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UC BERKELEY'S COWELL HOSPITAL RESIDENCE PROGRAM:
KEY ADMINISTRATORS AND CALIFORNIA DEPARTMENT
OF REHABILITATION COUNSELORS

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Disability Rights and Independent Living Movement Oral History Series

UC BERKELEY'S COWELL HOSPITAL RESIDENCE PROGRAM:
KEY ADMINISTRATORS AND CALIFORNIA DEPARTMENT OF REHABILITATION COUNSELORS

Henry Bruyn	DIRECTOR, STUDENT HEALTH SERVICES, 1959-1972
Edna Brean	NURSE COORDINATOR, COWELL RESIDENCE PROGRAM, 1969-1975
Lucile Withington	DEPARTMENT OF REHABILITATION COUNSELOR, COWELL RESIDENCE PROGRAM, 1969-1971
Karen Topp Goodwyn	DEPARTMENT OF REHABILITATION COUNSELOR IN BERKELEY, 1972-1983
Gerald Belchick	DEPARTMENT OF REHABILITATION COUNSELOR, LIAISON TO THE COWELL PROGRAM, 1970s
John Velton	DEPARTMENT OF REHABILITATION ADMINISTRATOR: PROVIDING OVERSIGHT FOR THE RESIDENCE PROGRAM, FOSTERING CAREER PLACEMENT AND COMPUTER TRAINING, 1970s-1980s

Interviews Conducted by
Sharon Bonney
Mary Lou Breslin
and Susan O'Hara
1994, 1995, 1997, 1998

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It is recommended that this oral history be cited as follows:

To cite the volume: *UC Berkeley's Cowell Hospital Residence Program: Key Administrators and California Department of Rehabilitation Counselors*, an oral history conducted in 1994, 1995, 1997, and 1998, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2000.

To cite an individual interview: [ex.] Henry Bruyn, "Director, Student Health Services, 1959-1972," an oral history conducted in 1994-1995 by Susan O'Hara in *UC Berkeley's Cowell Hospital Residence Program: Key Administrators and California Department of Rehabilitation Counselors*, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 2000.

Copy no. 1

Cataloging information

UC BERKELEY'S COWELL HOSPITAL RESIDENCE PROGRAM: KEY ADMINISTRATORS AND CALIFORNIA DEPARTMENT OF REHABILITATION COUNSELORS, 2000, xxii, 290 pp.

Henry Bruyn (b. 1918), *Director, Student Health Services, 1959-1972*: early experience with infectious diseases; services for disabled students at Cowell Hospital and staff response; reflections on Ed Roberts, John Hessler, and the Rolling Quads. Edna Brean (b. 1919), *Nurse Coordinator, Cowell Residence Program, 1969-1975*: John Hessler, Ed Roberts, and other disabled students; switch from medical model to independent living; training attendants, self-help talks, orientation for parents and new students; early days at Center for Independent Living (CIL). Lucile Withington (b. 1933), *Department of Rehabilitation (DR) Counselor, Cowell Residence Program, 1969-1971*: requirements for Cowell students; electric wheelchairs, vans, and other DR costs; revolt of Rolling Quads; rehab research reports and testing of incoming clients. Karen Topp Goodwyn (b. 1943), *Department of Rehabilitation Counselor in Berkeley, 1972-1983*: intermediary between clients and DR; reflections on John Hessler, Zona Roberts and Mark O'Brien; evolution of Physically Disabled Students' Program (PDSP); peer counseling; Computer Training Program and assistive technology; trends in DR under Director Ed Roberts and others. Gerald Belchik (b. 1928), *Department of Rehabilitation Counselor, Liaison to the Cowell Program, 1970s*: the Rolling Quads' political power, disability rights; adapting DR rules to needs of students; Ed Roberts and Judy Heumann as spokespeople; cost-ratio formula as applied to client services in DR; reflections on Gwin Hinkle, John Velton and others. John Velton (b. 1928), *Department of Rehabilitation Administrator: Providing Oversight for the Residence Program, Fostering Career Placement and Computer training 1970s-1980s*: conflict between Cowell students and DR counselor, formation of Rolling Quads; move from Cowell Hospital to residence halls; PDSP director John Hessler; buffer between DR and PDSP; Computer Training Program at CIL; Career Planning and Placement Program, UCB; Ed Roberts and others' influence on disability rights movement.

Interviews conducted in 1998 by Sharon Bonney, Mary Lou Breslin, 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

The Disability Rights and Independent Living Movement Oral History Series was funded primarily by a three-year field-initiated research grant awarded in 1996 by the National Institute on Disability and Rehabilitation Research (NIDRR), an agency of the United States Department of Education, Office of Special Education and Rehabilitative Services. Any of the views expressed in the oral history interviews or accompanying materials are not endorsed by the sponsoring agency.

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.

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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

Single-interview volumes

Mary Lou Breslin, *Cofounder and Director of the Disability Rights Education and Defense Fund, Movement Strategist, 2000.*

Joel Bryan, *Founder and Director of Disabled Students' Services, UC Riverside and UC Davis, 2000.*

Kitty Cone, *Political Organizer for Disability Rights, 1970s-1990s, and Strategist for Section 504 Demonstrations, 1977, 2000.*

Charles Grimes, *Attendant in the Cowell Residence Program, Wheelchair Technologist, and Participant/Observer of Berkeley's Disability Community, 1967-1990s, 2000.*

Deborah Kaplan, *National Policy Advocate and Leader of Disability Rights Organizations, 1976-1990s, 2000.*

Johnnie Lacy, *Director, Community Resources for Independent Living: An African-American Woman's Perspective on the Independent Living Movement in the Bay Area, 1960s-1980s, 2000.*

Joan Leon, *Administrator at Berkeley's Center for Independent Living and the California Department of Rehabilitation, Cofounder of the World Institute on Disability, 2000.*

Susan O'Hara, *Director of the UC Berkeley Disabled Students' Program, 1988-1992, Coordinator of the Residence Program, 1975-1988, and Community Historian, 2000.*

Corbett O'Toole, *Advocate for Disabled Women's Rights and Health Issues, Founder of Disabled Women's Alliance, 2000.*

Zona Roberts, *Counselor for UC Berkeley's Physically Disabled Students' Program and the Center for Independent Living, Mother of Ed Roberts. Appended: Jean Wirth, Counselor at the College of San Mateo and Early Mentor to Ed Roberts, 2000.*

Susan Sygall, *Cofounder and Director of Berkeley Outreach Recreation Program and Mobility International USA, Advocate for Women's Issues, 2000.*

In Process, single-interview volumes:

Judy Heumann, Deputy director of the Center for Independent Living, cofounder of the World Institute on Disability, assistant secretary of the U.S. Department of Education. (in process)

Arlene Mayerson, Directing attorney, Disability Rights Education and Defense Fund. (in process)

Pat Wright, Director, Governmental Affairs Office of the Disability Rights Education and Defense Fund, strategist for the Americans with Disabilities Act. (in process)

Multi-interview volumes:

UNIVERSITY OF CALIFORNIA'S COWELL HOSPITAL RESIDENCE PROGRAM FOR PHYSICALLY DISABLED STUDENTS, 1962-1975: CATALYST FOR BERKELEY'S INDEPENDENT LIVING MOVEMENT, 2000.

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: Transition from the Cowell Hospital Program to the Residence Halls, 1975.*

UC BERKELEY'S COWELL HOSPITAL RESIDENCE PROGRAM: KEY ADMINISTRATORS AND CALIFORNIA DEPARTMENT OF REHABILITATION COUNSELORS, 2000.

Henry Bruyn, *Director, Student Health Services, 1959-1972.*

Edna Brean, *Nurse Coordinator, Cowell Residence Program, 1969-1975.*

Lucile Withington, *Department of Rehabilitation Counselor, Cowell Residence Program, 1969-1971.*

Karen Topp Goodwyn, *Department of Rehabilitation Counselor in Berkeley, 1972-1983.*

Gerald Belchick, *Department of Rehabilitation Counselor, Liaison to the Cowell Program, 1970s.*

John Velton, *Department of Rehabilitation Administrator: Providing Oversight for the Residence Program, Fostering Career Placement and Computer Training, 1970s-1980s.*

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY VOLUME I, 2000.

Herbert Leibowitz, *Research and Training Specialist for the Rehabilitation Services Administration, 1971-1990.*

Mary Lester, *Grant Writer for the Early Center for Independent Living in Berkeley, 1974-1981.*

Bette McMuldren, *Assistant to Judy Heumann and Grant Writer at the Center for Independent Living, 1975-1980.*

Kenneth Stein, *Public Information Coordinator for the Center for Independent Living and Participant/Observer of the Disability Movement.*

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME II, 2000.

Carol Fewell Billings, Attendant and Observer in the Early Days of the Physically Disabled Students' Program and the Center for Independent Living, 1969-1977.

Michael Fuss, Attendant for Cowell Residents, Assistant Director of the Physically Disabled Students' Program, 1966-1972.

Linda Perotti, An Employee Perspective on the Early Days of the Cowell Residence Program, Physically Disabled Students' Program, and the Center for Independent Living.

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME III, 2000.

Eric Dibner, Advocate and Specialist in Architectural Accessibility.

Hale Zukas, National Disability Activist: Architectural and Transit Accessibility, Personal Assistance Services.

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME IV, 2000.

Janet Brown, Student Member of the National Federation of the Blind and First Newsletter Editor for the Center for Independent Living, 1972-1976.

Phil Chavez, Peer Counselor at the Center for Independent Living, 1970s-1990s.

Frederick C. Collignon, UC Professor of City and Regional Planning: Policy Research and Funding Advocacy.

Hal Kirshbaum, Director of Peer Counseling at the Center for Independent Living.

Michael Pachovas, Berkeley Political Activist, Founder of the Disabled Prisoners' Program.

Raymond "Ray" Uzeta, Independent Living Centers in Berkeley, San Francisco, and San Diego: Perspective on Disability in Minority Communities.

BUILDERS AND SUSTAINERS OF THE INDEPENDENT LIVING MOVEMENT IN BERKELEY
VOLUME V, 2000.

Jacquelyn Brand, *Parent Advocate for Independent Living, Founder of the Disabled Children's Computer Group and the Alliance for Technology Access.*

Doreen Pam Steneberg, *Parent Advocate for Educational Rights for Children with Disabilities.*

MAINSTREAM MAGAZINE: CHRONICLING NATIONAL DISABILITY POLITICS, 2000.

Cynthia Jones, *Mainstream Magazine Editor and Publisher.*

William Stothers, *Journalist and Managing Editor of Mainstream Magazine.*

UNIVERSITY ADMINISTRATORS RECALL ORIGIN OF THE PHYSICALLY DISABLED
STUDENTS' RESIDENCE PROGRAM, 1987.

Arleigh Williams, *Recollections of the Dean of Students.*

Betty H. Neely, *Recollections of the Director of Student Activities and Programs.*

In Process, multi-interview volumes:

Neil Jacobson, *Cofounder of the Computer Training Project and Cochair of the President's Committee on Employment of People with Disabilities.*

Scott Luebking, *Cofounder of the Computer Training Project, Specialist in Accessible Technology. (in process)*

Maureen Fitzgerald, *Early Deaf Services Programs at the Center for Independent Living. (in process)*

Anita Baldwin, *Deputy Director of the Center for Independent Living, Early 1980s: Observations of Blind Services and Staff Strike. (in process)*

Joanne Jauregui, *Activist in the Deaf Community: Deaf Services at Center for Independent Living. (in process)*

VIDEOTAPED INTERVIEWS:

Mary Lou Breslin, Kitty Cone, Neil Jacobson, Joanne Jauregui, Deborah Kaplan, Johnnie Lacy, Joan Leon, Susan O'Hara, Zona Roberts, Ken Stein, Herb Willsmore, Hale Zukas.

Regional Oral History Office
The Bancroft Library

University of California
Berkeley, California

Disability Rights and Independent Living Movement Oral History Series

UC BERKELEY'S COWELL HOSPITAL RESIDENCE PROGRAM:
KEY ADMINISTRATORS AND CALIFORNIA DEPARTMENT OF REHABILITATION COUNSELORS

Henry Bruyn

DIRECTOR, STUDENT HEALTH SERVICES, 1959-1972

An Interview Conducted by
Susan O'Hara
in
1994-1995



Henry B. Bruyn, M.D.

Photo by Barry Evans.



Henry Bruyn, M.D. with Ed Roberts at Twentieth Year Reunion, Physically Disabled Students Program, 1982.

Photo by Beth Medsger.

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INTERVIEW HISTORY--Henry Bruyn

Henry Bruyn, M.D., was interviewed for the Disability Rights and Independent Living Movement Oral History Series because of his role in opening the Cowell Hospital facilities as a residence for students with significant disabilities. Dr. Bruyn had worked in three polio epidemics in the 1940s and 1950s and felt that young people with disabilities deserved an opportunity for an education.

As medical director of the Student Health Service on the campus (1959-1972), Dr. Bruyn welcomed Ed Roberts in 1962 as the first disabled student to live in Cowell. By 1975, when the campus offered housing in integrated residence halls to students with disabilities, several dozen students had spent a year or more living on the third floor of Cowell. Dr. Bruyn was unwavering in his support of this fledgling program and had assured its continuation by being a buffer in a medical environment where control of client/consumer lives rested traditionally in the hands of health professionals.

The interview took place on July 12, 1994, at New Bridge, a beautiful converted mansion in north Berkeley, now a residential treatment program for substance abuse. Dr. Bruyn founded New Bridge in 1968 and is clearly proud of it. He continues an integral involvement in the program.

Dr. Bruyn's enthusiasm for the Cowell Residence Program is apparent in his interview. He has obviously recounted the story throughout the years, to visitors, at conferences, and elsewhere.

He lightly edited the transcribed 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

December 1, 1999
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 Henry Bicker Bruyn

Date of birth Jan. 24, 1918 Birthplace Brooklyn, New York

Father's full name Henry Bicker Bruyn, Sr.

Occupation Stockbroker Birthplace Kingston, New York

Mother's full name Mary Jeannette Retter

Occupation Homemaker Birthplace Utica, New York

Your spouse Jennie Low

Occupation Registered Nurse (retired) Birthplace Visalia, California

Your children (1) Martha E. Widdicombe (2) Barbara J. Holstrom
(3) Charles D. Bruyn (4) Jonathan H. Bruyn

Where did you grow up? Long Island, N.Y. and Big Moose Lake in the
Adirondack Mountains in New York State

Present community Kentfield, California (Marin County)

Education Amherst College, Yale School of Medicine,
St. Paul's College Prep School

Occupation(s) Physician and Educator, University of Calif. School of
Medicine : Chief of Isolation Service, San Francisco
General Hospital : Private Practice in Berkeley, Calif.

Areas of expertise Pediatrics, Board Certified : Infectious Disease : and
Severe Disabilities

Other interests or activities Cabin owner in Lassen National Forest.
Enjoy outdoor activities such as fly fishing,
hiking, sailing, etc.
Still active with case consultations.

Organizations in which you are active Retired from: Academy of Pediatrics,
Child Health Disability Prevention, World Institute on Disabilities, Carmel Valley
Labor Retirement Home, and New Bridge Foundation.

Still ACTIVE: National Forest Homeowner's Inc. , American Foundation for
Traditional Chinese medicine and Private Case Consultations.

INTERVIEW WITH HENRY BRUYN

I EDUCATION AND EARLY MEDICAL CAREER

[Interview 1: July 12, 1994] ##¹

Amherst College, Yale Medical School

O'Hara: Well, shall we start with your background--where and when you were born and your education?

Bruyn: Yes. Well, I was born in Brooklyn, New York in 1918 and took my education in New England. I went to Amherst College in western Massachusetts, graduating in 1940. Then I went to Yale Medical School in New Haven, graduating in 1943. Due to the war and the fact that they kept us all summer, we were able to get through early.

Interest in Infectious Diseases

Bruyn: I became very interested in infectious disease as a career in medicine. I worked with polio victims at New Haven Hospital, working with Dr. [John Rodman] Paul and Dr. [James D.] Trask who were pioneers in the polio research. They were the ones who discovered that polio was an enteric, that is to say, a bowel infection. That was a very important discovery because that led to all sorts of excitement about children in the summer getting into swimming pools. We had a lot of, I think, overreaction to that kind of discovery.

¹## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcripts.

Polio Research and Epidemics

Bruyn: Leaving New Haven, after an internship in pediatrics and working a lot with infectious disease and polio, I went to Buffalo, New York, where I found myself in the middle of a polio epidemic. It was the second polio epidemic that I worked with. In Buffalo, I got very interested in the rehabilitation aspects of polio. We had two buildings at the children's hospital there devoted to long term rehabilitation of polio victims.

I think it's very hard nowadays for people to realize the devastating effect of polio on the young people of the United States. We would have 1200 or more cases a month in California. And these were paralyzed people. This was a frightening thing. Nowadays, we haven't had a paralytic polio case in the United States--we had eleven cases within the last two years in the whole of the United States. All eleven of those cases were unvaccinated, uninoculated, unimmunized so to speak, young people in a school, a special school for Christian Science people. They don't believe in any immunization. All eleven of those cases were in that one school.

Anyway, after my training in pediatrics at Buffalo, I was taken in the navy and headed for a hospital unit that was going to invade the island of Honshu in Japan. As some of us with that unit said, they heard we were coming and they surrendered.

Chief of Pediatrics, Oakland Naval Hospital; Faculty, University of California, School of Medicine

Bruyn: Anyway, I was then very lucky in the sense that I was appointed Chief of Pediatrics at the Oakland Naval Hospital. When my tour in the Navy was up, I heard about a fellowship at UC [University of California] San Francisco, the medical school, in infectious disease and applied for it and was accepted and worked in research with virus diseases--in particular, mumps and influenza. Following a year of that fellowship, I was recruited to the full-time faculty of the medical school where I've spent a great deal of time ever since.

Part of that responsibility was chief of the so-called isolation hospital at San Francisco General. That's where all the polio cases went. So I spent a lot of time in my third epidemic of polio--I had twelve respirators going at any one time and was deeply involved with rehabilitation in the cases of polio.

Just before the immunization procedures for polio came out, I had the privilege of putting on a symposium on immunity to polio. And hardly had we finished our symposium when the new vaccines were out. The Sabin oral vaccine was the real conqueror of polio. I like to emphasize that because people keep talking about Salk. The Salk vaccine, which was a supposedly killed virus vaccine, did not work because when it came on the market there was still live virus in it and seventy-two children got paralyzed with that first Salk vaccine. Sabin's vaccine is a housebroken strain of all three types of polio and is taken by mouth and works beautifully. That's what conquered polio worldwide.

O'Hara: Can we back up just a minute? Where were you for the first epidemic?

Bruyn: I was at New Haven for the first one. I was an intern. Actually, I had the longest internship in pediatrics because I was in my fourth year of medical school. They needed an intern in pediatrics so I took it. Then they took me on as a full-time intern when I graduated. So, I had, instead of a twelve-month internship, I had a twenty-four month internship. So, I went through that epidemic in the hospital. But anyway, with the advent of the Sabin vaccine, polio quieted down and we had a lot more to do with rehabilitation and a little less to do with acute cases. That's in San Francisco.

II DIRECTOR, STUDENT HEALTH SERVICE, UNIVERSITY OF CALIFORNIA AT BERKELEY

Bruyn: In 1959, I was recruited to the position as director of the Student Health Service in Berkeley on the University of California Berkeley campus. I say recruited because, as I remember it, I was reluctant to take the position. I was very happy in the city. I had my lab and I had my research and my full time faculty position. I did come to Berkeley and it was a great experience because I was able to do a great deal of research. And in the student population we did all sorts of projects.

Cowell Hospital: A Full Service Hospital for Students

Bruyn: We also set up a teaching service at Cowell Hospital which fourth-year medical students could choose as an elective and spend three months here in Berkeley. At one point it was the only elective in which they had to draw the names out of a hat. It was so popular because they saw things here in the student population that they didn't see in the medical school such as measles, mumps, chicken pox and things that the medical school doesn't fool with. The medical school attracts exotic diseases, you know, and the things they don't see in private practice very often. But by coming to Cowell, they saw all the things that they were going to be seeing in general practice.

Anyway, but a word or two about Cowell. Cowell Hospital was the first student hospital--in the world--on a college campus going back to the early 1900s. Cowell Hospital was--Ernest V. Cowell was the first foundation that donated the first hospital. That, then, was added to by the Samuel Cowell Foundation, his brother. That building was developed and opened during my first couple of years here in Berkeley. That was 1960-61. The hospital, as it was at its height, was 110 beds. We did everything but brain surgery. We had doctors from the community

and from the medical school who took the positions and took the responsibilities, not as much for money as for loyalty to the university and enjoyment of working with young people. We had full-time doctors and part-time doctors to a total of about 120. And we had a nursing staff of around eighty. It was a major operation serving from twenty-eight to 30,000 students. The hospital had an emergency room, of course, twenty-four hour coverage. It was a "community hospital." It was the best way to describe it.

The major purpose of the Student Health Service was, in my tenure, to keep the student in school. We were able to get him back to classes even while he was in the hospital because we were on campus. A student who got, for example, rubella, three day measles, without the Student Health Service, without the hospital--and we had plenty of examples of this--would go home and their family doctor would say, "Well, you can't go back to school because you're contagious." So he would have to drop out of school for that semester, most of which was spent in good health. But by staying on the campus and taking care of him in the hospital and in the outpatient clinic we were able to keep him in school. We had a social service department that got him his books and got him his make-up exams and all of that. Our major effort was to keep him in school.

Ed Roberts' Arrival, 1962

Bruyn: Anyway, it was during that time that I got the first indication of the challenge of the disabled students program. That was a phone call from the dean of students, who was then Arleigh Williams. He called me and said, "Henry, I've got a very disabled young man who's done very well in San Mateo Community College. And he would like very much to come to Berkeley. But," he said, "he's in an electric wheelchair and he has to sleep in a respirator. I don't know how in the world we could take care of him. I thought I'd better talk with you." I said, "Well, you better send him right up here because we could open up space in Cowell Hospital." I didn't go beyond my own judgment in this thing. With my background, I was eager to get into it. I didn't ask any questions of anybody. We had, at that time, empty beds. And we didn't need all those beds. We had a whole floor at Cowell Hospital with no patients on it at all, the third floor. I thought it was disgustingly logical if we could get some cooperation from lots of people. So, I said to Arleigh, "Please send him up."

That's when I first met Zona and Ed Roberts. My first reaction with them was, yes, we're going to do it. The rest is going to--we're going to do it with the academic and we're going to have to administer it and we're going to have to get some money. And that's where Carl Ross was a lot of help. He was the administrator of the Student Health Service. He worked with the state rehab services [California Department of Rehabilitation]. I was the medical--well, I was the director, so to speak. Because I worked with the environmental people. I worked with the employee programs. I worked with the health of the campus. Carl Ross was the administrator in the hospital. He was a hospital administrator. He worked out the business aspects of it with the state rehabilitation services in which we were able to get some money from the state.

We made several policy decisions early on. One of them was that if we took any more students besides Ed, they would have to be qualified academically. And they would have to keep up academically. We would not make reservations or concessions because of their disability. We would try and make the community and the environment acceptable to them and after that it was up to them. Ed was then installed in a room with his Emerson respirator which was one of the tank type respirators which I think he still has.

There's a story on the respirator that I have to stick in here. The Emerson respirator was developed by a New Englander named Jack Emerson. I knew him in New England. He came out here once and looked at some of the equipment I had at San Francisco General. The Emerson respirator was a tube, a tank thing, into which the patient was placed with a rubber collar around the neck. And there were two types of tank respirators like that. One of them was the Drinker and the other the Emerson. The Drinker respirator had a rubber bellows on the bottom with a machine that pumped those bellows up and down and created a negative pressure inside the tank which got air into the patients' lungs. The Emerson had a leather bellows on the end of the tank. The whole end of the tank was leather bellows and a machine that then pumped those leather bellows in and out.

I asked Jack Emerson, "What in the world did you choose leather bellows for?" He said, "Well," with his New England accent, he said, "I once went to an old museum in Vermont. They had a blacksmith bellows there, with leather bellows, that was over two hundred years old. It was working fine. I figured that was a good kind of material." So, that started the Emerson tank. I don't think Ed has had his leather bellows ever fixed. I mean, it's going on and on and on.

But anyway, one thing that Ed had when he first came in, and still does, he had the ability to "frog breathe." Now, frog breathing is also called glossopharyngeal breathing, which means you swallow air into your lungs just as some people swallow it into their stomach. There's always been the practical joker at the party that can belch on command and talk while he's belching. That's not what we're talking about, because if your chest is paralyzed, as Ed's was, when you swallow like that it'll go into your lungs and not into your stomach if you learn how to do it. Ed was the world's expert. I say that with feeling and conviction on glossopharyngeal breathing. During the time he was at Cowell, I was still attending in the city. I used to bring him over to teach some of the severe polios that we still were having, teach them how to frog breathe, because he was so good at it.

Anyway, one thing that gave Ed an advantage was that if the electricity went off and his Emerson tank wouldn't run, he would frog breathe. He was not completely dependent on that tank. He was comfortable in it to sleep in it at night, which is what he did.

John Hessler, Second Student With a Disability

Bruyn: I guess he'd [Ed Roberts] been in the program for about six or eight months, maybe less, when I got a call from a doctor in Contra Costa County in Martinez and I'm sorry, I can't remember the name. But the doctor said, "You know, I've got somebody in the hospital that might be a candidate for your program at Berkeley." I said, "Well, what program in Berkeley?" He said, "I hear you have a program for disabled students." I said, "Well, not yet we don't. I don't know what you could call it, but I have a disabled student and it's working fine." So, he said, "Well, come out and talk to this guy."

So, I went out to Contra Costa County Hospital in Martinez and this doctor took me into a room where he said, "Here we have four severely disabled people." He said, "I want you to meet John Hessler." And as I stood in the door of the room, there were three beds in which people were lying there watching television and the fourth bed was surrounded completely by books and a large amount of radio equipment. I said, "Is that John?" He said, "Yes." John was over there listening to French broadcasts from France on a short wave radio. He wanted to teach languages and he had a burning desire to learn. I said, "Fine, he's taken, he's accepted as of now." So John joined the program as number two.

We didn't have to advertise. The state rehabilitation services did a lot. I mean, they would bring candidates. But we stuck to the condition that they had to be academically qualified for Berkeley.

O'Hara: And then John was the second one there?

Bruyn: For the program, John was number two up there. As we expanded then, we eventually got to fifteen. That was a comfortable number we could deal with. Some of the elements that came into the program are worth mentioning. We decided we needed, really, a full-time nurse, an eight-hour-a-day nurse, to work with them and supervise them because I couldn't take nurses from the second floor where all the acute illnesses were and surgery and trauma. I couldn't take them off and assign them to this. So, I wanted to get a special nurse. So with the help of the state rehabilitation and also Carl Ross's financial efforts we got a nurse, an eight-hour-a-day nurse.

Edna Breaun, Rehabilitation Nurse

Bruyn: The first one did not work out well. But the second one was Edna Breaun and she worked fine. She developed the program, really. What did she do with these people! We had a number of different problems. But one of them was we had to teach them how to hire and fire their attendants. Because if you're totally disabled, it's very hard, you're completely dependent at times on that attendant. And to think about, even though you know that you don't like them and it's not working out, you hate to fire them because then what do you do? So early on, Edna set up a program to train them on all that personnel management stuff and how to do it.

O'Hara: Do you recall at what point she came into the program?

Bruyn: Well, she was, as I say, she was the second nurse I had. The first nurse lasted about six or eight months and then Edna came in.

O'Hara: The first nurse didn't work out?

Bruyn: She didn't work out too well, no. I'm not sure that I remember how. But I know that some of the disabled students didn't get along very well with her and even though she'd had some pretty impressive experience.

But we did get down to our total of fifteen which we set as our limit. We had some of the students who graduated. They went on to further education elsewhere. But we liked the idea that we were getting them ready for independent living. Edna worked on the meals and the diets and how they should prepare some of their own meals and worked with them. At one point we got a grant from PG&E [Pacific Gas and Electric] to develop a demonstration kitchen with low level stoves that would come up against a wheelchair, at a wheelchair level, so they could cook for themselves.

Cowell as Living Quarters for Disabled Students

Bruyn: That did not get going because about that time, I transferred back to the San Francisco campus because I left the Berkeley campus about 1972. My reason for leaving was that the chancellor at that time, who was a new one on the campus, did not look at the Student Health Service in the same way I did. He thought there was no reason students couldn't get their care in the community from doctors in the community and that the university should discontinue Cowell Hospital and just have an outpatient clinic and refer them to doctors in the community. I didn't agree with that philosophy, so I resigned and went back to teaching in the city on the San Francisco campus. Anyway, about that time was when the PG&E program was beginning and it died.

O'Hara: Were you instrumental in setting up the pool room with a tilt table? Was that there while you were--?

Bruyn: At Cowell Hospital? No, I don't remember that at Cowell Hospital. I do remember though, that probably two years before I left the campus, about 1970, I'd say, I had a--it was a very significant event and that was the--one afternoon, my secretary said, "Dr. Bruyn, the disabled students want a meeting with you this afternoon about four o'clock." So, I went down and I think all of them were there and gathered in one of the bigger rooms. They all smoked a lot, you know. And they were all smoking away and Ed was in his tank. Ed was sort of the leader of the group and always had been. So I said, "Okay, Ed, what's our agenda?" He said, "Well, Dr. Bruyn, I want to tell you that we've organized and we're taking over." I said, "Boy, that's terrific." That's when the Rolling Quads came in to being, which led to the Center for Independent Living down on Telegraph Ave. The CIL was then duplicated around the country in other campuses and eventually led to the World Institute on Disability.

When Ed graduated with his graduate degree, he was able to teach. I think he taught on the Peninsula in one of the community colleges there.

O'Hara: Nairobi College?

Bruyn: Probably. In East Palo Alto? Yes. And then when Jerry Brown was elected governor, he was appointed director of rehab for the state. Somewhere along in there, and I'm not sure when, he got the MacArthur Award which is a large grant, a substantial grant of money with no strings attached. He was able to use that money to get the World Institute rolling. But at that point he was off campus.

When I left the program at Cowell, I don't know what happened to it but very fast, the program was discontinued, and it moved into the residence halls. I had nothing to do with that. I don't know where that started. But I know that the chancellor was very eager to do that.

O'Hara: Was there any agitation among the students to do that while you were there?

Bruyn: I don't know of any. No. We had to make a number of adjustments at Cowell. One of them was we had to have access twenty-four hours a day. So we had a wheelchair access. We had to install an electronic lock on the ground floor, lower than first floor, to let them in at night so they could come in and out at night.

##

O'Hara: Where did you get your idea for the electronic door?

Bruyn: Well, it just was obvious they couldn't use a key, necessarily. They had a panel that they pressed. And--

O'Hara: Was that a doorbell?

Bruyn: No. As I remember it--see, the problem was that when the hospital closed down at night, the emergency room was open--that door was open--but it was not wheelchair accessible to the rest of the campus. It was on the uphill side. The emergency doctor would close up his roll around ten or eleven at night and slept in the hospital. If a student or an accident occurred after ten or eleven at night, somebody would come in the emergency room and that was fine. Then there was a nurse there and an attendant and so on.

But we wanted to make life as easy as possible for the Rolling Quads. So we wanted them to come in on the downhill side, right off the campus so they could roll right up to this door, press this button and come into their room.

Tensions of "Hospital or Apartment"

Bruyn: The initial problems we had was to try--they were in a hospital, but they were not. They were living in an apartment also. So, the problems we had with them were very often focused around this business of are you in a hospital or are you in your apartment. They wanted to come in any time they wanted to and we accommodated that with this door. But the nurses then were insecure because who else would be coming in through that door? So, they had to identify themselves through a speaker system. Then they came in that door and they could take an elevator right up to the third floor. But the nurses had to know, the nurses on the second floor, the night crew, so to speak, they had to be made secure because they didn't want, you know, anybody and his uncle coming in at night.

O'Hara: I lived there in the summer of '71 and it seemed to me that we were ringing a doorbell and someone came to the door. Was that a change or something?

Bruyn: That was a change because we found that when you rang the doorbell, who comes, you know? If they're in the middle of something and the emergency room and then you can't come right away, et cetera. So, we had to change that.

O'Hara: What other preparations--? I believe Zona Roberts told me that you had a backup generator for Ed's respirator.

Bruyn: Well, we have a backup generator for the hospital in general. You know, you have to in a modern hospital. But as I say, Ed, and Ed in his case, was such an expert frog breather that we didn't worry a lot about it. But the auxiliary generator for the hospital would have helped, would have taken over.

We had other problems in the sense that they would have parties. On one occasion I had a delegation of nurses that came to me and said, "We're sure they're smoking pot." But you can't smoke pot in a hospital, you see. It's okay in an apartment but not in a hospital. So I had to calm the ruffled nurses on a number of occasions over issues like that.

O'Hara: Ed Roberts has described you as a buffer when they were noisy and drinking.

Bruyn: Yes. Oh, I had to be--you mean a buffer between them and the nurses.

O'Hara: The staff.

Bruyn: Oh, yes. I didn't have trouble with the doctors, but I had trouble with the nurses who just couldn't conceive of anything but the usual hospital thing at night and in the evening hours. Patients are in bed and they're getting medications. On the third floor there wasn't anything like that at all, you know.

And the attendants, also, we had trouble with them because they would come into the dining--we had a dining room and, of course, a complete hospital kitchen--and the attendants came into the kitchen to get the trays to take up to them for their meals. Some of the attendants were dressed in the style of what I call "goodwill chic," and they would come strolling into the hospital dining room with everybody sitting around in whites or greens and just fresh from surgery and/or sterile procedures and in would come these scruffy looking people. They said, "Who are they?" you know. Well, they're the attendants. Then I'd get another bunch of complaints about, "Can't you get these attendants to dress more appropriately and so on?" The answer was, "No, I can't. And I'm not sure it's important."

O'Hara: Did you ever have to go to the students and say, "You've reached the limit and you're going to have to change"?

Bruyn: No. Whenever I got a big enough issue, I would go to them and we'd talk about it. I would say, "Well, let's do it. But try and understand." I would try to get them to understand the attitude of the nursing crews, the evening and night shifts. The day shifts were no problem because they were in classes on campus. But no, I would meet with them and just try to explain that, try to get them to understand.

But we had a couple of nurses that were just rigid. One of them was a retired navy commander, nurse commander. And she, as you can imagine, was a strict disciplinarian and she was a damn good head nurse. But she was not a very good "apartment manager." That was the problem. We had to work those two things together.

There's one question that came up. That was, how did people hear about the program. As far as I know, it was the state people, the rehab people, that knew about it. There was also word of mouth. We had one student from Honolulu who was from a very

well-to-do family there. His family heard about it and brought him here.

O'Hara: Do you remember that student's name?

Bruyn: No, I don't. I know he was a problem because he was very depressed. He really was not academically motivated. He had good grades from a two-year college experience in Honolulu but when he at once got to Berkeley, he was not motivated well.

O'Hara: Was he one of the two that dropped out? I read somewhere that two dropped out by '69 or '70.

Bruyn: No, I don't remember. We had some that dropped out academically, as I think this student did. He was one of those that dropped out academically. I don't think they dropped out because they couldn't handle the thing physically.

O'Hara: Were you involved in the day-to-day lives of the students or did you--?

Bruyn: Lives?

O'Hara: Yes. Or were you up on the third floor every day?

Bruyn: I think most every day I'd wander through there on some excuse or some reason.

O'Hara: What impression did you get as you were up there?

Bruyn: Well, as I say, during the day most of them are on the campus. But on weekends and nights I could come by. I'd go in and see most of them. I knew most of them by the time they'd been in about a month or so. I'd go by and see them. And with their problems, very often with their problems with the attendant or something that wasn't working well.

O'Hara: Can we go back to Ed just for a minute? You met him one afternoon, I'm told by Ed. Do you think Arleigh Williams thought you were going to say yes?

Bruyn: I almost told Arleigh yes on the phone because it was so familiar to me. It was something--see, I was leading a double life. I was administrating a large student health program. But I was also teaching regularly in the city and attending on the isolation service. And I was still working with polio.

O'Hara: Do you have any recollection of Ed that afternoon, what his sort of general attitude was?

Bruyn: Oh, he was highly motivated to go on in education. That's the way I would summarize it. He really wanted to get in.

O'Hara: And you mentioned earlier that he was always the leader.

Bruyn: Yes, well, as the first person in the program--the others that came in, he was always the old man. He was the pioneer. So, I think he sort of naturally fell into that role of leader.

O'Hara: I found a quotation in an article that I wanted to show you. From California Health, January, 1971: "Chiefly responsible for this unusual program is Dr. Henry Bruyn, chief of student health services on the UC campuses." Was it all the UC campuses or just Berkeley?

Bruyn: No. No, that was the UC Berkeley campus.

O'Hara: Yes, I think it was a typo in the article. "It was his vision that got the program off the ground although he had a very practical awareness of the realistic difficulties involved." I was wondering what those realistic difficulties were.

Bruyn: Well, I think I've mentioned some of them. I mean, the apartment versus the hospital, the idea of trying to live a normal residential life, such as they would be living in the residence halls and being able to do it in a hospital because we did have need of the hospital thing. There would be occasions when we needed medical, professional, health professional judgment at night or weekends or something. In other words, we had to adapt the hospital, it seems to me. That's what I tried to do from the very beginning was to adapt the hospital to fit these needs.

Health of Students With Disabilities

O'Hara: Speaking of medical, what kind of health problems did you see in general in those years among the disabled students?

Bruyn: Well, the same problems we have now, the principal one being the urinary tract. Most of the patients, with the exception of Ed, were spinal cord transection. So they had bladder problems. Some of them had problems with their bowels. They hadn't yet gotten into bowel training. That was, again, a challenge for the nurse. She had to put them through the bowel training procedures that we would use early on in a spinal cord transection. Those are the principal problems.

Sometime after I left the Berkeley campus, I was asked to take on a program at the hospital that was then called Herrick Hospital. Herrick Hospital wanted to have a clinic, special clinic, for severely disabled people. A Dr. [Chester] Wong was going to be running it. He was a rehabilitation doctor. We set up the clinic to do--at Herrick--and we did a complete physical evaluation of disabled people. That gave Wong and me a good insight into some of the people who are disabled and out there in that community of ours.

Many of them were getting all their care by going into an emergency room to get their catheter changed or something like that. We came across some of the damndest problems. I mean, thyroid deficiency, severe anemia, and an intestinal obstruction. But what that told me was that a severely disabled person needs skilled and regular medical supervision because these people were getting intermittent care in an emergency room. They were not necessarily welcome in any doctor's office. A lot of doctors don't know much about severe disability and about the problems they have.

O'Hara: Even now.

Bruyn: Even now. Many doctor's offices are not accessible, believe it or not, to the wheelchair. But anyway, that program died very fast, incidentally, because of financial problems. We could not finance it well. It was not appropriate to put it into a hospital. A hospital is a very expensive place to take care of people. And somebody once said a hospital was the most expensive motel in America. But anyway, we realized that hospital expenses, even then, were running almost a thousand a day and now run two or three thousand a day, just to walk in the door.

But the clinic there did have a brief moment of research interest about what are the medical problems of severe disability. It didn't apply to the students because with the students we had a good medical work up when they came in the program. We had a good idea what their health was when they came on campus. Of course, the idea of a complete check up, physical and historical, medical evaluation is a long-term interest of mine.

Complete Medical Workups: New Bridge Program, Entering UC Students, Disabled Students

Bruyn: One thing I did here in this program, in this program in Berkeley --the New Bridge program, which is drug abuse rehabilitation--we started this in 1968. Until two or three years ago, I had a

complete medical evaluation of every new client that came in the program. We have fifty to sixty clients in residence at any one time.

O'Hara: Right here?

Bruyn: Right here. This program has been a thrilling success.

O'Hara: And this was founded by you.

Bruyn: I started it with Jack Goldberg in 1968. About three or four years ago, I presented a paper in Athens, Greece, on the health status of drug abuse in young adults. I did that by just pulling one out of every twenty charts. It gave me about 400 samples. At that point I had a complete medical workup of the newcomer with my evaluation as well as the individual's evaluation. That is, he gave a "yes/no" history. You know, "Have you ever had...? Answer yes or no." And then I had my own history. We had a complete multiphasic technical workup. Audiometry, optometry, EKG [electrocardiography].

O'Hara: Now, are you talking about the disabled students?

Bruyn: We did a complete medical workup of every entering student every fall. We would do as many as 10,000 students in a two-week period, station to station. As I often said, you don't develop a doctor-patient relationship. But we'd do station to station and we got a lot of data on what we found on those students.

These students were upper 12 percent of their high school class. They were intelligent. And we found a remarkable number of them that had never had proper immunization. Every fall we found at least twenty thyroid nodules, of which four turned out to be cancer, average, each year. You say, "Where have they been all this time?" Well, we had more data on that. We found that the young adult, age eighteen, coming into college has not seen a good medical workup since he was five years old.

Severely disabled students got the health service the same as any other student.

O'Hara: I noticed in an article written in the 1960s that students had to go through quite a few steps before they even went to the admissions office. First of all, a referral by the Department of Rehabilitation.

Bruyn: Yes.

O'Hara: Then an interview with the UC committee, which consisted of you, a psychiatrist, I believe--

Bruyn: No.

O'Hara: Dr. Berg?

Bruyn: Dr. Berg was one of our part-time psychiatrists. And one time Dr. Berg got interested in them and he was interviewing them for his own interests. But it was not a criteria for getting in. The first criteria for getting into the program was the same as any other student applying to the Berkeley campus, the academic requirements. But we didn't have any special requirements for getting into the Cowell program.

O'Hara: This one article went on to say that they had one interview with Carl Ross.

Bruyn: Yes. Carl did interview them on the financial aspects, of what kind of arrangements he would make with the state bureaus.

O'Hara: And then someone from the UC counseling department.

Bruyn: I don't know of that. The counseling service on the campus usually was doing career stuff, vocational guidance and academic guidance.

O'Hara: So your memory of this is that it was more of a standard, "When you apply and are accepted then we'll see what we can do."

Bruyn: Yes. And you can use the counseling services like any other student.

O'Hara: You mentioned that the nurses were interested in sterile procedures and you didn't see much of that on the third floor. Can you elaborate on that?

Bruyn: Well, I don't mean to say sterile procedures. The nurses were used to the standard hospital routines. That is, that you wash your hands before you examine the patient and you wash your hands when you left the room. You used all of the usual routines that a nurse in a hospital would use. But that certainly didn't occur on the third floor. For example, we didn't have any visiting hours on the third floor. But nurses need visiting hours in order to get their work done in the usual hospital. Nowadays we've gotten very loose on visiting hours in most hospitals. But it still interrupts nursing procedures.

- O'Hara: It seems to me I recall that at night when Edna Brean wasn't there, that the students could call on a nurse from the second floor if they needed something.
- Bruyn: Yes. If they had trouble the nurse would come from the second floor, yes.
- O'Hara: And you had arranged for that.
- Bruyn: Yes. Even the doctor who--we had a doctor in the house for the emergency room, the emergency services, every day of the week--and he would get called on. Once in a while, the nurse would call him. Then often he would call me at home and ask for advice and counseling, whatever the problem was.

Department of Rehabilitation

- O'Hara: Can we go to the Department of Rehabilitation for a minute? Did you have direct dealings with them, or was that Carl Ross?
- Bruyn: Carl Ross did most of the dealings with them.
- O'Hara: Catherine Butcher was spoken of very highly as a counselor for the Department of Rehabilitation.
- Bruyn: Oh, yes. Yes, she was here frequently and was a great deal of help.
- O'Hara: And then there was a contract established with them, a five-year contract that would cover the room and board.
- Bruyn: That was Carl Ross's contribution. It was a very important one.
- O'Hara: Can you tell me, is Carl Ross available to talk to?
- Bruyn: I don't have any idea where he is.
- O'Hara: I'd like to show you another quotation. This is about the Department of Rehabilitation. I'll read it for the sake of the tape. It's from the Department of Rehabilitation periodical, the Rehabilitation Research Reports, from November 18, 1969. "The Cowell program was described as a research and demonstration project of the Department of Rehabilitation with purpose to make a rehabilitation residential unit available for quads, paras [paraplegics] attending UCB. Later, the program was enlarged to include evaluation of prospective students demonstrating potential

for professional skill level occupations." Is this an accurate interpretation of what the program was?

Bruyn: Yes. This is, to the best of my memory, this is part of that contract that was developed. It was put in as a demonstration project. The important part of it is demonstrating potential for professional skill level occupations. That was something that was important to the State Department of Rehabilitation.

O'Hara: It almost seems as if it now belongs to the Department of Rehabilitation in this quotation as opposed to a university program which is where it was when you started.

Bruyn: Well, it doesn't belong to anybody. That describes the reason they're giving money to it.

O'Hara: In that same report, it said the Department of Rehabilitation counselor meets with students once a week. And you said that--

Bruyn: That was Butcher or somebody.

O'Hara: Somebody. It didn't name them.

Bruyn: We had several different people and they would come by--I'm not sure it was once a week--but they would come by off and on.

O'Hara: Another quote that I found in that article said, "A large number of students," but I don't know what we mean by large here, "initiated contact with the staff psychiatrists and met as a group once a week." Do you have a recollection of that?

Bruyn: No, I don't. I know that Dr. Berg became, in particular, interested in the disabled students and I think it was mostly his interest in their psychiatric problems brought about by disability, severe disability. I don't--I think he met with them every--he met with them regularly.

O'Hara: Did he ever write any reports or publish any work?

Bruyn: Not that I know of. I ran into him lately and I asked him if he'd ever done anything more about it. He said, "No. It was a passing interest."

O'Hara: One other thing in that article, it says, "Due to changes in the program counselor," referring to the Department of Rehabilitation counselor, "and changes in referral procedure, the project is not growing at the anticipated rate." This was said in 1969. Is that--?

Bruyn: "Project is not growing at the anticipated rate." I'm not sure what they anticipated. I know I anticipated fifteen as the number.

O'Hara: And you got it.

Bruyn: And we got it, and that was constant.

O'Hara: All right. Is there anything else about the Department of Rehabilitation? Was that a sort of a formal arrangement or informal up until 1968? Did they pay for Ed right off the bat or was this--?

Bruyn: No, they kind of--they were very hesitant to get into it. I think they saw it as a risk for them, a financial risk for them. I think Butcher was a great deal of--Ms. Butcher was a great deal of help because she became very enthusiastic about the program. But I don't think they got into it early on with any enthusiasm.

O'Hara: But somehow they agreed to a contract for a five-year permit.

Bruyn: Yes. That came about eventually.

O'Hara: Do you have any recollections of Ed working as the assistant to Arleigh Williams?

Bruyn: No.

O'Hara: Or his consulting work at UC Riverside? It seems like at one point he started going to Washington DC and consulting with HEW.

Bruyn: I know that Arleigh called on him off and on for advice in regard to students who were applying to Berkeley. I think much of that took place after I left the Berkeley campus.

##

O'Hara: You started to say something about the Rolling Quads. I was wondering if there was an incident that coalesced the group into this, what appears to maybe have been politicization.

Bruyn: No, I think it started with just that business as I told you when Ed and the group of them said they had organized and they were going to take over. That's when they called themselves the Rolling Quads.

O'Hara: What exactly did they mean they were going to take over, aside from being facetious?

- Bruyn: Well, it was the time of campus unrest and that was a good term on the campus. It was just slightly facetious, I'm sure.
- O'Hara: Well, what did they want from you?
- Bruyn: They just wanted to--I think---I wanted from them that they were organized. That was great. Because then I could go to a group kind of thing. I didn't have individual beefs and individual problems. They took them up among themselves, talked about them and came to me with constructive thoughts.
- O'Hara: Do you think they got any hints from the movements that were going on on the campus?
- Bruyn: No, but I think they liked to consider themselves as participants. I remember Ed's respirator at one time was plastered all over with student poster stuff, you know, free speech and all the slogans that were bouncing around the campus then.
- O'Hara: Were you an observer at all of the grant that the students apparently wrote that ended up funding the disabled students' program--PDSP?
- Bruyn: No.
- O'Hara: 1969? So you weren't involved in the startup of PDSP at all?
- Bruyn: Well, except that they want to know about what--they told me about what they were doing and I said, "Great. Go."
- O'Hara: Did you ever visit the office behind Top Dog on Durant there?
- Bruyn: No--the CIL?
- O'Hara: I was talking about the one that John Hessler headed up which was the university PDSP.
- Bruyn: Yes.
- O'Hara: What about students moving out of Cowell? I know that that started to happen in the late sixties.
- Bruyn: Well, it started to happen when they graduated, you know. We had some of them--we had two of them went to law school, elsewhere. They didn't go to Boalt here at Berkeley. One of them got going at graduate school up in Davis that I remember. In other words, they--the only ones I remember moving out were the ones that graduated and then somebody else would take their place. I think Edna Brean had done a good job in training them about taking care

of themselves. That was one of the jobs I saw that we should be doing.

Additional Thoughts

O'Hara: Did you see this as a rather important program or the beginning of a movement or part of a national movement? Did you have a sense at any point that you had a tiger by the tail here?

Bruyn: No. We had a lot of visitors at Cowell, during my time there, from other countries. I had doctors from England. I had one from London, another one from Newcastle. They would spend time. Then I had a doctor from Ceylon, from Hong Kong. They would come here and spend two or three months. They were aware of this program, of the Disabled Students' Program.

O'Hara: How were they aware?

Bruyn: Because they were here. They weren't aware of it until they got here.

O'Hara: How did they even know to see it?

Bruyn: I took them there. They lived at Cowell.

O'Hara: Oh, they were your visitors.

Bruyn: They spent their days with me. I was their host, so to speak. They, all of them were very impressed with it. I don't know whatever came of it when they got back to their home territory. I was at one point president of the Pacific Coast College Health Association. I was also president of the American College Health Association which represented about 2,000 universities and colleges. In those two organizations, I presented a review of our experience at Berkeley with the disabled students.

O'Hara: And they probably published proceedings.

Bruyn: I don't know. But I tried to talk, tried to describe the Disabled Students' Program on several occasions to both of those organizations.

O'Hara: You mentioned wheelchairs before. Now, and I saw some notes in the early days that the Department of Rehabilitation paid for people to push the students around the campus and ultimately they

were issued electric wheelchairs. Were you instrumental in prescribing those?

Bruyn: No, I went through the thing about--

O'Hara: Actually, I read a letter, I think, from you, about John Hessler being ready for an electric wheelchair, 1965.

Bruyn: I see. Well, then they must have required my recommendation to fund it. I don't remember the details of that except I never had any hesitation in recommending it.

O'Hara: That must have been a revolutionary way to get around in those days.

Bruyn: The electric wheelchair, yes. I have a new gimmick that I want to show Ed Roberts. I've got a tape on it, even, that turns any wheelchair into an electric wheelchair. It's a good one to travel with because you can get a folding wheelchair and then this gadget that fits onto the back, or fits onto the front, and has the wand stuff. I saw it at a meeting and I wanted Ed to know about it.

O'Hara: Yes, very good for traveling. Another question about you personally. I wanted to go back--have you received a special order from the British empire? Ed Roberts reports to me that you were made a knight.

Bruyn: No, I was not. I was, and I'm no longer, I don't think, a Fellow of the Royal Society of Health, which is like the American Public Health Association, because I gave a paper in England once at a national meeting they had on student health in America in which, incidentally, I talked about the Disabled Students' Program. But I was not given any award. I was just mentioned.

O'Hara: You're not Sir Doctor?

Bruyn: No.

O'Hara: [tape interruption; hands Bruyn a quotation from Rehabilitation Research Reports and asks for his comments]

Bruyn: Well, this is a quote from a report in Rehabilitation Research Reports dated November 20, 1970, in which it says, "At the start, the students were 'treated so solicitously, their situation was so structured and protected that militancy and bitterness arose in some cases. Later, each resident was treated less as a patient and more as a student. Morale improved. The counselor then included the residents in discussions of decisions that would be affecting their entire future.' Morale further improved and

students joined together in a social organization, the Rolling Quads, now officially recognized by the university. The Rolling Quads sought and obtained federal money to set up an office for services."

My comment on this is that we've already talked about the problems we had in attitudes of a hospital staff dealing with a group of people that were living in an apartment situation or a residence hall situation and trying to bring those two attitudes together. I think the hospital staff was acting as a hospital staff, which is solicitous and protective. They had to adjust to the students who didn't want to be hospital patients. They wanted to be residents. I think that that attitude, the bringing together of those two attitudes was my job. I think it worked out eventually.

O'Hara: Can you comment on Arleigh Williams' comment that he thought the students were beautiful battlers when they were being tread upon?

Bruyn: Yes. Well, as I look at that, it's a very familiar experience with severely disabled people. Severely disabled people are realistically and entirely--in a very healthy way, they are dependent on other people and they don't like it. They are also helpless and that makes them frightened on occasions and therefore frustrated. I think those two things make them very good battlers. They've learned the hard way they have to battle. And they should be good battlers.

I have no hesitancy in saying that I'm very proud of this program. I think it accomplished a great deal and it still is accomplishing a great deal. I'm trying in my way, at this time in my life I'm still trying to help in working together. My current interest now is to try and get the wilderness areas of the United States opened to the disabled.

O'Hara: Thank you, Dr. Bruyn. That was wonderful.

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UC BERKELEY'S COWELL HOSPITAL RESIDENCE PROGRAM:
KEY ADMINISTRATORS AND CALIFORNIA DEPARTMENT OF REHABILITATION COUNSELORS

Edna Brean

NURSE COORDINATOR, COWELL RESIDENCE PROGRAM, 1969-1975

An Interview Conducted by
Susan O'Hara
in
1995



Edna Brean, July 1990.

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INTERVIEW HISTORY--Edna Brean

Edna Brean was invited to participate in the Disability Rights and Independent Living Movement oral history series because she was the nurse coordinator of the Cowell Residence Program for students with disabilities from 1969 to 1975. She knew most of the students in the entire program and shared their experience of "feeling like a pioneer" in a new movement.

In the course of four interview sessions in 1995, Edna Brean describes life on the third floor of Cowell Hospital, the area reserved for disabled students from 1962 to 1975, before the program moved into the general residence halls on campus. She talks about the traditional concept of a nurse versus her new role in "partnership" with the disabled students, each learning from each other. She recounts the occasional tensions within the hospital structure that resulted from this idea of disability not being viewed in a strictly medical framework. She describes her busy and kaleidoscopic days, her impressions of early student leaders, and the thrill of being in her position at a creative stage of the movement.

The interviews took place at the home of the interviewer, who has known Edna since her own student days in the Cowell program in 1971. Edna reviewed the transcript of the interviews and edited extensively, so no tape guide was generated. She has placed personal papers relating to her days at Cowell in the DPIM archive 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 10, 2000
Regional Oral History Office
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BIOGRAPHICAL INFORMATION

(Please write clearly. Use black ink.)

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 Date of birth 7-7-19 Birthplace MASSACHUSETTS
 Father's full name ISAAC ADELSON
 Occupation MERCHANT Birthplace SWEDEN
 Mother's full name DEBORAH SAMUELS ADELSON
 Occupation HEW Birthplace GERMANY
 Your spouse (DIVORCED)
 Occupation --- Birthplace ---
 Your children MAJORIE JANET BREAN
ELIZABETH IRIS BREAN STEINER
 Where did you grow up? NEW BEDFORD MA
 Present community ? Emeryville, CA 94608
 Education Post Nursing classes @ Simmons College + Boston University,
Post Grad classes on "Patient with Spinal Cord injuries"
Assorted courses on painting, lithography (private)
 Occupation(s) Instructor: San Francisco State U. (1975 to 1985) Course,
University of S.F. Instructor in MASTERS Classes in Rehab.
~~Short period - Reading + evaluations of grant requests for gov.~~
 Areas of expertise Health maintenance + rehab nursing, short
term courses in rehab for HEW - Rehab Counselor
Wrote complete books and lyrics for ^{full} length musicals, per
 Other interests or activities Wrote comedy material for TV + club ^{+ perform.}
performances and cartoonists (caps)
HELPED establish the Assoc. of Rehab Nurses (No. Cal Chapter in '78, '79)
 Organizations in which you are active Not active. Fully retired

INTERVIEW WITH EDNA BREAN

I FROM MASSACHUSETTS TO CALIFORNIA

[Date of Interview: July 19, 1995]

Family

O'Hara: Edna, tell me a little bit about your background.

Brean: My father came from Sweden, my mother from Germany. They married in Boston and settled in New Bedford where I was their sixth child, born in 1919, the youngest of an active, funny family. This was before television, this was practically before radio. My father had one of the first battery sets. He used to forget to put water in the battery so we couldn't hear the A&P gypsies, which put my mother in a lather. We discussed and argued a lot-- politics. Meal time in our house was challenging.

