or sit up--

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Rowan: --headset with a discreet speech--which is single-word recognition. That was really neat because now I was no longer tied to this cord. I worked with another guy in the agency and I figured out that rather than paying \$125 we got a seventeen-dollar Radio Shack solution to wire the thing into the batteries on the wheelchair. That finally got up and going and working good, and now I'm working with continuous speech recognition. The wireless mike just has so much noise in the transmission that it just won't go. I was starting to explore, before I got laid up, a lot of the wireless systems being used in the entertainment industry. You see everybody now on stage with their headmikes and their little belt packs? Those are all wireless voice, and they all have noise cancellation built into them so that you can set levels on them so that they would ignore the band or the audience and pick up only the voice. The thing is, you've got to really project into them on that level.

But I just want to find one where I could set levels. On a professional level, those receivers and transmitters are really good but very expensive. But to use them for an individual in an office situation, trying to get one that's wireless at a fairly reasonable price, that would be really nice.

Bonney: Has the new computer technology helped you communicate easier and do your work easier or not?

Rowan: I couldn't do it without it. The big limiting factor still is filing documents in folders in file cabinets. I found a lateral file cabinet I could use. I had to modify it and change some of the configurations, but if you had the money to have a team of sheet-metal workers and welders and electronic techs at hand, you could really do some neat stuff. The thing is to find something off the shelf that requires minor modifications, where you could really do all your own stuff. I operate a lot alone, but part of the reason I broke down this time was the person who was assigned to assist me with filing and paperwork was tied up. They got short-staffed and they transferred her over to other places. Just sitting up to do all the reading and manipulate the folders and papers and drag them in and out of the lateral file cabinet.... The other thing is that with the AT there's a lot of reading involved.

The thing I'm trying to work on now would be trying to come up with a combination computer, scanner, and overhead projector. I've dealt with a couple of people that have been reclining from pressure sores in bed so long they could only go forty-five degrees, high quads. I've dealt with four highly professional people that have carpal-tunneled themselves out into the cervical vertebrae to where they cannot even support their head. Their

wrist, elbow, and shoulder joints, their musculo-skeletal carpal system is totally painful and destroyed. So both for spinal cord quads--because I've been laying around for so many years thinking about it--I'm very familiar with their situations and their limitations.

What I'm trying to develop was to contact some software/hardware vendors and grantwriting things to try to develop a projection system where we'd get rid of the computer screen and go full voice actuation. You're going to need some kind of switching, because every now and then when the computer goes down you've got to reboot physically. So even with some kind of a head movement switch that could be wired into the reset button or the on/off power button combined with a voice actuation system, combined with a projection system where literally you could hang a screen. You don't want an eighty-pound monitor hanging in the ceiling over your head. It's just too big a problem. If you had a small version of an overhead projector, where you'd have a lightweight roll down screen on a tripod with a clamp that you could clamp on to a hospital bed rail or a wheelchair frame, you could set it at a focal length distance from the person's eyes that would be good for them.

There's a commercial product called In Focus, that you plug right into the monitor port on either a laptop or a computer. It's this really neat little thing about the size of a small VCR, and it projects your computer image. They're about \$2,000. If there was some way to get the technology down to where I could do that, and carpal tunnel people or even people that do a lot of programming get tranced out into the programming, they're working twelve, fourteen, twenty hours. All of a sudden they hit their late twenties and their bodies are destroyed. For all purposes, they're quadriplegics. Their arms are gone, sometimes their necks are gone. Their legs are fine. So in California I came across a vendor who's developed foot mice, so that you can activate your screen as you could through any onscreen keyboard and mouse combination using your legs. People who have tried that say that after about an hour [chuckles] you're tired.

So voice is something I've gotten into for my own disability and for helping others. Commercially they want everything on voice to where you could walk up to your bank machine, and if you limit the recognition vocabulary to four or five words it'll go across different speech patterns. So when you get into these 30,000-word recognition things, it's when the recognition really gets tight. But tied to that, credit card companies are going crazy with security. Once you get into a certain level, if you could like speak a phrase and it would run a voice print, you can't phony a voice print. That's what they're working on. It

just so happens this fits in with productivity. The thing is that what it comes down to again is high cognitive concentration.

But on the other end, because I've got all this time to think, one of the fortes of mental retardation is the ability to stay totally involved in repetitive tasks. So even something that could be speeded up through voice, like computer industry on-lines that demanded concentration to detail on repetitive tasks like assembly line Q&A, most people that are in mental retardation up to around sixty to seventy-five IQ levels, they could do this. It's all graphic, visual recognition, and a couple of word utterances like "pass," "no pass," "destroy." So I see it's all fitting in. But I've got to get me a wheelchair that I can float on like a low-gravity environment [chuckles], where I could sit without worrying about pressure sores.

Bonney: Jack, do you have any last words that you'd like to leave with the listener?

Rowan: Like on my tombstone?

Bonney: No [laughs]. Like any reminiscences or thoughts.

Rowan: Berkeley was the most fun city I've ever lived in. The social climate, the accessibility, and the thing to me that was just the best was to be a non-student and yet have access to the stuff that comes through the campus. Zellerbach Hall, some of the facilities on the campus, just such quality. The international groups of drama and movies and dance, it's a stimulating place. Just to be able to tap into that as a cultural resource was really nice. The diversity of the people living there. One of the great things was the diversity of restaurants. You could have an international cuisine in a couple of blocks.

Bonney: Right. And they don't close at nine o'clock either [laughter].

Rowan: I really enjoyed my time in Berkeley.

Bonney: This has been a wonderful interview and I thank you very much for your time.

Rowan: You're very welcome. It's been a pleasure.

Regional Oral History Office  
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University of California  
Berkeley, California

Disability Rights and Independent Living Movement Oral History Series

UNIVERSITY OF CALIFORNIA'S COWELL HOSPITAL RESIDENCE PROGRAM FOR  
PHYSICALLY DISABLED STUDENTS, 1962-1975: CATALYST FOR BERKELEY'S  
INDEPENDENT LIVING MOVEMENT

Peter Trier

STUDENT AT BERKELEY: TRANSITION FROM THE COWELL HOSPITAL  
PROGRAM TO THE RESIDENCE HALLS, 1975

An Interview Conducted by  
Susan O'Hara  
in 1996





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## INTERVIEW HISTORY--Peter Trier

Peter Trier was interviewed because he was a resident in the Cowell program in 1973, when the program was beginning to make the transition to the university residence halls. He was involved in the formation of the Disabled Students' Union and the politics of the disabled community in those early days. Mr. Trier is currently the president of the board of directors of Easy Does It, an emergency attendant service funded by the city of Berkeley.

In addition to describing his experiences as a disabled student at Cowell Hospital, Mr. Trier reflects on disability itself and political activism in the disability movement. Mr. Trier completed his studies at Berkeley with a doctorate in philosophy and taught at Fresno State University.

The two interviews were recorded on May 28 and June 5, 1996, at Mr. Trier's apartment in Berkeley. He reviewed the transcript and made few changes. He and the interviewer have been acquainted for many years.