O'Hara: Challenging in the sense of--

Brean: Talk, argue, political argument. Discussion about everything, ethics, peoples' behavior, why things are the way they are, people are the way they are.

My sisters and brothers brought friends home all the time so there were always at least eight people at the table, and on weekends there would be twelve or fifteen or gosh knows how many. My sisters were fond of making fudge almost every night. It's hard to believe we actually pulled taffy, can you believe that? It was a terrible climate so we were indoors a lot. It was all home and family. Oh, the library, the wonderful library! My chief joy. Our house was full of books, there were at least two of every kind of newspaper. Opera on the radio all day Sunday. And I also enjoy being with a lot of people--the hubbub of good talk.

Nursing in Boston

Brean: I had wanted to be a nurse since childhood, and since this was during the Depression, it seemed also very practical. Dr. Donovan said my mother would have made a wonderful nurse, but she couldn't be a nurse. And Dr. Donovan of course was a wizard doctor. He took our tonsils out on the dining room table in those days.

O'Hara: At the dining room table?

Brean: Oh yes, house calls, you know. I was the only one that had it done in the clinic. Nobody worried about those things in those days. You do know that I'm eighty years old?

My mother was a born teacher. She used every opportunity with any kind of plant or object, from soup bones to birds, to demonstrate what was remarkable about it.

So anyway, I went into nursing school at the Beth-Israel Hospital and Nursing School in Boston. I visited somebody there one day, I saw tennis courts. So I applied and was thrilled to be accepted. Little did I know they couldn't wait to get all this free labor.

I loved the nurses' training program--it seemed so exotic to me--so organized! So regulated! Such punctuality!

I remember when I had two hours off, I would rush to my room at the dorm, change my clothes, play tennis for one hour and forty minutes, rush back, take a shower, put on my uniform and work for four more hours. I was tireless. We had pediatrics at Boston Children's Hospital, and OB [obstetrics] at the Womens' Center.

O'Hara: This is called Beth Israel?

Brean: Now Beth Israel-Deaconess Medical Center. I met my husband there. He was a resident, starting several years of radiology. My husband was teaching at the medical school.

O'Hara: At Harvard?

Brean: Yes. I became a "Harvard Dame," which I thought was hilarious. The whole thing was extremely funny and really quite nice. We came out to California after another rotten winter of scraping ice off the car windshield.

Nursing in California

Brean: We read a WPA [Works Progress Administration] book on California. One page I still remember clearly. It said: "To describe this climate of the Santa Clara Valley without using hyperbole is impossible." And we just looked at each other and said, "That's the one," and were in Palo Alto in a year [1949].

After a divorce in 1964 I went to work as a nurse at Providence Hospital. There's been a huge change since the sixties, as you know. It's become highly technical and highly complex and overwhelming. These days, Susan, I cannot understand the Journal of Acute Care Nursing. I can and do read medical journals, but I cannot understand that one. It's that arcane. And you can keep that in mind when you realize that now every hospital and every doctor's office is hiring six-week wonders.

O'Hara: What do you mean?

Brean: Health assistants and office helpers. They're doing a lot of procedures that nurses used to do. I feel all the goodwill in the world does not substitute for rigorous training. How carefully we were brought into nursing--and how many safeguards and dependable rules that made for a real security for the patient. Then I got the job at the School for the Deaf and Blind as it was called on Warring Street.

O'Hara: You left Providence?

Brean: They'd call when they needed a nurse. That's "on call."

II COWELL RESIDENCE PROGRAM, UC BERKELEY, 1969-1975

Recruited by Henry Bruyn

Brean: Later I took a job at UC. I liked the students there, I like that age group and I like the idea of health rather than illness.

O'Hara: What job was that?

Brean: Working on the admissions. I don't know if you remember what it was like in the good old bad old days. When Henry Bruyn was running the student health service, there was a very complex, time-consuming and probably expensive physical review that took place every September. Every single student had a physical exam. I'm sure it was expensive, but it's my idea of good preventive medicine. We picked up important stuff with these young people, all kinds of problems that are mainly remediable, that would affect not only their scholastic careers but their lives. It was done by having "stations" like they do at Kaiser in their multiphasic.

O'Hara: And this was done by nurses?

Brean: Doctors and nurses.

O'Hara: That was your first job at Cal.

Brean: It was very important. I felt it was one of the greatest things a university like that could do. There were a lot of people coming in from out of the country. We didn't know a thing about whether they were immunized against anything, if they ever had TB test, et cetera. They often were afraid if they said they'd had a cold, we'd send them back to wherever. But you could tell a lot, with a good p.e. [physical exam]. Well, that ended. So then I worked on the second floor for a short while.

I was curious about those people here in wheelchairs. They were obviously not sick. They'd had a rehab nurse that had left abruptly, and they needed a replacement. Dr. Bruyn said it was a whole new idea. "We're going to have students living up there. They're not going to be patients; they're not sick. They are boarders. It hasn't been done before. There are no directions. You can make your own hours. You're going to be a kind of an independent agent."

So I accepted. Several people, mainly the nurse who had left, said that I'd never be able to do the job.

O'Hara: You mean the fact that, what couldn't be done?

Brean: I would not be able to understand or know anything about them, there was no body of literature about this stuff. There was no other place in the country like that. What I should be doing or what they should be doing was a big unknown except that there was a perceived need for a residence program, and it was funded by the California Department of Rehabilitation.

O'Hara: Edna, did you ever in all of your nursing experience or training ever have experience with permanently disabled people?

Brean: No, I did not. But in Boston, at the Robert Breck Brigham Hospital--referred to as the "other Brigham hospital" usually in a sneering way--I never knew of anybody who ever worked there, but I imagine that there were a lot of people with orthopedic difficulties. This was before the big polio epidemic you see, so I don't know who was there. But we didn't see disabled people or chronically mobility-impaired people.

O'Hara: Were there any in your acquaintance or your family? You had just no experience.

Brean: No, no exposure to it at all. I don't remember seeing--oh yes, what I did see in New Bedford was a lot of people who were, later I found out, born with congenital dislocated hips, and these were something you didn't see later because it can be remedied at birth by an alert pediatrician.

O'Hara: So when did you start on the third floor of Cowell? Did you start immediately after your conversation with Henry Bruyn?

Brean: Sure.

First Impressions

- O'Hara: What did you first see up there on the third floor of Cowell?
- Brean: About eight boarders. John Hessler was there, I can remember the names of the people, given some time, I'll look it up, but, see if I can recall. Oh, Bill--who's that blond guy from Weed, California?
- O'Hara: Glenn.
- Brean: Bill Glenn. And one girl--Cathrine Caulfield.
- O'Hara: Now, did you meet them right away?
- Brean: Right away. They were very interesting. They had forced the "retirement" of a nurse who had been there for a short while before me. I went up and I immediately felt comfortable. Their assertiveness seemed very healthy to me. It fit in with what I thought how people should behave.

When I started up in this job, I immediately found these people attractive. And they all looked me over, really carefully. And they were suspicious, I felt.

In the memorial, this little thing I wrote for John's funeral, I'll give you a copy. That although the university could appoint me, Bruyn could ask me to do it, the Department of Rehab could pay for it and agree: without any questions, no contracts, no written nothing, no, we'll try it and see, all unknown to me, the students on the third floor, the ones who were there were watching me like a hawk. And after I was there for six months, I remember John asking me if he could talk with me for a minute.

And he directs me into his room, closes the door; this was very, it was really unusual. And as I write in this thing, if he could have toed into the ground, he was so embarrassed, he would have done it, but of course he--and he said I just wanted to tell you, uh--and he hemmed and he hawed, and he hawed and he hemmed. And he said, I just wanted to tell you that we trust you. Oh, okay. And I didn't think about it until much later, that they were really in charge. And I didn't know that they were watching, but they wanted me to know that I was okay. And I was really very pleased, because I didn't have to answer to anybody and I knew that I liked working there, and I knew that I liked what I was learning, and that I was able to sort of impart and share and so on and so forth, but didn't realize how the power lines really ran up there. And I don't think anybody else did.

I don't think they knew that these were not just students, that there were a few people up there who were going to be very hard to cross. And I feel that they had their heads on straight. So I really, really liked them, and I felt very pleased to be part of that group, because they were just right.

O'Hara: They accepted you.

Brean: Yes.

O'Hara: You passed.

Brean: I passed, and I didn't even know that I was on trial.

O'Hara: Fascinating. Where did they get this power?

Brean: I don't know.

O'Hara: Was it a couple of people, or all of them?

Brean: There was an orderly up there who seemed to have real knowledge of how the "system," the political system, really worked. He was an intimate of John's and a couple of the others, and Don Lorence. Don Lorence was nobody's sweetheart. He was a tough cookie. He wouldn't win any awards for congeniality--I liked him because he was smart and he was brave.

O'Hara: The students had rallied around him, even before you got there, hadn't they?

Brean: Yes, they did.

O'Hara: Wasn't he the object of the rehab decision?

Brean: Well, probably. I never went into that very much but I know I met that woman, and she said to me very contemptuously (she left not one shred of records or anything I could look at), "You're never going to make it." She said, "I give you two weeks. The whole program will collapse."

I worked like a Trojan. I went to the drugstore on Telegraph Avenue, what was the name of that Rexall drugstore. There was a pharmacist there, all the prescriptions went through him. I got copies of everything that had come to him from any disabled student, so I could figure out what their medicines were and what their histories were. I got their medical records from the record room to study them. I pieced together whatever I could get my hands on and I talked with them and said where were you, what happened, what do you have. Tell me what I need to know, I

mean they were wonderful teachers, so I found out what their backgrounds were and what their disabilities were. They had all kinds of unusual things to tell me. I hunted through textbooks, I couldn't find anything, there was nothing, you know. There was nothing about cord injury, there was nothing about all the myatonias. God, there was just nothing. Those people had some rare genetic disorders.

Learning on the Job

O'Hara: You learned it on the job.

Brean: On the job, I went to every V.A. hospital, I went to meetings, I went to seminars, I went to Rancho Los Amigos, went through all their files, I made friends with them, made copies of everything I could find. I went to the V.A. hospital at Long Beach because they had a lot of World War II refugee doctors there who were utterly devoted to anybody who'd been hurt, any American who'd been hurt fighting the Nazis. And they were helpful, Dr. Comars was there, a lot of pioneers were down there.

O'Hara: Why was there no literature?

Brean: Nobody had written it up in more than a paragraph or two. Also, they were never seen out in public. People with cord injuries didn't last long before that, so there was no point apparently. And the polio epidemic made Rancho Los Amigos a major rehab facility because Rancho was the county hospital. You know, out in the country, chickens and cows, et cetera, they raise their own food. In the fifties, when everybody got polio, that's where they sent them. Doctors who took care of them became the first really devoted rehab specialists. Dr. Bruyn was a pediatrician and widely known as an expert. He was interested in Ed Roberts--arranged for Ed to live at Cowell and be cared for by the nurses while he went to UC. Then John Hessler came in. And so Henry said--not in so many words--if they can do it here they can do it anywhere, because this campus is very rugged and it's a very tough school. Anyway, the whole thing--just the right people at the right time in the right place. And Dr. Bruyn was not averse to taking risks like that, he really took a big risk with me too. Have you interviewed him? I don't know if he's told you about all this.

O'Hara: Yes, he has, but it's very nice to have comment about his risk taking, he didn't--

Brean: He wouldn't put it that way. He was brave. And he was right.

Don Lorence we were talking about. I didn't realize it but it was important to have him on your side. We got along fine. I thought he was splendid because he was really fearless. And funny.

O'Hara: Don Lorence was?

Brean: Yes, he was writing notes to the, who was it, Mr. Ross or somebody was running the--

O'Hara: Carl Ross was the hospital administrator.

Brean: He was a burr under his saddle, Don was. He was a thorn in his foot, that guy was such a pest and he enjoyed it so much! He would show me the letters he wrote to Mr. Ross, and answers from Mr. Ross, and would put them on the bulletin board, so everybody could see them. Don thrived on this version of "mano a mano."

O'Hara: What was he writing about?

Brean: I don't know, the laundry, the food--

O'Hara: Conditions.

Brean: Conditions, lack of respect, harassment by people on the second floor. All trivia. He really was Mr. Ross' very own nosebleed.

O'Hara: What did Dr. Bruyn expect you to do on the job?

Brean: I don't think he could indicate a plan.

O'Hara: But he wanted somebody up there, he felt like he needed some--

Brean: Some kind of a health--somebody who knew--see because I knew about the basics of health, way beyond nursing because for years I read all the journals. The weekly New England Journal of Medicine always has a case that you're supposed to diagnose from reading, it was very interesting, I learned a lot. So I had a lot of information, and I guess he didn't know what needed to be done, but my god, something needed to be provided up there.

O'Hara: So you had to kind of just go up there and see what your role was going to be.

Brean: Absolutely. I had no idea what I was supposed to do but I knew basically that their health was very important to maintain. I didn't quite know how, I know basic principles, and the other

thing was that these were not, and underline, repeat, not patients, they were not to be treated as patients, I was not their nurse, I was just an administrator and a health resource person. And a peacemaker, I discovered.

O'Hara: Dr. Bruyn made a point of saying a couple of times that there was often a sort of a--oh, a conflict between hospital staff who looked at the place as a hospital and students who looked at it as more of a residence, an apartment. Did you notice that too?

Brean: All the time. It was worse as time went on because we got a new director, a different supervisor of nursing but--

O'Hara: Was that the military, the ex-military disciplinarian?

Brean: She was terrible. Yes. She was beyond the pale. She could not understand why I didn't take their temperatures every morning, et cetera, et cetera. She made "rounds" every day, wanted to check my "work schedule"--this soon stopped. When I came into work in the morning, I would often find a note pinned to my door from the night nurses. Mrs. Brean, your students blah blah, blah blah, da dah da dah. I put it on the bulletin board. And blah, blah blah, you got a blah de blah, and why are they so, and you know they're having girls up there and candles, and maybe they're smoking something. If nobody's getting hurt, I don't want to know about it. I didn't want or need to know everything. In fact, the big rule was don't hurt the program, or yourself. No drugs! No booze! That was their program, and they knew how good it was and how important it was. They were not infants, they were grown people.

O'Hara: How were the doctors at the Student Health Service?

Brean: They were very good. They were some of the best doctors I've ever known. They were good and they were careful. But people with high cord injuries are always and ever singular in the symptoms, the problems they present. They needed to develop a lot of courage and assurance in dealing with health professionals who can be intimidating, and not always informed.

These were outstanding physicians, really first class. But "independent living" with "major disability" were mutually exclusive terms for them. The business of hyperreflexia, for example, is something that was not understood by many medical people because it was arcane. I wasn't Ms. Congeniality, I'm afraid! But I did feel the need to speak up, and to show the students they had a lot to teach, even to bossy nurses--like me!

O'Hara: Do you think the doctors learned as they went? Learned some things from the students as you were saying earlier?

Brean: Very much, very much, and so did I. The students were the best teachers imaginable.

O'Hara: This is a rather different idea, wasn't it? The old medical model says nurse and doctor know best, and here you're saying as a nurse they were teaching you.

Brean: Well, see, we had a very loose partnership, I knew stuff that they didn't, and they knew stuff that I couldn't have possibly imagined. And together we made up kind of a whole person. I knew all the basics that are very important in staying out of trouble medically, healthwise and so on. There was a pattern of dumping all your medicines into a drawer and telling an attendant, "I need one of the purple ones and one of the blue ones today."

Students would come in with a variety of medicines, some of which should have been discontinued ten years prior, and they were still getting them refilled by pharmacists. I'd visit new entries and get acquainted with their needs and problems, medical issues and histories, and gripes and special whatever. One said he takes a sulfa drug, and I said, "Oh, do you have a bladder infection?" He says, "No, not now." I said, "Well, how long have you been taking sulfa?" He said ten years. I'm not kidding! Apparently a doctor gave him a "refill as needed," or the pharmacist just kept refilling it.

O'Hara: Why did they do this?

Brean: I don't know. It's a matter of continuity of care, or the lack thereof.

O'Hara: Were things a little less strict in those days?

Brean: Not that as much as prescribing medications in a kind of birdshot plan. The "outside" or previous doctors seemed a bit prone to that, with enormous amounts of Valium, and tranquilizers and sleeping medicine. We got them off much of that and onto simple, non-addictive meds that work, ones that have no charm at all.

There was so much to learn and there was so much information to learn. We felt like pioneers, you know.

O'Hara: It was an exciting time.

Brean: It was very exciting.

Description of Third Floor

[Interview 2: August 3, 1995]

O'Hara: Would you mind describing a little bit about the third floor, what it looked like, what it felt like. Maybe a typical student room or two but also there was the big room, and there was a dining room and you had an office. What else? But I'd like to know what they looked like, what was in it and what people did in it.

Brean: Okay. When I first came up there, which was in 1969, that was the height of, the depths if you want to call it that, of the hippie movement. The whole thing of tie-dyed shirts and drop out from school and all these patchouli scents, not to mention marijuana. And drapes of tie-dyed stuff, creatively draped, often Indian bedspreads, and they were all burning candles. My first impression was, oh boy, this does not look safe but I certainly cannot pass some edict and say you can't put--it really worried me because disabled folks probably could not pick up a candle that had fallen over. And there was a lot of soft and flammable stuff all over the place.

O'Hara: Was there incense also?

Brean: Incense, yes. So, when you got off the elevator on the third floor, you would be in the center of large intersecting corridors. The east wing on the third floor housed the medical research department for the Lawrence Radiation Lab. We never went in there, there would be no reason.

O'Hara: The students always thought it was a bit mysterious, didn't they?

Brean: Well yes, because you were not welcome in there. Nobody said keep out. The people were pleasant. We met at the elevator, we might even have coffee or lunch in the cafeteria, but I wasn't interested and they never volunteered anything. I know the students wondered what was going on in there. I did grasp that the research was significant. Very important stuff about radioactive isotopes, cancer treatment. And very safe, just specialized.

O'Hara: I remember that there were people with bone--

Brean: Oh yes, people with acromegaly there, great big hands and great big jaws. They were doing pituitary gland studies, endocrine studies. The people there were not "patients," but they were research candidates and ambulatory. Then the wing that went from that central intersection, you could say north, we did not use

then. I don't think we ever had any--did we have any people in rooms in that wing?

O'Hara: I don't remember any.

Brean: I believe we had several later, when the census rose. We used the south wing, with maybe six sizable rooms on each side. These were originally two-bed rooms, each of which was now occupied by one boarder. There were two large corner rooms which originally would have been four-bed wards. Those large corner rooms were kept for people who had iron lungs. Every two rooms shared an ample bathroom. My office was the first room on the left of the west wing. Room 303 was it. Some of the students were in that wing, too.

O'Hara: Bigger than I thought.

Brean: Yes, and we had three or four rooms that were used for various activities. At the end were the two square four-bed rooms. One, I believe, had a pool table, in it. I think it was a pool table.

O'Hara: Yes, there was a pool table--there wasn't always one but somewhere, you got one.

Brean: We conned one up. The reason we were gifted with a pool table--many of the quads had upper extremity function, so they could shoot pool. The opposite big room was the dining room, and the dining room had--again we got gifts, we got donations. That room was painted. We were in the "psychedelic period." The students knew people who'd be happy to paint it, so we got it painted. I mean it was painted in great sweeping colors, it sure did not look like a hospital. That was great you know, just colorful shall we say, free flowing color, big black round table in the middle. Everybody could gather around it. It was a great place--much admired. How I wish all the pictures we took were not lost when we closed the program!

We also eventually got a microwave oven. Wheelchairs take up so much room, there was little else in there. One of the very nice doctors downstairs raised finches. I said a couple of finches would be very welcome, so she brought us a pair of finches and got a cage for them and we had lots of fun with them. They were named Ike and Mamie, because of course I think Eisenhower was--well, I don't know if he was president then. Well, after a while poor Mamie died, so we got another female, the guys named her Tina, so it was Ike and Tina. Poor little birds. Forever laid eggs in the little nest, a little basketty thing, but eggs that never hatched, it was too noisy and exciting around there.

All these people trying to chirp and saying, "What's happening, Hello Ike! Hello Tina!"

So that was the dining room, and people could eat of course in their rooms but a lot of people liked to gather there and there was always plenty of hot tea and hot water, and people smoked, smoking was pretty common then. Warm blankets were plentiful in rainy weather--hospitals have warming cupboards.

O'Hara: Where did the food come from?

Brean: From the kitchen in Cowell. It became so stressful, because some people ate in their rooms and some people shared food with their attendants, which I didn't see, you know. Some people liked the food which then was prepared fresh from a wonderful kitchen. I thought it was really quite good. But eventually a rebellion against "hospital food" grew strong and active. And they decided that they could hire somebody to cook and bring them food. They did so.

It was a disaster. The person they hired, he claimed, "Oh, I'm a wonderful, wonderful chef. I can make the Taj Mahal out of mashed potatoes." That's the one that got me--I was just fascinated by it. I make a Taj Mahal out of mashed potatoes, I can make Rome's Parthenon out of--something, you know. So he brought in home-cooked food. That was a big hassle because he didn't get there on time, his car didn't start, he didn't have wheels. Sometimes it was wonderful and it rapidly went downhill. So then they got rid of him.

O'Hara: Did students pay for this?

Brean: Oh yes. They hired and fired "food people."

O'Hara: They pooled their money?

Brean: Yes. Finally they got rid of him and then it was the Leaning Tower of Pizza. No comment. But that was getting toward the end, when things got sort of a little unraveled because the hospital was suffering such budgetary cuts.

O'Hara: Who played pool?

Brean: Many of the boarders liked to play. You could do it seated, you didn't have to have a lot of upper extremity strength or manual dexterity and you could wear an aid.

O'Hara: You mean something for the hand?

Brean: Yes. The same kind of velcro straps that could hold a spoon, or a pen, or a pool cue. It wasn't used a great deal, as I remember. And then the typical rooms that the students had were equipped pretty standard fashion, regular hospital bed, mattress, pillows, blankets, sheets, so on. I can tell you that there must be countless dwellings that have sheets marked Cowell Hospital. Blankets marked Cowell Hospital. Pillows, pillow cases. Towels. All over this country.

O'Hara: Is this something else you didn't see?

Brean: I did not see it. They moved out into real apartments. A real thrill! Well, these people are not going to go out shopping for sheets. Maybe they brought them back in a few days for all I know. But each room had a bed, the typical adjustable hospital bed, cranked upward--this was before the electric bed--a bedside cabinet and table with a swing around top, and a table that rolls up over bed. A work surface, handy and useful. A couple of lamps, a couple of chairs. It got filled up pretty fast with personal belongings. Pictures, paintings, and art objects: incense burners, you know, and everything else. Bedding that was more distinctive, quilts and Indian serapes, and whatever.

Let's see--in my office, my office was open all the time except at night. Then the night orderly had the key. It irked one person--a wonderful attendant. Black beard. Excellent, excellent orderly. Very crisp, very sure of himself, you know. He thought my locking the supply closet was an assault on the students, since of course the Department of Rehab was paying for it. But when we ordered these, the stuff that came up was enough for months. There was no reason to leave it hanging around. Anybody could get whatever he needed.

It wasn't a good idea to leave it unlocked for all the street people who were up there. I felt responsible for all those extra syringes and the basins and the packs, and you know, the catheters. These were dealt out when supplies came and extras were in there for the use of everybody.

I was required to write periodic reports on the progress of the students' health, et cetera. I also wrote to UC personnel (also routine and brief) on the paid orderlies.

Orderlies, Nurses, Attendants

O'Hara: Could you describe the sort of--who was employed there? You were one of the administrators.

Brean: Yes.

O'Hara: And who else was employed by Cal?

Brean: When I first got there, students had to ring the phone on the second (hospital) floor and ask for orderly help. Regular hospital orderlies who said, "Now what? Already overworked downstairs. Now come on, anybody else, because I'm not coming back here until five o'clock." It was terrible. I mean they were nice guys but they were persona non grata. A few of the nursing staff on the second floor had mixed feelings toward people with disabilities. A gulf between me and the other nurses developed. I did not want to be a registered nurse--in white! At first I had to wear a uniform. It took me a while to convince them, to get up the courage to wear street clothes.

The staff nurses were very capable and very good bedside nurses, excellent. But they had aboriginal ideas about people with disabilities. They either patronized and infantilized folks in chairs, or they had dark suspicions of wild and weird sex performed, if you only knew!!, by disabled folks. But they never talked straight about anything, it was just this kind of, mmm, you don't know what goes on up there with all the--what, what? But then I finally realized what they were talking about.

O'Hara: Why would they even think to complain, what was their--

Brean: They didn't know enough about the whole thing--of disability. They did not have any function on the third floor, but in case of emergency at night or on weekends (in my absence), they would come up to help. It was decided by all that students on the third floor should be treated at night as regular students through the emergency room downstairs. They were not "inpatients," they should be treated by whomever's on call at the time. That put a very different face on the whole thing. I mean they took care of whatever they took care of. As far as the nurses--

O'Hara: Were there a lot of calls to the nurses?

Brean: I don't know, no I don't think there were a lot because they had their own attendants, even then. But the nurses didn't like the attendants, they didn't like the way they looked, and they didn't

like the way a lot of street people looked. They did look odd, Susan.

O'Hara: How did they look?

Brean: Well, we had one attendant who came in, was trying to sleep in peoples' bathrooms. This is the guy that had blue sequins pasted on his eyelids. These were the students at Cal who wanted to make some extra money and couldn't work regular hours, that was great. We had people who came there running away from the draft, dropouts from Yale, from Harvard, from MIT, from every place you could imagine. Berkeley was the place to be! They became friends with the students; they were intellectually alert or they would have been looking for work elsewhere. We were very lucky. There were a lot of awfully bright people, and nobody asked them a lot of questions. We were so lucky. Amazing.

O'Hara: I read somewhere that attendant work, or maybe it was only orderly work, was allowed by the draft board if you were a conscientious objector.

Brean: Yes. People who wanted to be COs had written to their draft board that they were terribly religious and were against war, and they were going to do their service if possible in a hospital, which was certainly allowed. But in order for them to be qualified, the hospital would get a letter to qualify their service. Pretty soon I started getting letters questioning this from a Colonel McCann, in Texas somewhere, asking me about so and so. "He says that he is a conscientious objector and blah blah, and that he wishes to provide service to disabled, to crippled students or something like that in Berkeley. Would you please (since I was an RN) advise us of exactly what the status is, what he will be doing so that we may process this."

Dear Colonel McCann--I used to just love writing those letters because I would detail body functions. I could just imagine Colonel McCann saying to his colleagues, "Hey fellas, here's another letter, boy I bet this kid wishes he were in 'Nam right now."

O'Hara: You have mentioned street people being up there a couple of times. I think for the benefit of future historians, what was a street person?

Brean: Oh, a street person was a dropout. These did not live on the street. They were just the kids outside.

O'Hara: Flower children, they would call them?

Brean: Yes, they were flower children. Hippies. They congregated as you know in Berkeley like iron filings to a magnet. When they saw people in wheelchairs, their peace and goodwill was transformed into a wish to help. So guys in the wheelchairs were very happy with attendants who felt that there was more to life than keeping regular hours and doing what your parents felt you should be doing. And it worked out beautifully, so the word got out that there were a lot of nice people, that it was "different" up on the third floor, and they learned a lot.

We were on first-name terms but there was an important awareness of a generation gap. I wore office clothes to work when I stopped using uniforms. I didn't come in jeans.

Partnership with Students

O'Hara: Last time you said that John had said after some months that they trusted you. Do you think that it had anything to do with the fact that you came from a medical background?

Brean: Yes.

O'Hara: What would make them mistrust someone from a medical background?

Brean: They are perceived as medical failures. Their disabilities reproach and even embarrass the doctors. Nobody likes to feel like that, especially those with an exaggerated sense of self worth. Often are not included in decision making, often lofty and patronizing. That is going out of style--but slowly! Never mentioned, often palpable.

They had been overly directed, perhaps intimidated. John Hessler had been warehoused in an old folks home for many years before he came to UC. They didn't have any place else to put him. He once told me of having a doctor come in with a group of students and then pick up John's hand to demonstrate and then just drop it on the bed and walk on to the next bed. John felt insulted. The experience of being the only young person among many old helpless and hopeless people was horrible for him, he said, and led to hostility.

We had plenty of differences over the years, but I miss him and I miss Ed. I just cannot believe they're gone.

O'Hara: Twenty-four years later now.

You mentioned that you learned from the students and they learned from you. Can you give me some specifics on the ways you were teaching some things and you were learning something?

Brean: Yes. Every single student in that program came from a different place. They came from different rehab backgrounds too, so each of them knew different things in self-care techniques.

O'Hara: You mean ways of doing things?

Brean: Absolutely. We had one student who had a way of emptying his leg bag easily. He demonstrated it to all of us. A cheap and simple clamp which you squeeze to open and empty. There he was in his bathroom, with everybody crowding in their chairs and all the attendants hanging around. He throws open the toilet lid with a wonderful gesture, flung the end of his drainage tube over the porcelain, and then to everybody's astonishment, leaned on the clamp.

O'Hara: With his elbow.

Brean: With his elbow. We all go wow. It was a wonderful, wonderful trick. He didn't need anybody to drain his leg bag, because he could do it himself. Free. You won't be able to find that in a book.

O'Hara: And that was a major thing in those days wasn't it, the leg bag.

Brean: Oh yes. Because you had to hire people to do stuff like that.

O'Hara: Can you explain the leg bag, for future historians, what are we talking about here?

Brean: But first, before I do that, just let me tell you one thing about the third floor and some of the atmosphere of the place. At the time, Reagan was governor. And whenever he was in Berkeley for the Regents' meeting, that nice little old lady in the Campanile tower who played the chimes daily at twelve noon would play the Mickey Mouse anthem. The students would stop and say, gee, Reagan's in town.

O'Hara: It would play only when he was in town?

Brean: That song.

O'Hara: Oh, I didn't know that.

Brean: So to the leg bag. One major fact about cord injury is the problem is that the kidneys produce urine in the normal way, but

the valves that control the flow out through the urethra are not functioning. In other words, they are incontinent. A collection device was used on men, from a condom and tubing. They were not ready made at that time, but were made by attendants.

O'Hara: You made them? Out of what?

Brean: A condom, with a little catch end. The attendant fastened one end onto the drainage tube and the other onto the penis of the quad. The leg bag would hold probably a liter, and was strapped onto the lower part of the leg, under the clothing. It had to be emptied frequently because the people drank a lot of water to keep their kidneys functioning.

One boarder came from a rural place in northern California. He had been cared for at home by a pair of loving parents for about nineteen years. They'd never heard of pads and tubes and collection devices. They kept him diapered, and he never had a pressure sore. They must have stayed up and worked for him night and day, for nineteen years! Then somebody who heard about the program got him admitted. He was at UC, just all agog. He was a student. He was provided with a waterbed, a "first." Folks had to try his waterbed, when he was up in his chair. It was a very exciting innovation.

O'Hara: Was it a water mattress or just the cover, the thin covering over a mattress?

Brean: No, it was a bed in which there was a very wide waterproof, fitted mattress filled with water and a thermostat-controlled heating element. The space program labs in Downey, California, were right by Rancho Los Amigos, famous for rehab research. Similar problems and needs made for relevance. Stuff not even marketed yet were highly useful to us, so reflector tape, materials, "multiple use" devices for self-feeding, et cetera. Anyway, we had lots of different kinds of things there, and we had lots of experiences that students could talk about.

Somebody broke his neck skiing. He fell down a mining shaft in the Sierras. Others in rehab facilities who couldn't get it together. Things didn't work right for them. Some were in an automobile that hit a deer. Or fires. Or diving in the surf. We didn't have Vietnam vets, though we tried recruiting. It seemed that Berkeley was anathema.

We could not get veterans interested at all, because of UC Berkeley's reputation. We also tried women students, because at that time it was nine to one.

Weekly meetings--time, Tuesday afternoon, four to five p.m, was set up and everybody was welcome. Policemen and firemen came. They learned how to assist wheelchair riders who showed up in ever greater numbers with fan belt, battery problems, et cetera.

O'Hara: So did attendants come to the meetings?

Brean: Oh, yes. Quads came, the students came. I would pretty much announce what it was going to be, it was pretty much the same, skin, bowel, bladder, food, drugs, emergencies, alcohol.

O'Hara: You mentioned cigarette burns?

Brean: Many of them smoked. Those were terribly dangerous circumstances, people getting a cigarette burn. If these people were smoking in bed with the ashtray by his face, he'd turn his face and shake the ash into the tray, and then when he finished smoking he'd just drop it into the tray.

They didn't need me to point out the danger, so I found a device, using a weighted-down ashtray with a little pipette. A lit cigarette that would stay in the ashtray. Too "Rube Goldberg" and those wondrous devices joined many others in storage.

Never a "Typical" Day

[Interview 3: August 17, 1995]

Brean: Well, I found stuff: records, my own notes, log books of mine, I used to keep a spiral notebook so that I could keep track of everything was happening all at once.

O'Hara: Oh, really?

Brean: Since everything was coming in at the same time and all of it was important, and related to the students' needs, I had to keep track of stuff. I had a secretary for one glorious period of about four months, it was wonderful. But I did everything; otherwise, I typed everything and kept copies and carbons and I routed them to the right place, and I told you what my duties were.

Berkeley was attracting more and more disabled people who needed help or advice, everything from wheelchair repairs to managing a cold, or for company, or for a true emergency.

O'Hara: Were they coming to see you?

Brean: Yes, they came in to talk about things that they needed. Health problems, supplies, where to get what, how to get it. Could I order it for them, which I could. All their catheter needs and pads and Spenko boots, you know--skin friendly tapes, padding, coughing techniques, spasms, sweating (which is way beyond mere perspiration), et cetera.

O'Hara: What's a Spenko boot?

Brean: A lightweight protective foot cover, carefully padded with foam. Expensive.

When the School for the Deaf and Blind moved, we got permission to use their swimming pool for disabled students. Also we got a Hoyer lift.

O'Hara: You did?

Brean: Yes. And we had had good communication with the California highway system, CalTrans. I knew they were doing research on reflecting material. We had samples not available commercially yet, of reflecting tapes on wheelchairs highly visible at night.

O'Hara: You wrote to CalTrans? Or phoned?

Brean: Yes. We got lots of stuff, and lots of information. Freebies, different types of tapes--you could stick it on the wheelchair. You saw it later, and see now on highways and signs, reflecting material. It's one thing to have a light on the front of your wheelchair, it's another to be seen from the side or from the back.

O'Hara: It sounds like there was a certain excitement about creating something, there must have been something that drove you to do this.

Brean: Yes, it was evident that there was much we needed and could use. It was a remarkable program with so many interesting and worthwhile people in it, I hadn't the slightest qualms--I felt that there wasn't anybody who wouldn't think it was worth paying attention to it. And I was right. The telephone company painted the whole department. PG&E was ready to put in a whole remodelled kitchen when we closed the program. We worked hard on the blueprints, everybody was involved in it.

O'Hara: People were impressed then.

Brean: Yes!

O'Hara: They caught your enthusiasm, or--

Brean: Absolutely.

O'Hara: High energy. I was going to ask you what a typical day is like, but it sounds like you didn't have a typical day.

Brean: Well, no I didn't. But the typical day, was truly atypical, but it followed a strange routine, a kind of a pattern.

In the first place, our physician, Dr. Wong, was a physiatrist. That is, a specialist in physical medicine and rehab. Every single thing that came from a pharmacy or a supply house had to be prescribed by a physician. It was cumbersome--especially as many items were routine.

For every student and every item, a separate prescription in triplicate was required. We used several supply houses. Once a month I would canvass everybody for his/her needs and make out the list of needs, sizes, preferences, et cetera.

I would write a prescription for everything, every darn thing. I mean I got to be such a good typist, I wish I could type like that now. I knew, and wrote everything by number, by name, the size, the amount, pure gum rubber, could it be plastic, what color, what brand--so many choices. I would carry them, signed by Dr. Wong, over to the pharmacy on Telegraph Avenue. Faster than mail.

O'Hara: Did you just bring them stuff back too?

Brean: No, they would deliver it, the orderly stored it appropriately in peoples' rooms.

I came in usually between nine and ten because I would stay until seven in the evening. I never had any "regular" hours. The students did not get up and get active, much before that, when their attendants arrived.

I read the log, see what had happened overnight. We had a green copy book, which was dated and time noted for all entries. I would leave messages in it for the night people, or reminders so that a new student coming in next week, maybe he's going to go into room so and so; night man, could you clean the place up, wash the bed down, make sure everything was clean and fresh. Or someone has a cold, and he's on medication, he should get something. You know what I mean, that sort of thing.

O'Hara: Who would read this?

Brean: The night people. Everybody.

O'Hara: From downstairs?

Brean: I doubt it.

O'Hara: So it was open for students, attendants, anyone could read it, anyone could write in it?

Brean: Theoretically, yes. Anybody could write in it, anybody could read it. There were two rules: sign what you write, and second, you mustn't really hurt anybody. Say what you want about public figures, but no mean things about each other. It was very useful and often fun. I'd read the log in the morning. The night man would say, so-and-so did not eat, has a cough, somebody left fried eggs on the counter. Or somebody would write, "everything quiet, no problem." Or quotations from Omar Khayyam. Or lengthy excerpts from Henry James, or Montaigne. I've brought a sample.

O'Hara: Was there someone there on duty at night, is that what I'm understanding here?

Brean: Yes, we had an orderly twenty-four hours a day, chosen from the ranks of the attendants by the students and okayed by me. This person was not to do attendant work; they were available for emergencies and routine tasks. Cord injured people had severe spasms--often.

O'Hara: Could you explain spasms, just as a parentheses here?

Brean: Oh yes. Involuntary, severe shaking, sometimes indicative of a problem somewhere in the body; less severe is normal for a person with a cord injury.

O'Hara: I've distracted you from your typical day, and you were talking about--

Brean: The kind of thing we would talk about in the so-called "clinics." They were not a lecture, but a group discussion. You know, what do you have? How do you figure it out--

O'Hara: This is with students?

Brean: Students and attendants. They were very interested. A twenty-year-old does not want to learn about how his bowel functions, he doesn't want to hear about his bladder, and he does not want to know about pressure sores. Is he ever going to walk? Will he be able to have sex? Post-injury hospitalization teaches much

confusion, pain, and anxiety of all kinds, but in a period of rehab, they can barely pay attention to that stuff.

So when they came into the program, and started to deal with life--going to the bank, or out to play poker with the guys. Going to classes, riding down the Avenue and talking to people, it was worth learning about. That kind of "re-education" was very important, because they were ready for it. They needed to be brought up to speed and to pay great attention to body functions.

O'Hara: You had these on a regular basis?

Brean: Yes, Tuesdays.

Let me take you through a typical day. I'd read the log book and see what was going on. I'd read my mail. I'd read the complaints from the second floor. I visited each boarder if invited in.

Then to my office and I would return dozens of calls, long-distance, local, foreign countries. Questions, needs, problems, and appointments. Talking to DR. Checking with doctors if something were going on.

We were always trying to recruit people. You would have thought, in the beginning, that everybody wanted to enter. But it was so strange and new, it seemed risky. We would call saying, "Listen, we've got this program for disabled students." DR did that too. When people came to visit, they were frightened by what they saw on the campus. Hundreds of shouting students confronting the national guard, fully armed, weapons fully loaded, tear gas at the ready (and used often).

But, so it didn't look safe. It was the sixties, it was Deadhead time, it was tie-dyed and slogans and you know, loud music. Loud chanting. Damp towels were stuffed under the front door to keep out tear gas.

O'Hara: So that was--part of your day was escorting people and entertaining families?

Brean: Oh, yes. Answering questions. Our goals. Our methods. And we had a lot of visiting firemen. The program had become quite well known. Australians came, with English, and people from the health department, from the social welfare departments, people from social services, school teachers, doctors.

Different agencies asked me to speak. Insurance companies. Government agencies. Sand Hill Road in Palo Alto had the big

insurance headquarters. They wanted to know about employing disabled folks. Can epileptics work? Diabetics?

There was terrifically high esprit in the whole department, everybody felt good about it, and everybody felt good about what they were doing. Nobody was helping the war effort. Nobody thought they were wasting their lives or wasting time working as a C.O.--and there were many conscientious objectors who were doing good stuff. Everybody learned a lot, they liked that too.

So the log book was very important. Of course stuff would come in that didn't belong in an open notebook--requests for admission and all that regular stuff.

O'Hara: You were in charge of admission for the Cowell program or--

First Contact with New Students and Parents

Brean: No. Recruiting was done by the Department of Rehab, the health service, et cetera. And later by the Disabled Students' Program and, of course, by the university. The family brought the new admissions to the department. They were so anxious, they told me of their doubts. They were reassured by the presence of a nurse--a real adult.

O'Hara: And your presence probably helped them do that, maybe because you didn't look like a hippie.

Brean: Oh no. I wore regular tailored "business" clothes. Never slacks or jeans. I was well into my forties and looked it.

O'Hara: And you were a professional that parents could identify with.

Brean: Yes. I had a job there--responsible and serious. I would keep in touch with them, they could call me any time. They confided a little bit, at first, and became very comfortable and would call. It became evident that this person was enjoying himself and doing very well.

O'Hara: You said, on the same line of thinking, that some people, however, were intimidated and didn't come once they saw the lay of the land.

Brean: One or two. The whole campus looked--was!--a battleground. The city was full of armed troops. One Christmas, a new student was carried into his room by his father. I introduced myself, we

talked in my office. He was really worried. He said, this Berkeley, this Cal. We come from Minnesota. He said he was a little worried--no, he was scared stiff. He thought he was putting his son in jeopardy. I said I'm there every day. They have my home phone number. I just live up the street. They have good and skillful attendants, he should talk to them. They may look strange, but they're very smart and very nice. The students trust them and so do I.

So he went home. His boy got an adapted van and learned to drive it in the parking lot. He got his license in June. His sister flew out to keep him company, and he drove that van all the way back to Minnesota himself. I wish I could have been there when he drove down his hometown street.

O'Hara: Oh, wow, right up to the driveway.

Brean: Six months. He was strong and confident. I love that story. It's not unusual.

O'Hara: That's right, that's the whole program.

More Activities

O'Hara: Going back to a typical week, you said there were some things you did by the week, and one was the clinic.

Brean: Absolutely, yes.

O'Hara: And then there was Robin-Aids.

Brean: Robin-Aids came on Tuesdays.

O'Hara: What is Robin-Aids?

Brean: Well, Robin-Aids is a company that was headquartered in Vallejo, and was named after Robbie Robinson who started the company, and his partner in World War II--they were corpsmen.

Robin-Aids came down weekly with new equipment, replacement parts for wheelchairs, et cetera, and I'd relay the new orders. We were having trouble in those days with an unusual one.

O'Hara: The Motorette?

Brean: Motorette, yes.

Special equipment made for use by one took time and persistence. The fight about motorized beds is a good example. It could take more than a year of documenting by letters the very real use and safety or the cost in dollars and time lost from school if it was denied.

The letters for chairs would include elevated leg rests, elevating back rest, what kind of wheel assemblies, what size chair, what cushions, we'd fight over the cushions with Spenko because they were very expensive. You remember that.

O'Hara: I do.

Brean: After a while they didn't fight anymore. But it took a long time. Those specific details are vital. Anyway, what I also learned was that some funding agencies would pay fifty dollars a month for a hundred years for a piece of equipment rather than pay five hundred dollars to buy it outright. They couldn't make that leap. Sometimes. So, that had to be done too, and it took a lot of time to get the results that you wanted. Robin-Aids was very nice, and this other wheelchair place was not so great.

Meanwhile, word was coming in from places like Minnesota on research on human sexuality and disability, and we were determined to get some of that for our students. I borrowed some films from them and reserved the library one or two evenings for "lectures," we called it. It was galvanizing, for some a shock, for some liberating. Some of the people did not want to see those movies. "That's fine," I said, "I don't watch them either," you know. If they were erotic, fine, but this is what was in the forefront of human sexuality and it needed to be explored. Given permission, as it were.

One morning, the supervisor came up on her "rounds," I guess, like a ship in full sail. Blinding in her cap and her white uniform, her white stockings and her white shoes and a big smile. And she says, "Hi, what's new." And this guy rides up to her in his wheelchair, and he says, "You will never guess what we did last night." He was sparkling with enthusiasm. I was behind her signalling no, no. And he comes down and says, "We saw movies about fucking." And she turned pale as a sheet. She said, "Well, I think I have to go back to my office now."

O'Hara: Oh, my.

Brean: It was so unlike him to say anything like that. He was carried away by freedom or something. Of all people. It was funny, and it was really quite an experience for all.

[Interview 4: November 1, 1995]

- O'Hara: I wondered about this osteoporosis study with Dr. Goldsmith--did that ever happen?
- Brean: Yes. It never got very far--I don't know why. I think they moved to Seattle perhaps. I found some sheets from that proposal and brought them with this.
- O'Hara: What was the significance of studying osteoporosis in this population?
- Brean: When I found out about quads and fragile bones which broke very easily--.

One time a student started to have lots of sweats and spasms. He said the only thing he noticed was he kind of bumped the back of the elevator with his (metal) foot rest. He had x-rays--it was a spiral fracture.

Now, that also led to some things where Jerome--we called and sent him over to Alta Bates, I think, because we didn't have facilities to set the bone at Cowell. When I left work, which was about seven or eight that evening, I went over to see how he was feeling. We'd sent him there with an attendant and his x-rays, and he was still sitting there. I said, "Jerome, what are you doing?" And he said, "Well, I'm waiting."

I spoke to a nurse and said, "We brought this man here at two o'clock in the afternoon and here it's eight o'clock! Has anyone seen him?" They said, "Well, we didn't know what to do." I said, "Did you ask him?" Hospitals were not used to disability and ambulation, and whatever.

Anyway, osteoporosis has special significance for quads.

- O'Hara: Was it known at all that it was the lack of standing on the bones and using the bones? Was it known at that time?
- Brean: There were articles warning about bed rest. You know, being in bed is a bad thing. Get out of bed. The space program spotlighted osteoporosis. Weight bearing was vital to keep bones strong. Lack of weight bearing leads to rapid loss of calcium from bones. The result is kidney stones and fractures. This has been a great problem in space research and rehab. Anything that prevents sitting in a wheelchair (like surgery--for stones or pressure sores) leads to bed rest which is undesirable. One stabilizes when sitting in that chair, and putting good weight

pressure on important bones, when you're flat on your back, you are not.

O'Hara: Do you recall if this Doctor Goldsmith published a report?

Brean: I don't know. Perhaps Dr. Bruyn does.

O'Hara: Another subject--I see you wrote a whole memo, "To the Volunteers," and I wondered if you had a lot of volunteers? I was under the impression that with the students employing people and Cowell employing people there weren't many.

Brean: There weren't. Which volunteers are you--

O'Hara: Well, it's volunteers that apparently wanted to help around Cowell Hospital. And these are your instructions.

Brean: Oh, yes. Excuse me, yes, I do remember "To the Volunteers." Oh yes, you know, there were many. There were not many of them on the third floor.

O'Hara: So really they were not a significant part of the program?

Brean: No, but they were nice.

O'Hara: Another item that I found is a memo--it's an agenda for an orderly meeting, obviously typed up by you for 1973. And once again I find you saying, "Your personal hygiene is important--not only the usual showers, but non-scratchy fingernails, hand-washing, etc." Was this a common problem, personal hygiene?

Brean: Not per se. The students hired their own attendants for bath care, et cetera. It is easy to tear the skin on a quad--a ring or scratchy watch, a broken fingernail--it can become a major problem for some people. "No dragging people up in bed in the time-honored way. You slide him, and you take the skin off his back." The attendants learned these things in our weekly meetings and from their employers, mainly.

O'Hara: I found another set of notes. This was another "Thoughts" on the Disabled Students at UCB from February 11, 1975. And among other things you were saying we need a rap group for quads and staff for problems of independence, both as a disabled student and as a young adult leaving home, and black/white relationships inter-group--and not restricted just to the residents there. I wonder, what prompted those two items, do you recall?

Brean: I don't remember specifics that about that period when several African American students were admitted.

Waning of the Cowell Program

O'Hara: You said at one time you felt like a pioneer.

Brean: Oh my, yes, I did.

O'Hara: And then at the end what did you feel like?

Brean: Tired.

O'Hara: [laughs] Why did the program close at Cowell?

Brean: The advent of Chancellor [Albert H.] Bowker was key. Dr. Bruyn left and the cutbacks swept over the whole hospital, ending many programs deemed frivolous, such as in-house care, the kitchen and food service. The new people could not see the forest for these little trees. I could not reach them.

O'Hara: What were some--

Brean: And there was a nurse.

O'Hara: Oh, nurse--nursing staff?

Brean: From several staff meetings--conferences on "the new crowd"--I gathered they wanted very much to take this really remarkable and by now very famous program and incorporate it into the student health program. I called John. I said, "I just came from a remarkable meeting," and described it.

At one point during the meeting, the head nurse, whatever her name was, says brightly in my presence, "Oh, goodie, goodie, now we can get a grant and it'll pay for the student health service." That's when I called John. And that's when a lot of things happened because the need for them to take these people and make them patients--that was not acceptable; it was a violation of the whole concept.

O'Hara: Make them patients?

Brean: Well, make them part of the student health--

O'Hara: Oh, I see.

Brean: When you're there, you're being medically cared for. But when they were there they were not being medically cared for; they were living in a dorm. And nobody was taking their temperature and nobody was making rounds. Nobody was saying, "Did you move your

bowels?" Or, "Visiting hours are over." You know, they were private, independent people in a shared living arrangement. But had they gone into the student health service--it was evident that the program would really be destroyed. And it was pretty close, I think.

O'Hara: Now, had the leadership among the students changed? Was there kind of a turnover in students? Was it a different kind of person living at Cowell at that time?

Brean: Oh, yes. By this time we had three or four guys whose wives had shot them or who'd been injured in gang fights. They were not ready for the University of California.

O'Hara: So that was a factor, then, in this deterioration?

Brean: Yes. Education, yes. They would be fine for Laney [College]--great! I arranged with John. If they had a year or two at Laney they would be great, but it's too fast for them now. They cannot hold their own with what's happening on the campus. And they'd get very discouraged and I would, too. But he insisted, saying, "They'll get tutors and so on."

O'Hara: And then there was tension with the orderlies, wasn't there?

Brean: Well, it was with one orderly. I'll tell you, I got--I don't know if I've brought you documents on him.

O'Hara: Oh, I think I read one or two.

Brean: Besides many infractions of basic rules, he kept trying to convert the students to his religion. You could not tell him, "This is not appropriate and it does not belong here. So stop."

O'Hara: Was he able to influence the other orderlies or the staff?

Brean: No, but people complained to me.

The Cowell program became very expensive. We were paying--is that on now?

O'Hara: Yes.

Brean: Because the inflation in the seventies was terrible. And the costs became enormous because DR was paying for a lot of the hidden costs: they were paying for the elevator, the janitorial, the laundry, the maintenance of the building, the roof--you see what I mean?

O'Hara: Yes.

Brean: Sort of pro-rated and it was very expensive. And it became untenable.

The personnel office at Cal was timid. They were so unwilling or unable to fire an unsuitable orderly. I was looking for a job that one in particular would prefer so he would just get out--that's how bad it was.

O'Hara: I think the tape wasn't on when you said that the students wouldn't tolerate that kind of--the earlier students wouldn't have tolerated that.

Brean: Not for a minute. They would have laughed him out of the program.

O'Hara: So is it true to say the leadership from the late sixties was gone then, doing other things in the community, and the program had lost its--

Brean: In about the seventy-three's--that earlier student leadership, seemed to be watered down by in-fighting and the new Cowell director, et al, took a dim view of the whole program--too noisy, too informal, et cetera.

O'Hara: Were you involved at all in what--

Brean: Probably. [laughs]

O'Hara: --in what I have heard was a very heated series of arguments about moving to the dorms?

Brean: I don't think I ever had--

O'Hara: I understand that Michael Pachovas and John Hessler were at odds over the move.

Brean: Oh, and John--Michael didn't want to move, John did? I don't know.

O'Hara: I'm not even sure what points of view--

Brean: It was an uncomfortable time all around.

III REFLECTIONS

On Early Leaders

- O'Hara: You mentioned that not all the students were leaders, but you [also] mentioned one time that there were three that you thought were good leaders and that was John Hessler, Ed Roberts, and Don Lorence.
- Brean: There were several. Herb Willsmore was very steady, influential.
- O'Hara: Don was such a quiet person. What was his strength? What gave him power?
- Brean: Don? He seemed very quiet, sure. But he was sort of the group mascot.
- O'Hara: He studied the regulations in detail, didn't he? I mean, whenever he was fighting, he knew the rules.
- Brean: Well, yes. I think he was a very interesting guy. I didn't have any trouble with him--mostly saying he shouldn't eat so many jars of pickled olives because he complained of heartburn. I'm sure his esophagus was in knots, you know. He did not hesitate to be forthright and that made a lot of flack come his way. Early on it was very inspiring to the other people.
- O'Hara: And you said that about John, also.
- Brean: Oh, John was excellent.
- O'Hara: John didn't care if you liked him or not.
- Brean: No, he did not. John was very strong and independent. We got along very well.
- O'Hara: What made the students follow him, or what made him a leader?

Brean: John exuded an air of gravity and of maturity. He could be very helpful but was not easy to get to know.

And Ed was the other side of the coin. Ed was smart, politically adept, and very charming. Now, if we had a problem in the department, a couple of students not getting along, I might ask Ed to come by. He dropped by for coffee and to visit a little, he'd hear about it and pretty soon it would be straightened out.

Ed would solve it. Somehow he knew how to solve some personality problems. The younger students looked up to Ed.

O'Hara: They were very different personalities.

Brean: Very different.

O'Hara: But astute politically in their own ways, is that correct?

Brean: Oh my, absolutely.

O'Hara: They knew how to get their way.

Brean: And they also knew what was good for those students, pretty much.

O'Hara: Would you say both of them were visionaries?

Brean: Both of them were ambitious. And persistent. And shrewd. But John, I think--I don't think he saw himself, you know, in the distance, as Ed sort of sensed that there could be this for him. I think John just was much more flat-footed about what's the thing to do and, "Don't let them get away with it," kind of thing. "Don't let this be diluted. Don't let it turn into something that's not what we see it should be." And so he was tougher.

O'Hara: He kept his eye on the ball.

Brean: Absolutely. He was not into rap groups and meetings and feely-touchy stuff--which Ed took us through at the outset of the CIL. Such a time! est types--you know.

O'Hara: Est came to CIL?

Brean: No, but "estian" people. Did you ever hear about Don Lorence going to est?

O'Hara: No. [laughs]

Brean: It was one of the high points of our lives. We laughed about it for years.

O'Hara: Oh?

Brean: He went to est. And apparently they lock the doors and nobody leaves. They refused to let him out. There apparently was a huge fight and he left, sued them, word was, took his money out, which was unheard of at est. [laughter]

O'Hara: Oh, that's terrific.

Brean: I said, "You are my hero, Don." He said, "I just had to go to the bathroom."

Personal Legacy

O'Hara: Well, what survived out of the Cowell program? It's still very famous, I think.

Brean: Yes. It was wonderful. Probably unique. And I knew it then. The time, the place, the people. It led straight to the emancipation of disabled people worldwide today.

O'Hara: What are you most proud of as you look back?

Brean: As I look back? I guess maybe just that I stayed the course.

I met people that I think are wonderful. They are still my friends.

O'Hara: I think from what I have heard over the years, students felt in general you were always on their side.

Brean: Oh, no question.

O'Hara: If there were fights, you were with them.

Brean: No question. And it wasn't out of a sense of loyalty, it was because they were so right. Absolutely. I'll show you that little thing I wrote about John Hessler at his death. And about Ed--when I met him.

O'Hara: Oh, yes.

- Brean: These students knew the difference between authority and power. That's why it worked. Isn't that right?
- O'Hara: Yes. Did your Cowell experience influence any of the rest of your work in your life?
- Brean: Yes. I taught rehab counselors at San Francisco State for many years--at the University of San Francisco with their special masters program.
- O'Hara: We don't want to skip over your CIL experience. You worked at CIL part time?
- Brean: No, full time after the Cowell program. There were some eighty people working there then. I did the same things--teaching, health needs, et cetera.
- O'Hara: What were you doing at CIL?
- Brean: People would come in just as at Cowell for repairs, for supplies, for equipment, for whatever they wanted, whatever they needed. I would check their skin if they requested, I would help them get referrals, and also did in-service clinics.
- O'Hara: Who was the director when you were there?
- Brean: At CIL?
- O'Hara: Yes.
- Brean: Ed Roberts.
- O'Hara: Ed was--the whole time?
- Brean: After the World Institute on Disability (Ed's next project) was begun, Phil Draper was the head of the CIL. And there was a difference in management style. You know, Ed was so charismatic and had such ability to hold people together through his force of personality. And Phil Draper was quite different. Phil was good. He did good stuff, he just wasn't showy about it. He wasn't a good speaker either. Phil Draper should be recognized for leading the expansion of the services beyond Cowell. It became obvious quite early that disabled folks came to Berkeley in large numbers. Some even hitchhiked. The Cowell program was limited to the "affinity group"--UC students--but helped anybody who asked--they showed up on the third floor for health needs, for the clinics, or just because it was welcoming.