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Susan O'Hara, Interviewer/Editor

July 7, 2000  
Regional Oral History Office  
The Bancroft Library  
University of California, Berkeley



Regional Oral History Office  
Room 486 The Bancroft Library

University of California  
Berkeley, California 94720

BIOGRAPHICAL INFORMATION

(Please write clearly. Use black ink.)

Your full name PETER LOUIS TRIER  
 Date of birth OCT 17/50 Birthplace PORTSMOUTH, VIRGINIA  
 Father's full name WILLIAM CROWIN TRIER  
 Occupation PLASTIC SURGEON Birthplace JERSEY CITY, N.J.  
 Mother's full name KATHLEEN BENZ TRIER  
 Occupation HOUSEWIFE Birthplace SARASOTA, N.Y.  
 Your spouse ---  
 Occupation --- Birthplace ---  
 Your children ---

Where did you grow up? NAVY CHILD - DIFFERENT PLACES IN EAST

Present community BERKELEY, BERKELEY QUINN

Education DIPLOMA IN PHILOSOPHY FROM UC BERKELEY

Occupation(s) PHILOSOPHY TEACHER

Areas of expertise ETHICS, POLITICAL & SOCIAL PHILOSOPHY

Other interests or activities MOVIES, FRIENDS, READING

Organizations in which you are active BERKELEY POLITICAL SOCIETY





## INTERVIEW WITH PETER TRIER

## I FROM VIRGINIA TO CALIFORNIA

[Interview 1: May 28, 1996] ##<sup>1</sup>

Military Family

O'Hara: Peter, can you start out by talking about where you were born and the date of your birth, your family, your school background?

Trier: Sure. My father was a physician with the military. When I was born, which was October 17th, 1950, my father was stationed at Portsmouth Naval Hospital in Portsmouth, Virginia. That's where I was born. We lived there all of six months and then moved back to the New York area, where my father was at St. Albans Naval Hospital for a number of years.

O'Hara: St. Albans?

Trier: Yes. I don't know exactly where it is, but somewhere in New York. And then my father moved around it seemed every three years or so, somewhere else, until he got out of the navy in 1967, so I moved with him.

O'Hara: Did you have brothers and sisters?

Trier: I have one brother, who is eighteen months older than I am, Bill. He is not quite as disabled as I am but has the same general type of disability. It's a very strange disability.

O'Hara: What is it?

Trier: Well, it's juvenile spinal hereditary muscular atrophy.

O'Hara: What's the word before "muscular"?

---

<sup>1</sup>## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

Trier: Hereditary. It's apparently like you have about one in 1.7 million chance of getting it. It depends upon your father and your mother having a fairly rare recessive gene. Anyway, they didn't have a diagnosis of it until I was almost fourteen, so when I was little there wasn't a lot known by neurologists. Basically, I was diagnosed as either an unknown muscle disability or an atypical muscular dystrophy. Some people would say it definitely was a muscular dystrophy, but no one knew what it was. Now they know what it is and know what the gene is, but they didn't have a diagnosis of it till I was fourteen.

O'Hara: Were you in general good health all those years?

Trier: I was in general good health. I mean, I lived with my family, and I never, except for having some muscle biopsies on my leg, I never spent a night in the hospital until I moved out to Berkeley. I lived with my parents. I was in good health. I did, when I was sixteen, have a spine fusion. I had a metal rod put in my back.

O'Hara: A spinal fusion?

Trier: Yes. I had a Harrington rod put in my back, which otherwise I probably wouldn't have been able to continue to sit up. But other than that, my health was good. Fortunately, we moved to New Jersey when I was about ten years old. This was 1960. New Jersey was one of the few states that routinely mainstreams disabled kids, so I was mainstreamed from that time onward.

O'Hara: Your father was in the army, but--

Trier: Navy.

O'Hara: --you didn't go to army schools?

Trier: Navy. My father was in the navy. No, no, when I was a child, my father was always in the United States, so I went to the public school. When we were in New York, my parents tried to get them to let me go to regular public schools, but they wouldn't do it. I guess now they have to, but in those days they didn't have to.

O'Hara: Where did you go?

Trier: Well, there was a school named after Eleanor Roosevelt founded for kids who had cerebral palsy, but they had a whole range of kids with disabilities there, and I was enrolled in there. But basically for three years most of the time you drew pictures and listened to stories. Fortunately, we moved in three years. Otherwise, there would have been an educational [...].

O'Hara: This was age six to nine?

Trier: Yes. Seven to ten.

O'Hara: And at age ten?

Trier: Ten, we moved to Barrington, New Jersey, which is a suburb of Philadelphia. There they admitted me to a regular elementary school, and from there I went to public school all through high school, and then I went to the University of Arizona. After graduating from the University of Arizona, I decided I didn't want to keep living with my family. I wanted to move away. Until then, I lived with my parents, my mother taking care of me, primarily.

#### Searching for Graduate School and Disabled Student Services

O'Hara: Your family was in Arizona at that time?

Trier: Right. My father was at the University of Arizona Medical School. He was on the faculty. So I began to hunt around when I was a junior in college to see where there were good graduate schools and also where they might have programs for people with disabilities. I wrote to about twenty schools, and only two of them gave me any kind of decent reply around disability. One was the University of Texas, and the other was UC Berkeley.

After my junior year, my parents drove from Arizona to Berkeley, and I visited with Zona Roberts, and I think I met Hale Zukas but I didn't meet Ed Roberts. I visited Cowell Hospital, and then decided to apply for UC Berkeley. That was the only school I applied for, for graduate school, and got in. Then in '73 I moved to Berkeley. [tape interruption]

O'Hara: What field were you applying in?

Trier: I applied to the philosophy department because I wanted to be a philosopher since I entered junior high school. Fortunately, that was the only place I applied to, and they accepted me. Then the chair of the philosophy department at Arizona wrote an extremely misleading and illegal letter to the D.R. [Department of Rehabilitation] representative at the time, before Karen [Topp], telling her that if I got my doctorate the philosophy department at the University of Arizona would hire me for a job, which thrilled her. Ordinarily, D.R. did not want to pay for graduate

school in those days. She was thrilled that I had employment prospects.

O'Hara: Why did he write that?

Trier: Well, it was written by the chairman of the department at Arizona, just to be helpful to me. I mean, it was good. Probably if he hadn't written something like that, I would have had some difficulty. I didn't ask him to do it; he just wanted to say it. I didn't argue with it.

O'Hara: So you got into the philosophy department and then you talked with Zona.

Trier: Well, once I was in the philosophy department, I had contact with Donald Lorence at that point. He was doing advocacy for the Disabled Students' Program, then the Physically Disabled Students' Program. So I basically was able to arrange, as much as I could, to apply for attendant care and SSI and all that stuff, and got approved by D.R. to move into Cowell Hospital.