O'Hara: Edna, rumor has it that you did some television writing.

Brean: Oh yes. I used to--I wrote stuff for some lesser stand-up comics.

O'Hara: Here? In California?

Brean: In San Francisco. "Stand up" just became popular. So I sold freelance stuff. I never took it very seriously. I wrote several revues.

O'Hara: Now is it true that you wrote for Joan Rivers?

Brean: No. Phyllis Diller, for one.

O'Hara: Phyllis Diller.

Brean: Phyllis Diller, who's still a very nice person. But anyway, but she wanted me--

O'Hara: How did you hook up with her?

Brean: Well, I wrote some stuff for her. She was floundering around in some club in San Francisco, and I--

O'Hara: Oh really? Oh, I didn't know that.

Brean: Anybody can talk to anybody, Susan, people don't realize. If you want to--I just went there and I said to the waiter, "Tell Ms. Diller I'm a writer, I'd like to talk with her." And she was very funny, she was very nice. I offered her about three pages of stuff and she bought some. She was very encouraging.

O'Hara: This writing background served you well later, I'm sure.

Brean: Yes.

O'Hara: Have we left out any major ideas?

Brean: No, I don't think so.

O'Hara: Can you think of anything you wanted to say, or that history needs to know, or that has been left out of the tale?

Brean: Of course! But many personalities, anecdotes, et cetera, while great fun to have at maybe a coffee-klatch, don't belong here. I've covered the complicated history as well as I could.

O'Hara: Well, you were a big part of it.

Brean: So it was fun.

O'Hara: Thank you, Edna.

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Disability Rights and Independent Living Movement Oral History Series

UC BERKELEY'S COWELL HOSPITAL RESIDENCE PROGRAM:
KEY ADMINISTRATORS AND CALIFORNIA DEPARTMENT OF REHABILITATION COUNSELORS

Lucile Withington

DEPARTMENT OF REHABILITATION COUNSELOR, COWELL RESIDENCE PROGRAM, 1969-1971

An Interview Conducted by
Sharon Bonney
in
1998



Lucile F. Withington, 1998.

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INTERVIEW HISTORY--Lucile F. Withington

In 1969, Lucile F. Withington was recruited by the California State Department of Rehabilitation in Oakland as the Northern California Rehabilitation Specialist for the Severely Disabled and assigned as counselor to the Cowell Hospital program on the University of California, Berkeley campus. Ms. Withington participated in early funding of the Cowell Hospital Program by the California State Department of Rehabilitation and served as the counselor for most of the earliest students in the program.

Ms. Withington tells of the early Department of Rehabilitation requirements for entrance into the Cowell Hospital program, criteria students needed to meet to remain in the program, the costs associated with students, and the issues and troubles that arose. She tells of the major incident which prompted the formation of the Rolling Quads student organization, which became a political power that could not be ignored. As a result of the confrontation of the Rolling Quads with Ms. Withington and the Department of Rehabilitation, Ms. Withington was transferred to another position within the Department of Rehabilitation.

Some years later, Ed Roberts, the first student in the Cowell program, became director of the California State Department of Rehabilitation. Ms. Withington talks about Director Roberts' attempts to shift emphasis to clients with the most severe disabilities and the department's response to this shift.

Ms. Withington was interviewed on March 23, 1998, in Surprise, Arizona, where she lives in a senior residential retirement resort. The interview was taped in a room in the community center building while Ms. Withington's dog, waiting outside, looked through the window. No pre-interview session was held, but there was a phone conversation prior to the interview.

The taped interview was transcribed, then lightly edited by the interviewer, and sent to Ms. Withington for her review. She lightly edited the first half of the interview and heavily edited and added information to the last half of the interview. Ms. Withington placed several of her personal papers relating to her work with the Cowell Hospital program in the Disabled Persons' Independence Movement collection at The Bancroft Library. The Rehabilitation Research Report quoted from in this interview is attached in the appendix.

Sharon Bonney, Interviewer/Editor

November 12, 1998
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 LUCILE F. WITHINGTON (FRANCES)
 Date of birth 6/24/33 Birthplace CAMBRIDGE, MASS
 Father's full name NELSON EUGENE WITHINGTON
 Occupation BUS. MANAGEMENT Birthplace JAMAICA PURIN, MASS.
 Mother's full name FRANCES ELIZABETH KNOWLES
 Occupation _____ Birthplace DORCHESTER, MASS.
 Your spouse 0
 Occupation _____ Birthplace _____
 Your children _____

Where did you grow up? BELMONT, MASS. UNTIL AGE 12 THEN BRATTLEBORO, VT.

Present community HAPPY TRAILS ADULT RESORT

Education PLEASE USE WHAT YOU WOULD LIKE FROM THE ENCLOSED BIOGRAPHY

Occupation(s) REHABILITATION CONSULTANT - BUILDING NEW WHAT MAKES LIFE EASIER CURRENTLY AND IN THE FUTURE

Areas of expertise ARCHITECTURAL DESIGNS FOR EASIER LIVING

Other interests or activities USE OF DOGS AS COMPANIONS - AS WELL AS PROTECTION AND DAILY HELP INCLUDING CARTING - TRAINING MY ROTTWEILER "DENI" IN SCHUTZHUND.

Organizations in which you are active UNITED SCHUTZHUND CLUBS OF AM.

UNITED STATES ROTTWEILER CLUB -

SIGNATURE Lucile F. Withington

DATE: 10/19/99

INTERVIEW WITH LUCILE F. WITHINGTON

VOCATIONAL REHABILITATION COUNSELOR FOR THE COWELL HOSPITAL
RESIDENCE PROGRAM, 1969-1971

[Date of Interview: March 23, 1998] ##¹

Cowell Hospital Residence Program Special Assignment, 1969

Bonney: Lucile, maybe you could start by telling me how the Cowell Residence Program at UC Berkeley got its start.

Withington: The idea of having students live at Cowell Hospital, on campus, University of California, was originally initiated by a lady who was just about to retire, name was Catherine Butcher, in the Oakland office of the Department of Rehabilitation at 1111 Jackson Street. She had interviewed a number of clients and felt that they had every--there was every--reason to give them that opportunity to go further on in their education.

I was brought into the picture in 1968 because Catherine was retiring, and I was working the San Francisco District under Janet Pence, at that time. They were looking for a counselor who had an interest in working with people who had less mobility than others, including quadriplegics, paraplegics, et cetera. Muscular dystrophy was included as well. And they recruited me from the San Francisco office to become the Northern California Rehabilitation Specialist for the Severely Disabled. And I had just begun with the department in 1966, October 22nd, so that it was really in about 1969 that I transferred to the Oakland office and was given the special assignment of developing the program on the third floor of the hospital at Cowell, which is right below the women's soccer field, on the upper level of the campus.

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

- Bonney: So what did you do, how did you start the program or develop the program?
- Withington: It had been Catherine's idea--and I'm from Boston, sorry, that "r" [laughs]. Different counselors from different districts would submit their clients' names who they felt might be appropriate for the program. I worked closely with Ed [Davies], psychologist, Oakland office, at the time, because we wanted to develop some method of screening in order to project, we hoped, successful candidates for the University of California who would be able to graduate, given that opportunity to attend classes. As a result of this, we ended up using the verbal portion of the Wexler Adult Intelligence Scale [WAIS], because we were able to look at, not only the verbal knowledge, but their spatial, as well as numerical skills, through the verbal section of the WAIS. So, if the counselor referring the client was from a district that had the availability of being able to produce this end of the scale for one of the requirements, then I would review them and interview the people.

The main person who helped this program work was Eleanor Smith, R.N., of Hanly Road, Oakland, because she was a bowel and bladder specialist for practically every client, or patient, I should say, with that type of problem, from Oakland and northern California. She worked for the Department of Public Health at the time, along with Chester Wong who was a physiatrist in Berkeley. They worked very closely together. Eleanor was the one that really put the nuts and bolts together and assisted in making the third floor of Cowell Hospital appropriate for our Department of Rehabilitation clients. She was, as I said, a bowel and bladder specialist, and needless to say, her nickname was "Shitty Smitty."

- Bonney: Let's go back just a bit, because Ed Roberts first came to the University in the early sixties, so he had been living at Cowell for a while. How did DR [Department of Rehabilitation] eventually get involved in paying for some of the program elements, and what did it pay for?
- Withington: Ed Roberts was a client initially of Catherine Butcher's. I think it was through his efforts, and his mother's, who worked as an attendant for him, that a lot of this began to get off the ground. And the only problem with this was that the clients who needed attendant care--and needed money to pay for attendant care--were having to use all kinds of different excuses with the Department of Social Welfare in order to try to get this money. So, with Ed's inspiration and tenacity, and my feeling that not telling the truth, in order to get

money, was inappropriate, I went up with the facts to the Department of Social Welfare and said, "Let's get the show on the road the way it should be, and let's not be teaching people how to manipulate the system. Let's get the system setup appropriately so that it can assist lawfully."

From my files, I have here a letter, Department of Social Welfare, 2415 First Avenue, Sacramento, August 2nd, 1968. Title of the letter is "Circular Letter No. 2178 (ATD -Aid to the Totally Disabled)." It is "To: County Welfare Departments. Subject: Disabled Students Living in Cowell Memorial Hospital, University of California, Berkeley."

The Department of Rehabilitation and the University of California have worked out a plan whereby a small group of severely disabled individuals are able to live at Cowell Memorial Hospital, the University of California Infirmary in Berkeley, and attend classes at the university.

The project was planned to facilitate the rehabilitation of severely disabled young people in order to avoid permanent dependence on public welfare.

These students are living in a room and board arrangement, and are not considered to be hospital patients.

Their care is budgeted as follows: \$87 for Room and Board, \$50.50 Personal and Incidental Expenses, \$300 Attendant Care, for a total of \$437.50.

In most cases, the difference between Cowell Hospital charge of \$450 and \$437.50 is being met through county funds. In circumstances where this cannot be done, please contact Mrs. Catherine B. Butcher, Department of Rehabilitation, 1111 Jackson Street, Oakland.

A question was recently raised regarding federal participation in these payments. There is federal participation in payments for these cases.

End of letter and notation, "Remove and destroy this circular letter after 8-1-69." So that apparently is about the beginning date for me in the program, as Catherine was retiring.

I went to the County Welfare Department in Sacramento and said that this wasn't enough money. That room and board were the responsibilities of ATD [Aid to the Totally Disabled], the Welfare Department. And the Department of Rehabilitation was there to pick up transportation expenses, this had to do with whether somebody needed a pusher to push their chair to class, it was to cover their books and supplies, on some occasion it was to cover clothes appropriate for school, and then of course, it got into things that became very expensive items. Whereas, we would help, along with the county, and that got into transportation expenses and trying to get ATD, Medi-Cal schedules from years before [prior to 1969] to put in money towards wheelchairs that were appropriate, upgrading from push to electric wheelchairs. Thus greater individual independence. Whereas these people, some of them have been in one room in a house for twenty-eight years, because they couldn't afford an electric wheelchair. But if you're going to be independent in a college, you've got to have these. It started to become a very expensive program. I believe they finally ended up, probably under Gerry Belchick, block-funding it. That is the State Department of Rehabilitation would commit a certain amount and get matching or more from the federal government.

Bonney: Now, "they" is DR [California State Department of Rehabilitation, previously Vocational Rehabilitation], they block-funded it?

Withington: Yes. And that would be more Gerry's ball game, than mine. My part of the program was trying to select people who could best benefit, and use the program, and also, from my knowledge of other clients from where I had been in San Francisco, and interviewing clients at Kaiser Rehab Center in Vallejo who might come in. I have a list of the clients that--a few were already in, but then I brought new referrals into the program. Do you want to have me read that list?

Bonney: Sure. Who were the people who were in the program?

Withington: I believe this list may be in order. I'm looking at something that I wrote twenty-seven years ago [laughs] of when they came into the program. But in some respects, that doesn't appear to be so. But--I see, we had some living off campus, but who were still considered Cowell clients. First name on my list is James Donald, he was living off campus. Jerome Frazee,

William Glenn, Donovan Harby, John Hessler was living in France studying French, Larry Langdon was living off campus, Ed Roberts was living off campus, at home, and his mother was serving as his attendant. He was about the first in the severely disabled students' program. We had Scott Sorenson who was living off campus on Dwight Way in an apartment near where the subway entrance is now, living on his own. Cathy Caulfield was a client of mine from San Francisco who came over to the program. We had Don Lorence, Herb Willsmore, Sue Ward; Larry Biscamp was a client of mine in San Francisco, and Charles Gwin Hinkle who lived at home. And that's number fourteen.

Program Requirements: Predicting Success in College

- Bonney: Now you mentioned, when you were talking earlier, that you worked with a psychologist on the WAIS. Students took the WAIS, and you were trying to predict who would be successful at the university. What were the other requirements that students needed to meet before they could get in?
- Withington: Well, we developed a number of minimum standards for academic performance, in the District State Department of Rehabilitation guidelines, Revised March 1968. And as I read, "These standards are designed to act as guidelines and are based on comparable standards for all students. If these standards impose undue hardship, they should be discussed with their rehabilitation counselor." In other words, these were the standards that were sent out to the surrounding districts who had outstanding severely disabled students that they wished to refer to the Cowell program.

Let's take a look. "1. For all first semester/quarter students, no less than nine units will be considered acceptable. 2. For all continuing undergraduate students, no less than twelve units will be considered acceptable. 3. Withdrawal from college courses requires prior consultation with your rehabilitation counselor. 4. Students whose vocational goals necessitate graduate training, will be expected to maintain a "B" average in their major field of study. 5."--and I have an arrow pointing towards that,-- "Initial selection of a major field of study must be mutually agreed upon by both student and rehabilitation counselor. 6."--also with an arrow,--"Any change in major field of study requires prior approval of your rehabilitation counselor. 7. It is the responsibility of the student to contact the

rehabilitation counselor towards the end of each term to discuss his current progress and his plans for the following term. During this contact, the client can arrange to receive his tuition and book authorizations for the subsequent term. 8. It will be the responsibility of the student to provide the rehabilitation counselor with the grade slips received at the end of each semester and quarter. (The grade slip will promptly be duplicated and the original returned to the student.)"

Bonney: And did all the students in the residence program follow those guidelines?

Withington: No. [laughs] Here's where it became a very interesting lesson. It was a tough one for some, and an easier one for others. And it really has to do with life, and that is if you have a bit of spunk, and are willing to challenge, that sometimes that is not a bad idea. However, at the time, the people were challenging what they should take, or how much they should take, and they were taking things that didn't look like they led to a vocational goal that would be not taking seven, eight, nine, ten years to get to.

The counselor would be challenged by her supervisor to try and redirect the clients into something that was possibly more easily attainable in the supervisor's eyes. And then we got to find out how the client and counselor got together, as to whether or not they could reach a rational reason for perhaps changing the goal, or arriving at a goal. So in answer to your questions, was this a simple thing, did everybody sit right in the groove? The answer is, "No!"

Bonney: Give me some examples of people who didn't fit into groove, or that an issue came up with. What were some of the things that happened to these students?

Withington: You're really working on my memory! The age of the students was from the low thirties down to the high teens, if I remember correctly. So the maturity was involved in this, not only chronologically, but also based on the amount of time they had spent out in the real world, as opposed to being in a sheltered situation.

Another point of view which was, and still is, I am sure, being used, is whether a person was succeeding in spite of the disability, or whether they were using the disability to get them "through the door." Going at it from a sympathetic point of view of "poor me, why shouldn't I do what I want to do?"

And then we had people who just had a hard time learning how to cope with a group-living situation.

One that I remember best was my client that I went to the ends of the earth for, from San Francisco, to get him into the program because he had lousy test scores, and that was Larry Biscamp. A very, very bright guy. But he got over to the program and I think, probably, the whole scene just was kind of so overwhelming, that without telling anybody he quit going to class, he also had his own personal problems, as well as physical problems. I remember at one point Eleanor told me that, going down the hall of the third floor you knew when you were about to come to Larry's room because he was on an external catheter, but kept taking it off, and that his room just reeked of urine, and his bed reeked of urine. She wanted him to "grow up" and get with the program.

Well, [laughs] one story I remember hearing about is, Larry's response to this was, "Well, I think I'll get drunk tonight, and I'm going to walk." And so I understand he used his arms to push himself up out of his wheelchair and collapsed flat on his face, and perhaps, out cold, I don't remember that end of the story. But, Larry was a part of the reason that Ed Roberts went to the newspaper, and got me involved, with the fact that perhaps I was being too harsh on criteria to maintain in the program.

We had another young man who also was having difficulties in this area. I believe it was--[consults documents] I think this was Donald Lorence. For reference, I do have Cowell Resident Project student grades for the fall of 1968, the winter, the spring, that will be submitted to the project. We have one student who was living off campus, Larry Langdon--did you want to know about individuals at this point?

Bonney: What about Larry?

Withington: Larry was further along in the program. His major was psychology and biology. And believe it or not, he had gotten through the basic study program at Cal and was doing an internship over at Langley Porter Neuropsychiatric Institute at 644 Parnassus, double-check that address, the University of California Medical Center. Unbelievably, is the fact that somehow the--this was, I believe, a little bit earlier--the Public Welfare Department would not assist him in his transportation. So this man, in a wheelchair, hitch-hiked from Berkeley to UC Med Center, right beside it, Langley Porter Neuropsychiatric Institute. He was independent, he was a great guy, but I didn't keep particularly close tabs on him.

He did his thing, he turned in his grades, and it was an absolute shock to me, later, when I found out that as part of his working in the field of psychiatry, psychology at Langley Porter as a, I guess he was an intern--I had been one myself there, although as a vocation rehabilitation counselor, from San Francisco State University now.

But he hired somebody to drive him down to the desert, and pitch a tent, and to leave him there. It's very hard for me to believe that Larry, with all his knowledge of biology and psychology, didn't realize that maintaining an adequate fluids level in the desert is extremely important. Essentially he chose that way as leaving the world. He was found many days later when the people returned for him. He had not planned adequately, or he had--this was his choice. And to that, I respect him. But on the other hand, you look at a person, you think he's really doing great on the outside. And the outside doesn't tell it all.

Electric Wheelchairs and Adapted Vans

Withington: The same was true of Ed Roberts who fought like crazy to make it, and by gosh, he did to become the director of the department [California State Department of Rehabilitation]. I remember the time when Eleanor [Smith] discovered he could move his little toe, I think it was the little toe of his left foot. And, aha! immediately she said that means that Ed should not have to have a pusher, and not be dependent on somebody to move him wherever he wanted to go. But, by gosh, I would find a way that we could manage a switch on the wheelchair so that he could drive his own electric wheelchair, and be independent. And this was probably one of the greatest days in his life, from what he said later. And it certainly was then.

Let's see, Ed spent so much time in an iron lung and then was able to be in a wheelchair, and of course, he was a post-polio individual. And the world just really opened up for him. He was also a political science major, and he made every use of that that he could. And ended up being the director of the department, which took the department in an interesting swing, away from "let's just work with the easiest clients, but let's work with the severely disabled." As people came through the program, Ed found jobs for them in Sacramento. One of them was Jim Donald. So it was like a pendulum, being a counselor in the department. First you're told not to spend

money. However, I was on the special project, was of course, spending money, but then that became a big no-no. "Oh-oh, this is going over budget," et cetera.

Bonney: This is before Ed became state director?

Withington: Yes. For instance, another interesting story, which might-- it's up to you all and it's--the story I heard, and I challenged the client on it, and my version of it may not be true. But the bone of contention between Jim Donald and myself, who later went on to Davis to the law school, was that one Christmas vacation, I understand that Jim really didn't like one of the wheelchairs he had and wanted another electric wheelchair. He didn't live on the third floor of Cowell Hospital. My understanding is that the wheelchair got stolen from outside his apartment, and that he wanted the department to buy him another wheelchair.

This gets really intricate, because, in order to get a new one, you have to prove that your old one is absolutely out of commission, and where did this wheelchair go? I was young, younger than I am now, and naive, and I'm still somewhat naive, but I didn't believe him [laughs]. We went round and round about this. I really had some reason to believe, and it was from other things said, that he really did still have this other wheelchair, but he wanted a another one.

Now at that time, one was considered enough. At this time, and twenty-seven years later, darn it, if I only had one chair to sit in for the rest of my life, I would really be pissed off. I would want a variety, and I want a chair to do this, one which would do best for this, and one which would do best for that. And some wheelchairs have come a fantastic long way. And people being able to do things from them; play basketball, tennis, et cetera.

At any rate, when Jim wanted to go to Davis, I didn't want to give him a reference to Davis. But anyway, Jim got in on his own and graduated from Davis and became a legal counsel for the Department for Rehabilitation. And my understanding is, thanks to Ed, the hierarchy built up in Sacramento, where we had a great deal of our budget going to our Sacramento office for staff salaries, and less going to the field counselors to be used for client's needs.

Bonney: Under Ed's directorship, you mean?

Withington: Yes.

Bonney: Now, I've heard a story that Ed bought vans for his pals in Berkeley when he got to be director. Do you know anything about that?

Withington: No, I could not say I knew about that. I will say this, I know that Jim Donald bought his own van directly from Phil Niles, who was also one of my clients from Vallejo, who built adapted vans for the handicapped. And I'm trying to remember Phil's business name, and I can't. I've even done work for him down here in Phoenix--

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Withington: --over the years, especially in assisting other clients get vans adapted for wheelchair-bound persons who are not in the program. And it's rather interesting because when I first came to Berkeley, and he was not in the Cowell Program, but he was not going to high school, either, he was sitting on his duff. I said to him, this was back in '68 or '69, I said, "Phil, why don't you just take some time off and grow up?" And so I closed his case for the time being. He actually did get out there and take some time, and what he really wanted to do was become a race car driver. He was a quadriplegic, and he was determined. He worked on this project, which eventually took him into the business of adapting vans for people in wheelchairs to drive. And on the side, unbeknownst probably to many people, he did get a race car and he did drive it one time. And I knew Phil and his dad, cause his dad used to bring him to work in Vallejo later. How that guy is still alive is beyond me, but I had even gone through a company down here in Phoenix to check out their manufacturing process for him, because he was ordering a van to be modified here and then taken to California. And that's been since I've been here at Happy Trails, in about 1992.

Bonney: So he's still active in the business then?

Withington: As far as I know because he has done modifications for another ex-client of mine. Alan Fabyancic, who I recommended you interview, deals with him regularly. Alan was not a Cowell student, but they rewrote the book when I managed, with Al's help, because he had graduated from the University of Santa Clara and wanted to go to law school, and he'd been turned down at Boalt. And given his grades and the fact that he had been in charge of directing the college's biggest show of the year, I went to the law school at Boalt, at the University of California, and said, "I'd like you to reconsider this man and also go back and take another look at his background, because what shows right here is not the whole person. This young man

has a tremendous amount of stick-with-itness, also very bright." So Alan was just delighted, and so was I, when Boalt decided to reverse their decision and accept him as a student at Boalt School of Law.

He lived independently, not at Cowell Hospital but in one of the graduate dorms. But, we did buy a van for him and adapt it, after he got through law school and landed a job. He didn't pass the bar the first time, but he did get a job with the Bank of America when they were first coming in with Visa cards. His job was on Van Ness Avenue, about five blocks up from Market Street. At that time the department had decided, "Well, we're not going to provide vans for students, we're only going to provide them if you actually have a job," because vans have gotten very expensive. Even the first one we were building ran about \$40,000 half and half, with the expense for the basic car and modifying it, which was also my involvement with Jim Boscacci.

But back to Alan, Alan learned to drive on Van Ness Avenue. I had one of the local television networks come in and take pictures of him, Channel 5, and I also did some movie work on him and some pictures, because Alan was very involved with the independent living group in San Francisco. He was also on the board of directors of Bay Area Rapid Transit. And, son of a gun, Alan who had, may still to this day, not be accurately diagnosed, had a handicap that started when he was about seven or eight, and he slowly lost control of the distal end of his extremities. And although this was not diagnosed as muscular dystrophy, he was in braces by the age of seven or eight, and he was darned if he wasn't going to be a Boy Scout, and he was going to be a Boy Scout in the regular Boy Scout troop, not in a handicapped troop. And his mother also had the same disability, so this disability was hereditary by nature.

So Alan came into the office one day, at this point, he'd gone from braces to crutches, in high school, he'd gotten into a wheelchair, now he was in an electric wheelchair but could still do transfers. I said, "Put up your hand and push." I wanted to see how much push strength he had since, if you're a quad and you've got one hand on the yoke of the steering wheel, and one hand on the yoke that handles the brake and the accelerator, whether he could handle this. And he demonstrated an unusual amount of strength. I said, "Alan, would you believe, I think you could drive." He said, "You got to be kidding, I don't believe it, but I'd love to."

And so, with Phil Niles, we developed a van for Alan. But the problem was, it was in the very beginning of the development here. And it didn't hold up well. Alan was having trouble in the steep hills of San Francisco, to keep from getting the van to stop when it should, and start when it should. We decided that his van was of more danger than a new one should be, so with Alan's help, we wrote a rationale as to why the Department of Rehabilitation should supply him with a second van. Because, actually, if he got in a whole bunch of mechanical trouble driving this van, the department would be liable.

Well, let me say, we pulled it off. He got into a second van. However, Sacramento rapidly changed the manual and stated that "the Department of Rehabilitation would only be responsible for acquiring one van, for a disabled person during their lifetime." Hopefully, there have been other people who have been able to keep up the persuasiveness and the stick-to-itiveness that Alan's had, because machinery has come so far in these twenty-seven years, that what we thought was great then, was an unknown menace in many ways!

Bonney: Now, this movie that was made, was this "The Road to Independence" movie?

Withington: Yes, "The Road to Independence" movie was not on a Cowell student, but was on a student of Catherine Butcher's, who had then been turned over to me. This was a young man who had broken his neck. It should be checked, but I believe it was a swimming accident. His name was Jim Boscacci. He had gone to a Catholic school, Saint Mary's, and wanted to become a teacher, had done his practice teaching.

His was the first van that the department adapted. Actually Jim and his parents went out and bought a bread truck that had the rolling down door in the back, it was high, so we had a ramp that came down from that. Then I worked with the engineers on this because, Jim, if he had stood up, would have been about six-foot-two, so he was a very tall guy, he didn't fit in a regular van. And as you all know, there were not the mini vans of today back then. We were taking roofs and cutting them off, and putting on bubbles and domes.

But the first van was a bread truck. It was adapted for Jim to drive. And lo and behold, the thing that kept him, as well as Alan Fabyancic, up against the steering wheel was a regular gate lock that swings shut behind you on a bar. And of course, on one occasion that lock opened when Alan Fabyancic had just come off the Golden Gate Bridge, and was

driving up Broadway, and the wheelchair started backwards. So the steering wheel did also in his hand, and he went right up on the sidewalk into a granite building. It's right there where the off ramp comes and you start up the hill for Broadway.

But, back to Jim Boscacci. As Jim was a teacher, and just a terrific guy, we wanted to record this. I was interested in photography and have done a lot of videoing since, and then was doing it businesswise in the dog world, training of dogs. What I did is, I got together and said, "Jim, let's make this a whole rehabilitation attempt by rehabilitation clients." And Jim thought this was a great idea. So the making and producing of the movie was my getting the money for the film out of the Department of Rehabilitation. And then another client, who wanted to be a radio announcer, interviewing Jim on a tape, after we did the movie. Then we had another client who wanted to be a court stenographer, who had to work up on her typing, she typed the script. So, in a way, it was the group of us against them (the budget-conscious Department of Rehabilitation) producing the movie.

The reaction to this was also very interesting, because having produced the movie, I was invited to come to Sacramento and show the hierarchy there the movie. And A. J. Garris was still on board, he was a very interesting man, he had had a great deal to do with the program in southern California, Rancho Los Amigos, as well as from the Sacramento office coming out to districts. He was handicapped by polio in the lower extremities, but it didn't stop him in doing his job. In fact, he taught me how to drive, right now, with my bad shoulder--to keep your hands in your lap and use both hands to move the steering wheel, because I can't take my right arm and go around the top of the steering wheel.

So anyway, A. J. Garris invited me up to Sacramento. I showed the movie and I keyed the tape to run with super-8 film. And there were ooh's and ahh's, and then there was silence. And the silence echoed, "Wow, the amount of money it costs for somebody to be independent, to be able to get back and forth, to work, or to the laundry, or to the store for their food."

This is where Ed Roberts got into the idea of trying to buy at fleet price a number of vans and keep them in Sacramento until somebody was appropriate for them in one of the districts. But there were problems with this, because the vans all need to be air conditioned, especially for a

traumatic spinal cord injury, because your temperature system goes out. And the vans were all different colors, dark colors, colors that the dealers couldn't get rid of, and apparently this item went through before people realized that they weren't getting cream colored vans or white vans. We ended up with trying to add on after-market air conditioner products. And then the department went crazy about that, too, because of the additional cost.

Well, again, this pendulum would swing back and forth as to whether we were to spend money for those who, interestingly enough, probably have paid the most taxes as a result of the department's assistance. But, it was very hard at that time to think beyond your current existence and plan beyond your tenure.

Cowell Student Revolt

Bonney: Let's go back to the residence program, Cowell program. You read a list of the requirements, it's sort of the guidelines for staying in the program and remaining a DR client while you were going through school. And you talked about screening people with psychological testing. Was the psychological testing a big thing in those days? Did people think that that really indicated who was going to succeed or who wasn't? What was the emphasis on that?

Withington: All we did was, we were looking at previous academic performance from high schools. Some people hadn't had much opportunity to do this in high schools. So, whoever was referred to the program, I would have a previous academic schedule and, you know, having a high I.Q. doesn't actually mean that you are going to do great in high school. In fact, some of our people in this program with lower I.Q's did greater than others with higher I.Q's. And, again, being somewhat naive, perhaps I matched I.Q. with performance too much. On the other hand, I had to go by history. So that with high school grades, for instance, my young man--and I wonder if he's still alive, I'm not sure--Larry Biscamp.

Bonney: Yes, he's still alive.

Withington: Where are you, Biscamp? [referring to documents] Down here, oh. Well, Biscamp decided not to go to school in the fall, winter, spring of 1968 as I look at it here. If my memory serves me, he had very, [refers to documents] very high scores

and, yes it does serve me, 'cause I have them right here. His City College and City of San Francisco College experience he had a 1.9 GPA. He, by far, had the highest recorded WAIS at the time. I essentially said, "Larry, you got to get out of here and give your bed to someone else." And that's when I hit the--Ed Roberts put me on the front page of the newspaper. And that's when Gerry Belchick was then called in as the great smoother of difficult incidents, and picked up the ball, and I was sent packing in disgrace by the department although one-third of the residents were on my side.

Bonney: Now, where did you go?

Withington: I went back to general caseload. From there I went to San Bruno in 1971, with the San Jose District.

Bonney: Now, did this incident happen in '71, in the residence program?

Withington: The only way I can give you the date--oh, here's even another thing, how much does it cost, how does one apply, financial aid. I have to look at the--I have to find that newspaper article to give you a date [searches through documents].

Bonney: Lucile, let's go back to the incident, you have alluded to it a couple of times where ultimately you ended up leaving as the counselor to the residence program. What specifically were the issues with the students in the program? Let's take, say, was there an issue with John Hessler in that program at the time?

Withington: Trying to remember, I think John was backing me. You're getting into another file that I don't have with me, because this was quite an experience. The incident that came up gave cause for the Rolling Quads to evolve, which was like the sign on my bookcase has always said, "Are you sure you can't do it yourself?" in terms of independence.

The students from the floor of the hospital got together and formed the group after the May uprising in People's Park. In a way it was almost negative psychology, because it brought them closer together, it gave them some strength, and it was essentially the start of the independent living centers that have occurred in almost every town. Marin County, I am still a member of, in San Rafael. I get their brochures, even though I've been here for five years. And Al Fabyancic was with it in San Francisco.

But, the issue that I was dealing with, with Don Lorence and Larry Biscamp, about "move over," was the fact they had not gone to classes for the previous quarter. Larry, in fact, as I mentioned earlier, hadn't gone, I think, earlier than that. And though living in a college campus is very much a part of growing up, it didn't fit the hierarchy of the Department of Rehabilitation, basically--how much room are you given to just use the funds and not perform towards your vocational goal?

And so I became the scapegoat, and actually was out of the country, when this wonderful newspaper article hit the stands about the fact that I was very upset that they were letting their hair grow and not using underarm deodorant. I didn't know anything about this until I got back to the States a month later.

All I had said was, "Look, I have asked you fellas to go to class, over and over again. It's part of the requirements of the program." They hadn't gone to class; they either had "Incompletes," or they were just horsing around. And there were other clients out there that deserved an opportunity, and we couldn't build a bigger wing on the hospital. So the people who were in the hospital, there was a division among them as to whether I was being rational or not. There were other quadriplegics who were very respecting of my decision and who wrote letters to the director, and all sort of things.

But at any rate, I had become kind of a hot potato. So that's why Gerry Belchick, who, to this day, is, or maybe two months ago, has been working as a special examiner for the Social Security Department Disability Division to determine whether or not someone should be granted Social Security Disability benefits. And Gerry and I have been friends over the years. I know that he's over in New Mexico at this time, just having had a very cold, snowy winter. But Gerry came in at that point, and I went back to a regular caseload.

And the Center for Independent Living got started. Whereas they started screening people to be note takers, they really got in there and started, you know, "Are you sure you can't do it for yourself? By gosh, we can." Later on, another one of my clients was Johnnie Lacy. She had been at San Francisco University and wanted to--I'm trying to remember what her goal was, whether it was therapeutic speech therapist, but San Francisco State University decided that she couldn't become a student because her wheelchair wouldn't make it up on the ramp for her to get her degree.

So Johnnie fought, she was a person who had had polio, her two legs and one arm were knocked out. But I helped her get a car. And later on, she became director of the Center for Independent Living in Hayward, as well as Client of the Year, because I put her up for that.

Back when I was still in Oakland, Maryanna Goslinger, who had completed a Library of Science program, who walked with a walker and had lived all over the world, she ended up getting a job in Texas at one of the universities, as an accredited librarian. And she was Client of the Year, another one of my clients.

Bonney: Now let's go back to Larry and Scott. Had you told them that they had to leave the program?

Withington: Oh, I had worked with them for months about, "Let's get it together and get to school."

Bonney: But was that the issue that you had said--

Withington: Yes, it was go to school, or move over, and let someone else in, and go do something somewhere else and demonstrate that you've kind of gotten through this particular stage in your life and you want to come back in and make good use of the facilities. It was very close to what Phil Niles did.

Bonney: Now, in this newspaper article you refer to, it also states that Don Lorence was involved. Were there problems with Don?

Withington: Don Lorence, also, [shuffles through papers] was misusing the program, in that the fall of '68 he had a "C" and a "C" minus. In the winter, he had a "D" and an "NR," and this didn't constitute the required number of units that should be taken a quarter. However, there was leeway within that, depending on the degree of disability. Of course, quarter systems are different from semester systems, in terms of, is it worth four, or is it worth three? But Don was going through a difficult time. It was one of those things that, you know, please shape up or ship out.

Needless to say, I know at another point in time in the spring of '68, he was able to convert one of his grades to an "A," perhaps an "A" minus, possibly a "B," and another to an "A," and another to an "A." In other words, he had the ability, but he hadn't been making use of the program. It was very interesting, too, because he was in the program when we had no I.Q. scores as a prerequisite. But at Foothill College he had a 3.5 GPA, and at the University of California a 1.9.

- Bonney: So with Don, it was mostly, "apply yourself, get your grades up, complete more courses," that was kind of the issue with Don?
- Withington: Well, it was with both of them, but they were both experiencing freedom. You know, I can't knock it at this point. There are times when, you know, devil take the hindmost, I've got to learn to live.
- Bonney: Did you recognize that when you were living through it?
- Withington: No. Perhaps I recognized it, but I also knew I had the pressures of the position. And we only had so many slots. In fact, I got the university to accept these students without going through the regular testing requirements the university gave them. Because--kind of sounds like the HUD Act again, so many of your apartments must be made handicapped accessible--so many of your slots, as became later, a much more prevalent issue, shall be given to people of skin of different colors. And you will allow them to see if they could compete on this level.
- Bonney: Now, what did the Rolling Quads do? You said that they organized, and they got political, and they got some power. What did they specifically do around this issue with you?
- Withington: They got me kicked out of the position.
- Bonney: And how did they do that?
- Withington: Well, they had a whole month while I was out of the country.
- Bonney: So this literally happened while you were out of the country?
- Withington: Right. This magazine, this newspaper article came out, and I left the next day, and I thought many things in the article were wrong, misquotes, even the fact that there were two quadriplegic students I was throwing out, when one was a para. Another point that they were just normal Cal students, when they were both flunking out. Another point is, Who actually had made this decision?, as I note my notes on this. So, I can't tell you what went on while I wasn't there.

But I know that there was a ground roll, and I also know that Eleanor Smith was behind me and was saying, "Wait a minute, you guys better shape up, or ship out." She backed me to the point where she eventually ended up leaving the program, too. She was so discouraged with this kind of "mes amis" method of dealing with this. (Meaning Lucile has

created a "political hot potato" which may damage the Department of Rehabilitation's reputation, so let them do what they want and cover this up.)

It was a wonderful learning experience for me, but I sure didn't feel like it at the time. It was like, I really wasn't any good. However, it's been rewarding to run into some of these people again who say, if it hadn't been for you, we wouldn't have fought for our independence and learned about the real world, and it never would have happened there. So, in hindsight, it has been helpful. I'm not a political person, so that I don't play politics too well. I'm me. And anybody that knows me, knows that that's been it. I've stuck up for what I wanted to think was a job well done.

Work With the Department of Rehabilitation in the 1970s: Easy Closures, Challenging Clients

Withington: And that was always an issue with the department in later years. I had a small caseload, I knew what everybody was doing. And as my supervisor said, "You know, once you accept someone into the program for services, we know that 99 percent of your clients are going to become employed." But, up in Sacramento, it doesn't fit the statistics, because you should have twice as big a caseload and do more creaming of the crop; go out and get some easy ones. I wouldn't do that.

Bonney: So the State Department, after Ed left, went back to the easy closures?

Withington: Oh yes, skimming was the word--

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Bonney: Lucile, you were talking about DR going back to the easy closure after Ed Roberts left the department.

Withington: Yes, I believe you were the one that brought that up. And again, the pendulum was swinging and the state realized that a lot of their money was going for salaries in the Sacramento office. Although it had employed a number of severely disabled people and had given them the opportunity to find out what the world was like. The big push then came. "Oh, we can't get matching federal funds if we don't turn out more rehabilitated people 'cause we are a state with such a large population." And so, it got back to some counselors running

out and finding people who had just gotten a job and saying, "Oh, I'll give you \$125 to get you clothes and get to work for the first month if you'll come in and be a client all of a sudden." And ethically, that's not my bag. I much prefer to work with the tough, difficult problems. When they say, "It can't be done," by gosh, I'll help you find a way to do it. And I continue to work with self-referred clients from all over the Bay Area. This was somewhat upsetting to my, then current, Pleasant Hill district. I had established a reputation working from San Francisco to Oakland, the Disabled Students' Program, to San Bruno to Redwood City. I lived in Marin County all this time, and I used to commute three and a half hours a day to Redwood City, which was hellacious. But I lived on top of Mount Tamalpais, where there is a beautiful view, and it was a mountain, and that's where I could rejuvenate and breathe.

So, there was an opening in Richmond. And a supervisor there, who is no longer with the department, later went to Florida, Bruce Cole, asked me to come and take this opening. They couldn't get anybody to come to work in Richmond. And he promised me that I would be able to transfer to the San Rafael office, where I had always wanted to work, since I lived in Mill Valley, within two years. Because the Richmond office was part of the San Rafael--Santa Rosa District.

Well, lo and behold, I went to Richmond, and believe me, we were right beside the bank. They used to hold the bank up about once a month across the parking lot where we parked our cars. Finally the department moved the branch office out of the Department of Employment building as it was pretty dangerous downtown there to the shopping mall across from Contra Costa College in San Pablo. Another move to a larger office with better transportation took place to San Pablo Avenue and San Pablo Dam Road. It was equally dangerous, because there, we were beside the Moose Lodge. On one occasion the police found a body in the dumpster behind the Moose Lodge next to our parking lot! In 1988, I was asked to work alone after hours. I even had a bullet shot through my window on the third floor, but the window wasn't changed out.

My supervisor representing the State Department of Rehabilitation told me, "You've either got to do it faster with more, or you've got to take in more and don't spend so much money on each." Because I always did a good diagnostic work up, I always spend more money than anyone else in the office for good medical and psychological evaluations. And I worked with people that had been turned down by others.

As I mentioned earlier, my reputation had gotten around so that I had clients coming from San Jose [laughingly] to the Richmond/San Rafael, San Pablo office. I had people coming from Oakland, San Francisco, Novato, and Marin County. Clients who had applied at some of these offices and had been turned down, would then be referred to me. And of course, it was the client's option to seek out a counselor they wished to work with. My supervisor had to make amends to his supervisor, the district administrator, almost on a too regular basis, as to why I was working for someone that was outside of the district. But I had special skills that seemed to work with some people and didn't with others. After fifteen or twenty years with the district, and with the department, you gain a reputation. I couldn't get into the San Rafael office, because, I believe, they didn't want a strong woman there, although I applied for every opening.

Bonney: So you never got to work close to home.

Withington: No.

Bonney: Lucile, looking back on the incident of the Cowell program, the immediate outcome, of course, is that you said that you were transferred out of the district, or out of the program. What do you think were some long-term effects of that?

Withington: Would you be more specific?

Bonney: Did it in any way help move the independent living movement along on some continuum? Did it give the Rolling Quads, as individual students, some sort of impetus to take more responsibility for themselves? That kind of thing--

Withington: Okay, I get your point.

Bonney: In the short run, it was hurtful and you were removed--

Withington: Absolutely. Long-term-wise, Gerry Belchick is the person who was told to handle this with kid gloves. And yes, of course it gave the Rolling Quads more impetus. It's what helped get the Center for Independent Living going. Because nobody in DR wanted to touch this, it was a hot potato. In retrospect, it was really great to see. Because instead of dealing under the table, these guys started dealing on top of the table, which was my whole point from the beginning. Don't tell ATD that you need one thing in order to get money for another. Let's go to them point blank and say, "This is what's needed for this!" and get them to come across, and they had.

So, in the meantime, these guys, and gals, Cathy [Caulfield] included, got together, and some of them were dissident about it, some weren't. But they got the movement going. And in hindsight, I think, if they hadn't had someone realistic, like me, they could have just continued to limp along. But they were given full control, because it was much too hot of an issue for the department.

That's what today we are all about. "To assist persons with all types of disabilities achieve their maximum level of sustainable independence as contributing, responsible and equal participants in society" including senior citizens. [Quote from the Marin Independent]

I'm on Social Security disability myself. And I'm fighting, and I'm starting a business again, fighting. I've worked with the homeless. When I had no money coming in except, quote, "Non-Industrial Disability" minus taxes of about \$75 a week, I was out there picking up cans, and picking up bottles from a local inn, and standing in line at the recycling place in Berkeley, along with the other regulars who had their push carts. And we all helped one another. That's the food money I had to live on, while I was fighting my Worker's Comp case.

Actually what happened to me is, it finally came down to, "You're either going to get more closures, or we'll give you the job of Vocational Evaluator for the branch office." I said, "What?" And they said, "Yes, start doing the psychologist duties. We want you to do testing; we want you to test ten people a week and do the reports that also go to Social Security, or for SSI, for people's disability evaluations." They said, "You will have two months to distribute your caseload and learn testing." I said, "Wait a minute, it's been twenty-three years since I took a testing course." And they said, "Well, we're sure you can do it."

So that was the start of my working seventy hours a week, and the clerks being angry that I, quote, was "promoted." Well, was I promoted? I didn't get more money. Bill Shaw, who was head of the clerical staff in the Pleasant Hill office said, "Lucile, why are you doing this? You should be making \$800 more a month." And I said, "Bill, you know, I've always been one who's been strongly supportive of testing." I'm fascinated with what it can and can't show. I have been working with a lot of people who had an "overall diagnosis" of dyslexia, and now we've found ways that people can learn in spite of this. So the staff psychologist in Pleasant Hill was asked to please cooperate with me. He said he was scared at

first. But then, what happened is, my reports were three and four pages long and were, as my supervisor, Warren Hayes, had requested them to be, in full detail along with testing.

The only problem was, I was working seventy hours a week, and I went into a total burnout and into a severe major depression. So that I left a message for my supervisor--I guess he was on military leave at the time, weekend duty--that the following Tuesday, or something, would be my last test day and I would have the reports available.

At the same time I was working on a special study with the psychologist from the district office on one of the reading tests. We were trying to see if it had a bias in it for clients of different skin color. But we never were able to complete that. Also, concerning my vocational testing reports, my supervisor had just come to me and said, "You no longer need to send them through me. Just sign them, and sign them as the vocational evaluator." He didn't know that I had been on heavy, heavy doses of anti-depressant medication during that past month, and had given [laughs] training on how to use testing efficiently. My tongue was sticking to the top of my mouth so much due to the medication effects, my hands were shaking so badly I couldn't get a stick of gum in my mouth to produce more saliva. And my boss did not appear to notice it, nobody had known that I was undergoing daily appointments for psychological evaluation, because he had told me to come and work at night. So I was working till two in the morning, I was working at home seven days a week.

It took until last year, 1997, this was in 1988, the last half of that, the first half of '89, for the Phillips vs. the State of California Overtime lawsuit for time and a half according to Fair Labor Standards Act, handled by Carrol, Burdict and McDonough, Attorneys at Law, Sacramento, that I finally got back pay, for 409 hours of overtime worked in a six-month period. I haven't worked since at a regular job, although I am still very active, a rehabilitation consultant for senior citizens, and have gone into my other interests of building for the future, incorporating the Americans with Disabilities Act of 1990.

Rehabilitation Research Report Series

Bonney: I want to go back to a report that you gave me to look at, called the "Rehabilitation Research Report." It was written

in November of '69. Can you tell me what this is? You said you wrote it. [See Appendix A]

Withington: Yes. Could you repeat the question, please?

Bonney: It's called "Vocational Rehabilitation of the Severely Disabled in a University Setting." Can you tell me what this document is?

Withington: Again, going back twenty-seven years, I'm looking at a letter from the State University of New York, College Brockport. And I see that on June 10, 1979, a person wrote me a letter saying, "Dear Ms. Withington, I'm starting an office for the handicapped on our campus and researching a grant proposal. If possible, I would appreciate receiving a copy of your publication, 'Vocational Rehab of the Severely Disabled in a University Setting.' Thank you, Patricia Laird, Resource Assistant for the Handicapped."

What I was asked to do was write a research report on what it took to form a program, such as the Cowell Hospital program, for people with handicaps. The foreword does state, and I don't intend to read the whole report, "Numerous rehabilitation research and demonstration projects are being carried on in California. Many of these projects are tested in developing new concepts, methods, and techniques which are of potential importance to counselors. In an effort to provide vocational rehabilitation counselors with timely and pertinent information regarding those projects, the research and statistics section of the California State Department of Rehabilitation has instituted this series of rehabilitation research reports."

It goes on to state that they are written jointly, although I wrote every word of this report. The foreword was written by Michael Savino. So, it goes on to state, "This project is 90 percent funded by federal, social, rehabilitation service, through provisions of Section 3 of the Vocational Rehabilitation Act. Its total annual cost is approximately \$35,000. It is a five-year project, expected to run from January 1, 1968 through January 31, 1973."

So the purpose of the report was to provide a residential unit where people with handicaps could live and attend the University of California, that would be on campus. The methodology was with the help of the Department of Social Welfare and the University Student Health Service. "The following would be implemented, a move to independent living." That was, in other words, for the client from home to

independence on a university campus. "Eleven quadriplegic people, resulting from a variety of medical problems, were in the project including amyotonia congenita, a rare disease marked by general hypotonia of the muscles, one is a quadriplegic polio who spends up to sixteen hours a day in an iron lung, the other eight are quadriplegics resulting from traumatic cord injury. Although all the clients are quadriplegics," and that is before the time of Larry Biscamp, "there is a wide difference in functional ability. It's our beliefs that the reorganization of services made possible by transferring of the financial responsibility of medical treatment and supplies to ATD resulted in real gains on the part of the clients, both in the terms of physical and emotional independence."

Bonney: Is this report something you wrote annually, or was it a one-shot--

Withington: It was a one-shot deal. I believe Gerry Belchick picked up the next part of it. And it is available to you. In fact, I have a copy to add to your research, if you have not found it elsewhere.

Bonney: So it really did, then, become a series of reports.

Withington: Right, this was the first in the series of the move to independent living. It goes through the move to independent living, academic goals, and eligibility, staff and supervision, which included a rehabilitation nurse, Eleanor Smith, when I was on board. A physiatrist, who was Chester Wong, a urologist, psychiatrist, plastic surgeon, vocation rehabilitation counselor, myself, and the hospital administrator. And they state here, "a male orderly hired by the hospital for daytime shift." This was before we had Cathy Caulfield in here. This was all men at that point. I wanted it to be open to anyone. It wasn't just the men that should get the opportunities. Then it went into "disabilities to be served, estimated funds under Section 2. The estimate in the application suggests twenty clients, at a \$3,500 a year, total of \$70,000 per year. As of March 31, 1969, Case Service Quarterly Report in the Cowell Residence Program Code 641 had encumbered a little over \$28,000 for eleven clients. As of February '68, there were six clients living at Cowell Memorial Hospital. One who started in June of '67, dropped out in September of '68. Additions to the program were as follows, one in March of '68, one in June of '68, two in September '68, two in January '69, two in June of '69."

In other words, I didn't just come in and pick up a program, I came in and assisted others getting into the program. This goes on further to be more specific, the duration of the project, the summary, and the services to the handicapped students expanded, "as of this writing, an effort to coordinate and expand these services was recently made with the appointment of an on-campus counselor for all handicapped students attending UC Berkeley." I do not believe this ever happened.

Department of Rehabilitation Funding

- Bonney: Tell me about funding just a little bit. What part of the resident's program, the Cowell program, did DR fund? You mentioned that it would be tuition and books for students, and sort of the academically related things. But did DR also pay for, say, Eleanor Smith to be there, or for some of these medical doctors and psychiatrists to be there? What did DR pay for?
- Withington: Interesting that you would ask such a question. Oh my goodness! I have so many statistics here, that when you come to \$28,000 for eleven students, and I'm looking at a breakdown of costs by client, and it's all in category "A through L," [laughs] in both ways of accounting, you count down, you count across--I'm not--
- Bonney: Now what are categories "A through L," do you remember?
- Withington: Ah ha! I have just found it on one of these. Let's see if it makes any sense. Ed Roberts, for instance--"cost transferred from San Jose, August 23, 1962 and included in." We get up to '66-'67 fiscal year, "A" which doesn't mean much to me, on Ed Roberts, was \$41.50. "B through E" was medical surgery and TR. \$5.30 in '67-'68 and the fiscal year '68-'69, \$91.25. Hospital convalescent care, "D and G." I guess that was "B and E," not "through E." "D and G" in '68 and '69 it looks like it was \$1,345. Training costs, say in '69, well let's go '67-'68, training amounted to \$2,953.14 in that fiscal year. The following one, '68-'69, \$2,823.79. Training equipment the earlier year was \$248.58. This is all very boring.

But then we get into maintenance, which would be expected to be picked up by ATD, and I guess we begin to see a little glimmer here that from earlier on--transportation--we have, a case of Ed Roberts went from '62 up to this time, '66-'67,

\$5,703.59. Then '67-'68, \$727.20. '68-'69, \$1,093.60. So, if you go from the beginning to '67, across all of these things, medical, surgical, possibly, maybe apparel, hospital, convalescent care, training, training equipment, maintenance, transportation, for Ed Roberts, you had an overall total for the entire time, \$26,014.16.

Bonney: So those are the kinds of things. Let me ask you the question, was Eleanor Smith paid by the Department of Rehabilitation?

Withington: You need to check with Eleanor on this, but I do believe that she was in the budget, from the Department of Rehab. You'll learn more when you get into the next part of the report, that I didn't write, in the further years, because this is where we got into block funding, and when Edna Brean, R.N., got on board.

And yes, there was a lot of disparity between her and Eleanor Smith. Eleanor Smith left the program because I didn't come back to it. That was her decision. Actually, the State of California, Department of Health made a special request for her exceptional talents: her natural ability to relate on a one-to-one level with them and the other health professionals (doctors, nurses, personal care attendants), and share her documented photographic slides of her findings when lecturing all over the state and country. She was a one of a kind individual within the disabled [community], understanding of his or her needs, related well, highly reputed, and just a wonderful person. So she worked out of the Berkeley Office as a rehabilitation nursing consultant, Services Approval Section. Based on her training, skills and degrees, they actually created this special position for her. We have kept in contact all these years.

Bonney: How long did she stay after you left, in the residence program?

Withington: Very short time. She resigned.

Bonney: And then Edna Brean came?

Withington: Yes. Eleanor Smith resigned as a result of, maybe it's good or bad, the fact that State Rehab didn't back me on my position statement. In the long run, I think it's good because I was able to broaden my experience within other offices in the Bay Area, therefore, meeting the challenges of other handicapped people. I had built the starting framework and set up the guidelines and standards. The department felt

moving me out of the way, they could then be adjusted, as the times and needs developed. In the early seventies, we went through crazy periods of challenging authority, window breaking and fire-led marches in Berkeley. Thus the start of the students' rebellion for independence.

I can remember, I wouldn't drive a state car on campus when I was leading this program. Because, identification with the state could and did create situations where the students overturned state-marked vehicles. The students would come out and pick up the bumper of the car and overturn it. In fact, I had a '68 Toyota Corolla, two-door. I remember driving up Dwight Way to get to the campus, having made a home visit with Scott Sorenson, who lived down by where the Bay Area Transit system access is now. I had the windows open and, by God, somebody pitched a ripe peach core, through the passenger window and it went splash on my dash!

But this was very typical, anybody who had clients up on the university campus would use their own cars, rather than take a state car. It was quite an uprising. But it got the ball going. You know, it was the start of testing the old system, with independent living, and that's fantastic.

Cowell Hospital Residence Program Legacy

Bonney: You talked a little bit about, sort of the long-term effects of all of this on the residence program. What do you think is the legacy of the Cowell Hospital program?

Withington: I have to go back and think, because I haven't been physically with the Department of Vocational Rehabilitation since May 1st of 1989. And I had been fifteen years in Richmond/San Pablo at that time. Stop me if I'm wrong, it's my understanding that the hospital wing was shut down--

Bonney: Yes.

Withington: --it was a transition, it was a fabulous transition, but it wasn't terribly practical to get the students into inaccessible regular housing. I had many Berkeley, California clients in my caseload when I was in the Richmond, San Pablo area, [laughs] strangely enough. At this point it was apartment living so let's get ramps made so they can live independently on their own. It was a transition step, although I hadn't thought about that for some time.

As time progressed, the city of Berkeley became more physically accessible. This attracted many more students with disabilities to challenge State Rehab for a university education. Judy Greenwood was one of my clients who first moved to San Pablo and her case was transferred to me. She had been in the back bedroom of her parents' home, with incredible increasing juvenile, rheumatoid arthritis. She was totally ankylosed, i.e. her whole body was locked in a reclined position. She could move her head at her neck one quarter of an inch. She became an "A" student English major and then wanted to go to law school, but ended up, I think, working on her master's degree in the field of social welfare. Then unfortunately, in her internship year, there was a mishap, which was not of her doing. Her electric wheelchair ran over some exposed roots in the sidewalk, causing the wheelchair to leave the sidewalk and turn over with her seat belted into the chair. She was killed by a passing car. This was, indeed, a unique tragedy ending the life of a physically inflexible woman whose gift to others was her flexibility and flashlight in the dark for others to follow.

I used to go and visit her at her apartment because she was my client. When I told her I would be leaving my caseload and becoming a psychologist doing vocational testing for our office, she wished me well, would miss my realistic approach, and that I would do a wonderful job.