## II COWELL RESIDENCE PROGRAM, UC BERKELEY, 1973

Memories of First Four Days

- Trier: My parents drove me from Tucson, where I lived, to Berkeley. We got here September 14th. It was about two weeks before classes started. Then I was at Cowell that next year.
- O'Hara: Tell me, did you come in a van?
- Trier: Yes.
- O'Hara: You had a van?! That was very advanced.
- Trier: Well, fortunately, my parents, actually--I mean, they bought the van so it would be easier to get me around.
- O'Hara: Did it have an electric tailgate?
- Trier: It wasn't that advanced. It had a pull-down ramp.
- O'Hara: Okay. How did you hear about Berkeley, about the Cowell program?
- Trier: I heard about it because I wrote to about twenty schools, and indicated that I was interested in going to--that I was disabled and wanted to know what they had available. Most of the schools would say things like, "We really don't have anything, but we'll help you as much as we can when you get here." Two of them were more helpful, and the one that was by far the most detailed was UC Berkeley--and talked about the Disabled Students' Program and the residence program and all the services that were available.
- O'Hara: Do you remember the day you arrived at Cowell?
- Trier: Yes. Vividly.
- O'Hara: What did you find? Describe it.

Trier: Well, the point which was very nice for me was I was somewhat nervous before I got here because, except for my brother, I had spent very little time around disabled people since I was ten years old, and I was a little bit concerned about how comfortable I would be, hanging around that many disabled people. But basically when I arrived there, there were either eleven or thirteen people in the program. Mary Ann [Hiserman] and Lennis [Jones] moved out soon afterwards, but they were still in the program then.

Everybody was very friendly. I got this ludicrously large room because it was the one that was available. Everyone was friendly. The first night, people were watching Planet of the Apes, I think, across the hall, and I went over and watched that. My parents stayed in town for the first week. They were nervous because it was very difficult for me to get used to driving. I had practiced driving my wheelchair in Tucson, but that doesn't really prepare you for driving in Berkeley, on campus.

But Zona had already picked out two really good attendants to work for me, both of whom worked for me that whole school year --they were very good--one of which was Paul McBride. First I was kind of nervous about hiring Paul because he described himself as a freak. Tim Daly said to me, "Don't be crazy. He's really good. Hire him." Which he was.

It took a few weeks to get settled into it, but was fairly easy. Everybody was pretty nice. Cowell was a very nice setting in many ways. I mean, there was always the problem that you felt cut off from the school in general, and it was very hard for people who were not tied into the disabled community, like other students you met come up to visit. I mean, it was a real big deal for them to come, and they were very nervous.

O'Hara: You had visitors who were not disabled?

Trier: Yes. I had a few. One of the first I had was sent by Bronson West. I didn't meet Bronson for over a year. Bronson's a very good friend of mine now. Bronson had friends in the philosophy department, which is one of his interests, so he asked one of them, Neal, who now teaches at Reed, to come visit me. So before classes started, he came in and filled me in about the philosophy department. Neal and I joked and disagreed years later because I claimed I wasn't very smart because I didn't follow his advice about preparing for the exams at all seriously. He claimed that I was right in not following him, just studying what I wanted to study.



I had a few friends come in the course of the year. Mostly it was a totally separate world.

### Meeting Disabled People for the First Time

O'Hara: Going back for a minute, you said that you were a little edgy about being around other disabled people. Now, future historians might wonder why that would be true for a disabled person to be edgy about being around another disabled person. Can you elaborate on that a little bit?

Trier: Well, growing up in the fifties, if you were lucky enough to be mainstreamed, you usually were very isolated from other disabled people. I talked on the radio with this guy who used to be director of United Cerebral Palsy, who was the first disabled person who had mainstreamed in New Hampshire, which was a few years before I was mainstreamed in [New Jersey].

Basically, the choice you typically had was either, if you were born disabled, either you went the route with disabled people, which meant you went to schools for disabled people, and ultimately the end route of that was typically a sheltered workshop of some kind. Or, if you were very lucky, you might be mainstreamed. If you were mainstreamed, that meant that you were --like, I was, throughout elementary school and junior high school and high school--always the only seriously disabled, certainly, and in many cases the only disabled person who attended the school, and so my relationships were with nondisabled students and nondisabled teachers and faculty.

Basically, relating to them, which in my case [was] primarily around trying to be a good student or trying to be outstanding in some way because you're obviously not physically outstanding. You really don't have much relationship with people who are disabled. My goals in terms of my parents apparently were that I would be an achiever academically so I could be some kind of professional eventually.

But there wasn't very much involvement with other disabled people at all. When I was a kid, I went to, I think, the first junior great books group in the country, or one of the first ones, that was in Maryland. I certainly didn't relate to other disabled people very much at all. So coming to Berkeley and going to the residence program meant that I would be very closely involved with disabled people and the disabled community in a way that I hadn't been before.

In a way, it was worse because even people who had spinal cord injuries, at least by the time they went to school, they had gone to rehab, so they were at least in some environment where-- not by choice but by circumstance--they were around a lot of disabled people. It turned out to be not a big deal, but it made me a little nervous at the time.

O'Hara: Why did it become not a big deal? What was the process?

Trier: One of the processes was that you quickly meet such a wide variety of people. I mean, Scott Luebking was one of the people I lived with. Mary Ann Hiserman was one of the people I lived with. Donnie Johnson was one of the people I lived with. People who really don't seem to have a whole lot in common. You can say that they're disabled, but that's about it.

But the first week after I moved there, Michael Pachovas-- who was a rather imposing person, just physically--came up. Michael wanted to start a disabled students' union. He wanted to have a meeting at the apartment he shared with Phil Chavez. So my first outing from Cowell--before classes started--was to go with four or five other students from Cowell Hospital to the campus and across a small part of Berkeley to Michael's apartment.

So fairly soon I was involved with the Disabled Students' Union. Ultimately, I was on the housing committee, the head of which flaked out fairly quickly, so I was the head very quickly.

O'Hara: The head of which?

Trier: I was originally, like, just deputy person to the housing committee. But the head of the housing committee flaked out very quickly.

O'Hara: Oh, I see.

Trier: So then it was my committee. There was a lot of activity for it. As much as anything else, we modeled ourselves on Martin Luther King and the civil rights movement. That was something really interesting to do.

The classes I had were very exciting. I had very good teachers that were intellectually interesting. I never felt that much pressure to accommodate myself to Berkeley. There was a running joke at Cowell Hospital how concerned I was to protect my rational characteristics from being overwhelmed by Berkeley, and it was kind of a running joke how long it would be before I would first smoke marijuana. I think I made it all the way through

Cowell without smoking marijuana, which was an extraordinary achievement coming from Cowell in those days.

The unjudgmental response at that point, which is a part of, in some ways, what drove the description we wrote for rehab assistance later on. It was a very tolerant atmosphere. There were people there who were very conservative; there were people there that were alcoholics or heavy drug users when I was first at Cowell. Everybody, the people that worked there and students, they had a pretty relaxed, tolerant, nonjudgmental attitude. I felt, to the degree that people thought that I was odd, they didn't usually say it, so it got to be fairly comfortable.

There were--a certain number of people that were there--Mary Ann was wonderful, and Paul McBride, one of my attendants, and others. I felt I was treated very kindly.

O'Hara: Was there a certain lore that was passed on to you by some of these individuals, these mentors?