That [being a vocational tester] I was for six months, and I will say that my reports were many times better than the district's vocational psychologist's. But that was because I took the time, I was very, very interested, I wanted to do a better job for the client and counselor. I've always been a resource and research person wishing to help others help themselves. I burned myself out, working 409 hours overtime in a six-month time span on my rehab counselor's salary. The compass turned 180 degrees and I became a client of the Marin Center for Independent Living. I was living on Social Security Disability, living through a debilitating depression. Four years later, I was enlightened when diagnosed with Fibromyalgia Syndrome in 1992, inherited from my mother. That knowledge has helped me continue the compass turning around toward the next 180 degrees.

Bonney: Lucile, thank you very much for the interview. I hope you enjoyed it, I did.

Transcribed by Willitte Herman
Final Typed by Shannon Page

REHABILITATION RESEARCH REPORT

Robert E. Howard, Director
DEPT. OF REHABILITATION
Human Relations Agency
State of California



*Vocational Rehabilitation
Of The
Severely Disabled
In A
University Setting*

ISS 69-11-3
Nov. 18, 1969

REHABILITATION RESEARCH REPORTS

VOCATIONAL REHABILITATION OF THE SEVERELY
DISABLED IN A UNIVERSITY SETTING

Progress Report for Fiscal Year 1968-69

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FOREWORD

Numerous rehabilitation research and demonstration projects are being carried on in California. Many of these projects are testing and developing new concepts, methods, and techniques which are of potential importance to counselors. In an effort to provide Vocational Rehabilitation Counselors with timely and pertinent information regarding these projects, the Research and Statistics Section of the California State Department of Rehabilitation has instituted this series of Rehabilitation Research Reports. Written jointly by a research staff member and a rehabilitation counselor or other non-research staff, these brief reports will be presented in terms which are especially suited to non-technical field staff personnel. More detailed and technical information can always be obtained by contacting the Research and Statistics Section. Additional copies of the report can be obtained by returning the form provided.

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This project is 90% funded by the federal Social and Rehabilitation Service through provisions of Section 3 of the Vocational Rehabilitation Act. Its total annual cost is approximately \$35,000. It is a five year project expected to run from February 1, 1968 through January 31, 1973.

VOCATIONAL REHABILITATION OF THE SEVERELY
DISABLED IN A UNIVERSITY SETTING

Progress Report for Fiscal Year 1968-69

PURPOSE:

The original purpose of this project was to make a Rehabilitation Residential Unit available for those severely disabled quadriplegic, triplegic and paraplegic students attending the University of California at Berkeley. This purpose has been enlarged to include the evaluation of prospective severely disabled students who can demonstrate the greatest potential to effectively utilize undergraduate and graduate studies leading to professional skill level occupations.

This project has required the cooperation of the Department of Rehabilitation, the Department of Social Welfare, including the local Medi-Cal Consultant, and the Administration of the University which is willing to make the necessary exceptions to meet the needs of the severely disabled who can utilize the University to develop their potential to handle professional jobs.

METHODOLOGY:

With the help of the Department of Social Welfare and the University Student Health Service the following have been implemented.

1. Move to Independent Living: Each student is issued an electric wheelchair which best meets his needs. The rehabilitation nurse, physiatrist consultant, and the students all share the responsibility of coming to a consensus as to which type of motorized wheelchair will best suit the needs of that particular student. (The Motorette Unit which attaches to a regular heavy duty E & J wheelchair supplied with semiballoon tires, including an extra tire in case of flats and carried in a bag behind the chair, appears to be the most popular and useful model for our students who have to get around on a fairly hilly campus.)

Of the 11 quadriplegics in the project, two are amyotonia congenitas (a rare disease marked by general hypotonia of the muscles), one is a quadriplegia polio who spends up to 16 hours a day in an iron lung, and the other 8 are quadriplegics resulting from traumatic cord injury. Although all the clients are quadriplegics, there are wide differences in functional ability. It is our belief that the reorganization of services made possible by transferring of the financial responsibility of medical treatment and supplies to ATD resulted in real gains on the part of the clients - both in terms of physical and emotional independence.

1. Move to Independent Living (continued): Room and board was found to be expensive. At first the Cowell Residence Program was set up in such a way that the client himself had to meet the difference between the \$350 room and board charge (which included an RN on duty from 11 at night until 8 in the morning and one orderly on duty from 12 to 2 and 4 to 6 in the afternoon) and his ATD grant of \$87.00 a month for room and board. It was discovered that actual room and board costs were \$226.20 a month - - \$26.00 towards the RN's services and \$58.60 towards the services of the orderly. Previously the clients were asked to go to the Board of Supervisors at the local welfare departments to ask for this difference of \$179.20 a month. There were some counties that were more liberal than others. As it occurred, eligible clients were being turned away because they lacked the monetary assistance for their preliminary room and board costs. In addition to the \$87.00 room and board which is allowed by ATD, each client is usually allowed \$54.50 at this time for incidental needs. It is very important not to cut into this sum as these people need clothes, cosmetics, and money for normal socializing on the college campus. In addition, each client is allowed a maximum attendant care allowance of \$300 per month which, on the basis of usual charges of \$2.00 an hour, amounts to 150 hours a month or roughly 5 hours a day in addition to the above mentioned care given by the hospital.

Since ATD has a legal limit which is less than the actual cost of room and board for a program client, the Department of Rehabilitation is paying the difference of \$179.20 per month. The Department of Rehabilitation sponsorship of this cost differential will not affect the ATD grant since it is not considered income. These costs meet the requirements of income and maintenance for the Welfare Department. The Welfare Public Service Manual, Section 4-111-474 states ". . . funds provided by public and private agencies to assist with a rehabilitation plan not available for any other purpose are exempt from consideration as income . . ."

We now have 11 students in this project who started out living at Cowell. Four students have been able to move to independent living in apartments close to the campus. As a result of being at Cowell Hospital, they have been taught how to hire and train attendants. It is not the intent of the program for the student to live on the third floor wing of Cowell Memorial Hospital for his entire time in college. It is hoped that with the knowledge gained from this type of living, under the direction of the rehabilitation nurse, the student will become more able to make his own decisions, and eventually be able to move out into the surrounding community near the campus and find out if he can live independently in an apartment.

2. Academic Goals and Eligibility: The University of California is on the quarterly system. Most project clients are taking between ten and fourteen units. Two students are in graduate school. Most students with verbal WAIS IQ's of less than 120 seem to consistently get C averages. Most students with IQ's of 130, are receiving grades that average B+. With a college average at this level obtained by a student participating in an active campus program, we find that they have a good chance of being accepted in graduate school which will lead to professional level occupations. It has been our experience that unless a severely disabled person can be trained in areas where he will be able to earn between \$12,000 and \$20,000 a year, he will be unable to meet his every-day living expenses, including attendant care, to enable a savings of public monies. In order to determine eligibility for this type of a training program, case evaluations include vocational testing using the verbal part of the WAIS, the Kuder Interest Inventory (Series BD) and the California Psychological Inventory. We are also quite interested in all reports prior to and after injury in terms of high school and college grades.

For those students applying to the University of California quadriplegic program, we have a regular referral procedure. Eligibility is determined by the district or branch office where the client resides. Then with close coordination between the project counselor and the counselor in the referring area, the above mentioned case evaluation information is secured. The case is then sent on loan or the important aspects requested are sent for review. Priority is given to those clients who can demonstrate the greatest potential to effectively utilize the program. The cases are then staffed at the University of California by a group which includes a representative of the Department of Rehabilitation, the medical director of Student Health Services, the psychiatrist, the hospital administrator, and the head of the counseling service at the University. If the client is felt capable of handling the program both medically as well as psychologically, an application is submitted to the Admissions Department at the University. When a case is turned down and it is felt that there may be undeveloped potential, the suggestion is made to the referring district that they might wish to sponsor the client in a nearby university or junior college in order for him to demonstrate as an active classroom member his potential for handling college training. Upon successful demonstration, the case can always be referred in the future for upper division or graduate training. It is our experience that the regular four year period for undergraduate training will take at least five if not five and a half years for a quadriplegic taking a reduced study load. When combined with two to three years for a master's degree and then possibly another two or three when working on a Ph.D., some plans can run eight to ten years in length.

Two clients are doing graduate work. One of these has had an offer to teach political science part-time next year, and it may well be necessary to supply this particular polio quad with a vehicle so that his attendant may drive him back and forth to his teaching position. This adds additional financial responsibility to working with this particular group of clients.

2. Academic Goals and Eligibility (continued): It is the responsibility of the student to provide the Department of Rehabilitation with the grade slips received at the end of each quarter, and to discuss his current progress and his plans for the following term. As all students have vocational goals necessitating graduate training, each is expected to maintain a "B" average in his major field of study.

STAFF AND SUPERVISION:

The staff most intimately involved with this project includes the Rehabilitation Nurse, a Physiatrist, Urologist, Psychiatrist, Plastic Surgeon, Vocational Rehabilitation Counselor, Hospital Administrator and a male Orderly hired by the hospital for the daytime shift.

Due to the complexities involved with coordinating services for this disability group, and in order to provide continued counseling, the project counselor meets with the students as a group once a week in addition to seeing them individually when the need arises.

A large number of the students living at Cowell have initiated contact with the Staff Psychiatrist and meet with him as a group one night a week. No request has been made for payment of this service to the Department of Rehabilitation.

POLICIES AND PROCEDURES:

See Methodology above.

DISABILITIES TO BE SERVED:

This program serves severely disabled quadriplegic, triplegic and paraplegic clients. Due to the change in program counselors, and changes in the referral procedure, the project is not growing at the rate anticipated in the initial application.

To date the project has served 12 clients with one drop-out due to emotional problems. Two more clients will be starting with the summer quarter and one, a graduate student, will enter the University in the Fall of 1969. Seven additional clients are in referral status.

A measure of the interest in this problem is the following: Thirteen vocational rehabilitation offices have made inquiries about the program, including questions from Maryland, Texas and New York; six county welfare departments have sought information; and specific inquiries have been made on behalf of 31 potential clients.

Following the revised referral procedure, three additional applicants are undergoing initial evaluation in their home districts prior to formal referral.

ESTIMATED FUNDS UNDER SECTION 2:

The estimate in the application suggested twenty clients which, at \$3,500 a year, equals \$70,000 per year. As of March 31, 1969 Case Service Quarterly Report, the Cowell Residence Program, Code 641, had encumbered \$28,335.93 for 11 clients. As of February 1, 1968, there were six clients living at Cowell Memorial Hospital. One client who started June 1967 dropped out September 1968. Additions to the program were as follows: one in March 1968; one in June 1968; two in September 1968; two in January 1969 and two in June 1969.

One of these thirteen clients has an income in excess of \$155 per month due to an accident settlement and thus is not on ATD. The Department of Rehabilitation is assuming his costs for tuition and books. Of the twelve remaining, the 641 project is covering those expenses not covered by ATD as none of the clients thus far qualify as a Social Security Trust Fund case.

It should be noted that students becoming adjusted to the University of California at Berkeley start by taking a reduced subject load, therefore expenses for typing and research assistants are not typical during this initial phase.

It is also recommended that careful consideration must be given each successful student in relation to feasible methods of transportation which will be required for him to get back and forth to his place of employment. In some cases a vehicle will have to be provided that an attendant can drive, and in other cases of C5-6 quadriplegics and lower levels, vehicles which can be adapted for driving from an electric wheelchair should be considered.

Specifically, the responsibility of the Department of Rehabilitation towards the rehabilitation plan lies in the area of financial assistance for room and board costs (over and above that allowed by ATD), tuition, books and supplies, secretarial assistance (which in some cases averages ten hours a week at \$2.00 an hour dependent on the number of papers the students have to write), research assistants (who are paid between \$2.00 and \$2.75 an hour to go to the library and select books for the students), equipment not otherwise supplied by ATD (such as hollow or solid-core doors with 30-inch legs to be put in the student's room to use as a desk), and initial help with transportation costs which consists of allowing the student to pay a wheelchair "pusher" \$2.00 an hour to push their non-electric wheelchair while they are getting acquainted with the campus. The Department of Rehabilitation is also paying for tutoring for some of our beginning and ongoing students in languages and for assistance in writing English papers. The students hire these tutors from Student Placement Service who with recommendations from their particular departments apply for tutoring positions. The average cost for the Department of Rehabilitation's participation in this program appears to be in the neighborhood of \$3,000 to \$4,500 per student, per year.

DURATION OF THE PROJECT:

February 1, 1968 to January 31, 1973 appears appropriate for exploration of the services needed to assist severely disabled clients in extended academic programs. However, as few of the currently enrolled clients will have completed their academic programs by January 31, 1973, ongoing provisions must be anticipated for covering the costs incurred by this method of rehabilitation training.

SUMMARY

This innovative project was designed to provide Vocational Rehabilitation services to a group of severely disabled quadriplegic, triplegic, and paraplegic clients who need special services in a university setting, in order to become vocationally rehabilitated. These severely disabled clients are receiving rehabilitative nursing, physical therapy, medical consultation, occupational therapy, tutoring, and other ancillary services within a special residential unit. These services are allowing them to successfully compete in a university academic setting.

Throughout the state there are severely disabled youth who have high potential for vocational rehabilitation via academic training. Because of the severity of their disabilities, the concomitant health problems and problems of logistics, college or university training can be so haphazard and cumbersome as to completely obstruct and prevent rehabilitation.

It is only through the cooperation of the University, their Student Health Service, and the Department of Rehabilitation, through this innovative project, that these high-potential clients can utilize this potential for independent living. Their high-potential is verified by their acceptance under the University's rigid admission screening policies. Without this service this group of young people would be life-long dependents on the State at very high costs.

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SERVICES TO HANDICAPPED STUDENTS EXPANDED

Until recently, no coordinated program of services for handicapped students was available at U.C. Berkeley. Besides this special project the services that were available were fragmented and, in many cases, limited.

As of this writing, an effort to coordinate and expand these services was recently made with the appointment of an on-campus counselor for all handicapped students attending U.C. Berkeley.

Mr. Kenneth Englebach, District Administrator of the Oakland District Office, announced at a meeting of the Dean of Students that "every effort will be made to adequately serve every handicapped student who attends U. C. Berkeley. With this in mind, all of the services of Vocational Rehabilitation on campus will be coordinated under one on-campus counselor." At the present time approximately 60 disabled students are receiving services from Vocational Rehabilitation. These services include payment of tuition, fees, books and supplies; tutorial and reader services for the blind; vocational counseling and guidance as well as assistance in job placement.

Lucile Frances Withington

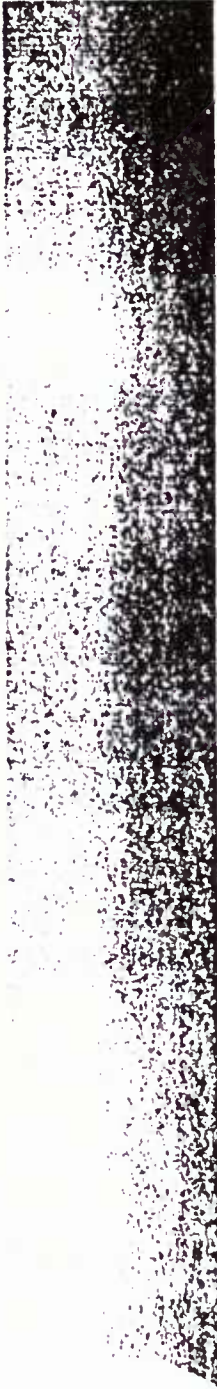
Residing in Surprise, Arizona, Lucile Frances Withington has accomplished a great deal throughout the course of her professional career. She began her college studies at Middlebury College where, in 1955, she earned a B.A. in the field of Sociology. At the Langly Porter Neuropsychiatric Institute, University of the Pacific, she pursued her education of sociology through graduate studies of sociology and mental health, accompanied by an internship which she completed in 1965. She received her M.S., rehabilitation, from San Francisco State University in 1966, and finished her educational studies in 1980, through postdoctoral studies in alcoholism at the University of San Diego. Currently she is the president/owner of Withington Diagnostic Technology-Archectual Design (WDT-AD), where she serves as a rehabilitation consultant, evaluating the physical and psychological needs of senior citizens and others, who wish to maintain themselves, living independently in the community long as possible to limit the costs of long term institutional medical care. Concurrent with this goal, Ms. Withington has designed and is physically assisting in the building of her retirement home. This house of the future presents the use of new high technical materials designed for twenty-first century living, including low maintenance vinyl and the use of solar energy applications for light, hot water, air conditioning, and heating. The American Disabilities Act of 1990 for functional living and complete wheel chair accessibility will also be applied. In June of 1997, Ms. Withington joined the company of Thermo Dynamics Solar Network, incorporated as an equal partner and Vice President of Development on the Board of Directors. The company markets products of Thermo Dynamics, Limited, a world leader in solar technology, manufacturers of solar heating equipment for a worldwide customer base in North America, Europe, Africa, and the pacific rim.

Over the years Ms. Withington has held numerous jobs, many of which allowed her to utilize her skills and abilities as a therapist and counselor. From 1960 until 1961 she worked as a recreation worker through the National Red Cross, Letterman General Hospital, and at the 121st Evacuation Hospital in Korea from 1961-1962. She continued in the counseling field as a staff recreation therapist from 1962 until 1964, in Tachikawai, Japan, at the United States Air Force Hospital. In 1966, back in the United States, Ms. Withington helped juvenile delinquents as a counselor to the mentally ill at the Marin County, California, Probation Department. Her next venture, lasting from 1966 until 1988, was as a vocational rehabilitation counselor in a number of California districts—San Francisco, Oakland, San Jose, Redwood and Pleasant Hill. In 1988 until 1989 she served as a vocational psychologist counselor for the Richmond/San Pablo, California Department of Rehabilitation. Throughout her professional experience she has also worked with psychiatric/recovering chemically dependent homeless individuals.

Aside from being a devoted therapist/counselor, Ms. Withington is also active in a number of organizations: the American Association for Counseling and Development, the Association for Measurement and Evaluation in Counseling and Development, the American Personnel and Guidance Association, National Rehabilitation Counseling Association. Along with her desire to support and assist individuals in need, she also has



xx



a love for outdoor activities—especially skiing. She has been certified with the Canadian Ski Alliance, an Eastern Division Certified Ski Instructor at the Hannes Schneider Ski School in Conway, New Hampshire, and also the Squaw Valley Ski School, with a Far Western Certification. She pursued her love of teaching and the slopes as the secretary for the North Bay Ski Patrol. Not only did she involve herself in skiing related activities, but she was also a First Aid Instructor and a Water Safety Instructor with the American National Red Cross, a founding member of Wilderness Finders (WOOF), and a consultant for the Humane Society of Marin County. She has also been the producer/director for *The Road to Independence*, 1969, a film about a young male quadriplegic learning to drive.

Ms. Withington is also the recipient of many awards. She has been a Honorary Member of the Norwegian Yacht Club, 1955; National Ski Patrol #102, National Appointment for Meritous Service, 1955; Distinguished Service Award, Veterans of Foreign Wars (Japan) 1963; California Counselor of the Year, National Rehabilitation Counseling Association, 1975; 25 Year Service Award, American National Red Cross, 1978; 30 Year Distinguished Service Award, National Ski Patrol, 1981. Currently, she has been appointed to the Advisory Committee by the Board of Directors for the Happy Trails Community, 1996-97, 1998-1999. She has been listed in *Two Thousand Notable American Women*, *Two Thousand Women of Achievement*, *The World's Who's Who of Women*, and *International Who's Who in Community Service*.

DEDICATION 166

Seeking the best in others,
We find the best in ourselves

✕
9/9/97

THIS 1997 EDITION JUST ARRIVED
AND I GUESS MUST CLEARLY
DEFINE MY FUTURE GOALS. TAKING
FIBROMYALGIA IN STRIDE, EVEN
ITS AFFECTS THAT SIDELINE ME
AT TIMES. PROGRESS ON BUILDING
IS SLOWED, BUT NOT COMPROMISED.

LUCILE



Regional Oral History Office
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Berkeley, California

Disability Rights and Independent Living Movement Oral History Series

UC BERKELEY'S COWELL HOSPITAL RESIDENCE PROGRAM:
KEY ADMINISTRATORS AND CALIFORNIA DEPARTMENT OF REHABILITATION COUNSELORS

Karen Topp Goodwyn

DEPARTMENT OF REHABILITATION COUNSELOR IN BERKELEY, 1972-1983

An Interview Conducted by
Mary Lou Breslin
in
1997-1998



Karen Goodwyn, 1983.

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INTERVIEW HISTORY--Karen Goodwyn

From 1972 to 1983 Karen Goodwyn was the California Department of Rehabilitation counselor for most UC Berkeley students with disabilities and many community activists. From early in her career she was committed to the proposition that people with disabilities are entitled to an opportunity to achieve their personal and vocational goals. She also recognized that social, architectural, and technologic barriers could prevent some people with disabilities from attending college and working. As a rehabilitation counselor she thought it was her role to provide access to training, education, and equipment that would help her clients challenge these barriers and reach their personal and professional aims.

Her interview discloses her personal philosophy about the role and responsibility of a rehabilitation counselor, which was not always squarely aligned with that of the department, and her recollections about key student and community leaders. In this role she established herself as an invaluable ally of emerging student and community leaders, arguing persuasively on their behalf for critical services.

After serving as a rehabilitation counselor she continued working for the department as a program supervisor and telecommunications coordinator, her position at the time these interviews were conducted.

Ms. Goodwyn's interviews were conducted during three sessions which took place between March and September, 1997, in Ms. Goodwyn's office at the Department of Rehabilitation in Oakland, and the home of Susan O'Hara in Berkeley. She spoke easily with good recall. Ms. Goodwyn had also served as the rehabilitation counselor for the interviewer during the mid-1970s. The interviews were lightly edited by Sharon Bonney and were then reviewed and lightly edited by Ms. Goodwyn.

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.

Mary Lou Breslin, Interviewer

January, 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 Karen Topp Goodwyn
 Date of birth April 10, 1943 Birthplace Marysville, CA
 Father's full name Alphonso Axel Topp, Jr.
 Occupation retired military officer Birthplace Indianapolis, Indiana
 Mother's full name Mary Catherine Virtue Topp
 Occupation housewife Birthplace Lebanon, Indiana
 Your spouse Albert Taylor Goodwyn
 Occupation Super Captain - San Francisco Opera Birthplace Montgomery, Alabama
 Your children none

Where did you grow up? Everywhere, including Japan and Germany
 Present community Crocker Highlands in Oakland, CA
 Education BS. Biology/Chemistry from University of New Mexico

Occupation(s) insurance rate clerk, social worker, rehabilitation counselor, rehabilitation supervisor, field computer liaison

Areas of expertise Assistive technology, telecommuting, universal access to electronic information

Other interests or activities super at San Francisco Opera, designer of stained glass windows and lamps for architects, private pilot, backstage support for local theaters

Organizations in which you are active RESNA (Rehabilitation Engineering Society of North America)

INTERVIEW WITH KAREN GOODWYN

I EARLY YEARS AND EARLY CAREER

[Interview 1: February 11, 1997] ##¹

Youth as Army Brat

Breslin: Karen, why don't you tell me a little bit about your family and your experiences--I know you have a large family; tell me a little bit about them and about your experiences in Germany too.

Goodwyn: I was born in 1943 and I'm an army brat. I'm the oldest of ten children, and we moved all over the world. Lots of my brothers and sisters were born outside of the United States. I think my favorite assignment of all was Japan, where we lived in Tokyo when I was seven and eight. Then we moved to New Mexico, one of my least favorite places in the world because it's so dry and windy, and the climate is either too hot or too cold. From there we moved to Georgia and then to Germany, where we spent five and a half years. I really liked Germany a lot. I almost grew up feeling like a native. I went to the American high school, and after I graduated I went to the Gymnasium, a school for girls, and took the Unterprima science curriculum.

Then when the family came back to the United States I came with them, and being the oldest of ten, my father was wanting to economize on college expenses, so I knew that if I wanted to go to college I would have to stay on their skirrtails. Since we had established residence in New Mexico, I went to the University of New Mexico [UNM]. The summer before I came back, I worked with Opincar Summer Camp for Retarded Children in Frankfurt, Germany, and took care of the children attending summer camp. That was fun. That's how I earned my tuition for the first year of college.

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

Young Adulthood, College, Marriage

Goodwyn: The first year of school at UNM I was in the honors program, which was a real strain, because I also had to work to earn money for books and tuition. I worked at the library binding books at eighty-five cents an hour and earned enough money to pay my second year of tuition, and I also received a small tuition scholarship which paid part of my college expenses. But I was fully self-supporting.

I lived at home with my family. We had a three-bedroom house, and there were twelve of us. That meant that there were four girls to a bedroom--there were eight girls in the family and two boys. My two brothers slept in the utility room on shelves over the washer and dryer. It was extremely crowded, and I became rather discouraged because there was absolutely no place to study. I didn't drive, so I had to depend on my very attractive and socially active sister for rides to and from the university. We were then in the same year in school. I found myself waiting endless hours for her, so in 1964 I engineered a marriage to a man who was trying to avoid the draft. We lived on campus in a house and took care of the house, and I continued working in the library and putting myself through school. So that's basically how I got my education.

Breslin: Let me just ask you about the engineered marriage. This was really an arrangement of convenience?

Goodwyn: He was a very nice man. He was the first and only man I dated. I just was so desperate to have more control over my rather complicated and busy life that I decided and he decided--I think he really loved me--that it would be a good thing to do. He was deathly afraid of the draft. Married men at that point, in 1964, were not drafted. So we got married, and then it turned out that that was no longer good enough and you had to be in divinity school or something like that. So he then applied for divinity school at the time that I finished my degree, and we moved to San Anselmo where he went into the San Francisco Theological Seminary to get his theological degree. Later he became a registered conscientious objector.

Move to The Bay Area, Apolitical Ideology, Pursued Interests

Breslin: That's what brought you to the Bay Area.

Goodwyn: Yes, that's how we came to the Bay Area.

Breslin: Let me ask you to say a little more about the environment of your family and UNM when you were in college. This was the sixties. This was sort of the peak of the counterculture revolution. Did that influence you in some way?

Goodwyn: I was always a very straight-arrow military type, and I was not particularly smitten by any of this movement. I knew coffeehouses were big, and beatniks, and flower children. But I was really kind of insulated, and even in Germany I had been relatively tied more into the German culture than the American, and I didn't participate much in American social activities with high school because I much preferred the opera and the ballet and theater. So when I came to UNM I really was unaware of all student political activity, except that my husband was sort of a peacenik and used to like to wear the peace symbol. He antagonized my father with his political views, but we were really basically an apolitical family. I think that's how good military families are. Their politics are very deeply buried. So I just was not that aware of things.

Breslin: Was your husband in conflict with your family because of his position about Vietnam?

Goodwyn: Yes. That was a very big issue.

Breslin: You pursued a science degree at UNM.

Goodwyn: Right. I had hoped to go to medical school, but I just found it too much of a strain. I could not sustain that kind of grueling activity--trying to work and go to school. So when I finished my B.S. and had a husband to support, because he was then the student, I just decided I had to table that. Later I went back to school and did all of the pre-med kinds of things, but then I decided who needs poverty at fifty? I decided I could not really endure the things that only a young person is equipped to endure.

Breslin: It's fairly recently then that you--

Goodwyn: Yes. In my mid-forties I went back, and I was at the point of applying to medical and dental schools. I really enjoyed going back to school, because so much had changed, and I enjoyed taking all the classes, and I met wonderful people. I think older students bring so much to education, and it was a very good experience. But then I had to weigh my various interests. I was flying at the time--I earned a pilot's license. I had started doing stained glass for architects. I just had too many other interests and I just didn't want to give them up. And I'm also a

supernumerary for the San Francisco Opera. When you make a commitment there as a nonsinging character on stage, it takes many, many hours--for rehearsals, makeup, wigs, costumes, and performances.

Jobs in Insurance and Social Welfare, 1966-1971

Breslin: In making the transition from New Mexico to San Anselmo--for your husband's education purposes--were you thinking in terms of your own career goals at that time?

Goodwyn: Not really. I was just so exhausted by the time I finished my degree. When you're taking a scientific curriculum you have lots of labs. And when you're trying to work in addition and you're maintaining a house on campus, it's like your life is not your own. So I was thinking that perhaps I would come back and get a degree in medical technology or something, but the pay was too low. My first job paid me \$325 a month, and I felt lucky to have it. I was working for Northwestern Mutual Insurance in downtown San Francisco. I really loved the job, but there was a definite disparity between the pay for men and the pay for women. I found that I was training men--some of whom are still my friends--who automatically earned more than \$200 a month more than I. And when I announced that I was leaving, they really wanted to keep me, and they checked with their headquarters, and headquarters policy was that no woman would ever be paid more than \$400 a month. Subsequently, there were class action suits and insurance company women, industry-wide, did win a lot of money, but I didn't.

Breslin: What year was this that you were working in San Francisco and what was the job?

Goodwyn: In 1966. I was a rate clerk, and I would help lots of men who could not figure out how to rate policies. I had one of the highest accuracy ratings of anyone. So if somebody had a complicated policy to write, they would come to me. The insurance company also wanted me to help them automate their insurance business. They had hired contractors, but they were still trying to figure out how this was done. I think I could have made a lot of money if I had stayed [chuckles].

Breslin: No doubt. So in terms of reacting or responding to this clear policy of discrimination based on gender, did you feel compelled to try to do something about it, or did you feel that there was no option available to you?

Goodwyn: I felt there was no option. When you're penniless you feel lucky to have a job. You just say "I'll go where there's more money." I remember I took a test, a state entrance exam instead of a general entrance exam, for state positions. There was one for food and drug inspector, which I really would love to have had, except that it required a training period in Los Angeles, and I didn't want to be separated from my husband for six months so I turned that one down. The next one that came up was a disability adjudicator for the Social Security program. That sounded like my cup of tea, so I took that job. It was very exciting, and I loved adjudicating the Social Security disability claims.

That's when I first learned about rehabilitation counselors as a career. There were several people in the group that was hired with me who had master's degrees in rehab counseling, and they kept talking about how wonderful rehab counseling was and how horrible it was to rate claims. Frankly, I enjoyed the rating of the claims but didn't know there was something even better called rehab counseling. It was really exciting to me.

So when the program decided that they would like to take some people in the rating side and allow them to try to rehabilitate some of the Social Security recipients, it sounded like a very exciting proposition to me so I volunteered, thinking that the people with the master's would be the natural choices, but I thought why not volunteer? It turns out that there were almost no takers, so they took me, and at the end they decided that this was not a program they wanted to continue. They said, "You have to choose whether you want to stay with the rehab side or the adjudicative side." The rehab side was just raving about how wonderful I was, so I went where the praise was the loudest [laughs].

The next thing I knew I was given the Cowell Hospital caseload.

Breslin: Let me stop you right there. I want to understand the period between 1966 when you graduated from UNM and 1971 when you began working as an adjudicator.

Goodwyn: I worked for the insurance company only about six months. I think I started in August, and I quit in January. The reason I quit was that I was on a civil service list to be a social worker for the county. So I worked for Alameda County for four and a half years as a social worker. I started out with OAS [Old Age Security], I worked with AFDC [Aid to Families with Dependent Children], and my first job was in Hayward. Eventually I was transferred to Oakland, and I was still commuting in from Marin. I worked in Oakland, and I ended up being an information and

referral services worker at the Alameda County Welfare office at 401 Broadway.

Breslin: We all know it well!

Goodwyn: Yes. Then I moved over to Highland Hospital. I screened people for eligibility for Medi-Cal and tried to figure out what their insurance coverage was. It was from there that I left work as a social worker for Alameda County.

Breslin: And it was possible to become a social worker and a rehab counselor in those days without a master's degree.

Goodwyn: Social workers didn't require a degree, but one of the things that really discouraged me was that they were trying to cut down on the cost of administering the welfare programs for the state, so they decided to have very few social workers and to have eligibility technicians do most of the eligibility determinations. At that point they were threatening to lay off about 90 percent of us. So that really got me serious about looking for other work. That's why I started taking exams and ended up with the options for different types of state employment.

Department of Rehabilitation and a Changing Caseload, 1971

Breslin: So you selected rehab counseling based on that series of events. Before you talk about your caseload, tell me a little bit about the Department of Rehabilitation as you found it when you became a rehab counselor in 1971.

Goodwyn: It was sort of like a breath of fresh air compared with the welfare department. People seemed a little bit brighter, a little bit happier, more sociable. We had an office that had lots of views from all sides. We were at 1111 Jackson Street. We were sort of in the center of things. We were close to Chinatown, and BART [Bay Area Rapid Transit] was just being constructed, giving people the ability to get places. AC [Alameda County] Transit still worked [laughter].

Breslin: A commentary on its state today [laughter].

Goodwyn: It was very nice. By that time I had moved from Marin over to the Rockridge area, and I lived right across from what is now the Rockridge BART station.

Breslin: So the tone in the office where you were working was positive for you.

Goodwyn: It was very upbeat and positive. I can't say anything about the quality of rehabilitation counseling that was going on, because I was very naïve and unaware and fully occupied with my own particular job assignments [chuckles]. But it was much more upbeat than working for the welfare department.

Breslin: You came into that job now having some experience in your summer camp situation with people with disabilities, some social work experience, some adjudication experience. So what kind of values and ideas did you bring to the job? Can you forget the ones you have now and harken back to--

Goodwyn: Well, I think the thing that was most interesting to me was that I got a chance to work with people in a very practical way, because if I had been a physician I would have been working with one aspect of their problems, and here I was able to deal with another aspect of people's health problems or physical problems. It was exciting to me.

Breslin: Did you have any notions about people with disabilities at that point in your career?

Goodwyn: No, but one interesting thing that happened was that I had a picture of my family in my office, and a man who had polio as a kid came in, and he looked at the picture and he started saying, "Now that's Astrid, and that's Heidi, and that's Eric, and that's Megan, and that's Katrina." And it didn't dawn on me that he shouldn't know who these people were, but I just sort of asked him, "How do you know them?" He said, "I knew them in Iran."

Breslin: Is that right? This is when your family was traveling?

Goodwyn: He had gone to high school with my younger brothers and sisters in Iran, and then he came here [laughter].

Breslin: It's too small a world. My goodness.

All right, so you've begun working as a rehab counselor. What was the first assignment that you got?

Goodwyn: The first assignment was to continue working with Social Security trust fund recipients. These are people with work histories sufficient to earn disability insurance coverage through Social Security. I liked that, but it was really kind of challenging, because a lot of people either had a short life expectancy, very little energy, or very little motivation. In fact, the problem

with that program was that people were referred to me before they knew if their claim was allowed or disallowed. So their incentive to show that they could actually work was absolutely zero. My little innovation there was to keep track of their names independently, because the department didn't think this was a very productive idea. Then a year later I would send them a letter saying "I'm still here, are you interested?" And people were actually much more interested a year later than they were at the time they were referred, because at that point they decided it was pretty dull staying home all day.

Breslin: Why would the department not have supported that position?

Goodwyn: Because they just thought it was unnecessary paperwork or unnecessary recordkeeping. But it was easy enough for me to keep a list of referrals and phone numbers and just follow up later. I figured if you're going to be successful working with a challenging population you had to use every tool in your arsenal.

Breslin: Is the Social Security trust fund group distinguished from another group of clients?

Goodwyn: I think that what has happened is that it used to be that welfare and Social Security were clearly different programs, and when the welfare programs kind of merged with the trust fund programs, and they changed the name--instead of saying Aid to the Totally Disabled, or ATD, and made it SSI [Supplemental Security Income], it's so much like Social Security Disability Insurance [SSDI] that people no longer draw the distinction between welfare and a trust fund insurance program. But trust fund people who were able to get insurance benefits at that time were truly quite severely disabled unless they had a temporary disability which was expected to go away, like a severely crushed leg or a condition that you were expected to recover from two or three years down the road.

II REHAB COUNSELOR IN BERKELEY, 1972-1983: THE DISABLED
STUDENTS' PROGRAM

Meeting Ed Roberts and John Hessler, December 1972

Breslin: So your first introduction to the UC Berkeley campus and its people and programs and the like was when?

Goodwyn: I think that even as a seminary wife we had made occasional forays over to Berkeley, and I had always seen what I considered to be a disproportionate number of people in wheelchairs milling around the Berkeley area. And I had always wanted to know how they got there and why they were collected there and what they were doing. And I of course had seen Ed [Edward V. Roberts] and I had seen John [Hessler]. So when I was given the assignment to work with them, I went up to the little CIL [Center for Independent Living] apartment--I don't remember where it was--and I met with John and Ed, who were recent graduates of the university. They read me the riot act: they said I was going to be working hard and I would have to be here and have to do this--they told me exactly what they expected from me.

Breslin: Do you remember what year that was?

Goodwyn: It was probably winter of '72. I could be a year off. I could be ten years off [laughter].

Breslin: That sounds about right.

Goodwyn: December of '72. I know it was December, because in December I lost sleep every night, because the preceding counselors--after Catherine Butcher, who was legendary for her wonderfulness--had not really gotten along very well with this population, and the UCB disabled students were legendary for being tough on rehab counselors. So I was afraid that I would be the next victim.

- Breslin: You said that you knew Ed and John. Had you had contact with them prior to this?
- Goodwyn: No, but Ed and John, when they learned that I was the next rehab counselor, lined up a meeting with me and they just told me how it was going to be.
- Breslin: Say some more about that.
- Goodwyn: It was interesting. I found them to be rather reasonable. I mean, I didn't hear anything outrageous--
- Breslin: You sound surprised!
- Goodwyn: I thought they were going to be horrible and awful. I've always worked hard; they didn't have to tell me to work hard, I was going to work hard. I was glad to have them be so frank. Communication was very easy and very natural.

Cowell Hospital and Disabled Students' Caseload

- Breslin: What was your introduction to the Cowell program? Tell me about the Cowell program.
- Goodwyn: The Cowell program was the residence program for UC students with severe physical disabilities, which was located in the third floor of Cowell Hospital, I believe, in one of the wings. Edna Brean was the nurse who was there as full-time as one person can be. I'm not sure if Ed was there then, but John was there and Michael Pachovas and several other people were living in the Cowell Hospital wing, and there were a couple of women--I think Mary Ann Hiserman was there. I can't remember all of the people who were there. But it was basically like a dormitory in a hospital. Unfortunately the hospital expected not college-student kind of behavior, but rather patient-type of behavior, so there were always these little insurrections as people exerted their normal youthful kinds of behaviors [laughs]. Some of it was sort of drug related and other things that were not necessarily looked on favorably by anyone. It was just your usual bright, mischievous group of young people.
- Breslin: Did you have occasion to visit the dorm, the Cowell unit itself?
- Goodwyn: Oh, I went there all the time. We'd have a meeting, I'd go see students in their rooms.

Breslin: How were you involved in these issues which arose?

Goodwyn: Generally I tried not to get involved. I tried to let Edna deal with them because she was more in touch with the hospital administration, and she dealt with the daily housekeeping issues. I was more concerned with academic work and accountability for money that we spent.

Breslin: What was the department's relationship with Cowell at that point?

Goodwyn: The department was paying for the rental of the wing and for Edna's salary, I believe. It was a contractual arrangement between the Department of Rehabilitation and the university.

Breslin: And what was your relationship to the students?

Goodwyn: My relationship was that I was their rehab counselor. I believe John Velton was the contract administrator.

Breslin: And you were assigned to be the counselor for all the Cowell students in the residence program.

Goodwyn: Right, and other disabled people in the Berkeley community, especially those involved with CIL.

Breslin: And were you also the counselor for other students who weren't in the residence program?

Goodwyn: Yes.

Breslin: How is it that that happened?

Goodwyn: I think that the caseload had been intact before, that one person had attempted to serve all of those people, and that it just came to me that way.

Breslin: It's an inherited function.

Goodwyn: I inherited that caseload, and it built up as other students attended UC [University of California] who had physical problems. They just naturally came to me because I had UC. So I ended up with a caseload of about 140 people.

Breslin: Is that a large caseload in relation to other--

Goodwyn: That's big, yes.

Breslin: Can you describe any particular early meetings or encounters or conversations that can give us the flavor of the time?

Goodwyn: All I remember now is that--I was much younger then [laughter]. And I thought that the appropriate dress length was about-- something that where you could curl your fingertips just underneath the hem. I think now that maybe that wasn't the best fashion for my young male student population [laughter]. But I don't remember any specific conversations.

Breslin: What was the perception of the department by the students you were working with?

Goodwyn: I don't know. We never had any problems. Now one of the things that I had to do was I had to make the students equally responsible for anything that they wanted done. So we would always kind of negotiate things. If I didn't understand a reason for a request, I would always tell them that I could not adequately represent them at the department level unless I understood the logic behind the request. In some cases there was no logic, but in most cases there was definitely a kind of logic and then I could really make a case for buying a particular item. In one case, one of the early issues was typewriters--it was pre-computers. And when I inherited the caseload we were renting typewriters by the month, and every month I'd have to renew these rental agreements, and quads [quadriplegics] needed to modify the typewriters a little bit, or at least they didn't look good after they had been used, and I was sure that the business renting them to us would never want them back again. So I started buying the typewriters instead of renting them, and I think it was probably partly my frustration with these ridiculous rental agreements and partly the students' suggestion that this was kind of a silly arrangement.

Role and Consequences as Buffer for Students

Breslin: I'm sure you're aware of this, but you were perceived by many as a buffer between the students and the department. I'm wondering if you see yourself in that light or if you see yourself differently.

Goodwyn: The department, depending on which people were directly responsible for the district, either created a favorable climate for providing services to people with severe disabilities or a less favorable climate. From time to time I did get buffeted around and so did anyone who supervised me, because they were always having to justify why I spent more than \$2,000 per rehab or why my rehabs didn't happen in a period of six months or less. Frankly, some of those cases were pretty old and pretty thick and

some of them occupied more than one volume. But when I look back, at least on the people I've kept track with, it was worth it in most instances.

Breslin: Say a little more about that, and about that dynamic between you and the department. Was it difficult for you? Had you found allies?

Goodwyn: I think it has made me some permanent enemies in the department, not that they will admit that it colors their thinking, but I think there is some kind of suspicion or distrust of someone who could work with a community that's perceived as radical. So I think the department's perception is that I was giving away the show, whereas my perception was that I was setting reasonable limits in many cases, and one of my greatest frustrations was having people come in from other parts of the state where literally they had given them everything, and then they would come to Berkeley and I would have to set limits or I would have to say to my UC students, "No, you can't have a van. I don't care if he has a van. You can't have this, or you can't have that." I had certain logical rules and everybody appreciated that I personally would not violate those rules, that I was consistent.

Breslin: Did the stress which flowed from that tension cause you any sleepless nights?

Goodwyn: Sometimes it did. In fact, Doug [Douglas] Ford, another rehab counselor, used to work at Santa Clara Valley Medical Center, which is a spinal cord injury center. He would make lots of referrals, some of which ended up being in my caseload, and he and I both felt that we were unappreciated, even disliked, by many people in the administration--not necessarily always the director, but by a lot of the middle management types. I mean, when John Hessler and Ed Roberts were administrators in the Department of Rehabilitation several years later, they were very supportive of what we were doing, but there were many managers in the middle who just didn't trust us at all and thought, "You can't work with people like this unless you're doing something wrong."

Doug and I were right at the top of a promotional list one time, and there was another man who was there as well, and they hired out of sequence to do an "affirmative action" hire. They broke the civil service rules to not hire us. Doug hired an attorney and won the case against the department for violating the civil service hiring rules. The department had to go back to the promotional list, and at that point I think one rank had been cleared, so they still tried to hire outside the sequence, and

the attorney went back and said, "You have to pick Karen or Doug." They chose me over Doug.

Breslin: Do you remember what year that was?

Goodwyn: That was the year I got promoted to RS [Rehabilitation Supervisor]--October of 1983.

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Breslin: Karen, you were reminiscing.

Goodwyn: I was talking about the promotion. Well, Doug and I still think that our advocacy position for disabled people has negatively affected us in terms of promotion.

Breslin: And is that alive and well today in terms of that effect?

Goodwyn: I think it may still have some residuals. You never know out there who's heard what about you.

Breslin: Do you have any regrets at this stage?

Goodwyn: At this point all I want to do is continue enjoying what I do. I've had a lot of fun making telecommuting work in the department, creating and implementing a telecommute pilot. And right now I'm having a lot of fun making sure that people get reasonable accommodations so that they can use computers, and I've started working with a lot of blind people, and now I'm having fun working with others internationally, on web access issues. So I have found--unlike what I expected--new territory to work in, and that will keep me happy. But if you had a little more influence over policy decisions, it would be rewarding, too.

Evolution of Physically Disabled Students' Program, Peer Counseling

Breslin: Let me ask you to think back a little bit about the organizations that you were associated with during those years. There was obviously the Cowell program, and I'd like you to say a little more about how you saw it evolving and changing. It became the residence program. What is your recollection about that process?

Goodwyn: When I first knew, as I knew it then, the PDSP--the Physically Disabled Students' Program--it was behind Top Dog. You had to go in the back, up a long ramp that went across the width of the

building, with a persimmon tree at the end [chuckles]. Zona Roberts used to engineer hot lunches for people who stopped by every day, and it was a bit like a social club.

Breslin: Chimichangas were a favorite.

Goodwyn: Yes. It was very informal and it looked absolutely hideous. It was dirty, run down, and really awful looking. But there were many really good times. One of the important things that I learned from the PDSP crew was that no amount of counseling could compensate for good peer support and good peer role models. All I had to worry about was giving people a general direction and the tools to get there. But the counseling was taken care of by peers, role models who had preceded them in trying to accomplish things. It was really wonderful to see that work. That was probably the most important thing that happened at PDSP: the role modeling that went on.

Breslin: Was that a new idea for you when you saw it there or had you experienced in other areas?

Goodwyn: I had never really figured how people would accomplish something. I just figured they would have a goal, and they would go for it. But I think that a lot of people simply had no idea of how much they could achieve because they just didn't have the imagination, they couldn't envision it. It was so alien to their perception of themselves until they developed the self-esteem and the independence that they simply couldn't conceive of being successful in a competitive society.

Breslin: What would the role of a, shall we say, more traditional rehab counselor have been in that context?

Goodwyn: I think they would have tried too much counseling. I think they would have tried to be overprotective. I was not really overprotective of my people. [laughs]

Breslin: Tell me what you mean by "counseling."

Goodwyn: Well, I read a lot of case recording from other people, and I saw a lot from people with master's degrees. Some of the counseling depended on your particular bent. But one particular counselor used to feel that the male quads needed a lot of counseling about sexuality. Frankly, that was not my focus. They had human sexuality programs they could go to, they could talk to their peers, they could do any number of things. But it was not up to me to talk to them about human sexuality. I figured they were more interested in how to keep their wheelchair running and how

to get their tuition paid and how to get their papers typed than they were in talking to me about highly personal kinds of things.

But other counselors felt that that needed a lot of attention, and other people felt they needed to address the issue of loss or the issue related to disability. I discovered that for a traumatic quad, no matter how much counseling you did, it was going to take about two years before a newly injured quad figured out which direction was the positive direction to go. In most cases you couldn't really shorten that time. But the most productive contribution you could make would be to find solutions for those kinds of little mechanical things that made a person's life work better. So I just concentrated on doing the things I knew would be effective and left the psychological sorting out to other people, because I'm sure that another quad can tell a new quad there is life after spinal cord injury, whereas it's pretty hard for me to make a strong case as an outside observer.

Breslin: What was the department's role in relation to the then PDSP--as fiscally or administratively?

Taking Risks in Interpreting Department of Rehabilitation Rules

Goodwyn: I think we had less of a role than--we basically had the contract with Cowell Hospital, including Edna's salary--I could be wrong, because I wasn't the contract administrator. But as the program evolved, we ended up paying a portion of a program administrator's salary in lieu of Edna Breaun, the Cowell Hospital residence program nurse. And we paid for the hiring of full-time attendants to be present or on call so that students wouldn't be at risk in the dorms and on campus. So I think that our dollar amount probably rose as we moved out of the Cowell setup. But not being the contract administrator, I can't really say.

Breslin: Do you remember when that transition happened?

Goodwyn: I don't remember the year, but it was probably a couple of years after I started. And I do remember that the thing that was going on then was that I had gotten some referrals from Fairmont Hospital and discovered that Fairmont had a ward where they were housing people who had had polio. They were just supposed to live out the rest of their days at Fairmont Hospital in these pale green rooms with staff that were kind of bored. It was not a very cheerful place. That's how I began working with Mark O'Brien and several other people. We cleaned out the polio ward of young people who had any potential at all. In fact, we

stretched our mission to recruit students for the UC residence program, because there was a community college program co-located on the UC campus that agreed to take those guys who weren't college material, so I was able to slip them into the transition from Cowell to community housing. We got several people who basically escaped from Fairmont Hospital through this mechanism but who never really amounted to much in terms of a vocational career.

Breslin: Thinking back about that particular period and that activity, you stretched the rules. You--

Goodwyn: You just interpret them broadly [laughs].

Breslin: You interpreted the rules broadly. What were you thinking about when you did that? What was your goal?

Goodwyn: Well, you have to take a calculated risk. It's clear that if you have somebody in a hospital and you narrow their opportunities to the point that it's almost impossible for them to achieve something, they will never achieve anything. But if you give them an arena in which they have more opportunities, you never know how they're going to expand their goals and what might happen. So I thought: These people don't have a good basic education and they don't look that bright, but if you get them out into a more stimulating environment, who knows?

Breslin: There was an entire rehabilitation establishment who had not taken that risk before.

Goodwyn: I don't think they had the facilities to do it. I had the ability to move them out into a reasonably safe, supportive environment and give them the opportunity to learn independent living skills, which I thought was the first level of making progress toward a career. I mean, you have to know how to take care of yourself. So to me, that was the first step. In rehab we always have the concept of an extended evaluation: you take people that you think might not make it but you give them the opportunity. I don't know now, because I haven't been counseling for a long time, but that was one of my greatest frustrations: Rehab didn't use the tool of an extended evaluation with more people. Rehab simply said, "You're not feasible" and sent them away. But to me the extended evaluation was an essential tool because otherwise how do you do know that some of these people can't be successful? You must give people a little bit of an opportunity before you know.

Learning from PDSP's Leaders, and Setting Limits

- Breslin: It's very interesting that the department had financial resources to create innovative ways of addressing problems for people with severe disabilities, but there wasn't a great deal of creative leadership, I think, until your generation--and you in particular. Obviously there was a program in the community, but you really took advantage of it in a most creative way.
- Goodwyn: I think the reason that happened was that there were disabled people in the community who acted as my mentor. For example, Ed told me about self-support plans for Social Security Disability recipients, and that's how we happened to write the very first self-support plan. There were very bright and capable people who could see that I had the potential to do things for them if they could educate me, and I think one of the key tools that we had was the ability to have an open dialogue, and I think that's often missing if a counselor feels intimidated or overwhelmed. I think sometimes professional people, doctors in particular, are just hobbled by the inability to fix something terrible that has happened to a person. So they try to take care of it with drugs or ignore problems altogether, but I figured we had to have an open dialogue to figure things out. I mean, here's the situation, we may never get as far as we want, but we've got to figure out a way to go as far as we can. And so we would negotiate or discuss or plan the best use of our resources to reach a mutually satisfactory goal.
- Breslin: Tell me about DSP--then PDSP--from a program perspective. Just your recollections of the people who were working there then, the effectiveness of the program, the goals as you recall them.
- Goodwyn: DSP was nice because it had so few rules. People could work around the clock and students could stop in anytime. Staff were always running out rescuing someone with a broken wheelchair. It was a very flexible operation. PDSP has become much more like just another business on campus right now, but in the seventies it was a by-the-seat-of-your-pants operation. We used it as a place where you would go if you had a problem that needed solving, and it didn't matter if it was an academic problem or a mechanical problem. It was a social outlet. They had a couple of vans that could be used for social activities, that people could reserve and go out and play with. It was a very useful, flexible tool.
- Breslin: The values that PDSP worked by or stood for seem important in this story. Can you say a little bit about that?

Goodwyn: Actually, I think we had a little bit of a disagreement with some of the things that happened there. Basically Zona and Ed had figured out ways to get bureaucratic organizations to jump. They didn't seem to have any set of limits. The more they could get, the better they thought they had done. I felt that there was some ethical limit to how much one should try to extract from an organization. I felt that disabled people had a certain level of responsibility to be responsible for themselves, so we had to negotiate a line beyond I could not be pushed.

Ed Roberts's Charisma and John Hessler's Maddening Charm

Breslin: When you first became associated with Ed, what recollections do you have of his general role, his influence, in the development of the program on campus and your personal sense of him?

Goodwyn: Ed was terribly charismatic and just a lovely, sociable kind of guy. He had political savvy that was beyond my comprehension. I was so naïve. He seemed to have a very good grasp of things and a real sense of direction. He knew what he wanted to do. He just did it. I guess what had happened was that the Disabled Students Program started on campus, and when he and John left and were no longer students, they had to form CIL. But they knew that they needed this kind of support group for the community, and they knew that they needed to have an effective way of dealing with the bureaucracies that provided essential levels of support. I think that's why Ed was interested in Social Security issues and in welfare issues and in Rehab issues.

Breslin: How about John? Do you have recollections of John?

Goodwyn: John was very, very charming and also maddening at times. I could have throttled him a couple of times. He was so headstrong sometimes. He would make decisions about which he would be totally inflexible. That just really aggravated me. I can't remember what any of them were. But he was just impossible to deal with sometimes.

Breslin: No particular examples that come to mind?

Goodwyn: No. But he was just impossible. And yet he was very charming. Coffee was always a good time with John.

Oh--I know an example. John decided that Susan O'Hara would be the perfect one for the dorm, to run the Disabled Students Residence Program. I didn't know Susan at all at that point--or

not very well--and I was sure that John was wrong, and he would not even discuss it. He assured me that Susan was perfect. And of course he was right [laughs], but I figured we ought to at least be able to discuss it and run by a couple of other candidates.

Breslin: Do you remember who was executive director of DSP when you first came to know the organization?

Goodwyn: I think it was John. John was still there. Ed was gone, but John was still there. Was Ed still there? CIL had already started, and Ed was very active with CIL, but John was definitely at DSP.

Breslin: John made a transition at some point to Sacramento with Ed, and I think it may have been a little later.

Goodwyn: Yes, it was later--so John was still at DSP.

Breslin: So in this example that you've given, John was executive director of PDSP and was exhibiting--

Goodwyn: This inflexible behavior.

Breslin: Do you have any sense of his own personal politics and goals for the student program?

Goodwyn: I think he always had grandiose plans. I think he wanted it to be big and wonderful. John was a nice well-rounded person in many ways. A lot of what I did with John had to do with a little more refined things like culture, and he was very interested in French. John was a fun person.

Zona Roberts's Influence

Breslin: Karen, I think we should backtrack just a little bit. I was interested in some of your remarks about Ed Roberts and Zona Roberts in regard to their roles in the disabled students program in the early days, as you described them from your memory. I'm wondering if specifically you could talk a little bit about your memory of Zona and her role at DSP as you perceived it then and as you can recall it now.

Goodwyn: Zona was kind of a housemother. As I recall, all of us who were sort of itinerant Berkeley types would fall into DSP about noon and have a hot meal. Usually something that Zona had cooked up--

I remember she used to use the Co-op Low-Cost cookbook, and she did a lot of exotic low-cost cooking. We'd all come in and have a big family-style lunch together and exchange ideas. Zona kind of made sure that there was some kind of order amidst the chaos that was DSP at the time.

Ed was like a patriarch. He and John Hessler took me under their wing when I first came there and sat down with me and told me exactly what they expected of me, which was more than forty hours a week and more than just being a simple bureaucrat. DSP was just a very warm and inviting place. It was on Durant, I think, behind Top Dog. They had that long ugly ramp that ran up to the back, and John used to come out on the porch and sun himself because he was invariably cold. There was a wonderful large persimmon tree that used to have huge persimmons on it, and I'd think "One of these days I'm going to get one," and I'd go to harvest a few persimmons and the day before they all would have been taken. DSP was just a very ugly, but warm and inviting, place.

Breslin: Do you think that Zona had some influence in shaping the politics of the organization or the sorts of services that were provided?

Goodwyn: Absolutely. I think that Zona shaped them based on what she felt was necessary in her dealings with getting Ed raised and independent and functioning as a young adult.

Breslin: Can you give some examples of the way in which that might have had an impact on the kinds of services that were offered?

Goodwyn: I think she was a terrific advocate. I think she was probably a role model for advocacy. I think that she knew how to use political influence and how to connect with powerful people in decision making positions to make things happen. I think that if she asked for something politely and didn't get it, she then became very political and got it another way.

Breslin: Do you think the services that were offered had some direct bearing on her experience as a parent?

Goodwyn: Yes, I do. I think that her emphasis on adequate attendant care and on adequate living facilities away from the home or outside the home and on campus were created in direct response to her needs in meeting Ed's needs.