Trier: Oh, yes, sure, right away, yes. Well, first, one of the pieces of the lore was language. If you lived at Cowell for a year, the way you describe people with disabilities to other friends or something, you describe such people as crips. That was a term I had only heard once in my whole life. When someone used "crip," it sounded wrong. Once, when someone tried to be cool, they used the word "crip." There was kind of a heavy silence for two or three minutes. Otherwise, it was natural.

I remember soon after I got there, there was a satirical article that was in *The Independent*, I guess, when that was still coming out, from CIL [Center for Independent Living]. Basically, it had to do with imagining "Ironsides"--the TV show--what life would really have been like, given that he was a quadriplegic living in San Francisco, describing him taking a suppository and having the suppository work in the middle of an interview of a suspect or something, or describing the incredible annoyance the guy who took care of him must have had at hauling this huge man up and down the steps in San Francisco all the time.

Because the premise of the show was the character would push Ironsides, and you'd see all these huge steps in front of a San Francisco house, and the next thing, Ironsides would be in the middle of interviewing a guy. In the scene after that, he'd be back in the van, going home or something. So they'd never actually show the logistics of it.

One of the first things was I was recovering from the flu and I was probably somewhat in a depressed mood. On a Monday

night--and I had never skipped a class in my life in school--and Monday night there was a small seminar that first-year students are supposed to go to, in the philosophy department. I didn't really want to go to it--beyond which they were showing the NBA All Star game that night--so I decided for the first time, All right, I guess I won't go. I'll stay home. I'll stay at Cowell and watch the game.

There's a phone call, which I didn't know anything about till the next day, that was answered by the orderly on duty, and the person who ran the seminar was concerned about me. So the person who answered the phone just told him, "Well, oh, Peter Trier. His wheelchair broke down." So it was funny. The next day I was driving my wheelchair to the Berkeley campus, and this professor passes me. He says to me, "Oh, is your wheelchair okay now?" Or "I guess your wheelchair is okay now."

I didn't know what to say. I sort of nodded and said, "Sure," and went on. Later on, I found out that even though I hadn't asked him to lie for me or anything, the person who worked for me was just being nice and he figured he was going to cover for me. Anyway, that was nice.

#### Politics of Moving Residence Program from Cowell to Residence Halls

Trier: Part of why we wanted the program to go to the dorms was that we felt like the separation of being a student at Cowell was so extreme from being an ordinary student and that that was probably not--historically, I mean, it was better than not having a program at all. There were other reasons we were happy to have it go to the dorms.

O'Hara: Something I read at a meeting that you chaired in March of 1975, the minutes, it sounded like the dorms were a second choice over possibly some kind of halfway house. Was that actually considered?

Trier: No.

O'Hara: It was kind of implied in this. I can't say that it was spelled right out.

Trier: No, I don't think--

O'Hara: People wanted to build a building?

Trier: No. I don't think this ever came from disabled people. You know all the fights that went on for years about People's Park. There was a time where one of the ways the university wanted to deal with the People's Park problem was to build a new dormitory there. They wanted to have a special area of that that would be especially amenable for disabled people. So not only could we live there but there would be a secluded area where people could go outside and sunbathe or whatever.

          Their thought was if they built this, then they could sort of get rid of a lot of the criticism of how they were dealing with People's Park because they could say, "We're doing this for disabled students."

O'Hara: Was this at the time when you were at Cowell?

Trier: It came up around the time, yes. The response of the disabled students was, "Forget it; this is your problem. We're not getting involved in that." The Disabled Students' Union started in 1973. We were told that the expenses of D.R. were so high that it was going to get harder and harder to be able to maintain anything at Cowell Hospital. We also were led to believe that if we could have a program in the dormitories, theoretically a little bit larger number of students might be able to enter the program.

          So all that happened was, as part of the housing committee, I went and met with people in the housing department that were very nice. Basically, I guess I mainly met with the orderlies and with a lot of different people at the university to try to see if we could come up with a plan for the dormitories to replace the Cowell program.

          Basically, most of that came together in '75. It came together fairly easily.

O'Hara: And quickly.

Trier: It came together very quickly.

O'Hara: Once it happened.

Trier: Part of what happened at the end of it--I don't know if you know what any of this part--is there was finally a picnic at Live Oak Park, where all the various parties were there.

##

O'Hara: You were talking about a meeting.



Trier: There was a meeting at Live Oak Park--picnic--but meeting, too. John Hessler couldn't come to that. Don Lorence represented the Disabled Students' Program. Everybody agreed there that--including D.R. and representatives of the dorms and the orderlies' representatives, the students--that we should do it.

Then there was a meeting after that at Disabled Students' Program, a couple of weeks after, in which John Hessler announced that they probably were not going to move to the dorms.

O'Hara: Were not?

Trier: Were not. His view was that if the move occurred, the disabled students' residence program would be nominally under the supervision of the Disabled Students' Program. That was what the university wanted, whereas before it really had never been directly under the Disabled Students' Program. It was under D.R. or somebody or other. John simply announced that he did not want his program to have that additional responsibility. A number of people, including a number of disabled students, were very annoyed at this.

O'Hara: Say that again.

Trier: A number of us were very annoyed at this. So a meeting was called, through Disabled Students, for the fourth floor of the Student Union. We called every former student that we could think of, and we got a lot of people there. A very strong view was expressed that the program should move into the dorms and that the well-being of the program was a lot more important than whether the Disabled Students' Program was stuck with additional responsibility.

Then Betty Neely apparently made the decision that the move would occur, so she overruled John. After that, the program moved, and we were in the next process, where people were interviewed to run the program, and then the program moved into the dorms. That's how it originally happened.

O'Hara: Was John a party of one in this, or was it a contingent of people? It seemed like there was an enormous controversy somewhere along the line.

Trier: John always played his cards very close to his chest, as they say in poker. The way John stated it was that "I don't want my program given responsibility for managing the residence program, and, therefore, I am not going to approve the program going to the dorm, and the move is not going to happen."



There may well have been other people that felt the same way. None of them voiced their opinion. Whether that would be whether John voiced an opinion on it or not, the only university administrator who ever voiced an opinion about it was Betty, when she approved it.

Now, I know at the time the students worked very closely with what they called the orderlies, and there was a lot of very angry feeling about things being suddenly changed. If there were other people who had objections to it, then they weren't as forthright as John in saying so, so I don't know.

O'Hara: When you said people objected to change, you mean going from Cowell to the dorms?

Trier: Right.

O'Hara: Or new job descriptions?

Trier: No, the only issue that was ever on the table was the issue of going from Cowell to the dorms. Is Jim Brown still around, who used to run Cowell?

O'Hara: No, he died.

Trier: Gosh sakes. I was under the impression that the residence program feature in Cowell was limited, but my direct involvement was in a process which went fairly quickly, in which a move into the dorm seemed to be fine. It was fine with the dormitories, as long as certain costs were assumed. D.R. seemed perfectly willing to pay those to the dorms as well as anywhere else.

The job description was never controversial. From the point of view of the students and of the SAs [student assistants], former orderlies, they felt quite strongly that the job description was important and expressed how they wanted the program to be viewed. But there was never anybody at a higher level at DSP or the administration [who] ever--it was written and accepted--but there was never anybody who ever said, "We approve it, and now it's official" or anybody who said, "We don't like it." It just sort of got included in the package.

The feeling we had at the time--I know I had at the time--was if we put something in writing and presented it at one of these meetings with various people involved, and nobody else had anything in writing, most likely--as long as it wasn't too objectionable--people would pretty well nod their head, "That sounds good." It wasn't like things would come to a direct vote or anything.

O'Hara: What was your idea of the role of the orderlies in terms of who was going to be the trainer in the program? Was it going to be peers or the individual student teaching themselves, or was there sort of a coaching approach by the orderlies?

Trier: What we would have said ideally--and what would have happened ideally--would have been that on a day-to-day basis, the director of the residence program and the SAs, who would have typically performed the "educational role" because they would have been typically dealing with students who had not lived independently before and they would be hopefully politely, without a heavy hand, they would be pointing out certain things, giving certain advice and so on.

We hoped it would be the case, which happened for a while, that students would make themselves available. It did happen at certain times, where they would talk about the program--in some cases work with students and so on. But we always made the assumption that the people that had paying jobs as part of the program would be the ones who would primarily be doing that.

One of the realities which occurred for us very quickly is that the Disabled Students' Union--and it turned out historically --was something which came and went. There were times when there was an active Disabled Students' Union. That usually meant that there were a few people running it. Then there were times where people had graduated and moved on to something else, and the next group of students wouldn't be that involved. Then there'd be a period again, like when Alan [Hayden] and Brian [Hogan] were involved, when it would be sort of reconstituted and active again.

O'Hara: When who and Brian?

Trier: Well, Alan Hayden and Brian Hogan. Then there was a Disabled Students' again.

But there would be other periods--some issue would come up about funding of the program and whether there would be a decrease in vans or whatever. Some people who were current students would decide to start up again the Disabled Students' Union. There would be other times--I'm sure--when basically the people that were running the residence program were the people in what previously was PDSP, and the people working in the residence program and old students didn't have much to do with it.

Formation of the Disabled Students' Union

O'Hara: Was there an event that was a catalyst for the formation of the Disabled Students' Union?

Trier: This is what I know. In the history. When Larry Biscamp was admitted to Cowell, as I understand the story, Larry had acceptable grades by Berkeley academic standards. But his grades were considerably lower than what had been the standard at Cowell. The students that had first come there--Ed [Roberts] and John and a few of them afterwards--partly took as their role setting an example for disabled people. They were very bright, so they tended to have very good grades.

The Department of Rehabilitation at one point said that they would not continue to fund Larry as a student because his grades were not high enough. There was a big argument that occurred because the students basically felt since he was a qualified student, then D.R. shouldn't be able to pull funding from him. At that point, there was an organization created called the Rolling Quads. I believe at one point Donald Lorence was the treasurer of it.

Now, this went on some time, like, late sixties, I guess. Then down the road, before I got there--Michael Pachovas was there the year before I was--there were various frictions, and there was just criticism--from Michael and a few other students--that John's role as the director of the Disabled Students' Program--and John actually usually when you talked about it, was fairly philosophical about this. His role was in that sense part of the university bureaucracy, so it was different than his role was when he was actually a student.

So Michael and some other people said, "We really need to have a student group again." Why they felt in 1973 that that was the time to do it, I have no idea. They decided to start the Disabled Students' Union. That's what brought Michael in September of '73 up to Cowell Hospital to try to get people to go out for the inaugural meeting.

When the organization was created, as I understand it, there was still money left in the treasury from the Rolling Quads. That was turned over to the Disabled Students' Union, and so in that sense they're a child of the Rolling Quads. That's how it got started.

Once it was created, it existed on a lot of levels. One of the first major things it was involved with was the residence program.

O'Hara: The move to the dorms?

Trier: Right.

### John Hessler's Leadership

O'Hara: You mentioned that John played his cards very close to his chest.

Trier: Yes.

O'Hara: What are aspects of his leadership? Since he's not around, I would like you to give sort of a characterization of his leadership.

Trier: One of the examples I remember with John--on the one hand--this was certainly true of Michael and other people. There was clearly a certain tension, and there were times where John would be fairly straightforward: "I'm a power player in this game, such as it is, and I want to make sure I get what I think should be done."

But I remember having other conversations with John, in which John would say--he thought it was really good, what I was doing and what Michael was doing, and that was because he felt like--there's always been the good old days; even in '73 there was the good old days--as opposed to--there was a time before when the Disabled Students' Program was created--CIL was created in what?--'72, so that's not that much earlier, when a certain number of people would be activists. [added during editing process: "I was wrong--the Disabled Students' Program was founded earlier than CIL."]

It was always the case. Most of the disabled people at Berkeley basically had enough to deal with in their own lives and weren't that interested in being "political." So John thought that what we were doing was a good thing and that we were being actively involved in trying to effect things. It didn't necessarily mean that everyone was of the same mind.

One of the things that went on around this time--I don't know if you know that the first director of CIL was Larry Biscamp. Originally, the grant for CIL came because Larry knew Fred Collignon in city planning. Fred Collignon knew people at federal

Rehabilitation and that's where the grant came. The first CIL actually housed itself in Larry's apartment.

O'Hara: Did he live on Haste then?

Trier: I don't remember. He moved CIL from there to University Avenue. I don't know where his apartment was. That was before my time. You could well be right.

There was a certain point when the program was at University, when John was on the board of CIL. The CIL board voted, like, six to five or whatever to ask Ed to be the director and remove Larry as director. After that time, CIL grew very quickly and they moved to where it is now. Now it's on Shattuck.

O'Hara: You mean on Telegraph?

Trier: On Telegraph, I'm sorry. On Telegraph, right. So through a lot of the period at the time--I mean, Ed and John were always very close. They worked very closely on a lot of these things. I think the original grant for DSP Ed helped get, and then John was the first director. I think they were fairly close to Hale [Zukas]. Hale was an interesting person because his mother moved to Berkeley so he could attend. He was one of the early, severely disabled people that attended Berkeley, even though he didn't come to the residence program.

So anyhow, there was that background history. Over the years, my sense of it was that even though it wasn't that many years difference that we lived there--I mean, John certainly responded--he wasn't rude about it, but he responded to the disabled students as sort of the new kids on the block, and they had to prove themselves as appropriately smart and responsible in knowing what they're doing. He wasn't going to concede--which is probably accurate--that we represented the students any more than anybody else.

But basically, when John was at DSP--then PDSP--basically John was the voice of DSP, for PDSP. I mean, he spoke for it. One of the other things in John's day--and you know more about this than I do--was one of the things that happened in the early days was friendly relations were developed with a number of the administrators at Berkeley, which was very helpful in the history. John certainly cultivated those relationships.

It wasn't really until after John had left and Donald was the director, and there were some difficulties that occurred, when it became a little bit more complicated. When John first arrived --when John was there--when I first came here, the Disabled



Students' Program was in the back of the Top Dog place on Durant, and it was a much more--everybody came by and had--when we wanted to, we could have a collective lunch there. It was much more ad hoc.