Breslin: Everyone knows Ed so well, Zona is I think--we're not talking as much as we need to about Zona's role. People who have recollections of Zona will be interested in your recollection of her role.

Goodwyn: Oh, Zona was wonderful. She was a fixture there, and I think it will never be quite the same without Zona hovering around DSP and taking care of people's needs or pointing out special needs to me and being the ever-present, ever-alert person, identifying what people needed, and helping me fulfill needs that I might not have been otherwise have been aware of.

Breslin: Do you have recollections of any other individuals that come specifically to mind?

Goodwyn: Oh, let me see. Don Lorence was there. I can't remember the names of the people in the wheelchair repair shop, but they were fixtures. They were indispensable fixtures. Zona was always around. There were a number of other people that I knew but just can't remember their names.

Early CIL: Hotbed of Grant Proposals and Political Activity

Breslin: Were you involved in any meetings or conversations about the idea of forming a community organization that offers some of the same services that PDSP was offering?

Goodwyn: CIL had already been formed when I started. It was in a little apartment just off campus somewhere, so it had just, just happened--within months of the time I started, I think. Then CIL moved to University Avenue--next to the porno business on the fourth floor of a building near the UC Theater [chuckles].

Breslin: Did you have any involvement in working with people who were then shaping CIL?

Goodwyn: Yes, I did. I can't remember the organizers of CIL--I think Phil Draper was involved. I was almost equally involved with CIL and the DSP folks, but the DSP folks were critical to much of my caseload. I mean, the UC students, even if they weren't resident students, still had to go through DSP, whereas other people who were not UC students--and some of my UC students--used CIL services.

Breslin: Any particular recollections or meetings or discussions that you participated in that characterized the mood of the time?

Goodwyn: I remember some of the 504 rally kinds of things. I remember the fire at CIL on University and how the firemen had to carry Michael Pachovas (Michael is an attractive but obese

quadriplegic) down three flights of stairs. I remember there was some major problem with that.

Breslin: Do you remember the first CIL office?

Goodwyn: They weren't there all that long, but I used to go there a lot to that apartment building. I always walked up the stairs; the elevator looked so bad. CIL was always a little hotbed of grant proposals and political activity and wheelchair repair and all kinds of other essential things.

A Great Social Movement

Breslin: Let me just ask you one final question today, and maybe you can think about and say a little bit about it. Maybe we can revisit it the next time. Do you see yourself or think of yourself as having participated at that time in the political movement?

Goodwyn: Being an apolitical person, I don't see the political side of it. But I see a great social movement that occurred in mainstreaming people who would otherwise be closeted. I saw more than my share of people who had spent their entire lives secreted away in a room of someone's home because they had been born disabled, who then got wind of the disability movement and came to Berkeley and had their lives changed. To me it was so exciting to see a radical change in the opportunities for people with disabilities. It was really amazing. I thought, never in my career would I see anything to equal that. When I left I thought that was the better part of my career and it would be all downhill from here. Fortunately that was not true, but it was truly a great, great social change. I mean, we went from no curb cuts to curb cuts.

Breslin: Why do you think that's true? What was the process that achieved the curb cuts, do you think?

Goodwyn: I think the process was that Berkeley is a melting pot for all kinds of input, and that it's a very open community. Because it's a university area we bring people in from all over the world and all over the country. It has a favorable climate. We had sort of a political radicalism, we had kind of a radical Berkeley city council, and the chemistry just conspired to create opportunities. Because the population in Berkeley comes and goes because of educational opportunities, people would come to Berkeley and they would take away ideas that they had seen there, and they would say if you can ramp curbs in Berkeley you can ramp them in Fresno. I remember working with one kid who had never

been off the farm, so to speak, who came to Berkeley and had never seen a street sign before. She spent her first day looking at labeled streets--she had been that isolated. So I think the chemistry was right and the time was right.

Breslin: All right. Terrific. Let's stop at this point.

Setting Boundaries with Clients

[Interview 2: August 27, 1997] ##

Breslin: The last time that we talked, you mentioned that DSP and some of the people who worked there--Ed and John among them--had the philosophy that it was necessary to push bureaucracies as far as they could be pushed for whatever--services or whatever it was that they were involved in providing. You said that it was necessary for you sometimes to set limits in relation to what could be asked of you, even though you were clearly going beyond what had traditionally been provided to people with disabilities. I'm wondering if you can think about that for a minute and say whether there are any particular examples of situations where you might have been pushed a little further than you wanted to be and you had to exert your authority to draw the line.

Goodwyn: I do remember at one point near the end of my work in Berkeley, Judy Heumann came back and asked if I would consider buying her a second van, and I said no [laughs]. I don't think too many people could have told Judy no and gotten away with it [laughter].

Breslin: I don't think very many people ever have.

Goodwyn: So that was one example of something where I assumed that in our original planning we had planned for a logical way to replace a vehicle when it was exhausted, and I didn't see any particular reason why I should be doing it a second time.

The other thing that I have been thinking on now as I'm working with a new kind of client population is that sometimes people would come to me with demands for things on their time schedule after they had had many weeks of time to work it out, but they've not gotten me the right information, so I sort of developed a little policy of if it took them three weeks to respond to my request before they got me the information then I had three weeks to respond to getting it done. If it was an

emergency that was great enough to have them get together the facts in one day I would have a one-day turnaround in response [laughter]. That kept me going.

Computer Training Program

Breslin: When you were working with the student group--you had said it was about 145 clients, I think, and that may have been some community people, but primarily Berkeley students.

Goodwyn: Mainly UC students or the Computer Training Program students.

Breslin: Actually, say a little bit if you would about the Computer Training Program as it relates to your client load. I don't believe we talked about it the last time.

Goodwyn: The Computer Training Program is something that we started after IBM came, when they wanted to start a training program for homebound people.

Breslin: Came to the department?

Goodwyn: Yes. Because they were looking for people with really severe disabilities, they came to me and said, "Could you find some way to get some reaction to this idea?" So I had John Hessler and Ed Roberts and some other people from the Berkeley community come and listen to their idea, and we were just appalled that they would want to train people to stay homebound. So we suggested that the training would be quite nice if it could integrate people with severe disabilities into a regular competitive work environment. So they changed their orientation, and we then had another alternative other than just sending people through UC--it was a shorter kind of training program with a more absolute vocational objective. So some of the students then were diverted into the Computer Training Program. That seemed a more appropriate objective. And two of the people I was working with actually taught the class: Neil Jacobson, who has CP [cerebral palsy], and Scott Luebking, who is a traumatic quad. They were both very gifted people going to UC. They taught the first class, and of course it became a very successful thing, and it's still going now.

Breslin: What year was it that IBM approached you? Do you remember?

- Goodwyn: I can't remember the year, but it was quite a long time ago, because the program celebrated its twentieth year about two or three years ago.
- Breslin: It might have been '73 or '72. [October 1974, and, more definitively, February 1975--Ed.]
- Goodwyn: Around in there. But that program became a model for other programs around the country.
- Breslin: How did IBM react to your suggestion that homebound work was not appropriate?
- Goodwyn: I think that they had never really considered that maybe this was an inappropriate thing, and they were very willing to listen. And it was through John Velton's patient arbitration, I think, that we actually even talked, because the rest of us were just sort of disgusted [laughter] and thought, "wasted time," and John saw some potential to pull us together and make us actually communicate about what the issues were and what could be done to reach a better solution.
- Breslin: Did IBM come to you all with an idea to do good works? What was the motivation?
- Goodwyn: It was a philanthropic sort of thing, and they had actually set up a training program on the East Coast that they were hoping to replicate on the West Coast.
- Breslin: A program training people to work at home?
- Goodwyn: Yes, homebound programmers.
- Breslin: And they liked that program, I presume?
- Goodwyn: They did.
- Breslin: Good for you guys for having held the line on integration [laughter].

A Memorable Meeting with John Hessler

- Breslin: One of the things that is so interesting to me and other people about you is that you came to the table with no training as a rehab counselor. Probably one of the great assets--your being open to doing things a different way. And over the course of ten

or eleven years--twelve years maybe--you provided rehab services to virtually all the people in Berkeley with disabilities, many of whom were also activists in the developing disability movement. I'm wondering if you would be willing to share with us some recollection of a few of those people in terms of where they might be today based on your experience in them as a client, or just recollections in general.

Goodwyn: Well, I think one of my favorite moments--and this was when I was really still new--I went over to interview John Hessler, and I had an appointment to see him at his house. When I went in he was in bed, stark naked with no sheets covering him [laughter]. I said, "Oh, am I early?" He said, "No," and I said, "Would you like me to cover you?" He said, "No," and so I did my interview in the most clinical way possible and left [laughs]. But I think it was John just testing my mettle as the new rehab counselor, and I think I passed his test.

Breslin: That's a great story. Did you ever talk to him about it?

Goodwyn: I never talked to him about it later. But that's the kind of thing that they would do.

Breslin: They? Who's "they" in this context?

Goodwyn: You know, John and others from the residence program. I wouldn't have been surprised if it had been Ed. They were always challenging me.

Mark O'Brien, from "Wild Child" to Gentleman and Scholar

Breslin: Are there other people who have had similar places in your memory in terms of experiences with them as clients? Or colleagues, I guess?

Goodwyn: I remember working with Mark O'Brien when he was still at Fairmont Hospital, in the early to mid-seventies. Mark was referred to me because when Ed was the director of the department he had a very high profile as a man who had had polio and who was doing pretty remarkable things. So Mark O'Brien's father asked Ed how to get something to happen for Mark, and Ed referred the father to me, so I went out to see Mark at Fairmont. Mark had spent most of his life sort of sequestered in his family home and really hated Fairmont. His only way of getting anything done seemed to be to shriek. In my mind I called him the "Wild Child" because he just had not had the opportunity to develop social

skills that were required to get things done if you were relying on people other than family members. And I know he was miserable there. But just to see the evolution from the "Wild Child" stage to being a gentleman and a scholar has been particularly rewarding for me.

Breslin: Talk a little bit about Mark in terms of his disability and the kinds of things he expressed interest in being involved with as--

Goodwyn: Well, Mark had basically been homeschooled, because he had polio as a young child. At one point when his parents were getting older they decided that he needed to get out of the home, because they felt that they couldn't take care of him as they entered their senior years. So he exhausted the Kaiser insurance coverage--or whatever insurance coverage they had--by staying at the Kaiser rehab facility. Then they tried to find his place where he could be in a convalescent care setting and still go to school. At Fairmont they had an arrangement with Cal State Hayward to bus students down to Cal State once or twice a week to take classes. So Mark was in the Fairmont facility getting bused into Cal State when I met him. His interest was in writing. We moved him into Cowell Hospital for a few weeks and then into the dorm program. He was active in an English major, got his English degree, then actually went into a master's degree in journalism before his health failed.

Breslin: What kind of obstacles, if any, did you encounter in thinking about or arranging for him to be enrolled at Cal?

Goodwyn: One was Susan O'Hara, who doubted my sanity [laughs] about bringing such a severely disabled individual into the dorm program, because she had to arrange to get his iron lung lifted by crane through the window of the dorm [laughs].

Breslin: And did.

Goodwyn: And did, yes. Of course, he had no motorized wheelchair, and so I worked with Stanford to make a wheelchair that he could operate on his own, because the only thing that he had that could move enough to operate a wheelchair was his knee, and of course he had contractures all over his body from not having been positioned and turned, and he never had any range of motion with him. So he had lots of contractures that really compounded the disability. So the first thing that the people at Stanford made for him was a wheelchair that basically looked like a coffin without a lid, and Mark just wept when he saw it. He couldn't even fathom being seen in public in something like that. So I told them that was not acceptable, and they redesigned it so it looked more like a gurney with a string of rear-view mirrors so

he could see where he had been or where he was going--I don't know which way this worked. It was a pretty bizarre arrangement.

Breslin: Was it originally designed to look something like a box?

Goodwyn: It was like a box without a lid.

Breslin: Were they concerned about him falling off?

Goodwyn: They were afraid that he would get jostled as he went up and down ramps and would fall into the street. What they did finally was put a couple of straps across the gurney-like platform. That way he stayed on top of this thing. I think with current seating and mobility they probably could have done a custom cushion and nestled him in some custom-fitted contoured seat, but since he couldn't sit up and since they had him on a flat surface they were afraid he would slip off.

Breslin: You were his counselor for a long time.

Goodwyn: I was his counselor, and he was still an active student--I can't remember if he was active when I left. I think he was in graduate school, and I think someone else closed his case when his health failed. Mark found me several years later and told me he had kidney stones that they couldn't dissolve, and he was in extreme pain. They said that doctors couldn't use any of the ways that they had of breaking up kidney stones, because he was too great a health risk. So he was in extreme pain for a number of months--if not a number of years--dealing with these things until they just sort of resolved on their own. He's periodically gotten in touch with me as major events have occurred in his life.

Breslin: Was there any resistance on the part of the department to take on someone with such a severe disability?

Goodwyn: Well, I'm sure there would have been had it not been for Ed Roberts saying that we would work with him [laughs]. I mean, I certainly was willing. I was a little frustrated because the parents at that point, I think, were feeling Mark's tremendous dissatisfaction, and they were putting a lot of pressure on me, and in turn I had a few short moments with them because he came pretty poorly equipped to deal with the outside world. He had no way of creating a legal signature, and I asked them to get a signature stamp, which they did, but I think I had to remind them that they had left a lot of unfinished business and they couldn't just hand this entire problem off to me and expect to have it fixed within a couple of weeks.

Moving Severely Disabled Youth from Fairmont Hospital to the Community

Breslin: He had been living at Fairmont Hospital at San Francisco?

Goodwyn: Fairmont Hospital is in San Leandro.

Breslin: Oh, San Leandro. And they selected that location for him because of this exhaustion of other--

Goodwyn: Yes. Their insurance coverage for long-term care had been exhausted, and Fairmont was the regional facility for warehousing people with severe polio residuals.

Breslin: Is that still the case?

Goodwyn: No. At that time what we did is we took all of the people in the polio ward who were young enough--into their forties, probably--and tried to get them into the community. Vista Community College had a program going on, co-located on the UC Berkeley campus, and so what we did the summer that we closed the Cowell Hospital program is we moved everybody who was even remotely interested in rehabilitation of any type into the Cowell Hospital and told them they had a few weeks to find an independent living situation near campus.

Breslin: It served as a transition even if you weren't a student.

Goodwyn: We used it as a transitional facility, and we used Vista as sort of our license to get people into Cowell for this short term.

Breslin: Who was involved in that transition? Are you free to say that?

Goodwyn: I know, unfortunately, Larry Gardner was one of the people who came out and he later died because the belt on the motor on his iron lung broke and he was unable to get help in time. So we've all felt really, really bad about that. And there were some other people I can't remember. But there were several black men that we got out of Fairmont Hospital who probably never would have gotten out--Larry was one of them. And there were some other people there who were in iron lungs.

Breslin: That must have been an amazing moment to realize that it was possible to really facilitate this extraordinary life change for people.

Goodwyn: It was easy to work with them and talk with them at Fairmont Hospital. When they got to Cowell Hospital and they realized the

clock was running out, and they had lost the security of Fairmont, and they were facing the great unknown. It was a very, very stressful time for everyone, including Mark. Everybody was just much more distressed than I had expected them to be. And it was stressful for me too because these people were absolutely frantic with anxiety.

Breslin: What was the source of the greatest anxiety for them?

Goodwyn: I think simply the change in physical security and having to arrange for attendants, not knowing if they would be reliable and show up, not knowing if the Department of Social Services or welfare people would come through with the attendant care monies. I think there was a lot of anxiety about making such a major physical and economic change.

More on Mark O'Brien and Other Clients

Breslin: Absolutely understandable. In terms of Mark's progress--I know you've followed him over the years--what's his situation now?

Goodwyn: I think Mark is probably having the finest years of his life right now. A year ago the lady who is now his fiancée threw a birthday party for his forty-seventh birthday. It was really quite a party because it had newspaper owners and publishers and filmmakers and all kinds of exciting people in attendance. Since that time he's become engaged. He and Jessica Yu have won the Oscar for Breathing Lessons. His life is not the simple, dull, ordered life that it once was.

Breslin: Do you attribute some of his successes to your services as a rehab counselor?

Goodwyn: I think sometimes it's hard to know what a person would have done on their own and what effect you've had, but Mark clearly thinks that things I did for him changed his life.

Breslin: I think a number of people would agree with that and would say that about their own circumstances too. Is there anybody else who comes immediately to mind on your very long client list that--?

Goodwyn: There was the cute and charming Gary Brickman, who called me after he had come to campus to tell me that he had accidentally opened a door and gone down a flight of stairs with his osteogenesis imperfecta. Fortunately he wasn't severely injured,

but I understand he's moved back to Washington, D.C. And then there is Fran Panganaban, our world gadabout who went to Spain, came back, and is now living in Spain. He was interested in linguistics. Then of course Peter Trier, who is becoming increasingly prominent as a philosopher. Then there are those that were contributing so much who have died, and it's kind of sad to think that John Hessler has died, Ed Roberts has died, Mary Ann Hiserman has died--people that I haven't thought about for a while and ask about, they've died. It's sad to see that we're all getting older and some are dying sooner than others.

Breslin: It's been a tough few years on the movement in terms of the toll of disability as well as the toll of aging in combination. It really has had an impact.

Confronting Discrimination: Clients' Job Struggles

Breslin: I wanted to ask you something related to a remark you made about a job you held in San Francisco when you first got to the area. You had said that you worked for Northwestern Mutual Insurance--your first job in San Francisco.

Goodwyn: Right. My first job in California.

Breslin: You said something interesting about that job. You said that you were earning very little money but that you had high-level responsibility for claim rating and had a facility for being able to do it.

Goodwyn: Basically, when they filled those jobs they filled them anywhere from \$275 a month to \$325 a month. When they hired me, they hired me at \$325 and then they gave me a raise to \$350. Basically, what we did--there were women in the office who rated auto insurance policies for the company, and we rated them based on the driving history of the applicant and the age and the sex and the physical location, and a bunch of rating factors. We used a manual calculator to crank out the rates. Accuracy was pretty important, because if you underrated enough policies the company would lose money. It was almost beyond the ability of some of their insurance agents to rate policies correctly, so we would rate them, and we also had a sales staff--only men were allowed to do sales--and I would train the men who would go out and do the sales how to rate the policies. They were automatically paid \$200 a month more than we were. They didn't seem to have any salary limit on what they could make.

But when they wanted me to work in helping them decide how to automate their system, and I indicated that I was leaving to take another job, they checked with headquarters to see if they could pay me more. They were told that the absolute ceiling for women in the company was \$400 a month. This was in 1966-67.

Breslin: That story prompted me to think about the relationship between gender discrimination and the kinds of experiences that the clients you were serving on campus and the Berkeley area might have been experiencing when they were going to look for work. Do you recall any incidences where people came to you and said, "I would apply for the job but they won't hire me because I have a disability"? Was there discrimination?

Goodwyn: There were several instances that still really gall me even now. One was that we noticed that employers were willing to let people with disabilities have menial, almost meaningless nonprofessional jobs. So one year we set up a contract, about \$120,000 or \$130,000 with the University of California, to get people into professional-level career tracks on campus. We did it as a one-year OJT [on-the-job training], and then the university was supposed to pick up the trained employees and put them into the regular career track if they performed adequately during the first year.

So the university accepted all of our money and at the end of each contract they said, "Sorry, we don't have the money to take these people. They're perfectly lovely, but we don't have the money." I felt that that was a tremendous breach of contract. I tried to get the people who had been involved, to sue them or to do something. Most of the people weren't interested, but I did get one man with a learning disability to do it, and he did get his job. I had John Wood, who had been an anthro instructor, and he did it, and he was allowed to continue teaching an extension course in anthropology.

Breslin: Did you have at that point some sense of the relationship between the disability movement and the laws that were developing--

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Goodwyn: It was everywhere, and then when any new rehab type of legislation happened, everybody would be so shocked and they'd think, "Gee, this is so radical." To me it was just business as usual; I didn't see any particular change, because it was the way I had been operating since I was trained by John and Ed.

Breslin: You saw a direct relationship between the advocacy and legal efforts and people's successes in challenging kinds of unfair practices that you've just described.

Goodwyn: Right. In fact, another one that I saved--and I will give you a copy of the letter--was from Mark Lee, and we got him a job working for the Social Security Administration. They said that he couldn't keep his job because his speech was not intelligible to the public who might call him. Frankly, his job didn't involve very much public contact. When I tried to discuss it with his supervisor, the supervisor's speech was much more mysterious to me than Mark's because he was a foreigner. He was from China or some Asian country, and his speech was terrible. It was English as a second language, and he was barely able to speak or comprehend English as nearly as I could determine. A legal firm did actually sue the Social Security Administration and Mark got back wages and some other kind of settlement and he got to keep his job.

III POSITIONS WITH THE DEPARTMENT OF REHABILITATION, SINCE 1983

Surprise Promotion and a New Caseload in San Jose

Breslin: In 1983 you moved on from your counselor role to a new position.

Goodwyn: Yes. There's a story behind that too.

It actually came as a surprise to me that I was even promoted at all, because I had taken the RS exam--rehab supervisor exam--each time it was given, and usually I made a score that was sufficiently low that I couldn't challenge it, but it was clear that I would never be promoted. Then on this one time, Doug Ford, another man and I ended up in the top three ranks. What happened is that the district administrator, Charlie Miggs, hired somebody from the fourth rank who was Hispanic, citing a need for affirmative action. Doug Ford was angry enough to get an attorney and challenge this. The attorney took them to court, and they were told to go back and use the rank of three and hire one of the people in the top three ranks. In the meantime the other fellow who was in the three ranks had withdrawn from consideration, so they said, "In that case we get to continue to hire Mario." So the attorney went back and got a judgment that said "as the list was originally constituted." So they had to choose between Doug, who had sued them, or me [laughs] who had no part in it of course. The lesser of two evils appeared to be me. So Charlie hired me.

Breslin: But at the heart of this is the role that both you and Doug played.

Goodwyn: Doug was also a very, very strong advocate for people with disabilities and had worked with the Santa Clara Valley Medical Center Spinal Cord Injury Unit. Doug, much as we saw eye to eye, was a much more liberal spender than I was. He liked to send people away from Santa Clara with vans already modified and with driving lessons given and things like that, which is a nice

idea but it's pretty hard for someone with a severe physical disability to generate the income to support a vehicle that has all kinds of special needs of its own. So I didn't particularly see eye to eye with him on everything he did, but I certainly did philosophically appreciate his desire to meet the needs of people with physical disabilities.

Breslin: The repercussions of both of your positions on services has dogged both of you to this day. I think it's certainly an important part of your story. The transition from the role with the UC Berkeley students to your position in San Jose was fraught with all of this, I assume.

Goodwyn: Charlie Miggs took me with great apprehension.

Breslin: He was the district supervisor?

Goodwyn: He was the district administrator. He took me with great apprehension. In fact, I had no sooner arrived there to my office in Los Altos when I was told that I would be moved to East San Jose, which is like the worst assignment in the district. So I moved to East San Jose and supervised the counselors there. We served kind of a rural, farm labor, minority, new immigrant population. Lots of Hispanics and Pacific Islanders. Charlie actually came to respect my work quite a lot [laughs]. I wasn't the evil, eccentric, litigious person he thought I was. I have many letters of commendation from Charlie.

Breslin: What was it like for you making that transition from what I just assume must have been kind of an extraordinary environment and caseload to something entirely different--not better or worse necessarily, but different?

Goodwyn: It was kind of interesting, because I was able to help train counselors to work more effectively with people with severe disabilities that they wouldn't have even considered working with before--wouldn't have known how to work with. Or if they had worked with, they would have worked with them inefficiently and badly. That was the important thing.

Supervising Graduate Students in Rehab Counseling

Goodwyn: I think the thing I wanted to tell you earlier that forgot was that when I was working with the Berkeley population, suddenly I became the favorite of the San Francisco State graduate program for rehab counselors, and they used to like to send their interns

over to intern with me until they discovered I had no master's degree [laughter]. Then they had John Velton be the official supervisor, but I still got to do all the work.

I found that their program had some serious, serious problems at the time. Basically, it was taking people who were hoping to get an MFCC [Master's in Family and Child Counseling] or a psych degree, and because there was a stipend associated with it, it was training these people to be rehab counselors and they had absolutely no interest in doing rehab counseling as we knew it in Berkeley. Their interest was more in counseling. So they wanted to talk and not do. There was just a lot of nuts and bolts stuff that had to get done. They just weren't learning how to do that part.

Breslin: Because the program didn't teach it?

Goodwyn: It did not teach it and it gave them a false impression about what rehab counselors did or were supposed to do.

Breslin: Did you have an opportunity to have any impact on the curriculum?

Goodwyn: I think that the curriculum has changed a lot. It helped when Edna Brean started teaching there. I think when some actual Berkeley people got over there and influenced the curriculum it changed for the better. Introducing rehab engineering has also helped give people a better focus on the fact that assistive technology can do amazing things for all kinds of people, including people without too many disabilities.

Breslin: Was there anybody involved in that program at the time who had a disability, either as an adjunct instructor--

Goodwyn: Not that I'm aware of. I occasionally went over and lectured some of Edna's classes, but I'm not aware of any faculty that had disabilities.

New Counseling Situations: The Developmentally Disabled

Breslin: In terms of your work in San Jose, were you able to make any linkages between the experience in Berkeley and the client group that you were working with, other than helping the counselors in that office to understand what the opportunities might be?

Goodwyn: It was pretty isolated. They were starting to work with a couple of new groups about the time I did that. One of them was what

they now call TBI, or traumatic brain injury. My only encounter with that had been just before I stopped counseling and it was very frustrating, and I really didn't understand what was going on. But even today I find that that's a really important population for the department. I'm working with people today who have significant brain injuries. It's kind of fascinating.

Breslin: That's kind of a new area.

Goodwyn: For me it's new.

Breslin: It's new because you haven't counseled them--

Goodwyn: I hadn't done it before. But it's really fascinating to work with.

Breslin: Why?

Goodwyn: Many of these people look physically normal. They have normal intelligence, at least superficially, and they're missing large blocks of abilities that--you don't always know what they are.

Breslin: What kind of challenges does that situation present to you as a counselor?

Goodwyn: I'm still learning how to cope with it. I'm still learning what the good resources are. I think that one of the things that I'm seeing that's very successful and we know that was successful for Berkeley is a good peer group support. I'm seeing where people who have that can learn an awful lot from each other, that it's pretty hard to convey just by lecturing or counseling.

Breslin: You had said during our first interview that the counseling approach to rehab counseling wasn't very effective, because in your estimation it took a couple of years for a traumatic quad to figure out how to put all the pieces together and that the best information they could get was from some other traumatic quad because they had credibility and not from you because you didn't have that experience.

Goodwyn: I think that's the same principle operating here. I think that somebody who has a head injury and has experienced a problem and figured out a way to handle that problem is probably a lot more effective in giving advice than one of us who looks at these people having problems and says, "Well, I've observed this person has this problem. Why don't you--" So I think that works a lot better.

Breslin: I think it does too.

Program Supervisor

Breslin: So you worked in the San Jose office from '83 to '89. Is that right?

Goodwyn: From October 24, 1983, to March 31, 1989, I was the program supervisor in San Jose.

Breslin: Are there any other experiences that that period of time brings up for you that--anything else that you can think of that drew on the Berkeley experience or that related to it?

Goodwyn: I think one of the things that was most pronounced was I realized the amount of stress I had been living under in trying to work with a group of very active, sometimes politically militant, very bright and capable people, and meeting their demands. I was exhausted and hadn't realized it.

The other thing that I realize is that life can be pretty dull without those kinds of influences [laughs]. We were serving a population of developmentally disabled people, and after Berkeley, that's pretty dull.

Breslin: That was a new focus for you.

Goodwyn: A new focus for me, yes. And there were sheltered employment workshops where these people were more or less in holding patterns, and they'd go in, and I think supported employment was just becoming the order of the day, and people were pursuing repetitive, meaningless kinds of activities, and we felt this was good. I just didn't quite really get it.

Breslin: Did you see that as any kind of an opportunity for the same kind of--there was very big reform in Berkeley that occurred, and the department, through your facilitation, was able to play a role. Did you see any of that same kind of opportunity with this population?

Goodwyn: I saw other people picking up the ball and running with that, because the DD [developmentally disabled] population is a tremendously influential one in terms of politics and money. I saw a lot of people building their professional empires based on figuring out how to leverage our money and other people's money into this great, giant empire for themselves.

Breslin: It doesn't sound like that includes benefiting the people that--

Goodwyn: I don't think it benefits the group of people that are the recipients of all of these public babysitting kinds of functions that we do. I'm not sure that people are any better off.

Breslin: Can you imagine what might be brought into play that would improve people's circumstances who have developmental disabilities? Is there some other thinking outside the box way to go about the problem?

Goodwyn: I think that independent living is rewarding; these people can accomplish that. Or semi-independent living. I think maybe independent living to the extent that one can do it, and then support where one needs support. I don't think we need to put people in some of these halfway situations where it's a business enterprise for somebody first and foremost, especially family members, and not necessarily in the best interest of the person that we're providing the service.

Breslin: Were you in a position to voice those kinds of views?

Goodwyn: No.

Breslin: They were held privately?

Goodwyn: They were private. No one was interested in our points of view.

Breslin: But why is that, do you suppose?

Goodwyn: I think it's simpler and easier for the department's administration to not hear our points of view, although the public hearing forum is certainly in right now. But I think for a department member to go out and express an opinion in one of those forums would probably be not a healthy thing for one's career.

Breslin: You haven't done very much that's healthy for your career throughout the entire--[laughter]

Goodwyn: I don't think I have too much smarts [laughter].

Breslin: You've done all the right things, but not necessarily for yourself.

Particularly in the San Jose situation, did you have an opportunity to work with parent groups at all? Because the positions that you're talking about are very close to the positions that many parent groups are taking.

Goodwyn: Well, no, I did not have a chance to work with parent groups, but I did have my staff working flex hours, which in some ways really benefited parents who had to get out and go to work and things like that, who were involved in their children's life decisions. And that made it a lot easier for them to communicate much more regularly. And I had some very talented counselors working there.

Breslin: The question actually that I was asking was about the parent groups. They had formed to advocate for various kinds of programs for people with developmental disabilities, and they, in many ways, advocate and articulate the same issues that you just articulated. They were a potential natural alliance, but it wasn't easy to come by, probably.

Goodwyn: It didn't happen there. I think it could happen much more easily in Berkeley, because I think Berkeley is much more politically astute than the backwoods of San Jose. But I know that DCCG formed about that time.

Breslin: Say what that is.

Goodwyn: That's the Disabled Children's Computer Group, which has split up into two things and I'm not quite sure how they're related, but one is Alliance for Technology Access, which deals with access to electronic technology, and the other is the Center for Accessible Technology System--I think that's what they call it--CATS. That's over in Berkeley where DCCG started.

Breslin: Did you have some relationship to those programs either during your time in Berkeley or--

Goodwyn: I think they started after I left Berkeley. Or maybe they were starting just as I was leaving--that must have been it. And I did have a little bit of involvement, and when I came back to see them again they actually physically moved to a different site. When we started doing computer things and I wanted to deal with access issues for our own employees, I wanted to talk to them about some of the access issues, and mainframe, and adding layers and layers and layers of access devices and software. They were somewhat helpful, but their expertise in dealing with mainframes was pretty thin.

Breslin: They were PC- or Mac-focused.

Goodwyn: They were basically Mac-focused at the time, and we were PC- or mainframe-focused. The best help I got came from the East Coast, from some NIDRR [National Institute of Disability Research and Rehabilitation] funded program. I can't remember what it was.

But anyway, a very good person there has now gone on to other fairly prominent roles.

Ed Roberts as Director of Rehabilitation, and His Successor

Breslin: This period of time around 1983 when you were making your transition from being counselor at Berkeley to the San Jose job also was the period of time when Ed Roberts was moving on from the Department of Rehab. Was there any noticeable difference for you in your role with the department before and after his tenure or not?

Goodwyn: When Ed was around, one of the problems I had with Ed was that Ed felt like he had a direct pipeline to me, and he would come to me and ask me to do things. I didn't realize the effect of lack of protocol on the people between him and me, and so lots of times I would have to go to Henry Leng and say that Ed just asked if I would do x, y, and z, and Henry would have a fit. So I had to ask Ed if he would kindly follow protocol, because it was causing me a lot of problems. But when Cecie came she never consulted with me on anything [chuckles]. Never asked me to do anything.

Breslin: This is Cecie Fontanoza.

Goodwyn: Yes. The next director. I was pretty much just a peon working in the field. The whole emphasis for Cecie was, I think, an educational influence, like learning disability and developmental disability. She was not particularly interested in the issues of people with sensory or physical disabilities. It was her background. I think she had been an administrator in the schools.

Breslin: How was that for you, having that kind of transition go on?

Goodwyn: I found her--given my own particular and very narrow interests--to be a very uninspired, uncharismatic, uninteresting director.

Breslin: How was that--in that regard?

Goodwyn: Ed was inflammatory. Ed insulted the staff who wanted to regard themselves as professional. He made them angry. He came in and tried to get rid of supervisors he didn't like by changing the job classification and then having all supervisors retest. It really did create a lot of nasty feelings toward him and the department.

- Breslin: How do you rank his overall impact on the department in terms of service to people with disabilities?
- Goodwyn: Oh, I think it changed it dramatically. That, and the subsequent legislation.
- Breslin: Changed it for the better?
- Goodwyn: Oh, yes.
- Breslin: Despite this inflammatory--.
- Goodwyn: Right.
- Breslin: Why? How?
- Goodwyn: I think he just created an awareness of severe disability and the potential that people might have that we hadn't really wanted to even think about before. It's too much trouble. And I think, also, that some of the tools that we needed to provide services became a little bit better funded and more reliable. We got better vehicle evaluation facilities. We have Project Threshold from Rancho Los Amigos Hospital that went into offices and did work site analysis. We could go into homes and do independent living analysis and things like that. We actually hired rehab engineers on our staff.
- Breslin: Was the classification of rehab engineer even something that was formalized?
- Goodwyn: It was kind of a new idea. I remember when we started the Computer Training Program, the closest thing I could find to a rehab engineer at the time seemed to be an occupational therapist.
- Breslin: Many of them turned into rehab engineers, I think. I don't know what the--
- Goodwyn: I think they were either engineers who had an interest in orthopedic mobility kinds of issues or they were medical people.
- Breslin: The certification program, I think--I don't know anything about it--but I know it was just phasing in in the early eighties as a relatively new specialty.
- Goodwyn: And RESNA [Rehabilitation Engineering Society of North America] is trying to set standards.

Breslin: You had to operate under Cecie's tenure for quite a while. Was there any noticeable change in any positive way during that period from your personal perspective as you were dealing with a very different environment than the Berkeley environment?

Goodwyn: I think we began to sort of dabble with supported employment and then get more and more heavily involved, and I think there were a lot of transition partnership programs set up with high schools. From my perspective in looking at the work that my counselors were doing, high schools were taking basically minimally disabled people and people were just writing rubber-stamp sort of plans, and it was just another way of generating more money for the Department of Education and the Department of Rehabilitation through the matching funds mechanism.

Breslin: Did it have an impact on most severely disabled people?

Goodwyn: No, it wasn't serving the most severely disabled. It was like another one of these programs geared to produce large numbers of rehabs, quickly with controlled expenses. Instead of serving felons and alcoholics, we were now serving minimally disabled high school students.

Technology and Telecommunications: Aiding Disabled Employees of Department of Rehabilitation

Breslin: In the late eighties--I think it was 1989--you moved on to become telecommunications--

Goodwyn: I became one of the field liaisons for the field computer program. And that's when the department went out to bid to get a contractor to help us automate our recordkeeping. I was hired in time to review the proposals. They were from Arthur Andersen, Price Waterhouse--lots of companies who have since merged and merged again and changed names. That was kind of an interesting process. These proposals literally filled a room. We divided each proposal into technical aspects and programmatic aspects. So we reviewed for programmatic aspects to make sure that what they were proposing was responsive to the program needs, and then the computer resources people reviewed to make sure that what they were proposing was actually technically feasible with a very out-of-date, very clumsy and awkward mainframe.

Breslin: Were you able to make the transition?

Goodwyn: In retrospect it was done poorly in some ways, because the department does not question its information systems services staff's judgment, and I think it really needs to be questioned. We got locked into some very antiquated technology. We also ran short of money and we shortchanged our staff on training. But I was able, with my limited budget, to work with a group of people who were employees of the department who had disabilities, which involved physical disabilities, hearing disabilities, and visual disabilities.

We arrived at a way of evaluating anybody who identified themselves as being disabled and devised an approach to meet their needs in terms of computer access. So I was able to, within budget, meet all of the needs. And I ended up working with about eighty either blind or visually impaired people, which I thought was a lot of fun. We ended up buying some really awful, unreliable stuff, state-of-the-art at the time.

Breslin: There wasn't much around.

Goodwyn: There wasn't much around. It was really very primitive. The first speech synthesizer we got--well, the speech synthesizers were very expensive then--and the first one we got was made through the Disabled Children's Hospital in Boston, using the Dectalk speech synthesizer. But it was extremely unreliable. So needless to say, we bought these [chuckles] not knowing they were unreliable. They were the more human-like of the speech synthesizers, so we gave them to the staff who preferred that to the Accent speech synthesizer, which produced a much more mechanical speech. The people with the Accent cards did fine. The people with the Dectalks had constant problems.

Breslin: What year was this? Do you remember?

Goodwyn: This was probably the end of the first year that I was doing all this. 1988 or 1989. And technology just changes. We were talking about Web years, and somebody said, "One Web year is ninety days." [laughter]

Breslin: That's exactly right.

Goodwyn: So this technology, by the time we managed to purchase it, was already antiquated. There would keep being new software products and new hardware products, and each time we'd have to replace equipment we'd have to kind of look at what was going on.

Breslin: Can't stay ahead of the curve these days, really.

Goodwyn: I know.

Breslin: That really took you out of having direct relationship with people who were clients.

Goodwyn: For the most part.

Breslin: Are there some exceptions to that?

Goodwyn: Occasionally people would ask me to consult with some client in some cases. I actually felt like our employees were my clients, because they had--

Breslin: They had access issues just like--

Goodwyn: I worked with a deaf and blind woman. That was kind of interesting, getting her access set up. It was kind of fun. Then the way I got started with the telecommuting was that a woman who had severe juvenile rheumatoid arthritis, who might have been a client of mine--I mean, she was simply--

Breslin: She could have been if she hadn't been an employee of the department--

Goodwyn: Yes, if she hadn't already been employed by the department. She had to have multiple joint surgeries, and she wanted to work at home, and she noticed that our work was highly transportable because we were working at a computer screen now. So she raised the question of whether or not she could take an Informer, which was a portable terminal, and work from home during her convalescence. And when I asked our executive staff if that might be possible, they said we had no policy, and would I please look into it? I looked into it and discovered that the governor was encouraging all of the department to develop telecommuting policies. So I developed one for the department and set up a telecommute pilot, allowed her to work at home, got a lot of other people with disabilities working at home--not every day of the week like she did--but got them working at home because it's a tremendous energy saver.

Breslin: It's also the trend of the future for everybody, I think. It absolutely is.

Goodwyn: Oh, it is.

##

Breslin: Karen, we're talking about your working for the department, setting up the telecommute policy. You were saying it's like having a caseload of the folks with the most severe disabilities within the department.

Goodwyn: Right. Well, not everybody in my telecommute pilot had a disability, but when I did my analysis it seemed that a number of people who were visually impaired had applied as just regular people who were qualified in every way, which was above average performance and reliable and trustworthy and knew the job. They had been screened in as telecommuters, and even people who were screened in that had no apparent disability had disabilities that I was unaware of, particularly people with restricted driver's licenses who were not allowed to drive on freeways or who weren't allowed to drive before or after dark. They said it was just a godsend not to have the stress of worrying about "Will I get home before I have to--before I turn into a pumpkin or something?" [laughs] People like Don Queen, who commuted in--he had had a heart attack, he's blind--commuted into the new San Francisco district office, which is down in China Basin. Very noisy, very unfriendly to get to if you're blind. He said that the two and a half hours that he had had to spend on a bus each day were just so stressful, especially in recovery from a heart attack. This was just the thing that allowed him to continue working.

Transition Back to Senior Counselor

Breslin: That's quite a legacy, really, that you put in the department. No kidding.

Goodwyn: Well, it's not appreciated.

Breslin: Why's that?

Goodwyn: Our current administration--Brenda Premo excepted, although she doesn't seem to have as much weight in these things as she once did--feels that if you're not sitting at your desk you couldn't possibly be working, and they're trying to--without looking too politically incorrect--to more or less make this thing go away. I have a feeling it's one reason that they moved my job to Sacramento. While they were forcing me to demote, because they moved my job out of town, the director of the department of personnel administration was writing me a letter of commendation for my work in telecommuting and in making it feasible to do by creating self-paced training manuals for telecommuters and telemanagers, for addressing disability issues, and helping to establish guidelines for people that didn't have the savvy to figure these things out on their own. I inadvertently just get into these things. I mean, I had no idea [laughs] I was getting into a politically sensitive issue, but I certainly did.

Breslin: I know you've had a pretty difficult time the last year making the transition from that job back to a senior counselor position in San Rafael?

Goodwyn: Yes.

Current Trends in the Department of Rehabilitation and Reflections on the Legacy of the Berkeley Experience

Breslin: I won't ask you to reflect on what you're doing now, but I'm interested in what your thoughts are on your work in Berkeley in terms of its impact on you professionally. I think it's been quite extraordinary, and I wondered what your sense of it is now.

Goodwyn: In a way, I'm sort of enjoying seeing people again, and I think that the resources that I developed in terms of skills and in terms of perspective enabled me to offer services that are probably a cut above what other people are offering to their clients. Just because I'm working in a rather sheltered, beautiful, insulated community, where people haven't had the exposure to the challenges of the Berkeley population, the resources of the Berkeley community, the connections with the politics of central office, and in interpreting and implementing government regulation.

Breslin: What do you think your legacy is to the disability community?

Goodwyn: Oh, I don't know. One of the things that Scott Luebking and I did recently that was fun involved the Internet. I'm interested --and I've always been interested--in technology and how it can help solve problems for people. What we did was a webmasters' conference on universal access. It was overwhelmingly positively received. It opened the eyes of people so dramatically that they're clamoring for more information. But I think that too was almost too successful, because it's the kind of thing that our own information services section should have been doing or supporting, and instead I was doing this just totally in isolation because Brenda had asked me to work on a committee where we had somebody rather ineffectual attending and nothing was going on. So I got involved and accidentally drew on my Berkeley resources and put together this fabulous day of training for web masters [laughs].

Breslin: In terms of the legacy, the people and the concepts came together with your predilection toward getting things done.

Goodwyn: Right.

Breslin: It seems like it was a synergy between your natural instincts and talents and the circumstances of the time. It now being 1997, what do you think the future holds? I guess that's a two-part question. Let me ask you what you think in terms of the department, because that's clearly one set of issues. What do you think the answer to that question is in relation to the movement also? Start with the department.

Goodwyn: I think the department's got some serious problems. They seem to fluctuate--it's like a pendulum swinging. We go from addressing one kind of issue--maybe the issue of severe disability--and then our attention focuses on learning disability, and then it'll go back to something else. I don't know--this order of selection and severity of disability is certainly a major boondoggle right now.

Breslin: Why is that?

Goodwyn: Because I feel that in order to protect some of the groups that are favorites of the current administration, they made this thing so complex and so subjective that people who are blind--and well-adjusted--can't qualify as severely disabled because they can think, they can navigate, they can dress themselves, whereas somebody with a learning disability could say, "I can't tell if this is the right shirt to wear with these pants."

Breslin: The purpose in order of selection was what?

Goodwyn: It was that with client choice it was anticipated that we would be spending so much more money providing services to meet the unreasonable demands of our client population that we wouldn't have enough money to serve everybody, and we would have to establish an order of selection based on severity of disability.

Breslin: Now that flowed from the 1993 amendments to the Rehabilitation Act.

Goodwyn: Right. From the amendments.

Breslin: What do you think about the idea that was incorporated in the amendments?

Goodwyn: I think that it's straight out of Berkeley, and I think that that is a direct result of the local Oakland district politics trying to restrict services to the severely disabled people who came into Berkeley seeking services and who were discouraged.

Breslin: The amendments are purposeful and have some value--

Goodwyn: Absolutely.

Breslin: It's the implementation that's the--

Goodwyn: I think it's a convoluted and warped implementation. I think people are trying to get around them.

Breslin: Are they doing it differently in other states? Because it's a federal mandate.

Goodwyn: It's a federal mandate, and I would really like to see what's going on in other states. I think that some states are handling it better than others.

Breslin: It's up to the states to determine the implementation.

Goodwyn: It's left up to the states. I had hoped that what they would do is work with other agencies. The trend now is to pool resources and not to duplicate efforts, that we're doing this one-stop kind of approach which I think has some good potential if it comes off right. I had hoped that we would let Social Security adjudicate the severity of disability, and then if they could have been allowed, based on not having to meet the earnings requirements or something else, then they would be most severely disabled and eligible for our services even when our money was tight. But that was too simple for them.

Breslin: The '93 amendments, it seems to me, really set in motion on a national level what you were doing as a counselor in Berkeley.

Goodwyn: I see it that way, and when I see people say, "Oh, these are so radical and so unrealistic," I look at them and think these just make sense to me. People get flashes of horror, thinking of the worst case scenario, but to me it means you have a dialogue, you reach an agreement, and then you fulfill your end of the bargain as long as the other person is fulfilling theirs. That's not so unreasonable.

Breslin: Exactly what you were doing twenty years ago.

Goodwyn: Right.

Breslin: However you see your legacy is very personal, but it does seem to me that the collection of energies and people and circumstances, yourself included, moved toward the '93 amendments, and that's an extraordinary role to have played.

Goodwyn: It was kind of exciting to be there. There were times when things got so successful, and it seemed like what we had set out to do had been accomplished. There was very little place for a person without any visible disability to even have a role any more.

The Future and the Role of Rehab Services

Breslin: We don't have to conclude this today, but let's think about whether you've got some closing thoughts about your contribution or situation now in relation to where you were when you were a counselor. What's on your mind in terms of the future?

Goodwyn: I would love to be able to influence or interpret policy and help state agencies get it right, because I feel like they are either intentionally or unintentionally missing the boat. I think they see the print on paper, and they're just not getting it. And there's no reason why they shouldn't, because it's better for all of us if they do. You waste a lot less money and people will be a lot happier and more productive.

Breslin: In terms of the disability movement, what do you see down the road? What do you think the issues are going to be? Where have the failures been? Where will the challenges remain?

Goodwyn: I think for me the most exciting new horizon is staying on top of access issues with the electronic technology, because I think that can facilitate lots of things for lots of people: people with physical disabilities, ordinary people who are tired or getting older, people with families, people with cognitive impairments or blindness. I think it's important to keep those avenues wide open. I think we're going to see a lot more work done at home or in satellite offices or virtual offices, wherever they happened to be. I think we're going to see a lot more education happen in virtual classrooms.

Breslin: It's hard for me to conclude this, because I have 10,000 questions that I'm curious about your opinion on. There was an OMB [Office of Management and Budget] study done--in the early nineties, '91 or '92--that looked at placement rates for DR [Department of Rehabilitation] nationally. Long term.

Goodwyn: Oh, terrible.

Breslin: And they looked at the five-year rates. The numbers were lower--there were fewer people working after five years than had

originally been working before they came to the various departments for services, nationally. These are not California statistics; this is a national statistic. I have no idea whether the methodology is sound for that study or what the basis was for the data that was used to draw those conclusions, but I'm wondering what you think about the role of rehab, from having seen it in all of its many incarnations, as far as a future resource to help people find both training and employment.

Goodwyn: When I worked with Sue Stoddard on the accountability aspect of the rehab amendments, she brought up the reports and research that have been done, and I was not surprised but I was alarmed at the same time, because I had hoped that if you looked at the big picture, it looked better than looking at it up close.

When I worked with people in Berkeley, I think that even where long-term employment outcomes may not have been absolutely wonderful for reasons of failing health, that to have given people the self esteem, the direction, the motivation to do something saved a lot of money just in terms of hospitalization for neglect to take care of one's self. So I think that's a hidden benefit, but I also see a lot of people who achieve very, very substantial things. If you looked at them on any kind of study you would see that these are major contributors. I think that one of the things that's complicated now is still the disincentives issue. Very complex laws.

I wrote the first self-support plan, and recently I've gotten reinolved because I'd like to see some of my clients use self-support plans, and I've looked at the regulations and they're so complex. On the form it says it's supposed to take about forty minutes to complete; it took me about forty minutes to read. To complete it, forty minutes is somebody's fantasy. I frankly would not do a self-support plan, or a PASS [Plan for Achieving Self-Support] as they're called now, for any of my clients because I feel that I'm not competent to do it. It shouldn't have to be like that; it should be very plain and straightforward, and there should be some kind of financial incentive to go to work and produce something.

One of the other things that we're looking into right now and I find is really exciting, and I see a lot of potential for this if we can change the way we handle income or simplify it, is the potential for self-employment. I think there's a tremendous amount of potential for self-employment, and a person shouldn't have to be tremendously successful to improve the quality of his life through self-employment. They should be able to improve it somewhat if they only are somewhat successful.

Breslin: You're talking about major reforms within the Department of Rehab in order to facilitate--not only rehab, but--

Goodwyn: Within rehab and outside rehab.

Breslin: To facilitate either of those two objectives, that I think completely coincided with the thinking of the policymakers now, but, which given what you know about the history of the department in California, how do you rank the probability of any of this happening? Just take the self-employment question for example.

Goodwyn: Not good.

Breslin: Is that a four on a ten-point scale?

Goodwyn: I know that I'm certainly encouraging people to pursue it, because I'm going to test it. Probably not a politically astute thing to do [laughs], but I want--

Breslin: No, but then again when did you ever allow that to stop you?

Goodwyn: I have some pretty remarkable people who thought they'd make good test material for my theories. I would like to see people try it, because I think that for some of them it's right. I have one person who wants to be self-employed as an artist and a graphic artist, and when I read it on paper I thought, "This is not going to work." When I saw her and saw her accomplishments before she had her mental health breakdown and learned that she had been living in Japan as a color consultant to Japanese corporations, I thought that maybe there's a little bit of potential to this.

Breslin: [inaudible] [laughter]

Goodwyn: Yes. And I do think it'll work. I think people will just have to be willing to get the facts before they say no.

Breslin: The new frontier is economic development absolutely--this is one chunk of it--seems like it's entirely sensible, and there you are out in front of the curve yet again [laughter].

Goodwyn: Every time I think there's nothing new, something happens.

Breslin: It'll never be a situation where there isn't something new.

I've basically asked you the questions that I wanted you to answer. Is there anything else that you'd like to say in general?

Goodwyn: I can't think of anything.

Breslin: If you think at a later point that you'd like to add more about any of these topics we can do that, too.

Goodwyn: Okay.

IV A BUSY LIFE: SOME FINAL THOUGHTS

[Interview 3: March 11, 1998] ##

Hobbies: Art, Opera, Flying

Breslin: I'm happy to see you again. I know we didn't plan to have further conversations, but we have a few more questions. Karen, tell me about your hobbies.

Goodwyn: Well, I do leaded glass windows for architects. I started doing stained glass when I was working with disabled students on campus, and the Stained Glass Garden was in an upstairs shop on Bowditch Avenue. I took a class there and immediately did a window for my house, and I've been doing windows for homes off and on since then, so that's now almost thirty years I've been doing windows.

I earned a private pilot's license and was quite active flying around the Bay Area for a while and have lots of pilot friends. Another fun pastime that I still do is to work for the opera as a supernumerary. I try to do at least one opera a season. I actually met my husband backstage doing La Boheme where he was a waiter, and I had on some very cumbersome yoke with milk pails and was trying to hideout behind the Cafe Momus.

Breslin: When was that?

Goodwyn: That had to have been about eleven years.

Breslin: When did you first get involved in the opera?

Goodwyn: In 1978, I believe.

Breslin: What prompted you to go through the process?

Goodwyn: I had an answering machine that I had just gotten, and one of the first messages was a garbled message from a friend of a friend

saying that, since we had a state holiday, we should meet at the opera and go do something. It turned out there was a cattle call for supers, and they were measuring people. They measured me, took my picture, and called me up.

Breslin: What is a supernumerary?

Goodwyn: A supernumerary is a person who is in costume and on stage, but has no singing role, just a character role.

Breslin: Do you have an acting role in some places?

Goodwyn: Yes, you do bit parts, character parts on stage. Most often, especially for women, they are very fleeting and insignificant roles in terms of carrying the story forward, but they kind of fill out the picture or fill out the stage. We're commingled with chorus most of the time. In some cases, we have lots to do such as Electra, which has no chorus, and we're on stage almost the whole opera.

Breslin: What's your favorite opera?

Goodwyn: Oh, I don't have a favorite. I think it just depends on the director, and the people you're working with.

Breslin: Any favorites in the last season or two?

Goodwyn: Well, Electra was really a lot of fun. We had snakes, and nude women, and a dead cow, lots of fun.

Breslin: It was a wonderful opera. Let's go back to your piloting for a moment. When did you get your pilot's license?

Goodwyn: That was about ten years ago.

Breslin: Is it a single-engine license?

Goodwyn: It's a single-engine, private-pilot, right.

Breslin: Do you rent?

Goodwyn: I was renting airplanes from Lou Fields at the Oakland Airport and flying locally. When I married and bought a new house, I found that the new house payment and flying were not compatible.

Breslin: I see. This has nothing to do with your having lost interest in flying.

Goodwyn: No, I still would enjoy it, but I think, unless you have a certain amount of income to spend to stay current and to keep flying, that you're not safe flying in a congested area like the Bay Area, so, for now, it's nothing I'm doing regularly.

Breslin: What prompted you to decide to do it?

Goodwyn: I had a friend who indicated that there weren't very many women pilots, and he was impressed by any woman who could do it, so I said I think I'll learn to fly. I heard that hardly anyone ever made 100 percent on the written test, and I said I think I'll make 100 percent, and I did. It was just a challenge.

Breslin: One of these days, you'll have to consider whether you're going to go back to medical school.

Goodwyn: It's too late for that. I'm too tired. [laughter]

Breslin: I can't believe that's true. Let me ask you one more question about your stained glass work. You're doing primarily windows for private homes at this point?

Goodwyn: I do windows, primarily, for architects who install them in private homes.

Breslin: They commission your work?

Goodwyn: The building owner, or the home owner, usually commissions my work through the architect.

Breslin: And, you're responding to their stylistic request, or their thematic requests?

Goodwyn: Yes, they give me, usually, a lot of license to develop ideas, but they ultimately have to approve it before I create the window.

Breslin: Have you thought of pursuing any of these interests, in particular stained glass, as an optional career?

Goodwyn: Well, I find that the materials for stained glass, at least the good quality materials, that I enjoy using are so expensive, and that people's expectations of what they should be paying for windows are sufficiently low that there is very little profit in it. I'm doing a lamp right now with Tiffany reproduction glass that I just happen to have from another job, and I'm probably making a dollar an hour. It's not a lucrative thing, but it is fun to do. It gives me a little bit of extra income, and it

gives me a lot of reason to go and visit buildings and other things studying designs and coming up with ideas.

I did a reproduction of a Frank Lloyd Wright lamp that I switched from a table lamp to a ceiling lamp with the assistance of the man who commissioned the lamp. We did the wood work for the lamp, and it turned out really quite spectacular.

Breslin: That's really wonderful. Do you get some opportunity to travel too as a result of your interest in stained glass?

Goodwyn: Well, I did have a commission in Hawaii, and I went over last summer just to supervise the installation of the window. I hope to do most of my work closer to home because it's difficult to work for clients who can't see the work in progress or help me make decisions.

Gender Discrimination and Career Choices for Disabled Students

Breslin: When we were first talking, you mentioned that you had been treated differently than, on the basis of gender, your male counterparts in one of your early jobs here in the Bay Area.

Goodwyn: Oh, yes.

Breslin: I'm wondering if you think any of the students who you were working with at the university experienced any of the same problems?

Goodwyn: In my job where I experienced that kind of discrimination was with an insurance company, and they had a long history of treating men and women differently. At the university, I think that the population I worked with was biased and included more men than women, so that you cannot conclude from the fact that my caseload was largely men that there was any kind of discrimination going on and that women were being excluded.

The reason I had more men than women was that my caseload was, primarily, traumatic quadriplegic. Young men tend to live a little more recklessly than women, and there were just more male quadriplegic than female quadriplegic. In terms of vocational choices that people made, I think that sometimes the seeds for those choices are planted pretty early in people's lives, and sometimes it was very difficult to encourage people to make decisions about careers that were as open as they might have been.