It was becoming more an organized institution by the time I got to town. Finally, my own feeling was, for good and bad, it became sort of more--when Sharon Bonney was the director of the Disabled Students' Program--it became more a part of UC Berkeley's bureaucracy, in good ways and bad. In the early seventies, anyway, it was always--even though it was a branch of the university, there was always something sort of independent about it.

One of the examples of the dormitories: for years, until, like, 1985, if somebody in Berkeley's wheelchair broke down, the Disabled Students' Program would pick them up and give them a lift. I mean, that was just totally accepted. A certain point finally came in the mid-eighties when the university said, I'm sure rightly, "Hey, wait a minute. All these people aren't our students, and we're not going to provide that service any more." This was, I guess, probably about seven years later, but it was a whole other world.

O'Hara: Going back to when you lived in Cowell, you didn't move into the dorms. You moved to an apartment.

Trier: No, I moved into an apartment.

O'Hara: By the time you did that, was that '74?

Trier: I moved out in '74.

O'Hara: Was this accepted then? Was that not considered a pioneer move at that time?

Trier: No. When Ed came to Berkeley in, like, '62 or '63 and for a number of years after that, it was an accepted thing that people would spend all or a good part of their years in school, living in Cowell. By the time I got there in '73, the assumption was--well, there may have been an exception made if there was some extraordinary reason--the assumption was that I would be in the residence program from September to June, and then in June I would be expected to move into my own apartment.

O'Hara: Do you know how that happened? Was that just because people then had the experience of moving into an apartment? Something changed in ten years.



Trier: Yes.

O'Hara: And then in another ten years have changed drastically again.

Trier: Well, I have some ideas of some of the things that changed. One of the things that changed, which is really crucial, is the residence program predated the Disabled Students' Program, so there were a number of years where there really wasn't any kind of support system out there for the community. I mean, in the early days, part of why Ed wanted to live in Cowell Hospital was because Ed and Zona felt that he would after all at least be in a qualified medical facility and there were people on staff there.

But gradually, over the years, first of all there began to be a number of people who had been through the program and had moved out into the community, people who graduated. There already was by the time I was there--the Disabled Students' Program was around for several years--and there was now a CIL out there. So it was accepted that one could live in the community.

When I first arrived, I was given a card with phone numbers, including Ed's home phone, and I remember the first year I lived in an apartment, one time, in the middle of the night, when I was very sick, I called Ed's home phone, and one of the people that lived there was not happy about it, but he did pick me up in Ed's van and took me to Alta Bates.

I think it was also a factor that by '73 the program was no longer something that an occasional student might live in. It had reached a level of sophistication and size that there were all these new students coming in, so there was a feeling, like, if you stayed more than one year in Cowell, basically there might be another student that couldn't go in because you were there.

Once it was established that people could move into the residence program and move out in a year, then they really lost any kind of claim they needed to be there any longer. I'm sure D.R. was also very happy not to have to pay \$414 a month, which had gotten huge.

#### Benefits of the Cowell Experience

O'Hara: Would you say that the experience of Cowell made a very big difference in your life--

Trier: Yes.

O'Hara: --or were you on that kind of path anyway?

Trier: It made a big difference.

O'Hara: And what was that?

Trier: First of all, I became committed in a practical way to notions of independent living and the value of having a disabled community and a community that was hospitable to that. Cowell was certainly the introduction to that. That, plus--I mean, it's hard to separate. First of all, there was the Disabled Students' Union--was mainly around the problem of housing, the residence program. That certainly shaped me. Part of why I'm having the conflicts I'm having with my job is because the attitude toward disabled people is so radically terrible in Fresno than it is in Berkeley. So I have the choice of either sticking to the view that I think is better, which is to be like things are in Berkeley, or try to figure out a way to sell out to Fresno State.

So it radically changed you. It's Cowell, but it's more than Cowell. I want to be clear about that. It was much more significant for me, like, what Ed did or what John Hessler did or what Hale did or what Greg Sanders did and so on--or what Biscamp did or what Michael Pachovas did--because it was always the case with Cowell that a certain number of people there were just, like anybody else you might meet in the street who happened to be disabled and needed a place to live. But there was also--besides Cowell, there was a history of creating programs and institutions that were disabled-friendly.

Just the fact that I remember when I first came here, I remember very clearly the sequence. If Hale Zukas and Ed Roberts could live independently, I don't have much of an excuse.

### III REFLECTIONS ON ACTIVISM AND DISABILITY

[Interview 2: June 5, 1996] ##

#### Political Organizing

O'Hara: You mentioned last time that you and possibly the other students modeled yourself on Martin Luther King and the civil rights movement. I wondered if you could say more about that. What were you looking at?

Trier: The one other person I'm pretty sure I consciously discussed this with is Michael Pachovas, who I still tell people was my political teacher. But I know we believed that we were trying to nonviolently, with as much persistence and chutzpa as we could, to help out disabled people and to basically try to get the community to treat disabled people responsibly.

Some of that had to do with things in the general heading of community organizing and trying to have an effective community of people, trying to see that services were provided and so on. A number of us felt that basically whatever the community was when we got there depended on certain history and certain activities people like Ed Roberts and John Hessler and Hale Zukas and Larry Biscamp and Greg Sanders and other people had done, including certain particular kinds of institutions.

There was a feeling, being at Cowell, that we had a responsibility to play our part. Now, it was also true that we felt like a lot of the people that were a part of the disabled community had a hard enough time navigating their lives. There was a lot of drug abuse; there were a lot of signs, directly or indirectly, of depression based on being disabled. So there was a sense that, at least, if you were going to be a responsible person in the community, then one should do certain things.

It wasn't thought that this was some kind of universal obligation. It was more of a sense--I remember talking with John

Hessler one time--if the disabled community was going to be effective, that meant that at least there had to be a few people out of each generation--the generation defined in years, really--that would make some kind of contribution.

One of the things where the Martin Luther King example came to mind, to me--I was one of the people in the sit-in on Section 504 in San Francisco. Some of us were very conscious in dealing with people from the government who came into the building, including employees who came to work, that we treat them in a polite and friendly way, that we not yell at them, jeer at them, that we have some level of humane response to them. In part, we were playing an educational role.

There was kind of a built-in thing always in the disabled community that on the one hand, you were representatives to the university, to the larger community, so you had to act fairly intelligent and polite and not hypersensitive and so on. I think it also was reflective of the fact that for a lot of the time, there was a very clear difference. If you were a disabled student, you were almost thereby a part of the community of disabled people in town, which also included some nondisabled people who worked in certain organizations.

Among that group, there was more of a relaxed feeling. You also had your relationship to the university and other larger institutions, and those interactions were much more formal.

One of the things for me personally--I mean, I decided somewhere when I was in ninth grade or something that I was going to be a philosopher. One of the things that always comes back to me is my friend Bronson saying to me, kind of, "If you're going to be a philosopher, you should be a philosopher-at-large or a philosopher in the world." In that sense, when I was a student in Cowell, it also meant that I had a role in the Disabled Students' Union and I had a role in terms of some housing things.

It also meant, when I finally got my degree and I got a teaching job at Cal State Fresno, in part it was a "political act," simply to be severely disabled and getting a doctorate and teaching. It also meant that in a certain way it was inevitable, however unpleasant, that I'm involved in a lawsuit with Cal State Fresno because Cal State Fresno decided they didn't want to allow disabled faculty to have any chance really to get permanent employment. If I believed in the things that I thought I believed in and some of the things I learned in Berkeley, I didn't have any choice but to challenge that. It isn't--that's occupied the last number of years of my life--

O'Hara: Teaching?

Trier: Dealing with that controversy. Unfortunately, I mean, I really like teaching, and I would much prefer, in a way, to have gotten my doctorate at Berkeley and gotten a teaching job somewhere. Really, I don't care whether that's in Fresno or [phone rings]--hold on a second.

[tape interruption]

Trier: I remember somewhere in the late seventies or early eighties being with a number of disabled people. We got together for a few weeks in a row and talked, including Michael Pachovas--it was at Michael's place--and Bob Metts and Mary Reagan and other people. A number of us really were at the point of being graduate students and hoping to get our degree and hoping to move away from the sheltered environs of Berkeley and be active in the world. But in some level we considered that to be an extension of what we did. I teach philosophy. I can't avoid talking about problems about how you live and make choices in the world. Simply by the fact that I'm disabled teaching, I can't avoid dealing with disability.

One thing that came to mind when I was thinking about disabled language, one of the times I remember having fun before I left Cowell was one of the people at Cowell, one of the students there had read this article about this woman who was a quadriplegic and just had a baby. He was sort of disapproving of this, that this wasn't a very responsible, smart choice on her part.

O'Hara: This is one of your fellow students?

Trier: One of my fellow students. I remember several of us taking great pleasure in calling him sort of a Uncle Tom, a Uncle Tiny Tim, and accusing him of holding onto a patronizing view about people who were disabled. Why couldn't this woman, after all, if she wanted to have children, go ahead and do it? Why did he have a right to be disapproving of it?

One of the mentalities from Cowell--and to tell you the truth, and it's true from Edna Brean, who was the nurse in charge of it, or some of the people that worked there as orderlies--was there was a real desire to be tolerant about people. I mean, part of the thing about coming to Berkeley was people got a chance to live independently, which meant that they got to have a certain range to be themselves in a way that they otherwise might not be.

So I never really felt that I could be that embarrassed by what some other disabled person did because ideally there were



hundreds of severely disabled people, and some of them abused their attendants and some of them were rude and ungracious people and some of them had whatever variety of sexual proclivity you could think of. But part of the success of whatever happened at Berkeley was that those people were able to make a home in Berkeley.

The down side--which I still have worries about--is circumstances change. I don't know that if circumstances change in Berkeley over the next ten to twenty years, and there is less money for helping people with disabilities, let's say the emergency attendant program comes upon bad days again and someone wants to end that--or somebody wants to cut the budget of the Disabled Students' Program or the Disabled Students' Program isn't really what it was anyway anymore; it's more a place for people who are labeled, self-labeled learning disabled or whatever and not run anymore by people who are disabled.

I have some concern that there may not be very many disabled people around who really feel a sense of responsibility to improve things or fix things. I think that's part of the consequences of what we've done. I mean, you included. It's a lot easier for people to come to Berkeley and set up a life here than it used to be. It's a lot easier to gain the various benefits that one may be able to get living in Berkeley if you're disabled. To do that really without having much of a sense of community spirit.

#### Civil Rights Movement

O'Hara: Going back to the civil rights movement, do you think that what you and the other students were doing at that time in the early seventies was any kind of reflection or related in any way to what was going on on the campus or the country or even the world?

Trier: Sure. I think that has to be true.

O'Hara: Were there any immediate events on the campus at that time, or was the campus very quiet then?

Trier: I think the campus was pretty quiet. In a way, disability was kind of a nice compromise issue, and that is we always found on campus that we could get support from liberal students, radical students, conservative students; that you could raise issues about the needs of disabled people in a way that campus administrators, who might turn deaf ear to what they viewed as radical pressures on them, might feel some desire to respond to.



It certainly is true--I mean, a lot of the things that we did depended upon social things like Section 504 of the Rehabilitation Act and [the] American[s with] Disabilities Act and so on. A lot of those things rose out of liberal activism in Washington and were reflected back. I think it's true that a lot of the people who in the early days of the disabled movement provided care for disabled people were conscientious objectors to the war in Vietnam, and one of the kinds of work that they were able to do was work for disabled people. That was helpful.

I think a number of us who helped develop things certainly had interests, and going back to some of the political activism of the time. Whether we supported McCarthy for president--I think Ed Roberts at one point was registered with the Peace and Freedom Party--it seemed appropriate to apply those interests to disabled issues, and there seemed to be no question whether there was a logical connection to such issues as when you decide that you want to open positions up to women that were previously closed or to people who are black that were previously closed to them.

Then the question is Well, why not allow people who are disabled? I'm sure historically there were people who had disabilities in those positions. They were much more likely people that started out not being disabled, and rose to some position or some importance and then suffered a stroke or some disease that forced them to do that.

But in our case, we were in a position where we could argue for changes being made socially or legally. I'm sure it's no coincidence that, Berkeley being Berkeley, it was easier to get curb-cuts and things like that put in. My sense of it is motives of people are very diverse. As I said, if you went back and looked at the Disabled Students' Union over the twenty-some odd years it existed, you probably couldn't find more than a dozen people that were very active in it or that went to a lot of meetings or took positions representing it, though they may have had a considerable amount of influence.

I think that among the people that were active it's more likely that they had some of these interests. I remember one time one of the leading experts on nonviolent social change was giving some talk at Berkeley in some small classroom somewhere in Dwinelle. I remember going to see him and being kind of surprised that one of a a dozen people in the audience was Michael Pachovas and Michael asked the best question there. It was not a coincidence.

One of the advantages, if you like, to being disabled, if you're in a position where quite clearly you know that changes

can't be brought about by your direct physical action, even if you'd like them to, then you're therefore forced to look at other ways of how things might occur. There's a certain built-in advantage [phone rings].

Sorry. Hold on a second.

[tape interruption]

Trier: My friend who just called--there's a scientist at Stanford who's basically dealing with being able to input the brain with electrodes so that you could then command and continue to do things, even though you don't have to move a toggle switch or anything--basically command his computer to do what he wanted it to do.

O'Hara: Ohhh!

Trier: He's telling me that he's setting up a tentative appointment in Stanford next week. Now, I know that if I'm willing to do that, I'm going to have to figure out transportation and figure out how I'm going to get up and figure out all those details. There is a certain kind of logistics about it. I mean, I know that saying I can do it implies really that I can arrange for attendants to do certain things and so on. I know either to get my attendant to come earlier or call the emergency attendant at five in the morning. Who knows?

A lot of political organizing, community organizing isn't really a lot more than calling people and trying to get people to go to meetings and so on. There is also this sense of--like, when the residence program was moved--I mean, there was a certain amount of organizing, but the neat thing about it was there really wasn't a need to vote on anything. It was more a matter of figuring out, for example, what the university housing department needed, what D.R. needed, and basically put together packages that satisfied everybody. That worked out fairly well. It's having that kind of notion of problem-solving.