I think, sometimes, women came pre-programmed to do social work kinds of things when, in fact, they could have been engineers, or attorneys, or any number of things. But, I think in Berkeley that we broke a lot of stereotypes, and it was easier for people to do. I know that we had, in the first classes of the Computer Training Program, a number of female students.

Breslin: Among the students who were in the residence program--I know most of them were men--were there any women who you recall that might have been in that program because they challenged some of those expectations that might have been imposed on them early in life?

Goodwyn: Well, we had Mary Ann Hiserman who was an architect, and I don't know that that's a traditional field for women. I think that, basically, she was pioneering in her own way. And, I had another woman who worked as a stockbroker for a short time, which I think is not a traditional woman's field, or at least it wasn't at the time. Then, we had a number of people going to law school, a number of women.

Breslin: It's interesting that the students in the program, the male students, were primarily spinal cord injuries, although not all of them were. Though there was a disproportionate number of men in the program, there's the likelihood that there will be people with various disabilities in the population who are more evenly distributed among men and women, yet the program tended to focus primarily early on, on men and spinal cord injuries primarily. Do you have any thoughts about why that was true?

Goodwyn: I think that spinal cord men were kind of an interesting population because their whole lives had been living in the mainstream until the point of injury. They were eager to return to the kind of life they had once known, or, at least, to something as much like it as they could, whereas people who were born with a disability were often separated from the rest of their peers and put into special schools, or had maybe very low expectations of what they could hope to achieve. I didn't see those people with the same frequency as I saw somebody else who expected to be able to go to school, go to a university.

Breslin: Among the people who you worked with who weren't spinal cord injured--. I'm thinking about Mark O'Brien at this point because I know you had a relationship with him very early on in terms of helping him move into the university community. At the same time you were working with him, were there women who you were finding were similarly situated who also might have been interested in coming to the university or not?

- Goodwyn: I can't think of any women who had disabilities quite as severe as Mark's. We did have quadriplegic women who came into the program. I remember Debby DiNardo, and Cece Weeks, Darryl Grauer. I can't remember them all right now, but we did have women.
- Breslin: They came in just a little later, but the early students were primarily--.
- Goodwyn: The first group, let's see--. I have a really hard time remembering back that far right now because they're all becoming one giant population. I know that Mary Ann Hiserman was among the first group.
- Breslin: Yes, I remember that too. Do you think that the students perceived any limitations on their own opportunities based on gender?
- Goodwyn: Not that I'm aware of. If they did, it was subtle, and I certainly wasn't sensitive enough to pick up on it.
- Breslin: Do you think that the department that you were working for sent any messages to you or to other counselors about what kinds of careers might be appropriate based on gender?
- Goodwyn: I think that the department really didn't make any particular judgments. I think what they would like to have accomplished was that people would be employable with a bachelor's degree. What I found was that we were not pushing people to make any particularly narrow decisions. We had lots of people majoring in things like philosophy, like Peter Trier, or history, like Gwin Hinkle, where it wasn't really clear what occupation they would be able to engage in when they finished their bachelor's degree. Mark O'Brien majored in English.
- Breslin: So, these folks were making choices not based on any limitations they saw in terms of career options but based on personal preferences.
- Goodwyn: They were making choices basically based on their own interests. We had Susan Sygall who started BORP [Berkeley Outreach Recreation Program]; she was interested in recreation for people with disabilities. She more or less created the field.
- Breslin: She sure did. Do you have any recollections about choices that women were making in terms of education leaning toward career choices? Again, I'm asking you to recall.

Goodwyn: I do remember some that I found kind of hard to reconcile, and those were women who thought that, maybe, severely physically disabled women, they should have a career in dance. I just couldn't quite comprehend that was likely to produce an income sufficient to support them.

Breslin: What was the justification for pursuing that kind of career from their perspective?

Goodwyn: I think they felt they had a right to do it.

Breslin: Did you have any conversations with any students in particular about this issue?

Goodwyn: I did, and I don't think we ever resolved our differences.

Breslin: Tell me a little bit about the differences.

Goodwyn: Well, I really felt that we needed to have a practical and accountable outcome. I didn't feel that pursuing what I considered a rather idealistic outcome was necessarily the job that I was hired to do. I felt that I needed an employment outcome within a reasonable time frame, and that to challenge society's stereotypes was perhaps beyond the scope of my particular mundane job.

Breslin: Beyond the parameters the department had set out for you. [laughter] What are your thoughts about the roles that people that you've worked with as clients in those days have assumed in the disability movement?

Goodwyn: I'm very pleased with them. I'm very pleased with Judy Heumann using all of her personality and her skill to get ever increasing responsibilities, and with Debby [Deborah] Kaplan being influential in technology issues, and with Neil Jacobson moving on to a prominent position at Wells Fargo Bank, and Scott Luebking having a nice career on campus after his teaching at the Computer Training Program and now being active in identifying issues that affect the lives of people with disabilities who are out working and doing things.

He's really interested in some unfinished business in terms of keeping an active, reliable attendant pool, and making sure the Internet is accessible, and dealing with the major software producers to make sure their products are accountable to the Telecommunications Act. It's exciting to see the real contribution that people are making.

- Breslin: Some people have said disabled women have done most of the work in the movement, but that disabled men tend to be interviewed in the press and receive the public acclaim. Do you have any thoughts about that?
- Goodwyn: Well, I can't say that I follow the contributions of people in the disability movement closely because I feel like I'm a little bit far afield from it. But, I know that you've done quite a lot with DREDF [Disability Rights Education and Defense Fund], and Susan [O'Hara] was instrumental in making the transition from the Cowell Hospital program to the dorms happen. I think that women have been kind of the solid force in the disability movement. Now, you can't say that Judy hasn't had her fair share of press, or even Debby Kaplan. Debby's been featured as a keynote speaker in lots of places.
- Breslin: I think that's right. I think from your perspective, someone who worked with a group of people early on here, your observations are important in terms of that time period in particular, possibly more so than even in terms of contemporary accomplishments or acknowledgements. Think back a little about whether you think there's any validity in this idea that women are likely to be less acknowledged in a public way? You may not find that you think it's true.
- Goodwyn: I can't really say that it's been something that's been a glaring injustice.

Influences and Impact

- Breslin: Who influenced you at some personal level in terms of your work during those years, particularly at Cal, and later in general at UC Berkeley?
- Goodwyn: I think the strongest influences were probably Ed Roberts who really was a mentor until his death. He was always interested in me and what I was doing. I think he was interested in everyone, but he was always interested and encouraging. And John Hessler, during the years I worked with him on campus. I lost touch with him after that. John was always kind of a philosophical kind of person. We would address sort of philosophical issues about disability.

Zona [Roberts] helped me with some of the social aspects of disability because she was just tuned into things, I think, from having a disabled son, that I would otherwise have been ignorant

about. Edna Brean helped in some way but not nearly as much as Zona.

Breslin: I know you just read the transcript of your interview. Is there anything you'd like to add yourself to what you've already said?

Goodwyn: Well, those years were so rich with experience, and in the transcript it seems that we just barely scratched the surface. I think that, when you collect interviews from everybody, maybe, the picture will come together a little bit better.

Breslin: Is there an example of that richness that you can add at this point?

Goodwyn: Well, I remember, when I was in about my tenth year of working with people in Berkeley, I could not even go a block without seeing five or six people that I knew. I felt almost imprisoned in the Berkeley community because I knew so many people, and I couldn't go to dinner, and I couldn't go anywhere without being inundated with requests from people for things.

It was a pretty intense experience, and it was not a forty-hour work week. It was like a life. In fact, that's why I started doing some of my outside interests because people said I was just too involved in working with that community.

Breslin: Did you perceive yourself as being too involved?

Goodwyn: I did, but people have serious needs, I mean great needs. Unless you set limits, you can get completely overwhelmed by trying to meet all the needs that you see around here.

Breslin: We've talked about this a little bit before. You were so integral in helping people realize their desires, ambitions, and dreams. I wonder if you, looking back now, can explain, or articulate, or describe your own perception of your impact.

Goodwyn: Well, I think that, as time passes, you kind of lose your perspective on it. I mean it just becomes a dim memory. My memory is not so good anyway. When I was doing it, I just did it out of a sense of accountability and efficiency. I mean I just knew that things had to be done, and I just did them. It involved a lot of work, and, in over ten years of working hard, you accomplish quite a bit.

Breslin: What's the impact of that work overall?

Goodwyn: Well, I think that each person that you really helped to become successful, you multiply your efforts. I mean your efforts have

a much greater impact than just doing some menial job where you can count 144 items produced. So, I think that it really did help a lot with the disability movement and really helped to get it launched successfully, not that it would have happened any less successfully without me, but I was there, and I felt like I was a part of it.

Breslin: Okay, anything else you'd like to add?

Goodwyn: No. [laughter]

Breslin: Well, all right, thank you very much.

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Berkeley, California

Disability Rights and Independent Living Movement Oral History Series

UC BERKELEY'S COWELL HOSPITAL RESIDENCE PROGRAM:
KEY ADMINISTRATORS AND CALIFORNIA DEPARTMENT OF REHABILITATION COUNSELORS

Gerald Belchick

DEPARTMENT OF REHABILITATION COUNSELOR, LIAISON TO THE COWELL PROGRAM, 1970s

An Interview Conducted by
Sharon Bonney
in
1998



Gerald Belchick, 1999.

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INTERVIEW HISTORY--Gerald Belchick

Gerald Belchick was asked to participate in this oral history project because of his four-year involvement with the Cowell Hospital residence program. He witnessed the students as they became politically active and powerful and observed the effects of the program on the people involved with it.

Gerald Belchick took over the California Department of Vocational Rehabilitation's activities in the Cowell Hospital program in the late 1960s, as a result of a student revolt against Lucile Withington, a Vocational Rehabilitation counselor assigned to the program. Mr. Belchick witnessed the students--calling themselves the Rolling Quads for the first time--stage a public battle, replete with media coverage, against the policies of the Department of Rehabilitation and win.

He discusses his belief that the original funding for the Cowell program came from the National Aeronautics and Space Administration, which wanted to conduct a bone loss study on the students. He describes the lack of support for the program from departmental offices in Sacramento and their attempts to impose a cost-ratio formula, which threatened the future of the program.

Mr. Belchick offers personal insights into the effects of the program on himself, John Velton, and others. Because their focus was on advocacy for the students, they lost their willingness to be "team players" with the rest of the Department of Rehab administration; several people were denied promotions.

Equally important are Mr. Belchick's recollections of Ed Roberts, both as a student in the Cowell program and as state director of Vocational Rehabilitation. He calls Ed the "greatest organizer of all times" while a student, and "a maverick, a loose cannon, a hair shirt" as director of Rehab. He describes Ed as very much out of favor with the district administrators and loved by people with disabilities.

The interview was conducted in one session in Mr. Belchick's home in Santa Fe, New Mexico on October 2, 1998. The interviewer lightly edited the transcript, and Mr. Belchick lightly edited the overall transcript but deleted a large portion about his personal and family background, because he felt the focus should be on the disabled student movement, not on himself. Copies of the interview tapes are available for listening and research use in The Bancroft Library.

October 13, 1999
Regional Oral History Office
The Bancroft Library
University of California, Berkeley

Sharon Bonney, Interviewer-Editor

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 Gerald D. Belchick
 Date of birth 7-21-28 Birthplace FLINT, MICH
 Father's full name CLARK FRANCIS
 Occupation INVENTOR Birthplace CALDWELL, MO.
 Mother's full name VIOLA MCDONALD
 Occupation HOUSEWIFE Birthplace JACKSON, MICH.
 Your spouse Ø
 Occupation _____ Birthplace _____
 Your children Ø

Where did you grow up? FLINT, MICHIGAN

Present community SANTA FE, NEW MEXICO

Education PHD -

Occupation(s) Retired - Psychologist

Areas of expertise Vocational Rehabilitation

Other interests or activities Vocational possibilities
of persons with head injuries.

Organizations in which you are active _____

INTERVIEW WITH GERALD BELCHICK

Early Years, 1941-1967

[Date of Interview: October 2, 1998] ##¹

Bonney: Gerald, could we start out by having you tell me a little bit about where you were born and when and a little bit about your family?

Belchick: Okay. I was born in Flint, Michigan, 1928. I was the oldest of ten children, big Polish-Catholic family. I left Flint in my seventeenth year and I did my undergraduate work at religious colleges in Tennessee and Florida. I finished my bachelor's there in theology. After preaching for the Churches of Christ a number of years I began working for a master's in counseling and guidance, finishing in 1962.

I taught high school English for a while, then became the dean of boys. In 1967 the state of California had a program which was called University Without Walls, which no longer exists as it did then, where if you were a state employee you could take any course work at any level at any campus at any time, and accumulate credit hours. The only restriction was that at the end of it all you had to pay for a mentor or a monitor.

So I started that program. My doctorate was completed in 1972, in California. I went to work for the California Department of Vocational Rehabilitation as a counselor and was there thirty years altogether. I was stationed in Oakland.

Bonney: For the entire time?

Belchick: No, for almost the entire time. I was in San Francisco for about two years. But I really was almost entirely in the

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

Oakland-Berkeley area. Then I went from counselor to supervisor to state training officer, back to supervisor, and then out during changes in the administration. It seemed like a good thing to do at the time. But I finally finished my doctorate. It's in counseling and guidance. That was what prompted the state to let me become the training officer, which is the only thing that I got out of that, I must say, as far as the state was concerned. But they did get it for me in the sense that I got reduced--the amount of money per unit--per credit unit was much reduced because I was a state employee and I could go to UC Berkeley, I could go to San Francisco State, anywhere I wanted to where they had a course that I needed to have.

Bonney: What is a training officer?

Belchick: For the California State Department of Rehabilitation, we went around the state and taught mostly case management, in compliance with federal law: things that had to be recorded, techniques for recording it, how to record client activities without overdoing it or underdoing it. My specialty was the vocational interpretation of psychological testing, which is what my field was. And so, you know, when a counselor would get a psych report that they had ordered or that they had gotten from another source, we gave them sort of preliminary information about what vocation and what this sort of meant. If you're at a certain level, at the I.Q. level or on some of the other testing that was done, made available, does this have any vocational implications? That's mostly what I did, although I taught the other classes, too. It's about a four-year project.

But more in keeping with the disabled students project or movement, Ed Roberts was a client of mine. I was his counselor at the very end.

Bonney: Ah. When he was in the residence program?

Belchick: No, no. When he was not in the residence program. In other words, he was a client of the department prior to the starting of the residence program. He became a client at about age sixteen, as I remember now. Of course, I got to know Ed real well. Knew Zona [Roberts] real well. Knew Ed's brother, whose name I can't think of now. And was in and out of their home a lot in Berkeley. Then, of course, when the residence program began, Ed was one of the seventeen that were part of the first program. It was [John] Hessler and Ed Roberts and Gwin Hinkle. I remember him. And others. But there were seventeen altogether.

Theory of Cowell Hospital Program Funded by NASA

Belchick: I think what's interesting from an historical point of view is that we always wondered where the money came from. Now, we knew it was a federal program. The money was not state. We knew that. The state never put that kind of money out, because we were able to rent a whole floor of Cowell Hospital, and we were able to fund not only the rent but we were able to fund attendants and page turners and tutors, and it was carte blanche. Of course, that has never been the program for the State of California because they nicked and dimed everything to death.

But that program had no such restrictions, and it went on for a number of years, and then one day just stopped. It stopped because the "funding" stopped. And the state wouldn't pick it up at that level.

Bonney: Where do you think the funding came from?

Belchick: We had a theory, but nobody would ever tell us for sure, if we asked. We had been led to believe that NASA [National Aeronautics and Space Administration] wanted to have an experimental program to determine the effect of weightlessness --this was before they had any concrete information--they wondered what happens to the body when there's no movement? Well, what better way to find out than to have seventeen paras and quads?

Now, we had been led to believe that that was what the story was, that they were looking into if there was a rate of--what's the word I want?--of bone loss, if it was measurable. In other words, if you were eighteen years old and you had this much, how much did you have when you were twenty? Or what does two years do? Or four years? Because the program was about a five-year program altogether.

We had a physiologist on staff, whose name I can't remember. We had a psychologist on staff, a psychiatrist, rather, who is still around Berkeley, whose name I can't remember right now. Then periodically people would wander in and review records and chitchat and be very nondescript about everything, and then go away.

One year, we had a man who came in, young fellow, who wrote several papers. He and I co-authored some articles, but I soon discovered that in addition to him and I writing some articles about, you know, "You, Too, Can Be Successful in College Even

If You're Wheelchair-Bound", I discovered that he was doing a whole lot more than that. So I think he was sort of summing up, without making a big issue of it.

I have always thought that was true. I never, from the beginning, ever understand after having as many years in state service as I had been, where I just didn't even have to ask if I could spend money. There was always a big argument: Is there a cheaper way to do it? Is there a less expensive way to do it? Never had that come up.

Bonney: Now, this was in the early sixties, right? Or mid-sixties?

Belchick: Mid-sixties.

Formation of Rolling Quads and Growing Political Power

Bonney: Were you around when the Cowell Hospital program started?

Belchick: I was around in the area, but I wasn't on the project. What happened was there was a counselor, whose name was--I had it on my tongue a minute ago--

Bonney: Woman?

Belchick: Yes.

Bonney: Ruth?

Belchick: No. I talked to Ruth, by the way, the other day. This was pre-Ruth.

Bonney: Lucile?

Belchick: Lucile, Lucile Withington. Lucile probably was the most knowledgeable counselor in the whole department on wheelchairs and accommodations. I mean, if you wanted to know anything about any of that, she knew it. But she also had absolutely no sense of propriety when it came to how much the person in a wheelchair could do academically. She expects you to be up at eight o'clock and in class. If you weren't up at eight o'clock--in fact, that's what generated that whole Rolling Quads Movement. It was a rebellion against her that started the whole Rolling Quads Movement. I was brought in, after they had moved her out, to be a peacemaker, which I think I did quite well.

Bonney: Now, tell me about the incident between the students and Lucile. What happened, and what did the students do?

Belchick: Well, first of all, if you were there in an academic program and if you needed to have a certain course and if that course was offered at eight o'clock in the morning, then you had to go to that class, whether you had to get up at five in order to be ready to be someplace at eight o'clock. They kept saying, "We can't do this. We cannot take a full load." She wanted them to take a full load, and she didn't want any distinction between you as a client and you as a student. If you're here as a student, we're paying all this money, then you become a student and do student stuff. She was very adamant and not very kind about it.

Now, I had known Lucile--I'm still sort of in touch with her, not much--but she was very difficult, extremely difficult person to be around. She absolutely was so sure that she had the right answer to everything. Finally, the group met together, the students, the clients met together.

Bonney: Now, this was Ed.

Belchick: Ed and Hessler, and there was a young man who became an attorney up in Weed.

Bonney: Jim Donald.

Belchick: Yes. You know who I'm talking about. He was one of them. And there was a girl.

[tape interruption]

Belchick: Peg Buley and Ruth Dushkin and another woman, whose name I can't remember right now, were sort of the "counselors" of the various students. They battled with Lucile, who was sort of the "program director". They battled with her. The department--our boss was a man named Norman Evans. He was a one-armed man. It was very obvious that he was disturbed but didn't quite know what to do with Lucile because she was a force to be reckoned with. Really was.

So anyway, the group got together, talking about the clients. The students got together, formed this phalanx, and in their wheelchairs they went from Cowell Hospital down to Sproul Plaza as a group. I sort of remember signs and banners, but I'm not sure. But anyway, when they got there, by pre-arrangement there was television, newspaper coverage, and it

was a big to-do. You know, Sproul was famous for big to-dos. This was a big to-do.

As a result of these complaints against Lucile, she was moved, removed, sent off someplace, and I was brought in, so I followed Lucile.

Bonney: Okay. How did the students become political?

Belchick: I don't think that was hard to do on campus. There was a lot of precedent for being--the Free Speech Movement and--you know, there was a lot going on. Those were flower power days, and there was a lot of agitation, in general: antiwar. We were all mad at the governor.

Bonney: Who was?

Belchick: [Governor Ronald] Reagan. He had just shut down the state hospital system, pretty much. All the activists in Berkeley had a half a dozen causes to rally around, and this was a very visible cause. It was everything--it would be an organizer's dream--because you didn't have to depend on rhetoric; you could just depend on what you could show. And, of course, this panorama of all them in wheelchairs.

Now, Gwin Hinkle couldn't even operate in a wheelchair because he was so disabled he had to be in an iron lung all the time. So here comes Gwin being pushed down in his power-pack iron lung. That was before the Bird respirator and all those things, you know. But anyway, it made all the papers, and it made it in grand style. The department was embarrassed. I think recognized that Lucile way overstepped her bounds. Pulled her out, and then Phase II began.

Bonney: We'll get to that. I want to pursue this just a little bit more now. What did the students say at that media event?

Belchick: Well, Ed Roberts and John Hessler were the spokesmen. They said things like, you know--essentially, we had been maybe brought here under false pretenses--because we had been led to believe that 1) we were going to have a first-rate education, taking into consideration the fact that we had special needs; we're not like all the other students. We're bright enough, sharp enough, but there are some allowances that have to be made. Of course, that was all true. It was all true.

I remember when people were sort of recruited for the program. Of course, we had more money than we knew what to do with. It was, "Don't worry. We'll work it out. If you need

this or you need that, yes, we'll get you an attendant; yes, we'll get somebody to turn the pages for you; sure, we'll get somebody to tutor you. No problem at all." So they had been led to believe that they were going to be in this situation where they would be accommodated in every respect.

They said, "The thing that's most difficult for us, in general, is the fact that it takes us longer to get up, longer to get dressed, longer to get somewhere. It takes us longer to get our schoolwork done because we can't turn pages in some cases, and etc., etc. To us, that's much more important." It was Hessler, I think, that said this, that, "It's much more important for us to have accommodations. The accommodations will make the opportunity a reality. Without the accommodations, there is no reality or opportunity that can be fulfilled."

He said, "We're lost if we can't have some consideration about how long it takes us to get dressed, we have to have an attendant, we have to be essentially bathed and fed" and blah-blah-blah. And, "We can't do that if we have an eight o'clock class, and we can't do it if we're taking a full load." So that's what Hessler said, and Ed. And they were both very eloquent.

Bonney: What was Lucile's response? How did she react?

Belchick: [chuckling] Well, she got mad at everybody, number one. She got very mad at me, but we patched it up later, sort of. But she felt that we were giving in and that it was not in the best interest. "You're making them wimps. One of these days, they're going to have to get out in the real world, and those kind of accommodations are not going to be made. They need to understand." You know, that sort of thing. This was "toughening up time."

No, she was very unhappy. Never did get happy, by the way. She never got happy after that.

Bonney: About this issue, you mean?

Belchick: And everything else. She had a real hard-on for the department, and she never gave up--she sued them, eventually.

Bonney: So this really affected her a great deal.

Belchick: Oh, yes. She brought several lawsuits against the department, in time. Not about this, but about the fact that she was

pulled off. They finally put her out in Contra Costa County, which is sort of the Siberia in Rehab.

Bonney: Can we go back and talk about the money for just a minute? You said that you never really knew where the early money came from.

Belchick: Or any of the money, for that matter.

Bonney: Okay. I guess I'm wondering how you got the money.

Belchick: Well, we had a procedure to go through. Everything had a code, as you could imagine. For example, if you were paying for an attendant, then you had a code. What you would do, we had a form, and you'd write the name of the recipient of the service. That would be on the top of the form. You'd just put down code whatever, certain numbers, and then you'd put down "attendant care service." Then you'd put the amount. Then that would be shipped off to the people who pay stuff, and then a check would be cut and a check would be delivered.

Bonney: Now, you think this money was coming from NASA?

Belchick: Well, I knew it was federal. That I knew. It was federal money because the coding was set up so we knew it was federal money. We didn't know where in the fed system it came from. It didn't come from national rehab. It wasn't that kind of money. It just wasn't because, you know, there was a matching arrangement. We got, well, it has changed over the years, but if the state put up three, the feds would put up five. That sort of thing. But this was not a matching thing at all.

We never, from the day I started on the program, did anyone ever suggest to me, "Well, let's back off on this," or "This is too much of an expenditure," or "We're getting over the limit." At the end of the budget year, we all had to cut back. Not this program. Everybody else was cutting back and scrimping to get through the year. We just spent money like, as we used to say, drunken sailors.

Bonney: That answers one of my questions to you, which was going to be, you know, why did DR [Department of Rehabilitation] decide to fund this program? What was it about the program that they liked?

Belchick: It was the national money. I think they were 100 percent matched, I think. But I don't know that. But, like I say, it was unlike any program. I've been with them thirty years or more. It was unlike any program that I had ever been involved

in, even some of the richer programs. Like, there was a period of time when alcoholism became a big issue in Rehab, and we were richly matched; but even at that, we always ran out toward the end of the fiscal year. There was always, "Let's not accept any new clients for a couple of months," and "Let's not write any master's programs for a couple of months." But this program, never once did anybody ever say, "Well, we need to cut back on a little of this." We'd just write the bills, and they sent the checks.

Bonney: Okay. Now, you said at some point that changed. The money stopped.

Belchick: Yes.

Bonney: And all of a sudden, you were on this "we don't have any money" track.

Belchick: And the program was disbanded.

Bonney: When did that happen?

Belchick: I had already left the program. It was during John's [John Velton] watch when the program was phased out. The bad part about it was it was not phased out well, not that that's any big surprise. But the Cowell site was no longer available to us. In other words, we had that whole half a wing. We had to vacate. Or they had to vacate it, so there was no longer going to be a dormitory/hospital situation. That was gone. [The Department of Rehabilitation continued to fund the program when it was moved out of Cowell Hospital and into the university's residence halls. --Editor]

Well, then the department made these few that were left into "regular" clients. Now, that meant nothing to the claimants; it only meant something to the department, which meant that they went into the general pot, for money purposes. There were efforts being made to find them dormitory space, which was very difficult to do. They even had sort of group home situations. I remember hearing something about that.

But anyway, what happened is they allowed it to peter out. I mean, there was never any "as of today, this program stops." They just stopped funding it, they didn't accept any new people, and the story was that regardless of what the state of your disability is, you're just like anybody else now. You come in, regular programs, all that.

- Bonney: Is that the time, then, when John Velton took over and Karen Topp started working with students?
- Belchick: Yes. But she started out of project though. The project was gone when Karen came.
- Bonney: Yes. So she just had a regular counselor-client relationship.
- Belchick: Yes. And John did, too, for most of the time, even though there were still remnants of the program around, because you couldn't just dump everybody out, which is what they would liked to have done. If I sound like I'm a little bitter about it, it's because I am. I just feel that they had raised expectations and had what was essentially a gold mine of an opportunity to serve a very underserved segment of the disabled population, and they fumbled it and dropped it, and it was all because of 1) money and 2) politics.
- Bonney: What you're basically saying is the DR really didn't have an interest in the program if NASA, or whoever, wasn't going to fund it.
- Belchick: Exactly. There would never have been a program, never, in my opinion, if there hadn't been this unlimited source of money. There never had been before. There never has been since.
- Bonney: Let's go back just a couple of minutes and talk about the incident with Lucile. Now, one of the immediate and long-term effects you mentioned was the effect that it had on Lucile, herself, which was not a positive thing for her. What were the immediate effects for students?
- Belchick: At her leaving?
- Bonney: Yes.
- Belchick: Oh, she was probably the most disliked person on campus. She didn't have any friends at all among the clients, students, that I can remember. She had no allies at all. She was ruthless in respect to, "You're here. You're a disabled person, but you're also a student at a prestigious college. Now go, thou, and do college things."
- Bonney: Were the students at that point allowed to take reduced loads?
- Belchick: Well, no, and that's the reason why we lost a few right at the beginning. She wasn't going to have it, and they fought her and argued and carried on. I guess some of them maybe won the

battle, but some didn't, and we lost students because they couldn't keep up. Obviously, they couldn't keep up.

Bonney: After she left, though, were they then allowed to?

Belchick: We had a whole different, more humanistic approach.

Bonney: What was that approach?

Belchick: Well, like, you know, we understand you can't be ready at eight o'clock. You can't take a full load; you just can't. So you take a reduced load, and we'll stagger the hours in a way that is more accommodating. It worked out beautifully because it was real. Otherwise, it wouldn't have worked. It just couldn't have, no.

Bonney: What effect, if any, did this incident have on department policy?

Belchick: Well, department policy was always such a weird thing. I don't think the department ever owned that program. It reminded me like sort of a wart on a frog. It was there, anybody knew it was there, but it wasn't anything very important in the long run of schemes. We got a lot of publicity out of it, a lot of good press. I mean, there were more articles written in national magazines about the program over the years. I mean, I'm not a great writer, but if it said Cowell Hospital Project, I could get it published in nearly any magazine that dealt with those issues. It didn't make any difference whether it was well written or not. That's why I'm published [chuckling].

Bonney: So there's a long-term effect: it helped you [chuckling].

Belchick: I guess. I put it all in my résumé: I'm a published person.

Bonney: Of course.

What were the students like? What did you see them doing?

Belchick: Well, at first, it reminded me--you have to understand that I wasn't directly involved during the initial part--I was on the periphery. But taking it from what I saw when I was on the periphery--because we had an office in Berkeley--so I was there occasionally and heard and talked, you know, like you do. I got the impression that it was--I don't think anybody was very serious about it all--because I don't think anybody ever thought they could get to this place under those circumstances.

You know, UC was never famous--now, other colleges may have been, but the fact that you could be a student at UC, come in through a special door--[NOISE]--I'll fix that.

Bonney: That's okay.

Belchick: Ordinarily, if you--you know, that was long before affirmative action really got a toehold. But you had to come in through the front door regardless. There were no exceptions. You had to have a certain SAT score; you had to have a certain this, a certain that. Here was a way to get in through a separate door.

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Belchick: I think all of a sudden, here they found themselves in a very nice setting. It was a hospital--there were rooms, like hospital rooms--but they became their own. They put things up on the wall, and it was no longer a hospital in the sterile sense. I don't think that they had a clue at the beginning of what was ahead of them, except that it was there and it was sort of like getting an inheritance you didn't expect.

In the beginning, my impression was that there was a lot of giddiness. I don't think it was a serious group that you would expect to see of people who would ordinarily have been coming in Cowell or coming into UC Berkeley. Not that they were frivolous; I don't mean that. But I think there was a sense of Wow and Golly Gee connected to it, Here I Am, big-eyed.

Then, of course--when classes started and the rigors of dealing with Lucile--I think reality hit, and I think there was a lot of sadness. We lost some students who just couldn't keep up. And, of course, Lucile's attitude was, "Well, that's what this program is for, to weed them out. If you can't do it, you can't do it." Well, that turned out definitely not to be so given the success that several of the students made, Ed Roberts being one, Hessler being one, an attorney whose name I can't remember being one.

Bonney: Jim Donald.

Belchick: Yes, Jim Donald, right. I don't think they got serious until they realized--I'm not sure how they realized this--but I think they realized that if something wasn't done, being proactive and being aggressive, if something wasn't done immediately, the whole thing would have folded, and it probably would have. I think they thought, By golly, we really do have something that's important to us and so we need to frame together.

Of course, Ed was the greatest organizer of all times, always had been. He was born to be an organizer. Hessler was a good second man, sort of--just a good second man. They made a fabulous team together, motivating the other group and giving the group a clear picture of where they wanted to go and how to do it. I mean, it was a master stroke for that whole crowd to come rolling down the hill from Cowell Hospital to Sproul Plaza. It was a stroke of genius.

Bonney: And whose idea do you think that was?

Belchick: Oh, it was Ed's idea. Oh, yes. I accused him of it many, many times. Yes, I'm thoroughly convinced it was Ed. He said, "Let's make a show. Let's make a splash." And they did. I mean, it was almost as good as the Free Speech Movement, for crowds.

Bonney: Do you think that Ed and John and others were influenced by the movements and the activities that were going on around them?

Belchick: Oh, I'm sure they were. Yes, we all were, yes. I mean, you caught the spirit. It wasn't hard to do. It's one of the few times we could be hip-hip-hooray. And we were. The antiwar movement was just cranking up, and the Free Speech Movement had just cranked up. That was sort of in the middle of that movement. Of course, I had been to Florida and had been in a religious environment most of my young life. I showed up in Berkeley and they were having, you know, a free clothing movement, with all the women showing their breasts, which they still do, I guess, but they did it big time there. The anti--I guess it was--the free bra movement or something. I've forgotten what it was. That was a sight to behold, especially for us country boys.

Bonney: Yes. Now, when Lucile was removed, you took over.

Belchick: Yes.

Bonney: Tell me what you did. It was in a shambles. What did you do?

Belchick: Well, I didn't have to do a whole lot because they already had an agenda. The agenda was sort of announced. The agenda was we have to have some special considerations. One, in the number of courses we have to take because, you know, in Rehab you had to take "x" number of hours; if you didn't take the hours, then we wouldn't fund them. So they wanted relief from that, which they got. Essentially, they got carte blanche, is what they got. There wasn't anything they asked for they didn't get.

But the two main things were the ability to arrange programs to meet their physical needs--getting up, getting clean, getting dressed and so on--and then the number of hours. Those were the two major criteria. And they got them. Some of them dropped certain courses below the level. We just studiously avoided seven o'clock classes. Got a good tutoring force in. Really got some really good students, graduate students, who became tutors, over a period of time, because there was such a plethora of students available who wanted to make a buck. We had no problems getting attendants, page turners. We even hired a prostitute once. Of course, we didn't know it, but that's an interesting story I'll tell you one of these days.

Bonney: Why don't you tell me about it now?

Belchick: Well, I had to okay all of the expenditures. I kept seeing this one expenditure. The thing that struck my fancy--that struck my interest, rather--was the fact that it was always on Friday night from seven till ten, never any other time. We had this woman's name, and she was listed as an attendant. It varied. She was an attendant for this one and an attendant for that one. I didn't know what was going on.

We used to get together and have sessions. I said, "Now, come on guys, tell me what's going on because this is not an attendant. This is not an attendant. No attendant is available between seven and nine or ten one night a week. Now, what are you doing?" It turned out she was sort of the seductress of Berkeley. I don't know what she did with them or for them [RINGING SOUND]. It didn't make much difference.

[tape interruption]

Belchick: Anyway, that was sort of fun.

Bonney: Did you continue to pay?

Belchick: Yes.

Bonney: So you sort of looked the other way? Did anybody ever fess up or say what she was doing?

Belchick: Well, a lot of grinning. She wasn't doing a whole lot, I'll tell you. But whatever it was, it seemed to be acceptable.

Bonney: How long were you the program director?

Belchick: About four years.

Bonney: Quite a while.

Belchick: Yes.

Bonney: I didn't realize it was that long.

Belchick: I'm not sure it was that long, but it wasn't a short period.

Working with UC Administration

Bonney: What was it like working with the UC administration?

Belchick: Well, we didn't work with the UC administration, surprisingly enough. Like I say, this was the most unusual crowd I've ever dealt with. We just sort of did it. We never asked permission. The only hassle we ever got was from--you'll know his name if I could think of it--who was a psychiatrist. He wrote a couple books lately about marijuana use and things. It's a Japanese name. Starts with an "M."

But anyway, he was the psychiatrist, and he wanted us to be more--. He's still around. I see articles by him still. But he wanted to be more involved. He thought that these were people with overwhelming problems that needed a whole lot more counseling than they were getting. It didn't go anywhere, but he was the only administration figure that we ever had a clash with at all. I mean, we paid the rent for the Cowell Hospital site, our clients/students registered, we paid the bill, and everybody seemed to be happy.

It was a very selective--no, that's not a good word. It was a very cloistered group, in the sense that they were almost totally immune from everything on that campus because they had people to run interference for them.

Bonney: Did you ever work with Dr. [Henry] Bruyn?

Belchick: Dr. Bruyn was the head of the hospital. I worked with him in the sense that we talked. There wasn't any work to do, especially.

Bonney: Not a lot of collaboration to get the program up and going?

Belchick: No, no, no, no. Of course, I wasn't there for the getting up of the program, but I don't remember much involvement, in conversation with other people. Now, Dr. Bruyn may very well

have been very active, but I don't remember him being active, but I also don't remember him being an obstacle of any kind.

Bonney: What about Edna Breaun? Did you work with Edna?

Belchick: Oh, Edna is a jewel, an absolute jewel.

Bonney: What was she like in the program?

Belchick: Well, she was probably, from the medical standpoint, was the best thing that ever happened to us. She was there, she was steady, she was dependable, they all liked her, we liked her, she had a good sense of humor, she really knew her business. Because we had problems with decubiti [decubitus ulcers; pressure sores], and she went to great extremes to ensure that she was up on everything and that she had the latest information available, way beyond and above, I think. You could just depend on Edna.

The main problem was this decubiti thing because these are people who are sitting in wheelchairs at odd times, for odd periods, that they may not have been used to, and in the beginning it was a mess. Not overwhelmingly, but it was a problem. It would have gotten out of hand. We used to laugh and tell Edna that she was the only R.N. we knew of who spent her whole day looking at people's rear ends. She would. She would insist. She had to see it. She wasn't going to take their word for it. She didn't ask them how their butt was; she wanted to see it, and she did.

Bonney: Was this kind of a new disability problem--

Belchick: Oh, sure. Oh, yes.

Bonney: --that came up because people were so active.

Belchick: Because we had so many of them, yes. There were seventeen in the program when I was there. There was more and less over a period of time. I don't think it ever got over twenty. Maybe it did, but I don't think so. But it was down to fifteen or fourteen on a few occasions, but stayed around seventeen. You know, we never had had that many people congregated together. They had been spread all over the state. In fact, we even had some from out of the state which was a big problem because there were people who wanted into the program who were not state of California citizens. Of course, by law we couldn't keep them out, and didn't.

Bonney: So Rehab was willing to allow them into the residence program?

Belchick: Well, they didn't want to. We had a boy from New York, I remember. Rehab fought it, because they knew that eventually this thing was going to stop and they'd be stuck with him. You can't just, right off, throw him out in the middle of a graduate program at Cal. And they did. They were stuck with him. California, as far as I know, never got reimbursed for it.

Thoughts on John Velton

Bonney: Tell me about John Velton a little bit. What was he like?

Belchick: Well, John is a delight. He's just a super young--man, rather. John is--God, I'm almost afraid to say this, for fear he'll read it.

Bonney: We can seal it [chuckling].

Belchick: John was the kind of a person, if you ask him what time it was, you got a dissertation on the clock. He was very thorough but very fair, and students liked him. He was somewhat of an advocate, more so than others had been. Really fought the program not being continued. Got into lots of bad trouble because he mouthed off about it.

Bonney: What kind of trouble did he get in?

Belchick: Well, because he thought that moving the program out of the residency hall [Cowell Hospital] and trying to stick them hither, thither and yon was wrong, and he was right. It was wrong. Now, I can understand saying, Okay, we'll keep the program till everybody matriculates through, but we won't let anybody else in new. When they're all done with, we'll all go home. But they wanted to stop it and say, Put these people in dormitories; put them in private group homes. John thought they were wrong, and he was right, and said so.

Bonney: Now, John and Karen both were advocates--

Belchick: Yes.

Bonney: --for the students because a lot of the kids--well, the residence program continued in the dormitories.

Belchick: Yes.

- Bonney: And it was sort of a modified version of the Cowell Hospital program, and both Karen and John pretty much ran that organization--
- Belchick: Yes.
- Bonney: --for years and years.
- Belchick: No doubt, yes.
- Bonney: How were they looked upon by other DR clients or Sacramento DR?
- Belchick: Well, John was never well thought of, Sacramento-wise. He was a hair shirt. He really was. In the best sense of that term because he was an advocate and because he felt deeply about what was going on or, more to the truth, what wasn't going on. He just was a hair shirt. The administration wasn't remotely happy with him. John probably got stuck where he got and never made it up the ladder, not that that made a big bit of difference. Well, it did, I guess. John always felt that he had been held back, and he had been. There's no doubt about that.
- Now, Karen I don't know that much about. I know Karen, but I don't remember a lot of activity with Karen. Because John and I were friends, both socially and professionally, so John and I used to cry in our beer a lot. But John really felt strongly about the program, the dormitory program, not the Cowell program. He felt that the department was trying to nickel and dime the "expensive" cases. You know, it's much better to rehabilitate a[n] alcoholic by four or five hundred dollars than to buy a van and a wheelchair and an attendant and a page turner and blah-, you know. So the department was not-- they were not happy campers.
- Bonney: Why did the department have that philosophy of helping the least disabled, let's say?
- Belchick: Because--
- Bonney: It's not their money. It's state money or federal money or a combination.
- Belchick: There's just something about it. You become--you own it. It's yours. I've always thought it's a power trip. I wrote an article one time, long after I left the department, that counselors in particular become sort of power objects: "I've got it," and, you know, "I'll dole it out." It's so much easier to be able to dole out the funding in a way that pleases

the administration than it is to do like John did and, I hope, I did, buck the administration and say, "This is important. [hitting table for emphasis] This person needs this to complete the program. I don't care if it's nine dollars or nine thousand; they need it. That's the important thing." and that was just not the philosophy, in general.

Ed Roberts as Director of California State Department of Rehabilitation

Belchick: Now, the funny part about it is when Ed was director, it didn't change much. It really didn't. Ed didn't have good control over the field. Unfortunately, he didn't have subordinates that were loyal to him. I think he thought they were, but they weren't. When it trickled down to the level of district administrators, Ed was very much out of favor. He was not a friend of the district administrators.

Now, counselors liked him at some level. The disabled loved him. Other organizations that dealt with the disabled admired him. But the district administrators of the eighteen or twenty districts in the state fought him every chance they could.

Bonney: Why was that?

Belchick: Well, because he was an outsider. He didn't come up through the ranks. [Governor] Jerry Brown picked him up out of nowhere and said, "Here, you're the director." No, he didn't come up through the ranks. It's like the army. If you don't come up through the ranks, you're not trustworthy. Now, he tried to surround himself with people, but by the time he got it done, it was too late, just way too late.

Bonney: Who did he surround himself with?

Belchick: Well, Hessler for a while. What's her name now? She's in Washington.

Bonney: Judy Heumann?

Belchick: Yes, Judy Heumann. Those are the two I remember most. Hessler didn't stay very long, you know. He transferred to another department, whereas Judy went on to bigger and better things. But there wasn't anybody around Ed other than Judy and Hessler that, you know, you could truly trust. Ed was loyal to a fault

to the people that he had respect for. Saved my ass. I got into real serious trouble with the district administrator in San Francisco, and I'd been with the department twenty years then, and he was going to have my behind nailed to the door, and Ed stepped in. Ed said, "No, we're just not going to have this." That was my short stint in San Francisco. They moved me right back to Berkeley, Oakland. Ed said, "Under no circumstances." He's not going to do that.

But there was no loyalty on the part of the district administrators to Ed. He was seen in the same light that Jerry Brown was seen by all bureaucrats, a maverick, a loose cannon, a hair shirt. Now, if Ed could have stayed on another term, things would have probably been different. But the one thing that the department never has done--never has done till this day, as far as I know--is ever make peace with the disabled community as far as organizations are concerned. It's always adversarial.

It was adversarial with CIL [Center for Independent Living]; it was adversarial with the Rural Legal Assistance Disabled Law Project. It was always adversarial. You know, it's "We've got it. You try and get it." Ed was just on the brink of changing that in the sense that Ed even was going to put Rehab counselors in the office of CIL. Now, they did that a little bit. I don't think it was ever very successful. But he wanted to do that statewide. If there was an advocacy group that dealt with disabled people, then we ought to have a counselor on site. And it made all kinds of sense to the John Veltons and people like that in the department, but it was just too unbureaucratic.

Bonney: Now, I've heard that while Ed was the director that he put out an edict or whatever that people with the most severe disabilities were going to have first priority.

Belchick: Yes.

Bonney: He did that?

Belchick: Yes.

Bonney: And that didn't work?

Belchick: No. You know why?

Bonney: No.

Belchick: Well, the reason why is because it was never implemented at the district administrative level. There were twenty districts in the state, I think. Eighteen or twenty. Each one of those districts had an administrator. They were career bureaucrats. To be able to get one of those moved out would have been a major production. But Ed could put out every edict he wanted to, and he did, but they would drag their feet. I mean, the talk around the department was "Well, he won't be here long." And he wasn't. Long enough to insist.

Like I say, Ed had no loyal followers out in the field who could say, "Ed, this is not happening." Ed wasn't in a position to say, "You'll either do it or I'll fire your ass." At least if he was, he didn't do it. I mean, that was a period of time when nobody wanted to rock anybody's boat. Jerry Brown was running for president or thinking about it. He didn't want any scandals. So that's what I mean when I say politics got involved.

Now, the Cowell Hospital program in its concept was probably the most innovative program that I'm aware of, and I've done a lot of reading over the years and keeping up on it. But it was doomed almost from the beginning because it just didn't have the smell of a successful bureaucratic program. It just didn't smell right, and it didn't. It was too free.

Bonney: To DR.

Belchick: Yes. Well, to bureaucrats in general. But it was too free, too loose, too huggy-huggy. That's just not how you run a business.

Legacy of Cowell Hospital Program and Emergence of Spokespeople

Bonney: What do you think is the legacy of the Cowell program?

Belchick: Oh, I think the CIL movement, without a doubt. The CIL program and allied programs was the legacy. I think the disabled--I think it was the time in which they lived, the political climate in which they lived, and then just sort of quirky twist of fate that put them all together in one place that said, you know, "We can organize, and we do have a voice, and we can insist that certain things be looked at." We don't have to be shunted hither and yon just because that seemed to be the way the government--I mean, they would have been more than happy, much more than happy, if they stuck them all in a convalescent

home. It would have been less expensive. God knows, it would have been less trouble.

Bonney: Those pesky disabled people.

Belchick: Oh, yes. It's so much easier, you just sort of get out of sight and go sit in a rest home. Why not? You get fed. You go through life. It's very discouraging, very discouraging. Hasn't changed. It's not changing now. Even with a [President William Jefferson] Clinton in office and a Judy Heumann up there, it still hasn't changed a whole lot. It's just too much trouble. It really is. It's just too much trouble.

Bonney: Do you think it had an impact on the disability rights movement?

Belchick: Yes. Only in the sense, well, not only, but in the sense that it produced spokesmen. When I was doing research for my doctoral thesis, I remember reading a comment that was made by some Southern congressman, I think [Senator] Strom Thurmond, but somebody like that. He was making a comment. Somebody asked him what was it that struck fear into the hearts of senators and congressmen? And he said, "To hear the tip-tip-tippy tap of blind people with their canes coming down the hall of Congress." And that's true.

I think when the disabled groups began to have spokesmen who were articulate and who were reasonable and they were being heard, I think it gave great impetus to the fact that maybe now we need to pay attention. I don't believe the blind would have gotten anything if they hadn't organized over the years. The whole physically disabled community is only where it is now because they have organized. You know, you're not a bunch of screaming radicals that don't have a program. It didn't come out that way. It came out reasoned, measured, reasonable--the spokesmen for the disabled groups. I think it made all the difference. I don't think we would have had what we've got now if it hadn't been for those kinds of spokesmen.

You know, Ed was a great one for that. I mean, he commanded attention wherever he went. And he was reasoned. He wasn't a [Senator] Jesse Helms. He was reasoned.

Bonney: What gave him his power?

Belchick: I just think he was an exceptionally bright man to begin with. I think it was a case of just not being willing to accept. You know, Rehab turned him down when he first applied for services as being too disabled. I didn't do that, but--. He was

sixteen, and they said, "No, you're just too disabled. You're in an iron lung. What can you do?"

Bonney: He showed them.

Belchick: He sure did.

Bonney: Even those kinds of examples to DR along the way, of Ed Roberts and of John Hessler and Jim Donald and Judy Heumann--all these people sort of marching along, showing that being disabled doesn't mean you can't do anything, but still it didn't have an effect on the department?

Belchick: It doesn't now, no, because they're removed from it. They're isolated. I mean, if the state capital was in Berkeley, things would have been different, but the state capital was in Sacramento, and there wasn't the movement. It was not there, then.

Bonney: Did you see the Rolling Quads go up to Sacramento and lobby for legislation?

Belchick: I didn't go with them, but I knew about it. Oh, yes, we did. Oh, yes. I remember it well. We'd like to have gone, if we could have.

Bonney: Was Jack [John] Rowan part of it?

Belchick: Yes.

Bonney: Tell me a little about Jack.

Belchick: Well, I don't know that much about Jack. Somehow, he doesn't have a niche in my memory. He came after I did. I knew the name. John would know more about it than I would. But I don't remember much about him. Hessler and Ed Roberts and Judy Heumann and Jim Donald and Gwin Hinkle, and then there was one little bantam rooster whose name I wish I could remember. He was just a--

Bonney: Don Lorence.

Belchick: Don Lorence, exactly. The part of bantam rooster fit [laughing]. And the boy who was CP [cerebral palsy]. He forced them to put him on a grand jury.

Bonney: Oh [laughing]. I don't know who that is.

Belchick: If I say his name, you'll remember. He was severely impaired but bright, just as bright as a tack. He was so bright. But he got called to jury duty, and when he showed up, they said, Well, no. And he forced them to put him on the grand jury [chuckling].

Bonney: Good for him.

Belchick: Good for him. Had to have a translator.

Contributions to the Independent Living Movement

Bonney: When you were working in the Cowell Hospital program and with the students, did you think you were involved with a disability rights movement?

Belchick: No, no.

Bonney: When did your consciousness kick in about that?

Belchick: Well, the consciousness kicked in when it became apparent to several of us, but to me it became apparent that this was not going to go away. I mean, they just didn't roll down that hill and make a big fuss and then disappear. They were agitating, and they were making a fuss right on, continually. I remember they invited one of the local congressmen up to spend the afternoon with them, one of our elected officials, and, man, they cornered him and they badgered him until he was awfully glad to leave. Because they had questions they wanted answers to, and they weren't taking the platitudes of usual politicians. They wanted concrete action.

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Belchick: In the beginning, there was much ado about nothing because I'd seen so much of that on Sproul. But it became very apparent to me--and to John, too, by the way, and to Ruth Dushkin and some of the rest of us who were sort of part of that--part of but not part of this "severely disabled counselors," and that's who we were. We were sort of an elite group. We were working with the hard cases, we used to say, because we very seldom ever got closure on them. Just never quite worked.

I must tell you this story: Gwin Hinkle was from Moraga, and his family was very, very involved in St. Mary's College. Gwin was congenitally malformed. His body was very small, and

he had a huge head. I'm not sure his head was all that huge, but it seemed to be. And he was in an iron lung and had to stay in the iron lung. He couldn't come out on a Bird respirator, mainly because I don't think they had them then.

But anyway, the agreement we had with St. Mary's College was that if we train him, the department would train him to be a Spanish teacher, that they would hire him as a Spanish teacher. So when we got him trained, got him his degree--and he had a blistering sense of humor--and we began to put the screws on the brothers of St. Mary's, and they were backing away, really backing away. Never did hire him.

So we were having this meeting. Gwin's mother was there. I think his sister was there and several of the rest of us. It became quite apparent that they were not going to hire him. He was not going to be on staff. We were all trying to make it sound better than it really was. Gwin made the comment, he said, "You know, after all these many quarters or hours that I've spent," he said, "all I've ended up being is just a great big head full of Spanish."

Bonney: [chuckling]

Belchick: And that's where we left it. A big head full of Spanish.

Bonney: That's too bad.

Belchick: Never did work out. But I forgot how I got off on that.

Bonney: We were talking about the disability rights movement. What do you think you contributed to that movement?

Belchick: Well, I think that the fact that we were willing to make--I don't mean "we"--but that I wanted to see and advocated for and tried to facilitate an easing of the restrictions and the regulations. Now, that was really not a very difficult job to do because, as I said, we had carte blanche anyway, so it wasn't like I was fighting uphill. But my heart really was there. I didn't want the program to fail, number one. I had gotten very close to all the clients, students, more so than just counselor and project director and person because it became much more than that for me.

This is true of John, too, by the way, and I think at some level, Ruth. But John and I both--we were never worth a damn to the department after that. We were never team players, never. It cost John a promotion, at least one, and a lot of bad press. It nearly cost me my job. If it hadn't been for

Ed, they'd have gotten me. Anybody who was connected with that program during the post-Lucile Withington days was never the same. It's like they say you go to India and come back; you're never the same. Well, none of us were ever the same. We were never team players. You could always count on us to make some sort of silly remark about how stupid it all was. We were not good team players after that. John paid a heavier price than I did, I think.

Cost-Ratio Formula Applied to Client Services

- Bonney: We have already interviewed John. He was talking about how there was this sort of cost-ratio formula that they tried to always apply to the residence program.
- Belchick: And for everything else.
- Bonney: And everything else. And it just didn't fit the program.
- Belchick: No.
- Bonney: But why did DR keep trying to apply that kind of analysis to a program if they knew it didn't fit?
- Belchick: Well, the truth of the matter is that it didn't fit anything. It didn't make a nickel's worth of difference to me whether you were talking about someone with mental illness or somebody who was a full quad. People need things to finish programs. And to say, well, we'll allocate 3.2 percent for the mentally ill and 6.9 percent for the physically disabled, it doesn't make any sense. You either have to say, Well, we've got "x" number of dollars and we're going to fully fund "x" number of claimants, clients, and whatever that takes, when we're done with it, we're done with it, but we're not going to nickel and-dime it. But they nickeled and dimed everything.

Of course, I supervised for a long time. I cannot remember a counselor coming to me that we didn't have to sit down and say, "Is there a way to shave this a little bit?" Instead of doing twelve sessions, can we do eight sessions? That sort of thing. You think, well, if the doctor said they needed twelve sessions, I assume they need twelve sessions of mental health counseling, and you want to cut it down to eight or seven. It's like saying we'll buy a prosthetic arm for you, but we'll only fund three fingers. You know, it just doesn't make any sense.

But that's bureaucracy, and that's government. And, again, I think it's power. "We've got the money. You're going to have to get it the best way you can." I think that's so wrong, so wrong.

Ed Roberts' and Judy Heumann's Roles in the Independent Living Movement

Bonney: You talked a little bit about Ed as director of DR. What are your thoughts on Ed in his role in the independent living movement?

Belchick: Well, I think the fact that Ed "achieved"--and, you know, at the beginning of all of this--Ed was confined to his full iron lung. We didn't have Bird respirators. Or at least they weren't successful until he got to be an older man. Surely didn't have it when he was a teenager. The fact that he was able to go to school--he graduated from high school in an iron lung. I think that when he was able to get out of that lung and get into a chair and function with a Bird respirator and began to be visible, that I think people began to say it's really not an impossible situation. It's difficult, maybe very difficult. But it's not impossible.

I think Ed got married, not successfully, but he got married and he fathered a child. I mean, what's not normal about all of that? He's got a job, he makes money, he has a wife, he has a child, he has a career, he has stature. What's different about that? I think people who really were discouraged, especially what I call the timid disabled, who would very well have been, at least at some level, content to be in a group home or in a convalescent hospital or something like that, and the sort of the, "Oh, my, this is my lot in life; I'll bear it with fortitude." I think he inspired that core.

That's the biggest core in the disabled community. You've got the fringes. The fringes are the Ed Roberts and people like you and Judy Heumann. But the bulk is in the middle. They're the unheard, unspoken, unrecognized, placid, do-what-you-want-to-do-I-don't-have-any-control. I think Ed energized part of that, or people like Ed.

I remember Judy Heumann. When I was training officer, we hired--we had a whole series of training programs with UC Medical Center in San Francisco--and we hired her and someone

else to do some teaching on sexuality in the disabled community. I remember Judy sort of flung herself in there. We not only had rehab counselors, but we had social workers because we made it open. We even gave credit for it. Judy talked about all sorts of things that you never mentioned in polite company and shocked most everybody that was there.

But it was the thing that needed to be said. Somebody needed to say that. Disabled people have sexual needs, and these are the problems, and this is what you ought to look for, and so forth. I remember some of the county welfare social workers were just aghast that you could say those words. But she, as far as I'm concerned, was a forerunner of, you know, take the cover off of this. It's there. Let's talk about it. What's the harm in talking about it?

They were interesting times. I miss them. I miss that, yes. I don't miss Rehab. I don't miss government. I don't miss any of that, but I do miss the contact that I had with, I think, some extraordinary people. If I was a good writer, I'd write a book.

Bonney: You should start.

Along that line, how did being part of the movement affect you personally?