One of the shots in Mark O'Brien's movie is where they're hoisting his iron lung into the dormitory. I find that moving, you know. It does give me a little bit of satisfaction--and we need some satisfaction--because in part the residence program was doing what it was meant to do. It was a very nice, successful thing. It was that sense of people doing things.

Mark is also a good example. Mark is a very talented writer. That may be what he is. I've never heard of any interest that Mark had in joining any movement or organizing anything

particularly. But what he does is a real substantial thing, and it's nice to know that if there weren't a residence program like Berkeley has, Mark would probably, as long as he was alive, would have probably stayed in a nursing home.

### Changes in the Disabled Students' Program

O'Hara: Yes. Is there--let's see--has the program as you've known it over the years, especially in the early days, like the late sixties and seventies, matched the description you heard elsewhere and you read about?

Trier: The program as it has been, and I hope it still is, was better than anything else at the time. I mean, it simply was. I wrote to every school in the western part of the country that had a modicum of a decent graduate program in philosophy, and the only one to write a good, detailed letter was Berkeley. Texas wasn't bad. The only one to say, "We have people here that will make sure that you get on the appropriate benefit program, we have people to make sure that you'll find a place to live, we have people that will make sure that you can have a functioning wheelchair and functioning transportation" and so on. So that was really unique. For me, it lived up to that.

As I say, in some ways things have become a little more bureaucratic, a little more distant, and I don't really know what to make of it. It was nicer in some ways to be able to go up to the terrible ramp at the back of Top Dog and hang out up there and have lunch with everybody, or being able to call Ed Roberts' house if you had bronchitis and get some help figuring out how you got to the hospital than knowing that you can call this program or that program for help.

It still bothers me. When they hired the last director of the Disabled Students' Program, some of it seemed to be strange. One of the people who I knew who worked at DSP, who I thought would have been marvelous, didn't even make the final list. So there was some sense of a new era, and there was some sense--the last days I saw of DSP--of becoming more sort of a regular agency of the university.

But in some ways, what else can you expect? The program was a successful program, was accepted by the university, and ultimately the university makes its program follow the university ways. The feeling that people had at the beginning, which was they could maneuver the university to do the good things they

wanted to do but still somehow be independent, probably was more romantic than anything else.

Some of the power of the disability programs--I think now--it does involve being simply a regular part of the budget, and that's okay.

### Disability Difficult and Limiting

O'Hara: Is there anything that I have not asked you that you think is important for the record that you were maybe thinking about?

Trier: Well, the one thing I would ask--and I don't know whether you need to be asking me--I still have a feeling like it's important to present how difficult it is to be disabled and how limiting it is. That is, I don't really know very many people who went through the program at Berkeley, went on and became teachers or counselors and are doing very well. I don't know very many people. I know Lennis Jones is in Fresno now, and he has a doctorate from the Wright Institute. He's a very bright guy, but in terms of his ability to get work, I don't know if it's that easy.

I have a doctorate in philosophy, and I know that I'm having essentially a horrible time getting regular work doing what I do fairly well, which is teach philosophy. I think Berkeley was more successful in allowing severely disabled people to have a place to live, to get a good education, and to be able to live somewhat independently. I think it's somebody else's challenge, if it's going to happen, to change the outlook of society sufficiently that people are able to go as far as they could.

Mark O'Brien is an example. Mark, to me, is a very good writer. It seems to me Mark has never been able to do as much professionally as his writing talents would allow. I mean, he's certainly much happier than he was when he was in a nursing home; he certainly had some success; but it's very limited. A lot of the phenomena of Berkeley--obviously we are both living in Berkeley right now--a lot of the phenomena of Berkeley is it's simply a lot easier to live in Berkeley and to do some things in Berkeley than it is to go elsewhere.

I don't think any of the general laws about employment discrimination and so on are followed particularly well. I think it's an uphill battle. I don't mean that it's not worthwhile, but I would be interested--and I don't know whether you've been following up the people that were in the residence program--in

seeing what happened in their lives. I think there's more of a real success in that most of them were able to establish their lives and have friends and live on their own. But I think their ability to be professionally successful or influential, I think probably it's been very hard.

That was the only question I had.

O'Hara: Well, thank you.





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Regional Oral History Office

Disability Rights and Independent Living

Movement Oral History Series

Sharon Bonney received a B.S. in Communication and Journalism from the University of Illinois and an M.A. in Public Affairs from the University of Iowa. After working as a reporter and freelance writer, she established the Services for Handicapped Students Office at Iowa before working in the Department of Rehabilitation as a client advocate in Tennessee.

In 1979, Ms. Bonney became director of the Physically Disabled Students' Program at UC Berkeley for nine years. She later was the assistant director for the World Institute on Disability. For the past two years, she has been an interviewer/editor for the Regional Oral History Office at UC Berkeley for the Disabled Persons' Independence Movement Project.

Her professional activities include numerous publications on disability issues; founding member, president, treasurer, and conference chair of the Association on Handicapped Student Service Programs in Post Secondary Education (now known as AHEAD); participant in the White House Conference on Handicapped Individuals; and current member of the Society for Disability Studies.

Ms. Bonney has muscular dystrophy and is a wheelchair user.



KATHRYN COWAN

Interviewer/Editor

Regional Oral History Office

Disability Rights and Independent Living

Movement Oral History Series

B.A. in Communications from California State University Hayward.

In the 1980s, she was a job developer for a disadvantaged youth organization. She developed a program that brought youth together with senior citizens who served as mentors by sharing their personal and work histories.

She has a long-standing interest in political and social change, and followed closely the civil rights, anti-war and women's movements. In the early 1990s she became interested in the disabled persons' independence movement. In 1995 she was diagnosed with muscular sclerosis.

She is currently the librarian for HomeBase, the Center for Common Concerns, a public interest law firm that develops and supports policies and programs to reduce and eliminate homelessness.

In 1997 she joined the staff of the Regional Oral History Office, The Bancroft Library, University of California, Berkeley, as an interviewer and editor for the Disability Rights and Independent Living Movement oral history series.



Susan O'Hara

Susan O'Hara proposed the idea of an oral history of the disability movement to ROHO in 1982, and currently serves as consultant historian and interviewer for the DPIM project. She was a resident in the Cowell program for disabled students in the summer of 1971 [a wheelchair user from polio in the 1950s] and became director of the program when it moved from Cowell Hospital to the university residence halls in 1975. She served as director of the umbrella organization, the Disabled Students' Program, from 1988 to 1992, and was chair of the campus Committee to Remove Architectural Barriers during that time. She has long been active in the disability community, including national and state associations on higher education and disabled students.

Ms. O'Hara holds a B.A. in history from Dominican University in River Forest, Illinois, and an M.Ed. in counseling from Loyola University in Chicago. She taught history in high schools in Illinois and California for thirteen years prior to 1975. She has an abiding interest in medieval French architecture and has published several articles on accessibility in France.









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