Belchick: Well, like I say, I ceased to be a team player. I became un-Rehab, not anti, but I was no longer a team player. I mean, there was a limit to what I could say and do. Maybe there wasn't. I may have just been too much of a coward to do it. But it was never the same. John and I talked about this a lot, and Ruth Dushkin, whom I still keep in contact with. It became very apparent that none of us were the same. We didn't trust--none of us trusted that crowd. I'm talking about the administration. We didn't trust them for a second. I mean, if Reagan could close down the mental hospitals, our department closed down--we had big projects at the hospitals for the mentally retarded. Closed them all down because it didn't fit the ratio or whatever.

Bonney: So it wasn't a matter of funding.

Belchick: Well, I guess it was ultimately, but it was a matter of we didn't get a big bang for our buck. You know, the department got its money based on how many "successful" rehabs we had. Well, if you were an Ed Roberts, we were looking six, seven, eight, ten years before we got a bang for our buck. If we were treating an alcoholic, we could maybe find him a job, maybe buy

him some work clothes, help him get his driver's license back; in six months we had a closure, and we got credit for it.

The numbers don't make a distinction between the catastrophically disabled and the less catastrophically disabled, so you know where the emphasis was going to go. Here's all these master's-level counselors who were trained in prosthetics, orthotics and all of those important things, dealing with a subject they knew nothing about, mental illness. They never trained in mental illness and in alcohol/substance abuse, where there was no training. They floundered; we floundered. It was just the easiest way out, and the easiest way out was to take a drunk, sober him up for six months, spend a couple hundred bucks on him, get him a job--it made no difference whether he kept it or not--but get him a job and get credit for it.

But if I spent six or eight years working with someone, spent thousands and thousands of dollars, and then at the end have the good brothers at St. Mary's say, "We can't use you." I was in desperate straits as a counselor. Do I sound bitter?

Bonney: No. How did you handle that as the counselor? I mean, here you worked with Gwin all that time. He did his part. He got the degree. He thought he'd have a job. How did you handle that personally?

Belchick: Well, I didn't like the brothers very well, that's for sure. I don't know. I think we treated it very much like a doctor treats a patient that dies. You sort of compartmentalize it into another area and just go on. Never felt good about that. Not till this day. Don't feel good about that. Because he really could have done a fabulous job.

Bonney: It's time to go back and ask about the psychiatrist.

Belchick: Mikariya.

Bonney: Mikariya?

Belchick: Tad. It was Tad Mikariya. First name was Tad.

Bonney: Ah, great, okay.

Being a disabled person myself, I kind of resent it when people say that I am supposed to have a lot of psychiatric problems that I need to work through. Why did he and people like him in that time period think that was true?

Belchick: Well, I can't read his heart, but I think that he saw it as an experimental project.

[tape interruption]

Bonney: Okay. I had just asked why--

Belchick: Well, in my heart of hearts, I think it's because he saw it as a marvelous opportunity to write a book. I think that he saw this as an experimental situation that would probably never come up again. I guess in that sense he was right. But he didn't handle it well. I remember a lot of the students smoked grass [marijuana]. I know he was very much opposed to that and had written a couple of articles about the dangers of it and so on. We found out later that his daughter committed suicide over some grass. But he was adamant that we had to be drug free, unfortunately.

Bonney: [chuckling] This was not the right group of students--

Belchick: No, no.

Bonney: --to try to study because I don't think they had psychiatric problems [chuckling].

Belchick: Well, even if they did, they resented it. They didn't want--I mean, they really resented the concept of being a guinea pig.

Bonney: Oh, absolutely.

Belchick: I think that may have been one reason why we never really found out where that money came from. That may have been a good move. I'm not sure. You know, to find out how much your bone loss is if you don't get up and walk around for a couple of years. I'm sure that would have been offensive, if they had known and if we had actually known. Never did find out. No one would ever admit to it.

Retirement and Consulting Work, 1993

Bonney: What did you do after you left the Cowell program?

Belchick: Well, I went back to be a supervisor. I was supervisor then, but I went back to supervising counselors separate and apart from the Cowell project, and then I became the training officer for the state, and I did that for a number of years. Then I

went back to being a supervisor. They moved me to San Francisco to be a supervisor, which didn't last very long, and then I moved back to Oakland and then retired.

Bonney: You retired in what year?

Belchick: I've been retired about five years now, I guess.

Bonney: So now you are retired.

Belchick: Well, I work for Social Security as a consultant. People who have been denied Social Security disability benefits have at the third level the right to a trial, to a hearing. They can bring attorneys, new evidence, everything. The judge has the right to have medical experts and vocational experts to answer questions. They call me, and I go in, and the judge will say, "I don't understand what this test means." And I tell him. Then he'll say, "Well, how does that impact employment?" I tell him. Then he'll say, "Well, tell me about the person's employment history." And I'll tell him. This is what he did. It's only fifteen years. This is what he's done the last fifteen years. This is the exertional level; this is the skill level.

Then his question is, "Given what you know and by the tests, can this person do any of those things anymore?" If I say no, then the judge has the right to further question me, if he disagrees. If I say yes, then he'll say, "Well, what could they do?" I'll tell him. He'll ask me why, and I'll tell him. Then the claimant's attorney can question me. They do the same thing with medical experts. So that's what I do.

Bonney: And you're living in Santa Fe and enjoying it.

Belchick: Right here. Yes, we bought this place two years ago in February. My partner is a pharmacist. I guess I told you that. He's a pharmacist at St. Vincent's Hospital. He does the whole infusion pharmacy for northern New Mexico. We very much enjoy this area. We're both into classical music, chamber music, and this is a great place for that. We just have probably the best chamber music anywhere. I mean, I think it's as good as New York or it surely is as good as San Francisco.

Bonney: Great.

Is there anything else you'd like to say that I haven't asked you that you want to cover?

Belchick: No, except that I'd like to emphasize that I really think that the Rolling Quads was sort of the shot over the bow of what has now become the whole disability rights movement and the ADA [Americans with Disabilities Act]. I think it all stemmed from that. Maybe not totally, but I think that was sort of the public declaration that things are going to be different. I've always believed that. I think it's a great tragedy that the concept, maybe not the exact form, but the concept wasn't continued. But it's not, not anywhere in the country, at least not when I left the department.

Bonney: Now, you don't see the residence program as the same thing?

Belchick: No.

Bonney: What do you think the difference is?

Belchick: Because you can't come in a special door. I think that special door was important, especially in California, with the battle over affirmative action and so on. It just isn't the same. It really isn't. If you go into the residency program, you go in just like everybody else does. But these programs were special in the sense that you could go in--at least you could start a little bit ahead of the game. And now you have to battle everybody else. I don't know that that's bad in the overall, but we're talking about people with special needs, and if that's what we're talking about, then they ought to have special consideration if they have special needs. They don't seem to have any trouble with any other concept like that in this country.

Bonney: It's true.

Well, thank you very much. I've enjoyed it, and I've learned a lot.

Belchick: Well, thank you.

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Berkeley, California

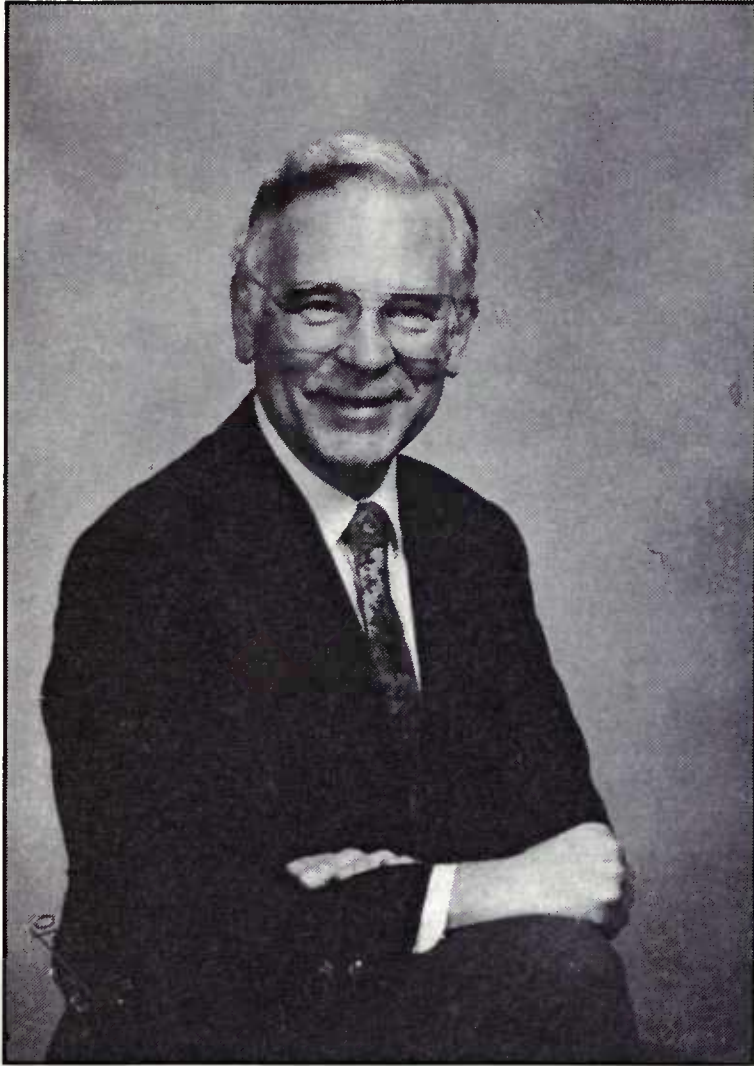
Disability Rights and Independent Living Movement Oral History Series

UC BERKELEY'S COWELL HOSPITAL RESIDENCE PROGRAM:
KEY ADMINISTRATORS AND CALIFORNIA DEPARTMENT OF REHABILITATION COUNSELORS

John Velton

DEPARTMENT OF REHABILITATION ADMINISTRATOR: PROVIDING OVERSIGHT FOR THE
RESIDENCE PROGRAM, FOSTERING CAREER PLACEMENT AND COMPUTER TRAINING,
1970s-1980s

An Interview Conducted by
Sharon Bonney
in
1997



John Velton, 1989.

Photo by Olan Mills.



Ed Roberts and John Velton at Twentieth Year Reunion of the Physically Disabled Students Program, 1982.

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INTERVIEW HISTORY--John Velton

John Velton was invited to participate in the Disabled Persons' Independence Movement oral history project in the Regional Oral History Office because of his role in three major disabled-directed programs in the 1970s--the residence program for physically disabled students, first at Cowell Hospital and then in the university residence halls, and the Disabled Students' Career Planning and Placement Program, both at the University of California at Berkeley; and the Computer Training Program, originally part of the Center for Independent Living. The interview documents his experiences as a California State Department of Rehabilitation administrator and witness to the birth of the independent living movement led by students with disabilities.

Mr. Velton's interview shows the conflicts he faced as a rehabilitation administrator who oftentimes identified more with people with disabilities than with the Department of Rehabilitation politics in Sacramento. He had to balance his role as an administrator responsible for upholding the policies and regulations of the department as supervisor of these programs while, at the same time, defending the programs from department skeptics who considered them too expensive and non-effective. He talks about his role supporting students in the programs as they learned about their self-determination, political power, and ability to lead independent lives away from the watchful eye of medical personnel. Velton's oral history provides observations of John Hessler, Ed Roberts, Neil Jacobson, and others as leaders as he worked with them to establish the programs.

Mr. Velton was interviewed on January 9, 1997, and again on January 21 in the home of the interviewer. The audiotape of the second interview was unintelligible due to an equipment malfunction, and Mr. Velton graciously agreed to do the interview again on February 4, 1997. One small portion of the January 21 interview was usable and has been placed at the end of the transcript to keep continuity in the interviews, although the interview dates are out of sequence. Mr. Velton was well prepared for the interviews with written notes on some topics and documents gleaned from his and others' files. He contributed a file of his papers to the Bancroft Library's Disabled Persons' Independence Movement Collection. The transcript of the first interview was lightly edited by the interviewer and reviewed by Mr. Velton, who heavily edited it, adding numerous names, dates, and clarifying statements. The second interview was only slightly edited by Mr. Velton.

Sharon Bonney, Interviewer/Editor

September 1997
Regional Oral History Office
The Bancroft Library
University of California, Berkeley

BIOGRAPHICAL INFORMATION

(Please write clearly. Use black ink.)

Your full name JOHN EDWARD VELTON, JR

Date of birth SEPT. 25, 1928 Birthplace TACOMA, WA.

Father's full name JOHN EDWARD VELTON, SR.

Occupation MGR, Met LIFE Birthplace MORENCI, AZ.

Mother's full name EDYTHE ^{GERTRUDE} LAWRENCE

Occupation ~~NSE~~, MGR. Birthplace WIS.

Your spouse PAULINE CLARICE KROGWOLD

Occupation RN Birthplace AMHEARST Jct, WIS

Your children LESLIE ANNE VELTON HILLIARD
CARA VELTON WARREN

Where did you grow up? OGDEN, UTAH

Present community BERKELEY, CA.

Education BA. UC BERKELEY MA. S.F. STATE UNIV. TOP GRADUATE
WORK - PUBLIC
ADM.

Occupation(s) ASST. CITY MGR, EMPLOYMENT COUNS.
VOC. REHAB. COUNS., REHABILITATION ADM., EXEC.
WITNESS - SOC. SEC. ADM.

Areas of expertise VOCATIONAL EMPLOYMENT POSSIBILITIES

Other interests or activities GARDENING, TRAVELING,
READING, HIKING

Organizations in which you are active NATE REHABILITATION
ASSOC. (LOCAL), EAST BAY LEAGUE I (S.F. Siphany Fund)
TREAS. Alumni

SONS IN RETIREMENT

RESUME'

John Velton

1234 Campus Drive
Berkeley, CA 94708

Goal: Administrative Career in field of Rehabilitation.

Education: M.A. 1968, California State University, San Francisco.
Major in Counseling with Rehabilitation emphasis.

B.A. 1953, University of California at Berkeley.
Major in Political Science with Public Administration
emphasis. Graduate work in Public Administration.

Management Development School 1972.

Present Assignment: Program Supervisor - Oakland District, 39190 State Street,
Fremont, California 94538

Previous Assignments: Rehabilitation Administrator I, Bay Area Regional Office.
Assistant District Administrator, Oakland District.

Contract Administrator for Special Programs for severely
physically disabled; Center for Independent Living -
Computer Training Program, Residence Hall Program,
University of California at Berkeley.

Rehabilitation Supervisor - San Francisco District.
Also assigned to Public Offender Program one-half time to
set up expanded Vocational Rehabilitation Program at
San Quentin State Prison.

Rehabilitation Counselor - Public Offender caseload, includ-
ing both Department of Corrections and Youth Authority
clients.

Previous Experiences: Employment Counselor in San Francisco - Industrial Service
Office; Instructor in Public Administration - Golden Gate
College; Assistant City Manager - Vallejo, California;
Metropolitan Life Insurance Company - Sales Representative.

Memberships: National Rehabilitation Association, Sierra Club,
Toastmasters.

Special Interests: Job Development and Placement: Special programs for severe-
ly disabled including spinal cord injury clients; develop-
mental disabilities.

INTERVIEW WITH JOHN VELTON

I THE COWELL HOSPITAL RESIDENCE PROGRAM

[Interview 1: January 9, 1997] ##¹

Family, Education, Career Background

Bonney: We're going to start out really easy, and I'm going to ask you to tell me something about yourself. Where were you born? When were you born? Tell me about your family, your parents, that sort of thing.

Velton: I was born when my father and mother were living in Medford, Oregon, but because my father had been recently transferred by the Metropolitan Life Insurance Company from Tacoma, Washington, my mother gave birth to me in Tacoma, Washington, where my grandmother and grandfather lived--her mother and father--on September 25, 1928.

Shortly thereafter, when I was just a few months old--I think about six--my father was transferred to Ogden, Utah, where he remained for many years until I was about twenty years old, I guess. I had gone away to college, and then he was transferred to Yakima, Washington. So I grew up in Ogden, Utah. As you know, Utah is a predominantly Mormon state. But Ogden, because it was a railroad town, was maybe only 50 percent or 60 percent Mormon. I happen to know this because of a graduate paper I wrote when I was at Cal [University of California at Berkeley] which researched the Mormon influences on Utah's politics. In that sense, I was always a member of a minority, being a Presbyterian, which is not typically thought of a lot [laughter] as being a minority, but that's what I was. There were very few Catholics and few Protestants. I never felt particularly isolated though, because we all participated together. The Mormons have a very active church: they had their church groups, and they had their baseball

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

teams and their basketball teams and so forth. That kind of separated me out that way, but it was not a problem.

So I went to high school and graduated in 1946, just as World War II was ending, and went to the University of Chicago. I met a lot of veterans who had returned from World War II, some of them disabled. It was quite an experience because I was taken into this fraternity, Alpha Delta Phi, and there there were quite a few veterans who were quite helpful. They talked, and I listened [chuckles].

I went there for three years. I met my wife, Pauline, there. Then I left the University of Chicago, and I proposed to Pauline and came west and got a job in California. I worked for a year and a half after we were married. Then, having become a resident of the state of California, I finished my education at the University of California. I graduated in political science, then went on to graduate school in public administration.

I did not get my master's degree; I never finished my thesis at Cal. I was hired to work in the city of Stockton as an administrative aide. After two years there, I went as assistant city manager to the city of Vallejo, where I was for six years. That was quite an experience: we became an "All-American City" after annexing 60,000 people. The city was almost bankrupt when I came there. We had a superb city manager, Lon Ficklin. He straightened that out and Vallejo became an "All-American City" in a contest sponsored by Look magazine.

Then I left city management. Partly, I did not like so many night meetings, but actually, for reasons not so directly related, I think I went through a rather severe depression. So then I had to reorient myself. I taught for a year at San Joaquin Delta Junior College, and then I went into vocational rehabilitation at San Francisco State. I attended full-time for one year, in 1963 and 1964, and then I continued part-time, earning my master's degree in 1968. I was an employment counselor with the Department of Employment for about two years--1966 to '68. Having my M.A., I passed the vocational rehabilitation counselor exam and was hired in the Oakland district as a counselor. I suppose partly because of my previous administrative experience, after two years as a counselor, I was promoted to rehabilitation supervisor. I was a supervisor for about two years in San Francisco. They had a special problem there in the multiservice centers which I was able to solve. Because the rehabilitation unit was in one location, only the central Afro-American community was served. The other service centers in Chinatown, the Mission, and Hunters Point also received service under a decentralization plan I devised.

In 1972 I went to the regional office in Berkeley. That's when I started becoming better acquainted with the disabled movement. I went up to the new Center for Independent Living. They had a little apartment that they were working out of that was the closest thing to bedlam [laughter] I could ever recall. Then they reorganized the Center for Independent Living, and they moved to this office on University Avenue. I also became acquainted with the Physically Disabled Students' Program [PDSP] at UC Berkeley, so I started to get to know the people then.

Bonney: Can we go back just a little bit? What were your mother's and father's names?

Velton: Edythe [Gertrude] Lawrence, and John Edward Velton [Sr.].

Bonney: And what did your father do?

Velton: He was a manager with the Metropolitan Life Insurance Company.

Bonney: Can you recall what year you were at San Francisco State when you went back?

Velton: I attended fulltime in 1963-1964 and then parttime 1966-1968 when I earned my M.A. in the spring of '68.

Bonney: And do you have brothers and sisters?

Velton: I have one brother. He's six years younger than I am.

Bonney: And his name?

Velton: William Lawrence Velton.

Bonney: You talked a little bit about how you got involved with vocational rehab, and that you had a deep depression. Was that--your going into rehab--a direct result of the depression and reassessing? What focused you into rehab rather than city management or something else?

Velton: Well, I think it was a series of steps. I did go see a clinical psychologist for over a year and a half. I decided it just wasn't right for me to remain in city management, so then I qualified to go into this teaching program in junior colleges. I tried that, but I didn't like teaching that well, but half of my assignment was as a student counselor. I found that I enjoyed counseling a great deal. I decided to explore vocational rehabilitation, and as I looked into it further and further I decided that that would be something I would enjoy doing. I found throughout my later career that it was significant that I identified with disabled

people a little more than most, because I considered myself as going through a period of being disabled.

It took me a long time to be able to appreciate the sort of sick humor that many social workers and counselors indulge in privately--you have to appreciate that they're under stress, but they make jokes. Some of them are even unkind about people that they have worked with--not all clients, but the worst ones. There's no doubt that a certain small percentage of clients are simply incorrigible: they aren't really trying to be rehabilitated; they're trying to work the system. But I always felt that most counselors and supervisors were way too hard on severely disabled clients.

I identified more with the disabled, which sometimes caused problems, especially when you're in administration. Sometimes you find that you get very torn in certain situations. You begin to see some issues differently from the disabled viewpoint regarding independence, motivation, and access. In order to make a hard decision regarding an individual, staff would too often get emotional and overly criticize the person before they could simply say, "You aren't going to make it; you're out of this program. You haven't tried." You do not have to go to such extremes. You could just say, "Well, maybe someday we can help you, but you haven't benefited, so when we have learned more and you are more ready you can reapply."

So that was that. To be a really good vocational rehabilitation counselor, you have to be very analytical and precise. There were some staff who--despite their attitude--were very honest with a great deal of integrity and ability to be precise. I think they could do a better job in some cases than I could in analyzing certain situations that required great detail. We can get back to that later when talking of the different characteristics of some counselors.

Bonney: Okay. What were some of your early assignments or jobs as a rehab person?

Velton: Well, they had actually hired me, to begin with, to be a counselor with youth authority clients and Department of Correction clients when they were paroled. A very high percentage of them didn't have severe physical disabilities, but they tended to have behavioral or emotional disabilities. Those clients were my first caseloads, and that's what I worked with almost entirely until I became a supervisor. Then, of course, the counselors I supervised had much more varied caseloads. When I went to San Francisco, a high percentage of minority clients were served by counselors under my supervision because it was in the service center at Turk

and Fillmore. Then later we decentralized the vocational rehabilitation units to all the seven centers. So then I had counselors at the Chinese center, the center at Hunter's Point, and the center in the Mission area as well as the Turk and Fillmore Center. These minority clients qualified as people with behavioral disorders in far higher percentages than as people with physical disabilities.

I didn't get involved with the severely disabled until I came to Berkeley, in the regional office.

Bonney: When you worked with the residence program at Cowell Hospital, were you the contract administrator or were you a supervisor?

Velton: When it first started off, I don't think they had the concept of contract administrator. After one year I was transferred from the regional office to be assistant district administrator in the Oakland district. The Oakland district had responsibility for all the programs in Alameda County, which included the Cowell Hospital program.

John Parks, who was the district administrator, assigned me responsibility for the Cowell Hospital program. The concept of contract administrator didn't actually evolve until we had moved the program from Cowell Hospital to the residence halls.

Bonney: Now when did you start working with the residence program? What year?

Velton: In 1973. Gill Johnson was promoted to supervisor, and he supervised Karen Topp [now Karen Goodwyn], who was liaison counselor for the Cowell program. For a while before that, Ruth Dushkin was the liaison counselor. Problems kept coming up. Some of them were amazing [laughs]. The disabled students at Cowell Hospital were in the hospital and the medical staff felt responsible for them as patients. They wanted to be students, so there was a constant tension there.

Things would happen, some of them ridiculous. Someone would bring his dog up when he went to visit, perhaps someone blind, and then the dog would have an accident on the floor, and the nurses would get upset, and the janitor would say, "That isn't my job!" and they would call us up to go up and clean up after this dog. Or someone would smoke pot, and staff would smell it, and they would know they smoked it, but the staff couldn't catch them. And then that was supposed to be our problem. Or if someone went out and got drunk or maybe appeared to be drunk--I don't know, I never caught somebody drunk--they would complain about that. Disabled students would get rowdy, they would get noisy, they would stay up

late: all things that students would do in the residence hall but were just beyond the pale in a hospital. According to the hospital people, disabled students were disruptive even though they were on their own floor, and I doubt that anybody could ever hear them other than staff [chuckles].

Bonney: Just to be clear then, how did you become responsible for supervising the residence program?

Velton: This program was assigned as my responsibility by John Parks, district administrator. It was really more than a supervisor could be expected to handle because it required liaison with Sacramento, writing and supervising contracts, and negotiating with the hospital administrator--at the time he was Mr. Campbell, I believe--and dealing with his complaints. It was just more than a supervisor could be expected to handle. So as assistant district administrator I went up and dealt with these problems.

It gradually evolved and finally became clearer and clearer that the students would always be in conflict with hospital routines. Naturally I talked with John Hessler about this. We gradually came to the conclusion that the only solution in the long run was to get out of the hospital. A surprising number of students that went through the program gradually became independent and lived on their own in apartments with the help of attendants. Even though some students might come in hardly able to care for themselves, eventually they would gain the skills to train their own attendant, and then they would either live by themselves or often with a live-in attendant or with two or three others in an apartment. This became more and more of a goal, a matter of pride--"I can go out of Cowell and live by myself. I don't need this dependent relationship." That was encouraged by Karen.

Cowell Hospital Program: Setting, Students, and Staff

Bonney: You started into it just a little bit, but describe to me what the residence program physically looked like on the third floor. What did you see when you got off the elevator or walked through the door?

Velton: The first thing you see when you come out of the elevator is this big pool table [laughter]. There was exercise equipment also, but seldom used. They didn't exercise very much; people were encouraged, but somehow they didn't really use the equipment.

Edna Brean was the nurse in charge and was there during the day. She kept order in the place, and supervised the attendants.

Students had their own rooms. Some of them would be shared space which would be private only if they pulled a drape. But there were spaces for both men and women there at that time. It started off with only men, but at this stage they had a few women, but it was predominantly men. They each had their own private space. And it was expected that they'd have spaces where they could study in quiet and so forth.

It's all torn down now, but it was an old hospital. Everything was massive and big. It was very institutional compared to more modern hospitals: big doors and so forth.

Bonney: What was the atmosphere?

Velton: Well, it varied. It had a lot to do with the attendants that were there. Some of the attendants were very popular and got on well. At one stage toward the end there, just before we set up the computer training program, they got one attendant who was very religious. He was very concerned that nothing questionable happened in the way of sexual behavior, and I think he really had it in his head that there was a tendency for quadriplegics and others to become homosexuals or something. They were really complaining about this as he watched them like hawks [laughter]. So that made for a rather a tense atmosphere; they were all laughing behind his back.

Most of the time it was a rather loose, friendly atmosphere. Edna always wanted to make sure that everything was up to par, and she was medically oriented, but she was aware of how they lived and how they needed this flexibility to a much greater degree than the rest of the hospital staff were. So she was easy to work with. I think she always had some misgivings about our moving the program. It was the final step, and she never really committed herself to the final step; she bailed out and said, "I'll be a consultant. I don't want to be running the program after the move into the residence halls." She went over to San Francisco State. It was very good for her. Actually, she made a good career move. Although she was very loyal to the program and always has been, I don't think she was totally convinced that was the way to go. She might deny that, and maybe I'm wrong. She seemed to see more things that could go wrong, and that was good. That was the suspicion I had [chuckles]. Fortunately, our medical consultant also reviewed our plans and made suggestions. He approved.

Bonney: Can you describe some of the people?

Velton: I didn't get to know a lot of them that well. Certain ones that come back to mind--Scott Luebking. He was there at one time. He was there actually at the time of the attendant that was so religious, whose name I do not recall. And Scott was a very intelligent man: he graduated Phi Beta Kappa from Knox College with honors. He had met Neil Jacobson. I don't think Neil lived there, but he was there for a short period of time when he was ill, just before the Computer Training Program started, which was in 1974.

Then I remember another fellow--Karen tried to bring some marginal black students in, where they would get intensive educational help to upgrade them so that they could enter the university and succeed. Some of them didn't make it. There was this chap I remember who was very determined. He had lived in Richmond [California] and had been shot, becoming a quadriplegic. He exercised a lot. He kept saying he was going to make it. He didn't make it into the university, and then he became very depressed, got bedsores, and died. I don't know exactly how fast, but he just went downhill very quickly.

Bonney: Was he in the Cowell program?

Velton: Yes.

Bonney: Was he in the Cowell program when he died?

Velton: No, I don't think so. I think he left. But it raised his expectations. You learn some bitter lessons there: that if you raise expectations beyond someone's capacity you may harm them forever. We were experimenting. In that sense, I have to admit that in some ways we were experimenting with people. Sometimes we overreached and thought we could do more than we could, and that was a sad example because you told him this and this and this could happen, but naturally it could only happen if he had had the inner, innate ability. There was a point beyond which he couldn't go no matter how hard he tried. That was rare, though; I also think we did push some of them overly when we finally made the move--pushed some of them out of the Cowell Hospital and into independent living into apartments sooner than they would normally have moved or been ready, and I think that was traumatic for some of them. But we didn't have any bad results [laughs], thank goodness.

Bonney: What were the reasons behind the department's willingness to assume the financial responsibility for the residence program in 1968?

Velton: That's an interesting question and I'm not entirely sure of the answer. It really started before '67, I think, the planning. I think it had a lot to do with Harry Lucas being willing to see this possibility. Ed Roberts and John Hessler in particular had done so well. Ed Roberts was doing quite well in school and successful. He was in political science, and John Hessler was in languages. They had gotten a lot of people to admire and respect what they had achieved. Then the university had decided that they wanted to expand the program. It was a time when funding was more readily available.

I think the first funding actually came from NASA [National Aeronautics and Space Administration], and part of it because they were interested in osteoporosis with respect to bone density. So part of the fund was NASA because of the fact that quadriplegics suffered somewhat the same problems that people in space did--lack of movement--and they designed an experiment to go with that. But I don't think they really followed through. Also Catherine Butcher, an experienced rehabilitation counselor, strongly supported the initial program.

So funding was more readily available than it certainly is nowadays, and it was an interesting and intriguing concept. The possibilities were beginning to open up like never before. Up until ten years before, most people thought quadriplegics didn't live more than two or three years. We just did not have the medical skill. Now medical staff were able to extend their lifespans so far that the possibilities kept looking more and more promising, and a lot of people were becoming interested. You had Dr. [Henry] Bruyn, who was very able, and he was pushing for it. And Catherine Butcher, who was a counselor that had been with the department for many, many years and well respected. Plus, she was soon retiring. All together, I think this was why it all fell in place. That's really the best answer I can give you because I wasn't actually there in the center of things then.

Bonney: Were there some key people in Sacramento that helped move it forward?

Velton: Well, I don't know. Harry Lucas possibly has spoken to that point, but I really don't know.

Bonney: And you mentioned Harry Lucas. What was his position?

Velton: He was the Oakland district administrator before Ken Englebach. Ken Englebach was the district administrator when I arrived. Harry Lucas was before that. He became the regional administrator, and then Field Operations Administrator. In the 1960s, the Department of Rehabilitation was under the state

Department of Education, and they really fared better--many people thought--under the Department of Education than they ever did as an independent department. Later the Department of Rehabilitation was separate. I'm not exactly sure when the separation occurred.

Then the Department of Rehabilitation had to negotiate directly for their budget with the governor's office. The department got more ample funding--that's what some people thought--when under the Department of Education. Since becoming a separate department our mission was modified to include a variety of non-physical disabilities such as drug abuse, alcoholism, behavioral disorders and learning disabilities for which the medical model hardly applied. This is another example of funding sources taking precedence over the department's basic mission of using a medical model to vocationally rehabilitate the physically disabled.

Bonney: Could we go back a minute to NASA? I had never heard about that before. Do you know what the experiments were or what they were contemplating doing for experiments?

Velton: All I know is what I've said based on what they say here in some of these reports [looking through documents]. I had even forgotten about that myself. I was intrigued. Bone density loss due to disuse was their concern. See, there was a lot of push from the chancellor's advisory committee and others also, to establish the Cowell Hospital program. You can't downplay the efforts of the university to push this; I think that's very important.

Bonney: Who were the players from the university? Do you know?

Velton: Only from what's written in here. [looking at documents] The Dean of Students' Office had been involved with the blind students in a variety of ways. And they were set up with their own space and equipment--tape recorders, brailers, and all of those--pretty standard. It was in Room T-22. At a recommendation of the chancellor's advisory committee on student health services--which I'm sure involved Dr. Bruyn--a special assistance program for all handicapped students was set up. Then they selected graduate students in social welfare to be involved.

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Velton: Dr. Henry Bruyn was still there in 1968, and now they had the program funded, with a registered nurse paid by DVR and other expenses. Well, that's about all I can say.

But there are other memos that I've read about how the university really wanted to expand the program. I wish I could tell you more about that NASA experiment and how far it went, but it seems to me that since we never heard much more about it, it must not have been followed to its conclusion. There's a certain logic to it, but apparently they found other ways to deal with studying osteoporosis.

Conflict at Cowell between the Students and the Rehab Counselor, 1969

Bonney: I want to ask you about an incident that evidently happened around 1969, where two students who were in the Cowell program were threatened to be dropped from the program. There were evidently different theories behind the reasons why they were targeted to be dropped. But evidently there were meetings held with UC administrators and department staff and all of the students, I'm told, who were in the residence program. They worked through it, the students were not dropped, and there were no changes made to the requirements to get into the program or what you had to do to stay in. I guess at some point all of that was up for grabs or in question about what was going to happen. Are you aware of this incident, and were you there?

Velton: I was a counselor at the time. This was still a time of considerable turmoil at the university. Students were not accepting any rules and regulations they didn't like without protesting. But what happened was the new counselor that came in, Lucile Withington--I actually went to San Francisco State with her--was very firm and conscientious. She had been with the Red Cross in Japan, and even taught the princess of the royal family how to ski, or improve her skiing ability. So she was quite a special person in many ways as a vocational rehabilitation counselor.

She was brought on to take Catherine Butcher's place when she retired and be the liaison rehabilitation counselor with the Cowell Hospital program. It was thought very important--and she emphasizes this in her interim report--it was very important that every student be serious and study with a goal that would allow them to come out of the program with a capacity of earning a substantial income of \$10,000, \$12,000, or \$20,000 a year so they would have--at graduation--a good salary to cover rather high expenses for attendant care and so forth. If they were to be independent they would have to develop a high level of skill, which someone who was severely disabled could perform. So she was

set on making sure that everyone was following a rather rigid program that was going to result in a vocational goal that would pay off.

She also had a conviction that she was best qualified in terms of deciding what kind of tape recorder and other peripheral equipment clients should get, to the point that she was very controlling. In the opinion of many of her peers--counselors--she was not handling this problem in a way that developed client independence. It seemed she was creating or perpetuating the very dependence that clients were trying to move away from. Although there was some effort by various counselors to kid her and josh her about it--none of us really felt it was our responsibility--but this finally erupted in a rebellion against her personally. She had found two students that simply refused to follow her dictates, and she was going to dump them from the program. She was unrealistic, like insisting severely disabled get up at six a.m. so they could attend eight o'clock classes.

Bonney: Do you know who the students were?

Velton: No, I do not. But I do know that this resulted in Ed Roberts and John Hessler and all the rest of them wheeling down to Sproul Hall and making a major issue of her role to the point that they went to the newspapers. They went public. They went to their congressman. They went to their assemblyman. They used every resource they could command. So this brought down a major investigation from the central office.

Lucile was very upset about this and started taking Valium in order to keep from getting too emotional or angry about it. She suspected that Gerry Belchick--he replaced her--engineered this because he wanted to be liaison counselor, which is totally false. It was because of her basic approach in my opinion. She's now in Idaho, and if you want to hear her side of it you can, but I think the consensus among counselors was that she just was not the right person for this program at the time. I think subsequent events have proven that, because it just is not the way to go. Actually, the reverse: you should let severely disabled clients make every decision they possibly can. If they want to get a tape recorder, as long as it isn't an unreasonable request, let them select it. If they make a mistake, then let them deal with it. That's the way they would gain independence, and that's what you want them to do.

So then Gerry Belchick came in as the counselor. There are several reports that he wrote in documents you have. The program still went into much more detail than in later years in terms of every conceivable medical condition. Parameters were set up for

accepting people, to the point that it was a very formalized program at that stage. That remained, but it was done in a gentler fashion.

There are even anecdotes, for example: one anecdote that Gerry tells--on himself--that never has reached official records [laughter]--is that you have to hire readers and notetakers and other peripheral people to help the quadriplegics and others who could not write, take notes, and so forth. Then there was one name that Gerry noticed that kept showing up more and more frequently: a lady. Finally, he became concerned about it and investigated. Finally, John Hessler confessed that this lady was providing far more services than notetaking [laughter] and so forth and so on and that she was very popular in the Cowell residence program. So he put a stop to that as it was quite a bit more than Gerry or anyone else could take with federal funds involved [laughter]. If they wanted to do that with their private money, that was another matter.

Gerry Belchick calmed it down, and everything started to go on a more even keel. But I think if the disabled students hadn't learned before, they then learned that they had power. And they learned that they could go to public officials, and that they would be heard. As we well know, they refined this tactic [laughter] much farther in later years.

This was also when they had those anti-Vietnam demonstrations there. I remember going up to Berkeley, and the streets were filled with demonstrators and officers--one quadriplegic insisted on going across the street when an officer told him not to and got himself arrested [laughter]. "I don't care who you are or what condition you're in. I told you to stay there!" He crossed the street anyway. So he got himself arrested. I don't know how they ever put him in jail [chuckles]; I don't think they did. But they arrested him.

Bonney: What long-lasting effect did this incident have on departmental policy?

Velton: That's an interesting question. Well, I think it had the effect of always making people think twice before they ever did anything to the Cowell Hospital program. They were willing to give them a little bit more leeway than they would have otherwise. Although there have been, over the years, various attempts to curtail it and change it and cut back on expenses and so forth, I think there was always the recognition that it could become an explosive issue. Therefore, the Department of Rehabilitation tended to handle the program differently than they would almost any other program in the state. That was the result.

Bonney: Lucile. Was she removed from the program?

Velton: Yes.

Bonney: Was this voluntary or involuntary?

Velton: It was involuntary. She transferred to another district. It was quite a blow to her. I think she's still bitter about it. She thought she was right. In the strictest sense, of course, she wanted to be sure that everyone had a vocational goal that was going to pay off, and that's not a bad aim. One would have to say that some of the students probably did move in better directions. But I'd have to say that in my later experience in working with the severely disabled, that it is such a reach, and it takes an extra level of motivation that it was worth letting them explore what they really wanted to do instead of saying, "Well, that doesn't pay very well," or "That isn't going to be a very promising vocation."

I can give you examples of students that weren't quite so demonstrative but later became particularly effective: Susan Sygall, for instance. Ruth Dushkin, when she was Susan's counselor, would not put her into a vocational plan for recreation director. So Susan went ahead and continued by herself, without DR's help, and obviously demonstrated that she could make a place for herself in the field of recreation. No one could deny it after they received widespread recognition for establishing BORP [Berkeley Outreach Recreation Program].

So that individual drive and interest was what you should nurture, even though it didn't necessarily make immediate vocational sense: occupations change, and no one had the perfect power of prediction. You could train to be a teacher and then find out that there were too many teachers. Or you could train to be a lawyer or you could train to be all kinds of things and then find out that there's a glut in that field, whereas in some other field there was a need. So there's a limit to how omniscient anyone--including counselors--can be.

I found that it worked better--within some limits--for people to explore what they really wanted to do. Peter Trier, for example, took a long, long time to get his Ph.D., but when he finally did he became a very successful instructor at Fresno State. For a while, I didn't think he was ever going to get his thesis done [laughter].

The Move From Cowell Hospital to the Residence Halls, 1975

Bonney: Edna Brean has said that she felt the Cowell program began to disintegrate and was out of control around 1973 and '74. How do you feel about this impression?

Velton: I certainly think that we were running into all kinds of pressure from the administrator to control it. John Hessler and I concluded that the only solution was to abandon this strict medical model and to move them into the residence hall. I give John Hessler credit for the idea that the students would have to take primary responsibility for their medical treatment from day one, but that we would support them when they first moved into the dorm with orientation and special training.

So we designed this program where we would have a full-time attendant there at the residence hall--twenty-four hours a day--and he would supervise the attendants that were hired by students to make sure that they were adequately prepared and trained. We had one dorm for those that had to be turned or looked after twenty-four hours a day. Of course, the responsibilities of these particular special attendants were greater at the beginning of the year than at the end of the year. Training of each student's attendant was an essential part of the responsibility, as we didn't expect students to be totally capable of independence when they arrived. But we were quite happy if they were ready to move out into an apartment after the first year, which a few did, but some stayed a second year. And if they wanted to stay a second year, that was all right. So there was a clear difference in concept. As we were moving in that direction, I don't think Edna was totally sold on the concept of moving away from the medical model by giving students primary responsibility for their personal medical care. It was a major change.

Now I don't know what she would say about it now, as it has worked. It amazes me: when I look at the kind of tight procedures we had in the beginning--looking at students as patients--how we moved to a less and less formalized procedure and gave more and more responsibility to the students. And they took it. Of course, we had support services. You had the PDSP, which could repair wheelchairs. You had peer counseling: you had peers that could come and give all kinds of friendly advice--"This is the way you do this, and this is the way you do that." It was quite natural, unlike that advice given by counselors and even the nurse--who were like parents--more often the advice was picked up and implemented and used a lot more quickly when other students would say "Why don't you do it this way or this way or this way?" and so forth.

It was definitely a period of transition. In that sense, I think she's right. But we had a different goal than she had. It hurts me to even say anything bad about her because I think she was such a tremendous help; it was just a difference in concept, I think. Maybe we did miss on some things because of that, and she was holding it together in terms of her concept. It's like I said, I know for a fact that we rushed some of the students that we moved out of Cowell Hospital--you see, the summer before we could go over to the dorm and they lived independently. For some of them that was a tough period of time. I suppose if you interview some of them they might remember. They were very nervous about it.

And I think that John and I, in a sense, were very daring because we were telling Betty Neely [Dean of Women and Associate Dean, Office of Student Activities] not to worry. Betty Neely was very, very helpful in getting this all worked out with the university. And we weren't that sure ourselves because we had never done it before; it was a whole new experiment. Sometimes I wonder if--I had confidence in John, and John had confidence in me, but it was kind of like we were both optimists, and if there had been a pessimist in there we might not have done it [laughs]. If one or the other had said, "Hey, wait!"--if you had somebody that wasn't that optimistic, it might have not been done that way. At least we had Dr. [William A.] Silverman, our DR medical consultant, supporting our concept.

But John Hessler was very significant at that stage because he had the courage to go ahead with his convictions. And I was able to get the funding, and DR supported the move, and it worked. We had an outstanding group of full-time attendants, too. Of course, we got a very good person to come in and supervise the program in the residence hall, and that was very important too. Her name was Susan O'Hara. There's a story there too, because--

Bonney: I'll get to that [laughter].

Velton: Of course, once we made the move, and there are memos [points to documents] about that, about how we went back and forth and the time schedule and all of that. I don't want to give the impression we didn't plan. We met all during 1974 considering alternatives until we got to a point where something had to be done. We had promised the attendants we were going to keep them involved, and then approval came so fast that we bypassed the attendants. I remember this one attendant, who was a very good attendant--he stayed with the program, but he threatened to leave because he was so hurt, even though they had helped develop their job description. Actually nothing was done to hurt him, but he felt like they weren't involved in the final negotiations because

we finally just rammed it through. We got the money approved, and we had to go ahead as we had committed to leave Cowell Hospital.

What John said when it got to the point where there's a little bit of dallying by the university and a little bit of dallying by the Department of Rehabilitation was, "We're going full speed ahead." They had to run to catch up, including me. He went faster than I would have preferred to go, but I think that in the final analysis that was the thing to do in that particular situation because that forced everybody to make a decision. We had thought originally, as you'll see in the proposal, that Edna would come over with the program. I have the impression that when Edna realized that the program was going to be under PDSP, of which John was the director, and that she was going to be responsible for this new concept--all those things together--that she didn't want to be under John Hessler, and she didn't want to be experimenting with this model, she left. So that's when she took this consulting role. But she was very helpful as a consultant. She helped us in getting things going as we changed over.

So then, of course, we had to recruit someone else. We got the committee together, and we interviewed several people, and John interviewed them separately. The process was that after we interviewed them, we would all get together and discuss who to hire. But John then said, "I'm going to hire Susan O'Hara." Well [chuckles], one member of the committee was Michael Pachovas, so you can imagine what happened. I mean, procedurally bypassed, he was hitting the ceiling. So Pachovas was automatically against Susan for the only reason that procedure hadn't been followed. I don't know if maybe he had someone else that he preferred that much, but he hadn't been consulted, and he was very angry. Karen had had some previous experience with Susan that wasn't 100 percent, so she wasn't that sure. John just toughed it out. It was up to Betty Neely, finally, to finalize the decision. I told her, "He's picked the right person. It's just the way he went about it." [laughs]

Bonney: Were you in those meetings and interviews?

Velton: Yes. I would have chosen Susan, but John just went ahead and said, "That's it." It seemed to me, frankly, he created a problem that he could have avoided by being just a little bit more adroit. Maybe he knew something I didn't know. I mean, when you consider his administrative ability, I think there are some things that he did very skillfully. But that one--it seemed like he bought a problem for himself that he didn't need to buy at that time. But there's no question that he made the right decision in terms of her subsequent performance.

Bonney: Maybe you have said all you can about this, but in the California Monthly article in 1976, it stated that [reads] "the residence program for disabled students was moved out of Cowell," and that the move had been "a part of PDSP's master plan from the beginning. But it was DSU, the Disabled Students' Union, that recognized first that all of the necessary support services had been assembled and then pushed successfully to move the program to the dorms." Now evidently there were some bitter battles around moving the program. I'm wondering if you were part of those discussions and what were the battles, what were the issues? That's something that we don't really know what went on, evidently, in those meetings.

Velton: Well, as I said, when you say PDSP, I really think of John Hessler. I mean, there wasn't any consensus building there; using DSU as a force was John's idea, and basically I think it was John's approach to have DSU appear independently in favor. John felt that if either DR or PDSP were overly identified with the move from Cowell, DSU and others would oppose the move. Just as an aside, I would say that many times over the years the Center for Independent Living and the Disabled Students' Program often took full, 100 percent credit--or seemed to--when maybe they should have gotten 50 or 60 percent of the credit for programs which DR helped to develop and fully funded. It stands to reason that they couldn't have done it if it hadn't been funded; I don't care how clever and adroit they were. The disabled movement benefited by taking public credit.

Aside from that, well, let me see. Here I have one memo that's kind of interesting. Let's look at that for a second. We took minutes on the discussion. This is the meeting that took place sometime early in March. The discussion demonstrates the wide, almost unmanageable range of opinions involved.

Bonney: March of?

Velton: Of 1975. Some of them wanted to find a house. This was one alternative; it was Eric Dibner's idea. Thirty-nine units with modifications, where they would move everybody. The whole student program--they could all live there together, new students and old students. And John Hessler [reads]: "Are we talking about moving the program or about CIL [Center for Independent Living] housing?" Things were getting mixed together in this discussion. He says, "We're talking about moving into the dorms only because no suitable housing is available." This is Peter Trier. "We should go to dorms until at least next year. If we should find an apartment or a house before April that is easily accessible and has low rent, we would of course move there." So we moved into the dorms in the fall of '75.

Peter felt that we weren't that ready to buy housing, that that wasn't feasible. And anyway, where was the money going to come from? Then a former architect student said, "It's better to build a facility than to redo one," which was also true. That was Eric Dibner. He was the CIL housing coordinator at this time. There's Michael Pachovas: "The master plan of the chancellor's committee has provisions to modify all dorms." He was for using the dorms. "And Housing is not clear about money available for modifications," but housing did come through with money for ramps when it came down to necessity. And the dorms were accessible enough at this point, but they did have to have some additional ramps installed. People wanted to do many different things, and in that sense, you see, this is where John's clear idea of what he wanted to do was vital. I mean, forget buying or building a big building, you know? We're going to go into the dorms and get out of Cowell Hospital, and we're going to make the move work, and then if they want to go somewhere else later, that's another issue entirely.

I'd say that John Hessler was focused; he wouldn't let all these cross currents deter him from actually getting something done. And thank God for that, because I don't know what would have happened if we had to respond to everyone's ideas. Since Mr. Campbell was medical director for the university, he might still have authority over medical personnel hired to work in the dorms. Well, we wanted to get totally free of Cowell Hospital and say forget it. They're just like any other student: if they get sick they can go to Cowell Hospital, and if they want or have to go to some other medical facility that's their business, so he would no longer be responsible for this program. He finally just said, "Okay, I've washed my hands. I'll have nothing to do with it." Although the medical staff did later say they would do some things. That's the way it was.

I don't see it as any overwhelming controversy; it was just getting the gumption to go and do it. To us, it was sort of a real adventure, something that we weren't really 100 percent sure --we knew it could blow up, and if it blew up in our faces I probably would have been fired. If it had blown up in John's face he would have been discredited and so forth. But we really felt we were right.

Bonney: Rumor has it that John and Michael Pachovas were sort of leading the battle and that they were battling each other, and that at the end of this time period they never spoke to each other again. Did you see that kind of activity or hostility? Do you know anything about that?

Velton: I think that's overdone up to the point of hiring Susan O'Hara-- that's where the rupture occurred. That was it. After that, Michael Pachovas always felt that he had been betrayed, that John couldn't be trusted about keeping his word. He would mutter things like that on occasion.

Michael Pachovas, of course, has been a force for many things. But he really does see things in black and white. Maybe that's why he's so effective sometimes. But that's what he does. When he writes you off, he writes you off. It seems that way to me.

I don't think there was any rupture that occurred until this decision. Maybe Michael Pachovas was really for somebody else, but I had always thought that his anger was because the consent process was not followed. It's possible that John knew that Michael wanted to get another person in instead of Susan, and he was convinced Susan was the best person. He never actually said that, but--.

II PHYSICALLY DISABLED STUDENTS' PROGRAM

The First Office on Durant Street

Bonney: Okay. Let's switch gears just a little bit and talk about PDSP itself. What did PDSP look like?

Velton: It was next to this ice-cream parlor. You'd take this long ramp in back of the ice-cream parlor, and the building was all in back. There was that ramp and then another ramp, and actually--

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Velton: The PDSP building was there behind this ice-cream building on-- what street is that? It's Channing Way, isn't it?

Bonney: Was it on Durant?

Velton: Yes, Durant, near College Avenue. So you'd go in on the side of the building, way to the back, where there was this long ramp you'd go up--first going straight back--and then turn and go horizontally along the back of the building. By modern standards it was a steep ramp. I know because one intern I had always felt that it was a little bit scary going up and down that ramp. You'd come in the back of the building, and there was the kitchen. You would come into the kitchen first where Zona Roberts really reigned, and she would fix the meals. They had a big table there where students would come in and have something to eat. Beyond that was another room where they also had offices. So PDSP was in back of the ice-cream store. Then there was still another room off the kitchen. It was a very crowded and somewhat chaotic situation. John Hessler and Don Lorence would have to share the same space at the back, and they would often have other people answering telephones and holding meetings. The sunlight only came in from the west side of the building, and even that was somewhat blocked out by the other buildings, so it was never really bright inside there.

But it was a very friendly, informal place. It seemed like the disabled really felt like they were welcome there. The room to the east, the other side off the kitchen, was where they had repair work going on for the wheelchairs. They had some very capable people that would repair wheelchairs. That was a very important adjunct to students because sometimes their electric wheelchairs would break down at odd hours, and someone would have to go out and repair the wheelchair or replace the battery or do something. Otherwise, people would be immobilized. Later they got a van, and that van certainly helped them because then PDSP could pile people in the van, which was accessible with a Tommy lift in back, and it would take people to medical appointments and to occasional recreation programs.

It was a cramped situation. There was a fence behind the parking lot. The workers that fixed wheelchairs would sometimes work there so long that when they didn't want to stay any longer they could pull this one board aside and go out through the back fence instead of the front way so they could escape when they felt they had reached their limits [laughter] and didn't want to repair any more wheelchairs or whatever.

Bonney: I didn't know that. I never saw the old place.

Velton: They made the change just before you came.

John Hessler and Ed Roberts as Leaders

Bonney: You talked a little bit about John Hessler and some of the things that he did with you. Can you tell me what your impressions are of John Hessler as a leader?

Velton: It's interesting. John told me that the way he became the head of PDSP was that he never told anyone that he wanted to do it. And he wasn't even sure himself that he wanted to do it, but that he knew that if he ever said that he did want to do it then he would be under pressure as the front runner, and someone else would get it. He said he got it because he never said that he wanted to be director of PDSP. Then they finally chose him as the one person everyone could agree upon.

John was a strong person with firm convictions, and if he made up his mind he could be very stubborn and determined. Some people were not always sold on the way he ran PDSP, but I think he brought it forward in a very successful way. I think that he was so strong and so focused that people functioned better under him

than--I don't think Don Lorence ever functioned as well after John left. He benefited from that direction. He really looked like a more capable person under John than he did afterwards, and I'm sure Don would hate me for hearing that. Don was never as strong a leader as John. I think it gradually wore him down to the point that he was less effective when you came on the scene than he was in the beginning.

Back to John. I would say that he could be very focused and very clear about what he wanted to do. I've always admired John. This is sort of an aside, but later on I went through this program with CIL where they talked me into experiencing a week as a disabled person. As a part of that program I went around in a wheelchair like I was a paraplegic. I remember the first night they brought me home, and the Tommy lift let me down, and I almost fell off the lift [laughs]. Anyway, I made it into the house--we had a condominium with an elevator--and when I got to the front door Pauline, my loving wife, had no sympathy for me whatsoever. It was difficult for her that week as she was working full time. I sat in the wheelchair all the time and transferred like I was a paraplegic and so forth. The next day I took the elevator down, wheeled myself to work, and I was exhausted by the time I got there. I got there late although I left at the regular time.

I always remember coming off BART [Bay Area Rapid Transit] there at the Lake Merritt station, and as I was wheeling along this man came along and wanted to help me. I thought that was okay. He turned out to be the assistant tax collector, and he dropped me off a curb that just jarred my teeth [laughs], and I thought, Oh, boy, I could have done without this. So I learned that you don't quickly accept help from strangers [laughs]. He meant well. So anyway, I had those experiences. Then I spent an evening with John Hessler. John fixed dinner in his apartment. He showed how he did it and how much it meant to him to be able to fix his own meals and have this higher level of independence. He enjoyed calling up on a talk show and discussing cooking. This gave him a great sense of being a whole person. So John and I had more shared experiences, actually, than I had with Ed Roberts. We did do things together like that.

But I don't think that John had the breadth of vision or the charismatic qualities that Ed had. Nor did he have the exceptional ability to delegate. I mean, he could certainly delegate adequately but not like Ed could. Ed had to learn how to delegate, but he usually did it wisely: he chose a lot of people.

John, despite being so daring with the residence hall program, was conservative. There were some things that Ed did that I didn't even understand at the time--they were hard for me

to take--which John never indulged in. John never really badmouthed counselors; he didn't even badmouth Lucile. Lucile approved his program to go to France to study French, and he was away when the toughest part of that controversy erupted. I remember seeing interaction between the two of them, and John felt differently about the crisis with Lucile than many of the others. And that more gracious attitude has a bearing on some of the things that Ed did and said after he became director of the department.

Bonney: Well, let's talk about Ed. What role did Ed Roberts play in those early days?

Velton: He was, by this time, very much involved with CIL, and that was his focus. They had by this time set up their headquarters on the fourth floor on University Avenue. They had offices there, quite a few with the whole front and back of this floor with one large room that faced on University Avenue. It had elevator access as well as a stairway, of course. It was something when you realized the potential danger. Once there was a fire alarm, and the firemen had to come to evacuate the building. I don't think the firemen ever got over this emergency as the elevator stopped operating and they had to carry the quadriplegics from the fourth floor of the building, and one of them was Michael Pachovas, who was perhaps a little bit lighter than he is nowadays, but still a pretty hefty 250 pounds. This they didn't appreciate, so they started pressuring CIL to get out of that building. They knew the location was potentially very dangerous in case of a more serious fire. It was at that time that we set up the computer training program at 2020 Milvia Street in a separate building.

Now Ed had a wonderful ability to reach out to people, to audiences. He would of course spend a good deal of his time in the iron lung, but he did have his portable respirator, and he could sit up in front of people and give dramatic speeches which would really appeal to people. He had a vision of what he wanted to do; he seemed to be able to get a lot of people in very high positions to respond to him.

One of the things that he did--and this is what really annoyed a lot of the rehabilitation counselors, supervisors, and administrators--was when he became director of the department he often told how badly the Department of Rehabilitation had treated him. DR had provided thousands and thousands of dollars of service to him--including buying him a van. When Ed became director, John Parks and I decided we should shred his file listing these services. We figured, perhaps wrongly, that was the proper thing to do. We doubted confidentiality could be maintained. So we knew personally he had benefited. Few knew all

the details, but many knew that the department had done a great deal for him. I grant he was initially treated ill, found ineligible in San Mateo County, and had to fight to enter UC Berkeley.

But he constantly used this ploy of how badly he had been treated by the Department of Rehabilitation in the early days. I think he was referring more to Lucile Withington than anyone else. Maybe Catherine Butcher wasn't perfect either since as I understand it she came down on him too somewhat. I don't know what she proposed to do or whether he was one of the people under pressure, but I know that he felt that the department had not adequately helped him. It is true DR didn't accept him as a client at first or support attending the University of California, but that was down on the peninsula. Then when he came to Berkeley DR may not have fully supported or understood what he was about for some time. But gradually they became more supportive.

Anyway, over and over again he would reiterate how the department had not seen the possibilities and how they had put up these barriers, and he had to overcome them. What I didn't like about this was that it seemed to me that by doing that--although he gained a great deal of support from congressmen, politicians, administrators and private people--he lost the counselors and supervisors in the department. Very few DR staff remained in sympathy with his fundamental goals. Now it may be that he was right, that there was nothing that was really going to change attitudes, because I don't think much of his legacy has lasted.

What has lasted is that he set up these independent living groups all over the state of California, and it may have been his vision, that it didn't matter. What he had to do was to strengthen the disabled as a group, and if the disabled were strong and representing themselves then they would get the services that they needed regardless. It wasn't going to occur because of goodwill or happenstance of having a few people in the right place. Political strength was the way to go, and if he had to sacrifice the goodwill of the counselors in the department to achieve these goals, so be it.

As I look back on it--although I didn't agree with him at the time--maybe he was right, because the department has always veered so much towards pandering to funding sources rather than holding to principle. I mean, wherever the money is to be found that's where DR will go. Even now when they're supposed to be prioritizing and serving the severely disabled, well, guess what disability is of the highest priority--learning disabled. Now why are learning disabled more disabled than severely physically

disabled, or mentally ill, or blind or deaf clients? There's only one reason: it's because that's where funding support is found.

But this is a trend that you see over and over again. This is how bureaucracies behave and probably how they always will behave. The reason they pay attention to the disabled and the rights of the disabled is because the disabled can represent themselves more effectively--disabled groups like the blind, the deaf, the physically disabled. Of course, the one group that often tends to get short shrift is the mentally disabled, though I greatly admire CIL's concept of being all-inclusive.

And that's part of his legacy too. In other words, it is not a narrowly based movement; he has not only gone for all types of disabilities in the U.S., but worldwide. He's had a vision which has gone beyond what any other disabled person had. Now, throughout the United States, you have centers for independent living or comparable programs, and you have programs in other countries, you have outreach going on all over the world. While it's certainly not exclusively Ed Roberts, I don't think that there's any one person you should give more credit to. So you have to say that that's a tremendous legacy.

Whereas John Hessler was certainly very capable, even outstanding, you have to say Ed Roberts was a giant.

Buffer Between DR and PDSP

Bonney: When I worked at DSP [Director, 1979-1988]--and Susan collaborates with me on this one--we observed that you and Karen Topp served as buffers most of the time between the department and DSP [chuckles]. Karen was also a very strong advocate for severely disabled persons and provided a lot of services for students especially. Can you describe how you saw your roles? And what kinds of problems or issues did that create for you with the department?

Velton: I don't like to be thought of as a buffer, but I know that I was constantly being pressured by management because Karen was spending so much money. I would try to find ways for her to save money without decreasing her effectiveness. Of course there was a great deal of experimentation: some of the equipment that first came out that we wanted to try was quite expensive. Then later we found less expensive substitutions that were equally effective. There was this occupational therapist, Elizabeth Esterly, who was really gifted. It's like some quadriplegics came out of the

hospital with hand splint devices that would come up like this on the arm [demonstrates] so they could hold a pencil or pen to write, and they would also be given a special tool to use on the typewriter. Eventually Liz would throw all that stuff away and give them a pencil [chuckles]. They could hold that pencil in their hand so it wouldn't come loose. It's like that trick--if you hold a cigarette between your little finger and this finger [gestures] it won't fall out even if you fall asleep. It's a trick I learned when I smoked [chuckles]. Certain natural movements replaced the need for expensive devices--that's just a very simple example, but she came up with a lot of ideas like that.

Anything that was generally available in the community was a better substitute than buying some expensive device that when it broke you'd have to repair, and parts weren't available, so then you had to make parts. So there was this simpler way. Then there were devices that were quite expensive originally, and then as more and more companies and people bought them, they became less expensive.

There was this constant pressure to keep expenses down. I gave her as much leeway as I felt that I could, though I suppose there were some times when I caved in, too, to this kind of pressure. The district administrator, Henry Leng, was under pressure too. But what I noticed is that while Henry would pressure me, when before some other private group--he wouldn't hesitate to brag about the program so long as it was to his advantage to do so. I suppose there were times when Karen could have said, "I can't do it because John won't let me," and there were times where I would tell Karen, "You can't do it because Henry won't let me." [chuckles] But usually we got approval when convinced that it was really necessary.

Some people would ask for the moon, and some people would be so reasonable you'd almost have to push things on them. But one of the principles we tried to follow was to encourage clients to make their own decisions as much as possible: "You find the tape recorder you want. You go find this, you decide, and come back and tell us. Give us a few alternatives. You can't spend more than two hundred dollars." When necessary we made suggestions. Whatever. Put some parameters on it. So that was the principle behind the way we operated. Whether it appeared that way to the people, I don't know. I always tried to be open to new ideas, but there were some ideas that I scotched. And there were some times when people would appeal to me over Karen, and once in a while I guess I would overrule Karen.

We did get annoyed with some clients who refused to keep their contract with us, like--we're one of the few that ever repossessed a van from somebody that simply did not follow the rules, and that event changed the whole procedure based on--if you don't follow the agreed procedure then this is what's going to happen. So then Ed changed the rules requiring repossession of vans under those circumstances by requiring an additional appeal process. It was hard on that one woman, but I'm sure it made things easier for a lot of other people. That's a bureaucratic ploy that I acknowledge. Sometimes if you get a rule that you don't like, one way to get rid of it is to just follow it to the letter [laughs].

Bonney: Now you rankled just a little bit when I used the word "buffer." Do you think you weren't? I feel like you protected us a lot, and that's more what the concept of a buffer is.

Velton: I guess in all honestly I was. I paid a price for that, I'm sure, but buffer was probably the right word. I'm sure that I turned down requests and so forth sometimes that other people thought I shouldn't have. Karen did also. Sometimes we would use each other, you know? But it was really wonderful having a counselor like that, and I think both Karen and I sacrificed a certain amount with the department in the sense that we were never thought to be team players in terms of the department's rules and regulations. That means that we really couldn't be trusted by management when they said or implied, "Well, do this but don't tell," because we certainly did tell on them sometimes. Though Ed did offer me a position in the central office, I could have gotten the promotion only by going to Sacramento if I wanted to, but Pauline had a very good job in San Francisco, and I didn't want to go to Sacramento. I think that was wise; I'm glad I didn't. At one time John Hessler asked, "What are you going to do?" I said, "I guess I'll just stay here and try and protect the people and the programs that are here."

Bonney: Did you take heat from people in Sacramento over DSP and other things?

Velton: Sometimes. They did some pretty dumb things once or twice. There was one study that they cooked up where they were going to measure the Computer Training Program and the dormitory program as if they were workshop programs. And the criteria just didn't fit. We told them several times it didn't fit. Then finally I went to that professor who became a city councilman--what was his name? His research organization was well known--last name began with a C.

Bonney: Fred Collignon?

Velton: Yes. And I told him about this and explained the problem to him, and he said, "Well, I'll fix it." Boy, he must have gone over central office's head [laughs]--they were very upset about that before it was over. It was a totally faulty study in the way they were going to judge the residence hall program and the Computer Training Program. I can't say the researchers didn't deserve criticism, because they persisted in wanting to evaluate in a way that was really totally unfair. So that was the end of that. They didn't like it. Soon after that I was replaced as contract administrator for both the residence hall program and the Computer Training Program. A year later I was transferred to the Fremont office because a supervisor position was eliminated in the Oakland District.

Poor Wheelchair Access in DR Berkeley Office

Bonney: Why did the department open the Berkeley office? And when did it happen?

Velton: That was about '79 or '80, I think. I don't remember exactly, but I'm quite sure it was right around then. That was because we went off-site and did a special study--this goes back to about '75, just before Ed Roberts became director--and analyzed what was happening with the population in Alameda County which comprised the Oakland District. We were aware that we had a lot of people in the northern part of the county, but when we analyzed the census data we could see that there's a much heavier concentration of population concentration in Berkeley than you recognize until you've studied the census data. Also that the population was expanding further south.

So we came to the conclusion that we should decentralize our offices and make the central office smaller, have a Berkeley office--we already had an office in Hayward--and set up an East Oakland office and an office in Fremont. This was the plan that we implemented, but it took quite a while to find space and actually make the decision to move. We thought it was really logical to be close to the computer training program, the residence hall program, and it would work much better to have an office in Berkeley to better serve the disabled community.

Bonney: Now were you the head of that office?

Velton: No. Marian McIntyre and I were joint supervisors in that office.

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Bonney: John, you talked about the new DR office being opened up in the city of Berkeley. How was the access in that office when you first moved in?

Velton: That office on Berkeley Way was not as accessible as it should be, particularly for people who came in wheelchairs. For a considerable period of time we had to put up with it because many of the people in the department thought that it was good enough. It was sort of a ramp and then the door, but the door had to be opened, and the door was so heavy that some wheelchair users could not open it. It opened outward. And even one or two people fell out of their chairs, and the secretaries had to run out and pick them up. So we struggled with that for over a year and a half before they finally agreed to put a ramp in at the right incline and an automatic door. In retrospect that was something to be ashamed of, I think. But anyway, the department finally did it, and now they have made a policy of being very careful about having all offices accessible everywhere, with automatic doors and ramps and meeting the state's specifications.

Bonney: Why do you think they were so reluctant for so long?

Velton: Well, a lot of them thought it was adequate. They came down and eyeballed it and thought it was good enough. I thought afterwards what we should have done was put a couple of the administrators that came down in a wheelchair and let them see what it was like from the ground where they would have had to experience it like a client would have. But that's hindsight [chuckles].

Bonney: You look like you're getting tired; are you done for the day?

Velton: I suppose we should stop there. [tape interruption]

Cowell's Impact on the Disability Rights Movement

Bonney: Okay, we'll go on and do one more question. Do you think that the Cowell program had an impact on the disability rights movement, and if so, how did the Cowell program affect it?

Velton: I think it did. It was the genesis of the movement in California, and California had an impact that was certainly significant throughout the United States. It started off with, as I say, Ed Roberts coming and then John Hessler. Then they had seven disabled students, and they formed the "Rolling Quads," and then they formed the PDSP--the Physically Disabled Students' Program--and then that program was serving so many disabled who were not on

the campus as students that they recognized that they had to separate. So they spun off, forming CIL, and that was a crisis response. I mean, PDSP was under a lot of pressure from the university--hey, we're spending all this money supporting this program, and half the served people didn't even go to the university.

So CIL was the result of the crisis, and I think John Hessler and Ed Roberts and many of the others, Herb Willsmore and others, had a lot to do--Phil Draper; I'm not sure exactly when he came in--with separating the two programs. So they formed the Center for Independent Living. When that program grew, and as they had this all-inclusive vision--they gained enough political moxie and know-how to go to the city and make the city more accessible and promote curb cuts. They started thinking about making the BART system more accessible, and they got involved with that. They got involved with the state legislature, with Hale Zukas going up to the state legislature, and he drove them to pass favorable laws. I remember Congressman George Miller saying that Hale Zukas came to his office so often working for disability rights laws and so forth. His staff would say, "Oh, no, here he comes again! We've got to get this law passed!"

III DISABLED-DIRECTED CAREER PROGRAMS

[Interview 3: February 4, 1997] ##

Computer Training Project

Bonney: This is our second session of the interview with John Velton from the Department of Rehabilitation on Tuesday, February 4, 1997.

Let's move on to the computer training project which you were also involved with. Can you tell me what the project was?

Velton: The computer training project was a project which was started in 1974. IBM, the International Business Machines organization, had set up a program with the Woodrow Wilson Rehabilitation Center back in Virginia where they were training people who were severely disabled to become computer programmers. Norm Hammond was the gentleman who was doing that. It worked well enough so that they decided they wanted to replicate this program throughout the United States, where they would train computer programmers and then have them work at home. This was the idea that they first proposed when they came out here in early spring of 1974. The IBM representative had gone all over the United States talking in many cities with limited success at that time.

So we took the idea under advisement because it was assigned to the Oakland district--John Parks was the district administrator, and I was the assistant district administrator at that time. I got together a committee with Karen Topp--we had Scott Luebking and a few others who were in the disabled community, and we told them about this project. And I remember particularly that Scott Luebking was very much against the idea of having trained computer programmers, no matter how disabled, working at home. He felt that the program should train them to work in the offices. So we took that message back to IBM because he was persuasive, and we were all sold on it. They agreed that they would try that.

Then we proposed that if we were going to train these very severely disabled, blind--and later deaf--wheelchair users and so forth, that we had to be sure that they were going to be employed. They assigned an IBM executive, Joel Parker, to work with us and recruit a committee of businessmen. Harry Orchard also was one of the key people who was working at IBM locally to further this project.

In the meantime, we then proposed four different locations: one was at Highland Hospital, one was the Center for Independent Living, one was at Franklin Hospital in San Francisco under Dr. Sheldon Berrol, and one was at Peralta College--the community college in Oakland. We used this Kepner-Trager approach to outline the pluses and minuses of each one, what could go wrong, and what was required. We concluded that since the major goal of the program was to focus on training very disabled clients to become competent computer programmers, it would be necessary that we join together with the business community and that we do this simultaneously, that we listen to them every step of the way so that we'd have their maximum support.

For this reason, we realized as we investigated various possibilities that we had to have a very flexible arrangement with some organization that could act very swiftly. We found that the hospitals had a medical setting, and there was a lot of various protocols we'd have to go through to satisfy the doctors, and they had a lot of questions and what-ifs and what could go wrong and looked at a lot of the negatives. The same was true and even more so with the community college because they had their educational bureaucracy and their committees which had to consider the program.

So we decided to go with the Center for Independent Living. And we also found two young men who were quite talented to become the initial instructors: Scott Luebking and Neil Jacobson, both of whom had graduated Phi Beta Kappa at their universities and were studying computer systems at the University of California at that time. Scott Luebking was a quadriplegic who had suffered a diving injury when he was at Knox College in Galesburg, Illinois. Neil Jacobson had cerebral palsy from birth--well, of course he had it from birth. He was very disabled; he was unable to walk more than a few feet and had a minor speech defect which people could adjust to after they had listened to him because he had a very wonderful personality which encouraged people to make that effort.

Scott was considered to be the director of the program initially, and he had proposed Neil Jacobson to help him because he felt that he was so talented. I have to say that I had considerable difficulty accepting that Neil Jacobson could be the

assistant instructor because of the speech defect that he had, and I thought long and hard about that--although I knew that Neil was an excellent student who had graduated summa cum laude and Phi Beta Kappa from Hofstra. But I decided to go with that wholeheartedly, and it turned out that he was a gifted teacher and that people responded to him--not only the students but also the business community--so positively that he became a tremendous asset and more than justified my taking what at that time I thought was a risk [laughs], and it was very successful.

We started planning for this in the fall of '74, knowing that the committee was going to meet late in '74 or early in '75, and found a location at 2020 Milvia on the fourth floor. I put together a proposal and got it approved by the central office. Ed Roberts, who was then the director of the Center for Independent Living, agreed to support us, and this allowed us to write a contract through the Center for Independent Living with the State of California.

So we were prepared to start the program early in 1975. This was essential, because the business community had then been recruited, and we had a large group attend the auditorium at Fireman's Fund in San Francisco on California Street. Ed Roberts and Scott Luebking and Neil Jacobson all came to that meeting.

It was interesting because the businessmen there--I don't think hardly any of them had had experience with disabled clients, and so I think some of them were somewhat appalled when Scott had several spasms and Neil's speech defect became apparent. But Ed Roberts was quite charming although he was obviously in need of his respirator, which he carried, portable, and had to breathe through from time to time as he spoke. Half of the people that IBM had recruited were never seen again [laughter], but the other half stayed, and afterwards I thought that was probably a wise approach because those that stayed had felt for one reason or another that they were willing to go ahead and see how this would work out.

Then we were able to organize the businessmen. Bob Smiley of Fireman's Fund was the first president, and there were others that were very significant: Dick Nugent of the Bank of America, Loman McCarley of Del Monte, Paul Knoll of AT&T, and Janet Bensus of Levi-Strauss, to mention a few. There was Joel Parker and Harry Orchard of IBM, and there was one instructor from Peralta College, Ron West, who had felt so bad about the way that Peralta had not responded more positively that he helped us also to initially develop the curriculum and the course.

Bonney: What were your expectations for the advisory committee?

Velton: I wanted them to participate in every way possible so as to help us design the curriculum so that we would meet the needs of the business community. I wanted them to be as involved as possible so that they would hire the graduates when they had completed the nine-month course. So right from the beginning we started thinking of every way we could to encourage their participation. We had them help design the curriculum; we had them come and give talks to the students; we had them set up tours of their various businesses so the students could have that experience; we had them donate equipment. We had them review the work of the students with review boards at three-month intervals and make recommendations and give us feedback as to how the course was proceeding and how the students were doing.

We also got them to agree to set up internships for a month after the students had graduated--which is actually the last month of the nine-month course--so they could actually see what these young students could accomplish. All of these things were designed to get them to know the students, know the program, feel like it belonged to them, and to be willing to hire the graduates when they had finished. Then we had a graduation ceremony at the end where we invited all the businessmen, parents, and counselors with a little humorous ceremony, gave them diplomas and told about the placement results.

So we did everything we could think of to involve the business community and keep them involved. I don't know if we had monthly meetings, but I think we tried to have monthly meetings at night, and some of the businessmen would come for brief periods to meet the students in some cases and also make more plans and give us more input. So that was the concept, and that worked. I know Neil Jacobson and I discussed that, and we concluded that it was because we had this focus--that the main reason the program was successful was because it was concrete, and we always evaluated our success by the number of students employed. We ended up with a 90 percent employment rate. Considering how disabled the students were I think that was excellent.

Bonney: John, what were the criteria for a student to get into the program?

Velton: We tried to develop a criteria--initially we had a cutoff of an IQ of 120, and we also looked for certain keys that would indicate that this person had the ability to manipulate another language precisely. This was basically what programming is--excellence or capability in math, in foreign language, in music, even in chess, would all be clues for this ability to manipulate another language or to manipulate symbols in a precise, logical, organized way. Not everyone that was admitted to the program initially was able

to succeed, but since most of them had some college--we found that a high percentage of those that entered the program were able to complete it.

Another criteria was the ability to communicate well with others. A computer programmer has to be able to collect information and interact with his peers and also pick up information in order to design programs. That's one of the reasons that college is so useful; it sort of prepares the person to interact more effectively. High school graduates can succeed and have succeeded, but they are at a disadvantage.

Later on we explored lowering the cutoff rate as far as IQ, and we found that it didn't work too well unless someone had a high degree of ability in some other area in terms of one of these clues that we talked about. So that was the criteria that we more or less worked with. Of course, it was based on interviews besides the tests.

Bonney: Neil has said that every student had to have a personal interview either with himself or with Scott. Did you ever sit in on any of those interviews?

Velton: I did on a few. But I felt that it wasn't really necessary; I thought they did a better job when I wasn't there because they would be more at ease and get more down to the nitty-gritty. We found very quickly that we couldn't ignore the other problems that some of the students had. They had to be able to either live very close to the training site or to have an effective way of commuting, and even though it was close to BART there were problems that could develop with BART. There were problems of course with bad weather, and we found that we had to depend on CIL to even bring some of them in a van, which would sometimes create other problems; the van would have to be doing something else or whatever. So they had to deal with the problems that arose in terms of independent living--more independence than some of the students had ever had before. This required a lot of extra work.

Bonney: Now was this something that they talked about in this initial interview?

Velton: I think they did. As they got more experienced they talked more about it. Of course, they had a staff that started off with Susan Shapiro, and then after she left Debbie Meehan and Terry Davis helped them as the secretaries. Later, Debbie became the recruiter for job placement, which she is still doing; she's excellent at it.

Bonney: How were potential students identified? Where did they come from?

Velton: We had hoped when we started the program--we went down south and told counselors at meetings about this, that we would get students from all over the state. We found that we really had to do some active recruiting and that most of the students came locally from the Bay Area. There was initially quite a backlog of students that had either gone to college here at the university or elsewhere and hadn't found jobs and they wanted to do something, and so we had quite a group of people wanting to take this program.

As time went by we were able to reach out to northern California and Sacramento, but we found that we really had to depend upon certain counselors who had an interest in the severely disabled--Doug Ford in San Jose and Lucile Withington in Contra Costa, Karen Topp--then Karen Newsome--in the Bay Area, and many of the other counselors in the Bay Area. We were able to reach out to them in San Francisco, but those three come to mind. Gill Johnson and Joan Groves--these were local counselors, and Joan is right here in the Berkeley office.

Then Doug Keene and other counselors for the deaf--we had a lot of support from local counselors, and that helped. But we found that sometimes districts that were farther away didn't want to send their clients this far, and sometimes clients would have to appeal in order to be able to be approved to come up to this program.

Bonney: Now why were counselors reluctant to send them this far away?

Velton: I think it was two reasons. One is that the Department of Rehabilitation always has been organized in twenty-six districts, and each district sort of takes pride of their own. They want to be able to say, "We can do it all here in our district." So there's a reluctance, especially when it's far away, although we got clients coming up from Rancho Los Amigos and Fresno where there were hospitals that especially concentrated on working with the severely disabled--and Santa Clara Valley Medical Center. But in general, the counselors wanted to keep them in their own area.

Then after the first initial course we had to require the district to transfer funds up to cover the cost of the course. That didn't continue, but that was another barrier we had to overcome until we got that changed where it was completely block-funded and then the course was paid for out of central funds in the department, so it didn't apply to any particular district. That helped.

Bonney: How was the program funded initially? Did you get money from IBM or the state? How did the first project get funded?

Velton: Initially I got a block funding grant from the department to pay for the salaries of the staff--Scott Luebking, Neil Jacobson, the secretaries--and the rent of the building. But we had to scrounge up the equipment, some of it was donated by the program for the blind--Bill Cerruti--and they had extra equipment for chairs and tables. IBM and other businesses donated computers. The University of California allowed us to hook up to their computer at Lawrence Hall of Science there, and that was only for a short period of time, but it got us started. Later on we had an IBM hook up. So we got a lot of help from a lot of different areas, and actually the businesses had set up what they called the Scrounge Committee to keep putting out lists for everything from paper, pencils, typewriters, computers, what have you. A lot of businesses donated extra items like that. So we didn't buy hardly any furniture, and very little equipment.

CIL in the Early Days

Bonney: You said that you finally settled on CIL as the site for the program. What was CIL like in those early days?

Velton: At that time, they had moved to University Avenue where they were on the fourth floor. There was an elevator, and they had a very cramped office up there that they were using. They had a number of different rooms that were connected by halls and so forth, which didn't allow them adequate space; they were really quite crowded. So people were always stumbling over each other.

Furthermore, the access was very difficult because of being on the fourth floor. Almost all the CIL members had to come up and down through the elevator. Finally they were actually requested by the fire department to move. It was considered to be a poor location for so many disabled people to be congregating.

As far as activity, they were still searching for how to fund themselves. They had to really work hard on that. They finally got the courage up and moved into the building there on Telegraph. With fundraising, they were able to lease the building initially, and then of course they had far more space, and they're still there today. It was an organization that depended on a lot of different people, and it was simply growing at leaps and bounds at that time.

Bonney: How was it making itself known nationally?

Velton: They were starting to become active because they had done a great deal locally--and in Berkeley in particular--to make the community accessible. Berkeley was a community because of the climate, which was very congenial to disabled people because we didn't have real cold winters or real hot summers. This was especially important to quadriplegics and others because they had difficulty adjusting to rapid changes in temperature and could be even caught unawares because sometimes they wouldn't even realize when they were getting real hot or real cold. They were fortunate and liked it in Berkeley, and of course a lot of students had come to the university program and had graduated and so they had a substantial number of capable people. They had started to become interested in accessibility and had participated in the Bay Area Rapid Transit System becoming accessible. They had also set up a transit system of sorts where they could move people around and take people to appointments and so forth.

So there were a lot of different attractions, and they began to reach out also through getting a certain amount of publicity. Ed Roberts had that ability to reach out to people, and he was becoming known beyond the city of Berkeley and California, and he was actually soon to become the director of the Department of Rehabilitation, which really got publicity for the department and for CIL.

Bonney: The first director of CIL was Larry Biscamp. The story has it that Ed Roberts unseated him as director of CIL after he was in the position just a few months. Do you know anything about this?

Velton: Not really. I only know what John Hessler told me about Larry Biscamp, that he had worked so hard to establish CIL, and then he had been sort of overwhelmed. And, perhaps he had started drinking too much.

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Velton: That's all that John ever said to me. He never said anything untoward about Larry Biscamp beyond that or Ed Roberts taking over or whatever. I don't know exactly what happened.

Bonney: Okay. When you all started the Computer Training Project, what were the goals for the project?

Velton: The main goal was to train the severely disabled to become computer programmers and have them successfully employed. Beyond that, we wanted to train them so well that they would have the self esteem and the knowledge to know that they could deal with any problem. In other words, we wanted to have them at a level where they were better than most computer programmers so that no

matter what they ran into they would feel they could handle it and so they would actually be in demand. Many of them have gone on to excellent careers with some of the companies that supported the program initially. I might mention, for example, Neil Jacobson now is a vice president with Wells Fargo with over 200 people, and Jeff Breilh is with Hewlett-Packard. Some of the others didn't continue in the program but they went on to successful careers. Wesley Whitfield is a successful singer, although she did work as a computer programmer for a while. Ansley Nies is with Hewlett-Packard and doing very well--Mark Gutherie also. You just go on and on. There have been a lot of successes.

Neil Jacobson as Computer Training Program Leader

Bonney: Neil Jacobson, when I talked with him, said that he was very surprised about how supportive you were about the program. He said that you had never met him before and that you could barely understand his speech but that you were his biggest cheerleader. He thought that you were very proud of the program and very proud of him as an individual. Is this statement true? And what are your thoughts on that?

Velton: I did a lot of soul-searching before I ever agreed with Scott Luebking that Neil could be the assistant. I don't know that I did it with Scott, but I did it with myself. And I finally decided that if I was going to do it, I should be wholehearted about it. It didn't take long for me to see that Neil was a very special and capable person. So I quickly got the idea, which I have always tried to push, that the best people for teaching the severely disabled and running programs like this would be successful severely disabled people themselves because they would not only be teachers but they would be role models.

I know that this is true. For example, others like Jeff Breilh have told me that when they walked into the program they were not believers, they didn't think this was real, they thought it was just something to do to pass the time. But when they saw what Scott Luebking and Neil Jacobson were accomplishing, they changed their minds.

But to go back to Neil, Neil grew on me because he was such a wonderful person. Apart from his being a workaholic and working very, very hard with great dedication, he was dependable, he was responsible, and he was extremely likable. Not only was he a fine instructor, but the businessmen quickly came to love him as someone that--they just enjoyed him, and he could say three words,

and they would laugh and smile. Then later on we got him a van, and he said that made a tremendous difference in his accessibility to the world. It opened the world up more than ever before.

He became a leader of the first organization of all the different computer programmer programs which were established around the United States; I think there were eight or nine. There was a meeting back in Gaithersburg, Maryland, which IBM sponsored after the third program. At the end of that program--that was in 1977, in the fall--they founded the ARPDP, which was the Association of Rehabilitation Programs for Disabled Programmers. Neil was elected its first president. I pushed him to do that because this was something that--I had hoped that a lot more of the programs would find capable disabled to run these programs. It never really caught on, but I think it's always been a very positive view.

I think that in the long run the disabled are people who can best speak for themselves, that none of us who have been looking on the outside can ever see quite as clearly what their actual needs are as they can themselves. Some people can come very close to it and some people can learn, but they are the ones who I think should lead their own movements for rehabilitation. So that's why I supported Neil, and I've never regretted it.

Bonney: Can you recall the very first time you met Neil and what happened and how you felt? What was the dynamic?

Velton: When I first met Neil, Scott introduced him to me. Neil has cerebral palsy, he's quite contorted, he can't sit straight because of his muscles pulling against each other, and I couldn't understand a word he said for maybe the first five minutes, which made me think to myself "This man is going to be a teacher? He's going to instruct?" But I found myself drawn to him, and as he talked you could start to pick up the cadence and understand what he was saying. And then he has this marvelous patience; I've often thought that it's a gift, because he has never shown irritation. If you don't understand what he says, he'll repeat it or he'll say it in another way. But never does he show that this is like your problem or he's impatient with you; he simply wants to communicate with you. So you want to communicate with him.

You find that this is a quality that can't help but appeal to you. It's something I've seen happen over and over again where people would come and started to listen to him and get this sort of quizzical look on their face, and then gradually you see they're drawn in and they can understand, and they're communicating with each other. That's all I can really remember.

Bonney: He was the head of the Computer Training Project for a while after Scott left. How long was Scott the head and how long was Neil the director?

Velton: Scott was there for the first and second class, and then Scott said, "Well, I think I want to leave now." I told Scott, "You've done everything you said you'd do, and I really can't complain," and Neil took over in January of '77. Then he taught a class and then started teaching two classes after that. He had to start getting an assistant; he got Sandy Vogan, who was one of the really excellent students. She had a very severe back problem, so she had to lie flat on her back a good deal of the time to teach, but she also was able to communicate and do very well. I think Neil stayed into '79, and then his last class was April of '79, and then Jeff Breilh, who was another student, and Sandy took over. Jeff Breilh started teaching a class with Neil, number five, in August 1978.

Bonney: Do you know what Neil did when he left the Computer Training Project?

Velton: He went down south. [phone rings; tape interruption]

Neil went to southern California to set up a computer training program down there and also direct a Center for Independent Living. I think that he found after a couple of years that that wasn't to his taste, and it was rather difficult with all the politics and problems that he ran into. So he came back and went to work for Wells Fargo. I'm not exactly sure how long he was down there, but I know that when he came back he was a little bit disillusioned with some of the disabled people, how they felt they were out to get all they could get without meeting their responsibilities. I don't think that that was a permanent view, because Neil's always been a positive person. He was a little bit down for a while. He was also going through a divorce; that didn't help either.

UC Berkeley Disabled Students' Career Planning and Placement Program

Bonney: Let's switch gears now and talk a little bit about the career planning program that started up with the University of California. Can you describe for me what that program was?

Velton: After Ed Roberts became director, Carolyn Vash was one of his assistants; she was a psychologist from down south. I think it

was in 1976 that she proposed that people submit proposals for grants to benefit the disabled in various ways. So I seized upon this opportunity to ask for a grant to establish a career placement program for the disabled at the University of California at Berkeley because it had seemed to me that the university placement office was not working as effectively with the disabled as they could. We quickly found that one of the reasons for that was that the placement office wasn't accessible to the disabled [laughter].

Bonney: That'll do it [laughter].

Velton: So that was corrected. A ramp was built; we got cooperation there from the university. Betty Bacon was the first placement person, and Ruth Dushkin was extremely helpful in training her. And the university was helpful in making space and helping us to concentrate on developing special programs for the disabled students to volunteer and to have summer internships and to place them in various opportunities so they could get exposure. It always helped if someone could say, "Yes, this person has worked for me in the summer and has volunteered and they can do it. You don't need to worry about them; not only are they capable but they can do everything else and work independently and interact successfully with everyone else." Some people would worry about those things when they hadn't had any experience; they wanted to be helpful, but they'd still worry many times more than they should.

The program was eventually accepted by the University of California after three years, and then they took it over, and it's continued as a responsibility of the university to help their disabled students find jobs just like all their other students. And that was the whole aspect of it.

We did have one problem which we never quite solved, and that is that we were constantly being challenged because not all of the disabled students were clients of the Department of Rehabilitation. Consequently, the program--of course, according to university regulations--had to serve everyone, whereas being funded with department funds it was only supposed to serve only clients of the Department of Rehabilitation. Therefore some of the auditors would point this out and challenge the program as being potentially illegal. But they never pushed it to the point of ending funding, and consequently we were able to succeed through the three years. Whenever we were challenged we would write memos and make explanations and so forth, and no one ever really made an issue of it to the extent that they cut off funding.

Bonney: When you made initial contact with UC Berkeley, did you go directly to the Career Planning and Placement Office or did you work through PDSP first?

Velton: In this case, I think I went directly to the Career Planning and Placement Office.

Bonney: And were they receptive?

Velton: They were helpful. I wish I could remember the name of the gentleman who was running the Career Planning and Placement Office at the time because he was really receptive and helpful, but I can't. I don't seem to find it anywhere here either.

I might add that after Betty Bacon left then we had Mary Lou Breslin come along, and she was also very effective. Betty Bacon took a job in Southern California, and Mary Lou Breslin later left to become very active in DREDF, the Disability Rights Education and Defense Fund, the disabled rights organization. After her, I think Jim Leinen came on to take over.

Bonney: What did the department want to achieve with this program?

Velton: We wanted to be sure that the disabled students at the University of California got the full range of services that they needed and, if possible, a little bit more because we realized that if they were going to be successfully placed, they couldn't just graduate and hit the labor market without some prior experience. Many of them had been somewhat sheltered before they went to college, and also it's very helpful to have some professor or some businessman or someone say, "Yes, they worked for me, and they can do the job." So the whole thrust was to increase their exposure while they were still in college and then help to place them.

Bonney: Was there an advisory committee attached to this program?

Velton: As part of establishing it with the university, then we did go to PDSP and ask them to participate and give us advice. So they had an advisory committee which helped us.

Bonney: And what kind of people were on that committee?

Velton: There was primarily people from the Physically Disabled Students' Program and faculty, plus myself and Karen Topp and Ruth Dushkin.

Bonney: Can you remember some of the critical incidences with the program?

Velton: With the Computer Training Program?

Bonney: No, with career planning.

Velton: Well, I only remember once that we were put under exceptional pressure and Judy Heumann was there, and we were trying to deal with this problem--particularly of illegality. We talked and talked and talked about it, and I guess we talked so much that finally they just sort of decided to drop the issue. Nothing ever really happened, although they talked as if they were going to have to do something. I think it helped a lot that Ed Roberts was director of the department, and this was a program for the disabled, and they finally decided to let it go and that it's not that serious [laughs]. Someone would have to come and really audit the program very carefully to prove that students that were not clients of the Department of Rehabilitation were receiving substantial services as well as students that were [clients]. It was one of those technical points that a lot of people thought could be ignored. I did, but the question kept coming up. That was the primary crisis that just kept coming up. We had quite a few more crises with the computer training program [laughs] than with this one.

Bonney: Betty was hired as the first director under COD--which I can't remember what it stands for.

Velton: Career Opportunity Development?

Bonney: Can you talk a little bit about why she was hired under the COD program?

Velton: I think it was just a way of hiring her before we got the funding approved so that we could have her available, so that she would be there. We didn't want someone hiring her somewhere else before we actually were sure we had the funding. It gave us an opportunity to get started sooner.

Bonney: What is the COD program?

Velton: It was a program that was supposed to help people find employment particularly with government jurisdictions through partial grants, I think, which would pay for their initial first year or first six months or whatever period. This was a program that was funded out of the central office and was actively pursued all over the state. It was an opportunity that was very helpful for the disabled. I can't remember the gentleman's name, but I should--Joe was his first name. He was pushing this program. Joe Kimmel was his name.

Bonney: Was this program replicated elsewhere in California or in the country, that you know of?

Velton: Not that I know of.

Bonney: What kind of reporting or tracking of students was done? What kind of reports did DR want on a quarterly basis or an annual basis about the program?

Velton: We wanted to know what was being done about placement activity. Particularly, we wanted to know how many students were ultimately placed. We had frequently tried to keep records of those students that graduated from the university--how many of them were employed after graduation and how many of them had remained unemployed. I know those records were submitted on several different occasions. Sue O'Hara, I know she put that together on several occasions and had that information for the celebration of the Cowell Hospital program after twenty years and that sort of thing. In '86 or something like that we had a celebration.

Bonney: Did the program do what you hoped it would do?

Velton: It seemed to. It seemed to me to really improve the access that the disabled had to the placement office and improved their chances. So I think it was not phenomenally successful, but it was successful.

Bonney: Are you aware of any collaboration between the computer training project and the career placement and planning project in the early years?

Velton: Oh, yes. I know that Mary Lou Breslin and Betty Bacon actually encouraged some of the students to come into the program when they were graduating the university because they had taken courses that seemed to be too general to really give them a good opportunity in the labor market.

Bonney: Betty Bacon tells the story that when the Disabled Students' Career Planning and Placement Program started up, the students who were in that program went over to the computer training project, and the people in the computer training program did the résumés for the kids who were coming from the University Career Planning and Placement Program. So there was a symbiotic relationship: the kids in the computer training project set up the résumés and printed them out and did them for the other students. Did you know that was going on or that that kind of thing was happening?

Velton: I didn't know that, no.

Bonney: I think it was creative [laughs].

Velton: Yes, it was, definitely. I think I certainly encouraged them to cooperate in every way, but I never knew about that. That's interesting.

Critical Incidents in the Computer Training Project

Bonney: You mentioned a little while ago that there were some critical incidents in the Computer Training Project. Can you tell me more about that?

Velton: After the first class, Ed Roberts still had not been selected as director of the Department of Rehabilitation, though this was in process, and people started to really suspect it might happen, we knew it was under consideration. Harry Lucas then was the director of regional operations, and he had a meeting with the regional administrators about continuing the funding for this computer training class, which was quite expensive. It was over \$100,000 in the initial budget. It went up to twice that when we started having two classes. We went to this meeting in the hopes that we would continue to have it block-funded so it would be paid for out of a block fund. We got turned down on that, and the regional administrators had us agree that, if we're going to continue the program and students were sent from outside of the district, that the other district would also have to send its share of the money.

Now, of course, we always insisted upon getting a share of the money prorated if a student came from outside the state of California, and we got that money from students that came from other departments. But we didn't like that idea because it meant that it was an extra hurdle, and with this chauvinism that I talked about before, they would set a higher standard before they would ever agree to send somebody. Disabled students would have to be absolutely right in all respects. So it did make the second class much more difficult to recruit.

We also had another serious problem when CIL--this was in 1981--got in trouble with the Internal Revenue Service because they hadn't paid their income tax withholding, and was actually in danger of going under. They eventually solved that by selling the building that they had partially purchased. But at that time we decided that the best answer was to separate the computer training program from CIL and incorporate it. And this had always been an initial vision of Ed Roberts anyway. CIL would start programs, and once they were successful and able to function independently, spin them off and put its energy into starting other programs. So

there wasn't any real opposition to this as far as CIL was concerned, but it was definitely a benefit to the Computer Training Program to have it operate independently although it continued to cooperate with CIL.

I know that Joan Breves at that time was the director of the program. She had come in as a counselor and then been promoted and had been trained by IBM, and she's still the director. She had felt that CIL was actually using too much of her time on matters that were unrelated to the computer training program--fundraisers, and having to attend other problems. So she felt it was better also to have it an independent, nonprofit corporation.

We did have another problem in increasing the diversity of the program, reaching out to the deaf and the blind and all the other disabilities. Neil came up with the objective of bringing in the deaf-blind, who could neither hear nor see. There was a deaf-blind gentleman who had worked as a computer programmer for the federal government who came out and tried to set that up. For various reasons, it didn't work. The gentleman from Washington didn't get along too well with many of the staff. It gradually became apparent that this integration was creating some real tensions in the program because even though there was a real desire to learn, they--the blind-deaf--simply could not communicate at the same speed. And it was slowing the class down and creating problems where everyone would have to wait for something to become clear and be communicated to the person that was deaf-blind. Finally I made a unilateral decision to separate the two. It wasn't a pleasant decision, because I know they were never happy about it, and they went out to Ohlone Community College in Fremont to establish their own program.

Bonney: So a separate program was not set up then--

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Velton: It was a marvelous program to work with because everyone agreed with the objectives. There was very little problem with ego. I can't ever actually recall it being a problem. We simply decided what we wanted to do, and everyone picked what they could do best, and we did it. It's like everyone was on the same wavelength so that everyone reinforced everyone else. And even though we were initially searching for the best curriculum and building the curriculum as we went along, everyone pitched in. We gradually improved it so that we quickly attained what I would consider to be excellence and remained at that level so that the students that graduated had the confidence that they could deal with whatever they would have to deal with and win people over by their competence. Not everyone succeeded; health problems sometimes

intervened and so forth, but it was very rare that any student lacked the confidence to be able to do well in the business that they were in. And so it's maintained a very good reputation to this day.

Bonney: Did the Computer Training Project ever get recognition for being an excellent program? Did it get awards?

Velton: I can't say that the program itself had ever gotten awards. I know that once I got an award when Ed Roberts was director. I know that it was something that I always felt was so special and the businessmen did and IBM did--they had been very proud of the program and continued to supply a part-time representative. I always remember one thing about that award--maybe I said this to you before--but I felt as I got the award, I said, "To paraphrase Franklin Roosevelt, to some generations much is given, of some generations much is asked, but this generation of the disabled has a rendezvous with destiny." And I think that was true of the whole movement at this time; there were so many things going on. The computer training program was just one aspect, and of course the placement program and the Cowell Hospital program and all of the activities--the disabled rights program and accessibility and "504". It just spread out in all directions where everyone was energized and benefited--people sort of drafted off everyone else. And that was true in this program too.

Bonney: Who gave you the award?

Velton: Judy Heumann, I think, gave me the award.

Bonney: From?

Velton: Ed Roberts, who wasn't able to come, but he signed it.

Bonney: So it was from the Department of Rehab?

Velton: Yes. It was really a very happy time. There were other times--I've thought now of one other time where they--after Ed Roberts had left, they decided they were going to do a special study of all the block-funded programs, which included the computer training program and the Cowell Hospital program. Of course, both block-funded programs are funded as though they were workshops where they send people on a daily basis. Records are required tracking each client and how many clients attend and there's always a certain minimum number that must be attending, which is a problem we had successfully dealt with from time to time by having two classes and so forth.

But this particular study was set up in such a way as to skew it away from the benefits, showing very little benefit in terms of cost for the computer training program or Cowell Hospital or the residence hall program--because of the cost per client served. It would really look like it was going to be a very unfair report, and we kept pointing out to them that you simply couldn't measure these programs the way you measured a workshop. They didn't listen. So finally when the report came out, we brought this to the attention of this city councilman--what was his name?

Bonney: Fred Collignon?

Velton: Yes. Because he was quite supportive of these programs. And we had support from state legislators, and the local assemblyman, Tom Bates, was very supportive, and Ron Dellums, the local congressman. They had attended computer training program meetings and spoken at the meetings and so forth. Politically, we had a lot of support. But within the bureaucracy this was looked upon as an expensive program.

Bonney: Why did DR look at it as an expensive program? You were serving some of the most severely disabled people in the state, and it had a 90 percent success rate in terms of people being placed and getting jobs, which is the ultimate goal of all of DR, and it was only a nine-month program. So even if it was very expensive for one person for that nine months, why didn't DR consider that a really good deal knowing that 90 percent of the people that went through it would be employed in good jobs--or could be if they had the potential to do that--from then on?

Velton: There was always skepticism. In Fred Collignon's case, he went to the state legislators, and they just blew the whole thing out of the water, but it was kind of a dangerous thing to do because it was doing an end run around the bureaucracy. And there was always a skepticism; at different times they'd say, "You aren't placing these people," and you'd have to come up with reports and show them that you were placing people. There were other factors which worked against it, I suppose, because this resulted in their counting this cost from time to time, off and on, in the costs of the Oakland district. So the Oakland district was always one of the most expensive districts in the state. Some people, without looking at the results necessarily, would simply say, "This is the most expensive; why are you so expensive? Why are you this expensive on a per-client basis or any other basis?" Some other time someone came through from Washington, D.C., or somewhere else, and they would brag about the program and then forget about the costs. It was sort of an ambivalence about the program.

I don't know, maybe I was never that able to come up with an adequate answer in their terms or anyone else's. It just always seemed to be that way even though they would acknowledge CTP's value and be proud of the fact that we had this very active business advisory committee. Maybe it was jealousy in some other districts that they didn't have a program like this, and they had to send clients there. I could think of various motives, but it seemed like we were never completely free of this skepticism about high cost.

Then later on, even though we had initially tried to establish a program here at the community college, they did succeed in establishing a program in southern California through a community college. That program incidentally had the same problem that the placement program had, but they sort of looked the other way.

It was mainly that you're spending money, but either the community college had to bend the rules or the department had to bend the rules because not all of the money that was spent on the program by the department could be spent exclusively on DR clients, or the community college was shutting out people who wanted to be in the program, and they were not clients of the department so they couldn't be in the program. But that was a question which they overlooked. It would be ideal to have the program supported by the community college and have it funded in some other way. But we were never able to find a way of doing that up here which would fully meet all the needs of the disabled clients.

It wasn't just a matter of teaching them computer programming; it was all of the supportive aspect of independent living and helping this person to move from someone who perhaps in some cases lacked full independence to someone who was able to go to work every day as a computer programmer when they graduated. It was quite a stretch for some of them to grow that fast in that period of time. I guess it makes me wish I had been brighter and more gifted in selling the program [laughter]. But anyway, it has persisted and has survived and that's what counts.

Bonney: Is it a matter of "bean counters" in Sacramento not talking with counselors or program people, so they didn't really know what the value of some of these programs were?

Velton: I suppose that's part of it. It seems to me that they really lose sight of their goal. And the department has often gone towards the funding source--even now. I'm not in the department, but I hear that they have a set of priorities where they're supposed to be serving the most severely disabled. But since the school

districts have a lot of funding for the learning disabled, they've found ways of defining the learning disabled as high on the list among the severely disabled because that's where the funding comes from. So they get more money that way. It also seemed to me, frankly, a third to a half of their people that would go through the Department of Rehabilitation before this priority--would have been able to get jobs anyway. It was a help to them, but it always seemed to me that our focus should be on the most severely disabled, that this was the actual mission of the department and this was where they could do the most good. And a lot of other programs could be designed to work with these other groups.

I think the department has hurt itself over the years trying to serve populations which it did not really have full expertise in working with, such as the drug and alcohol group. We've had problems working with other groups, whereas traditionally the department has been working with the deaf, with the blind, and with the physically disabled. What happened in the sixties is that medical science made such strides that suddenly there was a surge of people who had suffered traumatic injuries and other injuries or congenital conditions who were starting to enter the community to be able to attend college and enter the mainstream of society. It kept snowballing, because as it continued ancillary services developed: wheelchairs, accessibility, peer counseling, and a whole variety of services that build on each other so that far greater numbers of the disabled were able to actually attend schools and become competitive. I don't think the department had an easy time adjusting to this because many of the administrators had gone up before this had ever occurred--to higher levels.

Not too many of the counselors really enjoyed working with the severely disabled either. It wasn't like it was easy to have them, say, dispersed among all the caseloads; it seemed like it worked better to have those counselors specialize. We did have specialists who worked with the deaf, specialists with the blind, and it really seemed that there were certain counselors that were more able to work with the mentally retarded and developmentally disabled and those with traumatic injuries. I never saw anything really wrong with that, either. It's always been true of counseling: one counselor can relate to one person and be successful and then there would be someone else that, even though they're gifted and they're a very fine counselor, they simply can't connect. I don't think there's even going to be an answer for that other than hopefully everyone will finally be able to connect with the right person [laughter].

IV VELTON PERSPECTIVES

[Interview 2: January 21, 1997] ##

An Underworld in the Disability Movement

Bonney: John, several times you referred to an underworld in the disability movement. Can you describe what that underworld is to you?

Velton: Clearly, there's a different world that the visibly disabled experience than the rest of us do whether we're disabled or not. For example, I once came across these pictures which they were showing me of a party that they had had. At first they seemed somewhat reluctant, but then they decided, "Well, go ahead." I think it was--oh, I can't remember his name now--anyway, they had this party in this garage where everyone dressed up to be as ugly as possible. They told each other how ugly they were as sort of a catharsis for the experience that they have where they're looked at and many of them have feelings that they're different. People perceive them in ways that are unpleasant to the disabled, and they really wanted to have an experience where they sort of reacted differently to it and had some fun making fun of the dim-witted people that always stereotype them because of their physical disability.

Also, it's like Ed Roberts referred to this--but he seemed to have a very different take on this. He said, "I always felt like I was a movie actor when people stared at me or paid attention to me. I felt it was because I was somebody special. So I enjoyed it, and I played with it. It made them feel comfortable with me because I didn't feel uncomfortable about it." But he was well aware of how uncomfortable many or most physically disabled feel, at least until they find a way of accepting it. So this is part of that same experience. It seems that many disabled have this anger that they certainly feel initially when they have been injured in a traumatic accident or even when they're suddenly

struck down by an illness, and they have to go through a period of adjustment. From a rehabilitation counselor's point of view, this is an experience that usually seems to take a year or even two years for them to work through before they're actually ready to settle down and become serious about another occupation, although this isn't always true.

So coming back too soon can often be very dangerous because they are trying to deny something that is a reality that they have to accept. On the other hand, if they don't eventually work through this anger--and then it starts to corrode all their other relationships--this can be very damaging to their ultimate success.

I suppose it's a truism that in most cases there's nothing about a traumatic injury that's going to make you more mature in and of itself. If you were mature or had innate strengths beforehand, then you'll probably come to the fore. But if you had severe problems beforehand, it would probably continue. Like for example the client who tried to commit suicide and survived a gunshot wound. It would be very difficult because they hadn't come to terms with the initial problem that caused them to try to shoot themselves in the first place.

[Page 273a of the manuscript is under seal until January, 2060]

For me, it's just glimpses of an underworld. I've never felt that I had a need--in order to be effective in rehabilitation--to understand it thoroughly, but I certainly felt that I sometimes needed to make allowances for it. What really counted was their ability to return to work and become productive and become independent. That's somewhat of what I'm referring to.

Disability Rights Movement

Bonney: John, while you were working with all the different groups-- computer training project and the residence program and all of that--did you realize you were involved in a disability rights movement? When did that sort of occur to you?

Velton: That's an interesting question. I don't know exactly the moment it occurred to me. I do remember one meeting when Ed Roberts couldn't come but Judy Heumann came to give me this honor from Ed Roberts, and so I had to accept it, and I got up and made this little speech. I remember the phrase that I made--to paraphrase Franklin Delano Roosevelt, "to some generations much is given and to some generations much is demanded, and this generation of disabled has a rendezvous with destiny." I think it was very apparent that something really special was going on, and that it was gaining momentum. It's like we were all working in the same thrust and gaining strength from each other, and that it was getting more and more powerful because people were buying on.

I think that this was the concept that Ed took into the department and why he set up all these CILs around the state: the disabled had to be able to represent themselves effectively, and they couldn't depend upon well-meaning people to help them--and I think he's right--because I think there was always a tendency for people to create dependencies and also look at things in a different way or even try to push the disabled in directions which really aren't the way the disabled want to go. They have a right to have a say in what opportunities are open to them and how they're open to them.

Bonney: What year was it approximately when you first sort of got this impression that there was a movement going on and you were involved?

Velton: [chuckles] I guess it was about '74 or '75.

Bonney: Early on, then. Did the Department of Rehabilitation understand what it was involved with?

Velton: I don't think so. I think individuals did, but I don't think the department did. I think there was always resistance in the department as to how the disabled should handle themselves and that they should behave themselves. We were actually told not to get involved with that sit-in that occurred over there in San Francisco. I remember when I went over there to talk with the government administrator I had a clue before it ever happened, because he asked me to look at the restrooms and check them out to see how accessible they were. [laughs] Afterwards I thought, "That's pretty interesting," especially when it happened.

Bonney: Were you involved in the 504 sit-in [in 1977, at the Federal Building in San Francisco] at all?

Velton: No.

Bonney: So you didn't go over and take a peek? [laughs]

Velton: I had been upstairs in the building beforehand, that's all. It was their show, and I think that they were able to do it best by themselves. Whenever they could do something by themselves I think they should do it by themselves. There's been enough paternalism anyway.

Role of Non-Disabled People in Movement

Bonney: What do you think is the role of non-disabled people in the disability rights movement?

Velton: I think it should be to facilitate, to be an usher, to understand what actually is needed and to try to see how it can be fit in to the rest of society. I haven't always agreed with everything the disabled have asked for. I think, for example, that the accessibility issue was one issue which sometimes--it seems to me--has come down rather unfairly with some establishments. I've always felt that any new establishment, when it is built, should be accessible. And if it isn't accessible, and it costs \$20,000 to make it accessible after they had the code and the advice and everything, that's tough. They should just be forced to go ahead and do it.

On the other hand, there are some buildings which are very, very difficult to make them accessible. I think sometimes compromises are the only real reasonable answer because you can drive some businesses out of business by requiring them to become accessible. I don't know that anyone's ever made an issue, for

example, of Chez Panisse, but Chez Panisse is not accessible unless you go in the back way through the kitchen. And it never will be. I can't think of any conceivable way it could be made accessible, and that's true of some other places too.

Of course when I think about it, as an example to someone who I've liked very much over the years but I think he's gradually gotten more and more extreme, and that's Mike Pachovas. I think people misuse this to the point that it reflects adversely on the movement when they start to be seen as someone that is using this to vent their own anger or for their own personal vendettas. They can become a detriment to the disabled in general.

Bonney: What do you see has been your role as a non-disabled person in the independent living movement?

Velton: Even like the computer training program, or like we were talking earlier about the residence hall program, it seems to me that some of that was almost destiny: one way or another this was going to occur, and it was like I was more like an usher than someone that actually--it's hard to feel that this wouldn't have happened anyway in some fashion, but maybe I made it a little easier by being in the right place at the right time and doing what needed to be done. But I think that's about what I did, Not a very important role [chuckles].

Career Satisfaction

Bonney: One last question. I don't know if this will be an easy one or a hard one. What were or are the most satisfying moments of your career?

Velton: In total, you mean?

Bonney: Yes.

Velton: Well, of course when I was assistant city manager in Vallejo I was very satisfied to have solved this problem where we were able to double the population and size of Vallejo by annexation, and like I said, that was a great success, so I was nominated "Young Man of the Year" by the local Junior Chamber of Commerce in 1961. That was great.

And I think in the Department of Rehabilitation the computer training program, as a program, was the one that gave me the most satisfaction that it was successful. Not only that it was

successful initially, but it has continued to be successful. It was put together in such a way that it became a prototype for other programs around the country, and that it was successful, and there were such rewarding relationships.

And then, thirdly, it would have to be working with certain individuals. Of course, Neil Jacobson in himself--we got him a van, and in spite of everything he achieved he said that this really opened the world up to him more than anything else when he had a van. Everyone agrees, even the most skeptical people among the non-disabled, that Neil was way up there in terms of a successful example of someone who has benefitted from vocational rehabilitation. But there are other individuals too. There are some people that you never forget that you worked with. For one reason or another, you somehow feel you were able to do the right thing at the right time and made a difference in their lives. So that would be a lot of different individuals. I guess that's my peak experiences in terms of the "most."

But I'm really glad that I ended up working in rehabilitation particularly. I think it was a better place for me.

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Administrators, and California Department of Rehabilitation
Counselors

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SHARON BONNEY

Interviewer/Editor

Regional Oral History Office

Disability Rights and Independent Living

Movement Oral History Series

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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.

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Mary Lou Breslin co-founded the Disability Rights Education and Defense Fund (DREDF), a national disability rights law and policy center established in 1979. She has served as DREDF's deputy and executive director, and president and chair of the board of directors. She is currently a member of the board. She spearheaded that organization's leadership in the enactment of such landmark legislation as the 1990 Americans with Disabilities Act (ADA), Fair Housing Amendments Act, and the Civil Rights Restoration Act. In 1993 she founded the DREDF Development Partnership, a corporation dedicated to supporting and securing DREDF's programs. During her twenty-five year career she has served as a policy consultant, trainer and lecturer on diverse disability and related civil rights topics including working with disability rights leaders in Russia, Bosnia-Herzegovina and Japan on strategies to further the rights of individuals with disabilities in those countries.

Since 1997 Ms. Breslin has taught at the University of San Francisco (USF), McLaren School of Business, Executive Master of Management and Disability Services program. She also serves as senior investigator and consultant with USF's Disability Leadership Archival Research Project, and editor, researcher, and interviewer with the Disabled Persons' Independence Movement Project of the Regional Oral History Office of the Bancroft Library, University of California at Berkeley. She is presently a senior policy advisor with DREDF. Ms. Breslin received a Mary E. Switzer Merit Fellowship in 1995. Ms. Breslin had polio as a teenager and uses a wheelchair.

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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